

TITLE PAGE

Title: The role of art centres for Aboriginal Australians living with dementia in remote communities

Running title: Remote art centres and Aboriginal Australians with dementia

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Abstract

Objective

To explore the role art centres in remote communities play for Aboriginal and Torres Strait Islander Australians living with dementia. ‘

Method

A comprehensive literature search was undertaken; with no restrictions on articles regarding year of publication.

Results

Art programs have been found to be of benefit to both people living with dementia and their carers, particularly when programs are administered in environments that are culturally revered. Findings indicate remote art centres play a key role in maintaining traditions, culture, and practices unique to Aboriginal and Torres Strait Islanders, but there is a gap in knowledge regarding how they cater for the needs of people with dementia.

Conclusions

Addressing this gap will be helpful in remote areas where prevalence of dementia is up to five times that of non-Aboriginal people and there are limited health and support services. Further research is required to explore strengths and gaps of current practices.

Key words

- Art
- Aboriginal Australians; Indigenous
- Dementia
- Remote communities

Introduction

Older Aboriginal and Torres Strait Islander Australians (respectfully referred to as Aboriginal people hereafter) play a vital role in the health of their entire communities, including caring for family members, maintaining cultural rights and responsibilities for maintenance of connections to country and providing leadership within their communities [1-3]. Recent studies in the Kimberley [4], New South Wales [5] and the Northern Territory [6] have demonstrated that dementia occurs at up to five times the rate of the general population. The rates within the Aboriginal population are slightly higher in remote compared with regional and urban areas. Dementia also occurs at a significantly younger age of onset in Aboriginal Australians as compared with non-Aboriginal Australians [7].

Improving health literacy regarding preventative measures, early identification and psychosocial approaches to managing symptoms of dementia and providing appropriate support to the individual and those who care for them are vital. With multiple co-morbidities and the complexity of social and economic disadvantage, geographical challenges [7] and cultural differences many Aboriginal Australians experience failure of mainstream services in meeting their needs. In remote communities lack of service availability is also an issue.

Despite these challenges, many Aboriginal people residing in remote communities hold a strong desire to remain living within their community 'on country' to fulfil an integral part of their cultural identity [8-10].

By definition, remote communities are located a long way from significant population centres, and many are located on land owned or managed by Aboriginal Land Councils. Remote Aboriginal communities are diverse, ranging in size from a few families to two thousand people [11]. Despite their diversity, they often have some shared features including the existence of basic services such as a store, a health clinic staffed by nurses (and possibly Aboriginal Health Workers and/or a doctor) an airstrip, and a school. Others include council offices, a facility where Home and Community Care type services are administered, and an art centre.

The term 'art centre' "is used to describe any organisation operating in remote Australia that is owned and controlled by Aboriginal people, where the principle activity is facilitating the production and marketing of arts and crafts" [12]. Almost all are dependent on government funding in addition to the income generated by the production of art and crafts for the commercial market [13]. Art centres are acknowledged as central to the social, cultural and economic wellbeing of many artists and communities [13]. Artists aged over 55 years are estimated to comprise around 30% of the remote artist population [13], while the number with dementia is unknown; the evidence suggests the numbers are likely to be significant [4-7].

In the broader Australian and International community there has been increasing interest programs to support both people living with dementia and those caring for them to remain connected and engaged in their communities. In this paper we have chosen to focus on remote communities where the burden of dementia is highest and explore art centres as a potential player in linking with services to enhance prevention, early intervention and management of symptoms in contexts where services are limited.

Method

A comprehensive search was conducted in 2015. Four databases, including AIATSIS (informit), CINAHL, Medline and PubMed, were searched using a combination of three

groups of key terms: “Aboriginal OR Indigenous”, “dementia”, and “art centre OR arts centre OR art facility OR arts facility OR women centre OR women’s centre”. The search was limited to articles published in English, but there was no restriction on the year of publication. This search yielded no articles.

