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A ‘key worker’ model to improve service pathways for Aboriginal people with dementia in remote Central Australia

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Introduction: The provision of support services to Aboriginal Australians living with dementia in remote communities is complicated by factors such as cross-cultural and language barriers, long travelling distances and often inadequate resources. Poor coordination of services and other problems of service access and lack of service awareness can lead to many unmet needs including delayed assessment and diagnosis. This project builds on a previous research study in the region that highlighted the urgent need for improvements to implementation of recommended service pathways for dementia care. The project aimed to achieve this by developing a model for appropriate ‘case management’ or ‘key worker’ approaches to coordinating.

Method: A qualitative study was conducted in 2013-14 that included six in-depth interviews with key informants and thematic analysis. The researchers used the themes to develop a model which was then validated by a local reference group.

Results: Our data to date have enabled us to develop a model where one ‘key worker’ takes the lead in the assessment and coordination of provision of services with no expectation that they will provide any services outside their own area of expertise.

Implications and conclusion: Significant principles of the ‘key worker’ model include that it is person-centred, culturally safe and contextually relevant. Introduction of the model needs to be accompanied by workforce education so that there is a shared understanding of how care coordination should be implemented ranging from the broad principles (such as culturally appropriate relationships, and service flexibility) through to the more micro elements of the model (such as communication methods between services, record keeping and handover mechanisms). The principles and the process for developing the model are transferrable to other remote service delivery contexts.

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Introduction

Dementia is a major social, welfare and health problem for Indigenous people, with rates in rural and remote communities significantly higher that the non-Indigenous population (1, 2). However, under diagnosis of dementia, misdiagnosis and poor care pathways are common in remote Aboriginal communities (3, 4). The provision of support services is complicated by a range of factors such as cross-cultural and language barriers, long travelling distances and often inadequate resources (3, 5). Poor communication and coordination, high turnover of staff and a perceived lack of interest/knowledge by health services in conditions associated with ageing can also contribute to many unmet needs (3-5). An under-utilisation of government funded community programs by Indigenous people with dementia reflects a failure of referral and care planning following diagnosis (6). Service delivery models need to be based on a sound understanding of the needs of consumers/clients as well as the context in which they live (4, 7).

A dementia pathways ‘template’ was developed nationally, to be adapted at the level of local service jurisdictions (7). The pathways detail critical elements to be addressed through the stages of awareness, recognition and referral; initial assessment and diagnosis, and post-diagnosis support; management, care, support and review; and end of life (7). A project in Central Australia adapted these pathways for the local context (4, 8). They include detailed description of the stages in the dementia journey and ideal service and care responses at all stages with particular consideration of the Central Australian service system including client data recording and follow-up triggers at critical points. Despite high stakeholder support, there was limited success in implementation of the pathways in the pilot communities, ostensibly because there was no designated person overseeing the person’s care journey. Care planning was found to be undertaken by a variety of service agencies, of variable quality, and dependent on staff skills and organisational systems. The project highlighted the urgent need for improvements to implementation of recommended service pathways (4, 8). Recommendations of the project included a case manager or key worker to be selected for individual consumers/clients to be responsible for developing, implementing and reviewing a comprehensive care plan for that person. Building on this earlier work (4, 8), the current paper reports on a subsequent project aimed to develop such a model.

Defining care management and key worker approaches

Case management is generally accepted as a “collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost-effective care” (9)p.8. Case (or care) management places emphasis on the person with the condition (and their family), encourages their involvement in the care plan, advocates, implements and monitors the care design and coordinates external agencies (10, 11). While there are different approaches, the primary aim is to ensure that the community care system (referring to both formal *and* informal supports) facilitates an individualised response that is closely matched to the client's particular needs (12). Accepted stages in case management include screening and intake; needs-led (as opposed to service-led) assessment; care planning; implementation and monitoring; review and evaluation (12). Some Indigenous people with dementia in remote Australia may require 'intensive' case management such as organising telehealth for connection with specialist services, diagnoses and multidisciplinary support, assistance with service access, following up that care is established, and working with clients and caregivers to identify rehabilitation goals such as education, counselling, in-home services and behavioural management (3). Others may need a lesser degree of management/coordination.

