Although 2.4% of Australia's population are Aboriginal or Torres Strait Islander (ATSI), their geographic distribution across Australia is quite different. ATSI people comprise 1% of the population in major cities, yet 15% in remote areas and 49% in very remote areas [1]. Many ATSI people experience Chronic Kidney Disease (CKD), often as a complication of diabetes and heart disease. As the disease progresses, they need to access regular dialysis and specialist care. This leads to people leaving their homes and families in order to receive care in larger towns and cities. They then have to navigate numerous appointments across disjointed sections of healthcare. Attending dialysis three times a week, appointments for other health conditions, managing accommodation, financial challenges and transport issues can lead to missed appointments and a further decline in health. The need for equitable access, well-coordinated care and improved health outcomes has been identified in recent studies [2].

A set of ATSI patient journey mapping tools were developed [3] that identify the complexity within patient journeys, highlighting the critical steps and gaps between services and provided a focus and options for targeted action by health care providers. Therefore, this education initiative invites ATSI kidney patients to identify gaps in their care and suggest improvements. As part of this education initiative the renal patient mapping tool is used and identified in detail exactly what happens when multiple health appointments are scheduled across different parts of the health service and show where “links in the chain” are missed that then lead to patients feeling unsupported.

This education initiative has involved senior health professionals, managers, researchers and educators to develop support services to improve indigenous patient journeys and care outcomes. Long-term changes will be made to clinical practices and health care policies, with ongoing reference to patient values and priorities. Overall, this education strategy looks at staff understanding cultural competence as an integral part of any health journey. Training is being provided for staff and new case studies of the patient journeys will be used to improve the education of doctors, nurses and other health professionals in health care and university settings, which can respond to identified needs and ensure staff cultural competency [1].

It is hoped that this new educational strategy can assist with better understanding and addressing the gaps in care, increasing the cultural competency and responsiveness of staff and services and lead to significant improvements in patient outcomes and patient satisfaction. This presentation will explain the development of the mapping tools and how they are being used to inform health journeys for renal patients and beyond.

Keywords: Aboriginal, Education, Patient Journey, Rural.

1 INTRODUCTION

Racial discrimination is well documented as a contributing factor to poor health outcomes for aboriginal and torres strait islander (atsi) australians [4]. Australians need to recognise our country as a culturally and linguistically diverse nation. Atsi people have inhabited and cared for this land for millennia, and have uniquely shaped our nation. Progressing atsi health has now become a priority for both state and federal governments, health care workers, patient advocacy groups and atsi australians.

Nationally almost one in five people live with indicators of ckd (albuminuria or low egfr) but nearly 90% of people are unaware of this [5]. At present, there is also minimal understanding among the broader health professional community in australia regarding the psychosocial and spiritual support needs of atsi people living with ckd and the burden that this causes. There is also a large geographic variation in the burden of ckd, which affects a higher proportion of people living in remote australia, most of whom are of atsi origin [5].
Improving health requires health care workers to provide culturally competent care and a willingness to work in partnership with their ATSI counterparts [6, 7, 8, 9].

2 BODY

Health professionals have historically had insufficient culturally appropriate training, which has led to difficulty, frustration and even patient disengagement from care. Important messages can be lost or distorted when the patient feels the doctor is not taking a holistic approach or when the patient is “blindsided” by a health assessment, which reveals that they have a multitude of long-term health issues. Health professionals often teach patients with a variety of western models and this is not always the best approach for some people as ATSI people can respond better to intergenerational learning. Their knowledge is obtained through first-hand experiences. Addressing the care needs of ATSI patients without inclusion of their family and support persons can limit the success of our interaction, and may lead to lack of understanding on both sides.

The Australian code of conduct for nurses [9] recognises the importance of family, community, partnership and collaboration in the healthcare decision-making of ATSI people for both care delivery and prevention strategies. Yet health professionals who do not also consider family and community involvement and its importance for patient demographic often undertake decision-making. An example of a resource to assist patients, their families and communities to become more informed and engaged in their CKD care underpins supporting patient empowerment through provision of kidney health knowledge and facilitating appropriate questions regarding their treatment. The Aboriginal Educational Philosophy education resources is one example of this. The '8 [Aboriginal] Ways of Learning' framework (Regional Aboriginal Education Team, Western area 2012, RAET, Dept. of Education and Communities, Dubbo, N.S.W) has been used in Aboriginal education and provides a culturally competent structure of teaching and reflecting key processes [10].

The relationship between patients and health care providers is the foundation of care and requires communication across cultures, geography and life experiences. As a staff member in one rural ATSI Community Controlled Health Service put it: ‘It’s like managing two worlds together, it doesn’t always work’. Therefore, work commenced on a tool and patient journey modelling and mapping commenced and has been used to highlight gaps in access, continuity and quality of care for ATSI people. A range of methods including interviews, focus groups, review of health service care plans and observation of a patient’s actual journey from diagnosis to completion, have been used to highlight some of the hidden issues [10].
This became the “managing two world’s” project and a set of mapping tools were developed and these have been developed further for use with our university students where we use them to help improve student understanding of cultural safety. We continue to use the five dimensions of health as selected by this project to recognise the whole person entering the patient journey (physical or biological; psychological and emotional; social and wellbeing; spirituality; cultural integrity). This highlights the impact of underlying social and system factors on access and quality of care for country or rural ATSI patients. There is also an ‘Issues’ column which can be could be adapted for other patient groups. The chronological mapping of the journey enabled the project team to see clearly, what was happening for patients, carers and health staff/services and to see where gaps within the system occur [10, 11].

![Example of a patient mapping tool](image)

In 2019 work commenced on “aKction” – “Aboriginal kidney care together- improving outcomes now” project. The project brings together for the first time, ATSI renal consumers, health care staff, service providers, educators and researchers to transform research findings directly into renal care improvements and education.

