Evaluation of a dementia awareness resource for use in remote Indigenous communities

Hazel Hawke Research Grant in Dementia Care Final Report

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1. Executive Summary

Dementia is a growing health care issue for remote Aboriginal communities and has received relatively little attention to date. The awareness of dementia and related issues is low among community members who experience linguistic and cultural barriers to becoming well informed. In 2008 Alzheimer’s Australia Northern Territory (AlzANT) identified a lack of appropriate resources for talking about dementia with remote Aboriginal community members, including those suffering or at risk of dementia, those caring for someone with or at risk of dementia and those service providers who may be involved in supporting such individuals.

**Background**: With a small seeding grant to develop a pilot resource, AlzANT produced a 16 minute DVD in English and three Indigenous Languages (Warlpiri, Kriol, and Djambarrpuyngu). The content aimed to raise awareness of dementia. A flip chart written in plain English accompanied the DVD and a poster identified the resource to community members. The resource was then piloted in several remote communities.

**Evaluation objectives**: Before seeking to further develop the resource and to implement it more broadly, it was agreed that a formal evaluation should take place to answer some of the questions as to the resource’s effectiveness in achieving its goal of raising awareness as well as considering how the resource might best be implemented.

In 2009, a research group at the Centre for Remote Health in Alice Springs was successful in obtaining a Hazel Hawke Grant to evaluate the resource *Looking out for Dementia*. The aims of the evaluation were to:

- assess whether the resource was effective in achieving the aim of awareness raising
- evaluate the role and value of using Indigenous Languages within the resource
- identify enablers and barriers to using the resource in remote Aboriginal communities
- make recommendations for further development and implementation.

**Methodology**: A qualitative evaluation design was used employing a triangulated approach to data collection (including observation, focus groups and individual interviews) and in data analysis. An Indigenous researcher participated throughout the evaluation process and Indigenous advisors were individually consulted at critical points. The majority of the data was collected in Indigenous communities/organisations where the resource had been implemented by external dementia educators as part of their normal work role.

**Findings**: The findings of this evaluation related to the following themes:

- Overall response to the resource
- Impact
- Content, breadth and depth of information
- Layout and design elements
- Indigenous Languages and cultural and local appropriateness
- Identified need for resource
- Dissemination and implementation
- Suggestions for improvement
The resource Looking out for Dementia was effective in raising awareness of dementia as a health issue for remote Aboriginal communities. Although not absolutely essential, the role and value of using Indigenous Languages was important for community members, and enhanced engagement with the information. What was considered important was the capacity to contextualise discussions within a structured implementation program. The use of the resource was strongly recommended as part of an integrated whole of community approach to dementia awareness. A major gap in awareness was found to affect not only community members but health service providers as well which was exacerbated by a lack of collaboration within and between community services.

**Recommendations:** Several recommendations are proposed for consideration by policy-makers, dementia educators and others with an interest in the use and further development of this and similar communication resources for Indigenous community members. In accordance with the original philosophy behind the development of “Looking Out for Dementia”, further production and dissemination of the existing resource should include the following enhancements:

1. Further translation of the DVD into other Indigenous languages should take place (on the advice of Aboriginal Interpreter Services and in consultation with individual service providers and community representatives) and a limited number only produced in each language to suit language group needs.

2. Further production of the existing resource (without further translation) could be limited to the DVD and the flipchart.

3. All Indigenous people involved in the resource should be named and acknowledged and those appearing in the DVD should be more clearly identified as acting their roles.

4. Training in intercultural communication and cultural safety should be developed and made available for dementia educators who wish to use the resource.

5. A specific training and information strategy should be developed for health professionals and organisations that could have a role in dementia care in Indigenous communities (particularly health clinics) to raise awareness of the resource and how they can assist to support it and maximise outcomes.

6. Each Looking out for Dementia resource distributed by AlzANT in the future should be accompanied by:

   a. a feedback and suggestions form so that practice-based information from the field can be incorporated into any further developmental process;

   b. brief written information highlighting key points from this evaluation that will enhance successful implementation (such as target audience, intersectoral collaboration, tips for effective facilitation etc).

Overall, Looking out for Dementia has a significant role to play in addressing a gap in the education of Indigenous populations and relevant workforces.
2. Introduction

Educating families and individuals about dementia is challenging irrespective of the social context of participants. Added to the challenge for Indigenous Australians are complexities of cross-cultural and language influences. These present barriers to Indigenous Australians becoming well informed about dementia and other health issues. Health related resources and education programs need to ensure that they are not only culturally appropriate, but locally appropriate in order to be accessible and acceptable to their intended audience.

Research into the provision of quality dementia care and the support of carers will contribute to improving quality of life for people with dementia, their families and carers, and should be a high priority. In cross-cultural settings such as Indigenous communities, mainstream approaches to dementia care may not always be applicable or acceptable. When families and individuals are appropriately and effectively informed they will be better positioned to seek early assistance and quality care for those affected by dementia. In Indigenous communities, chronic diseases, acute illnesses and injuries occur at levels often beyond that of other Australians. Ensuring that effective communication about dementia is not lost in the ‘normalising’ of ill-health experienced by Indigenous Australians takes on an added significance.

This project aimed to determine the effectiveness of a multi-media resource in enabling primary health care workers to communicate effectively with Indigenous community members. It is envisaged that the evaluation of this resource will better inform the development of communication strategies in dementia care, and potentially for broader health and wellbeing topics. As Ingram (2007, p.32) notes:

“(W)ithout a specifically designed communication strategy, research projects are burdened with ill-informed cultural views incorporated with undisciplined communication processes. Thus, a project is inchoately weak if cloaked in what non-Aboriginal people believe to be appealing to Aboriginal audiences”.

Where projects and researchers have addressed communication issues they remain categorical about the need for further research in the area of communication in Aboriginal health (Ingram 2007). Ineffective communication with Aboriginal language speakers has been shown to impact on health, access, compliance and informed consent (Taylor & Guerin, 2010). In spite of significant expenditure on Aboriginal health and education, health literacy and awareness of dementia and other issues, has traditionally been limited through ineffective or inappropriate communications. The role of Aboriginal Languages in health education is suggested to enhance understanding of issues and has been a feature of the multi-media resource that is the focus of this evaluation. The evaluation of targeted resources for Aboriginal language speakers is integral to any education and health promotion strategy and will help to ensure the development of future resources that are informed by key findings.

Evaluation aims

Specific aims of the evaluation were to:

- assess whether the resource was effective in achieving the aim of awareness raising
- evaluate the role and value of using Indigenous Languages within the resource
- identify enablers and barriers to using the resource in remote Aboriginal communities
make recommendations for further development and implementation.

### 2.1. Development of the resource

In dementia care as well as more broadly, there is a need to ensure that primary health care workers are equipped to communicate effectively with carers and community members. Clear communication is consistently highlighted by clients and carers as critical in the assessment and diagnosis process, including the requirement that health professionals clearly explain to the person with dementia and their carer what is happening (Williamson 2008). Particularly in the case of working with people of linguistically diverse backgrounds, this involves the availability of appropriate resources and communication tools, as well as cross-cultural communication skills of the individual workers. The work of the 10/66 group\(^1\) demonstrates the importance of building up a resource of translated instruments and training materials in local languages as a step in the process of raising awareness, countering stigma and improving service access and addressing unmet need (Prince, Graham et al. 2004).

In Australia to date, little has been developed to assist workers in communicating the important facts about dementia with Indigenous community members. As one approach to addressing this gap, Alzheimer’s Australia NT (AlzANT) developed a multi-media resource targeted at changing misconceptions surrounding dementia and improving the understanding of dementia within an Indigenous community setting. The following highlighted text provided by AlzANT describes the reasons for and process of development of the resource.

**“Looking out for Dementia”** is a resource consisting of a locally produced DVD in English and three local languages of the Northern Territory, Warlpiri, Djambarrpuynu and Kriol. Also included is a training flip chart in English and a community awareness poster. This resource was developed, produced and distributed by Alzheimer’s Australia NT (AlzANT) in 2009.

This project was initiated by local staff with input from an advisory group who identified a gap in existing resources. The advisory group recognised the prevalence of dementia among Indigenous elderly people and that community and aged care workers urgently needed an appropriate training resource. This resource would be designed principally for remote Indigenous communities. It would inform, educate as well as increase the awareness of the community of the special issues associated with the care and management of clients suffering with dementia.

There are currently a number resources being used in the Northern Territory but with limited success, although none have been formally evaluated. Health professionals have expressed informally a number of reservations about the two main existing resources.

**Indigenous Resource Pack**

The first of these resources, the Indigenous Resource Pack (Dementia learning resource for Aboriginal and Torres Strait Islander Communities), was developed by Alzheimer’s Australia South Australia. This

\(^1\) The 10/66 Dementia Research Group is a collective of researchers carrying out population-based research into dementia, non-communicable diseases and ageing in low and middle income countries (http://www.alz.co.uk/1066/).
resource was based on the accredited Certificate III in Aged Care CHCAC15A, in which the learning objectives are to teach workers how to provide care for patients with dementia and Unit HLTHIR404B, which introduces students to working effectively with Aboriginal and Torres Strait islander people.

This package has a number of shortcomings when applied to Indigenous communities in the Northern Territory. The course and structure required a certain level of literacy which is unrealistic in remote NT. It was felt that the content was very general and aimed more to a population living in urban areas, and that the learning activities were not culturally appropriate to the Northern Territory. For example, the image used to depict dementia was that of a black hawk descending onto the head of an Aboriginal person. To some local Indigenous people this is a sacred totem and thus was perceived as confronting. There were a number of issues about format, layout and style.

It was acknowledged that there were some positive elements in this training package. For example, one of these was a 3D jigsaw puzzle of the brain. For visual learners, the appreciation of the form, size and fragility of the brain facilitates the understanding of the disease process.

**Kimberley TAFE Certificate III Aged Care Course**

As with the former resource, the Dementia Story DVD forms part of a resource produced by Kimberley Aged and Community Services (KACS) and has been used by Kimberley TAFE to assist with the delivery of Certificate III Aged Care Work. It includes three DVDs, one of which is ‘The Dementia Story’. It also includes a health promotion computer program for animated graphics (‘Marvin’ - developed in the Northern Territory). Unfortunately, this resource failed to engage the Northern Territory target audience - the speech was rapid, provided too much detail and was in English. It also targeted paid aged care workers, and hence was difficult to use with members of the community, clients and families. Because of the comical nature of Marvin, it would solicit humor and it was felt that the seriousness of the message was diminished.

**Looking out for Dementia: the Northern Territory Resource**

Alzheimer’s Australia NT was in position of having worked with a number of imported resources, of having assisted with the development of the Kimberley resource and of having local knowledge of remote communities of the Northern Territory. Furthermore AlzANT works in close collaboration with a number of agencies that provide training and care for aged and dementia clients. These health professionals expressed the urgent need for a basic resource that was accessible to both aged care workers and to the community.

