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A community-led design for an Indigenous Model of Mental Health Care for Indigenous people with depressive disorders

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Mental illness is a significant contributor to the burden of disease for Indigenous Australians.¹ A report from the Australian Burden of Disease Study² also found that mental and substance use disorders were the leading causes of living with ill health among Indigenous Australians.³ Indigenous Australians also face an increased risk of common mental disorders (CMDs)^{4,5} and comorbid mental and physical health conditions.^{6,7} Rates of self-reported high or very high levels of psychological distress among Indigenous Australians are twice those of the general population⁸ and rates of depression⁹ are at least twice the rate of the general population.¹⁰ Recent evidence indicates that the standardised prevalence of CMDs among Indigenous Australian adults is more than four times that of non-Indigenous Australians,¹¹ a gap much larger than previous estimates. Among CMDs, depressive disorders are the third-highest cause of the burden of disease, because of the total years lived with disability.² In the particular case of Indigenous Australians, access to appropriate services is limited despite high levels of trauma, grief and loss, identity issues, family violence and suicide,^{12,13} putting communities at further risk of distress.

Abstract

Objective: To generate outcomes for the development of a culturally appropriate mental health treatment model for Indigenous Australians with depression.

Methods: Three focus group sessions and two semi-structured interviews were undertaken over six months across regional and rural locations in South West Queensland. Data were transcribed verbatim and coded using manual thematic analyses. Transcripts were thematically analysed and substantiated. Findings were presented back to participants for authenticity and verification.

Results: Three focus group discussions (n=24), and two interviews with Elders (n=2) were conducted, from which six themes were generated. The most common themes from the focus groups included Indigenous autonomy, wellbeing and identity. The three most common themes from the Elder interviews included culture retention and connection to Country, cultural spiritual beliefs embedded in the mental health system, and autonomy over funding decisions.

Conclusions: A treatment model for depression must include concepts of Indigenous autonomy, identity and wellbeing. Further, treatment approaches need to incorporate Indigenous social and emotional wellbeing concepts alongside clinical treatment approaches.

Implications for public health: Any systematic approach to address the social and cultural wellbeing of Indigenous peoples must have a community-led design and delivery.

Key words: social determinants, social and emotional wellbeing, mental health, depressive disorders, Indigenous mental health

In addition to the persistent crisis of poor mental health, the lack of treatment uptake is also significant. The World Health Organization's World Mental Health (WMH) survey highlights that a considerable number of people experiencing mental disorders

do not seek treatment.¹⁴ When mental health conditions are not addressed, there is an increased risk of ongoing distress and the development of comorbid mental and physical health conditions.¹⁵ Adequate and appropriate treatment of CMDs is an

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urgent priority for Indigenous Australians. A history of social and cultural control¹⁶ from colonisation and ongoing discrimination and inequality also create significant barriers to the use of mainstream treatment options and services. Further, no robust evidence exists regarding the efficacy and cultural acceptability of treatments^{17,18} for Indigenous people.

For Indigenous people, concepts of mental health revolve around central concepts of social and emotional wellbeing (SEWB);¹⁹⁻²¹ they recognise the importance of land, culture, spirituality, ancestry, family and community, and how these affect the individual.^{16,19} A collaborative Indigenous-led approach^{22,23} is therefore essential to ensure the appropriateness of adequate service delivery. Such approaches should adhere to community and cultural protocols that incorporate the significance of family, nature and spirituality.^{17,24}

Objective

Previous research conducted in collaboration with participating Indigenous communities continues to highlight the effects of poor mental health and gaps in culturally appropriate and effective treatment options.^{4,25} From these studies, major depressive disorder was identified as the issue most prevalent among Indigenous adults.⁴ As a result, a randomised controlled trial (RCT) to design and develop an Indigenous Model of Mental Health Care (IMMHC)²⁶ for the treatment of depression was designed.

Funded by the National Health and Medical Research Council of Australia through a Global Alliance for Chronic Diseases grant (APP1144765, ANZCTR Registration Number: ACTRN12618001746224), the RCT aimed to evaluate an innovative, culturally acceptable model of mental health care. The IMMHC sought to develop a culturally appropriate trans-diagnostic cognitive behavioural therapy (CBT) treatment that could be incorporated as part of the SEWB concept.²⁷ The CBT intervention could draw upon the strengths of the person and their community to develop agency and positive health.¹¹ Moreover, the CBT component of the program would be part of a total SEWB intervention. The aim of the IMMHC was to develop, deliver and evaluate the primary outcome of the severity of depression symptoms as determined by changes in the

Beck Depression Inventory-II²⁸ score at six months post-intervention. The first phase of the project, prior to the commencement of the RCT, was to develop a culturally appropriate protocol that would be designed in consultation with Indigenous community members, Elders, psychologists and other experts. Phase II involves the conduct of the RCT, and the final phase will be to gauge participant feedback to inform future research directions.