This project is an extension of the existing renal clinical-research-education collaboration developed over the past five years, following the involvement of an Adelaide public hospital in an ATSI patient journey mapping tool development project [10]. That project provided the impetus, resources and focus needed to make significant progress and sustainable changes. The aKction research team are working closely with Kidney Health Australia (peak consumer organisation) and (Kidney Health Australia –Caring for Australians with Renal Injury) Guidelines Group to develop ATSI specific renal guidelines. Another project led by Dr Jaqui Hughes, ATSI nephrologist and the Rapid Applied Research Translation for Health Impact Grant entitled Catching-Some Air (Asserting Indigenous Rights in Kidney Disease) has already highlighted effective ways of improving partnerships and establishing Indigenous governance in kidney care. Both of these previous projects have informed our aKction project and the health impact goals of this first South Australian ATSI renal research collaborative project.
The over-arching aim of this collaborative project is to improve kidney care for ATSI people in South Australia. The project focuses on the needs and priorities of ATSI patients with complex care needs. Many country ATSI patients leave their homes and families to receive renal care in a city hospital, which may be over one thousand kilometres from their home. They often experience a range of health issues including diabetes and/or heart disease. Attending live-sustaining dialysis three times a week, attending appointments for other health conditions, and managing accommodation and transport issues can be difficult and exhausting. This often leads to missed appointments and a further decline in health.

This project includes ATSI kidney patients identifying gaps in care and suggest improvements in community consultations, which have been held across city and rural and remote areas of South Australia. ATSI people live across urban, rural and remote areas of South Australia and are over-represented in end stage kidney disease (ESKD) [1]. The incidence of ESKD for ATSI people is especially high in remote and very remote areas of Australia, with rates up to 20 times those of comparable non-ATSI peoples [12]. They often have complex care needs linked to higher rates of comorbidities, specific communication needs (language, health & health system literacy), separation from family and community members, and relocation, transport and accommodation situations. Patients also experience significant end of life challenges requiring timely and supported return home to family and country [13, 14, 15, 16]. ATSI patients describe being confused and concerned about their care options and end of life plans, and being overwhelmed by the number of different appointments in different parts of the health system [17]. This results in them missing dialysis sessions and medical appointments. Receiving generalised rather than personalised care affects their morbidity and mortality and furthers the ATSI community’s negative perceptions of health care.

The need for equitable access, well-coordinated care and improved health outcomes has been identified by earlier studies 5. The 2017 National Safety and Quality Health Service accreditation standards include assessment of health services’ ability to work in partnership with consumers, accurately identify Aboriginality, provide a welcoming environment, demonstrate responses to identified needs and ensure staff cultural competency [6].

The aKction project plans to map ten ATSI dialysis patient journeys in detail to identify exactly what happens when multiple health appointments are scheduled across different parts of the health service. This can then guide the research team, senior health professionals and educators to develop support services to improve patient journeys and care outcomes. Cultural competence assessment and training will be provided for staff, with pre and post surveys to determine effectiveness. This training and new case studies of the patient journeys will be used to improve the education of doctors, nurses, student nurses, medical students and other health professionals in health care and university settings.

As the patient journey mapping tools were developed in collaboration with a range of health professionals over the preceding years and have been shown to be useful to highlight areas where we as health professionals can improve patient care. This has meant they are now used in a variety of settings across ward and hospital units within both city and rural areas across not only South Australia but also Australia. They are beginning to be used in Northern Canada to assess and improve Indigenous patient journeys across jurisdictions.

ATSI renal patients have been involved in the development of the renal patient journey/pathway mapping tools through interviews, sharing their journey experiences and perceptions of care. ATSI and non-ATSI health professionals, researchers and educators then completed the analysis. In this project, ATSI patients will become more meaningfully involved in the analysis and translation phases, being positioned as expert patient co-researchers in a strengthened partnership approach.

3 RESULTS

The study is continuing and so there are no results available. It is hoped that by better understanding patient’s experiences and health care staff perceptions and mapping Aboriginal patient journeys we can provide better care to the integral patient population.

This project addresses five priority areas and hope to improve access to, experience of and coordination of care within and between primary and acute care and outpatients renal health services for ATSI patients. ATSI patients with ESKD often experience co-morbidities, and at younger ages, which significantly increase their morbidity and mortality. Attending live-sustaining dialysis three times a week, attending appointments for other health conditions, and managing accommodation and transport issues can be difficult and exhausting for these patients and often leads to missed
appointments and a further decline in health. It is imperative that gaps in care and improved clinical pathways and care transitions are identified and these results will be available in 2020 once the project is completed.

Collaboration between Aboriginal patients, their family members and health care services is required to improve coordination of care and the results we hope will identify areas where they can inform policy, clinical and health service changes and improve collaboration and patient care outcomes. Effective strategies for improvement in-patient journeys involving complex clinical care will be prioritised and incorporated into the Adelaide Hospital policies and practices, University of Adelaide Medicine and Nursing courses, and shared nationally and internationally through Kidney Health Australia.

4 CONCLUSIONS

By allowing us as clinicians and educators to know how patients navigate through the health system will identify where improvements can be made from the perspective of the patient, their family, health professionals and health services. We also plan to incorporate clinical and cultural care needs of ATSI patients and their families into health professional education in renal health care and university settings.

By bringing together the perspectives of patients, their families and communities, health professionals, academics, and researchers, this project will identify, develop and embed pragmatic improvements in kidney health care in South Australia. Positioning Aboriginal patients as Aboriginal Reference Group members and co-researchers enhances Indigenous governance and community involvement health care delivery. This will enable us to better meet the needs of this important client group.

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