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## Better medication management for Indigenous Australians: findings from the field

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*This paper reports findings from interviews and focus groups conducted within a multi-dimensional action research project concerning medication management among Indigenous Australians. Participants were Aboriginal people with mental health problems, carers and family members, and health and social service workers from different regions in South Australia. A meta-analysis of findings from each regional project component was conducted, and major themes conceptualised and developed into a coherent summary. The findings revealed problems of a magnitude not previously realised—mental health problems (including alcohol and drug problems) and medication management among Aboriginal people clearly are major issues requiring immediate and sustained attention if the health and welfare of the Australian Indigenous population are to be improved. Findings concerned eight major areas: social and emotional wellbeing issues; stressors on Aboriginal health services and providers; training for the Aboriginal health workforce; mainstream health services for Aboriginal people; trust and confidentiality within Aboriginal health services; English language literacy and numeracy skills of Aboriginal clients; remote living arrangements for many Aboriginal people; problems with alcohol use; and institutionalised and individual racism in the community at large.*

**Key words:** Indigenous, Aboriginal, Health, Medications, Research, Mental health

The topic of Australian Indigenous health in general has attracted abundant literature; Australian Indigenous mental health has attracted some, while there is very little on medication management among Aboriginal people. Considering the literature on Indigenous mental health and medications together, an obvious gap presented. The forerunner to this project, a pilot conducted by this team (de Crespigny, 2002) within northern metropolitan Adelaide, revealed a concerning lack of attention to medication issues for Aboriginal people with mental health disorders and pointed to the need for a wide-ranging investigation. For example, it was evident that “medications were not always used safely or optimally, potentially putting some people at risk”.

Increasing focus on the continuing poor health of Aboriginal Australians is apparent in the literature. This has been accompanied over the decades by calls from Aboriginal and non-Aboriginal authors to understand the situation from historical and cultural perspectives and to act in accordingly sensitive ways. Government and non-government interventions (often funded research projects) designed to improve the health of Aboriginal Australians have also increased over the

years, and been implemented increasingly by Aboriginal leaders and health professionals. A major national development was the comprehensive health strategy laid out by the National Aboriginal and Torres Strait Islander Health Council, involving the set-up of numerous Aboriginal-controlled health services (The National Aboriginal and Torres Strait Islander Health Council, 2001). At the same time, state initiatives such as The first step ... The South Australian Aboriginal Health Partnership (Walker, Milera, & Goodes, 1998) were occurring throughout the country.

Some major mental health developments for all Australians such as the National Mental Health Strategy (National Mental Health Strategy Evaluation Steering Committee, 1997) and Burdekin Report (Human Rights and Equal Opportunity Commission, 1993) acknowledged the particular needs and issues impacting on Aboriginal mental health. Conceptualising mental illness among Aboriginal people as a comprehensive and embracing notion related to social and emotional wellbeing was an important breakthrough. Health professionals or Aboriginal health service providers were no longer limited to traditional psychiatric diagnoses and treatments. Instead they could take

a more useful, holistic perspective that included all aspects of an Aboriginal person's life and circumstances, including family, history, social, economic and emotional factors affecting both physical and mental health status and wellbeing.

The Ways Forward report on Aboriginal mental health (Swan & Raphael, 1995) and Bringing Them Home report (Human Rights and Equal Opportunity Commission, 1997) were enormously influential in highlighting the need for specialist social and emotional wellbeing services for Aboriginal people. Subsequently, Aboriginal people were identified as a priority group in the National Action Plan for Prevention and Early Intervention for Mental Health (Commonwealth Department of Health and Aged Care, 2000). Recommendations within this Action Plan informed our research project, particularly in terms of understanding Aboriginal mental health within a context of whole community wellbeing and historical events, increased culturally appropriate initiatives, joint planning between Aboriginal and mainstream organisations, and increased training of Aboriginal people as practitioners in Aboriginal health and education settings.

Countering this raft of initiatives to improve Aboriginal mental health were the latest, sobering national statistics on the health and welfare of Indigenous Australians (Edwards & Madden, 2001). Based on expectations for all-Australian rates, there were markedly more deaths from mental health disorders, more suicides, more hospital separations for mental disorders including alcohol/drug diagnoses and assault, and proportionally more incarcerations among Aboriginal people than among non-Aboriginal people.

