

Health information system linkage and coordination are critical for increasing access to secondary prevention in Aboriginal health: a qualitative study

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Keywords: Cardiac rehabilitation, health services, Indigenous

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Abstract

Background: Aboriginal Australians have low participation rates in cardiac rehabilitation (CR), despite high rates of cardiovascular disease. Barriers to CR participation reflect multiple patient-related issues. However, examining the broader context of health service delivery design and implementation is useful.

Aims: To identify health professionals' perspectives of systems-related barriers to implementation of the National Health and Medical Research Council (NHMRC) guidelines *Strengthening Cardiac Rehabilitation and Secondary Prevention for Aboriginal and Torres Strait Islander peoples*.

Method: Semi-structured interviews were conducted with health professionals involved in CR within mainstream and Aboriginal Community Controlled Health Services in Western Australia (WA). Thirty-eight health professionals from 17 services (10 rural, 7 metropolitan) listed in the WA Directory of CR services and seven Aboriginal Medical Services in WA were interviewed.

Results: Respondents reported barriers encountered in health information management and the impact of access to CR services for Aboriginal people. Crucial issues identified by participants were: poor communication across the health care sector and between providers, inconsistent and insufficient data collection processes (particularly relating to Aboriginal ethnicity identification), and challenges resultant of multiple clinical information systems and incompatible technologies.

Conclusions: This study has demonstrated that inadequate information systems and communication strategies, particularly those representing the interface between primary and secondary care, contribute to low participation rates of Aboriginal Australians in CR. Although these challenges are shared by non-Aboriginal Australians, the needs are greater for Aboriginal Australians and innovative solutions are required.

Introduction

Aboriginal Australians suffer a greater burden of disease and die younger than non-Aboriginal Australians.¹ They are twice as likely to suffer from cardiovascular disease (CVD) than non-Aboriginal Australians and premature mortality from CVD is the leading contributor to the Aboriginal life expectancy gap.² Cardiac rehabilitation (CR) is an evidence-based strategy to improve function, quality of life and survival rates following a cardiac event.³ Despite this widely endorsed intervention⁴, participation rates in CR range between 10-30% in the Australian population.⁵ These rates are even lower among Aboriginal people and the challenges faced by Aboriginals and health professionals alike are complex and multifaceted.^{6,7} Transportation difficulties and competing life pressures are common problems. These are likely to be amplified in the Aboriginal population in WA where cultural insecurity of mainstream services, rurality, isolation, and poverty challenge health service providers to deliver equitable access to care⁸.

Barriers to Aboriginal people's participation in CR

Problems relating to communication, coordination, cultural safety, and workforce have been cited as inhibiting Aboriginal people's involvement in CR.⁹ These areas are indicative of flaws in the design and execution of health service delivery. In particular,

the small numbers of Aboriginal and Torres Strait Islander people employed across the health workforce, difficulties in communication and education between service providers and clients, poor discharge planning, fragmented continuity of care, poor linkages between primary, secondary and allied health services, and significant under-involvement of Aboriginal clients, communities, and services in the development, implementation, and evaluation of CR programs inhibit Aboriginal people's participation.¹⁰⁻¹²

Investigations in rural and remote areas have revealed barriers to participation in CR involving lack of services, long travel distances and lack of transport to regional centres, health workforce shortages and high turnover.¹³ In regional and urban centres, a lack of flexibility and responsiveness in CR program structures creates obstacles to participation.¹³ Other reported barriers include lack of knowledge about CR by patients and health workers, costs, and family issues.¹⁴