In November 2008 AlzANT was successful in gaining funding through the Northern Territory Government Community Benefit Grant. This acknowledged the importance of developing an appropriate and accessible tool to respond to a health problem which will increasingly affect Indigenous Australians, particularly as the population ages in a remote environment, where services are at a minimum and stretched.

**Deliverables**

This initial grant only allowed for the costs associated with the production of a DVD in Language. Funding did not allow for a pilot or subsequent script changes, and other constraints limited the quantity of the resource to twenty DVDs and posters and ten only flip charts. The script and technical information was developed with the help of a reference group, who were supported by their local organisations.
3. What the literature tells us

As the Australian population increases and ages, the number of people with dementia is expected to rise, increasing the requirement for appropriate care services and placing significant demands on the amount of time and help provided by carers (Australian Institute of Health and Welfare 2007). It is essential that information about dementia, including causes, symptoms, care and support strategies, is available and accessible for the broader Australian population. This necessarily includes more targeted information appropriate for culturally and linguistically diverse (CALD) groups within the Australian population. Indigenous Australians remain heterogenous in cultures, languages and histories, reinforcing the need for alternative ways of presenting health information.

Recently published research findings, conducted in the Kimberley, found the prevalence of dementia among Indigenous Australians to be 12.4%. This is substantially higher than that found in non-Indigenous Australians and all other studied populations, and is 5.2 fold greater than the overall Australian prevalence (Alzheimer's Australia 2007). That study found that the prevalence of cognitive impairment (not dementia) was 8.0% (Smith, Flicker et al. 2008). Recent research indicates that Indigenous people experience ongoing challenges finding services which are appropriate to their needs and circumstances; and that they often have problems accessing services, if they exist (Broe, Jackson Pulver et al. 2009).

Brief, simple interventions focusing on caregiver education and training, may be of particular benefit in settings where awareness of dementia is low and support from formal services is limited (Dias, Samuel et al. 2004; Gavrilova, Ferri et al. 2008). Randomized controlled trials have targeted the main carer and immediate and extended family as the focus of basic education about dementia and specific training on managing problem behaviours (Gavrilova, Ferri et al. 2008), resulting in significant improvements in caregiver mental health and burden of care (Dias, Samuel et al. 2004). The contexts of these studies and others undertaken by the 10/66 dementia research group (developing countries) and the evidence of the impact of these interventions, has resonance for remote Australia. Elsewhere, in ‘low density population areas’, caregiver training has been shown to result in more use of supportive services, more effective care-giving strategies, and improved caregiver wellbeing (Smith and Bell 2005).

Primary health care workers should be equipped to communicate effectively with carers and community members, specifically in the assessment of care and support requirements. Clients and carers, critical to the assessment and diagnosis process, consistently highlight the need for clear communication. Effective communication necessitates that health professionals clearly explain to the person with dementia and their carer what is happening (Williamson 2008). When working with people of diverse backgrounds, clear communication involves using appropriate resources and communication tools, as well as relying on the cross-cultural communication skills of individual workers. The work of the 10/66 group demonstrates the importance of building up a resource of translated instruments and training materials in local languages as a step in the process of raising awareness, countering stigma and improving service access and unmet need (Prince, Graham et al. 2004).
3.1. Incidence and prevalence of dementia in Indigenous populations

The epidemiology of dementia for Australian Aboriginal and Torres Strait Islanders has not been fully described (Low, Gomes et al. 2008). Data collected in the Kimberley region detail prevalence (Smith, et al. 2008), but little is known about the incidence of dementia in Indigenous populations in Australia, or the prevalence of dementia in other regions of Australia. Indigenous Australian and other CALD groups have been the subject of limited research but no studies of sufficient reliability were found in a systematic review of the literature in 2009 (Runge, Gilham et al. 2009,p.3). Amongst seven recommendations for further research, Runge et al (2009) suggested the evaluation of early intervention services for care receivers and caregivers to support care in the community.

Of those with dementia in New Zealand, 3.6% are Maori, but by 2026 it is expected that Maori will be 5.8% of the total (with higher prevalence of females due to longer life span) (Alzheimer's New Zealand 2008). In Canada, there are no statistics for Indigenous people with dementia. Aboriginal populations in Canada are diverse and multi-jurisdictional, as they are in Australia, which severely affects both the access to comprehensive health care, and the collection of reliable health-assessment data (Smylie and Anderson 2006).

Health professionals are recognising the importance of interdisciplinary care and, as McAiney et al (2008 p.117) point out, the “demographic pressures of an ageing population can no longer be ignored or shuffled off to someone else” (McAiney, Harvey et al. 2008). However, accurate health data on Indigenous populations must underpin any approach for the provision of care and of services.

3.2. Cultural issues in dementia care

Building on the cultural safety work of Ramsden (Ramsden 1990; Papps and Ramsden 1996) and the Nursing Council of New Zealand (2009), the complex health care needs of Indigenous people living within a dominant culture has become evident. Although cultural safety was developed initially within the context of Maori health service delivery, it refers to any cultural difference between the service provider and the recipient of care. Cultural safety explicitly incorporates the experiences of the recipients of care that enables them to be active participants in programs and services directed towards improving their health.

Cultural safety has been the cornerstone of nursing education in New Zealand since 1990, and is defined as:

“The effective nursing practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability…. Cultural safety is underpinned by communication, recognition of the diversity in worldviews (both within and between cultural groups), and the impact of colonisation processes on minority groups. Cultural safety is an outcome of nursing education that

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2 Number of cases at a particular point in time
3 Number of new cases in a given period of time
enables a safe, appropriate and acceptable service that has been defined by those who receive it” (Nursing Council of New Zealand 2009).

In Australia, cultural awareness and cultural sensitivity are widely acknowledged as the forerunners to a suite of cultural frameworks that have been developed to guide health care practice involving multicultural groups. Cultural safety arose in the 1980s from an acknowledgement that awareness and sensitivity were not enough to achieve a truly ‘safe’ environment for minorities and vulnerable groups. Whilst there is some disagreement in Australia over consistent terminology, another emerging theory that purports to align to cultural safety is that of ‘cultural competence’. Cultural competence requires structural change focused on the individual providing the service and the health system’s capacity to integrate cultural needs into service delivery (Nguyen 2008). Medical, allied health and other service providers may have paid attention to communication and socio-cultural issues while still relegating the cultural experience of the client to the realm of personal activities.

However, cultural competence still focuses on culture in terms of ethnicity and health professionals becoming competent in responding to various cultural needs of their clients. Cultural safety on the other hand views culture more broadly and avoids fixing culture in terms of discrete knowledge that one can become competent in using to provide care. Instead it is a reflective process for the providers to examine power and practice in response to clients who differ from themselves in relation not only to ethnicity, but in relation to socio-economic status, politics, religion, gender or sexual orientation (Ramsden, 2002). Whichever framework is adopted, the need for training in cultural safety, cultural competence, and especially cross-cultural communication exists at every level of the health service (Davis and Smith 2009).

As Nguyen (2008) points out, cross-cultural communication is often managed poorly and, as well as reinforcing entrenched attitudes and beliefs, has resulted in negative health outcomes for indigenous peoples. In an African American dementia study, “historical suspicion and mistrust of formal systems and fear of institutional racism” delayed community awareness, dementia diagnosis and service delivery (Clutterbuck and Mahoney 2003). When diagnosing and managing dementia, it is culturally significant to maintain respect for elders, and caregiver respect for the personhood of the person with dementia. The perceived disrespect inherent in health care providers’ negative attitudes and behaviours has in the past resulted in delays in diagnosis and lack of support for families and caregivers.

Thus, care providers’ negative attitudes and behaviours and the depersonalising tendencies in some treatment contexts, “fail to acknowledge that the body is a fundamental means of communication and as such, the body is essential to the expression of personhood” (Kontos and Naglie 2007). According to the findings in their study, Kontos and Naglie (2009) suggest that resources alone are insufficient in providing humanistic care, especially if caregivers assume that with advancing dementia there is a corresponding loss of selfhood. People with dementia continue to experience the range of human emotions including fear and humiliation. Kontos and Naglie (2009, p.551) advocate for a “new care ethic that underscores the communicative capacity of the body ... to connect us to the personhood of others, thereby fostering ...person centred dementia care”.

In a review of the literature on dementia in Australian Aboriginal and Torres Strait Islander peoples, (Broe, Jackson Pulver et al. 2009), found that “Aboriginal elders wished to be cared for in their own communities where they are close to kin and can die on their land”. They also found that little is known about care arrangements or impact on families caring for elders. The crucial roles played by older Indigenous people and how these roles have adapted over time to contemporary circumstances have been highlighted (Warburton and Chambers 2007). Broe et al (2009) point out that there is a “strong
Aboriginal belief that a ‘life out of balance’, having lost connection to the land and to traditional relationships, causes sickness” and some have described dementia as a “sick spirit”. Aboriginal health “incorporates a whole of life outlook” (Hampshire, Broe et al. 2005) that focuses on the family and community. Psychosocial, emotional, physical, spiritual and cultural health all are facets of personal, family and community responsibilities. Thus, the development and provision of Aboriginal aged (and dementia) care should reflect their holistic needs (Buti 1996) although there remains a general lack of knowledge among the general population about how to care for older Aboriginal people (Keleher 2003) including those with dementia.

Similar concerns about cultural issues and caring values unique to the Chinese people were considered in a study of an early dementia program of educational activities (Chung 2001). This program did not replicate similar programs in Western countries but was based on Chinese values of “filial piety and marital obligations” (Chung, 2001, p.86). Close familial relationships and intra-family support meant that those with dementia and their carers were actively involved in their own education and empowerment. Just as this small qualitative study demonstrates the importance of acknowledging cultural issues in dementia care in the community, a 10/66 randomised controlled trial in Goa, India (Dias, Dewey et al. 2008) illustrates that community managed dementia care has benefits for the caregiver. Inherent in home based dementia care are all the cultural and familial customs, beliefs and language necessary to care for people with dementia. The study “developed and evaluated the effectiveness of a home based intervention in reducing care-giver burden” (p.1) utilising low-cost, locally available people as carers. This study demonstrated that home based support leads to “significant improvements in care-giver mental health and the burden of caring” for people with dementia (Dias, Dewey et al. 2008).

3.3. Economic factors in dementia care

The direct economic cost of dementia care in Australia is expected to rise exponentially as the “dementia epidemic” continues (Low, Gomes et al. 2008). Annual expenditure is currently $12 billion and is projected to increase by $8.2 billion by 2023. However, economic modelling has demonstrated that if the requirement of specialised care could be delayed by five years through caregiver support and therapeutic programs, there would be significant savings. According to Low et al, (2008) dementia research in Australia is significantly under funded relative to other chronic diseases. Although it is a major health problem for Indigenous peoples, dementia and dementia care in Aboriginal communities is even less understood and resourced.

Through the NZ Government’s health policy of ‘ageing in place’, people with dementia are initially cared for in the community, decreasing the financial cost of care. Access Economics in NZ undertook a cost benefit analysis by delaying entry into residential care by three months. In 2008 this represented a 23% reduction in costs and a saving of $62.3 million. However, this was offset by costs incurred by the community, including costs to the family, of an estimated $30.5 million. Overall, the net benefit from institutional delay was $31.8 million in 2008 (Alzheimer's New Zealand 2008).

