

# Attachment 8

## Pilot study in Northern Metropolitan Adelaide

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## Introduction

Poor health, premature death and grief continue to severely impact on the cultural, physical, psychological and family well being of Aboriginal communities. Accidents, infections, renal disease, diabetes, hearing and sight loss, heart disease, poor nutrition, smoking and excessive alcohol consumption, dementia, acquired brain injury and other mental health problems can all be directly linked to chronic poverty, social dislocation, grief, lack of culturally appropriate services and the long term cultural disruption of Aboriginal Australians, wherever they live[1-8]. Therefore, many Aboriginal people with mental disorders such as dementia and Korsakoff's Psychosis also have coexisting health and social problems, and require ongoing, intensive support from their carers and other family members. The ongoing burden of caring for someone living with such complex health problems places inordinate strain on the physical and mental health of Aboriginal carers and diminishes the overall well being and capacity of these individuals and the Aboriginal community as a whole.

The literature highlights social and economic issues associated with the use of medications, such as intoxication, excessive use and dependence, adverse drug reactions, hospital admissions, accidents and falls, misdiagnosis or exacerbation of dementia, and psychological effects of polypharmacy[9-11] . A search of the literature did not reveal any research on medication use specific to Aboriginal cultures other than that reported by one of the investigators on this project[9]. Medication management for Aboriginal persons and their carers is problematic because of cultural issues, limited access to quality culturally appropriate medication information and support, as well as differences in knowledge, personal resources and skills[9]. Previous research has indicated that older urban Aboriginal women, like their non-Aboriginal peers, recognise medications by shape and colour, and rely heavily on memory for dosage and time of administration, often involving more than one medication[9]. There was evidence that medications were shared amongst family and friends or reduced in dosage, and that personal medication management for diabetes, and prescribed diet and exercise, were poorly understood and/or managed[9]. Further to these findings, the cultural beliefs of older urban Aboriginal women may be that 'white man's medicines' are not always valued or complied with from their cultural perspective[9]. Aboriginal home care workers in contact with Aboriginal clients and their families have also highlighted the lack of culturally appropriate medication education and support for their clients and themselves[9].

There have been few comprehensive national studies into the nature, context and impact of excessive alcohol or other drug use on the morbidity and mortality of Aboriginal Australians[1], apart from investigations based on national statistics [4, 7, 8] .

The Aboriginal community in South Australia is gravely concerned about the impact of excessive drinking and other drug use on their people, even though this behaviour occurs in a smaller percentage of Aboriginal people than non-Aboriginal people[1, 12-14]. Excessive licit and illicit drug and alcohol use are bound within a range of complex life issues, being intertwined with medical, psycho-social, mental, generational, spiritual and cultural conditions experienced by Aboriginal people. These conditions can in turn reflect and compound the already markedly poor health status of many Aboriginal Australians.

The combination of prescribed medications together with other substance use, eg over the counter medicines, illicit drugs or alcohol, can compound the physiological, psychological and social problems of mentally ill persons[12]. Medication use in persons with dementia requires special consideration because of declining cognitive ability, memory impairment, co-morbidity and loss of physical function. Furthermore persons with dementia illness may not be able to express verbally their pain or other symptoms and may not be able to communicate their need for appropriate treatment[15]. Quality use of medications by mentally ill persons, and their need for palliative care has been recognised but this requires extension into culturally specific groups such as Aboriginal persons.

## **Aims and objectives**

The aim of this study was to explore the particular needs, experiences and contexts of Aboriginal people diagnosed with a mental health disorder, their carers and other family members, focusing on issues relating to management of medications. The project was supported by a grant from the Australian Rotary Health Research Fund. Funding constraints limited the scope of this project to interviews with consumers and a focus group discussion with health professionals in the Northern metropolitan area of Adelaide. This project was a pilot for a larger project currently in progress to investigate these issues SA-wide and funded by the Quality Use of Medicines Evaluation Program through the Commonwealth Department of Health and Aged Care. Taken together the findings of both projects will inform statewide recommendations and strategies for improved, culturally appropriate policies and practices for medication management by mentally ill Aboriginal Australians and their carers.

## **Participants and methods**

### **Research Approach**

A collaborative approach was taken involving a partnership between the investigators from the School of Nursing and Midwifery at Flinders University and the Aboriginal Drug and Alcohol Council (SA) Inc. The research was planned and conducted in consultation with representatives of the Aboriginal people living in the Northern metropolitan area of Adelaide, to ensure that the research was responsive to the needs of the Aboriginal community and conducted in a culturally acceptable manner. A qualitative research design was chosen, in which rich experiential data was collected through in-depth interviews and focus groups with consumers and service providers, followed by thematic interpretation. The detailed research plan was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, Yunggorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Council of SA. The research conformed to the NHMRC guidelines for ethical Indigenous research[16].

### **Steering Committee**

A steering committee comprising the research team, representatives of Aboriginal groups and those who provide health and social services to them was convened to guide all aspects of the research (Appendix 1). Quarterly meetings of the steering committee were scheduled. The steering committee advised on recruitment of an Aboriginal research assistant acceptable to local Aboriginal communities, engaging potential participants, drafting and piloting the interview guide, followup on issues raised by participants, and draft reports and recommendations. We have used a similar approach successfully for previous research on medication use by older Aboriginal women[9], consumer-driven projects[10, 17-19] and other research[20, 21].

### **Selection of Participants**

#### ***Clients and carers***

Potential interview participants were adult Aboriginal people diagnosed with a mental health disorder, their carers or other adult family members, living in the Northern metropolitan area of Adelaide. Potential participants were identified by the Northern Metropolitan Community Aboriginal Health Team. The Aboriginal research assistant contacted them, and invited them to be interviewed for the project. It generally took several meetings to build a sufficiently trusting

relationship, which was facilitated by the Aboriginal research assistant's ongoing professional health worker and advocacy roles in the community.

### ***Health professionals***

In addition, a group of health professionals and other service providers from the Northern Metropolitan Community Aboriginal Health Team was brought together for a focus group discussion. The inclusion criteria for this group were that they provide professional health services or social support to Aboriginal people diagnosed with a mental health disorder, their carers or other family members. The focus group discussion was delayed for a considerable time due to a number of deaths and crises in the community.

## **Data Collection**

### ***Clients and carers***

Interviews were conducted by an Aboriginal research assistant, loosely following an interview guide. Participants could be accompanied by a friend or relative if they wished. Interviews were recorded on audiotape with written and/or verbal informed consent of participants. Participants were assured of confidentiality and anonymity, and could choose not to answer any question and withdraw consent at any time. The interviewer made notes (written and/or taped) to supplement the taped interviews. Eight interviews with clients and carers were completed. Another interview was conducted, but consent was withdrawn and tape destroyed.

### ***Health professionals***

The focus group was facilitated by members of the research team who made notes to supplement the tape recording. Ten health workers participated in all or part of the focus group. The same interview guide was used to steer the conversation. One Aboriginal health worker was interviewed on a separate occasion.

## **Transcription**

Tapes were transcribed verbatim. Sometimes the taped conversations were hard to understand and transcribers indicated missing words or phrases with question marks. A researcher listened to all the tapes and filled in some gaps in the transcripts, and made some corrections. The Aboriginal research assistant who conducted the interviews checked that transcripts were accurate.

## **Analysis**

Preliminary qualitative analysis of each transcript was conducted, based on the four major headings in the interview guide, ie demographics, health services, current health, medications. Key information and quotes were put under those headings while reading and rereading the transcripts and listening to the tapes. These were then categorised further, based on the issues and concepts mentioned in the grant application and interview guide and others that emerged from the interviews. A short summary was then prepared for each transcript. Finally, the findings from all interviews and the focus group were integrated into one document, to give an overall picture, highlighting common themes, key issues, similarities and differences. The process was iterative, beginning as soon as the first transcript was made, and continued to develop as new data arrived and as deeper analysis occurred[22]. Other researchers from the team cross-validated the analysis[23].

## **Development of Recommendations**

The draft report was disseminated to the steering group and the Northern Metropolitan Community Aboriginal Health Team. Recommendations were developed in collaboration with these groups, based on the findings of the report.

## **Findings**

### **Demographics**

#### *Clients and carers*

Two interviews were with elderly Aboriginal women who care for family members with mental health disorders. Six interviews were with Aboriginal people who have a mental health disorder themselves (two women, four men, aged from early twenties to middle age). These participants were formally educated to primary or secondary school level. None were in paid employment or studying at the time of interview, although several of the younger men with a mental health disorder were thinking about looking for work soon, as their mental illness resolved. The women interviewed (carers and women with a mental health disorder) all had considerable family responsibilities. Interestingly none of the men interviewed spoke of their responsibilities to their families, although some acknowledged their families' support. All these client/carer participants received some sort of pension, sickness benefit or other government assistance.