Systems-related barriers

Although documentation of barriers to CR participation have previously highlighted multiple patient-related issues,¹⁵ findings centring on Aboriginal participation in CR highlight a range of systems-based factors.⁹ This is particularly concerning given that healthcare systems are vital to increasing individual participation in CR, are necessary to achieve sustainability of projects,¹⁶ and are critical in achieving improvements in chronic illness. Given the complex service delivery in Aboriginal communities, cross-sector collaboration and effective coordination and communication in primary care are necessary.¹⁷ Wagner's Chronic Care Model delineates systems issues as relating to clinical information systems and system delivery design within the context of community

and policy frameworks.^{17 18} Clinical information systems can assure access to data for individuals or populations and provide reminders for services and assistance with tracking and planning care.^{18 19} An information system should at least function as a registry for a target population, provide timely reminders to primary care providers on gaps in guideline compliance, and provide feedback measures relevant to assessing quality of care.²⁰

Previous investigations into clinical information systems in providing care to Aboriginal populations have shown systems-based failures to be associated with diminished clinical outcomes. In the case of a once-successful chronic disease program, a funding shortfall and computer system deficiencies, including problems with generating lists for screenings, treatments, diagnoses, and test results, led to decreases in regular community testing, staff reassignment, abandonment of the program, and deterioration of health outcomes.²¹ Hoy et al.²¹ concluded that a successful and sustainable program is reliant on commitment of ongoing chronic disease surveillance, treatment and education.

Systems-related barriers (termed ‘coordination’ barriers) revealed from a consultation process to inform guideline development concerning cardiac rehabilitation for Aboriginal people⁹ included inconsistent recording of Aboriginal and Torres Strait Islander status, failures to provide culturally sensitive care and education to Aboriginal inpatients, non-communication between different parts of the health care system, weak links between mainstream health and Aboriginal health services, inadequate discharge planning and

follow-up of continuing care and medication regime, and a lack of coordination between different phases of CR.⁹

A cross-sectional assessment of chronic illness care systems was conducted in Northern Territory (NT) Aboriginal community health centres to improve understanding of Aboriginal primary care systems.²² Clinical information system components assessed were population and patient registers, reminders and feedback to providers, and patient treatment plans. Results indicated that despite wide adoption of computerised systems, high system complexity and lack of IT maintenance and upgrade support hampered its potential benefits. It was found that IT systems often lacked the capacity (or were not used) to supply staff with population-based information on quality of chronic illness care, had poorly integrated system components, had limited sharing of information between out-of-clinic community programs and clinical services, and had less developed provision of feedback measures.

Delivery system design is defined as 1) defining and distributing roles and tasks among team members; 2) using planned interactions to support evidence-based care; 3) providing clinical case management services for complex patients; 4) ensuring regular follow-up by the care team; and 5) considering and ensuring that patients understand and that care is culturally appropriate.^{18 23} Examples of delivery system design failures that can inhibit CR programs include absence of local CR programs, failure of doctors to refer, lack of clinician awareness of program availability, absence of a dedicated CR coordinator with whom to liaise, insufficient time to arrange referral, unfamiliarity of

clinicians and hospital CR coordinators with referral process, distance and transport problems, and inflexible structure and times of operation of traditional hospital-based programs.⁷ Studies have demonstrated a positive relationship between delivery system design and intermediate outcomes of diabetes care underscoring the importance of investigating service delivery models.^{24 25}

In light of these issues, *Strengthening Cardiac Rehabilitation and Secondary Prevention for Aboriginal and Torres Strait Islander Peoples: a Guide for Health Professionals*⁹ was developed with the aim of providing definitive information to help better plan CR services for Aboriginal Australians. Topics central to the *Guidelines* include cultural competence, the importance of engaging and supporting Aboriginal Health Workers (AHWs), linking with existing local services, ensuring community involvement at all stages, tailoring CR approaches to needs of communities, and developing supportive policies and procedures to sustain partnerships and services. The *Guidelines* were distributed in 2006 to all Australian health facilities.

We undertook this study as part of a larger investigation into the implementation of the *Guidelines* in Western Australia.²⁶ As health information systems are considered crucial to provide effective chronic care, this paper reports on health professionals' perceptions of such systems and the impact that this has on accessing CR and post-discharge follow-up.