'Key worker' approaches have arisen in response to the need for greater flexibility in the type and level of support for people and families with special or complex needs than that offered by more formal case management services. Key workers do not necessarily have a particular agency focus but provide support and advocacy and act as the primary point of contact (13). These approaches typically do not require the same level of formality such as assessment for eligibility. Some clients may not be eligible for case management but may benefit from having an advocate and key contact person to help navigate the system, understand entitlements, and help them come to terms with their health condition and changing support and information needs. In 'the younger onset dementia key worker' program introduced by Alzheimer's Australia (14), key workers (employed by Alzheimer's Australia) have the flexibility to deliver services and undertake activities that clients themselves identify as important, as well as offering an advocacy and educational role for service providers about the special needs of younger onset dementia. The 'key workers' aren't bound by rigid referral structures often found in other case management services, and allows more adaptable support that responds to individually identified needs (14).

Method

This was a small qualitative study conducted in 2013-14. In-depth interviews were undertaken with six key informants purposefully selected because of their extensive experience in aged and/or dementia care in Central Australia. Interview questions focused on current practice relating to dementia pathways, perceived barriers to case management/key worker approaches and how these can be overcome. Interview transcripts were analysed thematically (initially by author one) and cross-checked by all authors. Table 1 shows the major themes and sub-themes with examples of supporting quotes attributed to participants using a pseudonym. From these, the available literature, and other key worker 'templates' available in the public domain (13, 18), a draft model description was developed. This was then validated in a separate focus group of four key informants (selected on the basis of their experience and current service delivery positions) invited to critique the model. Adjustments were made based on their feedback and consensus reached. Quotes from the validation stage are attributed as 'focus group'. The final model is included as Appendix A.

Results and Discussion

In order to adhere to required word limits, we restrict our discussion to considerations for ‘key worker’ characteristics and information provision roles, some of the more important considerations for service delivery in the remote/Indigenous context. Some themes from the data have informed the broad principles to underpin the model. For example the emphasis on culturally appropriate relationships relates to the principle of cultural safety (15) and helps to guide the appointment of the key worker. Others describe more operational considerations such as service system agreement and organisational support; appointing the key worker; and communication.

Case management/key workers approaches are a different form of individualised practice from traditional casework and as such staff and organisations require reorientation and preparation (10). Critical to their success are outstanding communication and negotiation skills, and the capacity to form and maintain effective interpersonal relationships (9, 12). They also require skills and abilities beyond the scope of any single professional discipline, making specialist education and support critical for the role (11, 16), including knowledge about dementia and the service system (17). Such specialist training may be particularly important in rural and remote settings where context provides particular local, and cultural considerations (4, 11, 17, 18). For example, leadership and advocacy skills to negotiate what are often ‘closed’ systems in rural/remote settings may be particularly important (11).

Some key worker models suggest that the appointed key worker is most likely to be the first practitioner dealing with the primary issue (such as nurse, GP or HACC coordinator) (19), others that it is a specialised role in itself and undertaken by designated people in a particular agency (14), and others suggest it can be either as long as the roles are clear and accepted by all relevant agencies (13). An emphasis on individualism can be a poor fit with Aboriginal communities’ values of shared responsibility and collectivism (10). Therefore, cultural safety and person-centred principles (20) should dictate who is best placed to take on the role and to mitigate any cultural dissonance arising from the individualist nature of the approach. For example, a Western Desert person on dialysis, and in the early stages of dementia, may prefer their ‘Malpa’[1] - who already provides advocacy, practical assistance, pastoral care, and spiritual support (21) to act as key worker for the dementia journey. The Malpa does not have clinical expertise, but offers a kind of individualised ‘cultural brokerage and support’ role for the person on dialysis and their families in ways unique to them. In this case, the Malpa may have particular education needs in order to be a dementia key worker, as reflected in the model (Appendix A).

