The validation of a culturally-specific measure to identify depression in Aboriginal and Torres Strait Islander people with or without chronic disease

ACKNOWLEDGEMENTS

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Background

There is no culturally meaningful, appropriately valid, simple, free-to-use tool to screen for depression in Aboriginal and Torres Strait Islander (hereafter referred to as Indigenous) peoples, attending Primary Health Care Services (PHCS) in Australia. In previous work by Professor Alex Brown and others, five Aboriginal language groups of Central Australian Aboriginal men independently selected the 9-item Patient Health Questionnaire (PHQ-9) depression screening tool from a selection of screening tools, as the most appropriate to adapt for use with Indigenous people. The PHQ-9 was adapted to the local needs of all five language groups over 12 months and consensus regarding wording was reached. The PHQ-9 wording was modified, using simplified English, to make the ‘adapted PHQ-9’ (aPHQ-9) culturally meaningful and give it face validity. In qualitative interviews with the same participants, seven critical domains of depressive experience within Indigenous men were identified that were not covered in existing depression case-finding measures: anger, weakened spirit, homesickness, irritability, excessive worry, rumination, and drug/alcohol use.

This study aims to validate the aPHQ-9, against a gold standard (criterion standard) the MINI International Neuropsychiatric Interview (MINI) 6.0.0 (Sheehan et al., 1997) as a screening instrument for depression. This study will also assess the contribution of the seven additional domains identified during the interviews.

Prior literature and studies

Australia’s Indigenous population is estimated to make up 2.6% (575,552 people) of the total Australian population (Australian Bureau of Statistics., 2009). Chronic disease (cardiovascular disease, cerebrovascular disease, diabetes, chronic kidney disease, and chronic obstructive pulmonary disease) accounts for 80% of the life expectancy gap experienced by Indigenous people (Australian Institute of Health and Welfare., 2011).

It is estimated that 20% of the general population surviving a stroke or heart attack, and a greater proportion of those with heart failure or diabetes will develop a Diagnostic and Statistical Manual for Mental Disorders, 4th edition (DSM-IV) diagnosis of major depressive disorder (Anderson, Freedland, Clouse, & Lustman, 2001). Approximately similar proportions will meet DSM-IV criteria for moderate or minor depression (Burg & Abrams, 2001; Dobbelts et al., 2002). This risk of depression remains elevated for at least a year after a vascular event (Lesperance, Frasure-Smith, & Talajic, 1996).

Depression has profound effects on the development, course and prognosis of a number of conditions, such as diabetes, coronary heart disease, stroke and cancer (Cassano & Fava, 2002; Evans, Charney, Lewis, & al, 2005; Moussavi et al., 2007; Salaycik et al., 2007). Among people with existing chronic disease, co-morbid depression is associated with significantly poorer outcomes (Moussavi et al., 2007) including increased disability, longer length of hospital stay, reduced quality of life and higher costs amongst patients who suffer an acute vascular event (Glassman & Shapiro, 1998). It also significantly complicates the long-term management of co-morbid conditions by negatively impacting upon adherence to medications and other secondary preventative strategies (Joynt, Whellan, & O’Connor, 2003).

Mental illness and depression are also considered to be key contributors to the development of chronic disease (Australian Institute of Health and Welfare., 2011; Brown & Blashki, 2005; Kuper, Marmot, & Hemingway, 2002b; Patten et al., 2008; Salaycik et al., 2007). The presence of depression approximately doubles the risk of first myocardial infarction or cardiac death but amongst patients with established ischaemic heart disease the risk of a future serious cardiovascular event is increased three to four fold (Burg & Abrams, 2001; Hemingway & Marmot, 1999; Van der Kooy et al., 2007). Individuals with a history of major
depression have a 37% increased risk of developing type 2 diabetes (Knol et al., 2006). However, none of this research has been conducted with, by or in Indigenous populations.

The presence of other medical conditions can impact on the diagnosis of depression. The DSM-IV diagnostic criteria for depression include slowing of thought and movement, fatigue, sleep and appetite disturbance, all of which may be a consequence of chronic disease and independent of mood. In contrast, disturbances in behaviour, facial expression and verbal communication resulting from events such as stroke may mask or mimic symptoms of depression. Screening tools for depression must be able to accurately identify depression in people with and without other chronic disease.

The identification and proactive management of depression in general primary care in Australia has been shown to improve outcomes (reduced depression and improved treatment intensification sustained over 12 months, with a reduction in 10-year cardiovascular disease risk) in people with diabetes and heart disease (Morgan et al., 2013). However a culturally valid depression screening tool is required to achieve the same benefit in Indigenous populations.

