BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-013064
Article Type:	Research
Date Submitted by the Author:	17-Jun-2016
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Primary Subject Heading:	Public health
Secondary Subject Heading:	Health services research
Keywords:	Dementia < NEUROLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE, PUBLIC HEALTH

Development of a model of dementia support and pathway for culturally and linguistically diverse communities using co-creation and participatory action research

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Abstract

Objective

To develop an inclusive model of culturally sensitive support, utilising a specialist dementia nurse (SDN), to assist people with dementia from Culturally and Linguistically Diverse (CALD) communities and their carer's to overcome barriers to accessing health and social care services.

Design

Co-creation and participatory action research, based on reflection, data collection, interaction and feedback from participants and stakeholders.

Setting

A SDN model of dementia support, embedded within a home nursing service in Melbourne, Australia was implemented between October 2013 and October 2015.

Participants

People with dementia from CALD backgrounds and their carers and family living in the community setting and expert stakeholders.

Data collection and analysis

Reflections from the SDN, analysis of case notes recording interactions with participants and expert stakeholder opinion informed the design and refinement of the CALD dementia support model and pathway.

Results

Interaction with sixty-two people living with memory loss or dementia from CALD backgrounds, carers or family members receiving support from the SDN and feedback from 13 expert stakeholders from community aged care services, government and consumer advocacy organisations and ethnic community group representatives informed the development and refinement of the CALD dementia model of care and pathway. We articulate the three components of the model: organisational support; the role; and the competencies needed and an

accompanying pathway for use by health professionals delivering care to consumers with dementia from CALD backgrounds.

Conclusions

Our culturally sensitive model of dementia care and accompanying pathway allows for the tailoring of health and social support to assist people from CALD backgrounds their carer's and families to adjust to living with memory loss and remain living in the community as long as possible. The model and accompanying pathway also have the potential to be rolled out nationally for use by health professionals across a variety of health services.

Strengths

- We have developed a culturally appropriate framework for providing support to people with dementia from CALD backgrounds and their carer's and families living in the community. A co-design approach was used to influence the model's development to ensure that it met the needs of CALD community members and included feedback from experts in the field of dementia care and addressing the needs of CALD communities.

- We outline the resources required for an organisation to provide culturally sensitive dementia care, what the specific role of the specialist dementia nurse involves and the attributes and skills required to fulfil the role.

- We also provide a detailed CALD dementia pathway quick reference guide for health professionals.

- Not all participants spoke English and therefore interpreters were used to overcome any language difficulties. The use of interpreters when providing care to people with dementia from CALD backgrounds is in line with the recently released Guideline

Adaptation Committee, Clinical Practice Guidelines and Principles of Care for People with Dementia 2016: Recommendation number 9.

Limitations

- Referrals to local councils for hygiene or domestic assistance could be challenging when trying to find a worker from the same cultural background or who spoke the same language. This could sometimes be overcome by building a trusting relationship with the consumer and negotiating acceptance of an alternative worker or the use of sign cards, basic interpretation sheets or telephone interpreters.

- Although some information and forms were available in languages other than English this was not always the case.

- Although, the SDN was usually able to access culturally appropriate planned activity groups, activities were not always compatible with client needs.

Background

With a rapidly ageing Australian population and a strong preference for older Australian's to remain living in their own homes for as long as possible the development of strong systems of support for all community members are vital [1]. In 2011, there were 200,000 informal carers of people with dementia, in Australia, living in the community [2]. In recognition of the need to relieve the burden on carers both Federal and State Governments provide Home and Community Care (HACC) services to assist with the activities of daily living (ADLs). ADL's can be described as bathing, eating, shopping, toileting, home medication management and home maintenance [3].

Despite the existence of these services, however, there is often a failure to access them [4]. In 2014, Phillipson et al, reported that despite formal community based services being available the use of these services by carers is quite low [5]. In the case of respite this was attributed to the services not meeting carer or care recipient needs or the belief that the service would result in negative outcomes [5]. People from Culturally and Linguistically Diverse Communities (CALD) are particularly at risk of not utilising services due to the numerous barriers they face accessing healthcare services [6]. Often this is due to difficulties with language, approximately 16% of the Australian population speak a language other than English at home [6], and a lack of knowledge of health care service systems. Currently, in Australia, there are limited language and culture specific supports for people with dementia and their carers and a shortage of culturally appropriate assessments [7]. This deficit is a major impediment to the accurate diagnosis and treatment of dementia, consequently diagnosis of dementia in CALD communities often occurs in the later stages of the disease as first contact with health professionals most often happens at crisis point [4][8]. Factors that have been identified as impacting on early detection of dementia in older people from Asian backgrounds in addition to a lack of CALD appropriate diagnosis tools and services, is level of dementia literacy, symptom interpretation and dementia related stigma [9]. It has been also been purported that health services need to consider language, religious belief and observance, cultural practices (including food handling and personal care practices), social support and coping mechanisms during service provision [10]. Studies have also found that perceived cultural sensitivity in relation to health care leads to greater satisfaction with health care providers and also influences adherence to treatment and better health outcomes [4].

Models of support utilising a ‘support worker’ have been developed and implemented both in Australia and overseas to assist people and their carers to adjust to living with memory loss and functional decline. Support workers are workers who are usually skilled in assessment and able to provide ongoing support to someone with a cognitive impairment and their families and carers. The support worker role also provides assistance with navigation of the health and aged care system, accessing of services, information and support, and advocating between health professionals, services and service uses [11]. However, few support worker models address the needs of those from culturally and linguistically diverse (CALD) communities [12].

Culturally sensitive health care has previously been described as ‘the ability to be appropriately responsive to the attitudes, feelings, or circumstances of groups that share a common and distinctive racial, national, religious, linguistic or cultural heritage’ [13] in a manner that is relevant to clients needs and their expectations [14]. This project aimed to establish and refine a culturally sensitive model of dementia support and accompanying pathway through the implementation of a Specialist Dementia Nurse (SDN) to act as an advocate, navigator and strategist for the culturally and linguistically diverse (CALD) person with cognitive impairment living in the community and their family or carer and most at risk of adverse dementia outcomes.