Given the lack of research in this area, two further searches using the same databases were then conducted to inform the discussion.

The first search was conducted to identify articles on arts centre and Aboriginal and used a combination of two groups of key words: “Aboriginal OR Indigenous”, and “art centre OR arts centre OR art facility OR arts facility OR women centre OR women’s centre”. This search yielded a total of 25 articles, including those from Australia and overseas. The abstracts of these articles were checked and using the inclusion criteria that these articles discussed the role of arts or arts centres for Aboriginal people, four were suitable to inform the discussion .

The second search used a combination of two different groups of key words: “Dementia” and “art centre OR arts centre OR art facility OR arts facility OR women centre OR women’s centre”. This search yielded over 100 articles. Of these, 10 were used to inform the discussion based on the inclusion criterion that they discussed the role of arts or arts centres for people with dementia. We did not assess the quality of the articles arising from these two searches. Additional articles were sourced from the reference lists of these 14 articles and from recommendations provided by the authors..

The papers were grouped into five broad themes according to their focus, and some were allocated to more than one theme: community; health and wellbeing; economic; services and remote context; and connection to country. Individual authors took responsibility for critically reviewing and summarising papers in their allocated theme. These summaries were then combined and provided to all authors for comment. Three authors incorporated the analysis and aggregated the information to form the paper. All authors critically reviewed the drafts of the paper in its entirety and approved the final version.

Results and Discussion

There were no articles about Aboriginal arts centres supporting people living with dementia. Due to the lack of published research, the discussion was drawn from the literature on Aboriginal art centres in remote areas and on the role of arts for people with dementia. Articles informing the discussion comprise of narratives, case studies, prevalence studies, and literature reviews. Where these articles are not directly related to art centres in remote Aboriginal communities, they are often referred to 'arts programs' conducted with the broader community and designed for those living with conditions such as dementia. General arts programs, which may be run through galleries or other community organisations, operate differently and have different goals to art centres. The results, however, suggest there may be some synergies that can be drawn when considering opportunities to support those living with dementia in the future.

Remote context

Remote communities are diverse in nature [14] due their physical location, sometimes complex environment [15] social structure and history. They are sparsely populated [9] with communities ranging in size from about 50 to 2000 people [11] and they are, by definition a long way from other population centres. Welfare dependence [15, 16] and an economy that is based on state provided services [17] has had an impact in terms of the availability of meaningful activities as well as income. Art centres have the potential to provide small scale enterprises which can fulfil both these roles [18, 19].

People living in remote communities tend to have poorer health than those living in metropolitan areas. This is due to the social determinants of health common in more remote regions including limited access to education and employment [9], limited income, poor quality housing [11, 15, 20], limited access to health services [15] and limited access to transport [20, 21]. Most communities have a variety of services located within the community and an even greater number of visiting service providers which means a complex service delivery web. Health services are characterised by having a small number of staff who have high and complex workloads and undertake multiple roles [16, 22] and the quality of communication and collaboration between these services is varied [23, 24].

A primary health care approach is considered the most appropriate service model for health and aged care in all remote communities [22] and must include intersectoral collaboration or

even a 'whole of community' approach to be effective [25]. While art centres can be a valuable collaborative partner in health [18], new conceptual understandings may assist to enhance such collaborative possibilities.

Art provides a way to maintain connections to community and country

In Aboriginal communities, the production of art is widely recognised as an important form of cultural expression of spirituality [26]. This is closely linked to the importance of being 'on country' which remains an important determinant of personal identity, social cohesion and ultimately health [27]. Guerin et al. [28] report that maintaining an attachment to country has a range of positive outcomes that contribute to mental health and wellbeing, these include a sense of identity and belonging. The production of art also facilitates an intergenerational exchange to win "back the hearts and minds of the younger generation to their responsibilities under the Dreaming" [29]. This is a central motive referred to by many painters across remote regions of Australia [30-33]. A painting asserts the specific rights and responsibilities of the painter to produce these images of country. "In Aboriginal communities cultural knowledge is owned collectively rather than individually. While certain people are the senior custodians for particular sites, songs and ceremonies, big cultural decisions must nonetheless be collectively endorsed" [34]^(p20).