This paper covers Phase I, where the IMMHC protocol was developed and presented to community members. The IMMHC framework, the potential culturally adaptable CBT protocol, SEWB concepts, and other useful skills and resources were presented to community members as part of this phase.

Methods

Community-based participatory research (CBPR) provides a methodology that equitably involves community members, organisational representatives and researchers in all aspects of the research process and where all partners contribute expertise and share decision making and ownership.^{29,30} The use of CBPR within Indigenous communities has been shown to be particularly constructive when incorporating phenomenological methodologies.³¹ Interpretative phenomenology provides both a methodology and a culturally safe and thus appropriate philosophy to investigate mental health issues in Indigenous communities, particularly given the subjective realities and interpretations of participants. Understanding the impact of the epistemology of Indigenous communities on the findings from this study is also imperative – this was informed by the collaborative relationship between an Indigenous researcher (MT) and community participants.

This approach provides an informed, in-depth community perspective while driving the research consultation process.³² Informed by guidelines from the Consolidated Criteria for Reporting Qualitative Research (COREQ)³³ and further described using the Standards for Reporting Qualitative Research (SRQR),³⁴ the study was conducted over six months from January 2019 to July 2019. Focus groups were arranged in culturally safe spaces situated in remote, regional and rural locations across South West Queensland.

The following five key semi-structured questions were used to gather feedback from focus group participants:

1. What causes mental health problems?
2. How does the health system affect mental health treatment approaches?
3. How can we heal our mob?
4. What supports do we need?
5. How can we pass knowledge down through the generations?

As the analytical process required sensitivity to language and meaning, anonymous findings from all stages of analyses were verified by participants to confirm the final models of understanding. Our study design included a subsequent feedback loop where the findings were shared with participants and community members, who then considered for their relevance for the purposes of validating the model of understanding. The one-on-one interviews with the Elders were conducted with the same purpose and were provided back to the Elders for validation. Given the imperative role of Elders in the community,²¹ analyses of data from the focus groups and interviews were performed separately.

Study participants

Indigenous community members, Elders, psychologists, mental health workers, participating Aboriginal Medical Services (AMS) staff and current and former health service-users were recruited purposively via word of mouth and targeted convenience invitations. Purposeful, respectful recruitment ensured that any power imbalances did not affect the data collection process and that all participants felt they were in a comfortable, safe and culturally appropriate environment during the focus groups. Three focus groups were initially planned, with the option of conducting further focus groups if data saturation was not reached to ensure that the predetermined questions discussed during the sequentially held focus groups were explored in depth. Eligibility criteria for participation included being 18 years or older, providing written informed consent and having previous experience or exposure to mental health services and treatment models. Participants from the focus groups indicated the need for community Elders, who were both traditional owners and spiritual healers, to be consulted and involved in this study. We subsequently planned and performed

one-on-one interviews with two Elders from outer regional and remote Queensland regions. Questions were specifically worded in reference to the role and position of the Elders undertaking the interviews; however, they remained the same in terms of context.

Data analysis

Data were generated from the in-depth, semi-structured focus groups conducted by the Aboriginal lead researcher (MT), research project manager (BFN) and two traditional healers.

Participant demographics and names were not recorded to maintain confidentiality. Participant gender information was derived from the anonymous transcription process. Focus groups and one-on-one interviews were audio-recorded and transcribed verbatim. Anonymous transcriptions were verified by the interviewers for completeness and accuracy. After importing into NVivo software,³⁵ the transcripts were systematically and thematically analysed to identify the coding schema, which was then peer-reviewed to confirm dependability. From these codes, patterns of categories were identified that encompassed phrases and terms commonly used by the participants. Finally, from these multiple categories, analytic domains were assigned, which then indicated the semantic relationships between specific phrases/terms and thus identified a model of understanding shared by the participants. To prioritise the imperative role of Elders in the community, analyses were separately performed for the focus group and interview data.