Methods

We developed an inclusive model of consumer-directed community-based dementia care and dementia care pathway that uses culturally appropriate assessment tools [15] and reaches individuals, the family and carers from CALD backgrounds.

Study design

Theoretical framework

Our qualitative study utilised a co-creation and participatory action research (PAR) approach [16]. The increasing move to re-design health care systems around patients' needs influenced the choice to use a co-creation and participatory action approach to developing an effective clinical model of support and pathway based on patients' experiences and expert stakeholder opinion [17][18]. PAR in this instance was based on reflection, data collection, interaction with participants and feedback from stakeholders in a cyclical manner throughout the duration of the study [16].

Participant and stakeholder selection

Stakeholders representing community aged care services, government, consumer advocacy and ethnic community groups were selected purposively. People from CALD backgrounds experiencing difficulties with memory loss or dementia over 65 years of age who were living in the community, or their families and carers receiving support from the SDN program. Community nurses providing care to people with dementia from CALD backgrounds made referrals to the SDN and details of the service were also disseminated to other health services, ethnic communities, local government, radio interviews and announcements and advertisements were placed in Ethnic specific newsletters. Information about the service was also made available when presenting the study at dementia related conferences. Participants who were unable to speak English were not excluded and interpreters were made available to anyone who needed this service. People with cognitive impairment undergoing palliative care or experiencing psychiatric issues were excluded. The SDN used a capacity checklist together with expert knowledge and assessment skills to determine the ability to consent to participation.

Settings

The SDN role was embedded within a not-for-profit home nursing service, that provides support to a large number of community dwelling people with cognitive impairment including many from CALD backgrounds in Melbourne, Victoria. The SDN was integrated into normal services and was available for all clients from a CALD background experiencing memory problems and/or their carers and family members. The program was not, however, limited to the organisations clients and any one fitting the criteria was able to access it. The intervention was conducted over a two year period between October 2013 and October 2015.

Data Collection

Case notes

The SDN recorded case notes, describing interactions with each participant and using reflective practice methods [19] to document experiences and observations following each client visit.

Expert reference group meetings

The expert stakeholder reference group members met together with the research team on four occasions throughout the duration of the study. Initially, to contribute to a proposed model of dementia care that would address current service delivery gaps, review functions and establish competencies and then thereafter to provide feedback on the implementation of the new model, identify any remaining gaps in service delivery and contribute to the CALD dementia pathway.

Data Analysis

The SDN reflections and case note data was presented to the expert stakeholders for discussion at each reference group meeting. The final model of CALD dementia care developed by the SDN and the research team in conjunction with the reference group informed the content of the CALD dementia care model and accompanying pathway quick reference cards (see figure 2).

Ethics approval

Ethics approval to conduct the study was obtained from the Royal District Nursing Service Human Research Ethics Committee. All participants provided written informed consent prior to being interviewed.

Results

Participants

Thirteen stakeholders representing community aged care services, government, consumer advocacy and ethnic community groups were engaged as members of an expert reference group. Sixty-two people (41 female, 21 male) received support from the SDN. The average age of participants was 69 ± 14 years. The majority of participants, 36 were people from CALD backgrounds living with dementia or memory loss 15 were family members and 11 identified themselves as carers (table 1). Fourteen participants were from Italian backgrounds. Other ethnicities were Maltese (n = 8), Vietnamese (n = 7), Turkish (n=7), Greek (n=6), German (n=6), Burmese (n=4), Chinese (n= 3), Iraqi (n=2), Dutch (n=2), Australian (n=2) Hungarian (n=1) and Nepalese (n=1) (See table 1).

Specialist Dementia Nurse reflections on the type and frequency of support needed

The SDN identified that many participants lacked the confidence or knowledge to overcome barriers or may have had bad experiences in the past when accessing health care services and recognised that advocating for the client, their family and carers was paramount to the success of them achieving their goals and enabling them to live well at home. The SDN implemented a variety of interventions tailored to meet individual needs of CALD consumers. Interventions included: brochures translated into their own language; information on Forward Planning; accessing local council home care and personal hygiene services; incontinence advice; referral to consumer and carer advocacy groups; community assessment services; behavioural management services; music therapy; assistance in accessing financial reimbursements; aids and assistive technology. While all participants were provided with information brochures in their own language, 33 participants were provided referrals to Alzheimer's Australia Victoria and 25 to Carer's Victoria for further information. The SDN provided in-home strategies or advice to 34 participants including advice on incontinence and resolving unmet needs. The overall number of interactions between the SDN and the 62 participants was 406 (see table 1 for details on interventions and interactions). Interactions consisted of a combination of face to face visits and telephone contact. Support from the SDN was provided on an 'as needs based service' and participants could step in and out of the service as required. There was no time or length of service restrictions. No participants exited the service due to dissatisfaction or needs not being met.

Components of the Specialist Dementia Nurse Model

The SDN and the expert stakeholders identified an overarching framework and three components of the SDN model based on analysis of case notes and the SDNs self-reflections, as being required to facilitate the implementation of a culturally sensitive SDN model. The over arching framework consists of culturally appropriate assessments, referral and linking; a diversity framework with guidelines, policies and education and understanding and acceptance of difference cultures [20].

The three components of the model that were identified are: organisational support, the support worker role and the competencies required to undertake the role ie. attributes, skills and knowledge. (see figure 1). Each component of the model is discussed in turn below.

1. What resources does an organisation need to provide?

Resources required to support the implementation of the SDN model for CALD communities include access to office space, a mobile telephone, computer, a dedicated vehicle and interpreters. Facilitation of access to specialised services and other organisations with expert dementia knowledge and skills, ongoing professional development and education opportunities including attendance at conferences, seminars and relevant education is also essential as is the availability of debriefing and counselling (see figure 1).

2. What does the Specialist Dementia Nurse Role entail?

The SDN role needs to have sufficient autonomy and flexibility to allow for the tailoring of support to assist people from CALD backgrounds their carer's and families. The SDN provides assistance to navigate the aged and health care service systems, provides culturally appropriate information to assist people with dementia and their caring unit to adjust to living with memory loss by increasing their understanding of dementia and the need for forward care planning, identify unmet needs and provide in-home strategies to manage change in behaviour to improve the quality of life of people with dementia and reduce carer strain, obtain culturally appropriate assessment and diagnosis and act as an advocate when necessary (see figure 1).