In Canada, the prevalence of dementia is estimated to increase by 55% by 2031. Of these, 50% of people with dementia reside in their own homes, most living with a caregiver usually over 60 years of age (McAiney, Harvey et al. 2008). Even though dementia care is mostly provided in the community, Alzheimer’s and related diseases have the second highest impact on health care costs (McAiney, Harvey et al. 2008). Again, there is a dearth of literature on Indigenous perspectives on health and ageing and the costs associated with it.
Informal caregivers provide most of the care for people with dementia but informal costs of care are seldom identified. These may be higher than formal costs, highlighting the amount of time that family and others in the community spend giving care. Dementia costs caregivers their wages, it costs employers and businesses through absenteeism and loss of productivity, it costs the community through caregivers’ loss of time and energy for community based activities, social isolation of carer and increased morbidity of carer (Dias at al, 2008). These costs are common to informal carers, and provide further support for ensuring education and awareness of dementia within communities. One randomised clinical trial, which attempted to evaluate the extent of these losses, was carried out in Memphis USA (Nichols, Chang et al. 2008) with both African American and European participant dyads. Telephone support and direct home based support sessions were provided. The authors concluded that any intervention that saves caregiver time would alleviate some of the informal cost of care. The economic cost of dementia in rural and remote areas and the family costs of the disease are significant. A broad perspective of dementia costs should always be included when health policies are being designed and when health services are delivered (Allegri, Butman et al. 2007).

3.4. Evaluation of selected dementia care programs

In Australia to date, little has been developed to assist workers to communicate the important facts about dementia with Indigenous community members. Resources that are developed are not targeted to particular cultural or language groups, and have not been effectively evaluated. For example, the “Dementia learning resource for Aboriginal and Torres Strait Islander communities” (Alzheimer’s Australia 2007) is intended for use by educators, trainers and facilitators of service and care provision, as well as for general dementia education and awareness-raising. The resource was produced only in English and may have limited application to members of remote communities. Brief information sheets developed in the Top End⁵ of the Northern Territory about delirium, depression and dementia (Australian Integrated Mental Health Initiative NT 2007) convey only very basic information in simple English and have not been evaluated. This can pose a problem for ethical health care delivery because cultural perspectives on health and illness define what behaviours are ‘normal’ and have consequences for care giving and for accessing health care (Brief 2009).

It is not surprising that most of the studies of early dementia are focussed in the community and on caregivers’ mental health and ‘burden of caring’. In Canada, the First Link Collaboration between the Alzheimer’s Society, primary health care providers and other health professionals, allowed people with dementia and their carers earlier access to services in order to support caregivers and reduce the number of crises (McAiney, Harvey et al. 2008). The evaluation of the program examined the impact on primary care providers and described the implementation of First Link, using a mixed method prospective cohort design. This collaboration included the person with dementia and their caregivers as participants and focussed on the ability of carers to access resources for the person with dementia. The authors found that while the benefits of collaboration were significant, establishing partnerships amongst all parties was challenging.

The randomised controlled trial in Goa, India (Dias, Dewey et al. 2008) evaluated the effectiveness of home based intervention in reducing caregiver burden, promoting caregiver mental health, and reducing

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⁴ Research from Aboriginal, CALD and other minority groups was accessed for this literature review

⁵ Top End refers to a geographical region that commonly implies the top third of the Northern Territory.
behavioural problems in elderly persons with dementia. In this study, one group of the dementia-caregiver dyads received the intervention and another group waited six months for the intervention. The family identified the principal caregivers, although the person was usually the spouse. This 10/66 Dementia Research Group study concluded that “home base support for caregivers of persons with dementia which accompanies the use of locally available, low cost human resources is feasible, acceptable and leads to significant improvement in caregiver mental health and burden of caring” (Dias et al., 2008, p2).

In Taiwan a controlled clinical trial was conducted of a home-based caregiver training program for improving caregiver self-efficacy and reducing behavioural problems of elders with dementia. The experimental group of participants was given a two-hour in-home training program and the control group was given only written materials. The overall effect of the in-home training program was positive and beneficial in reducing behavioural problems of elders with dementia compared to the delivery of written materials to the control group (Huang, Shyu et al. 2003). Caregiver literacy and time constraints may hinder the efficacy of written educational or support materials.

Family caregivers are often the “second victims” of dementia and are at risk of stress related illness, depression and social isolation (Winter and Gitlin 2006). In this study professionally led telephone based support was evaluated utilising interviews and psychometric scales. They concluded that there is some benefit for older women carers especially in underserved populations such as in Aboriginal communities, and that especially in rural and remote areas, telephone support is an untapped but feasible modality, which requires further research. However, the regions that formed the study context for this evaluation may prove less feasible than other areas, as home telephones in remote Aboriginal communities are not common. Often there are one or two public phones which are subject to high use, limited privacy and frequent maintenance problems. The impact of the recent trend toward mobile phone use in remote communities is yet to be known.

The ‘Making Memories’ program for people with dementia living at home and their caregivers (Brodaty and Low 2004), was carried out with non-Aboriginal participants. However, the program seems to fit with customs and beliefs about elders and ageing in Aboriginal culture. The study evaluating the program concluded that the processes decreased psychological stress in people with dementia but had only short-term benefit for caregivers (Brodaty and Low 2004).

The goal of a rural and remote memory clinic in Canada was to streamline interdisciplinary assessment of dementia in order to reduce travel time and to shorten the time to diagnosis (Morgan, Crossley et al. 2009). This study sought to develop a ‘one stop clinic’ and culturally appropriate assessment protocols for dementia in Aboriginal elders, taking referrals from any health professional or family member. Based on three years of operation, the authors concluded that “telehealth videoconferencing” and the “interdisciplinary approach provided an efficient use of patient and provider time because of a coordinated model of care” (Morgan et al, 2009, p.27). Community consultation was critical to the success of memory clinics in rural and remote areas as people with dementia and their caregivers are often dependent on their community for transport and support.

### 3.5. Summary

Availability and access to dementia care support services, both for the individual with dementia and for the caregiver in the community, are critical factors in rural and remote health service delivery. Critical too,
are the various measures of financial and psychosocial stressors that need to be taken into account to develop and provide any dementia related health service. Interdisciplinary and transdisciplinary collaboration is essential for early diagnosis so that caregiver support can be initiated, delaying institutional care. The principles of cultural safety and cultural competence must underpin further research into dementia in Aboriginal communities so that culturally appropriate health services can be developed and delivered. Different models of information exchange about dementia and for offering support to families and carers should be explored for remote Indigenous communities in Australia.
4. Evaluation context

Context has a significant impact on not only the delivery of health education, but on the evaluation of any such education. This evaluation took place in areas classified as “remote” and “very remote” according to Australian Standard Geographical Classification-Remoteness Areas (ASGC-RA). The evaluation involved conducting interviews with participants who lived and work in three different cultural and Indigenous language speaking communities. One community was accessed via a major highway but was still affected by flooding during the data collection. The other communities were geographically isolated and access was similarly subject to climatic conditions, making rescheduling of data collection necessary.

<table>
<thead>
<tr>
<th>RA1</th>
<th>Major Cities of Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>RA2</td>
<td>Inner Regional Australia</td>
</tr>
<tr>
<td>RA3</td>
<td>Outer Regional Australia</td>
</tr>
<tr>
<td>RA4</td>
<td>Remote Australia</td>
</tr>
<tr>
<td>RA5</td>
<td>Very Remote Australia</td>
</tr>
</tbody>
</table>

Indigenous communities in the Northern Territory are characterised as areas in which Indigenous languages are in common usage. For many Indigenous Language speakers, limited communication with mostly English language speaking health professionals has thwarted efforts to provide safe and effective health care and education (Trudgen 2003; Taylor and Guerin 2010). This study evaluated the efficacy and cultural safety of an educational resource for communicating with Indigenous people about dementia. Knowledge obtained from this evaluation may have relevance for communication with other linguistically diverse Australians, although the context of remote and Indigenous health remains an important characteristic to be considered in interpretation of evaluation findings.
5. Evaluation method

A qualitative evaluation design was used employing a triangulated approach to data collection (including observation, focus groups and telephone interviews) and in data analysis. Indigenous input was incorporated into the evaluation process through an advisory group and with the involvement of an Indigenous researcher throughout the process. The majority of the data was collected in Indigenous communities/organisations where the resource had been implemented by external dementia educators as part of their normal work role. A detailed description of each component of the evaluation method is described below.

5.1. Advisors

An advisory group contributed to the evaluation process through informal meetings via phone or individually. Several attempts at formal face to face and teleconference meetings were abandoned in favour of individual feedback via phone or in person where possible. Advisors considered the findings and communications about the resource, the evaluation process, and dissemination of the key findings with a broader audience.

5.2. Ethics approval

Ethics applications were submitted to:

1. Central Australian Human Research Ethics Committee (approval granted on 29/10/2009)
2. Human Research Ethics Committee of NT Department of Health & Families and Menzies School of Health Research (approval granted on 1/1/2010).

5.3. Data collection

5.3.1. Selection of communities

After the dementia educators delivered their training session in selected remote communities (optimally three to four weeks later), evaluation project staff went to those communities to gather data. Evaluation project staff kept in close liaison with the organisations who agreed to their education sessions forming part of the data collection. Data collection occurred during the period November ‘09 to March ‘10, and incorporated one of each of the language groups represented in the DVD, including English.

5.3.2. Observational data

Evaluation project staff accompanied a member of Alzheimer’s Australia NT to observe implementation of the resource in communities one and two (G5). This observation provided context for the evaluators, and enabled recording of some of the processes that dementia educators use in implementation in Aboriginal communities. General information such as the visibility and accessibility of the resource (e.g. where and if
the poster was displayed) and the use of the resource (e.g. whether the DVD was shown to individuals or groups) and whether any related events focusing on dementia awareness were generated. Evaluation project staff also recorded observational data during the follow-up visit post implementation of the resource in community four (G6).

5.3.3. Follow-up focus group interviews

According to the original project design, project staff visited communities after the multi-media resource had been implemented in that community. This occurred in four communities (see table 1). Focus groups were conducted with people who had participated in the session run by a dementia educator. Interpreters were used where necessary. Examples of questions asked in the focus groups are:

- What did you think of it (the DVD ‘Looking out for Dementia’)?
- Was the DVD helpful? In what ways?
- Did you learn anything new about dementia?
- Do you think any differently about dementia now that you have seen this DVD?
- Did it help to hear the DVD spoken in Language?
- Do you have another name for what the doctors call dementia?
- How would you know if someone in your family or community had dementia?
- What are some things you should do to look after someone with dementia?
- Who do you think should see this DVD? Flipchart?
- Have you seen the poster?
- Do you have any other comments about the resource and how it was used in your community?

Other questions were asked as appropriate, and expansion sought where necessary, as is the case with semi-structured interviews.

