Bundap Marram Durn Durn: Engagement with Aboriginal women experiencing comorbid chronic physical and mental health conditions

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Abstract

Objective: To explore antecedents of health service engagement and experience among urban Aboriginal[a] people with comorbid physical and mental health conditions.

Methods: Focus groups and interviews were conducted with Aboriginal people who had comorbid health conditions and were accessing Aboriginal and/or mainstream services.[b]

Results: Nineteen participants, all women, were recruited. Participants' personal histories and prior experience of health services affected effective service utilisation. Participants' service experiences were characterised by long waiting times in the public health system and high healthcare staff turnover. Trusted professionals were able to act as brokers to other clinically and culturally competent practitioners.

Conclusions: Many urban Aboriginal women attended health services with multiple comorbid conditions including chronic disease and mental health issues. Several barriers and enablers were identified concerning the capacity of services to engage and effectively manage Aboriginal patients' conditions.

Implications: Results indicate the need to explore strategies to improve health care utilisation by urban Aboriginal women.

Key words: Indigenous women, urban, co-morbidities, chronic physical conditions, mental health

a: In this paper, Aboriginal people encompass all Aboriginal and/or Torres Strait Islander people – Australia's First People.

b: Mainstream services are services operating outside of the Aboriginal community-controlled health sector and include hospitals, primary health care, community health and a broad range of specialist services.

The Wurundjeri people of the Woiwurrung language group are one of five Aboriginal tribes of the Kulin Nation in south-east Australia. Wurundjeri country extends from the inner city of Melbourne north to the Great Dividing Range, west to Werribee River, south to Mordialloc Creek and east to Mount Baw Baw.[1] The Bundap Marram Durn Durn project 'Good' 'Mind' 'Body' in Woiwurrung was initiated and driven by the Wurundjeri community, who identified the increasing need to support the physical and emotional health and wellbeing of community members.[2]

The ongoing impacts of colonisation have contributed to significant differences in the health status between Aboriginal and other Australians. Across all age groups, Aboriginal people are in poorer health compared with non-Aboriginal Australians.[3] The average life expectancy at birth for Aboriginal people is 10.6 years (males) and 9.5 years (females) less than non-Aboriginal people.[4,5] Aboriginal people experience 2.5 fold greater total disease burden and spend a greater proportion of time living with a disability than the general population.[6] Chronic disease, in particular cardiovascular disease and diabetes, and mental health disorders are the leading contributors of these disparities.[6]

While the contribution of discrete physical conditions and mental disorders to Aboriginal health disadvantage and prevalence data for certain conditions have been reported,[6-8] scant data are available regarding the types and prevalence of comorbidities experienced by Aboriginal Australians, especially by Aboriginal women. Comorbidity is defined as 'two or more coexisting medical conditions or disease processes that are additional to an initial diagnosis'.[9] Nationally, the closest approximation of comorbid mental health and physical health prevalence data is provided by the 2008 National Aboriginal and Torres Strait Islander Social Survey (NATSISS).[10] NATSISS confirmed the high proportion of Aboriginal adults who experienced high or high levels of psychological distress and the associated poorer health outcomes.[10] In 2012, the Australian Institute of Health and Welfare

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reported the prevalence of co-occurrence of a mental disorder with a physical condition among all Australians at 12%.[11] Given that Aboriginal Australians have higher prevalence of physical illness and mental disorders, it is likely that comorbidity in this population would be substantially higher than the 12% reported nationally.