3. What knowledge, skills and attributes does a Specialist Dementia Nurse need?

Implementation of the Specialist Dementia Nurse role revealed that in order to meet the needs of consumers and provide person-centred care the SDN role required the ability to build trusting professional relationships, excellent assessment abilities, an in-depth knowledge of dementia, excellent interpersonal, listening skills, and advocacy skills and an acceptance and understanding of different cultures and strong leadership skills (see figure 1).

Development of the CALD Dementia Care Pathway

A set of quick reference cards, to be used in conjunction with a consumer directed care approach to care and based on the SDN model, was designed to be used as a point of reference for health professionals undertaking a support worker type role in CALD communities.

The CALD dementia care pathway quick reference cards provide an outline of steps to consider prior to meeting with the client, engaging with the client, taking a clients history in a culturally appropriate manner, culturally appropriate assessment tools, goal setting and care planning, monitoring and review, exit planning, details of the diversity model and where to find further information, support and resources (see figure 2).

Discussion

This study articulates a framework for providing support to people with dementia, from CALD backgrounds, and their families and carers. The inclusion of stakeholders in the co-creation of a culturally sensitive model of dementia support and accompanying pathway has provided a means by which to appropriately respond to the attitudes, feelings and circumstances that are relevant to client needs and expectations and address the inequities currently faced by CALD communities. The effectiveness of our person-centred inclusive model of community based health and social care for CALD communities was demonstrated by the uptake of numerous community support services including aged care assessments, planned activity groups and respite care, an area previously reported as having low uptake [5].

A systematic review of support worker interventions for people with dementia and or their carers reported on 36 models of support for people with dementia and or their carer's, however, only four of the models were provided to people from CALD backgrounds [21]. As three of the four models identified provided support to Chinese people with dementia and /or their caregivers living in Hong Kong they cannot be considered as culturally or linguistically diverse models of care [22-24]. Therefore, only one of the papers, by Boughtwood et al, actually reported on a CALD model of support for people with dementia and their families/caregivers living in the community setting in the Australia [25]. The model reported on by Boughtwood et al, focused on the experiences and perceptions regarding workers perspectives on the dynamics and management of family care-giving for dementia in CALD communities and how this influenced decisions made about family caregiving [25]. Three main themes: cultural and familial norms pertaining to illness and older people; understanding and naming the term carer and patterns in family care giving were identified [25]. A number of sub-themes were also identified these included: keeping dementia in the family; being judged by the community; women as carers; children carers; spousal carers and family sharing care which demonstrated the expectations that elderly people would be cared for by one or more family members [25].

Our novel model of dementia support provides a significant contribution to the literature as it is the first such model specifically developed for people with dementia from CALD backgrounds living in the community setting. The accompanying CALD Dementia Care Pathways quick reference cards also provide a valuable reference for health professionals providing care to people with dementia from CALD backgrounds.

Conclusions

The Specialist Dementia Nurse model of care and CALD dementia care pathway addresses current health care system service gaps by providing culturally and linguistically diverse communities with health and social care services that are culturally appropriate. There is potential for this consumer directed model to improve the wellbeing of persons with dementia and their carer's and family members from minority, vulnerable groups and assist them to adjust to living with memory loss. Embedding this persons-centred culturally appropriate model of care into health services nationally would provide equitable access to vital services that enables CALD communities members across Australia to remain living at home as long as possible.

Funding:

Funding for this project was proudly provided by the Lord Mayors Charitable Foundation

Acknowledgments

We would like to acknowledge the contribution of participants, all members of the expert reference group and Senior Dementia Advisor Ms Fleur O'Keefe.

Authors contributions

DG & SK conceived and initiated the study. JK undertook the role of the Specialist Dementia Nurse. DG,JK undertook the data collection, DG, JK & SK undertook the data analysis and the final drafting of the article and revised it for critical content, approved the final version of the paper and accept accountability for all aspects of the work. JK and DG developed and refined the CALD Dementia Care Pathway.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Data Sharing

No additional data is available

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Fig 1: CALD Specialist Dementia Nurse Model