Ethics approval

The University of Queensland Human Research Ethics Committee approved the study prior to its commencement (Clearance Number: 2017001872). Necessary permissions and approvals were sought from the Board of Directors of the participating Aboriginal Medical Services. Permissions from Elders were obtained before recruiting study participants and conducting the focus groups and interviews. This study was also conducted in accordance with the NHMRC Guidelines for conducting Aboriginal and Torres Strait Islander Health Research.³⁶

Results

All focus groups were held in the Darling Downs – South West Queensland areas.

Group 1 belonged to Inner Regional Australia (Australian Standard Geographical Classification-Remoteness Area [ASGC-RA³⁷] 2) and included both men and women (n=8). Group 2 was gender-specific, each with eight participants (total n=16) belonging to Outer-Regional and Remote Australian locations (ASGC-RA 3, ASGC-RA 4). Abiding by community protocols and respecting cultural sensitivity, gender-specific focus groups were necessary. The one-on-one interviews with Elders (n=2) were conducted on Country in the remote South Western Queensland region. For Indigenous peoples, the concept of 'Country' incorporates an interdependent relationship between the land and its inhabitants;³⁸ this mutual connection is sustained by the cultural knowledge of the environment, which includes ancestral land and seas.

Focus groups

Analysis of transcripts from the focus groups revealed nine inter-linked themes about mental health and treatment approaches (Table 1). These themes are inter-related and describe the strength of a broad, holistic and whole-of-life approach to understanding the lived experiences of participants. They also provide an in-depth overview of the priorities that need to be kept central in developing a mental health model of care. The three most common themes of Indigenous autonomy, wellbeing and identity are discussed in detail below.

Theme 1: Holistic conceptualisations of wellbeing

Spirit and spirituality were frequently described as key elements to health and wellbeing, given they are an inherent part of Indigenous cultures. The loss of spiritual connection and misunderstanding of Indigenous spirituality by non-Indigenous people exacerbated cultural disconnection and illness. Participants linked the impact of past and continuing colonisation as the cause for spiritual disconnection leading to illness. Subordinate themes within 'illnesses' included spiritual, physical and mental wellbeing, addiction and mental illness, misdiagnosis and miscommunication, medications and trauma.

... Our old people wasn't allowed to speak our language, so therefore we weren't taught. Tell us anything about our culture and our lifestyle and our tradition. And through that we became more sicker, physically and spiritually. And that, in my opinion, that led

Table 1: Inter-linked themes resulting from the analysis of focus group interviews.

Themes	Subthemes
Systems	<ul style="list-style-type: none"> Care systems Education systems Justice systems Economic/Employment systems Re-establishing culture Removal of culture
Health	<ul style="list-style-type: none"> Addiction Medication Mental Health Misdiagnosis and miscommunication Physical Spirit/spiritual Trauma
Identity	<ul style="list-style-type: none"> Aboriginality Connectivity Country Passing of knowledge Skin colour Stolen generations
Family & Community	<ul style="list-style-type: none"> Family Children and grandchildren Elders Nature Assistance Disconnection Non-Indigenous
Knowledge & Knowing	<ul style="list-style-type: none"> Fear, rejection and protection Innate Lost and disappearing Traditional knowledge deficit Unspoken, unshared between people
Spirituality	<ul style="list-style-type: none"> Feared Health Innate Intergenerational Valued
Tradition	<ul style="list-style-type: none"> Changing values Fading away Pride
Non-Indigenous Australia/ns	<ul style="list-style-type: none"> Lack of understanding Open/empathetic Racist Spiritual
Elders	<ul style="list-style-type: none"> Lore Responsibility Health determinants Connection to culture and Country Systems

to a lot of problems now with mental health, drugs, alcohol, physical abuse...

... we've got to remember a lot of our people have suffered trauma. And so that comes through with the mental illness and that, and it's just not part of the trauma, but when you look at the research of people who have gone through trauma, they normally die a lot younger than most people, and they have all of the illnesses under the sun. And that is something else that we've got to be mindful

of, that you may not just be dealing with the mental thing ...

... health for our people, and especially our younger generation, is the education and knowledge of our past ...

Participants associated trauma with whole-body health outcomes, noting differences and similarities between clinical and cultural definitions of mental and physical health. These differences were cited as part of larger health determinants including access and acquisition of appropriate care.