Insofar as the literature was concerned, the research team comprising a partnership of researchers from Flinders University School of Nursing and Midwifery and the Aboriginal Drug and Alcohol Council (SA) Inc., thus entered a highly complex and bemusing arena lacking any comprehensive reports about medication management among Aboriginal people with mental health problems—apart from the pilot project cited earlier (de Crespigny, 2002).

The aims of the interview and focus group component of the project were to:

- elicit direct and particular experiences, knowledge, concerns, contexts and issues associated with living with and/or caring for an

Aboriginal person with a mental health problem, focusing on medication and other substance use

- identify and discuss pathways used for service provision and giving medication/health information
- examine the usefulness of information, advice and support regarding medication use and related health issues
- explore Aboriginal carers' and others' education and training needs relating to safe medication use by Aboriginal people with social and emotional wellbeing problems.

## Method

### **Research design**

The design for the overall project (of which this report comprises one component) was action research (Meyer, 2000). This approach was chosen for its participatory and democratic features, as well as its flexibility in enabling triangulation of methods (interviews and focus groups being two). The creative cycles of planning, action and re-planning were well suited to the iterative process described below for the meta-analysis of data and eventual formulation of recommendations. Action research also facilitated empowerment and practical outcomes, both important to our research interest. The project design of action research was developed and extended throughout the research, culminating in our articulation of a "Partnership model of ethical Indigenous research", published elsewhere (Kowanko, de Crespigny, & Murray, 2003; de Crespigny, Emden, Kowanko, & Murray, 2004).

### **Participants**

Participants comprised a convenience sample of volunteers. Some were purposively invited to maximise representation of all major stakeholders. The inclusion criteria for interview and focus group participants were:

- Aboriginal person with mental health problems such as anxiety, depression, psychosis, dementia, acquired brain injury or other mental illness, or social and emotional distress, including problems related to drug and alcohol use; resident in South Australia, not hospitalised and adult; or

- carer or family member of the above; or
- worker who provides health, social and other services to the above, such as Aboriginal health workers, social workers, registered nurses, doctors, pharmacists, educators and other key service providers.

Altogether 58 interviews/focus groups were conducted, with a total of over 130 participants, the majority being Aboriginal. Participants were drawn from urban, rural and remote regions of SA, including metropolitan Adelaide, Port Augusta, Port Lincoln, Coober Pedy, Riverland, Murray Bridge and Maitland.

### **Ethical considerations**

All participants were fully informed about the research and gave informed consent in accord with national and state guidelines for Indigenous research. The research proposal was approved by the Social and Behavioural Research Ethics Committee of the Flinders University, the Yunggoorendi First Nations Centre for Higher Education and Research at Flinders University, and the Aboriginal Health Research Ethics Committee of South Australia. In addition, local boards of Aboriginal health services gave their consent and offered to host the project in their communities. The welfare of participants took precedence over project aims at all times throughout the project, and the utmost care was taken to ensure cultural sensitivity and safety was maintained.

### **Data collection**

Semi-structured, face-to-face interviews and focus group discussions with Aboriginal people with mental health problems, carers and other family members were conducted by specifically trained Aboriginal research assistants, or other members of the research team who were acceptable to participants. A member of the research team or an Aboriginal research assistant also conducted interviews/focus groups with a range of professionals who provided services to Aboriginal people. The researchers recorded their reflections and ideas emanating from interviews with key informants, focus groups and steering committee discussions, and these too were included as data. This study design had previously been used by us successfully (de Crespigny, 2002; de Crespigny, Grbich, &

Watson, 1998; de Crespigny, Groenkjaer, Casey, Murray, & Parfoot, 2002; Paterson et al., 2003).

An interview guide was used that included a section for recording demographic data and sections for collecting open-ended qualitative data (available in the full report: Kowanko et al., 2003). Interviews were audio-taped for later transcription, or handwritten notes taken at the time of interview.

### **Data analysis**

Analysis involved two major stages—analysis of data from each region (seven in all) and meta-analysis of the seven regional analyses.

### **Regional analysis**

Each interview/focus group transcript was subjected to a preliminary content analysis, based on the headings in the interview guide. Key information and quotes from interviews were coded under those headings while reading and re-reading the transcripts and listening to the tapes. These data were then developed further into themes (based on the interview guide and other concepts derived from the interviews/focus groups) and incorporated within the final report for each region (Morse, 1994)

The analysis process was iterative, beginning as soon as the first transcript was made, and continued to develop as new data arrived and deeper analysis occurred (Strauss & Corbin, 1990). Preliminary findings were presented to regional steering committee members and key informants for further elaboration and validation. Notes from these meetings were included as data where appropriate. Different researchers from the team cross-validated the analysis (checked for commonality of understanding), enhancing rigor. Regional reports are included as appendices to the full report (Kowanko et al., 2003).