Table 1: Participant Characteristics number of interactions and interventions

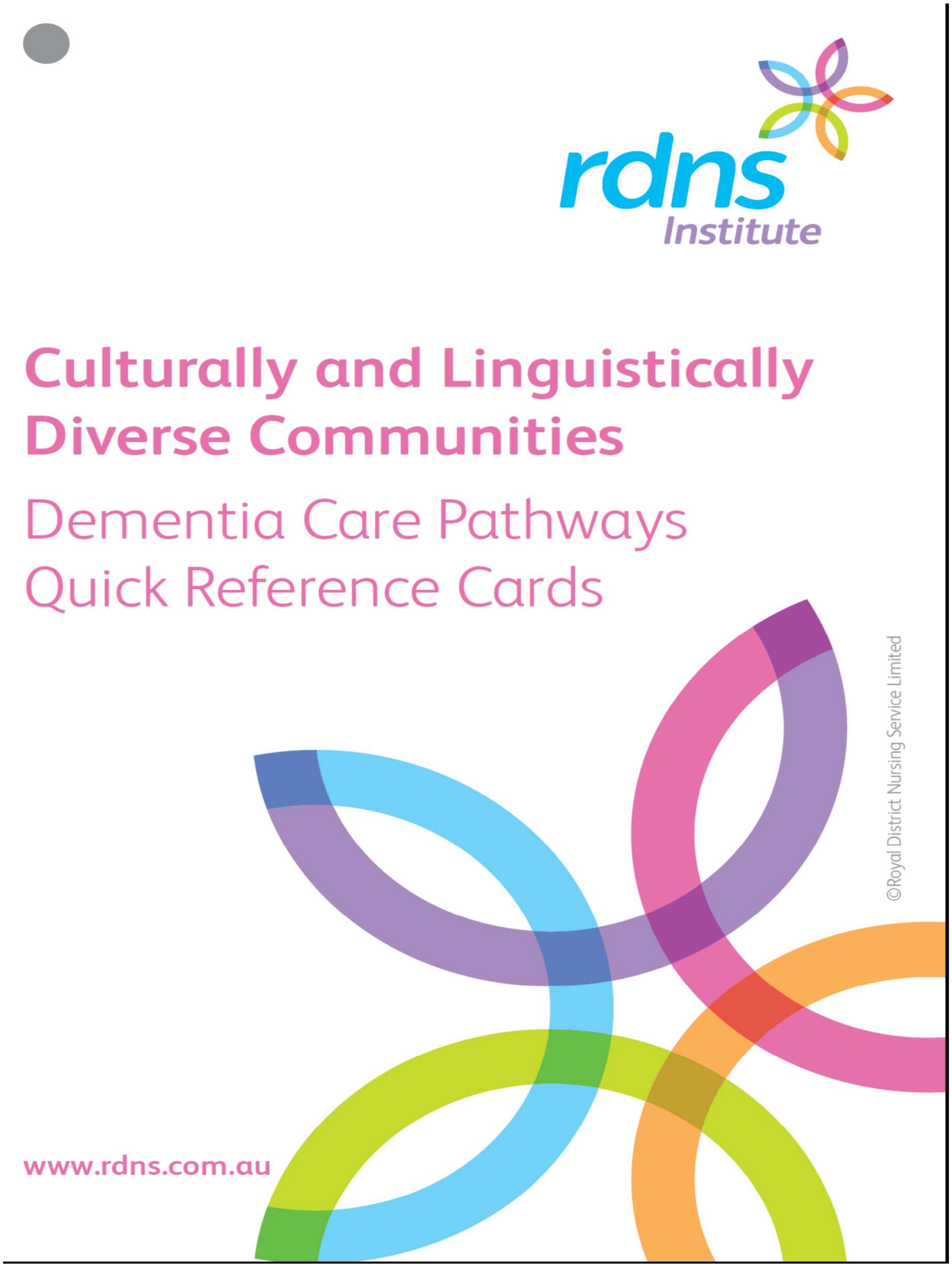
Clien	Age	Gender	Ethnicity	Participant Ty	Number Interactions	Brochuresres	Forward Planning	Hygeine Assistance	Domstic Assistance	Alzheimer's Australia	Carer's Victoria	Respite Services	Music Therapy	Planned Activity Group	DBMAS	ACAS	CDMAS/ geriatrician	SDN in-home strategies	Centrelink
1	33	Female	Italian	Family	10	✓	✓			✓		✓		✓	✓			✓	
2	43	Male	Iraqi	Family	2	✓				✓	✓								
3	44	Female	Maltese	Family	6	✓	✓			✓	✓	✓		✓	✓		✓	✓	
4	46	Female	Italian	Carer	24	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓
5	46	Female	Vietnamese	Carer	7	✓				✓	✓			✓		✓	✓	✓	✓
6	47	Female	Turkish	Family	6	✓	✓	✓	✓	✓	✓	✓							
7	48	Female	Italian	Family	4	✓					✓		✓						
8	48	Female	Maltese	Family	6	✓	✓			✓	✓	✓		✓	✓		✓	✓	
9	51	Female	Burmese	Family	1	✓				✓	✓							✓	
10	52	Female	Maltese	Family	5	✓					✓								✓
11	52	Male	Maltese	Family	4	✓				✓	✓	✓						✓	✓
12	53	Female	Greek	Family	2	✓					✓							✓	
13	53	Female	Italian	Carer	2	✓					✓							✓	
14	54	Female	German	Family	5	✓	✓		✓	✓	✓	✓	✓	✓		✓		✓	
15	57	Female	Greek	Carer	3	✓					✓	✓							
16	61	Female	Turkish	Family	7	✓				✓									
17	61	Male	Turkish	Family	8	✓				✓	✓								
18	62	Female	Italian	Carer	48	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
19	65	Female	Burmese	Consumer	1	✓				✓									
20	65	Male	Vietnamese	Consumer	2	✓				✓									
21	66	Male	Italian	Consumer	47	✓	✓	✓		✓		✓	✓	✓		✓	✓	✓	
22	66	Female	Iraqi	Consumer	1	✓												✓	
23	66	Male	Australian	Family	4	✓				✓	✓								
24	69	Female	German	Consumer	4	✓				✓			✓	✓		✓		✓	
25	70	Male	German	Family	1	✓			✓	✓	✓		✓	✓		✓		✓	
26	72	Female	Italian	Carer	18	✓	✓				✓					✓		✓	
27	72	Female	German	Consumer	4	✓	✓				✓								
28	72	Female	Dutch	Consumer	6	✓												✓	
29	72	Female	Maltese	Consumer	7	✓				✓								✓	
30	72	Male	Italian	Consumer	3	✓				✓							✓		
31	73	Male	Hungarian	Consumer	4	✓										✓			
32	73	Female	Maltese	Carer	4	✓					✓							✓	
33	74	Female	Chinese	Consumer	5	✓	✓							✓				✓	
34	75	Female	Vietnamese	Carer	10	✓	✓			✓	✓	✓			✓		✓		
35	75	Female	Australian	Carer	8	✓	✓			✓	✓	✓						✓	
36	76	Male	Maltese	Consumer	4	✓				✓									
37	77	Female	Burmese	Consumer	2	✓												✓	
38	78	Female	Italian	Consumer	4	✓													
39	78	Male	Italian	Consumer	12	✓	✓	✓		✓						✓	✓	✓	
40	78	Male	German	Consumer	2	✓													
41	78	Male	Dutch	Consumer	8	✓	✓											✓	