**CHRONIC DISEASE AND DEPRESSION IN ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE**

Strategies to maintain psychological well-being have not been systematically incorporated into chronic disease prevention and management in Australia generally, or in Indigenous populations specifically, despite Indigenous people being at particularly high risk of psychological illness (Swann & Raphael, 1995). The loss of land and culture, racism, marginalisation and powerlessness have been highlighted by Indigenous peoples as fundamental causes of ill health (CSDH, 2008; Swann & Raphael, 1995), and rates of self-harm and suicide are higher than in the non-Indigenous population (Cantor & Neulinger, 2000; Parker & Ben-Tovim, 2002; Social Health Reference Group, 2003; Zubrick, Silburn, Burton, & Blair, 2000). Indigenous people are more likely to be hospitalised for or die from mental disorders than their non-Aboriginal counterparts (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2008). In 2008, 31% of Indigenous adults reported high or very high levels of psychological distress compared with 10.8% of the general Australian adult population (Australian Bureau of Statistics, 2010).

The absence of a culturally meaningful, appropriately validated measure of depression for use with Indigenous people inhibits our understanding of the burden, identification, prevention and management of depression in Indigenous people with and without chronic disease.

**DEPRESSION IN A CROSS-CULTURAL CONTEXT**

The concept of depression, its manifestation, the expression of symptoms, the antecedents and consequences are expressed in varying linguistic and behavioural ways in different cultural groups (Beeman, 1985; U.S. Department of Health and Human Services, 2001). Culture may determine or frame causative, precipitating or maintenance factors, influencing the onset, impact, course and outcome of mental illness (Marsella, Sartorius, Jablenski, & Fenton, 1985). It is essential to understand the broader social, political, historical, physical, spiritual and psychological worlds in which health and illness is constructed and experienced to overcome health and social disadvantage experienced by Indigenous people.

The Men, Hearts and Minds Study (Brown et al., 2012), completed by Professor Alex Brown, was a multi-stage project exploring the interplay of psychosocial factors and cardiovascular risk in Indigenous communities. The first stage (ensuring that depression could be measured as the primary exposure of interest) involved detailed qualitative research with
Indigenous men within remote and urban community settings, including Aboriginal men and senior Ngangkari Tjuta (or traditional healers).

The underlying premise was that depression would be experienced by Aboriginal men; that it would share features of depression with that seen in non-Indigenous populations; and that local idioms of distress, expressions and modes of communication would be culturally specific. These assumptions were demonstrated in the field work. Depressive symptoms were common and depression as a clinical entity was recognizable. Aboriginal participants endorsed excessive worry, grief and loss, and concern for family as the primary contributors to depressive moods. Key mood symptoms were excessive sadness and feelings of grief, irritability and anger. Cognitively, excessive focus on distress and bad feelings, homesickness when away from their family and suicidality, were frequently expressed emotional elements of depressive affect. However, the most consistent symptoms of depressive affect among Aboriginal men were the feelings of a weakened spirit and anger, and frequent/heavy use of alcohol and marijuana and acts of violence.

**PRIMARY CARE AND CHRONIC DISEASE PREVENTION AND MANAGEMENT**

Primary health care remains the principal setting for co-ordinated chronic disease and mental illness identification and management within Australia and internationally (Commonwealth Department of Health and Aged Care, 2010; Nagel & Thompson, 2006; WHO, 2001). Despite this, up to 50% of main stream patients with depression attending primary health care are not diagnosed or treated (Fuller et al., 2011a, 2011b; Gunn et al., 2008). The reasons for this include: incomplete knowledge of symptoms and treatment; the complexity and interplay of chronic disease comorbidities; time constraints; and concerns with the utility of diagnostic tools (Mulrow et al., 1995).

For Indigenous Australians, the role of primary health care, particularly the Aboriginal community controlled sector, has been clearly established; with high attendance rates, enhanced accessibility and evidence to suggest improved delivery of evidence-based care for Indigenous people (Peiris, Brown, Cass, Patel, & al, 2009). Little is known about the patterns and burden of depression in Indigenous primary health care attendees, or its interplay with comorbid chronic disease. Professor Brown and others have published audit data from 62 primary health care centres as part of the Audit and Best practice for Chronic Disease Extension project (D. Si et al., 2010; Damin Si et al., 2011) exploring the identification of depression among Indigenous patients with diabetes. Randomly selected files of 1592 diabetic patients were audited to determine prior diagnoses of depression and prescription of antidepressant therapy. Fewer than 10% of patients with diabetes had a recorded diagnoses of depression, with a wide variation across primary health care centres (0-37%), and ‘assessment for depression’ was not documented in any patients in over one-quarter of primary health care centres. Given the post-hoc nature of these analyses, however, it is critical to examine the identification of depression in a more explicit fashion.

Antidepressants, known to be effective in primary care, are commonly used to treat depression, (Arroll et al., 2009) as are psychological therapies, or a combination of both. Guidelines recommend treatment response is monitored using freely available depression measures that have been validated for use in non-Indigenous populations.