### **Meta-analysis**

Qualitative meta-analysis is defined as “the aggregating of a group of studies for the purpose of discovering the essential elements and translating the results into an end product that transforms the original results into a new conceptualization”, and the end product described as “thickly descriptive” and “more complete and comprehensive than any of the original studies” (Schreiber, Crooks, & Noerager Stern, 1997, pp. 314-315). In this case, some difficult decisions inherent in meta-analysis

were avoided because all the regional studies were contextualised by essentially the same literature, research questions and processes. This congruence strengthened the process of the meta-analysis.

The process of meta-analysis was basically the same as that for the regional analyses, the principal difference being that the data were the regional findings (themes supported by original data) and not the original transcripts themselves. The iterative process of grounded theory has been described as appropriate for meta-analysis, as has a team approach to “provide more lenses through which to view and question the data” (Schreiber et al., 1997, p. 323), the latter increasing rigour as with the regional analyses.

Outcomes of the meta-analysis were shared and discussed with the state-wide steering committee and the rigor of the analysis put to the ultimate test: “The findings should be immediately recognizable to those who have experience with the phenomenon of study” (Schreiber et al., 1997, p. 317). The findings comprised eight themes (statements) that were considered collaboratively by the project team and state-wide steering committee (together with findings from other components of the overall study) and recommendations developed—these recommendations appear elsewhere (Kowanko et al., 2003; Kowanko, de Crespigny, Murray, Emden, & Wilson, 2005).

### ***Special challenges***

The findings of this project could not be narrowly conceived. While the research focus was specific—medication management among Aboriginal people with mental health problems—the outcomes were far reaching in their context and implication. This is reflected within the full report (Kowanko et al., 2003) where regional findings and subsequent discussions go far beyond the specific research topic to issues of profound significance to Aboriginal people. The interview/focus group component of the project reported here clearly required a richly contextualised approach, such as that afforded by the regional and meta-analyses.

### **Results**

The major themes presented below represent SA-wide findings and are contextualised only as indicated by the data; that is, all concepts derive

from the data. While the questions posed to participants might have been quite specific, the responses ranged over issues of very wide concern. This produced a “ripple” effect, whereby it was necessary to locate the specific medication management problems within ever widening parameters. Not to adopt this approach would have done an injustice to our participants who courageously shared elements of their life stories with us (and whose verbatim quotes below provide the merest glimpse of the data appearing in the full report).

#### ***1. Social and emotional wellbeing issues deeply pervade the lives of all Aboriginal people and seriously diminish the value that individuals place upon medicines and the potential of these medicines to improve their quality of life***

Mainstream definitions of mental illness proved of little value in this project. While we encountered some individuals who had been diagnosed with a condition such as schizophrenia or bipolar disorder, and were being treated accordingly, the broader definition of social and emotional wellbeing was much more useful. It was meaningful to participants, as it touched upon all aspects of their lives including not only social and emotional factors but also economic and physical factors—it was a whole-of-life approach. Significantly, many Aboriginal participants (clients, carers and workers) had chronic physical health problems like diabetes and cardiovascular disease.

Findings from all regions, whether at individual, family or whole community level, revealed social and emotional wellbeing issues—aspects of Aboriginal people’s lives about which they were deeply unhappy, felt heavily burdened by, or knew were badly out of balance but had no control or power to change or bring back into balance. These issues related especially to:

- grief for family members who had died through suicide, overdose, violence, accident or ill health, and associated traditional grieving processes
- anger at past and continuing injustices towards themselves as Indigenous people by the white population (invaders) of Australia, including incarceration issues
- feeling overburdened and overwhelmed by constant carer responsibilities

- chronic poverty, substandard living arrangements, inadequate transport, malnutrition and poor physical health leading to chronic feelings of hopelessness, inadequacy and powerlessness
- confusion and unhappiness over stolen generation family members—being unable to find a family member or finding a member only to experience rejection
- disputes and tensions between family and community members concerning marriage breakdowns, children's misbehaviour, unemployment, lack of money, inter-community conflicts and rivalries, and issues to do with visiting relatives and relatives on parole or recently released from prison.