Methods

Health service organisations listed in the Directory of Western Australian Secondary Prevention Services²⁷ and Aboriginal Community Controlled Organisations in WA were eligible to participate in this study. Reasons for non-participation and exclusion from the study included being a private facility, servicing low numbers of patients for CR, and providing negligible services for Aboriginal people. Ethical approval was obtained from the WA Aboriginal Health Information and Ethics Committee and a University Human Research Ethics Committee.

Procedure

Health professionals involved in CR or secondary prevention services at rural and metropolitan health services listed in the CR directory were contacted by a CR nurse who explained the study. Between November 2007 and June 2008, these health professionals were asked to participate in face-to-face semi-structured interviews which were conducted by a CR nurse in conjunction with an Aboriginal nurse whenever possible. The majority of interviews were conducted with a single informant, but in some cases, more than one member of the CR team participated. Data collection concluded following participation of all eligible non-excluded services with health professionals available for participation within the data collection period. Respondents were asked about their awareness, implementation, and perspectives of barriers to implementation of the *Guidelines*²⁶. Of particular interest were their perceptions of systems used within their services with regards to processes enacted upon and following discharge from hospital, CR referrals, identifying Aboriginal ethnicity, and barriers to accessing CR services. All but three interviews were audio-recorded with permission of participants. Recorded

interviews were transcribed verbatim while written notes were taken for those who declined audio recording. Data were analysed using thematic content analysis whereby participants' responses were hand-coded or broken down into distinct units of meaning²⁸. These codes were then continuously compared with one another to discover links between the categories. Related categories were combined and compared to new data. Efforts to maximise reflexivity and rigour of the data occurred when the research team met to verify and clarify themes which emerged from the data²⁹.

Results

Study participants were health professionals from 17 of the 31 organisations comprising the Directory of Western Australian Secondary Prevention Services²⁷ and staff at seven Aboriginal health services organisations. In total, 38 interviews were conducted each lasting between 30 – 90 minutes. While data reflecting aspects of health professionals' awareness and implementation of the *Guidelines* has been reported elsewhere²⁶, this paper reports on barriers encountered in health information management and its impact on access to CR services for Aboriginal people in WA. Crucial issues identified by participants were: inconsistent and insufficient data collection processes (particularly relating to Aboriginal identification), multiple clinical information systems and incompatible technologies, challenges in storage and retrieval of information, and communication across the health care sector and among providers. Given these descriptions, the findings are presented according to elements of Wagner's Chronic Care Model¹⁹, namely, delivery systems design and clinical information systems (Table 1).

Examples presented in Table 1 highlight that it is the whole system of care that needs to work effectively to ensure the delivery of quality cardiac rehabilitation.

Delivery system design barriers

The lack of coordination and communication between healthcare facilities and health professionals, particularly between hospitals and primary care, disadvantages both staff and patients. Respondents indicated that inadequate referral systems and a lack of awareness of available services in various regions were the main barriers to provision of CR to Aboriginal patients. Some hospital-based participants were unaware of who to contact for additional information when seeking to link a patient to a local service. A lack of communication and subsequent referral pathways between hospitals and primary care meant patients were not followed up after discharge and therefore did not initiate CR. In many cases, there was no designated CR coordinator and few or no AHWs, much less an AHW designated as CVD contact/coordinator in any of the health facilities; positions considered necessary and appropriate to ensure continuity of care of Aboriginal patients.

Several respondents stated that they had no system for identifying Aboriginal status, relying instead on making assumptions based on referring facility or physical appearance. Reasons discussed for not directly asking patients whether they were Aboriginal, despite the information being required on medical record forms reflect participants' lack of appreciation of the importance of this information and management oversight.

Clinical information system barriers

Respondents explained that many government health services and Aboriginal Community Controlled Health Services function independently and do not use compatible clinical information management systems, thereby impeding information sharing, service linking, and referrals. Referral systems to primary care, including updating the primary care providers on what has been done and recommendations for future management, were perceived as inadequate with many Aboriginal patients lost to follow-up upon discharge in Perth. The large transient Aboriginal population in WA presents a challenge to health services given the inability to access patient records from other areas. Participants viewed that improved IT systems and transfer of patient information, such as discharge details, will save staff time in taking patient histories and locating medical notes. The disparate clinical information systems likewise have different functional capacities with some reported as not sensitive to co-morbidities or having inadequate output options. These deficiencies exacerbate the challenges to follow-up of Aboriginal people recently discharged from hospital.