... Doctor put me on drugs, and they did more damage... And all this medicine, it messed our mind up and our lifestyle and our whole being, our bodies ...

... A lot of people don't require the medication. With Aboriginal people, they used to sit and just listen, and have those conversations ...

According to participants, the presence of spirit, inward connection and ancestral communication brought messages of guidance, confirmation, connection and protection. These connections were an integral element of Indigenous culture. Several participants expressed fears and experiences of sharing spiritual experiences, inextricably linked to experiential racism. These spiritual experiences could be misconstrued as mental illness; participants spoke of following spiritual guidance as a private and unsupported process.

... Well, see they're losing their identity. There could be something important in our community. If they were allowed to express themselves more...they're afraid to say

anything because everybody will think they're a bit touched and that. So, they won't say nothing about what they see and hear ...

You don't need this. It's like saying, "No, you need to get back to spirit. You need to get back to what's inside you. You don't need that". I struggled a lot with that, just this feeling inside, knowing your ancestors are telling you, "No, this is not good. This is not good". So instead of me getting better, I was getting worse with these tablets, and I'm going, "No, I can't do this anymore". So, once I went off there and started, everything connected up from them on ...

... And I think the way to overcome our mental health, is we've got to educate our younger ones, this medicine is here [spiritual and cultural connection and practice] and it's still there and it is the strongest one we can have ...

(Figure 1: Word cloud describing the autonomy domain recommendation of the need for change.)

Theme 2: Indigenous autonomy over social and economic structures

A thematic focus was on non-Indigenous defined structures of education, health and wellbeing, and the impacts of policy and Indigenous and non-Indigenous belief systems on social, cultural and economic inclusion and exclusion. Focus group participants discussed the need to negotiate existing structural systems to re-establish Indigenous autonomy, indicating that practical and positive outcomes would be

achieved when operated by, and inclusive of, Indigenous people.

... because we live in a white society, we've really got to hold our cultural pride within... So if we don't hold that within us, then we become broken, our spirit gets lost, and we're in a world that we really don't understand, in the white man's world, so we don't really understand, our traditional ways just don't fit in, and then you become, you're lost, you're broken ...

... You've got to walk in both worlds and how do that healthfully and survive, to do that, which is hard ...

I ran the first children's shelter on Aboriginal community in Queensland [remote location]...I worked with the court system in [city] for 12 years in all our remote communities...And it just works. And they turn up and, "Uncle, what are we going to talk about today?" I say, "Well, you tell me. What do you want to talk about?" And, "I've got a question". I said, "Good, I like questions". And then we're going to start a Strong Women's group very soon, it's already on the way ...

Conversely, general structural systems, including health and mental health services, were repeatedly cited as the dominant source of the removing, devaluing and prejudicial actions towards Indigenous being, identity and culture.

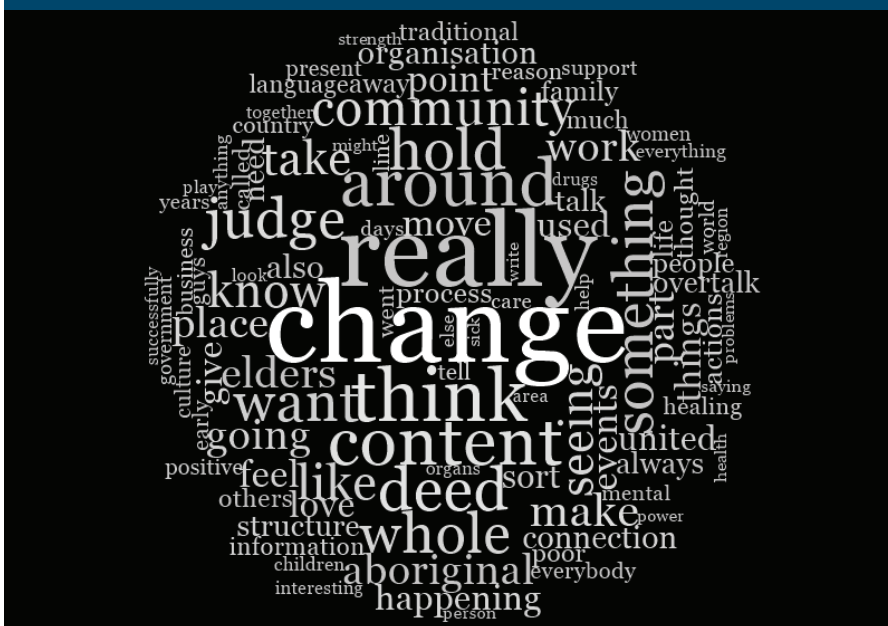
It's not just connection to your past and everything else, it's connection to other people, you get, you start doing drugs, you go to jail, you have any sort of thing that society doesn't agree with and you get segregated and pushed to the corners of society, instead of being embraced and getting the help you need ...

