

Adapting wellbeing research tools for Aboriginal and Torres Strait Islander people with Chronic Kidney Disease

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Abstract

Background There is an acute need to develop wellbeing measures and interventions that are appropriate for Aboriginal and Torres Strait Islander people, including residents of remote communities who have chronic physical conditions. The Kessler 10, Patient Health Questionnaire 9, and EuroQoL are valid, reliable, and commonly used tools to assess various aspects of wellbeing but have not yet been translated to Aboriginal and Torres Strait Islander languages. Similarly, the Stay Strong App is a brief, culturally responsive, e-mental health intervention, but has not been used with Aboriginal and Torres Strait Islander people with Chronic Kidney Disease.

Methods We aimed to pilot test the above tools with Aboriginal and Torres Strait Islander Australians with Chronic Kidney Disease Stage 5 (CKD-5) and develop revised versions suitable for use in a clinical trial using a four-stage multi-method approach. Stage 1: Pilot testing of outcome measures and Stay Strong App intervention in a purposive sample of five haemodialysis patients and carers to examine acceptability. Stage 2: Translation of outcome measures through collaboration between the Aboriginal Interpreter Service, Aboriginal and Torres Strait Islander research officers and research team. Stage 3: Conversion of revised outcome measures to electronic format. Stage 4: Collaboration of research team and an Expert Panel in an iterative approach to adapt the Stay Strong App.

Results Stage 1: Pilot testing of outcome measures identified three areas of difficulty: explanation of time frames and frequency responses, translation of the terms 'worthless' and 'hopeless', and fatigue and boredom related to the assessment process. Stage 2: Translation of most items was uncontroversial. Discrepancies between team member views and local interpretations of specific terms were addressed. Final drafts were forwarded to the Aboriginal Interpreter Service for translation. Stage 3: Audio translations in 11 languages were integrated into an interactive Outcome Measures App. Stage 4: A new renal version of the Stay Strong App was developed through research team and expert panel consensus.

Conclusion The four-stage approach allowed adaptation of the tools for use within a future trial of wellbeing interventions for Aboriginal and Torres Strait Islander people receiving haemodialysis. Trial registration: ACTRN12617000249358 Registered 17 February 2017.

Introduction

The health and welfare of Aboriginal and Torres Strait Islander Australians is improving in many areas, including life expectancy, educational attainment and child mortality [1]. Furthermore, a significantly higher proportion of Aboriginal and Torres Strait Islander people aged 15 and over reported good health in 2012–13 (37%) than in 2001 (33%). However, chronic kidney disease (CKD) is a serious and increasingly common health problem for Aboriginal and Torres Strait Islander people, especially those who live in remote communities. In the 2012–13 National Biomedical Risk Factor Survey, it was estimated that one in ten Australians have biomedical signs of CKD. However, 23% of Aboriginal and Torres Strait Islander adults were estimated to have CKD, with a heavier burden of 39% of adults affected in remote areas [2].

CKD is categorised into five stages according to kidney function and evidence of kidney damage. End-stage kidney disease (ESKD) or CKD–5 is the most severe form of CKD, where renal dialysis or kidney transplant is required for survival [3]. In 2012–13 the incidence rate of CKD–5 among Aboriginal and Torres Strait Islander Australians was 6.6 times that for non-Aboriginal and Torres Strait Islander Australians, and Aboriginal and Torres Strait Islander Australians were ten times as likely as non-Aboriginal and Torres Strait Islander Australians to be hospitalised for this disease [4].

People with CKD sustain many losses - physical functions, cognitive abilities, and role in the family and workplace [5], and depression is common in those undergoing dialysis (25% when assessed by clinical interview, 40% when assessed by self-report measures)[6]. Depressive symptoms increase the risk of poor outcomes in people with CKD–5 on dialysis [7]. A Central Australian qualitative study describes the intense loneliness and social isolation of haemodialysis treatment as a prominent factor in missed treatment attendance [8, 9]. Most Aboriginal and Torres Strait Islander people with CKD–5 in the Northern Territory of Australia have to relocate several hundred kilometres from their remote and very remote communities to access centrally based assisted-haemodialysis which is required thrice weekly [10]. This results in dislocation and social isolation, and the possibility that personal circumstances deteriorate further with time and disease progression [11].

