

Original Research

Chronic disease, medications and lifestyle: perceptions from a regional Victorian Aboriginal community

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ABSTRACT*

Background: Poor medication management may contribute to the increased morbidity and mortality of Aboriginal people in Australia. Yet while there is extensive literature about the perceptions of healthcare providers on this issue, there is limited information on the perceptions of Aboriginal people themselves.

Objectives: To investigate the perceptions of a group of Aboriginal people attending a Victorian regional Aboriginal Health Service (AHS) with diagnosed medical conditions requiring medications, of their lifestyle, disease management and medication usage.

Methods: Data was collected through one to one in depth interviews using a semi-structured 'yarning' process. Twenty patients were invited to participate in the study and were interviewed by Aboriginal Health Workers in a culturally appropriate manner. The interviews were recorded and transcribed verbatim. The data were analysed using descriptive statistics.

Results: Our results show that the majority of participants perceived that changes in lifestyle factors such as diet, exercise, and smoking cessation would help improve their health. Most patients reported having been counselled on their medicines, and while the majority reported adherence and acknowledgement of the efficacy of their medicines, there was a lack of clarity regarding long term maintenance on regimens. Finally, while the majority reported taking over the counter products, some did not see the need to inform their doctor about this, or chose not to.

Conclusion: Chronic illness was perceived as common in families and community. Patients relied mostly on their health care professionals as sources for their drug information. Patients may have benefited from further counselling in the area of complementary and other over the counter medicines, as well as on the necessity of maintenance of regimes for chronic disease management. Finally, lifestyle changes such as dietary improvements and smoking cessation were identified as areas that may assist in improving health outcomes.

Keywords: Oceanic Ancestry Group; Health Services, Indigenous; Health Knowledge, Attitudes, Practice; Chronic Disease; Medication Adherence; Life Style; Patient Education as Topic; Australia

INTRODUCTION

It has been well established that the health of Aboriginal Australians is poor and that there is a disparity in health standards and life expectancy among Aboriginal populations compared to non-Aboriginal groups.¹⁻⁵ The transition to western diets and lifestyles and ensuing chronic disease has been previously identified as a major contributor to the increased morbidity and mortality of Australian Aboriginals.⁶⁻⁸ Many Aboriginal people are diagnosed each year with chronic diseases such as hypertension, diabetes, obesity, cardiac disease, chronic obstructive pulmonary disease, kidney disease and depression.⁹ Risk factors such as obesity, malnutrition, tobacco smoking and alcohol consumption that contribute to the development of these chronic illnesses are multifactorial and often related to socio-economic disadvantage and poor access to service provision.⁹

Adequate solutions for the inequity in Indigenous health and wellbeing standards require rigorous national political effort.^{4,8} The 'Closing the Gap' strategy aims to reduce Indigenous disadvantage and achieve Indigenous health equality within 25 years.¹⁰ Much of the existing research available to inform healthcare policy and procedure has been conducted from a non-Indigenous "scientific" perspective without consultation with Indigenous people. In recent times there has been extensive information available to educate researchers about culturally appropriate methods for undertaking meaningful research partnerships with Indigenous people and the risk of misrepresenting and stereotyping Indigenous experiences if appropriate methods are not employed.¹¹⁻¹⁹ One serious and possibly underestimated ramification of non-Indigenous accounts of Indigenous information is the potential for the transformation of Aboriginal reality; an example of which is the creation of a "non-complier" stereotype commonly applied to people who struggle to adhere to prescribed medication regimens.²⁰

Most of the available information on management of medication by Aboriginal people discusses medication compliance²¹⁻²³, poor medication management and underutilisation of health care resources²⁴, from the healthcare provider viewpoint. There is scarce information regarding the perceptions of Aboriginal people and their management of chronic illnesses and medications.²⁵ More research and information from the Australian Aboriginal perspective is required to facilitate better health outcomes for this population. This research

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Table 1. Interview questions

1.	How long have you been taking medicines for your sickness? How old were you when you started taking medicines for your sickness?
2.	Do you know what each of your medicines is for? Can you tell us about them?
3.	When you started taking the medicine, who told you about them?
4.	What sort of information did they tell you?
5.	Did you also get information from someone else?
6.	Do you think the medicine is helping you?
7.	Do you think the medicine is causing you problems?
8.	What do you do if you think the medicine is causing you problems?
9.	Who do you tell about the problems?
10.	What would make you stop taking the medicines?
11.	Do you know how long you will have to take the medicines?
12.	Other than taking the medicines, what else do you need to do to look after yourself?
13.	Do you smoke? Have you been ordered anything to help you give up smoking?
14.	How hard is it for you to make lifestyle changes? Can you tell us about this?
15.	Do many people in your family and community need to take medicines? Can you tell us about this?
16.	How old are people when they start needing medicines?
17.	Where can you get information about medicines?
18.	Do you take more medicines than those the doctor orders? PROMPT: from the supermarket/health food shop/bush medicine/other people
19.	Did you know that you should tell the doctor about those other medicines?
20.	Do you think the medicines will help cure your sickness?

aims to investigate the perceptions of a group of Victorian Aboriginal people taking medications for diagnosed chronic illnesses regarding their lifestyle, disease management and medication usage.