42	78	Male	Maltese	Consumer	4	✓	✓												
43	78	Female	Nepalese	Consumer	3	✓								✓				✓	
44	80	Female	Greek	Consumer	3	✓				✓									
45	80	Male	Burmese	Consumer	2	✓												✓	
46	80	Female	Turkish	Consumer	3	✓				✓				✓				✓	
47	81	Female	Italian	Consumer	6	✓		✓											
48	81	Female	Chinese	Carer	8	✓	✓				✓	✓				✓			
49	81	Female	Vietnamese	Consumer	2	✓				✓									
50	82	Male	Italian	Consumer	4	✓												✓	
51	82	Female	Vietnamese	Consumer	6	✓	✓							✓					
52	83	Male	Greek	Consumer	3	✓												✓	
53	83	Female	Italian	Carer	6	✓				✓	✓	✓						✓	
54	84	Female	German	Consumer	7	✓			✓										
55	84	Male	Italian	Consumer	2	✓				✓									
56	84	Female	Vietnamese	Consumer	4	✓	✓												
57	84	Male	Turkish	Consumer	5	✓												✓	
58	85	Female	Greek	Consumer	4	✓				✓									
59	87	Male	Chinese	Consumer	8	✓	✓									✓		✓	
60	87	Female	Turkish	Consumer	4	✓				✓									
61	88	Female	Greek	Consumer	3	✓				✓								✓	
62	88	Male	Vietnamese	Consumer	8	✓	✓							✓				✓	
		Total				**62**	**21**	**5**	**5**	**33**	**25**	**14**	**6**	**15**	**6**	**12**	**9**	**34**	**5**

Legend:

A	Brochures	H	Music Therapy
B	Forward Planning	I	Planned Activity Groups
C	Local Council - Hygeine Assistance	J	Dementia Behaviour Management Services (DBMAS)
D	Local Council - Domestic Assistance	K	Aged Care Assessment Services (ACAS)
E	Alzheimer's Australia	L	Cognitive Decline & Memory Services (CDAMS) / Geriatrician
F	Carer's Victoria	M	SDN In-home strategies
G	Respite Services	N	Centrelink (Access to financial assistance/carer payment)

Figure 2: CALD Dementia Care pathway



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Culturally and Linguistically Diverse Communities

Dementia Care Pathways
Quick Reference Cards

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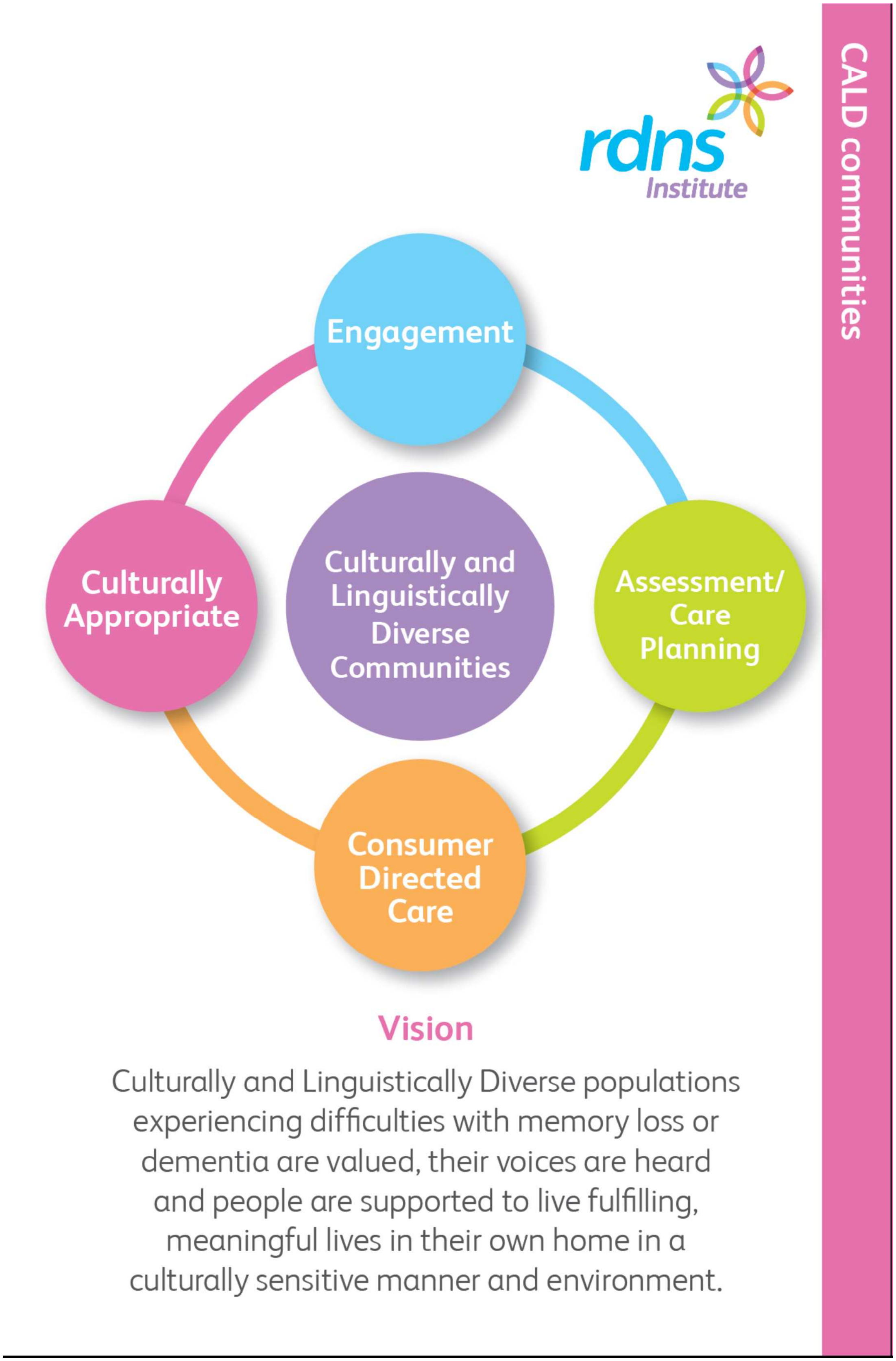

Vision

Culturally and Linguistically Diverse populations experiencing difficulties with memory loss or dementia are valued, their voices are heard and people are supported to live fulfilling, meaningful lives in their own home in a culturally sensitive manner and environment.

CALD communities

This set of Quick Reference Cards is designed to provide an on-the-spot point of reference for health professionals and care staff to care for people from Culturally and Linguistically Diverse backgrounds who may have signs of memory loss or have a diagnosis of dementia.