Problems such as poor communication and coordination between agencies arising as a result of current (silo) funding models (22) were commonly raised. Again, as our data confirms, the need for intersectoral education of workers about issues such as dementia then becomes necessary if all services are to respond adequately (5). Coordination needs to feature consideration of the needs of the whole community, cultural sensitivity and provision of adequate resources (22). As noted in the focus group “it takes a whole community to care for a person with dementia, so education

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[1] A Western Desert word meaning ‘companion’ or ‘friend’

needs to be provided on that basis”. Thus, a role of a key worker in this context may to arrange (or deliver, if appropriate) best-practice dementia education (5, 23) for the family and community of the person with dementia in a timely manner and where it is needed most.

Stages of knowledge exchange in the dementia care journey can be broken down to six distinct stages: early symptoms, diagnoses, beginning loss of independence, in-home care, respite, long term care, and palliative care (17). Each stage has particular knowledge needs and understanding these stages can be useful to assist key workers to support the dementia care journey, and also in supporting other healthcare practitioners and service provides with their information role (17) (a theme commonly raised by key informants). Inadequate information and education about dementia for carers and workers, and a complex web of services, are significant issues in Central Australia (4). Key workers will be well placed to improve information provision for community members, aged care workers, and health professionals (4).

Conclusion

Management of a person with dementia requires a comprehensive plan that includes a partnership between doctors, health care workers, families (24) and community members. However, in order to achieve a partnership approach for all Aboriginal clients with symptoms of dementia, a mechanism needs to be in place for this to occur routinely. Our data have enabled us to develop a model where one ‘key worker’ takes the lead in the assessment process and coordination of provision of services with no expectation that they will provide any services outside their own area of expertise. Person-centred, culturally safe and contextually relevant are the main underpinning principles. These principles and the process for developing the model (including the stages of the preceding project), may be transferrable to other remote service delivery contexts. Implementation needs to be accompanied by workforce education so that there is a shared understanding of how care coordination should be implemented, ranging from the broad principles through to the more micro or operational elements of the model (such as communication methods between services, record keeping and handover mechanisms).

References

1. Smith K, Flicker L, Lautenschlager N, Almeida O, Atkinson D, Dwyer A, LoGiudice D. High prevalence of dementia and cognitive impairment in Indigenous Australians. Neurology. 2008; 71(19):1470-3.
2. Li SQ, Guthridge SL, Aratchige PE, Lowe MP, Wang Z, Zhao Y, Krause V. Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory. Medical Journal of Australia. 2014; 200(8):465-9.
3. Smith K, LoGiudice D, Flicker L. Dementia care and best practice in rural and remote settings. A literature review. Dementia Collaborative Research Centres, The University of New South Wales, Western Australian Centre for Health and Ageing. 2010.
4. Jensen H, Flicker L, LoGiudice D, Lindeman MA, Atkinson D, Smith K. Pathways to care for Indigenous people with dementia in Central Australia. Services

for Australian Rural and Remote Allied Health (SARRAH) National Conference; 20-23 Sep; Launceston. 2012.

5. Lindeman MA, Taylor KA, Kuipers P, Stothers K, Piper K. ‘We don’t have anyone with dementia here’: a case for better intersectoral collaboration for remote Indigenous clients with dementia. Australian Journal of Rural Health. 2012;20:190-4.

6. Broe G, Jackson Pulver L, Arkles R, Robertson H, Kelso W, Chalkley S, Draper B. Cognition, Ageing and Dementia in Australian and Torres Strait Islander Peoples: A Review of the Literature. Dementia Co-operative Research Centre University of New South Wales. 2009.

7. KPMG. Dementia services pathways Canberra: Australian Government Department of Health,; 2011 [cited 2014 30 May]. Available from: http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm.

8. Jensen H, Flicker L, LoGiudice D, Lindeman MA, Atkinson D, Smith K. Dementia service coordination in Aboriginal communities in Central Australia. Alice Springs: Western Australian Centre for Health and Ageing, University of Western Australia. 2012.