5.3.4. Follow-up individual interviews

In the original study design, it was intended that follow-up interviews would be conducted with key primary health care staff (usually by telephone) involved in dementia assessment and care in the selected communities to determine: a) the potential impact of the information on their client’s/patient’s and their family’s understanding of dementia, and b) any perceived change in the general community awareness and understanding of dementia. However, it became clear during the implementation phase, that awareness of the resource beyond those aged care services in which the resource was implemented was very low or even non existent in some communities. Despite efforts of the dementia educators to engage non-aged care services (such as clinics) in their education sessions, participation was mostly limited to people associated with the aged care services. This issue is discussed in more detail in later sections of this report.

Coordinators of the aged services in which the resource was implemented participated in follow-up interviews (D3) or focus groups (C1). Additional post participation telephone calls to aged care coordinators did not reveal any additional data and are thus not included as data sources. Other interview participants arose opportunistically as is often the case in qualitative data collection, and especially in
remote community contexts. The ‘aged care trainer’ (G1) had implemented the resource with Indigenous aged care and Home and Community Care (HACC) trainees in five communities and had considerable experience in using the resource in both Warlpiri and English. This interviewee spent considerable amounts of time in remote communities delivering certificate-level training on site in aged care services, often for two-three weeks at a time. Three dementia educators who participated in the evaluation (G2, G3, G4) were employed by either AlzANT or the NT Dementia Behaviour Management Advisory Service (DBMAS). Two in particular had extensive experience in working with Aboriginal communities and had regularly used the resource in the different languages.

Examples of questions asked during these individual interviews are:

- What did you think of it (‘Looking out for Dementia’)?
- Was the resource useful for you/your clients?
- What impact, if any, did the resource have on your practice or the work of your team? (DVD, flipchart, poster)
- What impact, if any, did the resource have in the community(s) you work with?
- What difference, if any did it make to have the DVD in Language?
- Can you provide examples of how the resources have been used?
- Are you aware of any significant discussions with or among clients around dementia issues since viewing the resource?
- How confident would you feel in using the resource in the community(s) you work with?
- Do you have any other comments about this resource and how it has been delivered / implemented in your community?

5.3.5. Summary of data sources

Tables 1 and 2 present a summary of the data sources and methods of collection. Each data source is also given a code and these codes are provided throughout the report to refer to direct quotes or summarised information.

**Table 1: Community-specific interview and focus group data**

<table>
<thead>
<tr>
<th>Community &amp; language group</th>
<th>Method of data collection(^6)</th>
<th>No. of individual participants</th>
<th>Coded as...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community 1 (English - Eastern Arnhem)</td>
<td>Focus group comprising aged care workers, Aboriginal Health Worker, community member</td>
<td>3</td>
<td>A1</td>
</tr>
<tr>
<td>Community 2 (Djambarrpuyngu - Eastern Arnhem)</td>
<td>Focus group (aged and disability team)</td>
<td>4</td>
<td>B1</td>
</tr>
<tr>
<td>Community 3 (Kriol - Katherine Region)</td>
<td>Focus group (aged care workers, including non-Indigenous coordinator)</td>
<td>6</td>
<td>C1</td>
</tr>
<tr>
<td>Community 4 (Warlpiri - Central Region)</td>
<td>Focus group (service users, community members, carers)</td>
<td>8</td>
<td>D1</td>
</tr>
</tbody>
</table>

\(^6\) Unless otherwise specified, all focus group and interview participants were Indigenous.
Community 4 (Warlpiri - Central Region) | Focus group (aged care workers) | 5 | D2
---|---|---|---
Community 4 (Warlpiri - Central Region) | Individual interview with non-Indigenous aged care coordinator | 1 | D3

Table 2: General data

<table>
<thead>
<tr>
<th>Description of data source</th>
<th>Method of data collection</th>
<th>Coded as...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged care trainer</td>
<td>Individual interview</td>
<td>G1</td>
</tr>
<tr>
<td>Dementia educator</td>
<td>Individual interview</td>
<td>G2</td>
</tr>
<tr>
<td>Dementia educator</td>
<td>Individual interview</td>
<td>G3</td>
</tr>
<tr>
<td>Dementia educator</td>
<td>Individual interview</td>
<td>G4</td>
</tr>
<tr>
<td>Observational data</td>
<td>(field notes recorded during observed implementation by a ‘dementia educator’ recorded in communities 1 and 2)</td>
<td>G5</td>
</tr>
<tr>
<td>Observational data</td>
<td>(field notes recorded during data collection in community 4)</td>
<td>G6</td>
</tr>
</tbody>
</table>

5.4. Limitations and contingencies

This evaluation was targeted at a limited number (4) of remote Aboriginal communities in which the resource, *Looking out for Dementia* was implemented. The timing of the commencement of the evaluation was problematic in that it was necessary to undertake initial contacts and visits during the Northern Territory summer months. In the remote and very remote contexts, employees are often either on annual leave or their communities are inaccessible for periods, so availability of potential participants was affected. These and other factors outlined in the following sections, present an acknowledged limitation on the generalisability of this evaluation’s findings to other remote Aboriginal communities.

5.4.1. Selection of communities

Certain factors impinged on the selection of communities for the evaluation and follow-up:

- Seasonal weather conditions, particularly in the Top End, prevented access by road to some communities. The focus group in community 3 (C1) was conducted as a teleconference. Weather conditions at the time - at the beginning of the wet season - precluded the project staff travelling to the community to conduct the follow-up interviews. Further time delays would have compromised the validity of the data and participants who had attended the original education session could not have been guaranteed to attend the focus group at a later time. While teleconferences are acknowledged as an unsatisfactory method for obtaining data from Indigenous participants, an Indigenous researcher was present in the teleconference who also transcribed the focus group data to ensure accuracy.
Organisational issues also impacted on the evaluation. AlzANT and DBMAS generally approach the aged care service providers in remote communities as the first point of contact for arranging their visits. Thus, the aged care organisations in each selected community had to agree to both the education session, and to the follow-up visit by the project staff. In one community, the education session and follow-up visit were delayed by several weeks until the aged care service had received permission from their Shire Manager (based in Alice Springs). Local consent had been granted (and welcomed) but had been questioned, and therefore significantly delayed, by a line manager who was not based in the community.

5.4.2. Language barriers

At all stages of data collection, Indigenous participants in the evaluation were offered the use of interpreters during the focus groups. Community members’ preference not to use interpreters should not be taken to imply that use of interpreters is unnecessary or that resources in Indigenous Languages should not be considered. On the contrary, the preference to speak in English to English speaking health professionals has been identified in the literature as an example of what is seen as ‘good manners’ and pride at being able to converse in the language of the interviewer and/or health personnel (Taylor 2009). This limitation in data collection highlights the very issues prompting the need for resources in the First Language of target audiences. Although the research team is confident of having obtained substantial and sufficient data, the language issues presented significant challenges that were only overcome through use of triangulation of data and the experience and local insights of the researchers and advisors.

5.5. Data analysis

The initial analysis comprised a “cross-case” method (Patton 2002). In this approach, data from all interviews and focus groups were assembled under common categories, usually those that had been determined in the interview guides. Evaluators grouped the data according to the content of the interview questions. This analysis provided broad categories to be compared to emergent themes from the next stage of analysis. The next stage – a thematic analysis - involved four project staff (including an Indigenous researcher) independently reading through transcripts and identifying themes. This second analysis provided a fuller reading of the text, searching for other, new, data categories. This is described as “unitizing” or “culling meaning” from the transcripts (Maykut and Morehouse 1994). The themes were then grouped, compared to the original cross-case results, and a consensus reached as to the major themes from the combined data to be presented in the findings.

This Indigenous researcher listened to focus group recordings to ensure that data had been transcribed accurately, and in some cases undertook parts of the transcribing. Her interpretation of silences and Indigenous participants’ use of particular words ensured accuracy in analysis.
6. Findings

The resource *Looking out for Dementia* was developed specifically for use with Indigenous communities, including Indigenous language speakers across the Northern Territory. The project aimed to evaluate to what extent the resource achieved its intended goal of raising awareness of dementia within remote Aboriginal communities, improving understanding of dementia and changing misconceptions around dementia.

Specifically, the evaluation considered issues of design, need, and appropriateness for target audience, role of Indigenous languages in the resource, impact and implementation. Specific findings reported in this section relate to:

- Overall response to the resource
- Impact
- Content, breadth and depth of information
- Layout and design elements
- Indigenous Languages and cultural and local appropriateness
- Identified need for resource
- Dissemination and implementation
- Suggestions for improvement

6.1. Overall response...`We found it to be one of the better ones...’

G1: *We found it to be one of the better ones, actually. It was very clear, and it was easy ...because it’s in Language*, but also in English...

When considering the question of how effective the resource is in raising awareness, improving understanding of dementia and changing misconceptions around dementia, the response was unanimous overall. *Looking out for Dementia* was effective as a starting point or “trigger” (G1) for further education and discussions (A1, B1, C1, D1, D2, D3, G1, G2, G3, G4). However, not all components of the *Looking out for Dementia* resource were rated as having equal value in these responses.

All participants identified the DVD as having the most potential to raise awareness, while the flip chart and poster were considered less useful by some dementia educators (G2; D3). The flip chart was described as a useful tool to leave for further review and discussions after the DVD had been viewed (G1). The poster however, was not seen as contributing to awareness of the resource or the issue of dementia more broadly.

Responses from Indigenous participants in the research were entirely positive, suggesting the information provided did meet a need, raise awareness and at the very least, provided an opportunity to further discuss dementia and its impact on families and communities. It should also be acknowledged however, that within Indigenous communications, there is a tendency for individuals not to wish to be seen as critical or confronting when asked questions (Taylor & Guerin, 2010). It was important therefore to

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7 Language written with a capital is taken to imply an Indigenous language.
triangulate data from Indigenous participants with data from dementia educators, other relevant non-Indigenous workers and field notes and observations.

The responses from Indigenous participants were largely reinforced by non-Indigenous aged care trainers and dementia educators who were also interviewed. Comments that were more constructively critical stemmed mainly from one of the dementia educators, and tended to relate to limitations of using the resources as a stand-alone strategy, rather than a criticism of the resource itself. Observations from the field (G5; G6) also affirmed the engagement that the DVD in particular had for participants and the desire for further information and discussion of dementia.

As an overall assessment of the multi-media resource, Looking out for Dementia, the prevailing view was that this is worthy of further development and roll out to other Indigenous communities. Focus groups A1 and B1 described the DVD as excellent, as there had been little prior knowledge about dementia within their communities, before viewing the resource. However, there were also a number of suggestions for improvement in relation to content. In addition, there was a strong recommendation from the aged care trainers, facilitators and dementia educators, for a clearly articulated and adequately funded implementation strategy (G1; G2; G3; G4).