Although the outward mode of production of art in art centres has altered from a ritual context to a secular one, the contemporary production of paintings "emerges from, and maintains Aboriginal traditions and practices" [35]. The production of art is noteworthy that in this aspect the production of Aboriginal art is "quintessentially different" from Western art production [35] and as such, the business of art centres in remote communities is quite different to the nature of art programs designed for the broader community. In an examination of data from the National Aboriginal and Torres Strait Islander Social Survey, Dockery [36]^(p315) found that "a stronger attachment to traditional culture is found to be associated with enhanced outcomes across a range of socio-economic indicators". There is thus an opportunity to explore whether art centres offer a uniquely cultural approach to encouraging those with dementia to maintain participation in community life..

Art centres in remote communities

Art centres are places where community members can come together to produce art and simultaneously engage in culture, which reinforces intergenerational learning and validates

cultural practices [13, 37-39]. However the full extent of the value of art centres is probably underestimated [13, 37, 39] and in “the absence of the services and options taken for granted in less remote, better-serviced parts of Australia, Arts Centres create multiple forms of value” [13]^(p7).

Ware [18] reports a wealth of evidence demonstrating the beneficial effects of participation in the production of art for supporting healthy Aboriginal and Torres Strait Islander communities. Activities facilitated by art centres provide a safe place for people to learn new skills, explore and deal with both personal and community trauma and dysfunction, and build social networks. We also know that remote community art centres provide respite and informal care and support for older people in the absence of other social services that may be found in larger settlements [40]. Less well known is the specific contribution to people with dementia and their carers, and how this contribution can be incorporated in the broader role of these centres.

Whilst there was no reference in the literature to supports for people with dementia being provided by art centres, there were many references to the multiple layers of value the centres have to the people living in the community. In a study in remote Western Australia, Cooper et al. [39] noted that an art centre acted as a conduit for other agencies and as such were playing an informal yet important role in an intersectoral approach to delivery of services in the remote context.

Whilst not focusing directly on people with dementia, Allain [16] reports on an initiative in a remote art centre to address mental health related determinants. In drawing on specific examples from participants, Allain reports that the activity gave a sense of purpose, self-worth, improved self esteem, cross generational strengthening of cultural and family values and connecting with country.

At present art centre staff have diverse backgrounds and there is little consensus as to the most appropriate professional categories to suit the role [12]. Their role is highly complex and many tasks fall outside of official duties [13]. Art centre managers are often confronted with work they are not trained or supported to carry out, which is outside the realm of “art business” and can find themselves dealing with personal support of the artists themselves such as negotiating with Centrelink, transporting sick people to access medical care etc. [38], and potentially working with frail older people and people with dementia. The true value of

art centres in areas of community life outside of art business has been, to date, largely unexplored [39].

A recent study conducted in the Anangu Pitjantjatjara Yankunytjatjara Lands explored the health promoting benefits of art centres in this region [41]. The study will go some way towards identifying the social health benefits derived from the process of painting in art centres. The researcher, also an author on the current paper (MM), notes that while people with both physical and cognitive disabilities are included and will always have a place 'at the table' at an art centre, communities did identify that they may require additional inputs to support those with specific health and functional needs. Communities also noted that art centre staff require a greater understanding of these conditions.