Discussion

This paper presents a description of health professionals' perceptions of health information issues impacting on Aboriginal people's participation in CR in WA. A lack of communication and coordination of health information systems and processes to enable integrated and coordinated care and follow-up were seen as major barriers that could be readily addressed. Participants perceived lack of continuity of care brought about via disparate non-collaborative IT systems, different processes, and a lack of

networks and partnerships both within and between health care facilities throughout the state. Although these challenges are not unique to Aboriginal people¹⁹, it is likely that these are amplified and play a significant role in contributing to inferior health outcomes.

A significant delivery system design flaw highlighted in the present study as well as in previous research involves inadequate referral systems which are linked to workforce issues and coordination of CR referral processes.⁷ In addition to the need for procedures to identify and refer eligible patients to existing programs to ensure continuity of care critical to management of CVD³⁰, attention must be paid to workforce allocation, support, and development opportunities for AHWs. Aboriginal Health Workers are instrumental in providing care to Aboriginal people in Australia as they foster access and assist provision of culturally competent care³¹. A recent study examining the effects of a cardiology-specific AHW in a metropolitan hospital in WA revealed improvements in culturally appropriate care and communication, reductions in discharges against medical advice, provision of cultural education, increases in inpatient contact time, improved follow-up practices, and enhanced patient referral linkages³². Importantly, AHWs are an integral and vital source of health information and link to communities. Yet, their numbers are few and their integration within and bridging to mainstream health systems remains undeveloped.³³

The health information management issues presented in this paper reflect inherent limitations in information systems in the Australian health care system³⁴ and weaknesses in computerised clinical information systems in Aboriginal primary care.^{21 22}

Collectively, these findings highlight the complex delivery design systems challenges relevant to Aboriginal health. Technologies already exist to enable interactive IT systems that can improve efficiency, however such shifts would require sharing of patient data across applications and jurisdictions and enhancing existing IT.³⁵ If not addressed at organisational and policy levels, these systems issues will continue to hinder improvements in Aboriginal health.

Progress has been made over the past decade in the recording of Aboriginal status for hospitalised patients in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory, however improvements are still needed to ensure appropriate allocation of resources to care for Aboriginal people.³⁶ As was found in this study, hospital staff are sometimes reluctant to ask patients if they are of Aboriginal or Torres Strait Islander descent,^{37 38} although it has been found that few patients mind being asked.³⁹ Previous studies have called for the development and use of standardised questions to provide patients with the opportunity to disclose their status^{39 40}, and increasingly attention is being given to better identification of Aboriginality in patients overall, including within primary health care.⁴¹ Despite the request for this information on paper and computer-based forms across various clinical information systems in WA, our data show that staff sometimes fail to complete components important to care. The lack of documentation of Aboriginal status not only contributes to funding deficits for Aboriginal health and wellbeing initiatives that require demonstration of a 'critical mass' of patients or participants, but also means that advice and support are not tailored appropriately.

Conclusion

In 1977, Wenger argued that “...all aspects of the long-term care and rehabilitation of the patient after myocardial infarction must remain under the aegis of the primary physician, ultimately using the personnel, facilities and services of the local community”.⁴² This study has demonstrated that inadequate information systems and communication strategies contribute to low participation rates of Aboriginal Australians in CR with too little emphasis being given to transfer of care by linking patients with primary care. Both Aboriginal and non-Aboriginal organisations in this study recognised the challenges of cross-sector collaboration, despite issues varying between regions. Although these challenges are common within the Australian health care system, the needs are greater among Aboriginal Australians. Leadership, organisational commitment, and innovative solutions are required and improving information exchange is a pivotal step in improving care. The limitations in information management identified in this study is of concern. Coordinated strategies to improve health information management, including methods to promote Aboriginal identification within a framework of cultural competence and effective mechanisms for sharing information across sectors are urgently needed. These systems based issues should be considered within the context of patient factors and provider characteristics. Overcoming endemic racism and increasing skills in cultural competence are also important solutions to improving the cardiovascular outcomes of Aboriginal Australians. Ensuring smooth transitions between primary, secondary and tertiary care are important steps in ensuring that Aboriginal people receive appropriate and timely care.