6.2. Making an impact...‘I know what’s dementia now’

Findings quickly emerged that related to the impact of this resource in those communities who had viewed it. Prior to the availability of the resource it was suggested by participants in this study, that awareness across the target audiences was relatively poor. However, even with minimal implementation, such as showing the DVD to a limited number of people in the community, participants identified examples of increased awareness and understanding about dementia that led to noticeable behavioural and attitudinal changes in some cases. For example, one participant (G1) identified families and aged care workers who had previously been frustrated and impatient with individuals who may have been exhibiting dementia related symptoms that had been unrecognised prior to viewing the DVD. This participant noted that the ‘situation was much calmer after showing DVD...’ as people had begun to realize the cause of the uncharacteristic behaviours of those who may have dementia.

Some participants (D2, G2, C1) also cautioned about the potential to misinterpret the resource information if not presented in a supported and coordinated way. In one community, showing the DVD to a group of elderly women created some anxiety that they were being shown the DVD because they had or would get dementia, which was not the case. It highlighted both the immediacy of the impact and the need to ensure an appropriate implementation strategy that allowed for prior, and follow-up, discussion with viewers (G6). As one Indigenous participant said following a viewing of the DVD ‘I do all the right things – how come I get dementia? I don’t drink, smoke, I pray to God...I don’t want to get dementia’ (G6). Focus group D2 also were somewhat shocked and fearful of what was essentially new information for many of them and there was a clear need for skilled facilitation and guidance with interpretation. It did also however, allow focus groups (D1; D2) to identify behaviors such as individuals ‘stealing’ other’s bread, tobacco and other items as possibly being related to dementia. The lack of awareness led to family and others ‘getting rough’ with individuals who were upsetting them or not cooperating.

In all of the communities in which the DVD had been shown, it was easily remembered by those who had seen it. Links had been made by viewers between what they had seen in the DVD and people who had dementia within their community as evidenced in the following excerpt from a participant:
D1: ‘….She’s always stealing…they had dementia…and if you look (and) there’s something missing, it’s probably her because she’s got that same problem…that’s why I’m telling them, Nancy\(^8\) got dementia, she’s been picking up everything, bread, in her pocket even when she had breakfast she put that bread in her pocket…they might get arrested!’

Several participants (D1; D3; G1) said the DVD helped alleviate some of the tensions that exist in situations where someone may be suffering from dementia. This respondent identified the hidden but real risk of abuse of dementia sufferers, and the increased stress on the families:

G1: ‘I actually have seen a difference on one community where there was a lot of yelling and a lot of in fighting…it has changed. It’s a lot calmer, the client is calmer because we’re not yelling at the client, and they’re not pushing them…They’re taking them by the hand or that nice little soft touch of the back and pointing…’

The increasingly out of character behaviour of some members of the community was of concern to family who had feared their relative might find themselves in trouble with the law. The viewing of the DVD had an immediate impact in helping to explain what might be going on with some individuals and how this information could be used to support rather than punish people with dementia. (D1, D2, G1). Other examples of the impact were offered by aged care workers who had witnessed a change in attitude toward those with dementia from their carers:

D3: ‘….Janie’s patience was wearing pretty thin with Molly…it got to the stage where I had to step in, and just explain …to Janie that you can’t force Molly. …into the shower …so I just sat and spoke to her, and it was two days later that we had this DVD and Janie kept looking at me and smiling…’

Interviewer: ‘She made the connection?’

D3: ‘Yeh, thinking,… I knew where I went wrong…’

This increased awareness was noted in other communities and was credited with helping to calm situations that had previously become strained in families. Focus group C1 were very interested in the disease process as it helped workers identify deteriorations in clients, and understand the behaviours of clients who had become angry and lashed out at carers. Dementia educators all agreed that there was a high level of engagement and recognition when the DVD was shown in each community. For example:

D3: ‘You can see ….they associate someone with that… especially after they watched the DVD…Janie who is a carer for someone with dementia, she really opened up and talked too… and they all … started to have a little bit to say…’

G1: ‘I’ve had a male member of staff, came and …said ‘oh can I see that video again the one about the crazy people?’ I said ‘… Dementia…?’ He said ‘that’s the word, Dementia, I have to remember that word’s Dementia, that sick brain, that’s right sick brain’…. He watched that video for three hours repetitively! He really wanted to understand what it was about…’

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\(^8\) All names used in the data are pseudonyms.
An Indigenous participant in focus group D1 quickly made some important links between the information from the DVD and the social and cultural practices within her community. Football is one common social activity that the participants related to the incidence of head injury among young men. This, coupled with high levels of alcohol misuse, was seen as a risk factor for dementia that gave relevance to the information for more than just the older members of the community.

One other key issue for the participants of D1, following their viewing of the DVD, was the connection they perceived between dementia and mourning rituals during ‘sorry business’. This was also identified by other participants (D2, G1). For example, one member of D1 made the connection between one woman’s dementia and her self inflicted head wounds linked to bereavement:

D1: ‘She lost her youngest daughter; she hit herself with an axe. That’s why she can’t remember anything new...’

Another member of D2 focus group stated:

D2: ‘That’s what I was telling this lady, if its sorry time, I told them in my language, don’t grab a stone or stick and start hitting your head, you’ll damage your head...and they understand that, what I say.’

One carer, present during a focus group (D1), reported that until she had seen the DVD she had not known that her aunt had dementia, despite the fact that she had been the main carer for her for the past six years. Although her memory problems had not been present for all that time, this carer had experienced considerable difficulty in understanding and managing her aunt’s changed behaviour in recent years.

D1: ‘...no I didn’t know about dementia, then when ... I didn’t know about that, but when I looked at the movie ... three weeks ago and I know what’s dementia now.’

These responses indicate that the Looking out for Dementia resource had a substantial impact in communities in which it was delivered. They also reflect the potential of the resource to make a difference in the lives of individuals and families affected by dementia in remote Indigenous communities. It appears that the materials contained in the resource resonated with Indigenous viewers who were able to make connections to their own, or others’ circumstances, within remote communities.

6.3. Content, breadth and depth of information

Overall, the resource was found to be clear and concise. For example:

B1: ‘very positive, easy to explain, clear and informative’,
C1: ‘appropriate for the general community’ and ‘answered a lot of questions...’

G1 described the content as ‘basic’ and depending upon the skill of the implementer, ‘could go further’. She felt it was an appropriate length and the flexibility to stop the DVD for discussion was a positive with the resource acting as a “trigger” for discussions. G1 further advised that the resource should not be

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9 Sorry time – mourning period
considered to stand alone without other activities such a discussion and follow-up. G2 felt that there were some problems with the content, as it left viewers with few practical strategies and some confusion regarding the matter of prevention. This was reinforced in the observations (G6) where one Indigenous woman felt she took preventative measures, but was alarmed to find this would not safe-guard her entirely from dementia (see also 6.2). However, it was also highlighted by the resource developers that the initial development was only intended to raise awareness and further development of the resource in relation to additional content was not possible at that stage. This considered, G2 noted that Indigenous people ‘get a gutful of (disease) prevention and good food messages...’ She suggested that there was a need for more realistic and helpful information that could be presented rather than detailed dementia risk minimisation information that just duplicates messages received elsewhere (see also 6.8).

The majority of participants felt the DVD provided an adequate breadth and depth of information. However, it was mostly regarded as a useful starting point for further discussions and education around dementia. Given that the targeted communities had very little prior awareness of dementia and related issues and that no resources previously had been designed specifically for use within remote Indigenous communities in the Northern Territory, the Looking out for Dementia resource fills an unmet need. It was evident from observations and feedback from non-Indigenous dementia educators, that the success of implementation was dependent upon the skill of the facilitators and individual approaches used.

6.4. Layout and design elements … ‘it catches them right away’

The potential value of localising the content was mentioned by the majority of participants. Although not considered essential by everyone, the content that was local or included local community members either as presenters, actors or voices in the DVD gained immediate recognition and engagement from those watching (G1, G2, G3, G5, G6). When asked how well the participants related to the content of the DVD, the geographic and cultural location was quickly noted, and if local to the audience, there was intense interest. However, where the location was not specifically associated with the audience, this did not adversely influence interest in the topic.

‘Oh they all know it’s not down here (Central Australia)...its gotta be Top End... they recognise that its not a local thing, but ...no-one’s stopped paying attention...because of that...’

The consensus from each community was summed up by G3 who stated: ‘having local content and actors made it more engaging’. Other participants of the focus groups also indicated that having some local connection was really important to gaining the attention of audiences (B1, C1, D3, D1, G3), even wanting to see the names of the actors and people who provided the voice-overs (B1, C1), as finding a local connection was important.

There was some critique by one dementia educator (G2) that the communities and family contexts depicted in the DVD did not relate well to the realities of life in most remote communities: ‘It was too sanitised...’ This participant felt it would be more useful to have more realistic situations, noting how to address difficult behaviour, including aggression, and the potential for neglect and abuse of the person with dementia that she has witnessed. However, it was also acknowledged by the resource developers that not all communities are characterized by substandard housing and living conditions and the resource producer did not want to portray negative images as representative. It was difficult to gauge how well

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10 The code for this quote has not been included as to do so may identify the participant.
Indigenous audiences related to the scenes depicted, as it was noted in the field observations at one community, that the women watching gave the impression they could have been watching any television show rather than something intended to depict their own circumstances (G6). G1 felt that 16 minutes for the DVD component was appropriate for beginning the process of raising awareness:

Each individual component of the resource, the DVD, flip chart and poster was considered separately.

- The bright colours and cultural relevance of the colours was commented upon in relation to the flip chart. The use of realistic images for body parts, specifically for the brain was thought to be especially useful and suited the visual learning style of Indigenous people. One participant (G1) recalled the response of audiences to seeing the brain graphics and related it again to the protocols of sorry business. She felt that the image of the brain had an impact on Indigenous people by giving an indication of how vulnerable the brain was to damage from sorry practices, such as hitting one’s head to demonstrate grief.

- It was agreed by most participants that the poster had the least impact, and achieved the lowest level of awareness. Few if any, in the focus groups remembered seeing the poster and none of the dementia educators had seen the poster displayed within the communities. In communities visited by the evaluation team, there was no evidence of the poster being displayed or information about where to obtain the resource (G5, G6).

- Perspectives on the Flip Chart differed between communities. B1 felt the flip chart was good, and G1 (who works mainly with aged care workers) valued it highly: ‘...the flip chart’s excellent because when you’re away from the video, once you’ve watched the video you refer then to the flip chart and you can just show pictures...’, G2 (who works with both family and community members, and aged care workers) on the other hand, gave it very little value:

  G2: ‘I don’t use the flip chart as a resource...I’ve just been using that when I want to use something visual for something that I’ve already been saying, so the flip chart hasn’t had a lot of use... the flip chart’s very busy, the written stuff that I use is much more simple and plain...there’s a lot of stuff on each of those pages. The literacy is really poor so I’m not quite sure what the value would be with the flip chart anyway cause they’re not going to be reading it...’