The cards are intended to be used in conjunction with a Consumer Directed Care (CDC) approach to care; being mindful that getting to know the individual, is fundamental to the provision of high quality care. You can find more information on CDC here **www.cshisc.com.au/media/295440/Consumer_directed_care_booklet_FINAL_web_version.pdf**

These quick reference cards are provided as a guide only. It is recommended that the resources on which they are based, listed on the cards, be referred to for more comprehensive and detailed information.

This resource has been devised by the RDNS Institute through a study 'Dementia care in the community – Access for CALD Communities' with funding for this project proudly provided by the Lord Mayor's Charitable Foundation.

Home and Community Care (HACC) services provided by RDNS are jointly funded by both the Victoria and Australia Governments.

Prior to client meeting

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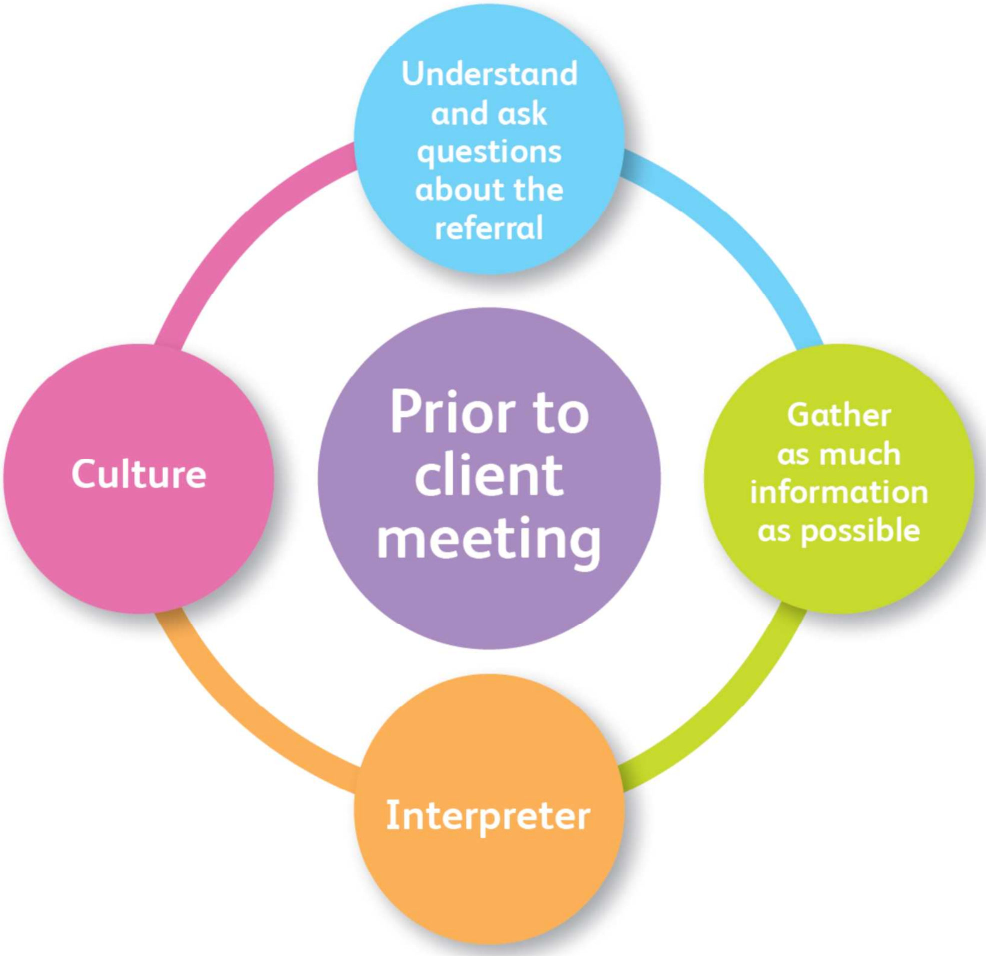

Understand and ask questions about the referral

Culture

Prior to client meeting

Gather as much information as possible

Interpreter

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Prior to meeting with a client for the first time

Prior to meeting with a client, their family or carers it is important to:

- Ascertain from the referral service or worker what they understand to be the needs and issues facing the client/family/carers and why they are making the referral.
- Ask the referral service or worker what assessments or background information they may have already collected, and whether they can share that information with you, to avoid duplicating assessments and questions that may have already been obtained.
- Organise a professional interpreter where appropriate (see **www.multicultural.vic.gov.au/images/stories/documents/2014/omac%20using%20interpreting%20services%20guidelines%20on%20policy%20and%20procedures%20online.pdf** for information on using interpreting services).
- If possible ascertain what culture the client may identify as and familiarise yourself with their cultural customs and beliefs. This will help you to be culturally appropriate during your visit (information on different cultures can be found here **www.culturaldiveristy.com.au/resources/practice-guides/cultural-awareness**).

Use information about specific cultures as a guide only, it is always important to identify individual needs and preferences. Within any culture, peoples' values, behaviour and beliefs can vary enormously.

If after meeting with the client, their family and carers you would like to make a referral to another agency, seek the client's permission to make contact and consent to disclose information and what they referral is for.

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Client engagement

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Client engagement

The clinician must always be attentive, responsive and respectful. Clients from CALD backgrounds must feel that the person they are engaging with is friendly, knowledgeable, helpful, approachable and most of all trustworthy. It is vital to build trusting professional relationships with the Client's family and carers, and also be culturally aware and appropriate. Ways in which you can build a trusting relationship with CALD client, their families and carers:

- Always treat people with respect
- Allow plenty of time when visiting clients, do not rush, building this relationship may take time
- Always use a qualified interpreter when required, briefing the interpreter on the situation prior to entering the clients home
- Avoid using family members or carers to provide interpreting as this may be counterproductive to the information you are seeking
- If you tell the client you are going to do something, make sure you follow through
- Conduct assessments in an informal and friendly manner with minimal use of forms and computers
- Be transparent and predictable, providing options whenever possible (e.g. where to meet, asking if they would like you to take your shoes off or close the door when entering their home).