Recent policy changes have enabled funding for renal nurses and Aboriginal Health Practitioners working in remote dialysis services [12]. Despite this investment, most renal patients from remote communities will continue to be treated in urban centres in the foreseeable future. The psychosocial implications of CKD–5, compounded by the separation of patients from their communities and families, requires attention and targeted interventions. Evidence of effective treatment for depression or other mental illness in Aboriginal and Torres Strait Islander people (with or without co-occurring disorders) however, is difficult to find. Despite recognition that psychosocial factors are associated with morbidity and mortality in many chronic conditions, including CKD, well-designed intervention studies are lacking [5, 7].

One of the only formally evaluated, culturally responsive, mental health interventions for Aboriginal and Torres Strait Islander people was developed through the Northern Territory (NT) Aboriginal and Islander Mental Health Initiative (AIMhi). This intervention, 'Motivational care planning' (MCP) was designed in collaboration with local Aboriginal mental health workers (AMHW) through exploration of local Aboriginal and Torres Strait Islander perspectives of mental health [13, 14]. MCP combines problem solving therapy and motivational interviewing, to create a 'low-intensity' treatment utilising a holistic, strengths-based approach with pictorial tools. The AIMhi MCP intervention has been translated into an electronic (i.e. tablet application) format (*the AIMhi Stay Strong App*) making it even more interactive and visually appealing. Given that the App was developed initially for clients with mental health concerns, the present study describes the process of adaptation of the Stay Strong App intervention prior to a clinical trial of effectiveness of wellbeing interventions in Aboriginal and Torres Strait Islander people with CKD–5. The trial will measure outcomes in the domain of wellbeing, depressive symptoms and quality of life.

Testing of a wellbeing intervention also requires the use of appropriate and psychometrically sound measures. The Kessler Distress Scale (K-10), Patient Health Questionnaire (PHQ-9) and EuroQoL (EQ-5D) are valid, reliable, and commonly used tools to assess these aspects of wellbeing in the general population. K-10 is a measure of psychological distress with strong links between high scores and anxiety and depression. It is one of the routine outcome measures used by Australian public mental health services and has been used in full and abbreviated forms in state and nation-wide Aboriginal and Torres Strait Islander health surveys. PHQ-9 assesses severity of depression and has shown diagnostic, criterion and construct validity [15]. It has been tested with Aboriginal and Torres Strait Islander groups and adapted to include plain English response categories [16, 17]. This study uses a version which was specifically adapted for the Central Australian context [18]. The EQ-5D is a widely utilised multi-attribute utility instrument used for estimating utility weights for calculation of QALYs [19].

Although important work has been undertaken in Central Australia and nationally to adapt the English version of the PHQ-9 into Aboriginal English, none of the above outcome measures have been translated to Aboriginal and Torres Strait Islander languages [20, 21]. This is particularly relevant to research in the NT setting where most Aboriginal and Torres Strait Islander people speak English as a second or third language [22, 23]. This study describes the process of adaptation of outcome measures and the MCP brief intervention for use in the above mentioned clinical trial, seeking to render the tools appropriate, respectful, and relevant to the study population [24].

Methods

Study Design and ethical approval: A four-stage multi-method approach was adopted. Stage 1: Pilot testing of the paper based outcome measures and Stay Strong App intervention. Stage 2: Translation of outcome measures into 11 Aboriginal languages (Warlpiri, Arrernte, Luritja, Pitjantjatjara, Alayawara, Tiwi, Kriol, Yolngu Matha, Ngangikurranggurr, Murrinh Patha, Anindiliyakwa). Stage 3: Integration of translated outcome measures into electronic format with associated user protocols. Stage 4: Adaptation of the Stay Strong App for use with Aboriginal and Torres Strait Islander people with Chronic Kidney Disease. Ethical approval for the research program was granted by relevant ethics committees (ref HREC 12-1881 and CAHREC 12-100,) including an Aboriginal sub-committee.