6.5. Indigenous Languages and cultural and local appropriateness

Looking out for Dementia demonstrated an understanding of the diversity of Indigenous peoples and need to localize content by using local Indigenous languages, images and participants. One of the key considerations for this evaluation was whether or not it was important to have resources that used Indigenous Languages to engage Indigenous viewers and whether this enhanced understanding. Findings were inconclusive based on interview data only, as the focus groups differed in their responses to the issue of local language. However, in all the communities in which this evaluation took place, having a resource in the local Indigenous Language was appreciated. Appreciation of the effort to have material in Indigenous languages was also a point made by a participant who had experience implementing the resource in many different communities (G1). Groups D3 and D2 liked having it in Language, but noted there was a lot of English words. D2 participants indicated that new staff understood the language but not necessarily all of the ideas and thought further training in caring for someone with dementia was needed.
Having a resource in Language was said to be ‘very important, essential for understanding’ (B1). Further, A1 noted ‘it's an excellent put together DVD, to give out information on dementia, and the way it's been set up in a clear language for Yolngu people...’ although they did note that the DVD contained different dialects within the Yolngu version (G5). G2 however, stated that: ‘...when I tried the Warlpiri everyone just laughed so we went back to English...they thought that it was hilarious so told me to go back to (English)...they couldn't understand it’.

The focus groups from the Warlpiri communities all appreciated the use of their language, but also felt that English would be acceptable as someone in the group would generally undertake to interpret where necessary. G1 described the response of one Warlpiri man in viewing the DVD during some training she had delivered for aged care workers:

G1: ‘He watched it in Language and then he asked just to watch it in English. So he's happy to have it in English. He has watched it in the Warlpiri...they got the giggles at first when it was in Warlpiri. They were a bit surprised (be)cause people on community watch a lot of videos and they're not in Language of course, and then all of a sudden you present something in Language. It was 'wow this is in Language!' so it was interesting to get that initial shock of all these giggles but they were happy with that, but then after awhile they asked for it in English so...’

C1 focus group described the language as ‘good, clear Kriol’. Participants were appreciative of having a resource in their Language. It was concluded that developing resources in Indigenous languages is important to Indigenous people as it helps validate their cultures, enhances engagement and provides opportunity to develop health vocabularies where there is no existing translatable term.

The evaluation team also sought to identify any components of the resource that might be considered inappropriate within the different communities. The major male character on which the DVD centred was not considered a barrier to women’s viewing of the DVD, although it was suggested by focus group D1 that additional characters might ensure women and differing ages were represented in any future development. There was also discussion about the graphics used to depict body parts. None of the focus groups identified any concern with the images used in either the DVD or flip chart and in fact responded positively to the realistic depictions of the brain.

Most of the participants interviewed and shown the resource were Indigenous women. Gender is often cited as a barrier to Indigenous male participation in activities deemed as women’s issues. However, the Looking out for Dementia resource has shown the value of including Indigenous men in the education around dementia, evident in the following response and the cultural acceptability of this particular resource made it appropriate for use with male and female audiences

G1: ‘...he's sort of so intrigued now that ...he's actually learnt to identify two members on his community...two of the men who have, starting with dementia. ...to me that's a success story that he's actually grasped it and can understand and know, they're forgetting things, or they're talking about things that aren't associated with the present time so he's, he's really done well.’

When asked how people spoke about dementia or if they spoke about dementia, all groups interviewed advised that it was not terminology that was well known nor conceptually understood (A1, D1, D2, G1, G3) as evidenced by G1’s response about how Indigenous people describe someone with brain problems:
G1: ‘…just crazy, they’re crazy people. Unless they’ve had some training …or the clinic sister has intervened or the doctor’s intervened and said ‘well they’ve got Dementia’. They might have heard the word (dementia) before but … - they don’t have that understanding’.

This participant, and others (G3, D1, D2) also pointed out that there was no traditional explanation for dementia and therefore no effective way of talking about it. Indigenous participants, following the viewing of the DVD began to identify the distinction between dementia and other forms of brain problems and reinforced to one another the importance of using the term dementia rather than local Language terms that equated to ‘crazy or mad’.

6.6. Identified need for resource...‘People here don’t know about...dementia’

It was identified repeatedly that there was relatively little known about dementia prior to the resource being used in the target communities. There was a general grouping of ideas and understandings about brain related problems, but participants suggested the specific issue of dementia was poorly understood or acknowledged. The limited community awareness was seen as one cause for the relatively low levels of service uptake, and resulted in some individuals remaining undiagnosed or unrecognised as being at risk with dementia. Focus group data (A1) indicated a belief that the community had very little prior knowledge of dementia as a discrete health problem. There was a tendency to consider all problems with the brain as mental health issues rather than separate conditions:

A1 ‘...people here don’t know about the dementia, its fairly new and you know when they showing that old man getting cranky and angry and loss his mind and that some people might think mental health...so if they knew we had a patient here, a new one with dementia...’

The need for dementia awareness was found to also prompt people to connect to services, as well as reducing their sense of isolation in dealing with family members who may have or be at risk of dementia. For example:

C1 ‘... the girls were ...discussing it in our staff meeting, that they would like to learn a lot more about dementia ....we just found it quite pertinent because ...we did have dementia clients and they weren’t aware of the name of the deterioration or what the clients had, that they came across when they were delivering meals...more often then not, the sweet ladies that they knew and loved would have an episode where they were angry or lashed out at the girls. ...they weren’t understanding what was happening and they didn’t know what was wrong with them. So it’s been a fantastic resource, to ... learn about dementia. ... , because they really want to turn around and support the clients and their families’.

The resource’s usefulness as a tool to assist in communicating with families was also noted (A1, B1, C1, D1, D3, G3, G4). For example:

B1, ‘we often have clients with dementia and often we are asked to input with helping to educate families, so yes, definitely it will be a great resource.’

The need for the resource was evident and consistent across the communities included in this study.


6.7. Dissemination and implementation

In each of the communities where the evaluation took place, the Looking out for Dementia resource had been disseminated through the aged care services. Whether this was coincidental or not was not clear at the time of the evaluation, but resource developers had anticipated the resource being sent to clinics and community members more broadly. Participants generally suggested that the resource should be disseminated across the community in the clinic, women’s centres, schools, and not exclusively aged care facilities (G1, G2, D1, D2, C1, B1, A1). D3, and D2 focus group participants, agreed that everyone should learn about dementia, as they believed this issue was everyone’s business. These participants felt that children should be made aware of the issues and existence of people with dementia, as the behaviour of some of their family could frighten them, without such understanding. As reported above, it was identified as an appropriate resource that could be shown to families and carers, and could also be used with these other organisations that may have contact with people with dementia. By having the resource only associated with the aged care facilities, it may perpetuate an impression that dementia is an issue only relevant to the aged.

Although there was caution about the resource only being associated with aged care services, the cultural importance of seeking permission and advice from Indigenous elders in regard to dissemination and implementation was raised:

G2: ‘I’ve been told go to the elders¹¹, not the young people at all, (to ask) if it would be good for the school...because they’re telling me all the time that it’s the older people who will pass the information on...and that’s actually been an issue...because some of those people in aged care actually have no role in the community in that passing on of information, so I know in a couple of places...its got no further than aged care’.

As this participant noted, some of the older members of the communities may have changed their status with their increasing fragility and/or loss of roles, precluding them from being key resource people in terms of information sharing, so it was important to identify who might be considered the current community elders. Other participants (C2) suggested inviting elders to the school to show the DVD and recommended the need to prepare staff before the resource’s implementation.

Much of the successful dissemination and implementation was seen to rely on the skill of the individual facilitators in achieving the goals of the resource. Specific service providers in the Northern Territory were identified as having particularly good facilitation skills and established relationships with communities. This was a valued support that could be built upon by other service trainers within communities.

G1: ‘... we like her to come out ...and do that initial talk to the people about what Dementia is, go through it all, and then we come along and we’ll start training and really get in to picking it apart...We teach them to identify that it is a brain injury and that they need to be careful, that they can't help what they're doing’.

All participants who had implemented the resource agreed that there was a need for follow up to achieve the optimum benefit. In using the DVD in isolation, some viewers were still left unable to identify who amongst their community may have the symptoms. Time was needed for discussion and reflection.

¹¹ Elders are those senior (in status, not always age) members of communities who assume a leadership role.
G2: ‘The best feedback that I’ve had is when I’ve done it and I’m around for a couple of days and...they’ll point out people or they’ll come and ask for things as well...or say well maybe I should talk to the family ...about that...’

D1 and D2 groups highlighted the importance of not using the DVD as a stand alone resource, without ensuring opportunity for clarification and further discussion. During an initial viewing of the DVD, some of the older women were surprised to hear about the risk of dementia and began to express some concern that they were being shown the DVD because they had been identified as having dementia. This was not the case and it was reinforced by the group that the implementation of the resource needed guidance with interpretation. The need for carefully planned implementation, as people ‘would get confused’ if shown without explanation, was also reinforced (C1).

A finding that repeatedly arose during interviews with trainers and facilitators was the critical influence of relationships and collaboration between services and different sectors of community. For some (G1, G2) poor relationships, or lack of relationship, with remote clinic staff was considered a major barrier to the successful implementation and optimal impact of the Looking out for Dementia resource. In describing the relationship between facilitators and clinics in each community, they were either strained or non-existent. The reasons offered for this included the characteristic high rates of staff turnover in remote communities, a perceived lack of interest in issues deemed to be linked to aged care, a lack of awareness about people with dementia in communities and competing demands on staff.

It was agreed that in order for the resource to have substantial and sustainable value, greater collaboration and support was required from the clinic teams (G1, G2). According to G2, it was her experience that remote clinics showed no interest in training on the issue of dementia, believing that they had no clients who had or were at risk of dementia, even when the facilitator knew that there were in fact such individuals in these communities. The clinics’ failure to identify dementia patients was attributed to indifference arising as a result of the reported overwhelming workloads of remote clinic staff, but which remains a barrier to ensuring adequate care and supports are in place. According to G2: ‘...if they (clinic staff) don’t know, they don’t worry about it’ (dementia) and clinic staff generally appear not interested, and only ‘begrudgingly take pamphlets’.

The lack of collaboration and awareness of clinic staff was noted to be an impediment to the dissemination and implementation of the resource and dementia care generally (G1, G2, D3, G4). It was also noted (G5) that attempts to deliver awareness sessions in a regional hospital and a regional health centre did not proceed because relevant staff were unavailable at the agreed time despite this being organised well ahead of time.

6.8. Suggestions for improvement

There was reluctance among Indigenous participants to offer what might have been considered criticism of the resource, which necessitated obtaining feedback mostly from the non-Indigenous dementia educators. Those who had used the resource were generally positive about it, but had practical and constructive feedback to enhance any future development. G1 for example, felt that there was a need to make differential diagnoses clearer, and provide more strategies for dealing with someone with dementia in a remote community. G2 identified that aggression, both from and toward people with dementia was not dealt with adequately and suggested adding more information about this specifically. This participant also described the depiction of community and family life as ‘...quite simplistic, and ...very bland’. She
suggested that it might be useful to produce the DVD in a series format or chapters that can be used for different target groups and depict younger people.

There was agreement that the English version was worth keeping and if Indigenous languages were to be used, English subtitles would help facilitators and non-Language speakers to track the DVD content for teaching and discussion purposes (D3). There was no suggestion made of any value in having subtitled versions that were written in Indigenous languages, as literacy in Language is no higher or possibly less than English literacy given that Indigenous languages are orally/aurally transmitted.