All spoke English fluently, presumably as their first language. Their identification with particular Aboriginal communities or language

groups was not explored in these interviews. They all lived in the northern suburbs of Adelaide, generally in modest rental accommodation. Most lived with their families. The number of adults and children living in the home varied from 1-12. Several participants had been living at the same address for several years, but others had moved house frequently and a number travelled often (within Australia). Some were hospitalised repeatedly for extended periods as a result of mental health disorders.

No further information was obtained from interviews about the family and social contexts of the client/carer participants. However it may be surmised that most struggled financially with little prospect of improved socioeconomic standing in the foreseeable future. Many participants had close family ties which they relied upon for support, for example in caring for children, sharing of resources.

### ***Health professionals***

The health workers who participated were all members of the Northern Metropolitan Community Aboriginal Health Team, which is part of the Northern Metropolitan Community Health Service. They provided social and health support to Aboriginal clients in the community and clinic, including Aboriginal people with mental health problems and their families who lived in the Northern metropolitan area or who were transiently in the area. The Northern Metropolitan Community Aboriginal Health Team takes a holistic approach and deals with a range of issues including housing, finance, counselling, domestic violence, grief and loss, all of which impact on health.

Ten workers took part in the focus group, and of these all but one identified themselves as Aboriginal and were resident in the Northern suburbs of Adelaide. Four of these health worker participants also reported personal experience of caring for a family member with a mental health disorder.

## **Current Health**

### ***Mental health***

The client/carer participants named their mental health disorders as depression, schizophrenia, paranoid schizophrenia, manic depression, psychosis, anxiety and panic attacks, paranoia, bipolar disorder, psychotic episode, mental disorder, stress disorder, tension-related illness. They did not mention dementia. The mental illnesses varied in duration, from 2 months to 20 years. The onset of mental health disorders was mostly in early or middle adulthood.

Several participants who had suffered a psychotic episode spoke of their mental health disorder as transient, and were looking forward to a complete recovery. Others spoke of their mental health disorder as a long term health

problem of fluctuating severity, and believed that they had to live with their mental illness and take medication for life. A number of participants with a mental health disorder described their condition as stable or improving, but others were severely affected by mood swings, paranoia and sleep disturbances.

### ***Onset of mental health disorders***

Most participants first realised they had a mental health disorder after a psychotic episode, attempt at self-harm or other behaviours which led them to be admitted to a psychiatric unit. Generally they were first told by a non-Aboriginal health professional that the problem was a mental health disorder.

*The white folks told me, you know. (#9)*

*I was hearin' voices, I was seein' things...So I went to a white doctor, he diagnosed me as bi-polar, schizophrenic, suicidal, he slammed everything on me until – so he narrowed it all down that I've got bi-polar, mental disorderly and stress disorderly. (#5)*

Several participants linked their mental health disorder to heavy use of alcohol and other drugs.

*I think it was from the speed and the tablets and the whisky that I drank when I was ... young. (#2)*

Other client/carer participants felt that the mental health disorder was associated with traumatic life experiences such as abuse during childhood, grief, stress and tension.

*I believe that there's things there that have either happened to them, or things there that has happened within our family – in our extended family and our family, that is on their mind and they're not talking. (#1)*

*I went to [hospital] ... and they said it was severe grief, that's why I went there, I lost it, that's what they diagnosed, severe grief, that's why I'm on the Zoloft. It was in a way severe grief because before I went away I just locked myself away in the house...I had no one to talk to. (#2)*

*It's a tension illness, I think... Gotta learn to relax. (#9)*

The health worker participants echoed these views, suggesting that the cumulative effect of trying to cope stoically with prolonged stress, grief and loss often precipitates a mental health crisis.

Some health worker participants were concerned that mental health problems arising from traditional Aboriginal beliefs might be misdiagnosed.

*There have been people from traditional lands that have been brought*

*There have been people from traditional lands that have been brought down here and placed into [hospital], and been treated for some form of psychosis. We have to make the medical health teams understand that traditional people still follow the ways of the Law. And we must make the medical people aware of that because ... they can become physically sick or spiritually ill without it being anything in their minds ...and that sometimes they are wrongfully diagnosed as schizophrenics and that. (#11)*

One participant with a diagnosed mental illness believed initially that it was caused by a malevolent spiritual force:

*I thought I was caught because I was seeing [Aboriginal spirit]. I was hearing voices, I was seeing things, I thought I was caught. (#5)*

### ***Information about and understanding of mental illness***

Client/carer participants obtained information about mental illness from a variety of sources. Most were given basic information by general practitioners or on discharge from psychiatric units. The information was given as verbal explanations during consultations and in pamphlets. One carer said she only got information that she asked for and that she wanted more. Another participant was an avid reader and had obtained all the necessary information from books and pamphlets at various health services and community centres.

Some client/carer participants were sceptical and mistrustful of health professionals' diagnoses and physiological explanations of mental health disorders.

*I was trying to go cold turkey off dope and alcohol you know. I was going through withdrawals and I was having a few problems you know. Then I become suicidal and tried to [kill] myself and ever since then they've been pumping pills down my throat you know. And like I'm not suicidal you know like I don't want to take my life, I want to live man. I've got a lot to live for. (#7).  
They, they've given me pamphlets and that you know, about schizophrenia you know but I still don't understand it you know like, chemical, how can they tell if you got a chemical imbalance in your brain you know, how, how can they tell? (#7)*

The health worker participants also expressed reservations about medical explanations of their clients' mental health problems, and believed that some doctors may misdiagnose psychological problems as psychiatric illness. These health worker participants believed that their clients' mental health problems were often rooted in unresolved family stress, grief and loss, coupled with a tendency to not talk about problems due to perceived shame associated with not coping, and for

some people turning to alcohol or other drugs to blank out their pain. According to the participants such people eventually present in crisis at a hospital emergency department where they may be wrongly diagnosed as schizophrenic, depressed, psychotic, etc and be 'dosed up' with medication. There were suggestions that doctors might inadvertently put ideas or words into their patients' minds, (eg concerning self-harm, hearing voices) that confirm the suspected diagnosis. The following quote from the focus group illustrates this view:

*Everybody keeps stereotyping Nunga fellas, especially when the psychiatric assessment is being done in the hospital. You know, sometimes, it is just about depression, sometimes it is just about, like the Stolen Generation, all these issues, you know?.... No one is seeing it that way, you know, its just easy to fill out a medical file and saying they're schizophrenic or what. It's so quick, they're so quick to diagnose, like if you're quiet, or ashamed, which Aboriginal people are, but it's so quick to diagnose, that most of them are just seen as crazy – like schizophrenic or something.  
(#11)*

The health worker participants felt that psychiatrists were overly concerned with diagnosis and treatment of symptoms with drugs, and that this approach was not always helpful. Instead the health worker participants favoured early intervention by psychologists who were seen to take a more holistic approach, exploring and addressing underlying problems through counselling and advocacy. The Aboriginal health team described an innovative project to develop effective partnerships between Aboriginal health workers and mainstream general practitioners to assess and manage mental health problems in young Aboriginal people in the region[24].

Client/carer participants' understanding of mental illness varied widely, and seemed to be related in part to the clarity of health professionals' explanations and participants' ability to understand that information. It was apparent that some health professionals used language that was difficult for clients to understand.

*I've seen a psychiatrist yesterday, but then they're talking way over your head, you know. If you get an ordinary doctor, or get a doctor in that's willing to tell you in plain English, you're understanding what's going on. (#1)*

*I just couldn't really understand what they was talkin' about, you know, it was just going through one ear and out the other anyway. (#3)*

This sentiment was confirmed by the health worker participants who told how their roles included interpreting information for their Aboriginal clients and educating them about their health issues.

A perception voiced by one participant with a mental health disorder was that some doctors might not be interested in helping their patients to understand their illness.

*Yeah, it'd be good to know actually what it really is. I can't really understand my doctors anyway, you know, it's all big words. It's like they just want to talk just to get the money, you know. (#3)*

Participants' understanding of their illness appeared to be related also to their willingness to seek out health information.

*I like to read while I'm sitting there [in the health service waiting room] instead of just looking around so I just grab things and read them. (#2)*

One participant who had experienced a psychotic episode wanted to move on with life, and therefore did not actively seek information about it.

*I haven't really sat down with the doctor and asked her – said - ah - questions. And ah - But yeah, I just - I just try and forget about it all, so the quicker I forget about it, the quicker I'll heal. (#6)*

### ***The impact of the mental illness on mentally ill participants***

The impact of the mental illness on these people was severe. Feelings of shame, embarrassment and isolation were expressed by many client/carer participants. Some also spoke of strained and awkward interaction with their relatives and friends.

*First of all it was shame... I just locked myself in the room for years and years and years. I didn't leave my room, I didn't leave the house. (#2)*

*I had friends come in and see me in hospital... And made me feel - I don't know - fairly embarrassed, kinda thing. And I had this sheila, who I'd been seein' for a while, and she come in and seen me there and... Yeah, it's a bit of a shame job, ... to come and see me in a place like there. (#6)*

*There's a lot of shame in it you know like, because I don't talk to my friends or nothing about it you know. (#7)*

Similarly, the focus group of health professionals mentioned relationship problems, shame and depression, isolation, imprisonment and its ramifications, and financial difficulties as some of the problems experienced by people with mental health disorders.