Research team: The research team comprised five non-Indigenous members with expertise in mental health and kidney health research in Aboriginal and Torres Strait Islander settings, a Torres Strait Islander renal physician and research fellow, and two Aboriginal and Torres Strait Islander research officers, one of whom spoke five Central Australian Aboriginal languages. An expert panel was established, consisting of two renal physicians, a renal dietitian, four renal health nurses, one of whom is also Chief Executive Officer of Purple House (an Indigenous-owned and operated dialysis service based in Alice Springs), a cultural consultant and Aboriginal Elder from Central Australia, and a renal transplant recipient. The expert panel assisted the research team in adaptation of the Stay Strong App for renal patients. The

research team also worked in collaboration with the Northern Territory Government Aboriginal Interpreter Service (AIS), which has offices in Darwin and Alice Springs and employs approximately 30 interpreters. The service provides interpreting and translation for the major languages of the Northern Territory, and employs a further 400 casual interpreters covering nearly 100 languages and dialects.

Participants and Setting: The Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) Aboriginal Corporation runs Purple House, which has its headquarters in Alice Springs and provides dialysis and support to Aboriginal and Torres Strait Islander people with CKD-5. Pilot testing of the paper based version of outcome measures along with the Stay Strong App was carried out in a purposive sample of haemodialysis patients and carers, who were opportunistically recruited while attending Purple House on the morning that pilot testing commenced. Criteria for inclusion were identification as Aboriginal and Torres Strait Islander, ability and willingness to participate, self-assessed facility with English language (no funding was allocated for interpreters within the pilot testing), age of 18 years or more, provision of oral informed consent, and ineligibility for the later clinical trial. Those who were eligible for the pilot testing but not the later trial included haemodialysis patients usually living in remote communities who were visiting Alice Springs, as well as carers of haemodialysis patients.

Data collection: Verbal informed consent was obtained by the local (non-Indigenous) research officer, using a pictorial, plain English flip chart and a plain English information sheet developed in collaboration with Aboriginal research officers that explained the objectives of the project and the confidential handling of their data. The pilot testing process was divided into three parts: 1) completion of the three paper-based outcome measures 2) completion of the Stay Strong App intervention; 3) completion of a semi-structured interview exploring ease of use, appropriateness and relevance of each tool.

Responses during the first two parts of the pilot testing process were entered on the paper-based version of the outcome measures and into the Stay Strong App. The semi-structured interview responses were audio-recorded, and participant comments, suggestions, questions and non-verbal responses were noted, and later summarized and grouped into two different categories: content feedback and process feedback.

Results

Stage 1: Outcome measures and intervention feedback: content

Three haemodialysis patients and two carers (three females, two males aged between 51 and 60 years) who spoke English as a second or third language participated in the pilot testing process through two

individual and one group interviews (with three participants).

The outcome measures were generally well received, but several changes were recommended. The ten-item K-10 measure offers response categories of five frequency levels related to the past two weeks while the nine-item PHQ-9 uses four frequency levels and is scored with reference to the last two weeks. The transition between the four week and two week time frames in the different scales was not easily followed by the participants, and required further explanation. Two K-10 questions (relating to the experience of '*hopelessness*' and '*worthlessness*') elicited a lack of verbal response. The researcher intentionally paused to provide time for participants to reflect on the questions and avoided rushing the response or interpreting silence as lack of understanding. Often the silence represented contemplation from which an answer later emerged. This approach was valuable but contributed to the length of the process. Where problems with understanding were encountered, alternative wording was discussed. After alternative words in English were presented, the group of three discussed the concepts in a common Aboriginal language (Pitjantjatjara) for several minutes before reaching consensus about alternatives. Alternatives proposed to the term '*hopeless*' included '*without hope*', '*not feeling good*', '*waking up like there is no hope*', and '*what's the point of getting up*'. An alternative to the term '*worthless*' was '*no one want to know you*'.

One PHQ-9 question ('*Have you been talking slowly or moving around really slow?*') required further explanation. In addition, the transition from five frequency response options in the K-10 to four in the PHQ-9 led participants to request the missing category ('*some of the time*') as a useful available option. The EQ-5D was the easiest questionnaire to administer and was understood with ease in part because of its immediate time frame (today) but possibly also related to user-friendly and holistic attributes gained through its extensive development process within the multi lingual and multidisciplinary EuroQol Group [25]. There was nevertheless some difficulty in distinction between the '*slight*', '*moderate*' and '*severe*' response categories for some items with participants struggling to identify the difference between the three options.

