Bottling knowledge and sharing it — using patient journey mapping to build evidence and improve Aboriginal renal patient care

Janet Kelly, Cheryl Wilden, Kylie Herman, Gay Martin, Christine Russell & Sarah Brown

Submitted: 17 February 2016, Accepted: 17 May 2016

Abstract
In Australia, rural and remote Aboriginal people with renal disease undergo complex patient journeys. Experienced renal nurses provide patient-centred care, working with patients and their families to identify their priorities and the barriers and enablers to quality care. They coordinate patient journeys, utilising their knowledge of staff and services across the health system. But how is this knowledge and these skills shared with peers and hospital systems? This paper discusses how two senior renal nurses, one in a regional dialysis unit and one in a metropolitan renal ward, joined with peers to form a renal nurse focus group with the aim of improving the coordination and quality of Aboriginal patient journeys and care experiences. Using the opportunities provided through the Managing Two Worlds Together project, they adapted and modified a set of patient journey mapping tools, working with key stakeholders (patients, families, staff) to map individual journeys and critical incidents from multiple perspectives. Each journey was compared to standards of care, and written up as a case study, enabling both the process and findings to be communicated with peers and students. Working as a focus group provided safe spaces for nurses to discuss the current gaps in care, and the mapping tools provided a logical structure for making sense of complexity and identifying appropriate actions for improvement. This collaborative approach to knowledge making enabled these experienced nurses to ‘bottle their knowledge and share it’, as they combined their own tacit clinical knowledge with explicit evidence and external knowledge.

Terminology
In this paper we use the term Aboriginal rather than Indigenous, or Aboriginal and/or Torres Strait Islander as this is the term preferred by the patients themselves.

Keywords
Renal nurses, Aboriginal, patient journey mapping tools, quality of care, rural and remote.
Introduction

In Australia, a disproportionately high number of Aboriginal people experience chronic kidney disease (CKD) compared to the general population. CKD in this population is linked to higher incidences of diabetes, heart disease and social determinants of health disparities (Australian Institute of Health and Welfare, 2015). With progression to end-stage kidney disease comes the need to explore renal replacement options, preferably home- or community-based dialysis (Kidney Health Australia, 2015). In South Australia, approximately half of Aboriginal people live in rural and remote areas, with limited local access to dialysis and specialist services (ABS, 2011). Rural and remote patients may be required to travel vast distances to access care, and in some cases may relocate—moving away from their family and community into a larger regional centre or metropolitan city to receive ongoing dialysis care. Regardless of which option of care is taken, patients often need to travel to and from major hospitals for specialist care.

A recent South Australian health system study identified that regional and remote Aboriginal patients with a range of health care conditions undergo very complex geographical and health care journeys across multiple health care services and sites (Dwyer et al., 2011). Staff and services may or may not appreciate the personal and cultural preferences of regional and remote Aboriginal patients. Underlying factors that impact on access and quality of care include the location of services, an increased burden of illness and co-morbidities, varied responses to personal communication and language needs, availability of financial resources, and the provision of culturally safe and flexible services (Dwyer et al., 2011). While city hospital systems work reasonably well for most city patients (Aboriginal and non-Aboriginal), they are not always flexible enough to meet the needs of rural and remote patients. When the ‘multiplier effect’ of all access barriers for country Aboriginal patients is taken into account, it becomes clear that these patient journeys are complex and require tailored responses (Dwyer et al., 2011).

Renal staff work creatively to respond to the gaps, barriers and complexities that are associated with these complex journeys (Kelly et al., 2015). Experienced renal nurses take a key role in communicating directly with patients and coordinating care with staff across multiple sites. Having worked in diverse sites and roles, they hold in-depth knowledge of the system of care, and the people and services within it. They problem solve daily, bringing together patient needs and professional and health service responses, ensuring patient-centred care within a generally inflexible and disjointed health care system. These skills and abilities are crafted over many years, but how are these skills and knowledge transferred to others? Furthermore, to what extent is this intrinsic nursing knowledge recognised and utilised more broadly to influence policy and practice?

This paper discusses how two renal clinical nurse consultants (CSCs), one in a regional hospital dialysis unit, the other in a metropolitan hospital renal ward, worked with other focus group members to improve the coordination and quality of Aboriginal patient journeys and care experiences. In particular, they worked with a small group of senior renal nurse peers and a nurse researcher within the Managing Two Worlds Together (MTWT) project. Together they identified gaps, mapped journeys from multiple perspectives, compared individual journeys to standards of care, communicated the process and findings, and developed strategies and action plans. This approach to combining their own tacit knowledge with external explicit evidence enabled them to ‘bottle their knowledge and share it’.