### ***Impact of mental health disorder on family***

The health workers told how mental health disorders impact on the whole family of the affected person, and how family members seek help from them, including information, counselling, practical assistance and advocacy. However, most of the mentally ill participants had no awareness of any negative effects of their illness

on other family members' health and wellbeing. Indeed several mentally ill participants stated that their mental health disorder had little impact on the family. No-one mentioned loss of employment or education opportunities or the financial drain on family resources. The expectation that families will care for their mentally ill relatives whenever necessary was accepted by the carers.

*Nine times out of ten, they send them home to their family, you know ... families wouldn't turn them away. But you know, families get worn out too. (#1)*

Similar feelings were expressed by a carer about looking after a mentally disturbed relative's children.

*It's natural thing for me. They're my concern. Even though they mightn't be doin' me any good like 'ealthwise. (#8).*

Although not explored in depth during interviews with clients and carers, mental health disorders clearly had a great effect on the emotional wellbeing of families. This was usually not articulated, but seemed to be accepted with stoicism. One carer told of repeated verbal abuse and threats from a mentally ill relative, particularly after a drinking bout.

*Quite often when he's not well, he'll threaten me, when he's drunk, he'll threaten me, he threatens me and [name] quite often. ... "I'll bash you , I'll do..." and we just keep him back. But I say one day you know that might start and he might do it, who knows. I mean, he wouldn't do it intentionally, but he does get that way, gets really angry with – but he comes home from drinking and he gets really angry, and he'll – er - he doesn't hit us, but he'll abuse us. You know we've got ... kids here and he'll abuse us, the kids are asleep, and he'll wake them all up, you know. He's hopeless when he's on the drink...Next morning he's a different person altogether. (#1)*

Another participant with mentally ill family members had experienced negative impacts of their illness, including stress, verbal abuse and blaming.

Both women with mental health disorders acknowledged the negative impact of their illness on their children. One had to relinquish a child because her illness was so severe that she could not care for it. These women said that they did not want their children to see them in a very disturbed state or dependent on medication.

*I have always said that I don't want my [kids] seeing me going into a psychiatric ward because its not fair on them. (#2)*

*I used to wake up every mornin', "Where's my tablets, where's my tablets?" I didn't want my kids to see me like that. (#5)*

One positive impact of mental health disorders on the family was mentioned by a participant with a mental illness who returned home to recover. The participant told how the family had become closer, and now ate decent evening meals together rather than just getting take-away food, and how this would benefit the health of family members.

***Police attention as a result of mental health disorder***

Most client/carer participants did not talk about police attention as a result of mental health disorders. However, several mentioned that they had called the police or the Assessment and Crisis Intervention Service (ACIS) for help in emergencies, eg:

*When I get low, I'll ring up, always ring up with the police, I can't get any [medication]. Cos I'm frightened I'll hurt myself. But I always do that. (#5)*

*I tell them that I'm a schizo, I tell them I'm suffering from bipolar, I've got a mental illness, can ACIS come round and bring me some tablets. There's a team called ACIS, and they go out and get it out to the Aborigine guys here. (#5)*

Participants said that police were polite and helpful in such circumstances. Others called ACIS directly in such situations. Those who called on these services for emergency assistance were generally satisfied with them. However, one carer felt that the use of locked police vans for emergency transport of her mentally ill relative to a psychiatric hospital was inappropriate.

*He's sick, he's not a criminal, you know. (#1)*

One carer expressed a reluctance to involve police in a mental health emergency.

*I haven't got to the stage of ringing the police. Very nearly got into the stage of ringing the police for them, and you know, you think twice, you don't want to get 'em, police come and pick them up. (#1)*

***Factors that make the mental illness better or worse - medication***

The carers said that the symptoms of mental illness worsened markedly when prescribed medication was stopped, and improved when medication was resumed.

*He can go good for a while, and then he'll think that he's well, and then he won't take his medication, and then he'll break down. (#1)*  
*[Name] travels around a bit, and he might miss his needle, or he just came back the other day and he was very agitated, and he was a week over having his injection. So, we know he's had it [now], cos he's as okay as a fish today. (#1)*

The focus group of health workers also spoke of the tendency of some people to stop taking their medication when they felt better.

However, most of the mentally ill participants also acknowledged that the prescribed medications made them feel calmer, eg:

*The medication that you get – times you get the - throw things – smash things ... get a bit stressed out – just relaxes you more. (#3)*

***Factors that make the mental illness better or worse – alcohol, marijuana and tobacco***

Alcohol, marijuana and tobacco were named by many participants as substances that either exacerbated or ameliorated mental illness symptoms. Some participants believed that alcohol and/or marijuana were involved in the onset of their mental health disorder and therefore avoided them, fearing a relapse.

*Too scared to [have a beer]. In case I buzz out again or something. (#6)*  
*Others were making efforts to stop smoking marijuana and drinking alcohol on medical advice.*

*I gotta keep off the drink an' the dope an' that. But I smoke a little bit of dope. (#9)*

*I am surrounded by alcohol and smoke and marijuana. It's a hard way of living but I don't want to drink, the temptation is there all the time but I think that if I drink I'll have nothing. (#2)*

However many participants felt that alcohol and marijuana helped them to cope with their mental health disorder.

*Yeah, I smoke my [marijuana] pipe. That's good, that helps me stop hearing the voices, cos I hear voices too, and it stops that.  
...Because I have a smoke in the morning, to get me going... It doesn't affect me much, I tell you. (#5)*

Another participant with a mental illness who smoked marijuana habitually for many years expressed the belief that it was a more effective tranquilliser than prescribed medications. This participant felt that sudden withdrawal from alcohol and marijuana could exacerbate mental health problems.

*Well that's it see I've gone through the horrors you know like I smoke and drink for a couple of years and then when they lock me up in the psychiatric ward like you go cold turkey cos you're in a place where you can't go buy a beer over the counter or you can't have a cone you know. And like they keep you there for three or four weeks and your body's withdrawing from it you know. (#7)*

Tobacco was used by a number of participants as an aid to relaxation.

*What [tobacco] does is it relaxes me, mainly at night when the kids are asleep then and it's like a relaxant, like a herb to me, it relaxes me. (#2)*

***Factors that make the mental illness better or worse - family and friends***

The company of family and friends helped several participants cope with their mental illness. For example one person valued a sister's support during periods of depression.

*But my ...sister has been there for me you know, out all my family it's been my ... sister that's been there for me. (#7)*

Several mentally ill participants acknowledged the support of their families. Others felt that isolation made them feel worse and that simply chatting with friends helped them cope.

One mentally ill participant with young children said that her parenting obligations gave her the will to manage her illness, avoid alcohol and other drugs, and interact with the community.

*My [kids]s, they keep me strong mainly, my mother, yeah mainly my family. (#2)*

*I think that if I drink I'll have nothing, and I won't have my [kids]. (#2)*

*My [kids] make me do a lot of things, go to kindy, go to the school, mix with the teachers, mix with parents of the kids, they made me get out. (#2)*

*My [kids], they drive me crazy, but they give me something, I can't explain it but they make me do things, they make me be strong. They make me not want to be the depressed mother and I have always said that I don't want my [kids] seeing me going into a psychiatric ward because its not fair on them. I have to keep myself strong and if I need help its just on the end of the phone. Its so easy, why go stupid and end up in a psychiatric ward, I don't want my [kids] seeing me like that and then they have to leave you and that's very hard. (#2)*

***Factors that make the mental illness better or worse – professional counselling***

Talking over problems with health professionals was also beneficial for some participants with mental health disorders during stressful times.

*When I get stressed out here, at home, you know, and that's with my family because of their mental illness and I do go over there and talk to [name] the counsellor or the doctor, because I have to, because I feel as if the medication isn't doing any good for me. I go over there to get reassurance and then they talk to me calm me down and make me feel better. (#2)*

The health worker participants also spoke of the value of helping mentally ill clients to deal with their underlying problems.

### ***Carers' coping mechanisms***

One carer coped with the burden of looking after her mentally ill family members with a positive outlook and music.

*I won't let my mind, myself, think of anything destructive (#8)  
And talk about depression – oh, I just put my tapes on and sing  
some songs, and I'm back up again! (#8)*

### ***General health of participants***

The general health of participants with a mental health disorder at the time of interview varied. Several mentioned that they had other health problems such as diabetes, asthma and chronic headache. Similarly, the health workers reported that many of their clients were living with multiple health and social problems, including diabetes, renal failure, substance misuse problems, brain injury, homelessness, isolation, domestic violence and sexual abuse.