The deeply pervasive nature of these issues in people's lives meant that virtually no Aboriginal people were free of their effects. All Aboriginal participants in the project were suffering a degree of social and emotional stress. As one participant struggled to express: "It's so complex...just the inter-generational trauma. The grief and loss of disconnection with land and families and...not having a sense of belonging anywhere. It's all that...lack of self esteem, lack of identity...". The impact of this on medication management was that generally everything associated with medications took a lower priority to the issue (or issues) at hand. A participant might have expressed a keen desire to take their medication as ordered in an interview situation but also acknowledged this was unlikely to occur due to one or other of the issues raised above. In many situations and instances, taking one's medication was simply not important, even when not to do so might be debilitating or even life-threatening. As one participant said: "They (Aboriginal clients) really just didn't care...they could see the effects it would have not being compliant, but they didn't seem to worry about it, and especially when there's drugs and alcohol involved". Social and emotional wellbeing issues thus markedly and adversely affected medication compliance.

**2. Aboriginal health services and providers are themselves subject to the same stressors as the wider Aboriginal community, plus additional bureaucratic stressors, which weaken their ability to provide effective medication services**

The advent and increasing activity of health services dedicated to providing culturally appropriate care

to Aboriginal people is a major advance in promoting Aboriginal health and wellbeing. They are services run for Aboriginal people by Aboriginal people. Ideally, they are the answer to many problems in Aboriginal health care. Our findings showed this was indeed just an ideal. Not only were those running the services experiencing social and emotional wellbeing issues themselves and subject to the same stressors as the clients they served, they were also burdened by the wider bureaucracy in which they functioned. As one participant said: "It's daily and it's 24 hours...you are on call 24 hours of a day and it wears you out. It really wears you out...". And another: "I was really down...I just needed a break...I needed to disappear...all I wanted was a nice, peaceful, even a week's break".

The complexity of funding avenues, staffing arrangements, lines of authority, range of services, changing government directives and priorities, poor communication channels between Aboriginal and mainstream services, and poorly integrated services at all levels posed major challenges for staff in all regions. Inadequate funds, lack of resources, constant staff shortages and high staff turnover exacerbated the situation. The need for more accessible and relevant training was highlighted in every region, in particular regarding medication management, mental health, drug and alcohol use, and cultural safety. It was agreed that building the capacity of both the Aboriginal and mainstream workforce to provide effective, evidence-based care is essential.

From the medication management perspective, Aboriginal health workers, drivers and others played a very important and active role in delivering and administering medicines to Aboriginal clients, often located some distance from the health service, such as in outlying communities and camps on town fringes: ("...it may take you an hour, three hours, to find the client..."). However, this was only one of a very wide range of helping activities performed by these workers, who had limited time to devote to medications. This meant medications could not always be delivered at appropriate times or were left for the clients to take at later times when it could not be assured they were actually taken. Sometimes medications had to be left either with another person because the client could not be located, or in a potentially unsafe place. For example, as one participant said: "...if that client doesn't

happen to be there at that mealtime, the medicines were being left and they were still there on the window ledge Monday morning". Furthermore, the role and responsibility of different workers in relation to medication was often ambiguous.

Many workers acknowledged gaps in their knowledge and understanding of medications, and were concerned about putting their clients and themselves at risk. These difficulties were exacerbated by the personal stress workers were experiencing as members of their Aboriginal communities, and the stress of working in a bureaucratic maze. Medication management by Aboriginal health service providers was thus constrained by the personal issues, lack of training and bureaucratic challenges they faced.

### ***3. Mainstream health services are not structured to meet the lifestyles and health problems of Aboriginal people, preventing the appropriate management of medicines at the time and place of greatest need***

Some Aboriginal participants chose to use the local mainstream health service as their principal source of health care. In other instances, Aboriginal services were not available. Specialist service providers were almost always non-Indigenous. The mainstream services accessed were usually the local hospital or general practitioner clinic. Aboriginal people wanted and needed to access these services 24 hours a day, sometimes more often at night, and often as a result of an unexpected event, such as injury resulting from violence, illness resulting from a medication mishap or overdose, or misuse of alcohol or other drugs. They needed to be able to present themselves to a health service and receive prompt and comprehensive service. As one participant put it: "There's not somebody there available when you need it...by the time they do get in to see somebody, the sets of issues have changed". Findings showed Aboriginal clients' needs contrasted sharply with the nature of mainstream services offered, which generally required an appointment made in advance or a serious medical emergency for immediate attention. The expectations and practices of Aboriginal clients and mainstream service providers were obviously in conflict. As one participant stated: "There's nothing in the hospital that would actually make an Aboriginal person feel comfortable in the environment there".