... like you said, system, always putting up walls, make you doubt yourself or think... We need to bring it all back in with those respect and caring. You'll have the younger ones these days are disrespectful to the older ones and you think, 'Holy crap. If that was back in my time.' It's like they're walking on a treadmill that won't allow them to touch a – because of the system we have to roll with so much these days ...

Theme 3: Identity

Identity encompassed the inextricably entwined concepts of Aboriginality, belonging, skin colour, the impact of the Stolen Generation, connection to culture and Country, and the continuation of Indigenous knowledge and practices. Participants highlighted the importance of reaffirming Indigenous identity with other Indigenous people and communities by sharing stories,

Figure 1: Word cloud describing the autonomy domain recommendation of the need for change.



spirituality, knowledge and connections; Indigenous identity requires strengthening and protecting against non-Indigenous forces.

... to have that spiritual touch and connection, and to connect to themselves whilst doing it. Because Aboriginals are spiritual people, as we've all said ...

... they [Elders] used to tell me ... "Now that you're over here, you make sure you go and see an old person because you know you can't walk here, you can't walk there ..." It's like, "Okay, so they're guiding me". So, that's why I think connection to home is so important ...

... being in that yarning circle is so helpful to everybody because they can express what they're thinking and listen to other people. I find the guys we're talking with now, they think they're the only ones with a problem.

When they hear the next guy talk about his problem they say, "Oh, I have something similar to that". So, it makes them realise they're not just by themselves ...

The epistemology of Indigenous voices and experiences regarding loss of Indigenous identity and the importance of spiritual connection in that identity, and similarity in negative experiences, are reflected. Taking the non-deficit approach to these quotes, the imperative of voices and choices posits a strategic direction in enhancing the mental health of Indigenous persons by prioritising cultural retention and connection to Country, ensuring that a culturally safe mental health system is available that acknowledges the importance of spiritual beliefs and that Indigenous autonomy over funding decisions for mental health care is provided.