Some mentally ill participants self-managed their health effectively, eg:

*I look after myself because I don't want to get sick, I don't want to go to hospital. I have been a diabetic for [many] years... I just control it with what I eat and I don't take nothing (#2)*

Other participants did not manage their health problems so well, eg one person with a mental health disorder had severe recurrent headaches but had not discussed them with the doctor and took large amounts of paracetamol each day. Another suffered asthma but did not take medication prescribed for it:

*I just cope with it the best way I can (#7).*

Some participants mentioned recent elective surgery and self-inflicted injury, whereas others were relatively fit and well apart from their mental health disorder. Fitness training with a view to involvement in organised sport was important for two of the younger male participants.

### ***General health of carers and other family members***

The carers, who were both older women, had significant physical health problems of their own (cardiac and respiratory illnesses, diabetes). The general health of other family members was not much explored during interviews. One participant talked about her children's hearing and speech problems. The interviewer's notes/comments suggest that several participants had close family members with significant physical health and substance misuse problems.

It is notable that several mentally ill participants said that other family members had mental health disorders too. Both carers interviewed had several people with a mental health disorder and/or substance misuse problems in their direct care. The focus group of health workers also told of families in which up to five people were suffering mental illness.

## Medication

### *Types and sources of prescribed medications*

The participants had been prescribed a variety of medications for their mental health disorders. Medications were generally in the form of tablets and/or periodic injections. Many participants did not memorise the names or dosages of their medications, and one referred to them by colour and size. Several commented that they had been prescribed many different medications over the years.

Prescriptions were usually obtained from general practitioners, the South Australian Mental Health Service, hospital clinics or Brady Street Nunga Centre and filled at local pharmacies. Most participants with mental health disorders were responsible for obtaining their medications themselves, but several were taken to clinics for injections and tablets were dispensed at the same time. Others talked about medications being delivered to their homes.

*We know the nurse that comes around, yeah, and she – and SAMHS provides the medication for us, so they bring the medication here. And it's put out in their boxes, you know those little boxes, separate boxes, and that's each day, and each time they have to have them. (#1)*

### *Feelings about having to take medication*

Several mentally ill participants felt shame about having to take medication for their mental health:

*There's a lot of shame in it you know like, because I don't talk to my friends or nothing about it you know. Like that I have to have pills or whether I'm on pills. Do I have an injection, like, its just not talked about you know, like because of shame. (#7)*

Other feelings about taking medication included anger and annoyance, particularly for those on long term treatment.

*Oh it's really shit. (#9)*

*At first I think she was a bit angry, I s'pose, is the word that you're looking for. (#8)*

*Well, I don't know, just get pissed off at times and I don't want to [take medication], but I have to, just to keep myself at ease. (#3)*

It was difficult for some participants to accept the need for medication as they had rarely been ill before.

*It's bad enough just taking Panadol when you've got a headache or stuff like there. I'm a fairly average kinda person, never get sick or anything, and ah I used to hate taking medication. (#6)*

Despite these feelings, most participants took their prescribed medication because they believed it alleviated their mental health disorder.

*Well, they're just to make me - easy, more to relax, makes it easier to understand myself at times. (#3)*

*Not nice to take tablets, but you know, you know that this is going to keep you on that level, you do it. (#1)*

Another spoke of her relief at finally finding the right medication:

*I have found a[n anti]depressant tablet that suits me that doesn't make me half doped up all time, walking around like a zombie. (#2).*

In contrast, another participant with a mental health disorder felt forced to take medication.

*I feel like I have to take pills and medication against of my own will. (#7)*

*Well, well if I refused to take [medication] they would put me on treatment orders you know. (#7).*

However there was a tendency to reduce or cease prescribed medication when feeling well, evident in these excerpts:

*He can go good for a while, and then he'll think that he's well, and then he won't take his medication, and then he'll break down. He doesn't understand that he's going to break down. I tried to tell him that - like I take tablets every day, and I said well you take your tablets too, at the same time, and that worked for a little while, but then he said, Oh, I feel really good. And I said, Yeah, I feel good too when I wake up in the mornings, but I still take my tablets, you know? But I haven't been able to get that through to him. (#1)*

*The majority of the time I would just throw [prescribed medications] straight in the bin as soon as I got them because I didn't think I needed them. (#7)*

Several had experienced a decline in their mental health after ceasing tablets, eg:

*I took myself off the tablet, and I got worse, and now I'm back on the tablets. (#5)*

*I know that with the Zoloft I take 100mg a day. I don't take them all the time, I take them and then I might not take them for 5-6 days and then I think I feel I am losing it and I go back on them. (#2).*

A mistrust of medicines and a lack of confidence in them was apparent in some interviews with people suffering a mental illness

*Pills aren't going to solve my problems you know. (#7)*

*In my mind ... I think the doctor knows best, but really I don't think the doctor does know best, do you know what I mean? (#2)*

The health workers agreed that some Aboriginal people are suspicious of Western medicines. They were keen to offer traditional methods of

healing, but funds were not readily available to access the services of traditional healers (Ngangkari), who are not always regarded as legitimate by mainstream services. One participant with a mental health disorder was disillusioned with the continuous alterations made to the type and dosage of medications prescribed by doctors and wanted an Aboriginal treatment.

*I get sick of it. I want to go on black medicine leaf, if there is any. I know in my heart there is some there. The community that will find something for us Aboriginal people to help us. 'Cos the white people, I'm not being racist, I know it might sound it, but it seems to me they give me - a whole lot, like- two years ago I was takin' 6 - 8 tablets a day. Now I'm down to 4 tablets a day. ... but in another 2 weeks time I'll be taking another 4, then another 4, that'll be 8. Then I'll be askin' a lot of questions. (#5)*

Interestingly, the Aboriginal health worker participants also spoke of a subgroup of Aboriginal clients who followed their doctors' instructions unquestioningly.

*A lot of our elders in the community have got so much faith in the doctors. (#11)*

#### ***Information about and understanding of medications***

Client/carer participants obtained information about their prescribed medications principally from their general practitioners, hospitals and clinics. Much of the information about medications was given at the same time as information about mental illness (see elsewhere in this report). Leaflets were mentioned, as well as printed information on the medication packages and inserts. Other sources of information included television and Aboriginal health services.

*I get some off the TV, I get information from off the health shows programs on the TV, but mainly from Nunkuwarrin Yunti because I'm over there mainly and looking at the pamphlets and everything's there, and reading up. (#2)*

One person also told how a group of acquaintances with mental health disorders compared notes about medications.

*And we actually compare with each other, you know. What's that like? What's this like? It does this, it does that. (#3)*

The health worker participants believed that most of their clients had little knowledge or understanding of their medications, what they were, why they were prescribed, when and how to take them. Members of the focus group told how they spent a great deal of time interpreting and reinforcing medication information for their clients, particularly traditional or transient people who have difficulty with English language or those with cognitive deficits. They believed that

doctors and pharmacists provided their clients with insufficient information about storage, side effects and interactions of medications. The health worker participants felt that doctors and specialists should take the opportunity to review and explain medications and explore wider health issues during all consultations with Aboriginal clients.

Interviews with Aboriginal people with mental health disorders revealed varied levels of knowledge and understanding about their prescribed medications. Most understood their doctor's explanations, although it was not clear from the interviews what they knew. Some participants indicated that they would be confident to ask doctors for more information if they wanted it. In contrast, others knew very little about their medicines, either because they preferred not to know, or because they did not understand the words used. The issues impacting on understanding of health information are discussed elsewhere in this report in relation to information about mental illness.

A need for more information about medications and for more simple explanations was expressed in several interviews with clients and carers. One of the carers had asked doctors for information but wanted more, particularly about the effects of medication and the expected time before medicines work. A mentally ill participant who had experienced worrying side effects wanted more information about the long term effects of the drugs.

*I'd like to know the side effects that its having on my heart, on my ah kidneys and liver and all that you know. Like on my body organs like because I know the medication, like it wears me down you know and so I know it must be doing something to my heart and liver and kidneys you know. (#7)*

No-one had considered talking to a pharmacist about medications for mental health disorders, although one participant questioned chemists about over-the-counter medicines for her children's minor ailments. Most described their interaction with the pharmacist as an impersonal and rapid business transaction.

*I just walk in there, pay for it and walk out. (#3)*

*No. Don't really talk to him. I just go there, put my prescription in, get my medication, pay for it and that, that's it. (#7)*

One of the health workers believed that pharmacies were intimidating to some Aboriginal people.

*A lot of these people don't trust chemists – um - bit of a shame job there. ...Because they're not served – they're not treated very well at the chemists. Oh not always, but, - and one of the reasons ... is that chemists these days do not just dispense medication. There's an expectation that you'll buy something else when you walk in there.*

*There are all these different things on display. And 'Ooh, we don't have the money for that,' because in fact they don't have the money. They're there just for their health, scrape up their \$3.25 or whatever it is for the script, and so in the pecking order of things, if somebody's there looking as if they're going to spend – I don't know, oh buy, say, a \$10 bottle of Benadryl and um some perfume and that sort of stuff, and that seems that that person will get served before someone who's just got a \$3.25 script. (#10)*

### **Side effects of medication**

Side effects of prescribed medication were mentioned in all interviews. Participants had experienced a range of debilitating side effects including stiffness, lethargy, movement disorders, headaches, cramps, dizziness and more, as illustrated by the following excerpts.