- Explain your job using simple terms (avoid jargon or acronyms) and what you can offer by providing examples
- Explain the concept of confidentiality in clear, simple terms as well as limitations of confidentiality in relation to your duty of care. This may be a new concept to your clients
- Ask permission of the client if you can take notes, and offer to share what you have written, this will enable them to remain in control and reduce their anxiety about people accessing their information
- Explain the purpose of any assessments and forms, and why you need to document information, what will be documented, where it will be kept, and who will have access to it and how it may be used
- If after meeting with the client, their family and carers you would like to make a referral to another agency, seek the client's permission to make contact and consent to disclose information and what the referral is for.

Culturally appropriate history taking

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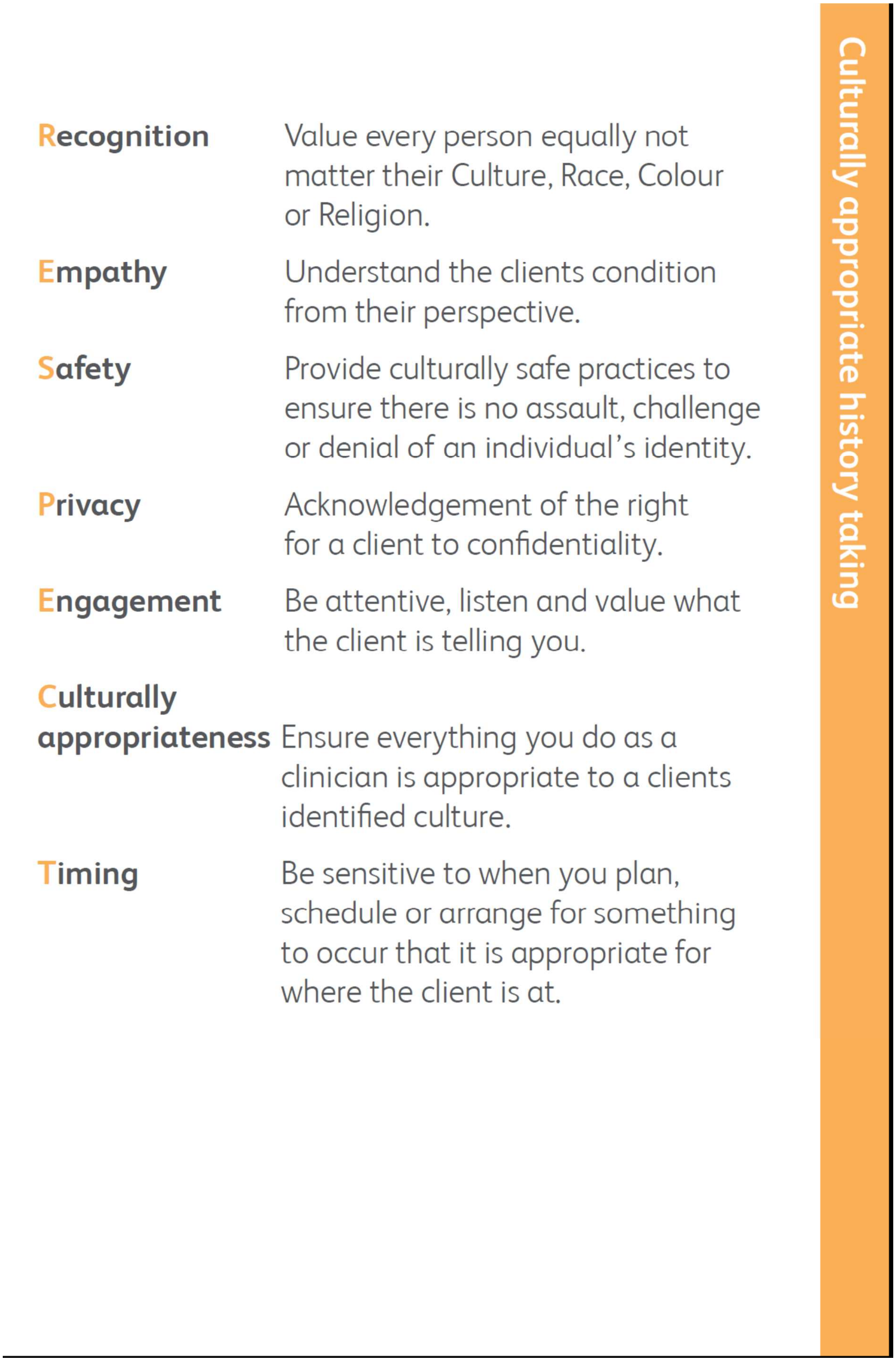
Culturally appropriate history taking

A thorough client history will form the foundation of the assessment process. The same information that you would normally gather for an English speaking client needs to be gathered for a non-English speaking client. However, you may need to allow extra time for this process with this group of clients and the history taking needs to be culturally appropriate and sensitive. Sensitivity will need to be given to issues such as trauma, war experiences, migration, family separation and education level.

The Respect tool may help in the appropriate use of assessment instruments and history taking.



Culturally appropriate history taking

Recognition	Value every person equally not matter their Culture, Race, Colour or Religion.
Empathy	Understand the clients condition from their perspective.
Safety	Provide culturally safe practices to ensure there is no assault, challenge or denial of an individual's identity.
Privacy	Acknowledgement of the right for a client to confidentiality.
Engagement	Be attentive, listen and value what the client is telling you.
Culturally appropriateness	Ensure everything you do as a clinician is appropriate to a clients identified culture.
Timing	Be sensitive to when you plan, schedule or arrange for something to occur that it is appropriate for where the client is at.

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Assessment Tools

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Assessment tools

Assessments also provide opportunity to understand your client's needs, strengths, resources, co-morbidities and goals as well as their housing, finance, social and family supports and existing relationships with other service providers.

During the assessment you will also have opportunity to explore their cultural identity and cultural needs.

The essential function of an assessment is to understand the client on their own terms, this includes:

- How they perceive **their** needs, problems and issues
- The solution **they** want
- The goals **they** would like to achieve
- The resources **they** feel they can draw on
- They strengths that **they** can draw on
- **Their** perception of their own deficits, barriers and limitations that could influence them reaching their desired goals and outcomes.

The Rowland Universal Dementia Assessment Scale (RUDAS) is a short cognitive screening instrument that is designed to minimise the effects of cultural learning and language diversity on the assessment of baseline cognitive performance.