A culturally validated, free-to-use tool to screen for depression in Indigenous people would enable the accurate identification of those with depression (with or without chronic disease), clinical evaluation of the effectiveness of currently available treatment strategies and quantification of the epidemiological burden of depression in Indigenous peoples. These data will be used to lobby for funding, plan service provision and determine if new interventions are warranted.
ADAPTATION OF THE PHQ-9

To demonstrate utility within Indigenous primary care settings, depression screening tools need to demonstrate face validity within the target population; be "translatable"; brief; self-administered or conducted/administered by lay interviewers; validated with Indigenous populations, the medically ill and community samples; and demonstrate robust psychometric properties (Sousa & Rojjanasrira, 2010).

The Primary Care Evaluation of Mental Disorders (PRIME-MD) (Spitzer, Williams, Kroenke, & et al, 1994) was the first instrument designed specifically for use in the primary care context that allowed the identification of specific disorders aligned with the diagnostic criteria from DSM-IV (Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV), 1994). The PHQ-9 (Kroenke, Spitzer, & Williams, 2001) comprises the 9 depression-specific questions from the instrument, serving as a valid case-finding diagnostic tool as well as reliably grading depression severity (Kroenke et al., 2001) in multi-ethnic populations in the United States (Huang, Chung, Kroenke, Delucchi, & Spitzer, 2006; Kroenke, Spitzer, Williams, & Lowe, 2010; Kuper, Marmot, & Hemingway, 2002a), with validated translations in over 30 languages. The PHQ-9 has been validated as a screening test for depression in patients with established chronic disease (Stafford, Berk, & Jackson, 2007), and has been previously adapted for use in a small sample (n=34) of Aboriginal primary care patients with coronary heart disease (Esler, Johnston, Thomas, & Davis, 2008) attending a single primary health care centre in the Northern Territory.

In order to explore existing tools for use in Aboriginal communities, Stage II of the Men Hearts and Minds Study involved the establishment of five Aboriginal language focus groups to validate, confirm, enhance (and where required, extend) the theoretical domains collated from the initial qualitative study; to choose a depression screening tool to use in field work; to translate and back-translate developed items to ensure equivalence of adapted tools, and support the appropriate measurement of items in terms of acceptability, semantics, recognised terminology and cross-language equivalence according to best-practice methods (Sousa & Rojjanasrira, 2010).

Each focus group independently chose the PHQ-9 to translate and undertook a structured in-translation and back-translation process, producing the aPHQ-9 depression inventory and the additional 7 questions.

aPHQ-9 RESULTS IN THE MEN, HEARTS AND MINDS STUDY COHORT

This adapted (and extended) aPHQ-9 tool was applied in a cross sectional survey of depression and cardiovascular risk among 186 Aboriginal men from Central Australian communities. Among survey participants, chronic disease risk was high, with significant rates of elevated blood pressure, dyslipidaemia, smoking, obesity and diabetes. Major depression was found in about 5% of the cohort. Elevated depressive symptom scores (but not fulfilling the diagnosis of major depression) were demonstrated in 40% of the cohort. Major depressive disorder (MDD) (based on PHQ-9 scoring criteria) (Kroenke et al., 2001) was the strongest independent correlate of prevalent cardiovascular disease (CVD) (Table 1). A separate model using continuous PHQ-9 scores, confirmed a graded association between levels of depressive symptoms and prevalent CVD.

PILOT VALIDATION DATA

Pilot testing of the aPHQ-9 (against a semi-structured diagnostic interview based on DSM criteria) was conducted in a community sample of 78 Indigenous people from Central Australia. Initial psychometrics in the pilot testing phase were promising. The tool was similarly internally consistent in Aboriginal men (α=0.776) and Aboriginal women (α=0.767). Further, using previously defined cut points Aboriginal women demonstrated more moderate
and moderate to severe depressive symptoms than Aboriginal men, as would be expected from gender differences observed globally (56% minimal-mild, 33% moderate and 10% moderate to severe symptoms). The corresponding values in Aboriginal men were 84%, 12.5% and 3% respectively.

Table 1. Clinical and social correlates of CVD

<table>
<thead>
<tr>
<th>Variable</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
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<tr>
<td>aPHQ-9 MDD</td>
<td>9.5</td>
<td>1.8-50.6</td>
<td>0.01</td>
</tr>
<tr>
<td>HT (&gt;140/90)</td>
<td>2.9</td>
<td>1.1-7.8</td>
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<td>Age</td>
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<td>1.0-1.1</td>
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<td>hsCRP</td>
<td>0.8</td>
<td>0.6-1.0</td>
<td>0.09</td>
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<td>HDL-C</td>
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<td>0.2-1.5</td>
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<td>Education ≥ 16yrs</td>
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<td>0.5-4.9</td>
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<td>0.1-2.5</td>
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<td>BMI</td>
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<td>Total Cholesterol</td>
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<td>0.7-1.8</td>
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Methods

This is an observational study to validate the aPHQ-9 for use with Aboriginal and Torres Strait Islander people attending PHCS, against a gold standard structured diagnostic interview (MINI 6.0.0). This multicenter study which is current in recruitment phase is being conducted in PHCS throughout Australia’s States and Territories. Each PHCS will be engaged for short blocks of recruitment, which will continue until the local target numbers are reached. We will recruit 500 adult Aboriginal or Torres Strait Islander people. Ideally we will recruit 10 PHCSs which will each recruit 50 participants.