METHODS

Through consultation and collaboration with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), our research team formed a co-researcher partnership with the Practice Manager and the Aboriginal Health Workers (AHWs) practicing at an Aboriginal Health Service (AHS) situated in a large regional centre. The AHS Chief Executive Officer, Practice Manager and AHWs verified the benefit of the research for their community, an important consideration in such collaborations.¹⁷ Academic members of the research team travelled to the Aboriginal Health Service on a number of occasions prior to the interviews being conducted, and in conjunction with the AHS Chief Executive Officer, Practice Manager and AHWs determined the content and style of interview that was most culturally appropriate. It was determined that AHWs would conduct culturally appropriate, one to one indepth interviews using a semi-structured 'yarning' process. 'Yarning' is an accepted Indigenous research method that encourages rich data collection by encouraging participants to tell their story in a conversational manner.^{11,12,25} Members of the research team who were experienced in interview methods provided training to augment the AHWs' skills in interviewing. Regular telephone contact was made between the academics and AHW team members for mentorship and discussion.

A purposive sample of 20 Aboriginal people over the age of 18 years who took medications as part of their chronic disease care were invited to participate by an AHW when they attended their AHS appointment. Potential participants were verbally informed about the study by the AHWs at the time of their health consultation and given written information to peruse in their own time. Participants were offered a gift voucher in appreciation for their

time and contribution to the research. The researchers obtained written support for the study from the Chief Executive Officer of the AHS and approval from the La Trobe University Human Ethics Committee (No. 12-057).

The interviews took place from October 2012 to July 2013. Table 1 lists examples of questions that were used as prompts. The de-identified interviews were recorded by dictaphone with the consent of the participants and transcribed verbatim. Transcripts were validated by members of the research group including the AHW research partners. Although the intention was to use a 'yarning' methodology, due to unforeseen staffing issues at the AHS, including the departure of experienced AHW and their replacement with less experienced staff, the interviews were conducted in a manner that did not generate rich, descriptive qualitative data. Instead, the data was analysed by a member of the academic team for descriptive statistical analysis.

RESULTS

Participants were taking medications to treat a variety of chronic illnesses, and many were treated for more than one disease. No personal identifying data was collected. The average age of commencement of medications for the management of chronic illness was 32 years (Range: 17 - 64 yrs). The average length of time that participants had been taking the medications was 11.4 years (Range: 0.5 - 35 yrs). Over half the participants had cardiac diseases and over a third reported mental health disorders (Table 2). Cardiac disease was equally distributed in men and women while mental

Chronic illness	(%)
Cancer	5
Cardiac	55
COPD	20
Diabetes	10
Mental health	35
Gastro-intestinal	20
Inflammation	15
Others	20

health disorders were more prevalent in females (42%) compared with males (25%).

Medication knowledge: The majority of participants reported that they knew why they were taking all their medicines; however when questioned specifically, less people than originally reported knew why they were taking some or all of their medicines (n=18 vs. n=14). It is not known if this was related to the length of time since commencement of their medicines.

Medication Education: On commencement of a new medication, the majority of participants responded that their treating medical practitioner from the AHS was the primary source of education. The most common recollections were: how to take the medication and how often (16 participants); potential side effects of their medications (10 participants); medication action (4 participants); and dose (2 participants). Half of the participants specified that one or more of these components of their medication education was missed by their health professional or that they did not recall having been informed about them. No participants mentioned having been educated about storage issues.

Following initial education about their medications, 13 participants gained further information from other sources. Five participants consulted pharmacists, and nurses were consulted by four participants, medical practitioners by three participants, Aboriginal Health Workers by two participants and information leaflets from the drug company by two participants. Some participants also sought advice from relatives and the internet. Almost half of the participants reported that they relied on the secondary source of education to clarify their understanding of their medications:

“Aboriginal Health Workers have helped me in a lot of ways by getting the Doctors and Nurses to express things to me in a plain English way.”