English was acceptable as long as there was opportunity for discussion in the local language:

‘Keep it in English...whether that’s the same view in the Top End... ...I know that their English has been very poor, or their literacy was ...non-existent...but there’s always someone in the group who kind of takes on that role if they’re asking questions...’

One suggestion for redesign was for information to be added to help develop the conceptual understanding that would distinguish dementia from other brain problems:

G2: ‘They’re all put in the same basket... (people with brain problems) so its only when you start breaking it up, the symptoms and stuff like that ‘oh have you got anyone that forgets a lot of things or tells stories, a lot of stories from the past but doesn’t remember anyone’s names or who’s getting a bit cranky with the grandchildren....’

Focus group A1, responded verbally to the preventative messages about eating well and looking after oneself. However, in a more critical reading of the transcripts and confirmed by field observations, these responses seemed more like conditioned responses and an example of gratuitous concurrence – the tendency to appear to agree:

A1: ‘yo12, getting all the muscles and body working – keep on working. Keep ourselves working, muscles and brain’.

Interviewer: ‘Another good reason to stay healthy because you might stop yourself getting dementia later’.

A1: ‘yo, keep good tucker’

G2 also felt that there was perhaps less need for prevention messages and more need for practical strategies to deal with existing behaviours:

‘I haven’t always shown the last section which is on preventing...dementia...because sometimes I think they’ve had a gutful of good food, all of that kind of thing, ...you’re preaching to people who have heard it a thousand times in a lot of different forms...’

The only mention of any technical issue with the resource was in relation to the DVD which didn’t work in all players. The other main suggestions for improvement centered on implementation and the need to overcome barriers as identified elsewhere.

12 Yo = yes in Language
6.9. Uncovering more than anticipated

This study set out to evaluate the resource Looking out for Dementia, to assess its value, effectiveness and the need for targeted approaches to dementia education in remote Indigenous communities. However, while collecting data to this end, other issues were identified that reinforced the need and value of such resources and highlighted the obvious gap in dementia care and related issues in remote Indigenous communities.

Data collection in each remote community, whilst focusing on the evaluation of a specific resource, also revealed something of the consequences of families and workers being uninformed about dementia. Without prompting, Indigenous participants and non-Indigenous facilitators revealed the stresses on families and individuals who were involved in caring for someone with dementia in a remote community:

D3: ‘I know Janie (carer for Molly who has dementia) gets tired but there is a little bit of a conflict. Irene (family member and aged care worker) gets a little bit annoyed with things that Janie doesn’t do and yeah, thinks that she’s not caring for her properly, and not consistent in what she’s been doing and so that’s where we try to help Janie out as much as we can … so I explained to Irene … if Janie wants Molly to stay here for the whole morning, let her stay here. If she wants to go the shop, we’ll take her to the shop, just to give Janie that little bit of a break.’

Some participants (G1, D2, G2) identified the existence of neglect, abuse and fighting that may have been linked to a lack of awareness and understanding of dementia and the resultant failure to seek out services to support carers in the community. Facilitators saw the value of the resource in providing knowledge which they believed helped with neglect and abuse through helping to identify people in the community who may suffer from dementia. The focus group D2 noted that the information provided helped people to understand that individuals who may take things from the shop or from others are not in fact stealing, but showing symptoms that require care and support. One participant of this focus group identified the need to tell community members ‘…not to get too rough with them’.

The lack of services, lack of collaboration and the lack of general awareness was implicated in the unacceptable state in which many older people and/or those with a disability (including dementia), are left in some remote Indigenous communities (G1). The impact of such deficits in services and responses place unsustainable pressures on already overburdened remote communities.

The unanticipated findings related to the stress and potential harm show the value of a simple educational resource such as the Looking out for Dementia DVD and associated discussions, as summed up here:

G2: ‘…because their families were quite confused as well and seemed to neglect them because they didn’t know what to do with them when they had these little episodes, and they found it quite strange, not knowing that person they used to know anymore. So it’s been a great support in the community as well as the aged care facility’.
L-R Chrissy Marfleet, Yvonne Woods, Samantha Woods, Michelle Huddleston, Susan Daniels, Gwen Rami

*All photos used with permission*
7. Discussion

*Looking out for Dementia* was developed by Alzheimer’s Australia NT to meet a need for targeted, culturally appropriate and accessible education resources for remote Indigenous communities including Indigenous language speakers. The process undertaken in the development of the resource was underpinned by cultural safety principles which have also been used to evaluate the resource. Cultural safety principles require service providers to engage in dialogue with their clients, reflect on power relationships and systems that may continue to colonise and disempower already marginalized people, and use reflective processes to minimize the risks associated with dominance and powerlessness (Ramsden 2002; Taylor and Guerin 2010). Issues arose from the findings that consider the influences that help and hinder reflection, dialogue, power and decolonizing practices. These are discussed in relation to the factors identified as critical to successful implementation of the *Looking out for Dementia* resource, with recommendations made for future use and development of this and related resources. These factors relate to:

- Contexts
- Intersectoral collaboration
- Implementation
- Cultural Interface and cultural dissonance
- Suggestions for improvement

The evaluation contributes to a nascent body of knowledge demonstrating that strategies involving caregiver education and training may be of particular benefits in settings where awareness of dementia is low and support from formal services is limited.

7.1. Considering the Context

Any discussion on the impact of a communication tool such as *Looking out for Dementia* needs to include consideration of the context of aged and community care service provision. Pertinent data relating to the context of aged and community care provision in remote communities were provided in some of the interviews and focus groups. We have included some significant quotes here, rather than in the findings sections, because they help to provide context for the discussion to follow.

G1: ‘...there’s a lot of people neglected on communities, older people with just a disability, they’re not catered for. It’s hard to get around community if you’re in a wheelchair, there’s no footpaths, there’s ... no services and they rely on HACC program, they rely on the clinic for that support, and clinic is so busy you know like they’re just flat out...’

G2: ‘...they can't stand up for themselves anymore or they don't have any role in the family or whatever, but ...I was there with somebody who hadn't seen any family for ages and on pension day you can be sure someone comes down and then you've got the problems. Obviously aged care is feeding them but ...they're often not getting the meals. The family are taking them or they've got dog bites cause they're fighting with the dogs for the food and ...they're locked up and they don't see anybody anyway. So ...they're part of a really vulnerable group and you know the fact that when people find out if they don’t want them around there anymore they also, they know...’
now that it means they lose their carer's pension. They don’t have access to the pension, the house might be in the name of the person who’s it is, so it fosters the level of neglect and abuse really because they have other vested interests in keeping that person there and the fact that they want to look after them. Some communities have been really good. ...(in others I see) abuse, give it any name, …. I’m told ‘oh it’s community business or culture business or family business sort of thing’ and I just say ‘that’s rubbish … this is what it is’… but again the system really fosters it. …We had someone taken back from a residential facility when the family found out they were going to lose the carer’s pension and they had trouble with the house so they were ‘kidnapped’ from the facility, and taken back. So, you know it’s a serious issue’.

These observations accord with others reported elsewhere (Lindeman and Pedler 2008) and highlight the challenging context for dementia educators and others who may use the resource. While their mandate is generally for raising awareness of dementia or connecting people with dementia and their carers with appropriate services, the contexts in which they work are often resource-poor and replete with competing priorities for service providers and families. They also reflect in some cases the impact of cultural breakdown and poverty that result in ongoing stress and pressure on families and individuals. Skilled facilitators need to be cognisant of these contexts and ensure their messages and strategies are realistic and appropriate for the individual community. The issue of intersectoral collaboration is particularly crucial and considered separately (below).

7.2. Intersectoral collaboration

One of the most significant factors in maximizing the potential of the dementia resource is the relationship with and interest shown by remote health centre staff. This relationship and interest in most instances was non-existent and/or tied to issues that influence remote health services generally, such as excessive workload, inadequate preparation and on-going professional education of health staff, recruitment and retention challenges and community cohesion. Comments from some participants suggested that there was a tendency to relate dementia issues and awareness as mainly relevant to the aged care sector. The seeming lack of awareness of dementia among remote health staff was emphasised in the findings as a source of great frustration and disappointment that left some staff of aged care centres feeling professionally isolated and unsupported. There was acknowledgement of the shared challenges faced by clinic staff, but a grudging acceptance that there was little opportunity or inclination for intersectoral collaboration in such circumstances. Generally, this evaluation has found that relationships between aged care facilities and remote health clinics were by and large poor in the communities in which the evaluation took place.

A low level of public awareness about dementia reduces the chance of correct identification and management of the behavioural and psychological symptoms of dementia and management within the community (Shaji et al 2009). The apparent low levels of awareness and interest in dementia amongst associated health services such as clinics is suggestive of potential problems in pathways of care for clients and families affected by dementia and is thus worthy of further investigation.

7.3. Implementation

Looking out for Dementia is effective in raising awareness of dementia within remote Indigenous communities. However, the success of the resource in achieving its aims is somewhat dependent on
effective implementation and dissemination including factors such as a strong level of intercommunity and intersectoral collaboration as previously discussed. Other key factors critical to successful implementation includes the target audience and the skills and qualities of the facilitators in using the resource.

### 7.3.1. Target audience

"Aware communities can provide support or at least not stigmatised and exclude those with dementia and those who care for them" (Prince 2009, p.7).

Relatives can frequently misinterpret the behavioural and psychological symptoms of dementia, even as deliberate misbehaviour (Shaji et al 2009). As was evident in the findings, some carers did not recognise their relatives as having dementia. In a group of women at one community, none were able to identify anyone among them who may have had overt symptoms prior to viewing the DVD and subsequent discussions (and in some cases more than one viewing). However, their understanding of dementia and associated behaviours was greatly improved once they had the opportunity of attending the education session. Other participants in the evaluation also offered concrete examples of improved care by aged care workers and informal carers in communities where they had experience of implementing the resource.

As others have noted, a critical mass of informed caregivers can assist awareness-raising, provide advice and support to families, and can contribute to advocacy around the need for more and better services (Prince 2009). *Looking out for Dementia* was found to be appropriate for aged care workers, informal carers, family members and the general community. Although some suggested that the DVD should be shown on a loop at the local health centres, evidence suggests that this strategy would be counterproductive. As a stand alone resource, without other enabling factors in place in individual communities, it may create confusion or become like ‘white noise’.

A considered implementation strategy can maximise the benefits of the information exchange in dementia education by broadening the target audience to include those identified by community members as important to have an improved understanding of dementia. These include schools and health clinics and any other place in the community where people with dementia may have contact. Community elders were said to be most appropriate in determining who should be targeted to receive this education, and thus implementation should be determined on a community-by-community basis.