Art production as a way to enhance social connection and participation

Arts initiatives have generally been shown to play a role in achieving social inclusion outcomes for disadvantaged individuals, groups and communities, particularly in the provision of interactive contexts in which difficult social issues can be addressed [42]. Research exploring ways to support people living with dementia has confirmed that cross-generational activities (not necessarily related to art-based projects) has beneficial impacts on cognitive functioning, social interaction in general and particularly with children, and psychological health [43]. While there are less conclusive positive results for depression, feelings of usefulness and purpose of life [43], the arguments for encouraging intergenerational interactions remain compelling. An emerging body of research is focusing on the impact of person-centred, creative-expressive arts activities on people with dementia with programs designed to facilitate opportunities to express behaviours of well-being, such as social interest, engagement, and pleasure [44].

There is an inchoate body of evidence globally on the role of arts for people with dementia and their carers. This literature is summarised in three recent reviews, Beard [45], Young et al. [46], and Zeilig et al. [47]. These reviews found that this research is still in its infancy, consisting largely of small-scale studies with methodological limitations in study design and evaluation methods. Most studies also lack a theoretical framework and focus on the short-term effect [45-47]. In spite of these limitations, most reviewed studies report positive effects of art therapies for people living with dementia, such as enhanced cognitive function,

reduction in problematic behaviors, stimulation of memories, enhanced communication, increased confidence, self-esteem, and social participation [45-47].

It is important to highlight that there are currently two contrasting views towards the role of art, with the former considering it as a therapy and focusing on treatment outcomes (such as reduction of symptoms and/or behavioral improvements), whereas the latter considering it as a meaningful activity and focusing on the process [45, 46]. Beard's (2012) research found that the current literature tends to focus on the former and pays little attention to the meaningful aspects of doing art [45]. It was suggested that incorporating subjective well-being into objective biomedical measures "would expand the evidence base and help ensure that those with dementia receive the services they want" [45].

Zeilig et al. [47] highlighted the potential role of museums and art galleries as a location for art therapies for people with dementia because these places are normal public places that are intellectually stimulating and non-stigmatising for social interaction. This view has been supported in more recent art gallery-based studies [48, 49]. Camic et al. [48] identified four key factors for the success of two art gallery-based programs, including: a valued place, intellectual stimulation, social interaction, and changed perceptions. That is, "the art gallery is seen as being a physically valued place that provides intellectual stimulation and offers opportunities for social inclusion that can change how dementia is perceived" [48]^(p1) and participants commented that the art gallery "enabled a sense of normalcy, equality, and personhood" [48]^(p4).

Conclusion

The benefits for Aboriginal people of producing art in remote art centres include a connection to the community, intergenerational exchange, and cultural maintenance..All this has been facilitated in an environment which holds significant social, cultural and economic value. However, no evidence was found that remote art centres have been providing programs to cater particularly for people living with dementia. This gap in knowledge is problematic for remote communities where the prevalence of dementia is up to five times that of the non-Aboriginal population and there are limited health and other support services [4].

Whilst there is no evidence in the literature there is enough evidence to suggest that a significant proportion of their users are older than 55. We can therefore surmise that it is highly likely that art centres are providing support in an informal way, and without any specific training or support. Several implications can be drawn from this including the need to ensure that art centre staff have the skills and knowledge to recognise possible of symptoms of dementia and are aware of referral protocols and care and support pathways.

There has been increasing interest in the role of art programs developed for people living with dementia in the broader population, and it is noteworthy that participants and their families have reported high levels of satisfaction being involved in a program that is conducted in an environment of cultural value that does not hold stigma. Whilst art centres and broader art programs are diverse in their design, context and purpose, there is enough similarity to explore how art centres are supporting people with dementia to participate in their communities and in turn what art programs more broadly can learn from them..

Key points

- There is increasing interest in the role that art programs can play in enhancing the lives of people living with dementia.
- Little is known about the way in which art centres, in remote communities, are supporting Aboriginal people living with dementia.
- Addressing this gap will be helpful in remote areas where the prevalence of dementia is up to five times that of the non-Aboriginal population and there are limited services.
- Art centres are valued places that encourage cultural knowledge transfer and practice, social inclusion and further research is needed to explore the role that art centres are playing in providing holistic support to assist older people living with dementia.

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