Notwithstanding these stark statistics, Aboriginal Australians have poorer access to a range of clinical and preventive services compared with their non-Aboriginal counterparts.[12] Many factors affect the way Aboriginal people access and use health services. A history of dispossession, marginalisation, racism and discrimination continues to have profound effects on the identity and health of Aboriginal Australians, and continues to contribute to the persistent health inequities in Australia today.[13,14] Other factors include low-health literacy, lack of appropriate services, lack of system support, distance to services, unemployment, financial constraints, and cultural and communication barriers.[13-18] Although the Aboriginal community health services address many of these barriers, particularly the cultural barriers, there remains a gap in appropriate health service delivery in the mainstream health care sector for Aboriginal people.[19]

Despite evidence that more Aboriginal women access health services than Aboriginal men, they are more likely to report their health as fair or poor compared with the men.[20] In many respects, Aboriginal women carry more of the disease burden with earlier onset and lower survival than Aboriginal men. More Aboriginal women reported having cardiovascular disease, diabetes and/or high sugar levels and certain types of cancers than Aboriginal men.[3] Aboriginal women had 15 times more hospitalisations for chronic kidney disease than non-Aboriginal women, compared with Aboriginal men who had 8 times more hospitalisations than non-Aboriginal men.[21] Aboriginal women were also less likely to report feeling calm or peaceful, full of life and having a lot of energy than Aboriginal men.[21] Rates of high to very high psychological distress were similarly reported to be higher among Aboriginal women than men.[21] The leading contributor to the burden of disease for Aboriginal women is anxiety and depression.[6]

A complex range of social, economic and environmental factors influences the health and wellbeing of Aboriginal women. They are more likely than non-Aboriginal women to have left school at an earlier age, to be unemployed, to have experienced violence and to be the main carer for the family.[22] Nevertheless, Aboriginal women play a critical role as leaders and advocates for their families and communities.[23]

The *Bundap Marram Durn Durn* project is a community-initiated project.[2] The Wurundjeri Elders and people are proud to be a strong Aboriginal community that finds solutions for its own issues. This is congruent with current knowledge that Aboriginal people's cultural and traditional knowledge can and must contribute to addressing the barriers to their health care utilisation and the importance of Elders as role models and in raising community awareness.[14,24] Research is needed to add to the knowledge base around mainstream health service use for urban Aboriginal people,[25] including the Wurundjeri people.[25] In particular, research concerning improving the access to and utilisation of health services by Aboriginal women will have the potential to inspire and empower the next generation to achieve better health outcomes. It is envisaged that rigorous research leading to evidence-based practice in the Melbourne Aboriginal community would have the potential to be applied to other urban Aboriginal communities both nationally and internationally, as well as other disadvantaged groups.

This study aimed to explore antecedents of health service engagement and health service experience among urban Aboriginal people with comorbid chronic physical conditions and issues of social and emotional wellbeing.

Methods

Study design

This is a qualitative exploratory study. Qualitative approaches are increasingly employed in social sciences, particularly in health-related research to explore sensitive issues.[26] Focus groups and interviews were used in this study because they have the potential to provide a broad range of information and a variety of opinions and have been shown to be effective in exploring issues with the Aboriginal community.[27]

A participatory research approach was adopted to facilitate engagement, consultation and decision-making with the Wurundjeri community through the Wurundjeri Tribe Land and Compensation Cultural Heritage Council. Representatives of fourteen Aboriginal and mainstream organisations, as well as community Elders, formed a project reference group. Ethics approval was obtained from The University of Melbourne Human Research Ethics Committee.

Participant eligibility and recruitment

Participant eligibility was determined following consultation with the reference group. Eligible participants included Aboriginal people 18 years and over with a diagnosed chronic physical illness and an associated social and emotional wellbeing concern who had attended a health-related service in the preceding 12 months. Aboriginal people usually take a holistic view of mental health and believe in a whole-of-life approach to the physical, social, emotional and cultural wellbeing of the community. Today the phrase 'social and emotional wellbeing' is used when talking about mental health in Aboriginal communities to reflect their holistic way of thinking.[28]

The recruitment strategy was also developed in consultation with the project reference group. Nine existing community groups for Aboriginal people, identified by reference group members, were approached by the researchers to host focus groups. Conducting the focus groups within the participants' own space ensured cultural safety and existing community group formats provided an opportunity to build on the high level of cohesion and trust within these groups. Two female researchers (one Aboriginal and one non-Aboriginal) personally approached the Wurundjeri Elders and community members to explain the project and seek consent. Negotiations about privacy and confidentiality, and the type of information they considered acceptable or unacceptable for dissemination to the broader community were undertaken. Such attention to cultural safety is consistent with National Health and Medical Research Council guidelines on research with Aboriginal people.[29,30] Mutually convenient venues and dates were arranged to conduct either focus groups or interviews.