*Walkin' crooked, drivin' crooked, getting sore glands in my throat... big guts, you know, loose bowels in the back, something like that – side effects. (#5)*

*Ah. They said you might feel a bit dizzy, like lightheaded - which I have been feelin' since I've been on the tablets, I haven't really felt like myself, like – feelin' lazy and feelin' like, really slow, and I'm starting in basic terms, like a robot. (#6)*

*Stiff neck, cramps in the guts, cramps in the kidneys, legs ah going stiff and that you know, and it feels sometimes like my arm is there but there not there like I got something wrong with my wrists you know. (#7)*

Side effects were described as life threatening in some cases. For example one participant told of almost choking in hospital due to stiffness of the neck and muscle spasm which were side effects of prescribed medication.

Memory loss was attributed to medications.

*Then these white[man's] medicines – it's - I can't remember when I was 5, I can't remember when I was 13, what I did, because all these things, tablets are takin' away our memories. (#5)*

*You know, when I was in hospital– I was in there for two weeks– and I can't remember the first week, and I said – I lay in my bed at night time trying to think what 'appened during that first week, trying to remember what 'appened and I can't. (#6)*

A number of participants had experienced particularly unpleasant side effects of lithium, of which one was bedwetting.

*That's the lithium, now they have side effects. I wet the bed, I don't want to go on with them. Like I have a big big big sleep, and I get out of bed. It's a bit embarrassing to me when I wet the bed at my age, like I was two years old. (#5)*

Participants all said that their doctors had warned them of some side effects from the prescribed medication. However it was evident that participants experienced many other side effects that had not been mentioned by their doctors. It is unclear from the interviews how much information was given or understood about potential side effects and what to do about them.

*When I first went in, yeah, he's mentioned, yeah, he's said a few things, but you know it's hard to really understand all the big words, try to break it down, you know. Virtually just gotta listen to what they say, take what they give, and out the door. (#3)*

Some said they had consulted the doctor about troublesome side effects, and that the dose was subsequently adjusted to reduce the problem.

One of the health workers believed that many people who experience unpleasant side effects may cease taking medication rather than seeking help to get more appropriate medication regime, particularly if the possibility of side effects was not explained satisfactorily.

*They're given a [medication] regime and expected to stick to it, and if it's not working, well then, people stop. (#10)*

Health workers agreed on the need for professional monitoring to ensure appropriate medication for each client and to increase compliance.

### ***Other licit medications***

The participants with mental health disorders were generally not using prescribed medicines for health problems apart from their mental health disorder. Indeed most were otherwise well. One had diabetes which was controlled by regulating diet. Both carers were taking prescribed medicines for cardiac and respiratory illnesses.

Most participants did not use over-the-counter medicines on a regular basis, apart from one mentally ill participant who took large amounts of paracetamol for recurrent headaches.

*Yeah, well – I sorta get up now, I'll just pop a couple of Panadol before [the headache] kicks in, you know, I know what's going to happen...I take three, straight away. If it's still there I'll just take another three again ... It all depends if I've still got the headache, if it's still there, I'll keep on taking couple more. (#3)*

This participant had not discussed this with the doctor and was urged to do so by the Aboriginal research assistant who conducted the interview. It was unclear whether the participant was aware of the potential for liver damage from excess paracetamol.

The health workers had experience of some mentally ill clients who took prescription medicines that were not meant for them, such as antidepressants and sleeping tablets.

Several participants told how they were not accustomed to pharmaceutical remedies until they became ill. One of the carers described growing up with little exposure to or awareness of health problems or medicines, and how this was in part due to being brought up not to ask questions of elders.

### ***Alcohol, marijuana, and other drugs***

As indicated elsewhere in this report, several participants with mental health disorders had a history of misuse of alcohol or other drugs, and/or mixed with people who used these substances frequently.

*Oh I still drink and smoke today you know. ...Oh well like most of the Nungas I know smoke and drink. (#7)*

The focus group of health workers agreed that harmful or hazardous use of alcohol and other drugs was common in their community. They felt that drug and alcohol problems were often rooted in a desire to block out pain and trauma, grief and loss, boredom, purposelessness and isolation. They described a deepening spiral of family and community breakdown associated with these problems. However, they also pointed out that alcohol and drug abuse is a learned behaviour, and cited the negative effects of peer pressure, poor role models in the family and community expectations. Illicit drugs mentioned by health workers included heroin, amphetamines and marijuana. They also mentioned how habitual recreational use of drugs may increase as users become accustomed to them.

Mentally ill participants had been advised to give up drinking and smoking, and most had done so, or cut down. Only one mentally ill participant continued using large quantities of alcohol and various other drugs as well as prescribed medication.

*I like drinking alcohol, you know. If I have a coupla beers I black out – and next morning, I'll be told what I've been doing but still can't remember, you know. (#3)*

*Taken other odd things, you know, like, been offered a few other medications, you know, bit of a mixture at times. (#3)*

*At the time it seems all right, you know, because your body just relaxes, my mind does too. Aw, next day you wake and it's all the same again. (#3)*

According to the health worker participants the use of cocktails of prescribed medications, alcohol and illicit drugs is common.

It was acknowledged that alcohol in particular led to conflict, eg one participant with a mental health disorder admitted that alcohol contributed to forgetfulness and feelings of anger.

*I get a bit forgetful at times, get at times a bit angry, you know. (#3)*

The carers talked about abuse and threats of violence associated with misuse of alcohol and other drugs, eg:

*They're smokers and they're drinkers. Moselle, wine, anything from a bottle...And that's when we have trouble... There's no control. We can't control them. (#1)*

One carer was concerned that using alcohol might interfere with a mentally ill relative's compliance with prescribed medication.

*The only thing I'm wary of is that's she's starting to have a - alcohol again, you see, and er whether she'll stop taking her medication I don't know, you see. Because um if I ask her, she'll get angry with me. And so er I just hope that she's - you know, knows what she's doing. (#8)*

Marijuana was popular with many participants. Being readily available and widely used, it was regarded by many as relatively benign.

*[Doctors told me] that I gotta keep off the drink an' the dope an' that. But I smoke a little bit of dope. (#9)*

One mentally ill participant preferred marijuana to prescribed medication, believing it to be more effective and less harmful.

*Even one of my cousins said to me like look I've seen you on dope and I've seen you on them pills and he said to me I prefer to see you on dope than what them pills do to you, you know. (#7)*

The section of this report on factors that make mental illness better or worse explores marijuana, alcohol and tobacco use in more depth.

### ***Compliance with prescribed medication***

Most participants reported that medications were taken according to the directions on the packet. Compliance with the treatment regimen was enhanced by taking the tablets at set times, such as with meals, or on waking or retiring. Sometimes family members reminded participants to take their tablets. Participants who accepted the benefits of prescribed medication were generally careful to comply. The health workers noted that homeless or transient people often have difficulty complying with medication regimes, as they may not carry their tablets or prescriptions with them.

Few participants with mental health disorders used a dosette to organise medications for the coming days. Those that did generally had the dosette filled by a health professional during clinic visits. The health worker participants felt that more widespread use of dosettes or bubble packs would enhance compliance, particularly for confused clients, or those with dementia or other brain damage. Several participants with mental health disorders admitted that sometimes they did not remember whether or not they had taken a tablet, but most said they would not take a tablet just in case.

Participants were asked if they had ever deliberately stopped taking medications. Several had done so, but had quickly noticed a decline. Some participants admitted reducing or ceasing medication when feeling well, and this is explored elsewhere in this report. It is not clear whether the potential danger of sudden cessation of prescribed drugs was fully understood by participants, or whether health professionals had discussed this with them. One person described how blood pressure dropped to dangerously low levels after suddenly ceasing to take tablets.

*I don't like taking the Zoloft mainly because I read about it in the little pamphlet that you get in the box. I did go off the Zoloft, cut off, and it ended up my blood pressure went down to  $90/70$  and I didn't know what I was doing. I didn't even know that they were withdrawal symptoms from the Zoloft, just automatically cutting them off. See I left it too long that time and I got back on them and I'm alright, I just have to take them. (#2)*

Another mentally ill participant was mistrustful of medications and had suddenly stopped taking medications on several occasions, resulting in withdrawal symptoms, followed by an improvement.

*[I sometimes stop taking medications] because I'm against pills.... Oh well maybe at first [I feel sick]but after a couple of weeks of eating right and exercising and like drinking plenty of water I start to feel better you know. (#7)*

Participants with mental health problems said that they sometimes reduced the frequency of prescribed medications to make them last until the next payday or clinic visit.

*If I've got 5 [tablets left] and I've got a week to go...then I will take one every second day to get me through. There are 25 in the packet and when I am down to the last 5 and I haven't got any money then I will spread them out. (#2)*

Others simply went without medications if they ran out. The health professionals said they knew of clients who would take extra medication to make up for missed doses.