9. Simpson-Young V, Fine M. Case management in community aged care: mapping the landscape in NSW. Sydney: Macquarie University Centre for Research on Social Inclusion. 2010.

10. Gursansky D, Kennedy R, Camilleri P. The practice of case management. Effective strategies for positive outcomes. Sydney: Allen & Unwin. 2012.

11. Dellemain J, Warburton J. Case management in rural Australia: arguments for improved practice understandings. Australian Social Work. 2013; 66(2):297-310.

12. Hughes M, Heycox K. Older people, ageing and social work. Sydney: Allen & Unwin. 2010.

13. Drennan A, Wagner T, Rosenbaum P. The 'key worker' model of service delivery: McMaster University. 2005 [cited 2014 30 May]. Available from: http://www.canchild.ca/en/canchildresources/keyworker.asp.

14. Alzheimer's Australia. National younger onset dementia key worker program. 2014 [cited 2014 30 May]. Available from: http://www.fightdementia.org.au/services/younger-onset-dementia-key-worker-program.aspx.

15. Taylor K, Guerin P. Health care and Indigenous Australians: cultural safety in practice. Melbourne: Palgrave Macmillan. 2010.

16. Joshi A, Pedlar D. Case managers for seniors - educational needs and opportunities. Educational Gerontology. 1992; 18(5):567-86.

17. Forbes D, Finkelstein S, Blake C, Gibson M, Morgan D, Markle-Reid M, Culum I, Thiessen E. Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. Rural and Remote Health. 2012 (2201 Online):1-15.

18. Lindeman MA, Dingwall KM, Bell D. Towards better preparation and support for health and social care practitioners conducting specialised assessments in remote Indigenous contexts. Australian Journal of Social Issues. In press.

19. South West Primary Care Partnership. South West Region Service Coordination Plan. Guidelines for use. Victoria. 2005.

20. McMillan F, Kampers D, Traynor V, Dewing J. Person-centred care as caring for country. Dementia. 2010; 9(2):163-7.

21. Rivalland P. 'It's more than machine and medicine: they should understand there’s a Yanangu Way'. Western Desert Nganampa Walytja Palyantjaku Tjutaku and Cooperative Research Centre for Aboriginal Health. 2006.

22. Stewart J, Lohoar S, Higgins D. Effective practices for service delivery coordination in Indigenous communities. Canberra and Melbourne: Australian Institute of Health and Welfare and Australian Institute of Family Studies. 2011.

23. Taylor KA, Lindeman MA, Kuipers P, Stothers K, Piper K. Intercultural communications in remote Aboriginal Australian communities: what works in dementia education and management? Health Sociology Review. 2012; 21(2):208-19.

24. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues in Clinical Neuroscience. 2009; 11(2):217-28.

Table 1: Themes and sub-themes

Theme and sub-theme	Examples of supporting quotes
Culturally safe - The right worker (individually determined) - Respect for language (e.g. use of interpreters) - Respect for relationships (e.g. involvement of whole family and community members) - Involvement of local cultural advisers	"natural ability to lead and natural ability to partake in task orientated activities and [who] really just falls into the role without any extra hassle … and they're keen, willing to learn, [and should have] good literacy and numeracy, and good people skills" (Wendy). "…not just working with the person with dementia, but working with the whole family in terms of how they're managing it. So it often focuses on well-being… of the carers in the family" (Graham). "The more you know you know about the person and their history, the easier it is to work with them" (Ivan). "Having that knowledge that we're doing this the correct way, the best thing for this particular person. If you're coming in from outside you wouldn't have a clue would you?" (Brenda). The 'cultural determinants of health' are so important – land, lore, dreaming, family - these all need to be incorporated up front" (Focus group)
Flexibility - Creative problem solving - Individualised solutions - Understanding context (of service delivery and for clients and carers) - Ability to mobilise other services (e.g. dementia educators)	"The whole service needs to be flexible, which means the case manager has to direct that flexibility…Particularly with dementia, what works today, might not work tomorrow… And there can be a real lack of knowledge about services thought, the case manager really has to be on top of what is available" (Ivan). "…People remain at home for long, long, long, long periods and it's a real strain on the inter-generational family and it's from quite young kids to a lot of older people as well" (Graham). "If they're coming in for appointments ... the issue will be how they're going to get into town, who's going to transport them into town and who's going to pay for the cost of them coming into town and where are they going to stay. …And if they've got complex needs, well who's going to stay with them to support that because the carers usually can only go so far with that extra needs, so you're sort of - that's the other tricky one around that. If you put them into an Indigenous hostel without a carer, well there's a whole lot of problems that'll come out of that" (Wendy). "I think it's just working with people really, and then deciding on who's managing, you know. And there can be dual management. And I think that does happen a bit, you know they'll manage that. Because we'll actually say 'Oh God, alright, you do that bit, you know