Data collection

Data were collected through a brief demographic survey and semi-structured focus groups and interviews with the participants. The two researchers described above were present at and conducted all focus groups and interviews collaboratively. Prior to focus groups or interviews,

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participants read a plain language statement and provided written consent. Where literacy was identified as an issue, the plain language statement was read aloud.

The focus group and interview schedule explored the way participants became aware of their chronic condition; the most recent time participants accessed a health service, doctor, program or group to manage their health; participants' experiences and the daily impacts of mood, anxiety and associated difficulties; and barriers and enablers to service use. These sessions used a 'yarning' conversational process involving the telling of stories and sharing of information within the context of a relationship, in which the participants contributed to the research directions and donated information.[31,32]

Focus groups and interviews were audio-recorded, transcribed verbatim and analysed using a grounded theory-informed approach.[33] The research team iteratively established a coding scheme based on analysis of the transcripts. The two researchers used this scheme to code all transcripts. Discrepancies were discussed and resolved separately by a third team member and collectively during research team meetings. The most salient codes were identified and developed into broader themes which provided the framework of the analysis. The presence of the Aboriginal researcher ensured the cultural appropriateness of data interpretation and enhanced the rigour of this qualitative process.[27]

Results

Participants

Although the project aimed to gather the experiences of both males and females, several factors resulted in participation by females only. Participants comprised 19 Aboriginal women ranging in age from 22 to 65 years (M=43.63, SD=15.01). Seventeen people participated in three focus groups; two participants opted for individual interviews. The two women who chose to be interviewed explained that they preferred to provide sensitive personal information in confidence. There was no difference between the two methods of data collection in the depth and content of information gleaned. Recruitment of additional women ceased once it was agreed that sufficient data had been acquired to reach data saturation and fulfil the aims of the study.

Although nine community groups agreed to host focus groups (including men's groups) only three focus groups were conducted. Factors impacting participation included deaths within the community (2 groups), illness of group members (3 groups) and organisational barriers (1 group).

Given the small sample size, only limited personal information is reported here to minimise the risk of participant identification.

Diagnoses

Participants self-reported 33 physical and 35 psychological health conditions. Table 1 lists these diagnoses grouped according to the DSM-IV diagnostic categories.[34] On average, participants each had 1.74 physical diagnoses (SD=1.19, range 1 to 5) and 1.84 psychological diagnoses (SD=0.96, range 1 to 4). Participants had an average 3.57 comorbid conditions (SD=1.43, range 2 to 7).

Themes

The stories shared during the focus groups and interviews highlighted an array of factors that influenced effective service engagement. Results are broadly presented under two themes: 'personal antecedents of health service engagement' and 'barriers and enablers to service engagement'. Subthemes are detailed for each of the two main themes.

Personal antecedents of health service engagement

Adverse life events and associated impacts

More than half the participants reported having experienced serious adverse events from a young age including removal from family, adoption, witnessing the traumatic death of a parent, and physical and/or emotional and/or sexual abuse. Experiences of abusive and/or exploitative relationships often continue into adult life.

> *"[Partner] was just bringing me down. Why I broke it off is 'cause of being abused sexually, mentally, physically as a child. And I went to sleep and he helped himself to me. And to me, it was like I was raped again, and I got a lot of memories back and I can't even look at him."*

The cumulative impact of early adverse events affected participants' capacity to trust and share personal information with others including health care providers.

> *"From a young age there's abuse of all shapes and manners. Then as you get older there's abuse, again of all shapes and manners. So you find yourself asking yourself 'who do you trust?'"*

This distrust was unanimously expressed across all focus groups and interviews. Several participants expressed serious misgivings about their past and current experiences with government agencies and health care services.