How this fits in with quality in primary care:

What do we know?

- Aboriginal Australians have high rates of morbidity and mortality related to cardiovascular disease
- Cardiac rehabilitation is an evidence based secondary prevention strategy that has low participation rates, particularly in Aboriginal Australians
- Effective information sharing and communication across care sectors are critical in improving outcomes from chronic disease

What does this paper add?

- Health professionals' perceptions of the health communication issues impacting on delivering effective post-discharge care for Aboriginal people in WA
- The absence of tailoring information systems to retrieve clinically useful information to promote coordination of care
- Referrals and transfers with inadequate information systems contribute to poor coordination and loss to follow-up
- Cross-sector collaboration and communication are crucial to share health information to promote coordination of post-discharge care and attendance at CR
- Primary care endorsement of CR is imperative to patients' engagement in this secondary prevention initiative

Acknowledgements

The research team acknowledges the funding support of the WA Department of Health through the State Health Research Advisory Council and support from NHMRC Project grant 479222. We thank colleagues Dr Tom Briffa, Ms Francine Eades, Ms Narelle Wilson and Mr Trevor Shilton for their assistance with this project and acknowledge the assistance of Royal Perth Hospital and the Heart Foundation of Australia (WA). MD is a postdoctoral fellow funded by NHMRC 533547.

Competing Interests

The authors declare that they have no competing interests. The paper has not been submitted elsewhere for publication.

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Table 1. Quotes regarding systems barriers from interviews with health professionals

Delivery Systems Design Barriers to Implementing CR Guidelines		
Deficiency in referral systems	Gap in referral process between metro and remote AMS	<p>Respondent 1: ...there is a gap between when they have treatment in Perth and then coming back here that there is a risk they could sort of slip through the net...in an ideal situation, you would visit someone in hospital. You know, you would have some sort of continuity before they are discharged. We can't do that and we don't know exactly what day they are getting back. There are issues around the continuity of care even though we should get a discharge summary.</p> <p>Respondent 2: Quite often what happens is they go from Derby to Perth and then they come back to the hospital and the hospital gets a discharge summary, but we (the AMS) don't...So sometimes – and that is not only for cardiac, but for other clients that has happened – we have nothing because it has gone to the hospital because they are not aware that there is an AMS here usually. (AMS, Remote area)</p>
	Gap in referral process due to lack of awareness of service	<p>I think this is our biggest problem, they are not getting referred. Like, every single person that is referred to us we contact and we see in some manner. But, it's probably our fault as well there is not a good relationship between us and the cardiologists in Perth or the surrounding areas, because people might not think the service is available, or they won't do it. Yeah, there's a huge gap. (Population Health Unit, Remote area)</p>
Referral systems require dedicated coordinator	Importance of referral person	<p>Important to the referral process is having a designated person in place to push/refer patients coming through the ED. Particularly given that there has recently been high GP turnover, so you can't necessarily depend on primary care to ensure continuity of care if they are planning to retire or move. (Health Service, Remote area)</p>
	Referral flowchart or referral contact sheet	<p>There are some missing links in the referral chain. Having a contact sheet or flowchart of the referral people might help. (Primary Health, Remote area)</p>
	Dedicated link person between hospital and AMS	<p>Trying to get a connection with AMS is the most important thing because that is where a lot of Aboriginal people get health care from. I mean, you would have to dedicate so much time I think to get that connection going, so I would say it really needs someone just dedicated in that role to try and get a link between the hospital and the AMS, because there is just nothing... there is just no linkage at all. There is that real divide. (Tertiary Hospital, Metropolitan)</p>