Participants were also asked about their perceptions of reliable general sources of information about medications. Pharmacists and medical practitioners were broadly recognised as the main sources of information about medications:

“Probably the best place to get your information is from a Pharmacist because they are going to be pretty much spot on with any information that they pass on.”

“Often the Pharmacist knows more than the GP. The Pharmacist seems to have it more on their fingertips because they’re trained in a different way. The GP, well the ones that I go to anyway, are very good and look it all up on the computer which makes it easy these days it wasn’t so easy for them before.”

In general, nurses and AHWs were not recognised as sources of information about medicines. In this study, more participants nominated that they would be more likely to consult the internet about medications than a nurse or AHW.

Role of medications in the treatment for chronic illness: 15 participants perceived that their medications played a role in the control and management of their illness rather than a cure; four hoped that the medications would help cure their illness; one believed that their medications would help cure their illness. **Efficacy:** 14 participants perceived that their medications were helping most, or all of the time. The remaining six participants were unsure regarding the efficacy of the medications, perceiving their medications were helpful some of the time or not helpful at all. **Side effects:** 15 participants, irrespective of whether they had actually experienced side effects, stated that they would ideally seek medical advice before ceasing their medication, if they experienced any. The majority of participants (n=15) stated that they would inform their AHS general practitioner, followed by nurses, AHWs and pharmacists. Most participants would also discuss their side effects with family members. **Experience of side-effects:** eight participants stated that they had experienced side effects from their medications. Actual responses to side effects varied. Two affected participants took no action and chose to endure the side-effects. The remaining affected participants reported that they had stopped taking the medication prior to seeking medical advice with the majority seeking their own alternative means to treat their problems.

Medication regimen: Most participants perceived that they would be taking their medications for life, or at least for a long, indefinite period. Participants were asked to report any perceived reason they may cease their medications either permanently or temporarily. Eight participants stated that they would not cease their medications unless directed by their doctor and for three participants this included continuing with medications that they perceived were making them feel worse. The 12 remaining participants stated that they would cease their medications if they felt sicker due to side-effects or if they perceived that the medications were no longer needed or were not helping. Seventeen patients reported that they adhered to their prescribed medication regimen. Three patients reported that their prescribed regime altered on a regular basis. Two reasons were given for this: forgetfulness or because they consciously stopped taking their medications when they wanted to drink alcohol:

“I forget a bit. And like I say, if I even lose two or three days out of a week I feel that my body feels it. I get very sick.”

“The side effects are quite demanding if I have alcohol. It means that I might not take it [medication] for two days.....so I can drink if I have a special occasion.”

Medicines other than those prescribed by medical practitioners: six participants stated that they did not take any other medicine or supplement (over-the-counter (OTC) or other) aside from the medications prescribed by their medical practitioner:

"Do I take more medicines? No way known. You have got to be very careful on what you take. Yeah, you have got to understand it and if you don't know, ask about it."

"I am only on the prescribed, what the doctor has already given me to take..... So if they want me to take any other different medications they would.....have wrote out a prescription for me wouldn't they?"

Nine participants stated that they regularly took a variety of OTC products including non-steroidal anti-inflammatory drugs and other analgesics; vitamins, minerals, omega 3 fatty acid supplements & herbal/spice/calming remedies. The other five participants said that they regularly took unspecified medications other than those prescribed.

Awareness of the importance of reporting all other medications to doctor: 15 participants reported that they knew that they should tell the doctor about any other medications or supplements that they were taking and complied:

"I would be wary because I don't know what clashes with the medication or not..... if I did [take OTC or complementary medicine], but I don't think that I would, because I would have to consult my doctor first."

Three stated that despite knowing they should tell the doctor about other medicines, they chose not to – some perceiving that if the other medicines were "natural", there was no need to report:

"I don't think it would actually have any adverse effect with what was prescribed because it is all natural products there is nothing been added to it. There is only a process like making tea out of it."

Two participants indicated that they were not aware of the importance of telling the doctor about other medicines.

Lifestyle influences. Aside from taking medications, participants were asked to describe their views about how to improve their wellbeing. Perceived important behaviours were: (i) eating a healthy diet, drinking more water, eating less and losing weight (identified by 15 participants); (ii) combinations of increasing daily exercise, adopting a healthy lifestyle, sleeping and resting more (identified by 15 participants); (iii) improving mental health (five); (iv) giving up smoking (two); (v) drinking less alcohol (one). The majority of participants (n=16) reported that even though they realised their lifestyles needed to change in order to enhance their wellbeing, it was very difficult to make the required changes. The main perceived barriers were due to competing demands (family, community and employment) and the self-perception of being too "set in their ways" to change.