> *"I don't have trust in the government".*

> *"The DHS, they tried to get [my children] off me".*

Table 1: Diagnoses of participants.

	No. of participants
Physical diagnoses	
Pain	7
Chronic pain (5)	
Fibromyalgia (1)	
Arthritis (1)	
Endocrine	5
Diabetes (3)	
Thyroid disease (1)	
Prolactinoma (1)	
Circulatory	5
Hypertension (3)	
Stroke (1)	
Heart Disease (1)	
Respiratory	4
Asthma (n =2)	
Sleep apnoea (2)	
Hepatic	3
Liver dysfunction (2)	
Gall bladder dysfunction (1)	
Gastrointestinal	2
Bowel polyps (1)	
Diverticulitis (1)	
Autoimmune	2
Psoriatic arthritis (1)	
Psoriasis (1)	
Renal	2
Kidney dysfunction (2)	
Cancer	1
Bladder cancer (1)	
Functional impairment as a sequelae of infectious disease	1
Polio (1)	
Other	1
Morbid obesity (1)	
Psychological diagnoses	
Mood disorders	17
Depression 14)	
Bipolar disorder (3)	
Anxiety disorders	9
Post-traumatic stress disorder (5)	
Anxiety (3)	
Agoraphobia (1)	
Substance related disorders	7
Substance dependence (7)	
Schizophrenia and other psychotic disorders	2
Schizophrenia (2)	

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Prioritising the needs of others

All participants reported that members of their family and extended social networks were similarly affected by health and wellbeing challenges.

> *"My mum gets depressed. And I go 'Mum, you can't be eating that for your diabetes' and she goes, 'I don't care. I feel down, I don't care whether I die, honestly.' I could cry just saying that."*

As part of the Aboriginal culture and values, participants felt a sense of responsibility to be available to support others even at the expense of their own health.

> *"That was what I was brought up with, is that you take care of your community. You don't worry about yourself, you don't take care of yourself."*

The drive to be resilient and strong was particularly apparent among women with dependants who might or might not be their biological family and were not restricted to children under the age of 18.

> *"It distresses them because you're the strong one in their life and as soon as they see you weak they freak out. Here's this invincible person suddenly worse off weaker than [them]. It affects them. The main bit is not family and love and that, its dependants – or people that look up to you, ones that don't know the world yet. You're teaching them the world, and that's what they see the world is – pain, suffering."*

Barriers and enablers to service engagement

Participants noted that they experienced barriers and enablers when accessing both Aboriginal and mainstream services. Barriers to health care service utilisation refers to factors that cause a person to delay using or to not use health care services including general practitioners, medical specialists and other health professionals, imaging and pathology tests, after hours care, and hospital/emergency visits.[35] Conversely, enablers for health care utilisation refer to factors that facilitate a person to use health care services in a timely manner.

Precipitants to health seeking

Participants related many incidents where health seeking happened when both personal and community resources had been entirely depleted, leaving service access the only remaining option.

For some participants, the wellbeing of their dependants was their only precipitant to health seeking.

> *"If I get all these supports in place ... with the doctor and physio ... all of them in place – they [DHS] can't touch [my child]."*

> *"I need to have my strength and my body, because I'm going for custody of my grandchildren and I need to be one [holistically well] person."*

Life crises that affected emotional wellbeing such as the death of a loved one, significant rupture in relationship with a partner and parenting challenges also precipitated participants' engagement with services.

> *"I tried to keep my strength and that, but I couldn't. And that's when I had to go into respite care."*

> *"I put myself in psychiatric care at a mental hospital."*

Many participants sought care only when they were physically very unwell. General practitioners, both in Aboriginal and mainstream health services, represented the most frequently contacted health professionals for many of the participants.

> *"I had that physical sign [blood in stool) in the first place and I was worried. And I'm thinking, 'Oh, you know, I've just gotta get this seen to.'"*

Health service engagement was equally likely to be precipitated by either social and emotional wellbeing challenges or a physical health concern. Despite the presence of comorbidities, participants did not identify these as precipitants for service engagement.