Methods

The focus group and renal patient journey mapping activities discussed in this paper took place within Stage 3 of the Managing Two Worlds Together — Improving Aboriginal Patient Journeys Project (2013–15). Stage 1 of the MTWT project (2008–11) involved interviews with Aboriginal patients and their family members, and with health professionals in urban, rural and remote settings about the barriers and enablers to quality care. In Stage 2, a smaller number of Aboriginal patients and family members worked with staff and the research team to map and record their patient journeys. Stage 3 focused specifically on how health professionals and educators could respond to the gaps identified within the health care system. Aboriginal patients and their family members were less directly involved in Stage 3. A participatory action research approach, with repeated cycles of Look and Listen, Think and Discuss, and Take Action, was used (Kelly, 2009, adapted from Stringer, 2007). Aboriginal clinicians, support workers, researchers and community members were actively involved in all stages of the MTWT project, as members of the research team and project advisory group.

Renal nurse focus group

A small group of experienced and interested renal nurses came together to modify and test a set of patient journey mapping tools for quality improvement and as part of the MTWT project. The group consisted of two CSCs, a renal nurse educator/facilitator, a coordinator of renal services in rural and remote South Australia, a transplant nurse, senior nurse clinicians/managers from the Western Desert Ngalampa Walytja Palyantjaku Tjutaku Remote Dialysis Unit, and a nurse researcher. After the first meeting, it was decided that the group would operate as a closed focus group, thereby enabling the development of in-depth confidential conversations, shared
meanings and targeted patient journey mapping activities.

The group met every one or two months, scheduled around people’s work commitments. Meetings were face to face when possible, linked to renal meeting schedules. Off-site members teleconferenced in, and most discussions lasted for one hour. Each member shared examples of recent patient journey issues that had occurred, and together the group prioritised two patient journey stories to be mapped and analysed in detail. These were brought to the group by two CSCs, one from a metropolitan hospital and the other from a regional dialysis unit. Both CSCs became actively involved in mapping the patient journeys, with the focus group providing support and discussion of issues and how the patient journey examples could best be addressed for quality improvement. The overall focus group activities are summarised in Table 1.

At the end of the project, renal focus group members evaluated the process and outcomes of the focus group, and of mapping and sharing patient journeys. This was done verbally at a meeting and/or individually via email and phone, and collected and collated by the nurse researcher. De-identified evaluation options (sending responses to a third party) were offered by the MTWT project but were declined, with preference given to an open, collaborative evaluation discussion.

**Mapping renal patient journeys**

The CSCs worked with the researcher individually at their workplace and via telephone calls and email. Activities were arranged flexibly around other clinical and management commitments. The patient journey mapping steps are outlined in Table 2 and are discussed in more detail in the case studies report (see Kelly et al., 2015, for more details).

This study was based at Flinders University, South Australia, with ethics approval provided by Flinders University Social and Behavioural Research Ethics Committee, Human Research Ethics Committee TQEHC, Aboriginal Health Research Ethics Committee (SA) and Central Australian Human Research Ethics Committee. Governance approvals and letters of support were given by each health site involved. Funding was provided by the Lowitja Institute Small Grants and SA Health.

**Results**

**Renal nurse focus group activities**

During the evaluation phase, the nurses reflected that the focus group had provided a safe space for them to explore the challenges inherent in their positions, and to strategise how best to provide patient-centred care, particularly when caring for vulnerable patients. They identified that the focus group was the only space where they could freely and flexibly discuss issues, and that interspersing the patient journey mapping with discussion of professional dilemmas and exchange of crucial patient information made these meetings incredibly useful. The inclusion of senior renal nurses from across such diverse geographical areas enabled a fresh understanding of patient needs and creative solutions to systemic barriers.
The renal nurses noted that having a nurse researcher who was not a renal nurse was useful, as she asked questions about renal care and patient experiences that prompted them to reflect further, thereby remembering things they ‘forgot they knew’. The researcher also shared de-identified mapping tools and strategies from across the wider MTWT Aboriginal patient journeys project, where cardiac, maternity and other patient journeys were mapped. This two-way knowledge sharing or ‘cross-pollination’ helped initiate new ideas within the renal focus group. The researcher also used a respectful facilitation and coordination approach, encouraging feedback and focusing on strengths, providing a flexible timetable while also assisting the nurses to keep up the momentum. The researcher, in turn, reflected on the incredible depth of knowledge, skills and passion that each of these experienced renal nurses brought. Together the group questioned how such knowledge, accumulated over many years of practice, could best be transferred to younger nurses.