### 7.3.2. Facilitators

Qualities of facilitators that enabled optimal impact of the resource included an ability to gauge reactions and adapt their approach flexibly, and acknowledgement that relationships may need to be established over time before individuals will approach for more information or advice. Given that dementia educators may not always be in a position to devote this time to being present in communities, it is essential that others in the community have sufficient knowledge about dementia to be able to respond in a positive and supportive way if community members approach them. Again, this suggests an improvement in intersectoral collaboration is needed and broader responsibility for dementia so it is not the exclusive domain of the aged care service.
The dementia educators participating in this evaluation had considerable experience in Indigenous communities and their culturally safe practice reflected the knowledge and wisdom built up over a period of time working in these contexts. The dementia educators demonstrated that they were constantly monitoring responses of participants in their sessions. Even though they spoke no language, the dementia educators were aware of nuances of communications, and generally able to read body language and signals. These intercultural communication skills are critical to the successful implementation of education resources such as Looking out for Dementia, and have obvious implications for any dissemination strategy. Further dissemination of the resource would ideally be accompanied by opportunities for new users of the resource to attend training in cultural safety and intercultural communication.

7.4. Cultural interface and cultural dissonance

Another key finding of particular significance was the impact and relevance of the resource to existing cultural practices. Some participants made connections between cultural practices known as ‘sorry business’ (or mourning protocols) and the growing incidence of dementia. The information provided in this resource had considerable importance to some who felt this information should be shared widely in order to inform cultural and social practices in the future. Football as a preferred social activity was also identified by the participants as a relatively new risk factor that needed to be considered for its impact along with alcohol and other substance misuse. The gap in the information presented in Looking out for Dementia, which has consideration for other targeted resources, is to highlight the relative newness of risks within contemporary remote community contexts to allow the development of appropriate local responses that would minimize risks for dementia.

The ritual of hitting oneself to demonstrate grief sees individuals engaged in ‘sorry business’ at levels never before experienced, multiplying the risks exponentially. Western health professionals often view such traditional Indigenous practices as harmful. When these concerns come face to face with long held cultural beliefs that do not perceive the same risks, but alternatively do perceive risks by not continuing established practices, then health messages may be blocked. During analysis of findings, there was discussion among the evaluation team as to the ethics of providing information that may result in changed cultural practices. The concern was around the potential to continue a harmful colonising process that has been implicated in significant loss of Indigenous cultural practices. However, it was agreed that the changed circumstances of Indigenous peoples’ health and living contexts would make it unethical not to share information about relatively new risks and allow the opportunity for dealing with such information as participants saw fit. From a cultural safety perspective, this resource provides such opportunities if implemented in a culturally safe way. What this resource enabled in one community was an important beginning dialogue that could incorporate new information and identify risk factors that may previously have been unknown. Indigenous people can make decisions about their health that incorporate both Western and their own world views (Folds 2001).

As we have identified, Indigenous world views and health beliefs influence the understanding of information presented. This evaluation suggests that the perception of dementia as a non-medical or simply behavioural issue for some Indigenous people influences the manner in which people with dementia are treated. Developing resources that complement rather than conflict with existing health beliefs and world views is therefore a necessary factor for the uptake of information (Arkles, Jackson Pulver et al. 2010). This is particularly important given the additional exposures to multiple risk factors across life span for cognitive decline and dementia amongst Indigenous populations (Arkles, Jackson Pulver et al. 2010).
Whilst conducting fieldwork for this evaluation, one of the researchers made the observation that the resource could be constructed as ‘Western messages delivered in a cultural way, but essentially still a western message’. This resonated within the evaluation team as others had experienced similar cultural dissonance in providing health information cross-culturally. The development of the Looking out for Dementia resource was done with involvement of Indigenous advisors, but this does not preclude the need for ensuring local sensitivities are identified when implementing the resource across different regions. Whilst the communities in which the evaluation took place had no obvious concerns about the graphics used in the resource, Trudgen (2001) has identified risks in using images that may have different cultural interpretations across the country. In an alcohol awareness poster for example, depicting a pregnant woman smoking and drinking with the unborn baby shown within the mother’s womb was acceptable in some communities, but highly offensive in others. The communities involved in this evaluation represented only three major language groups (Kriol, Warlpiri and Djambarrpuynngu), so although the findings suggest consensus about the use of certain images, this should be considered advisedly.

Of particular interest was the finding of a lack of appropriate vocabulary to discuss issues such as dementia within remote Indigenous communities. As knowledge and understanding of dementia as a disease is relatively new and poorly understood in non-Indigenous Australia, it was not surprising that there is no distinction made linguistically in the Northern Territory Aboriginal communities between dementia and any other problem with the head or brain. Few Indigenous participants had heard or used the word ‘dementia’ prior to the resource being introduced, even in cases where individuals with dementia were being cared for within the target communities. An individual whose behaviour was considered abnormal was generically described as ‘crazy’, or by the local Language equivalent of rama-rama or warungka for Warlpiri and other desert groups. Kriol also had no specific word to explain dementia, but the term yu gabarr, meaning ‘you can’t remember’, seems to be a common term used such as by the Aboriginal Interpreter Service and hospital staff in the Katherine region. This gap in the health literacy for remote Indigenous Australians raises the question of how to deal with something that has not previously been articulated and/or conceptualized appropriately and is something worthy of further attention.

7.5. Improvements to Looking out for Dementia

As indicated in the literature review, caregiver literacy and time constraints may hinder the efficacy of written materials. The poster was found to have little impact in promoting awareness, and the flipchart was effective only in well structured information/education sessions (most useful for aged care worker training). A supported, facilitated process for dementia education is superior to a reliance on written materials.

Research has suggested that English may be a barrier to the uptake of information for speakers of an Indigenous First or other language (Cass, Lowell et al. 2002; Taylor 2009). Although the issue of using Indigenous Languages was not clearly resolved, The Looking out for Dementia resource is innovative in its use of Indigenous languages to relay information to the intended audiences. However, rather than relying on the translation to convey all the information needing to be imparted, it enabled a level of trust and appreciation to be established which helped to create the right environment for further discussion and information exchange. Thus, the benefits of including Indigenous languages outweigh the arguments for not doing so.
Further development of this and similar communication resources should consider the benefits of using Indigenous languages but could be more selective about the information that needs to be translated. Some information may be better translated and discussed ‘on-site’ to allow for local interpretations and differences in information uptake and existing knowledge bases. In particular, the ‘prevention’ messages may be misunderstood or dismissed depending on the exposure of community members to other health promotion materials or other factors. Dementia educators and other users of the resource need flexibility in adapting their messages to suit the audience. The most important information to be included in a translated DVD would be the description of dementia and its signs and symptoms, the reasons for changed behaviours and strategies for dealing with changed behaviours. Even here, however, more information needs to be imparted in follow-up discussion sessions to deal with local information requirements and levels of understanding. As the DVD is presently only 16 minutes, the breadth and depth of information is very limited and thus relies on accompanying information/skilled facilitation to a considerable extent.

A relatively small change to the existing resource that would further enhance its effectiveness is the inclusion of all the names of Indigenous people involved in the development of the resource, including interpreters. Again, this helps to create an environment of appreciation, and engagement in education sessions. A reinforcement that all people appearing in the DVD are acting would also be helpful.

Further development of the content of Looking out for Dementia would be enhanced by a systematic collection of feedback from dementia educators and others who regularly use the resource. As such, a mechanism to collect such information routinely could be established that will enhance the ability of AlzANT and other organisations to incorporate feedback from practice into materials development. This type of feedback will, over time, inform the optimal breadth and depth of content that could be incorporated into future versions of the resource.
8. Recommendations and conclusion

From the preceding discussion, several recommendations can be proposed for consideration by policymakers, dementia educators and other with an interest in the use and further development of this and similar communication resources for Indigenous community members. In accordance with the original philosophy behind the development of “Looking Out for Dementia”, further production and dissemination of the existing resource should include the following enhancements:

1. Further translation of the DVD into other Indigenous languages should take place (on the advice of Aboriginal Interpreter Services and in consultation with individual service providers and community representatives) and a limited number only produced in each language to suit language group needs.

2. Further production of the existing resource (without further translation) could be limited to the DVD and the flipchart.

3. All Indigenous people involved in the resource should be named and acknowledged and those appearing in the DVD should be more clearly identified as acting their roles.

4. Training in intercultural communication and cultural safety should be developed and made available for dementia educators who wish to use the resource.

5. A specific training and information strategy should be developed for health professionals and organisations that could have a role in dementia care in Indigenous communities (particularly health clinics) to raise awareness of the resource and how they can assist to support it and maximise outcomes.

6. Each Looking out for Dementia resource distributed by AlzANT in the future should be accompanied by:

   • a feedback and suggestions form so that practice-based information from the field can be incorporated into any further developmental process; and

   • brief written information highlighting key points from this evaluation that will enhance successful implementation (such as target audience, intersectoral collaboration, tips for effective facilitation and so on)

This project evaluated a resource that has been developed specifically for use with Indigenous communities in the Northern Territory. It sought feedback from those using the resource as well as from those targeted by the resource, and included other relevant feedback such as field observations, literature and input from advisors. Information obtained from this evaluation may be used to inform the development of other dementia related resources for culturally diverse groups and/or other health issues for Indigenous Australians.
The responses of the various informants differed in a number of areas. For Indigenous participants of focus groups the resource made a positive contribution to increasing awareness of dementia within their communities. The resource was valued for being locally and culturally relevant and available in local Indigenous languages. Facilitators of the resource implementation however, differed in their assessment of the resource in key areas such as content and dissemination, but there was consensus overall that this resource was an important step toward providing accessible and acceptable information about dementia.

The idea of developing a ‘culturally appropriate’ resource is an admirable one, but one that needs careful consideration of what exactly this may mean. Looking out for Dementia was developed in response to an identified gap in knowledge and awareness among Indigenous populations. This evaluation found that the need was evident and the resource did fill a previously unmet need. Resources that were available for non-Indigenous target audiences were not always useful in settings where intended audiences’ lives and circumstances were unrelated to images presented in more generic resources. The development of this resource adhered to culturally safe principles by ensuring advice, involvement and input from Indigenous people at various stages in the resources development. Key design principles such as incorporating Indigenous Language and localising content, enhanced engagement with the resource. In some instances, the relevant messages conveyed in Looking out for Dementia took several viewings and long periods of reflection to be heard. In others, information was more quickly integrated and absorbed. Importantly, however, knowledge of what dementia is and the symptoms was retained beyond the immediate information session, indicating a long-lasting impact of the resource.

Particularly important messages from the findings in relation to the target audience include, firstly, that dementia awareness needs to be tackled from a ‘whole of system’ perspective and should not be the exclusive domain of aged care services. Strategies that can extend the reach of dementia educators across communities and services are essential to overcoming the age-related perception of dementia and limiting the support and information available to remote community members. Secondly, the way dementia education is delivered to Indigenous communities needs to be mindful of the appropriate people and groups to approach.

This evaluation adds to the body of knowledge around culturally appropriate health education resources through identifying the barriers to and enablers of effective awareness-raising. Overall, Looking out for Dementia has a significant role to play in addressing a gap in the education of Indigenous populations and relevant workforces.
9. References


Buti, T. (1996). After the removal. Submission to the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families, Aboriginal Legal Service of Western Australia (Inc).