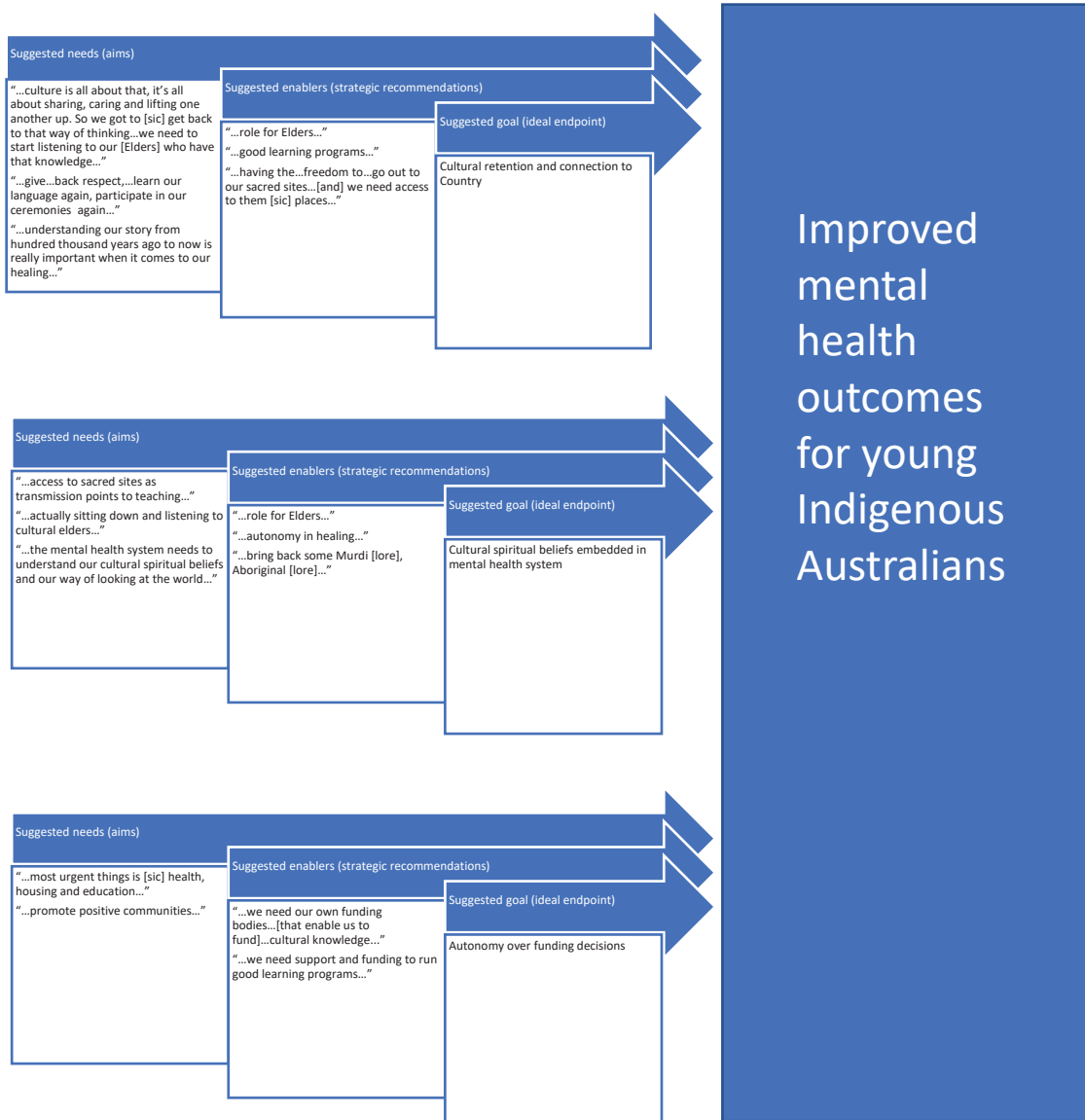
Elder interviews

Three key themes regarding ways to improve mental health for Indigenous Australians, especially youth, emerged from the Elders' interviews. First, the need for cultural retention and connection to Country; second, the need for cultural spiritual beliefs to be embedded in the mainstream mental health system so that there is relevance for Indigenous persons; and last, having autonomy over funding decisions and access to sacred sites and places to teach on land (Figure 2).

Theme 1: Cultural retention and connection to Country

Connection to culture and Country were described as inalienable Indigenous rights and as pathways to improved health and

Figure 2: Elder Interviews key themes.



wellbeing outcomes. Elders highlighted that enabling access and connection to Country and sacred sites would enable transmission points for the teaching and strengthening of culture.

Theme 2: Cultural spiritual beliefs embedded in mental health system: Lore/law

Notably, 'lore' referred to Indigenous social norms, customs and tradition. The term was used by the Elders to contrast with 'law', thus differentiating non-Indigenous cultural normative values from Indigenous traditions and normative standards.

Theme 3: Autonomy over funding decisions

The Elders raised the issue of insufficient funding for both essential programs and services and programs where the framework was dependent on Indigenous cultural and traditional practices. A substantial recommendation was for Indigenous communities to have independence and decision-making choices for any funding that is primarily for the benefit of Indigenous communities.

Discussion

The findings presented from this study highlight the importance of social and psychosocial determinants that underpin poor mental health and the subsequent lack of treatment uptake. It also places a spotlight on the need to involve Indigenous communities in all aspects that influence their day-to-day lives. It must be understood, therefore, that when the harmony of the interrelated factors of physical, mental and social wellbeing are disrupted, poor health outcomes for Indigenous Australians will continue to exist.³⁹ Indigenous conceptions of mental health are deeply rooted in the history of colonisation and cultural understandings; the intersection of conceptions of race and mental illness can be detrimental to the overall wellbeing of a group.^{40,41} As such, Indigenous concepts of SEWB have been acknowledged as protective factors that build resilience and influence mental health and physical wellbeing.

In this study, the most commonly spoken about themes that were identified provide an understanding of the underlying causes of mental health problems alongside the effects of the existing system and approaches to treatment models. Importantly, the lived

experiences of participants inform us that taking a holistic approach to health, which encompasses respect for Indigenous identity and connection to Country, may begin to positively influence mental health in Indigenous communities. However, for the mainstream mental healthcare system to reduce barriers to uptake will require more than piecemeal, short-lived and/or tokenistic efforts.