Participants responded positively to the Stay Strong App intervention, for example: '*ewa (yes) other people would like it*', '*when they see it (the people who keep me strong) on the app they'll start talking*', '*I think it's really good*'.

Stage 1: Outcome measures and intervention feedback: process

The assessment process included three components: completion of the three paper-based outcome measures; completion of the Stay Strong App intervention and completion of a semi-structured interview exploring ease of use, appropriateness and relevance of each tool. Feedback about the process of

completing outcome measures and the Stay Strong App intervention was limited. There were positive comments: '*good to answer*', '*made me feel better*', '*I really like that one, was good to talk about that*'. On the other hand, there were also indications that the process was somewhat arduous with comments such as: '*a lot to answer*', '*too long*', '*feel too tired*' with related body language noted during the session (standing up, walking away, or answering the phone). One participant suggested dividing the process into two separate sessions '*Maybe next time catch up again*'.

One other comment suggested the questions '*need more explaining... it's different English and Aboriginal and Torres Strait Islander languages... the words around feelings*'. While another said, '*That was a lot to answer in one go...(but) good to ask how I feel... let it out... made me feel better*'. Distractions within the environment (noise, people and activity) also appeared to contribute to difficulty in attending throughout the assessments and intervention process. The researcher observed that fatigue or boredom appeared to relate to two issues: the length of the assessment process (influenced by the above-mentioned challenges of language and distractions within the environment), and repetition within the outcome measures. The repetition within the outcome measures occurs because there is considerable overlap between the PHQ-9 depression scale and the Kessler 10 scale. For example, both explore symptoms of depression using similar wording.

Stage 2. Outcome measures revision: forward translation

The research team undertook a four-step process of forward translation of the outcome measures. The *first step* involved determination of the eleven most widely spoken Aboriginal languages (including Kriol) in each of the two regions in which the research was undertaken through consultation between research team, and the Aboriginal Interpreter Service and service providers.

Stage 3: Paper to electronic outcome assessments with guiding protocols

Stage 4: Stay Strong App revision

The Stay Strong App has five sections: review of family, strengths, worries, and tips for wellbeing prior to setting life style goals for change. The expert panel reviewed the app and proposed changes. For example, given the specific dietary needs of renal patients some of the dietary suggestions within the app required adaptation. The recommended changes were then presented to the research team (Table 1). Further consultation within the team, the panel and with Aboriginal research team members led to revision of wording and images until consensus was reached.

Finalised tools

The completed Outcome Measures App is in electronic tablet format. Each of the three outcome measures (K-10, PHQ-9 and EQ-5D) is supported by 11 language options with visual cues and optional audio files. The revised Stay Strong App has incorporated the recommended wording and image changes. Both tools were finalised in preparation for use as assessment and treatment tools within a clinical trial of effectiveness of the MCP intervention for chronic kidney disease patients.

Discussion

Time frames were one of the key concepts within the outcome measures that were not easily understood. This difference between Aboriginal and Torres Strait Islander and Western ways of measuring and anchoring time has been identified and described in detail in many other settings [26]. Difficulties with terms such as 'hopelessness' have also been encountered elsewhere. Brown et al reported similar translational difficulties for bilingual experts who felt that '*the overarching equivalent for the term was the constellation of depressive feelings and therefore left hopelessness out of the PHQ-9 adaptation*'[18]. Key solutions proposed to deal with miscommunication and fatigue were embedded into the accompanying assessment protocols and included:

- Identifying mutually agreed quiet places for the assessment
- Allowing participants time to contemplate and generate their responses
- Allowing interviews to be divided into consent, assessment and treatment sessions if required
- Presence of interpreters and Aboriginal and Torres Strait Islander research officers wherever possible
- Identifying alternative prompting phrases to deal with items linked with difficulty in translation

The addition of the prompt of "no one want to know you" for the K10 "worthless" item may be considered to introduce a social aspect that is not explicitly in the original item. This clarification reflects an important aspect of many Indigenous cultures including Aboriginal and Torres Strait Islander people, where self-concepts are inextricably linked to family and community [27].