Further, the timeframes to which Aboriginal people adjusted their lives (such as "sorry business" taking precedence over all else) and prioritising family responsibility over personal health problems, meant appointments, when they were made, were often not kept. Lack of transport for Aboriginal people was also reportedly a major concern in some regions, requiring long walks in adverse conditions that made time of arrival at the clinic uncertain and recall for regular appointments unrealistic. Whether or not clients chose to use an Aboriginal health service for their routine health care, many had to use mainstream metropolitan hospitals and mental health facilities at times of crisis or specialist need. There were many reports of lack of integration of mainstream, regional and local services, and poor communication between service providers and families/carers, which put clients at unnecessary risk.

From the medication management perspective, this mismatch between clients' needs and the health services offered often meant necessary medications were not available when needed, or when they finally became available, they were no longer the appropriate treatment. Participants reported much pain and suffering as a result of being unable to access health care when they believed they needed it. These instances usually involved a medication, often to relieve severe pain. Dissatisfaction with mainstream services also led to "doctor shopping", with Aboriginal patients going from one doctor to another to seek attention, and sometimes securing more than one prescription or dose of medicine—often analgesics—which are reportedly a major source of addiction among Aboriginal patients.

Mismatches between traditional understandings of wellness and sickness and Western medico-scientific understandings of health and disease exacerbated these tensions. Mainstream health services tended to follow the medical model, dealing with the various physical and mental illnesses and conditions in an uncoordinated fashion. The traditional world view requires a holistic approach that incorporates individual, family and community bio-psycho-social issues, which means taking the time to listen. As a result of these mismatched world views and expectations, some Aboriginal people are sceptical about diagnoses and mistrustful of medical advice about treatments and lifestyle change.

**4. Aboriginal health services can unwittingly erode trust and confidentiality in their clients, which can result in Aboriginal people not using the services and missing out on culturally appropriate management of their medications**

Because Aboriginal health workers and other Aboriginal service providers are members of the local communities they serve, they often know about, and might even be personally involved with, the issues about which their clients seek assistance. This poses a great burden of responsibility upon the workers to engender trust and maintain confidentiality. It might also detract from their ability to maintain a helping role because they are so close to the issues themselves. Traditional rules about interactions between family members add a further complication in some communities. As one participant put it: "There needs to be carefulness about what is said in the services and who says it. Confidentiality needs to be guarded very, very preciously". As a result of these complexities, some Aboriginal clients preferred to use a mainstream service such as a local general practitioner (from whom they experienced varying levels of satisfaction).

From the medication perspective, we found some Aboriginal people at risk of "falling between the cracks" of Aboriginal and mainstream health services. It was possible they were not receiving the culturally sensitive care hoped for at the Aboriginal service, or the kind of attention they desired at the mainstream service. As one participant said:

*I'd like it if we could go to Aboriginal people...because they understand where you're coming from, rather than going through the mainstream. Because like they've never sat and been broke or they've never sat and had a family member die ...*

Given the multiple, major health problems experienced by Aboriginal people and the important role medication has in managing these problems, the potential for further deterioration of health was very real for these people. The impact of social and emotional wellbeing issues in the lives of Aboriginal people meant it did not take a great deal to deter them from seeking or taking their medicine. There was almost always something more important to attend to. Thus, without the active support of an Aboriginal health service, some Aboriginal people experienced inadequate medication management.

**5. Many Aboriginal people lack English language literacy and numeracy skills, which seriously detracts from their understanding of their medications, including instructions for administration, purpose, actions and side effects**

Taking medication safely and effectively ideally requires acceptance of the health problem as one that can be controlled by medication, and knowledge and understanding of the drug itself and how it works, and why and how it should be taken as ordered. This represents a sophisticated grasp of the English language (in most Australian mainstream health services). Aboriginal people whose first language is not English and whose formal education may have been limited or minimal are thus severely disadvantaged.