Client/carer participants were also asked about any times when more medication was taken than prescribed. This was rare, with most instances having occurred long ago in the context of a deliberate overdose. Only one person admitted increasing the dosage according to how the participant felt at the time.

*Just take another one, and that's all there is to it. Depends how my mind is, I suppose. (#3)*

Most participants said that they would not take more medication than was prescribed if they were feeling low, eg:

*Um - I suppose I'll just have my down days. (#9)*

### ***Inappropriate prescribing/dispensing of medications***

The health worker participants told how some patients took unnecessary or duplicated medications following discharge from hospital:

*A lot of them, as I said, [are] getting discharged with tablets from the [hospital] pharmacy, going home, they've got them all lined up in the cupboards there, it says, 'take one here', then this other tablet says 'take one', and they're exactly the same tablets but they're not being explained all of that, and that's where that overdosing ... occurs within a lot of our elder fellas because 'the doctor knows best'. (#11)*

The health workers talked about how difficult it is to address such problems because the Northern Metropolitan Community Aboriginal Health team has no formal link with the hospital pharmacies. They believed that health workers, doctors and pharmacists should work together to ensure that clients understood that they should discard their old medications in such cases.

Several cases were described where people with a mental health disorder were provided with very large amounts of medication. For example a carer told how her mentally ill relative, acutely distressed and already on medication, visited the clinic and obtained a large quantity of additional medications, subsequently overdosed and was rushed to hospital. The carer felt it was inappropriate to send a depressed and suicidal young person home with a large supply of drugs. She complained to the clinic, saying:

*That's not right, you know. A ... kid goes over there, telling you he's depressed, why didn't you get him in to see, you've got counsellors, why didn't you get him to see a counsellor as well? Or send him down to SAMHS would be good as well as giving him tablets. Why give him 500 tablets? (#3)*

Another participant described attending two hospitals within a week and being discharged with supplies of separate medications from each hospital, about 30 boxes of tablets in all. The participant did not want to take them, and threw most of them away. Each fortnight more tablets were delivered to the participant's home, and again usually thrown away. There was no follow-up to determine compliance or whether the medication was helping. The participant simply accepted them to avoid treatment orders.

### ***Storage and disposal of medicine***

Client/carers participants said that medications were stored out of reach of children, hidden in bedroom drawers or up high, but not in a locked medicine cabinet. They were confident that no-one else in the

family had access to the medications and that children in the household would not take them. Medicines were stored in their original containers, and repeat prescription sheets were generally kept with the medicines. Participants knew how to tell if medicines were expired or damaged. Most discarded out-of-date and unwanted medications into the rubbish bin.

### ***Stockpiling***

Most participants used up their medications before obtaining a fresh prescription, and so stockpiling was rare. However, some participants admitted keeping quantities of medicines at home for emergencies.

*Look, you know, what I do is that I just stockpile these medicines at home, I've got the biggest heap of them at home, and I just keep 'em there in case I need 'em. (#5)*

Stockpiling was more likely if medicines were perceived as hard to obtain. For example one person mentioned how difficult it was to convince the doctor to prescribe a sedative. Another kept a large store of tablets designed to counteract muscle aches and stiffness, side effects of the medication.

### ***Sharing medications***

According to the client/carer participants, sharing of medicines did not occur, with most being aware of the potential harm that could occur from sharing medications. One told how an acquaintance became stiff and dangerously short of breath after taking the participant's medicine without permission. The participant recognised the problem as a side effect of the medication, enabling prompt life-saving paramedical attention. Most people with mental health problems or their carers emphatically disapproved of sharing prescribed medicines. Only one participant admitted ever deliberately sharing medicines with peers. In contrast, the focus group of health professionals believed that sharing of all types of medications is common, including prescribed medication for mental health disorders, particularly among transient people.

### ***Cost***

Client/carer participants were all in receipt of some type of pension or benefit. It appears that some people obtained medications free, whereas others paid the minimum amount for their prescriptions. A figure of around \$3 per prescription was mentioned by one participant. Several participants were taking a number of medications, and so the cost of these items was a strain on a limited budget. As mentioned elsewhere, some people said they eked out their medications to last until next payday. One of the carers told of lending money to a relative to pay for prescriptions.

The focus group of health workers agreed that cost was a major issue for many of their clients. They told how some people had to obtain their medications from the public hospital pharmacy because it was possible to obtain the tablets and be billed later. However this meant many hours of waiting in the emergency department and formal assessment, which may not be possible when clients have other responsibilities. The health workers said they sometimes paid for clients' medication from their own pockets in such cases, as illustrated by this quote:

*Yeah, there was one not long ago that needed heart medication and was um ringing us to see if we had the money to pay for his medication, he needed two different sorts of medication. I had to get back to him, but, like, if you're going through the hospital, and they give you a script for medication at the pharmacy over there, they will let – they will bill you and send it out. But he had an outside medication, so – which meant that the hospital wouldn't take an outside medication, so what he has to do is go back to A&E, go through – get assessed and everything, get the script, and go. And he wasn't prepared to do that, yet he really needed his medication, but he didn't want to go sitting in there for another six hours like he did the week before. So um what happened with him was, we ended up getting money for his medication, but – out of our own pockets as well. (#11).*

## **Health Services**

### ***Mainstream health and community services***

Mainstream services utilised by client/carer participants included South Australian Mental Health Service (SAMHS), psychiatric hospitals, other public hospitals with mental health facilities, mental health outreach services, Assessment and Crisis Intervention Service (ACIS), the Northern Metropolitan Community Health Service, local general practitioners and pharmacies.

Most participants with mental health disorders had seen health professionals in many settings, and told of having to repeat their story each time they saw another doctor.

*Yeah. The whole story, over and over. It's 'appened every time. I get tired of it. So I just sit back and wait, if they ask a question I'll tell 'em. (#5)*

There was a feeling of frustration and some had resorted to minimal conversation with their doctors.

*No, I just walk in and ask you know, he just asks me how I'm doing, I just tell him how I feel, and they give me a prescription, and I leave. (#3)*

In contrast, other participants had developed a good rapport with their health professionals and felt comfortable talking to them.

The health worker participants said that many of their clients, particularly those who were transient, did not visit a particular doctor or clinic regularly, and consequently had multiple, sometimes duplicated, medications. The health workers were concerned that the various doctors did not know what the others had prescribed, and the vulnerability of such patients to overdose.

Some GPs were known by participants with mental illness as *script doctors* (#2) who would write prescriptions without examining or questioning them. One participant spoke of having two doctors, one who monitored and prescribed medications for the mental health problem, and another who prescribed extra drugs *for a headrush* (#3) without asking questions. Health worker participants agreed that some people might visit several doctors to obtain other prescription drugs, but felt that this was relatively infrequent.

#### ***Aboriginal health and community services***

Services specifically for Aboriginals were widely used including Brady Street Nunga Centre, Nunkuwarrin Yunti and the Aboriginal Health Team at Lyell McEwin Hospital. The Aboriginal Sobriety Group was also mentioned. Interestingly, a number of the client/carer participants were unaware of these Aboriginal services, and relied totally on mainstream services. The focus group of health workers were from the Northern Metropolitan Community Aboriginal Health Team, which is part of the Northern Metropolitan Community Health Service. This Aboriginal Health Team was known to all the client/carer participants.

Several people expressed a desire for more Aboriginal services and supports in health and community services. For example a mentally ill participant wanted an Aboriginal doctor.

*I really like to go to an Aborigine doctor. (#5)*

A carer was concerned about the lack of Aboriginal-specific followup services for people coming out of hospital.

*You know? There's nothing for them. There's no place they can come, no place they can go. They can go to Midway Road, where they've got a little centre there, for people coming out of the hospitals, but they said, Oh we're not going over there, you know, they're all white people. There's no Aboriginal thing like that set up for them. (#1)*

This was echoed by the health worker participants who were frequently asked to help with hospital discharge planning arrangements for Aboriginal clients. They generally suggested

followup care from Brady St or recommended a doctor from a list of local general practitioners known to be sympathetic and respectful towards Aboriginal people.

The health workers' focus group argued that there was an urgent need to train more Aboriginal health workers to work in the community. Furthermore they called for an increase in the number of Aboriginal doctors, social workers, services, counsellors, liaison people in all mainstream services to deliver culturally appropriate care. They spoke of the reticence of some Aboriginal people to use mainstream services where they are likely to be stereotyped and labelled. The health workers knew of people who had discharged themselves from hospital because of rudeness and discrimination, and how they wanted members of the Aboriginal Health Team to accompany and advocate for them on their next hospital visit. According to the health worker participants, some Aboriginal people are ashamed to go to mainstream health services, especially if they have been abused and have physical injuries.

When discussing a need for mentally ill people to talk about their problems a carer suggested that Aboriginal clients would be more likely to talk openly with Aboriginal counsellors than with white people.

*I don't think they'll speak in a – in a hospital because it's all – all Goonyas, and white fellas. But if they um - if there was Aboriginals going in there that they made friends with, or knew, I think it wouldn't be too hard for them to open up. (#1)*

Several participants said they appreciated the fact that the interviews for this project were conducted by an Aboriginal researcher.