Participants in the study must meet the inclusion and exclusion criteria outlined below.

Inclusion Criteria

- Aged 18 years of age or over
- Self-identifies as Aboriginal or Torres Strait Islander
- Attending a PHCS
- Able to communicate in English sufficient to complete study instruments
- Able to give informed consent

Exclusion Criteria

- Known psychosis
- Known bipolar disorder

CONSENT

It is the primary responsibility of the investigator or the IRF (determined on a site by site basis as appropriate) at each participating site to obtain informed consent from clients to participate in the study.
Co-enrolment in a trial or another observational study is permitted. We request that the assessments for this study are completed before other trial or observational study assessments to avoid confounding the results.

**SCHEDULE OF MEASUREMENTS**

**Interview 1: Baseline Questionnaire**

Following informed consent, the IRF or other trained PHCS member of staff will be available to interview each participant using a short baseline questionnaire capturing basic demographics, or participants can answer questions directly using paper forms or the ‘computer assisted questionnaire’. We will collect information on the method of assessment (self-completed or interviewer-administered), gender, date of birth, identify as Aboriginal, Torres Strait Islander or both, whether an Aboriginal language is spoken, marital status, living arrangements (alone/with others), highest level of education, employment status, medical history (primary history of chronic disease and mental illnesses) and recent (in the last two months) bereavements.

In situations where it may not be considered appropriate for the IRF to ask about medical history, or social markers these questions will be asked by, or completed in the presence of a practice nurse, Aboriginal Health Worker or other PHCS staff member who will also administer the aPHQ-9.

All responses must be entered into the secure online web-based system.

**Interview 2: Adapted Patient Health Questionnaire (aPHQ-9)**

Immediately following the demographic assessment the participant will be asked to complete the aPHQ-9 questionnaire and the 7 culturally specific questions. This may be provided in a computer-assisted or paper format and be self-completed by the participant, or interviewer-administered. If a participant has difficulty reading or requires any assistance for whatever reason, the aPHQ-9 will be read to them by the IRF or local PHCS staff as appropriate. This person will also enter the responses on to the paper or computer assisted aPHQ-9 on behalf of the participant.

In situations where it may not be considered appropriate for the IRF to administer the aPHQ-9 and seven additional questions, these questions will be asked by, or completed in the presence of a practice nurse, Aboriginal Health Worker or other PHCS staff member. If required, this person will also enter the responses on to the paper or computer assisted aPHQ-9 on behalf of the participant. We anticipate that the demographic assessment and aPHQ-9 will take less than 20 minutes to complete for most participants.

After completing the aPHQ-9 participants will be asked to rate their agreement, or otherwise, with a series of statements regarding the acceptability of the aPHQ-9. These questions are followed by an open ended question where participants are asked for specific feedback about the aPHQ-9. Site staff will be asked to encourage participants to provide feedback about aPHQ-9 acceptability and any issues of concern. All responses must be entered into the secure online web-based system.

**Interview 3: Mini International Neuropsychiatric Interview (MINI) 6.0.0**

Within one week of completing the baseline and aPHQ-9 questionnaires, participants will be contacted to complete the MINI 6.0.0 interview and additional assessments. A computer assisted personal interviewing MINI will be used with paper MINI available for back-up. The following MINI modules will be administered: Major Depressive Episode, Posttraumatic Stress Disorder and Generalized Anxiety Disorder followed by general questions on smoking and alcohol consumption. We do not expect any interview to take longer than 20 minutes (even for someone with all four disorders).
Outcomes

All responses must be entered into the secure online web-based system. The MINI result including the total score and item responses will be recorded in participants’ medical records in all instances. Each participant’s MINI result will be provided to and checked by the PHCS. The general practitioner of a participant who is assessed as experiencing a psychiatric disorder will be encouraged to arrange re-assessment, treatment or formal referral for depressive or other abnormal mood symptoms according to their clinical judgment.

Results

The study is in recruitment phase. The following milestones have been achieved for recruitment sites (See Table 2) with 176 participants having completed the study to date.

<table>
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<th>Letter of Support received</th>
<th>Local ethics/board approval received</th>
<th>Ethics submitted</th>
<th>Ethics approval received</th>
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