The public health system

All participants accessed secondary care services via the public health system. Cost was cited as a barrier to accessing private health care. Significant waiting times were also associated with the public system experience.

> *"… the health service, they booked me into [hospital] but I waited a year-and-a-half for that appointment, see. 'Cause I'm a public patient."*

> *"… Five years later, I still haven't had my surgery … and now I am waiting, otherwise it's you know, 10 Grand [private health]."*

High staff turnover and its effects

Many participants commented on the high level of staff turnover at health services. They reported 'story-telling fatigue' associated with having to regularly repeat their personal narratives to new staff. This led to discomfort with new personnel and disengagement with services. For some participants, repeating painful personal narratives was particularly distressing.

> *"When they keep changing them [staff] you don't feel comfortable ... "*

> *"What they [staff] don't realise is when you've got to explain it again. You're bringing up your past and then you're going through all the trauma again, when you just don't want to do that."*

The General Practitioner experience

The importance of having a good relationship with a GP in both Aboriginal and mainstream health services was highlighted by all participants.

> *"I like to stick to one doctor."*

One third of the participants reported having inadequate time during GP consultations.

> *"They don't have enough time, the doctors. They just feel like they are rushing you out."*

Four participants described having experienced invalidation in the context of engaging with new GPs. Three participants reported having had negative experiences in one-off encounters that occurred when travelling interstate for family and cultural reasons. These experiences occurred across Aboriginal and mainstream services.

> *"I went to X (Service), and it was like I was a drug addict, they [GP] said, 'Oh we don't prescribe drugs of addiction'. I've been treated like a bloody criminal and I'm not."*

One participant recounted an instance where a GP invalidated her Aboriginal identity.

> *"They [GP] were so incredibly rude. Actually sat me down and worked out what per cent Aboriginal I was. Because I was just so overwhelmed, all I could say was, 'I don't think of myself as a percentage.'"*

System failures

Some participants described having experienced system failures around diagnosis, treatment and/or follow-up care.

> *"I was 14 years old and I was having a nervous breakdown. I was on the verge of suicide and then about a year later it was all fine. But I wasn't really. And then last year [aged 35] they diagnosed me with bipolar. And that's ever since I was 14, I've had it – but never been medicated. And wondering why I'm so high. Like, I'll be buzzing around, buzzing around like I'm on speed and everything and it was actually the bipolar."*

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The effects of these experiences on participants were varied and included protracted service disengagement, frustration and anger, a sense of hopelessness, and seeking alternative treatment.

Health professionals as trusted companions and service brokers

Two-thirds of participants noted that having a long-standing trusted relationship with at least one health professional was important. These relationships were often the product of considerable effort and perseverance punctuated with sub-optimal service provision experiences along the way. They occurred with both Aboriginal and non-Aboriginal health professionals in both Aboriginal and mainstream services.

> *"They've [trusted workers] been through everything with me. And they're amazing, and they've been here for me and I'm glad I had them."*

Such long-standing relationships, often of many years' duration, were particularly important for participants in terms of gaining access to a range of services. The workers may personally facilitate access to practitioners who have demonstrated exceptional cultural and clinical competence for participants, particularly those with highly complex presentations. Brokerage to culturally competent GPs was a recurring theme.

> *"They [GP] give you the time and they listen to what you've got to say and stuff. They're very, very thorough with everything. It's not just one thing."*

> *"[GP] gives you information about it too, so you understand it better. That's what I like."*

Discussion

There have been few Australian studies focusing specifically on urban Aboriginal women with comorbid physical and mental conditions. The *Bundap Marram Durn Durn* project, informed by the stories and experiences of urban Aboriginal women, highlighted the antecedents of health service engagement and the kinds of barriers and enablers experienced by urban Aboriginal women when accessing health care services.

The types of developmental and life experiences identified in the study are similar to those reported in O'Brien's ethnographic account of factors shaping Aboriginal mental health.[24] For Aboriginal people, the concept of health needs to be approached in the social-emotional context, which includes history of oppression, racism, environmental circumstances, cultural competence, psychological processes and physical ill health.[13] Trust is paramount and cultural competence is crucial in the context of Aboriginal Australians' need for equity in treatment and understanding from service providers.