Documenting Aboriginal status	Reliance on stored data to determine Aboriginal identity	<i>I pull up every patient on TOPAS and TOPAS identifies if they are Aboriginal. So if they are not identified on TOPAS, then they are not identified unless I can tell because of my own experience with the patient, you know, if I have met the patient and they are clearly Aboriginal or if I know the name and I think they might be Aboriginal. But usually I have seen most of the patients in the ward, but there are certain ones that I don't see on the weekends and things like that. (Tertiary Hospital, Metropolitan)</i>
	Lack of system to record status	<i>I am pretty sure there is a section in there that says, 'Indigenous, tick the box' or whatever, but no one ever does it. It is not a sort of a thing that we use. Obviously, there are some that you can tell straight away, and then there are others that you are sort of, 'Well, could be, could not be; I don't know' you know? (Population Health Unit, Remote area)</i>
Clinical Information System Barriers to Implementing CR Guidelines		
Multiple Incompatible IT Systems (impact on referral systems)	Un-linked systems within service impact on reporting	<i>It is very hard because our doctors will only use one system and the staff use the other system, and they don't link...So we have a very difficult time as far as getting the information off the two systems. We do have a difficult time reporting some of our statistics. So we are hoping that there will eventually just be one, because we actually have the two systems, plus we have notes. (Remote AMS)</i>
	Referral delays due to incompatible IT systems across different areas	<i>We have issues with when people get referred from the medical centre, we don't have the doctors, or what they write in their notes there, so we have to either get the patient to sign like a consent for sharing information – and that takes a couple of days to actually get it through to our computer, their latest results and things like that – or we have to contact PathWest. So there is a bit of running around considering that if they referred to us, it should automatically be available to us to find...And the same with AMS, you know, I might see someone at AMS and then I might see them in the hospital, but I haven't got my notes that I have written on their computer system, so I don't really know what I did with them last time or what we talked about. So, yeah, that could be improved too...One of the other things with the people is that they move around so much. So they might live in Burringurrah for like five or six weeks and then they will come into town, so their medical notes are everywhere. They are all over the place and no one really knows where they are.(Population Health Unit, Remote area)</i>
Unmet clinical information storage and	Input only non-specific health data	<i>I think it is an easy system to put my stats into, but it doesn't actually tell us anything useful at the end of the day... So you have got the circulatory system, and that would generally go down as probably heart disease, which is kind of broad.(Primary Health, Remote area)</i>

retrieval needs
(IT Systems
Design)

Lack of specific
health data output

Basically, the only thing you get out of it is how many people you have seen, and you can divide it up into ages and female/male, but you can't actually take out people who didn't arrive, cancellations. You can distinguish between areas. So, like I might have seen 12 people in Exmouth and five people in Denham or whatever, but you can't pull a lot of information, like what you are seeing them for. So you enter in all these stats about, 'Oh, I saw them for weight loss or nourishing diet' or whatever, but you can't pull any of that out again, so it is a bit restrictive... You can pick two (diagnoses) on HCARE, so you can divide it up. So you might have diabetes and then weight loss, but you can't choose more than two...you seem to put in all this information and you can't bring anything out of it. You put in whether it is a new referral or whether it is a review, and you put in all this stuff but you can't actually find out how many new people you saw or how many reviews. It is all just collated. So, definitely issues with that. We have been trying to get new ones for ages. (Population Health Unit, Remote area)

Lack of IT
capacity to store
health data in
remote areas

They are having a lot of trouble at the moment getting it to the remote area clinics. I know that the nurses out there - - I mean I am documenting notes that haven't had anything written in for three years, and that person could have had a CVA, an MI, everything within that time. There is absolutely no record for that locum nurse who is out there to even know what this person's health issues are. (Health Service, Remote area)