Our findings showed Aboriginal people in the main did not understand their medical diagnosis, the action or side effects of their medicines, the significance of the timing of administration of their medicines, or the consequences of not taking their medicines. Many were unable to correctly interpret administration and storage instructions on medicine labels or to identify when a repeat medication was required. Some were unable to tell clock time and so could not follow instructions as to when to take a medicine. Some Aboriginal clients reported being unable to understand their doctors' explanations and instructions, and were unable to satisfactorily request further information. As one participant said: "I can't really understand my doctors anyway...it's all big words. It's like they just want to talk just to get the money...".

Many participants were on multiple tablets dispensed in dosette boxes that required literacy and numeracy skills, as well as motor skills, to use safely. We were very concerned our participants could not maintain safe and effective medication management (to the point of their lives being endangered) because they were not adequately proficient in English. Further, health workers reported they themselves were inadequately prepared to help clients understand their medications.

**6. Inadequate living arrangements and remote living locations for many Aboriginal people mean the safe delivery, administration and storage of medications is jeopardised**

Housing, including sanitation, running hot and cold water, household effects, refrigeration, and

blankets and bedding were widely reported as inadequate, and rendered more inadequate by frequent additional family members visiting or staying a while. Further pressure was put on households because there was frequently at least one family member who was sick and required care from other members. It was not unusual for Aboriginal workers to go home from their carer responsibilities at work straight into carer responsibilities at home. As one participant reported: "I've never had respite, never". Or as another said: "... older people provide care for their children, and also look after their children's children. They often go without medication themselves, because they can't afford to pay for it".

Supplying an adequate quantity of healthy food in the home was a major concern for many Aboriginal people. Take-away food was an attractive option for some until money ran out, and carrying food long distances to prepare in the home, often when feeling weak with hunger, was not appealing. Living arrangements where too many people were crowded into too small a space with too few amenities, and where some family members were sick and unable to care for themselves, added to the risk of further health problems.

From a medication perspective, these inadequate living arrangements made the safe delivery, administration and storage of medications very difficult. Many homes were quite remote from the health services, making delivery dates and times uncertain. Sometimes health workers could not find the client when they arrived, or were advised by others they had departed for an unknown period. Sometimes there was no refrigeration to store medicines requiring low temperatures, or no safe cupboard to leave medications in. As one participant said in relation to dosette boxes: "...quite often they come back within two days 'cos the kids have got to them and thrown them up in the air so the whole box is mixed up, so it's all got to be redone". Sometimes other workers or volunteers delivered medicines with no knowledge of their administration or management. On other occasions, when the person for whom the medication was intended was not present, other family members took it instead, hoping it might help their problems. Overall, inadequate living arrangements impacted negatively on all aspects of safe and effective medication management for Aboriginal people.

### **7. The ill effects of widespread alcohol misuse within Aboriginal communities results in medicines being inappropriately combined with alcohol, and misused or neglected, to the detriment of the individual's health and those in proximity**

Health service providers across the board in all regions highlighted the problem use of alcohol as a major problem with destructive and tragic social consequences. Individuals' lives were reported as shattered, marriages broken up, children ill-treated and communities divided over the consequences of binge drinking accompanied by antisocial and usually violent behaviour. Despite numerous government and non-government interventions designed to address problem use of alcohol, the practice persists among some Aboriginal people. "Dry zones" were reported as compounding the issue and driving drinking into homes where women and children were at even greater risk of physical harm. Some found they were unable to resist peer pressure to drink alcohol, as they were ostracised if they did not join in. Others found drinking the only escape from their profoundly meaningless and unfulfilled life circumstances. And as one participant acknowledged: "I know I've got a sort of addiction ... if I to have one I want another one and another one and another one ... it's really hard to escape". Some did not appreciate that once available money was spent on alcohol, there was no means to buy food to sustain other family members.

In terms of medication management, Aboriginal people who misused alcohol usually did not benefit fully from their medications because they were not taken, the effects were not fully felt due to mal-absorption or non-absorption, or sometimes adverse reactions were experienced due to the combination of medication and alcohol. A one participant said:

*The only thing I'm wary of is that she's starting to have...alcohol again...and whether she'll stop taking her medication...if I ask her she'll get angry with me and so I just hope she...knows what she's doing.*

Alcohol use problems were often combined with mental illness and these individuals sometimes suffered major consequences (such as hallucinations or seizures) when they failed to take their medication as prescribed.

Perverse behaviour was another feature that accompanied misuse of alcohol, such as overdosing

or trafficking of medicines. As one participant said of their use of Panadol for pain: "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 a couple more". All aspects of medication management were thus found to be more difficult with those who misused alcohol.