Consistent with Aboriginal culture's concept of holistic caring and the role of Aboriginal women as leaders and advocates for their families and communities,[23] the participants' responsibilities to their family and extended social network and community were wide ranging. They described responsibilities that included providing emotional and practical support to other community members as well as providing guidance to younger community members. These findings that competing priorities, particularly family obligations, can impede prioritising health is consistent with findings from the work of Artuso et al.[18]

Personal and community resources were seen by many participants as being minimal or non-existent. Even so, health care services were often only accessed as a last option or during an emergency. This has important implications for health service and delivery planning to improve preventative health and appropriate use of services.

Long waiting times in the public health system, high staff turnover, health care practitioners' lack of cultural sensitivity, inadequate quality time with general practitioners to discuss their issues are all system failures and barriers identified by our participants. These further hinder Aboriginal people's management of their health and are again consistent with the factors identified separately by Shahid, Lau and Artuso.[13,15,18] Health care services must include access to culturally respectful and cost-effective health services, culturally and clinically competent health practitioners and culturally safe health practice environments.[13]

Establishing trusting and continuing relationships with health professionals was central to our participants' retention in the health service system. This finding reinforces the conclusion that failure to establish trusting, ongoing personal relationships impedes Aboriginal patients' acceptance of difficult diagnoses, their ability to follow complex treatment plans, satisfaction with medical care and having positive clinical outcomes.[15] Participants of this and other studies reinforce that Aboriginal health service consumers want ongoing, trusting relationships with a provider who is seen to genuinely care for their wellbeing.[13]

Substantial effort was reported to be required by our participants to find culturally competent staff. This flags the need for health services to ensure that cultural competence is continuously promoted and that staff are provided with appropriate ongoing training. Given that participants' reality has often been one of trauma, it is imperative that services develop culturally appropriate and sensitive service delivery. As O'Brien suggests, services need to be guided by their Aboriginal clients when designing treatment and care approaches.[24] Organisations should also be financially supported by government to engage in quality improvement activities. The Inala Indigenous Health Service, a mainstream health service in urban Brisbane that was funded to improve Aboriginal people's access, involved extensive community consultation. This resulted in dramatic improvements in Aboriginal clients' engagement and clinical outcomes.[16]

The limitations of this study include a small number of participants, the reliance on participants' self-report of diagnoses and the involvement of women participants only. Nevertheless, the number of participants in this study is comparable with other qualitative peer reviewed studies investigating chronic conditions among Aboriginal Australians.[14,15,18] The inclusion of women only, even though it was not the project's intention, is also a strength given the lack of research on urban Aboriginal women and the potential for long-lasting positive effects in the next generations if we are able to improve the health of Aboriginal women.

Conclusion

Urban Aboriginal Australian women attended services with multiple comorbid conditions including chronic disease and mental health issues. Personal adverse life events, competing family and community priorities, and past and present experience can impact on health care utilisation. Several barriers and enablers were identified concerning the capacity of services to successfully retain participants and manage their conditions. Barriers included cost of private healthcare, long waiting times associated with the public health system, lack of culturally competent healthcare practitioners, high health staff turnover as well as systems failures concerning diagnosis, treatment

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and the provision of effective follow-up care planning. Identified service enablers included established, positive relationships with general practitioners and access to staff who could provide cultural brokerage to appropriate services and culturally competent health care practitioners.

Implications

Findings from this study contribute to the sparse published literature in this area. The substantial range and extent of comorbidity provides a snapshot of the complexity such cases present to the health system. The findings will enable future studies to investigate ways to overcome health care utilisation barriers. Strategies such as case management involving collaboration between Aboriginal and mainstream services could be investigated to support long-term engagement of Aboriginal communities to close the Aboriginal health gap. Evidence-based practice in this urban community would have the potential to be applied to other urban Aboriginal communities and disadvantaged groups.

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