	I can do this bit, 'cos I know all this, and know family and contacts and even old people in other communities that are strong'..” (Brenda). “…really getting involved with somebody from go to whoa … I'm just really happy to do whatever” (Brenda). “Services need to be made to fit the person and their cultural needs, not the person made to fit in with services” (Focus Group)
Service system agreement and organisational support - Shared understanding who can take on the role (according to existing job roles) - Acknowledgement of organisational and individual roles - Negotiated role boundaries and role flexibility - Agreed definitions - Organisational and professional respect	“There's not a lot of opportunity to case manage. We're not funded for case management” (Kerryn). “... we have to wear both hats because the funding allows us to only have one person to sit there in a coordination role - to coordinate the facility as well as case manage and recognise clients with complex needs and the needs for greater involvement with external stakeholders” (Wendy). “I know for us to take on that active case management would probably be out of our scope” (Ivan). “…but we're also supporting and advocating for carers and sometimes that's, you know I think we're going outside our boundary, because we see there's a gap. So I think well if we don't do that, the person's going to fall through that gap or … nothing will be resolved. So we sort of take that on board, but it's not really what we're funded to do” (Evelyn). “The problematic one is the remote health clinic. Where do we step back and where do they step up. That's our grey area. That's the problematic area” (Wendy). “…it all depends I guess. But with XX at the moment, and because the clinic sister's very clear - so she's the one that talked to me about XX - she wanted me to case manage, because I know XX and the family a lot more…” (Brenda) “Services need to identify whether they support their staff taking on the role or not. It needs to be clear to all concerned” (Focus Group). “Implementation of the model should be accompanied by training and induction, funding, and mentoring for the key worker. The issue can be raised within the NGO sector now to ensure there is good take-up when, as a sector, we agree to implement and support this approach” (Focus Group).
Appointing the key worker	“It was probably coordination/case management type work involved where sometimes we would have to be

- Maximise existing relationships and rapport - Respect for different levels and forms of knowledge - Knowledge of dementia and local service system - Timely appointment	with them to go to an appointment and we would have to advocate for them sometimes and just basically organise their day sometimes" (Kerryn). "Some of those issues that are presenting for remote health clinics is purely around the fact that they're coming from a high level, acute medical model and they just don't really want to step in to give support to aged care which has been an issue" (Wendy). "… dementia care is not just about clinical services. It's predominantly about a well-being sort of approach. There is a need for more generalised community-led supervision and day care and those sorts of things and shared care arrangements to manage what's the big problem" (Graham). "People stay for two years. Well then it takes years to build up. I don't think I can see a better model at the moment I guess. You can't have an outside source coming in having an answer" (Brenda). "There's a lot of health worker trained Aboriginal people on the communities and they've got good skills and obviously they know their families, so they often have the ability to know the changes and often in dementia care what you're trying to do is track the changes... If you don't know the person you don't know if this is different from what was happening two months ago then you're pretty much stuffed really. … And also it becomes very difficult to track what might be a trauma related thing of abuse in their homes, because you don't actually know what they're normally like" (Graham). Key workers could be based in town, or out bush. If the key worker is Aboriginal and based in the person's; community, then we need to make sure they are not put in a compromising position culturally or as a result of gender issues" (Focus Group)
Communication - Agreed flags for intervention or further follow-up - Electronic communication system - Regular opportunities for provider meetings - Handover and information sharing supported by organisations	"…if there was some sort of shared…if they were on one access point..." (Ivan). "You know things would be duplicated because … this service or this allied health professional didn't tell you that this had happened, yet you were out there trying to work it out, but it's already been done, and nobody's told you. And you're the one who's doing that service you know and you think 'Oh, why can't you just communicate this?' If everybody was on the same page - that's why I think that proper training with case management is so important you know" (Kerryn). "I suppose you've gotta work out what's the best communication for this person, but I like e-mails …