During the course of the project, the focus group realised that mapping journeys and writing case studies involved explaining how and why they went about identifying and responding to patients’ needs, while also meeting external standards of care. Both the mapping and the focus group discussions enabled them to explore and explain how they developed their tacit knowledge, bringing them a step closer to ‘bottling their knowledge and sharing it’.

The two CSCs mapped recent complex journeys, one with a regional/remote focus, and the other involving a weekend transfer between a metropolitan and regional hospital.

**Case study: regional to remote end-of-life journey**

During a renal focus group teleconference, one CSC shared a recent patient journey that was extremely challenging for the patient, their family and for staff. It involved supporting a renal patient to return home to their community for end-of-life care, as they wished to reconnect with family and their community lands prior to passing. The CSC and the Aboriginal Patient Pathway Officer (APPO) worked together to coordinate the process, and found themselves scrambling to arrange the journey in time, as the person’s health was rapidly deteriorating. They sought advice on palliative care and transport options, and negotiated care with a range of medical, allied and support staff, and with the patient’s family. The renal focus group agreed that this was an important journey to map, as they had all struggled to support patients in similar situations, without adequate resources or agreed pathways of care. There were often issues associated with making appropriate and timely travel arrangements and the (limited) level of palliative care available back in the home community (Fried, 2003). Most Aboriginal patients and families they have worked with have stated a preference to be back home in the community at the time of dying, and this was recognised by the focus group. However, it was often difficult because there were no clear pathways to support ‘return to home’ journeys in South Australia.

The CSC and nurse researcher adapted the mapping tools so that the mapping of this person’s journey began when the person became ill, and wished to return home. The CSC used her notebook and discussions with the patient and their family members, patient records and dialysis unit records as data sources, as well as notes from reflective discussions with the APPO. A series of de-identified drafts of the mapping tools were developed during face-to-face meetings, telephone conversations and emails. A narrative was written, and a visual map (Figure 1) created to convey the geographic distances involved for the patient, their family and staff.

The social, emotional, personal, family, cultural and physical dimensions that were important for this patient were highlighted, drawing on discussions between the patient and the CSC over many years of dialysis care and, more recently, while making palliative care decisions. The CSC then identified the barriers and enablers to quality care in both the regional centre, and the person’s remote community. Next she mapped the patient journey chronologically, highlighting the perspectives and priorities of the patient, their family members, the regional renal dialysis staff, specialist staff in the major metropolitan hospital, Aboriginal, allied health and support staff in the regional and remote health services, and the remote area medical practitioner. This is summarised in Table 3.

Three main findings were identified from the case study: (1) specific processes and barriers to upholding end-of-life choices were identified; (2) the key role that the CSC needed to take to ensure patient-centred rather than system-centred care occurred; and (3) the logistical transport dilemmas and the rush to find suitable transport options for the rapidly deteriorating patient that occurred because no formal return to country pathway was available. Taking into account these findings, and the discussions within the focus group of other end-of-life patient journeys, a quality improvement action plan involving five steps was devised as follows:

1. Design a template for complex patient journey mapping, further adapting the tools to enable them to become a planning tool.
2. Develop a checklist for rapid transfer of palliative patients.
3. Work with the new palliative nephrologist to prepare a transfer kit for end-of-life transfers.
Table 3: Individual case study with chronological mapping from multiple perspectives