Recommendations arising from each of the three most common themes are:

Indigenous autonomy domain recommendations:

- Systems and structures that involve Indigenous communities must involve, listen to and engage with Indigenous people themselves.
- A systematic and methodological restructure in mental health treatment approaches is necessary to promote any positive outcomes for Indigenous people.

Health domain recommendations:

- In combination with medication (when it is required), psychological treatment should include cultural concepts of holistic social and emotional wellbeing and spiritual healing.

Identity domain recommendations:

- Nurture Indigenous identity, especially in young persons.
- Enhance spiritual connection and knowledge of Aboriginality by increased links with Elders and/or yarning groups.

The way forward requires providing avenues for Indigenous people to have sovereignty over social determinants that affect their wellbeing. Systematic, methodological and structural changes that involve, engage and – most importantly – are collaboratively led by Indigenous people themselves can create significant benefits and play a substantial role in tackling mental health issues. Likewise, Burgess and Morrison argue that by achieving a sense of autonomy, Indigenous people can move on to looking after others, rather than being looked after themselves. Without addressing these concepts, health interventions cannot engage Indigenous communities or address ongoing health outcomes.

The findings from this study also emphasise that recognising underlying deficits in social

and cultural determinants affect Indigenous peoples' health in general, particularly mental health. Holistic conceptualisations of health are, therefore, important for improving health and wellbeing. The Australian Bureau of Statistics (ABS) has identified eight areas for the measurement of wellbeing: family and community; education and training; health; work; economic resources; housing; crime and justice; and culture and leisure.³⁹ Notably, policy documents tend to use the terminology of 'mental health and social and emotional wellbeing'.³⁹ Therefore, mental health is seen as distinct from, but also related to, social and emotional wellbeing. Accordingly, the National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing is based on a definition of health that recognises that a holistic view is essential to achieve positive mental health outcomes for Indigenous people, and thus must be central to the design of any mental health treatment program.

For Indigenous Australians, culture and identity are central towards perceptions of health and wellbeing, and strongly resonate to being not just about the wellbeing of an individual, but also the SEWB of the community as a whole. The outcomes from this study provide an essential insight into this belief and highlight how this influences an individual's wellbeing. There is also emerging evidence for the link between health and Indigenous connections to traditional lands.⁴² Rates of mental disorders for those residing on Country (and therefore in touch with their culture and traditions) have also been identified as about half of those living in mainstream communities, despite there being similar major disparities in key social determinants.⁴ Evidence also suggests that positive health changes are experienced when Indigenous people reside, work and live on Country.⁴³ Garnett and Sithole found positive associations that resulted in health benefits and improved health outcomes linked to excess morbidity and mortality when activities that Indigenous people perceived as beneficial to their health were undertaken.⁴⁴ Maintaining a link to culture, community and Country are thus important influencers of the mental and social wellbeing of health for Indigenous people and subsequently will have the ability to achieve aspects of identity important for Indigenous people. This asserts that

initiatives to improve the mental health of Indigenous people must consider a model that incorporates a broader understanding of health and SEWB, rather than a model that is solely clinical.

Conclusion

Our results emphasise that treatment models for depression in Indigenous communities should extend beyond solely clinical approaches to wider socio-cultural determinants. These include cultural autonomy, beliefs, identity and wellbeing. Addressing factors identified in this study, a model of care that underpins these understandings can become a valuable way forward. The IMMHC has been developed by incorporating holistic, traditional and cultural components as part of a model of treatment for mental health that subsequently promotes retention of connections to community and Country, which can have significant impacts on improving Indigenous identity, and subsequently mental health and wellbeing.

Mainstream treatment models fail to incorporate the Indigenous understanding of mental health; the adaptation of mainstream services to suit Indigenous populations without consideration for cultural appropriateness and without any integration of 'holistic' aspects results in unsuccessful attempts at addressing health needs.¹² The IMMHC has been developed as a model of mental health care that is both effective and readily embraced by Indigenous people, which will be fundamental for its successful uptake and sustainability. Indigenous-led design and development of a treatment model of mental health care will also guarantee empowerment, adaptability and transferability.²⁶ The outcomes from this study provide an essential overview to inform participants lived experiences towards the development of the IMMHC. Furthermore, they provide a comprehensive understanding for future policy decisions, resource allocations and future research in ways that are meaningful and built upon a non-deficit model that focuses on social and cultural determinants of health.

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