#### ***Gender-specific and age-specific services***

None of the clients or carers interviewed knew of services aimed specifically at men. One mentioned a women's health centre that she had used in the past. Only one female participant with a mental health disorder expressed a particular need for gender-specific services. She said she had great difficulty talking to white males, and would be more comfortable talking to a woman or an Aboriginal person. However the worker participants said that mental health services aimed at men, women and youth were sorely needed in the Northern metropolitan region. In particular, there is nowhere for youths under 18 years to go in a crisis after hours.

#### ***Drug and alcohol services***

Drug and alcohol services named by client/carer participants included Brady Street Nunga Centre, Aboriginal Sobriety Group, and Warranilla.

However most did not know where to go for help or information about drug and alcohol problems, although one thought that information might be available from chemists, medical centres, welfare offices and schools.

One of the carers would have liked her mentally ill relative to be compelled somehow to address drug and alcohol problems, but understood that this had to be the relative's own decision.

*I asked about could there be an order put on him to - so he stops with the drugs and alcohol, or he goes, he goes and has some kind of treatment, and they said they can't do anything because it's a personal thing. But he needs to ask for that himself. (#1)*

#### **Respite care, home help, etc**

None of the client/carer participants had ever had any respite care. This included the carers who had been looking after their mentally ill relatives for many years, and mentally ill people with family responsibilities.

*I've never had respite, never. (#2)*

The health workers confirmed that many carers do not know that respite could even be a possibility.

One person with a mental health problem had been attended by a district nurse at home for post operative care. Some had limited help with daily living at home. Another had some assistance from a community service group with social activities, but was unaware of any other sources of help.

#### **Support for carers**

Although no complaints were voiced by the client/carer participants, it was apparent that money and resources were in short supply, and practical assistance was nonexistent, making each day a struggle. The carers had no access to respite care, which added to their burden. This is significant given that both carers interviewed were elderly women with severe health problems of their own and considerable family responsibility. The health workers agreed that carers are in great need of support. They told how carers are expected to look after their relatives, and of the difficulties this posed, particularly in families in which several people had mental health problems.

#### **Access to health and community services**

Most client/carer participants relied on public transport and walking to get to these services. Some were provided with transport to attend clinics, and this was appreciated. Carers had no help in reaching services which caused them difficulty, particularly when visiting hospitals far from home.

The health workers frequently mentioned the need for more transport assistance for their mentally ill clients.

*They won't access any services – if they can't get there, they just won't ... there are some people that just don't know how to get there unless we pick them up. (#11)*

The focus group of health workers described how mainstream providers misunderstood the role of the Northern Metropolitan Community Aboriginal Health team in providing transport for Aboriginal clients. The Aboriginal Health team has traditionally provided such help when there is no alternative, but it was perceived that this practice has been taken for granted and is sometimes used inappropriately by mainstream providers.

*We can't say no to our own, you know, that's how we are. But you know... the erm mainstream organisations are seeing that ... [the] Aboriginal Service ... they'll do it for their people ..., so you know... it's like a bit of a guilt trip you know? – like if we don't do it, they ring up and put the pressure on us (#11)*

#### ***How do participants know about the services***

Client/carer participants said they found out about health and community services themselves and by talking to their peers. Some admitted that they did not know how or where to access services:

*Oh – I know there's a few [health and community services] around – but there's – you know – no direction, I don't know where they all are. (#3)*

#### ***Satisfaction with services***

Participants' satisfaction with services varied considerably. A number of negative experiences were recounted, many of which have been discussed elsewhere in this report.

Problems included discrimination and rudeness, misdiagnosis of other health problems, dislike of particular doctors, inappropriate dispensing of medication, and inadequate supervision. One participant absconded from one psychiatric hospital and was not missed for five days, with the absence only becoming apparent after a telephone call advising that the participant was in another hospital.

However, several participants were quite satisfied with the health services they had received, or had eventually found service providers who met their needs. Services that were particularly appreciated by those fortunate enough to receive them included transport assistance to clinics, free medications, dispensing of medications in dosettes, prompt help from ACIS and referrals by general practitioners to specialists for other health problems. A number of participants praised particular services, eg:

*When you go to Brady street they always up to speed, they know all about you and what you're on about. (#2)*

*Yeah. I go through them guys and I reckon they're good. (#5)*

*I like my GP down the road, he's alright you know. (#7)*

### **Coordination of services**

A number of examples of poorly coordinated services were discussed in the interviews. General practitioners and health professionals in clinics and hospitals were not always aware that they were simultaneously treating the same person. Sometimes this had potentially dangerous consequences such as multiple prescribing and conflicting advice, as described elsewhere in this report.

Health workers were passionate about the need for better coordinated and more equitable resourcing of services. They wanted better links and communication between mainstream and Aboriginal health services to enable more effective service delivery. Currently mainstream service providers call on the assistance of the Northern Metropolitan Community Aboriginal Health team whenever there are problems with Aboriginal clients, leading to overstretched resources and pressure on staff. They wanted to be notified when Aboriginal clients from their area accessed mental health services so that they could arrange and coordinate ongoing support. The Northern Metropolitan Community Aboriginal Health Team was aware that acute care hospitals receive a 30% casemix loading for each Aboriginal client [25]. They felt that there were opportunities to use these funds creatively to improve Aboriginal-specific services. For example, allocation of a portion the money to the Northern Metropolitan Community Aboriginal Health Team would assist them to provide transport, arrange followup, assist with discharge arrangements and so on for Aboriginal clients.

## **Discussion**

The interviews analysed here provide a rich insight into the experiences and views of Aboriginal people with mental health disorders, their carers and health workers in relation to medication use. It seems that some people cope with their mental health disorders and manage their medications quite well, and that the Northern Metropolitan Community Aboriginal Health Team provide support and care beyond the call of duty. However it is also evident that medications are not always used safely or optimally, potentially putting some people at risk. Many Aboriginal people with mental health disorders, their carers and other family members are struggling to cope with multiple and complex problems in their lives and are not always receiving adequate or appropriate support. The major issues to

emerge from this research centre around:

- poverty
- shame
- understanding of mental illness and medications
- coordination of services
- adequate and appropriate services
- the relationship between alcohol or other drugs and mental illness
- burden on carers

## **Poverty**

There is a well known association between mental illness and socioeconomic disadvantage[5, 26-28]. It is also well known that Aboriginal people are among the poorest in Australia today[4]. Therefore, being both Aboriginal and mentally ill confers a double disadvantage[29, 30]. Poverty was an underlying theme in the interviews, though rarely articulated directly. The client/carer participants were all living in very modest circumstances, none were in paid employment and all struggled to get by on welfare benefits of some kind. Shortage of money meant that some people delayed buying medication, or eked out medication until the next payday. Poverty may lead people with mental illness and their carers to deprioritise the purchase of medication and other health-related expenses compared to immediate essentials such as food and rent. Solving immediate problems which impact directly on life, eg reconnecting the electricity, mediating a dispute, obtaining emergency funds, was considered to be more important to most Aboriginal people than buying medication. The prevailing view expressed in this study was that serious and sustained efforts must be made at high level to address socioeconomic disadvantage among Aboriginal people as a priority, otherwise specific strategies to achieve quality use of medications would likely be ineffective. Similarly, others have called for commitment to improving social and economic status of Aboriginal people as a necessary first step in achieving quality health outcomes[5, 27, 31]. This study also identified difficulties with transport and access to services, and the burden this placed on the Aboriginal Health Team, which also relate to poverty.

Furthermore, limited resources, complex funding allocations, lack of clarity about money flows between services and confusing subsidy arrangements contributed to the financial pressure experienced by the Northern Metropolitan Community Aboriginal Health Team.

## **Shame**

Shame was another theme which threaded through all interviews. Some participants with mental illness were ashamed of their condition and ashamed that they needed medication. This inhibited them from seeking information and medical assistance for their condition and/or their medication issues. Health workers talked about the tendency of some Aboriginal people to put on a brave face and carry on despite grief and loss and family breakdown, and how their clients felt shame at having to admit they needed help, sometimes turning to alcohol or other drugs in an attempt to block out their pain. Although the need for strategies to destigmatise and raise public awareness about mental illness, including specific programs for Aboriginal people, has been identified[32-34], negative attitudes and shame about mental health problems remain widespread in the Northern metropolitan Aboriginal community.

Some doctors misinterpret manifestations of shame, eg shyness and reticence to talk, and misdiagnose or fail to explore underlying issues. It was clear that Aboriginal clients felt more comfortable with Aboriginal health professionals. Development of partnerships between Aboriginal and non-Indigenous health workers, and cultural awareness training for mainstream service providers have already been recommended and piloted[24], and need to be extended and sustained in the Northern metropolitan region. These would facilitate respectful trusting relationships between Aboriginal clients and health professionals, lead to earlier identification of mental health problems and issues underpinning them, and enable prompt and appropriate referral to services such as the stolen generation team or drug and alcohol services. The consensus was that such initiatives could prevent mental health crises and consequent medication management problems.