<table>
<thead>
<tr>
<th>Perspectives</th>
<th>Patient history</th>
<th>Worsening condition</th>
<th>In aged-care facility</th>
<th>Supporting patient choices — end-of-life decisions</th>
<th>Discharge/transfer</th>
<th>At home</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient journey</td>
<td>Person in her forties — dialysis for 7–8 years</td>
<td>Organ failure, incontinence</td>
<td>Deterioration</td>
<td>Life decisions</td>
<td>Wants to get home</td>
<td>Very unwell but happy to be home</td>
<td>Perhaps realised too late the long-term effects of missing dialysis, or felt she had no choice — she needed to live life as best as possible</td>
</tr>
<tr>
<td>Patient priorities, concerns and commitments</td>
<td>Wishes to be with family and community as much as possible</td>
<td>When becomes unwell, seeks dialysis, feels okay for a while, and then doesn’t feel okay any more</td>
<td>Can’t travel</td>
<td>Doesn’t want to stay here</td>
<td>Wishes to connect with particular family members in Port Augusta to say goodbye and then go home to see family before dying</td>
<td>See family and be back on her land</td>
<td>Be with family, share stories</td>
</tr>
<tr>
<td>Family/carers’ priorities</td>
<td>Woman has lived between remote community and Port Augusta for seven years</td>
<td>Family would like her to come home</td>
<td>Very few family members can visit Port Augusta</td>
<td>Family work closely with CSC to make arrangements of palliative care</td>
<td>Limited options Assistance with car hire, flights</td>
<td>Family gather and provide support and caring duties</td>
<td>Family spent much time talking about what would happen and debriefing when she died</td>
</tr>
<tr>
<td>Health services priorities</td>
<td>Dialysis three times a week</td>
<td>Doctor explained that her underlying health had deteriorated and she had only months to live — focus on palliative care</td>
<td>End-of-life care Providing optimal medical care in regional city versus supporting the choice to return home</td>
<td>Availability, timeliness, cost, options, comfort, ability to travel</td>
<td>Comfort, pain relief, skin care Support family who are main carers</td>
<td>Service-based care versus patient-focused care — how to provide best level of care — what is best practice?</td>
<td></td>
</tr>
<tr>
<td>Service gaps</td>
<td>No dialysis near home</td>
<td>No palliative care options in remote area</td>
<td>No palliative care facilities at home</td>
<td>No palliative care in home community</td>
<td>Few options available</td>
<td>No palliative care services</td>
<td>What if the CSC and the APPO were not involved?</td>
</tr>
<tr>
<td>Health service response</td>
<td>Staff explain cumulative effect but person’s other needs outweigh her ability to attend for regular dialysis</td>
<td>End-of-life care Dialysis CSC visited to discuss end-of-life choices Using the Respecting Patient Choices guide to determine and support person’s priorities and wishes</td>
<td>Remote clinic not resourced for palliative care Port Augusta sent as many resources as possible Community social worker arranged home and yard cleaning</td>
<td>Negotiate with RFDS — patient flown directly home due to worsening condition</td>
<td>Local clinic supplied pads, sheets Renal clinic provided phone support Port Augusta palliative services sent items Social worker filmed stories</td>
<td>Renal CSC and APPO arranged multiple aspects of transport, care, discussions with staff, family</td>
<td></td>
</tr>
<tr>
<td>Family response</td>
<td>Family in home community and extended family in Port Augusta</td>
<td>No immediate family in Port Augusta Extended family could only offer limited support</td>
<td>Very few family members could visit</td>
<td>Family apprehensive, wanted remote clinic to help, then took on role</td>
<td>Will the person die on the way home? Pick up in car</td>
<td>Care and pain relief for the patient’s last few days</td>
<td>Family member rang renal unit to say the woman passed peacefully</td>
</tr>
</tbody>
</table>
4. Use the case study in education sessions for new and practising renal, Aboriginal and palliative staff.

5. Use the case study in the regional dialysis unit for pre-planning and preparing for journey and care complexity.

KH reflected that the process of supporting the patient felt messy and difficult to explain while it was occurring, but that the mapping process enabled her to envision and explain the entire process and any associated gaps more clearly. Once she had written and shared the case study with other staff involved in this patient’s care, they too were able to identify their own roles, and to consider strategies for improvement. In fact, one doctor who was initially uncomfortable with being involved in supporting the patient’s journey reflected that having seen the benefits of the return home for this patient and their family, he would be prepared to be involved for the next patient.

Following the completion of Stage 3 and the patient journey mapping, the CSC’s hospital and dialysis unit underwent hospital accreditation. When the accreditors enquired whether the staff had done any particular work focusing on the needs of palliative patients and returning home, the CSC was able to produce the case study report and describe their activities, resulting in an honourable mention. This reinforced for the dialysis unit, and the renal focus group, the role that patient journey mapping has in continuous quality improvement, and the benefits of developing practice-based evidence.

Case study: Friday night discharge from metropolitan to regional care

The second participant, a CSC in a metropolitan hospital similarly identified a recent patient journey whose pathway was concerning and had the potential for negative outcomes. A regional Aboriginal patient had recently been discharged from the city hospital on a Friday evening in response to bed availability pressures, negating the carefully prepared plan that had been put in place. This plan included hostel accommodation in the city with regular dialysis care, and then a supported and organised transfer of care back to the regional centre a week later.