	instead of having to sit down and write a file note separately" (Kerryn). "…the family's trying to do it on their own, or don't know what's available" (Ivan). "There is a dementia service provider's network group, and we have monthly meetings where we'll discuss problem clients or where there's issues … You send out group e-mails - this person's come up or this person's been especially problematic lately, can we discuss them at the next meeting" (Ivan). "…when you attend case meetings and there could be eight people sitting around a table and someone almost has to volunteer, you know they volunteer to take up the role" (Evelyn).

Appendix A: Features of proposed key worker model

Building on published dementia pathways (7) including those developed for Indigenous people with dementia (PWD) in Central Australia (4, 8), the following are features of a **key worker** model to ensure these pathways are followed.

Broad underpinning principles: • Person-centred • Culturally safe • Contextually relevant and flexible	• The right worker (determined for each individual • Respect for language (e.g. use of interpreters) • Respect for relationships (e.g. involvement of appropriate family and community members) • Involvement of local cultural advisers • Creative problem solving • Individualised solutions • Re-enablement focused
Worker attributes (skills, knowledge, attitudes) *Additional training and mentoring support may be required for individual key workers in certain areas (as listed) as well as in more targeted areas such as capacity assessment, running family meetings, elder abuse, guardianship, ethics, advocacy, chairing meetings.*	• Commitment to broad principles (as above) • Communication, negotiation and advocacy skills • Respect for different levels and forms of knowledge • Knowledge of dementia • Knowledge of local service system • Relationship and rapport with the PWD and carers • Understanding context (of service delivery and for clients and carers) • Ability to mobilise other services (e.g. dementia educators) • Respectful and supportive • Conflict management skills
Key worker appointment	• Maximise existing relationships and rapport • Timely appointment • Appointed (recommended) as an outcome of initial assessment • Permission obtained from PWD/carers about the level of information to which they will have access from other organisations • Time available to undertake the role
Roles and responsibilities:	• Participate in care planning process (with permission of the PWD and their carers) • Identify who is important to the PWD and who should be involved in ongoing communication about the person's care • Ensure all service providers have a copy of the plan detailing how services will be coordinated • Ensure review is carried out according to care plan • Keep a record of care plan items actioned/not actioned to report at the review process • Advocacy as required • Regular, planned communication with all involved in care provision (feedback loop in place)
Partnerships and organisational support:	• Organisational and professional respect • Definitional and service system agreement (MOUs in place) • Flexibility to act and recommend action (not bound by organisational constraints) • Agreement about how shared clients will be managed

	(particularly in relation to information sharing) - Key worker roles and responsibilities ‘mandated’ within the local service system - Shared understanding who can take on the role (according to existing job roles) - Acknowledgement of organisational and individual roles - Negotiated role boundaries and role flexibility - Inclusive care planning and dementia information provision to take focus beyond health and aged care (e.g. art centres)
Communication mechanisms	- Agreed flags for intervention or further follow-up - Supported with electronic communication system - Regular opportunities for provider meetings - Handover and information sharing supported by organisations - Commitment to reducing information duplication - Streamlined reporting and accountability to client/carer and care providers