In recognition of the burden of symptoms accompanying end stage kidney disease, patient experience measures are under development internationally to inform patient care needs and clinical quality measures [28]. We have demonstrated that Western understanding of ESKD symptoms differ from

Aboriginal peoples understanding of symptoms, but we have enabled a validation of Aboriginal-reported experience and symptom measures and scoring of measures in this study. This research is highly relevant to health services and patients, and will be transferable in quality audit and patient care for Aboriginal patients in this region [11].

Conclusions

Aboriginal and Torres Strait Islander people with Chronic Kidney Disease Stage 5 (CKD-5) face many wellbeing challenges. Their unique experiences require the development of targeted interventions supported by evidence of effectiveness obtained through robust research design. However, researchers must recognize that research practices and processes and related interventions are embedded in Western biomedical knowledge traditions; and may not translate into Aboriginal and Torres Strait Islander expectations of healthcare and research, ways of relating to people and broader ontologies of health and care. This study reports on the initial phase of preparation for a clinical trial seeking to find ethical, respectful and effective research strategies through translation and adaptation of the research tools and processes.

Abbreviations

AIMhi: Aboriginal and Islander Mental Health Initiative

AIS: Australian Interpreter Service

AMHW: Aboriginal mental health worker

CKD: Chronic kidney disease

CKD-5: Chronic Kidney Disease Stage 5

EQ5D: EuroQoL

ESKD: End stage kidney disease

K10: Kessler Psychological Distress Scale

MCP: Motivational care planning

NT: Northern Territory

PHQ-9: Patient Health Questionnaire

QoL: Quality of Life

QALY: Quality adjusted life years

RCT: Randomised controlled trial

WDNWPT: Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation

Declarations

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Availability of data and materials

Not applicable.

Authors' contributions

KD and TN were major contributors to the conception and design of the study, data interpretation and presentation and drafted the manuscript. MS was a major contributor to the conception and design of the study, conducted data collection and data analysis and assisted with writing and reviewing the manuscript. AC, JH, KH, and SP contributed to the design of the study, and assisted with writing and reviewing the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate

This study has been approved by the Central Australian Human Research Ethics Committee (CAHREC No: HREC-16-406) and the Human Research Ethics Committee (HREC) for the NT Department of Health and Menzies School of Health Research (HREC-16-2599), including an Aboriginal subcommittee. Verbal consent was to participate was used rather than written consent and this was specifically approved by both above ethics committees. Our target population is Indigenous people. Our previous studies suggested that some Indigenous people with low literacy find written forms of communication a disempowering experience. We sought individual oral consent from each participant after detailed discussion about the purpose, methods and demands, risks and potential benefits of the study (as outlined in the information sheet). We asked the participants if they understood the information provided and if they consented to participation. Their response was recorded by the researcher. Participant's

willingness to complete the assessment scales and brief intervention session were further confirmation of their consent to participate.

Consent for publication

Not applicable.

Competing interests

KD, TN and DK developed the Stay Strong App which is a paid App. Menzies receives the limited revenue from App sales which is used for maintenance of the App. JH, AC, MS, KH, SB, CS, and SM have no competing interests.

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Tables

Table 1. Stay Strong app changes for Aboriginal and Torres Strait Islander people with Chronic Kidney Disease

Original wording or image	Revised wording or image
Strengths	
Good tucker	Healthy food
Spirituality	Strong spirit
Think positive	Think happy
Exercise	Change image representing football to one which shows activities around the house or going for a walk.
Music or Dance	Change icon to man and woman with painted bodies
Missing culture and country	Change icon to man and woman with painted bodies and picture of landscape
Having goals	Music and Dance
Worries	
Unhealthy lifestyle	Combine icons to show both unhealthy food and inactivity
Physical Illness	Sickness / Being sick
Anxious and Sadness	Worried or sad
Stay strong tips	
Eat Fruit and Vegie	Understand what healthy diet works for you - talk to dietitian
Drink Water	
Make new friends and do new things	Use time wisely
Additional prompt	Attend appointments / clinics/ dialysis
Additional prompt	Talk to your care team