Smoking: 13 participants had a history of smoking: nine current smokers and four ex-smokers. All participants with a history of smoking were asked to identify reasons they would consider smoking cessation. Both genders nominated reasons such

as health issues and prohibitive expense. Females were also inclined to consider smoking cessation due to pregnancy and feelings of duty to children.

Six of the current smokers and three of the ex-smokers had been prescribed medications to help them cease smoking at some time. These included prescription medicines taken internally, as well as transdermal nicotine replacement patches. Seven of the participants who had taken these prescribed medications reported that they had ceased them mainly due to unbearable side-effects and because the medications were not working as hoped.

Perceptions about family and community: 18 participants perceived that most people in their family and community took regular medications for chronic illnesses:

".....everybody in my family takes medication."

Familial and community obesity and cardiac disease were identified by half of the participants as highly prevalent; followed by diabetes mellitus (identified by nine participants); mental health disorders (eight participants); cancer (four participants) and respiratory diseases (two participants).

Age at which people require medications for disease management: fourteen participants thought that most people would need to start taking regular medications by 40 years of age. Of this group, four perceived that the most likely time to commence medications is around late twenties while seven perceived that it would not be uncommon for children and babies to require medications to manage illnesses. Only one perceived that medications would not start until old age.

DISCUSSION

The range of chronic illnesses experienced by the participants in this study reflects the distribution of chronic illnesses in the Aboriginal and Torres Strait Islander community at large.⁹ The majority of participants in this study thought that most people would develop a chronic illness and require regular medications by the age of 40 years and some thought that it would not be unusual for children and babies to require medications. These perceptions are concerning as they generally reflect the incidence of chronic illnesses in Aboriginal people across Australia.²⁶

It has been reported that 80% of indigenous adults had confidence in their local doctors.²⁶ In this study, the local Aboriginal Health Service doctors provided the initial education for most of the participants on the commencement of medications, however half of the participants relied on a secondary source of information to clarify their understanding. This is possibly because only half stated that they recalled counselling for potential side effects, with only two recalling counselling about dose, from their doctor. The most common secondary sources of information were pharmacists, followed by nurses, other medical practitioners and AHWs. As the participants were attending an Aboriginal Health Service, it was interesting that Aboriginal Health

Workers did not rank higher as a source of information about specific prescribed medicines given their multi-faceted roles in the Aboriginal community and at the AHS.²² When asked to nominate credible sources of general information about medicines, participants nominated medical practitioners and pharmacists as the best sources followed by Aboriginal Health Workers and the internet before nurses. Although nurses were nominated as important secondary sources of education about prescribed medications, very few participants said that they would inform a nurse when experiencing problems with their medications. Additional enquiry is necessary to understand whether this is due to perceptions about Nurses' credibility or whether it is related to their accessibility in the community. More research is required to assess the eHealth literacy skills of Aboriginal health consumers in order to further inform their need for education and support their self-management of chronic illnesses.^{27,28}

There have been reports in the literature and anecdotally within healthcare services that inappropriately label Aboriginal people as non-compliant or poor self-managers of their medications for chronic diseases.²⁹ The majority of the participants reported here that they tried to adhere to their prescribed medication regimen even when experiencing side effects, because they believed it was in their best interests. A small number reported that they did not adhere at all times, due to forgetfulness or if they planned to drink alcohol knowing it was contraindicated.

Almost half of participants stated that they regularly took a variety of OTC products in addition to their prescribed medications. Yet while the majority of participants stated that they would report the use of any non-prescribed medication, supplement or complementary medicine to their prescribing doctor, a quarter of those questioned suggested that they would not. There was a perception among a small number of participants that there was no need to report the use of "natural" products such as herbs and supplements. Therefore, it would seem reasonable to suggest that education focussing on the potential adverse reactions and drug interactions associated with OTC products and complementary medicines would be warranted.

An area that has been highlighted recently is that of cultural barriers to delivery of health care for Aboriginal people, with Aboriginal patients valuing the interpersonal relationships between themselves and health practitioners.³⁰ While this was not investigated in our study, the participants here appeared to be comfortable with their Health Care Professionals.

However, this study does highlight the importance of ongoing patient counselling and education about medicines, no matter how long people have been taking their medications and how well supported they feel by their AHS.³¹ Addressing this issue may assist in improving the benefit derived from medicines by Aboriginal and Torres Strait Islander patients and their subsequent self-management of chronic illness. Particularly as chronic illness was

perceived as prevalent in families and community in this study. To this end, our studies suggest that it is important to stress to these patients that continued adherence to the medication regime is required in order for longer term health benefits to be seen. This is particularly so in conditions such as diabetes and cardiovascular disorders, and in light of the comments by some of the people here that they would cease their medicines if they perceived that they were no longer needed or if they thought they were not helping. Such education would also need to stress the importance of reporting side effects from medicines, so that alternatives may be prescribed, rather than patients ceasing to take them because of adverse reactions.