**8. Institutionalised and individual racism (covert and overt) is a widespread phenomenon in the community at large, which seriously diminishes feelings of self-respect and self-worth among Aboriginal people, which in turn diminishes their interest in personal health, including all aspects of their medications**

Many Aboriginal participants reported being spoken to in derogatory terms, looked down upon, refused health services, left waiting longer, ignored, and generally made to feel less important than non-Aboriginal people. As one participant said: "I don't want to go to the system. It's failed me dramatically and I don't like the way they look down on you—here comes another one who's got issues—it's awful the way they look down on you". Another participant commented: "Often what Aboriginal health workers ask for, doesn't get dealt with". And another summed up: "You feel unimportant because you are Aboriginal". While it was difficult for participants to show the cause and effect relationship between racism and their diminished self-worth, it was apparent to us as researchers and professional health workers that our participants were profoundly affected by racist attitudes and practices. Informed by our knowledge of the history of Aboriginal colonisation and subsequent oppression of Aboriginal people in Australia, the faltering stories of many of our participants, combined with their generally hesitant (or alternatively at times, angry) presentations, all pointed to low self-esteem and feelings of worthlessness.

It was apparent these racist elements existed across all regions, whether at an institutional level (e.g., a hospital practice of refusing to admit patients under the influence of alcohol), individual level (being ignored by a service provider), overt (in the face) or covert (behind the back). Indeed, it appeared some practices might have become so customary in the community at large that non-

Aboriginal members would vigorously deny holding racist attitudes. Our participants' reports and personal observations indicated otherwise.

From a medication management viewpoint, the effects of reported racism were troubling and we believe they are key to many medication problems for Aboriginal people. Often lacking assertion, self-worth and hope, many Aboriginal people also lacked conviction and positive attitudes towards their health and medications. Although they wanted to be rid of their health problems, they did not fully understand how their medicines worked or why it was important to keep taking them. They were easily deterred from taking them as instructed, took only those they perceived as helping them, or swapped them with other individuals' medicines that seemed to be better. If nothing seems worth striving for in life, or the future has no meaning, one's medicines are certainly not a priority. As one participant perceived the dilemma:

*It's hard, hard to normalise your lifestyle...so I guess a lot of (Aboriginal) people just give in, in the end...they tend to come in and they describe existing ...just existing...their testimony is never one of meaning or purpose...you rarely hear them talking about some goals, or setting goals.*

## Discussion

The major findings of this project indicate there is vast potential for improvement of medication management for Aboriginal people, all of whom suffer social and emotional wellbeing problems of some kind at any point in time. Indeed, we believe acknowledging the significance of this point—that all Aboriginal people suffer emotional wellbeing problems of some kind at any point in time—is a key to improving the many unsatisfactory findings about medication management described above. Each medication issue must be considered in the context of its associated issues and historical circumstances. While some positive anecdotes could be found in the data, the far greater proportion of findings reflected a seriously neglected aspect of health care, with grave implications for individual and community wellbeing.

This research helps fill the void apparent in the literature relating to the medication needs of Aboriginal people with mental health disorders

(more widely and appropriately conceived as social and emotional wellbeing issues). It has generated knowledge about medication issues hitherto neglected, unknown and generally unsuspected, and unreported. Strategic interventions to address these issues have been implemented in the course of the entire project (all components) insofar as was possible within the scope of the research, and further work is being implemented. Interventions have included: workforce and community education; improving access to and safe management of medications; coordinating care for Aboriginal people with mental health problems; and advocating for, and supporting ways to increase capacity of, Aboriginal service providers and communities (Kowanko et al., 2003; de Crespigny, Kowanko, Murray, & Emden, 2004).

Evaluations of these strategic interventions were positive and in many cases the interventions are either ongoing or have provided an impetus for other related activities. Particularly pleasing is the self-reported uplifting effect they have had on the morale, confidence and knowledge of those

involved, especially Aboriginal clients, health workers and carers. We believe the entire project, despite the gravity of the problems it has revealed, has achieved a degree of empowerment for those who needed it most—Aboriginal people and those who serve them. We remain concerned at the racism reported by Aboriginal people across all regions. We believe real progress with safe medication management (or indeed all aspects of social and emotional wellbeing and general health) will not be achieved until racism is eliminated at individual, institutional and wider levels in the Australian community.