All members of the renal focus group could relate similar situations and considered this to be an important journey to map, with the potential to create practice-based evidence that could inform policy change. The CSC worked with the researcher to map the journey from when the patient left home, was admitted to the regional hospital, transferred to the city hospital via ambulance, became an inpatient in the city renal unit for 10 days for treatment of an infection, was discharged to a hostel Friday night, returned to the satellite unit for dialysis Saturday morning and was then taken to the bus stop to travel home to the regional centre alone. This journey was recorded both as a narrative and visually (Figure 2). Recollection of conversations with the patient prior to discharge was used to highlight their home situation, preferences and any concerns expressed. One limitation of this study is that the patient was not able to be actively involved in the mapping process (due in part to communication challenges and the patient having no home or mobile phone available.

The barriers and enablers to care within and between all five sites — the regional dialysis unit, the regional hospital, the city hospital, the city hostel and the city satellite dialysis unit — were considered, and the impact of the changes to the planned transfer of care examined. These included communication breakdown between staff teams within the hospital and lengthy and unaccompanied travelling arrangements undertaken while unwell (Kelly et al., 2015). The journey was then mapped chronologically from multiple perspectives with significant service, communication and coordination gaps identified. In addition, the case notes were studied to determine exactly who made the decision, and how the decision was made to discharge this particular patient in response to bed availability pressures.

By mapping the journey, the significant increased risks involved with a regional transfer on the weekends became obvious. During the case note review undertaken as part of the patient journey mapping, it became apparent that the medical staff were waiting on a cardiac opinion before approving the discharge, but this wasn’t communicated to the wider health care team. It was only the informal goodwill, communication between, and independent actions of the metropolitan hostel staff and regional dialysis nursing staff that averted a negative outcome due to a lack of support services. The hostel staff

Figure 1: Arranging a regional to remote journey home — driving versus flying
Bottling knowledge and sharing it — using patient journey mapping to build evidence and improve Aboriginal renal patient care

The benefits of the mapping process include the ability to write up the case study in an organised way, highlighting the potential for harm for patients when there are communication, collaboration and coordination gaps. Adapting the tools to include an examination of decision-making processes enabled the CSC to identify, dissect and investigate exactly what had happened and proactively to conduct her own root cause analysis.

Discussion

In renal clinical practice and management, an interplay exists between externally generated evidence-based guidelines, individual patient needs and internal practice-based knowledge. Clinicians strive to meet nationally and internationally recognised standards of care, while relying on their own body of knowledge, and that of their colleagues, to provide quality care. This approach to sense making has been described by Gabbay and le May (2004) and Wieringa and Greenhalgh (2015) as “mindlines” — a collective set of guidelines informed by peers, interactions with patients, training, key opinion leaders and in-depth knowledge of the health care context.

Similarly, the nurses in this study found that the process of discussing issues in the focus group and utilising the patient journey mapping tools both mirrored and formalised the sense making they used in everyday practice. They reflected that using the tools felt intuitive; it assisted them to bring together their own experiential and practice-based knowledge, patient needs, and external best practice guidelines in a structured and transparent way. The mapping enabled them to record how they as nurses responded to complex issues by listening to patients and prioritising their needs, while also working with peers to create solutions within the health system.

Policy and practice changes are being instigated to improve communication and coordination as a result of this study. In the metropolitan hospital, communication ‘huddles’ have been instigated, with the renal ward and CSC taking a key leadership role in embedding improved communication into practice. In the regional dialysis unit, planning for and coordination of patient journeys for end-of-life care are being assisted by the creation of checklists and new working relationships with remote area staff.

Conclusion

Two senior renal nurse managers and their peers became meaningfully involved in co-creating knowledge, with the aim of improving regional and remote Aboriginal patient renal care. They developed a set of patient journey mapping tools that brought together multiple perspectives of patients, their families...
and of staff in a range of health care settings. The process of meeting as a focus group and mapping together enabled these nurses to prioritise patient needs, utilise their own tacit knowledge, compare their results to standards, record their concerns and communicate their findings. The mapping tools and resulting case studies enabled hidden complexities to become visible, and identified specific gaps and barriers. From there, the nurses were able to construct strategies for improvements and changes in practice and policy. Being senior nurses, they had a level of influence that enabled them to begin a change process. While the mapping process is too time-consuming to use in everyday practice, it is effective in highlighting and understanding complexities, and in building practice-based evidence by combining tacit, local knowledge and explicit external knowledge. The findings can then be used to improve everyday practice and the quality of care. This research highlights the complexities of discharging patients from hospital, in particular, where individual circumstances and ability to self-manage are compromised.

Acknowledgements

We would like to acknowledge the Aboriginal patients and their families who have informed this study, colleagues Deb Lilas, Toni East, Gillian Harvey and Tim Schultz, and The Lowitja Institute for providing funding, and assistance with writing and editing the Managing Two Worlds Together reports.

References