## **Understanding of Mental Illness and Medications**

Understanding of mental illness and medication varied widely, confirming previous research[27]. It is evident that most people with mental health problems and their carers wanted more information and clearer explanations in language they could understand. The Aboriginal Health Team spend a lot of time interpreting and reinforcing health information for their clients. This study showed that many clients did not understand their medications, the importance of compliance with the regime and potential side effects, a common problem in many populations[35]. However, it was agreed that better understanding of mental illness and medications may not necessarily translate into improved compliance unless more pressing problems with daily living are solved first.

It appears that traditional Aboriginal understandings of social and emotional wellbeing and mental illness, causes of mental health disorders and traditional approaches to healing have been largely disregarded by mainstream health professionals. It was not surprising that there was some mistrust of psychiatric diagnoses and drug treatments by some clients and health workers. These findings confirm previous reports[36, 37].

### **Coordination of Services**

Poor coordination of health services was a major issue to emerge from this research. Many examples were given of patients receiving treatment and advice from several doctors or clinics, without adequate communication between them, leading to unnecessary prescribing, conflicting advice and potentially dangerous consequences for clients. Doctor shopping for drugs is easier if services are poorly coordinated. Transient people, or those without Medicare cards tend to visit doctors or clinics convenient at the time, highlighting the importance of better service coordination. The Northern Metropolitan Community Aboriginal Health Team wanted improved communication from hospitals and clinics to enable them to provide more efficient followup and support activities. Although guidelines have already been developed to facilitate continuity of medication management between home and hospital[38], it appears that communication breakdowns still occur. The Aboriginal Health Team is currently spending much time and effort providing services such as transport that could be arranged by other agencies, putting pressure on their staff and resources. Finally, integration of health and other social services, eg housing, justice, welfare, social work is lacking. There are many published articles calling for integrated intersectorial responses to problems faced by Aboriginal people[39, 40]

### **Adequate and Appropriate Services**

A number of examples of racial discrimination, stereotyping and lack of cultural awareness were given. At the same time many participants were very satisfied with their treatment by Aboriginal health workers and services. It is clear that there is an urgent need for more Aboriginal service providers across all health-related portfolios and institutions, because many Aboriginal clients prefer not to go to mainstream services. There is also need for mainstream service providers in northern Adelaide to become more culturally aware and to modify their practices, as demonstrated elsewhere[41]. Furthermore, the Northern Metropolitan area has inadequate gender-specific, age-specific services, and drug and alcohol services.

Appendix 2 provides more information about culturally appropriate service provision, including underlying principles and indicators, based on the literature[3, 29, 42-46].

## **Relationship Between Alcohol or Other Drugs and Mental Illness**

Several participants believed that their mental illness was caused or triggered by excessive use of alcohol or other drugs. Health workers agreed that harmful or hazardous use of these substances was sometimes associated with the onset or worsening of mental health problems. Literature shows that long term alcohol abuse damages the brain, leading to mental disorders such as alcohol-induced dementia[47, 48]. Similarly other substances such as solvents damage the nervous system. Prescribed drugs for common physical illnesses may also result in confusion and cognitive impairment[49]. However, it was also evident that social dislocation, family breakdown, grief and loss issues, and other life events were involved in the onset of mental health problems among Aboriginal clients in Adelaide's Northern suburbs. Genetic factors could also be involved as there were a number of families mentioned in which several members had mental health problems.

Alcohol, marijuana and other illicit drugs are frequently used as an escape or coping mechanism to mask underlying mental health problems and social and emotional distress. A culture of acceptance and promotion of drinking and drugging in some sectors of society was highlighted by health workers. A number of participants told of difficulties in avoiding these drugs in such an environment. There is a need for more creative prevention and diversionary schemes, education and supports to minimise harm, and positive role models to reduce inappropriate use of these substances. Withdrawal from addictive substances, for example during detention in prison or hospital can exacerbate mental and emotional distress, and clients are at risk of overdose on discharge[50].

Domestic violence was another theme which threaded through the data. Mental illness may cause behavioural disturbances, but medications were a calming influence. Participants spoke of violence and agitation when compliance was poor. They were particularly concerned about escalating violent or abusive behaviour following excessive drinking. Mental illness is linked to domestic violence, both as a contributing factor, and as a consequence[51]

## **Burden on Carers**

Aboriginal carers are invariably family members, often older women with significant health and social problems of their own. The expectation of society in general and Aboriginal families in particular is that family members will care for their relatives. It appears that the resilience of many Aboriginal carers, and their apparent willingness and ability to take on ever more responsibilities may be taken for granted. There is an urgent need to provide support to these people, as the burden on their lives is crushing. In particular respite, transport, information, and financial help are desperately needed.

## **Recommendations**

The following recommendations were developed collaboratively by the Research Team and the Northern Metropolitan Community Aboriginal Health Team after significant deliberations on the draft findings. A focus group, face-to-face and virtual meetings were devoted to developing these recommendations. Some recommendations are broad recommendations addressing socioeconomic disadvantage, institutional racism and inequities in service provision, since these factors underpinned many of the medication management problems of Aboriginal people with mental health problems. Others are specific to medication issues or local concerns.

### **Recommendations**

1. That effective and multifaceted programs to address poverty and its root causes among Aboriginal people be implemented and sustained.
2. That health services and health professionals ensure that their practices and policies are culturally appropriate. Suggested strategies include:
  - cultural awareness training and support for non-Indigenous GPs, nurses, pharmacists and other mainstream health workers;
  - ensuring mainstream health professionals are educated about Aboriginal understandings and manifestations of health/illness, social and emotional wellbeing, and traditional approaches to healing;
  - dissemination of current referral information for a range of services relevant to Aboriginal social and emotional wellbeing issues (eg schemes to reunite families);
  - employing more Aboriginal workers across all health and social services in the northern metropolitan area of Adelaide;
  - clarifying, formalising and promoting systems for recognition and payment of traditional healers (Ngangkari).

3. That culturally appropriate information about mental health issues be made widely available to the Aboriginal community in order to:
- raise awareness and understanding of social and emotional wellbeing issues;
  - destigmatise mental illness;
  - increase understanding of the different roles of health professionals (eg psychologists, counsellors, psychiatrists, traditional healers), mainstream and alternative treatments;
  - encourage people to seek help;
  - increase general understanding of medications for mental illness, including purpose, safe use, compliance, interaction with other substances, side effects, storage and disposal.
- This information could be provided in multiple forms (eg brochures, posters, videos, stickers) and locations (eg health centres, pharmacies, community centres, sports clubs, schools).

4. That a range of culturally appropriate early intervention strategies for Aboriginal people with social and emotional wellbeing problems be developed and promoted. These might include peer group counselling and community support groups.

5. That integrated health service delivery systems be developed in the northern metropolitan area. Suggestions relevant to medication management include:
- adopting a regional approach to health service delivery and planning, involving hospitals, emergency departments, GPs, pharmacies and the Northern Metropolitan Community Aboriginal Health Team;
  - Aboriginal and mainstream health services in the northern metropolitan region together developing an equitably resourced system for distributing medications to those who cannot afford them;
  - using additional funds allocated to GPs through the Aboriginal Primary Health Care Access Program to provide extra consultation time with Aboriginal clients for provision of appropriate explanations and information about mental health and medications;
  - developing and implementing effective communication systems between health services, eg a simple interagency computer network. These systems should enable service providers to track individual clients so that overprescribing and conflicting advice is minimised, while preserving confidentiality;
  - developing and implementing systems for effective coordination of health and other service providers. In particular, better linkages between health services and

- correctional, educational, employment and social services are required; and
- fostering and strengthening collaborative networks of workers across health and social portfolios (eg Aboriginal Workers Forum and the Northern Interagency Group).
6. That all workers providing assistance to Aboriginal people with mental health problems and requiring medications have access to professional training about:
- social and emotional wellbeing issues in Aboriginal communities;
  - mental health problems;
  - alcohol and other drugs; and
  - safe management of medications.
- These topics should be included in curricula for Aboriginal health worker education programs such as the Certificate in Aboriginal Primary Health Care.
7. That gaps in service provision for Aboriginal people in the Northern Metropolitan area of Adelaide be addressed. In particular there are identified needs for:
- health services for Aboriginal youth;
  - gender-specific Aboriginal health services;
  - health services for older Aboriginal people; and
  - drug and alcohol services for Aboriginal clients, eg substance misuse clinics, harm minimisation schemes, health promotion activities and positive role modelling in schools and community groups.
8. That Aboriginal family members who care for people with mental health problem be supported in their role and recognised for their contribution. In particular, respite schemes, transport assistance and financial support are urgently needed.
9. That support and skills development be made available to Aboriginal clients in budgeting for medications.
10. That pathways be developed to for supporting quality use of medications by
- Aboriginal elders on discharge from hospital; and
  - Aboriginal prisoners with mental illness on and after release, eg by strengthening and formalising links between correctional services health staff, health workers on the outside and families.

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