By sharing their stories with us, our participants demonstrated their desire for a better and healthier future. Some clearly articulated a wish for Aboriginal people to become more self-reliant and assertive, not only in relation to medications but in relation to life generally. As one Aboriginal health worker stated: “What’s most important is being responsible for your own life really, ultimately”.

We respectfully dedicate our findings from the field to the pursuit of this goal.

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### **References**

- Commonwealth Department of Health and Aged Care 2000. (2000). *National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000*. Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care.
- de Crespigny, C., Grbich, C., & Watson, J. (1998). Older Aboriginal Women’s Experiences of Medications in Urban South Australia. *Australian Journal of Primary Health Interchange*, 4(4), 6-15.
- de Crespigny, C. (2002). *Better Medication Management for Aboriginal People with Mental Health Disorders and their Carers - A Pilot Study in Northern Metropolitan Adelaide*. Bedford Park, South Australia: Inprint Design.
- de Crespigny, C., Groenkjaer, M., Casey, W., Murray, H., & Parfoot, W. (2002). *Breaking down the barriers. Urban Aboriginal women, drinking and licensed premises in the southern metropolitan region of South Australia*. Adelaide: School of Nursing & Midwifery, Flinders University and Aboriginal Drug and Alcohol Council (SA) Inc.
- de Crespigny, C., Kowanko, I., Murray, H., & Emden, C. (2004). Implementing research outcomes for better medication management for Aboriginal people. *Aboriginal and Islander Health Worker Journal*, 28(4), 14-17.
- de Crespigny, C., Emden, C., Kowanko, I., & Murray, H. (2004). A “partnership model” for ethical Indigenous research. *Collegian*, 11(4), 7-13..
- Edwards, R., & Madden, R. (2001). *The health and welfare of Australia’s Aboriginal and Torres Strait Islander people 2001*. Australian Bureau of Statistics and Australian Institute of Health and Welfare. Retrieved from <http://www.aihw.gov.au/publications/ihw/hwaatsip01/index.html>
- Human Rights and Equal Opportunity Commission. (1993). *Human rights and mental illness: Report of the national enquiry into the human rights of people with mental illness*. Canberra: Human Rights and Equal Opportunity Commission.
- Human Rights and Equal Opportunity Commission. (1997). *Bringing Them Home: A guide to the findings and recommendations of the National Inquiry into the separation of Aboriginal and Torres Strait Islander children from their families*. Canberra: Human Rights and Equal Opportunity Commission.

- Kowanko, I., de Crespigny, C., & Murray, H. (2003). *Better medication management for Aboriginal people with mental health disorders and their carers*. Final Report 2003. Bedford Park, South Australia: Inprint Design. <http://www.nursing.sturt.flinders.edu.au/research/pages/reports/bettermed03.asp>
- Kowanko, I., de Crespigny, C., Murray, H., Emden, C. & Wilson, S. (2005). Improving Indigenous health through better medication management: an overview. *Australian Journal of Primary Health*, 11(1), 17-23.
- Meyer, J. (2000). Qualitative research in health care. Using qualitative methods in health related action research. *British Medical Journal*, 320(7228), 178-81.
- Morse, J. (1994). Designing funded qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks: Sage Publications.
- National Mental Health Strategy Evaluation Steering Committee. (1997). *Evaluation of the National Mental Health Strategy: Final Report*. Canberra: Mental Health Branch, Commonwealth Department of Health and Family Services.
- Paterson, J., Dunn, S., Kowanko, I., van Loon, A., Stein, I., & Pretty, L. (2003). Selection of continence products: perspectives of people who have incontinence and their carers. *Disability and Rehabilitation*, 25(17), 955-963.
- Schreiber, R., Crooks, D., & Noerager Stern, P. (1997). *Qualitative meta-analysis*. In J.M. Morse (Ed.), *Completing a qualitative project: Details and dialogue*. Thousand Oaks: Sage Publications, pp. 311-326.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park: Sage Publications.
- Swan, P., & Raphael, B. (1995). *Ways Forward. National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health*. Canberra: Australian Government Publishing Service.
- The National Aboriginal and Torres Strait Islander Health Council. (2001). *National Aboriginal and Torres Strait Islander Health Strategy: Draft for discussion*.
- Walker, D., Milera, W., & Goodes, L. (1998). *The First Step . . .* Adelaide: The South Australian Aboriginal Health Partnership.

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