Considering ways to help maintain or improve health aside from taking their medications, most participants stated that they wanted to adopt a healthier lifestyle but found competing demands of family and community responsibility and employment as barriers. Here the authors suggest that the input of allied health professionals such as dietitians, may be beneficial and effective.³² Apart from more general advice from AHWs, GPs, nurses and pharmacists, dietitians could more precisely advise on food intake and instigate manageable programs. For those participants who wanted to cease smoking, medication aides were largely unsuccessful due to side effects and unmet expectations. Further enquiry is required to explore whether these perceptions also reflect those of Aboriginal people who live in more rural and remote regions where healthcare resources differ vastly from those in the urbanised setting. Irrespective, healthcare providers in all settings could identify personalised, culturally appropriate strategies to help Aboriginal people adopt healthier lifestyles in their particular communities and circumstances. In the setting for our study, for instance, a concerted smoking cessation program could be initiated. This should involve input from the GP and pharmacists in particular, and include an assessment of the individual patient's lifestyle in order to guide therapy, as well as extensive counselling (with back up counselling) so that patients are aware of potential issues and side effects of the smoking cessation programs. It has been shown that community pharmacist led interventions can significantly impact abstinence rates in smokers³³, and the relatively familiar setting of the AHS may assist in such a program. Personalised medication for smoking cessation has been shown to be an effective and sensible approach to minimising adverse effects and maintaining abstinence.³⁴⁻³⁶ This involves the pharmacogenetic analysis of enzymes responsible for the metabolism of drugs involved in smoking cessation. Such an approach may significantly improve the prospects of people such as those we interviewed here in their efforts to quit smoking.

A coordinated healthcare network approach is also required to ensure regular evaluation of medicine use. Such regular evaluation may help with ongoing education about drug side effects, interactions and contraindications, as well as important issues around the storage of medicines. These are

particularly relevant for people who manage chronic illnesses while negotiating challenging and changing life circumstances.

To this end, pharmacist led education of AHWs has been proposed as a way of providing drug information to Aboriginal patients in rural and remote communities.³⁷ More recently, there have been calls for pharmacists to play an integral role within AHS, particularly in the delivery of Home Medication Reviews.³⁷ Being more closely involved with the AHS would enable pharmacists to attain appropriate education in the cultural sensitivities required to reduce barriers to delivery of such an important service in medication management^{38,39} and may provide a catalyst that would potentially be of benefit to such a co-ordinated approach.

Finally, an important over-riding issue which stems from this research is that while the non-Aboriginal health staff at the AHS had been trained in cultural awareness, it may be more helpful for Aboriginal people to be cared for by Aboriginal medical practitioners, nurses and pharmacists, as well as AHWs.⁴⁰ In Australia there is an urgent need for the education of Aboriginal students in order to increase the numbers of graduating Aboriginal doctors, pharmacists and allied health professionals.^{41,42} Aboriginal patients may benefit from this, in that it may help in their management of lifestyle, medications, and chronic disease.

This study has a number of limitations. Firstly, the results are derived from the perceptions of a relatively small number of Aboriginal people attending one Aboriginal Health Service and as such, may not be representative of Aboriginal communities at large. Secondly, the recollection of participants about their medication use and health care was not able to be triangulated with other health service records. Thirdly, given that the interviewer was a healthcare provider employed by

the Aboriginal Health Service, rather than a "neutral" party, there is the possibility that participants may not have been so forthcoming in their responses and discussion during the interviews. Finally, as was mentioned earlier, this study did not yield rich data stemming from a proposed 'yarning' process, and so it was necessary to analyse the results employing descriptive statistics instead. While these are important limitations, this study contributes issues and perspectives to consider regarding chronic disease management for Aboriginal people.

CONCLUSIONS

In conclusion, the findings may help facilitate better health outcomes for Aboriginal people by informing healthcare providers about issues that are important to Aboriginal people in their medication usage and management of chronic illnesses. Particularly, further education about over the counter and complementary therapies, the need for more effective counselling on all aspects of medications, the need for continued adherence to medications in order to gain maximum benefit from these, the implementation of programs involving dietetics in order to facilitate healthy lifestyle and diet management, and the instigation of dedicated and personalised smoking cessation programs within AHS.

CONFLICT OF INTEREST

The authors are unaware of any conflicts of interest.

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