Whilst the RUDAS instrument is considered one of the most appropriate tools for assessing baseline cognitive performance, clinicians must also determine:

- When to administer an assessment tool
- Who is qualified to administer it
- Who is qualified to interpret the score
- What to do with the results

Referral should be made to the local CDAMS or ACAS team for assessment and diagnosis.

There are guidelines available to assist with screening and diagnostic assessments of non-English speaking people with dementia available here:

https://fightdementia.org.au/sites/default/files/20101224-Nat-CALD-Screening Guidelines-07May.pdf.

Information of the RUDAS scoring, interpretations and actions are included with the scale (see the RUDAS information at **www.dementia-assessment.com.au/cognitive/index.html#rudas** for further information).

Goal setting & care planning

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Goal setting and Care Planning

When goal setting within care planning it is important that this is undertaken with the client, their family and carers to ensure it reflects the clients own expressed care and cultural needs. This will also ensure that all members of the team are working towards the same goals with the same expectations.

Goal Setting

- Allow time for family and carers to also express their goals and needs (this is vital in ensuring the client is well cared for and supported)
- Identify and prioritise realistic goals together, ensuring the goals highlight their strengths
- Give the client the opportunity to express what they would like to achieve, they may wish to do this by talking, writing, drawing or showing you photos or items
- Discuss possible options and opportunities that are culturally appropriate and available to assist with ensuring the client's goals can be achieved
- Identify gaps that you may need to fill whilst waiting for service providers to become engaged as you may find waiting lists for some services
- Review goals regularly with the client as these can change frequently.

Care Planning

- Ensure care plans align with the goals set with the client
- The care plan should target interventions to assist people to maximise and enhance their independence, choice and quality of life and minimise support required, enabling people to remain active and involved in their own health, wellbeing and participation in the communities
- Care planning must incorporate culturally appropriate interventions
- Include what family and carers needs are (this may incorporate a separate care plan for their needs)
- Timeframes should be incorporated into care plans to ensure progress and regular review of care plans will ensure the client's needs are being met in a timely and culturally appropriate manner.

Monitoring and review

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Involve family and carers

Communicate with all team members

Monitoring and review

Goal and needs being met

Having goals changed

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Care Plan monitoring and review

Care plan monitoring enables the clinician to re-evaluate the status of a client, their goals and needs and the interventions and services currently in place to address those needs.

It will enable evaluation of the progress towards the goals identified by the client, their family and carers and assess whether the provided interventions and services are being utilised and implemented in accordance with the care plan, including cultural appropriateness, and determine whether problems in service delivery require changes to the goal, care plan or service. Evaluation of a clients status will also allow for new goals, strategies and interventions to be put in place should new and emerging issues arise.

The frequency of monitoring varies depending on the intensity of the client needs and the type of services being provided.

What might trigger care plan reviews?

- Communication for client/family regarding changes to client need
- Feedback from support workers through service delivery observation
- Scheduled date for review

Reviews allow time for reflecting with the person on their progress towards their goals.

You may wish to ask the client these questions during the review:

- Are the interventions or services meeting your needs?
- Has it met your expectations?
- Are the goals we initially spoke about still meaningful and achievable?
- Do you want to alter a care plan to better suit your needs?

If changes to care plans do occur it is important that the adjustments are communicated to other people or agencies involved in using that care plan.

Case Study example

Mr L. and his wife Regina, have always been involved in their local community and until late have been active members of the Greek Senior Citizen's Club. Following some decline in memory over the past few years, Mr L. was seen by a Geriatrician and diagnosed with Alzheimer's disease.

Mr L. has continued to decline cognitively and his wife is concerned for his safety and she has no support. They have no children, and are unsure who may be able to help them. They do not want to go into residential care.

The coordinator from the Greek Senior Citizen's club made contact with them as they had not been attending to make sure they were well, as they had not been attending. Regina told the coordinator that Mr. L is not doing so well, that he has reverted to speaking Greek and he is having problems with incontinence and not sure how to get help.

The coordinator contacted RDNS for an assessment of Mr L. as well as provision of support and information. A nurse visited Mr L. and Regina at their home with a Greek interpreter to assist in communicating with Mr L. Mr L. was very suspicious as to why someone was visiting them and did not want to communicate.

The nurse was able to talk to Mr L. about other things such as his home in Greece, what he used to do for a job and about his garden. This enabled the nurse to build a rapport with Mr L. and eventually over a few visits he became trusting enough to speak about the difficulties he was experiencing.

Over the coming visits, assessments were performed, and goals and care planning started to take shape. Mr L. and Regina was very specific about what assistance they required. They both wanted a male to assist with showering Mr L. and needed guidance on incontinence issues. Mr L. stated that he didn't want to go to the Senior Citizen's Club as he was frightened of soiling his pants in public. The goals were agreed on and care plans devised.

Over the coming months Mr L. was being showered three times a week by a male care attendant. Toileting regimes and continence appliances were sourced along with funding. This enabled Mr L. to rejoin the Senior Citizen's Club confident that if he had an accident it would not be noticed by anyone.

Regina was put in contact with Carer's Victoria for guidance and counselling about how to best look after herself. Alzheimer's Australia were notified of the situation and Mr L. and Regina now attend cafe groups to meet people in the same situation and share and listen to others stories.

When the care plan was reviewed Mr L. and Regina were much better positioned to access suitable health care services when they needed to. Regina has contacted the council and now has someone once a week to help with cleaning the house.

Exit planning

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Review goals

Is the client managing without your help

Clients perception of health status

Do not rush this process

Exit planning

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Exit planning

Exit plans should always contain the following:

- Measurement of change in health status
- Satisfaction with service
- Perception on improved quality of life
- Review of goals
- Referral to other agencies if further support is required.

It is important to never rush this stage; you do not want the client, family or carers to feel abandoned or alone.

The client, family and carers should be educated to help identify early warning signs as needs change over time and a relapse care plan for them to use may be of use including contact details of services to contact should they require assistance.

Always make sure that they know how to contact you if they need further guidance or support.

Always provide follow up with a phone call to monitor the situation as needs may change and further assessments, guidance or support may be required.

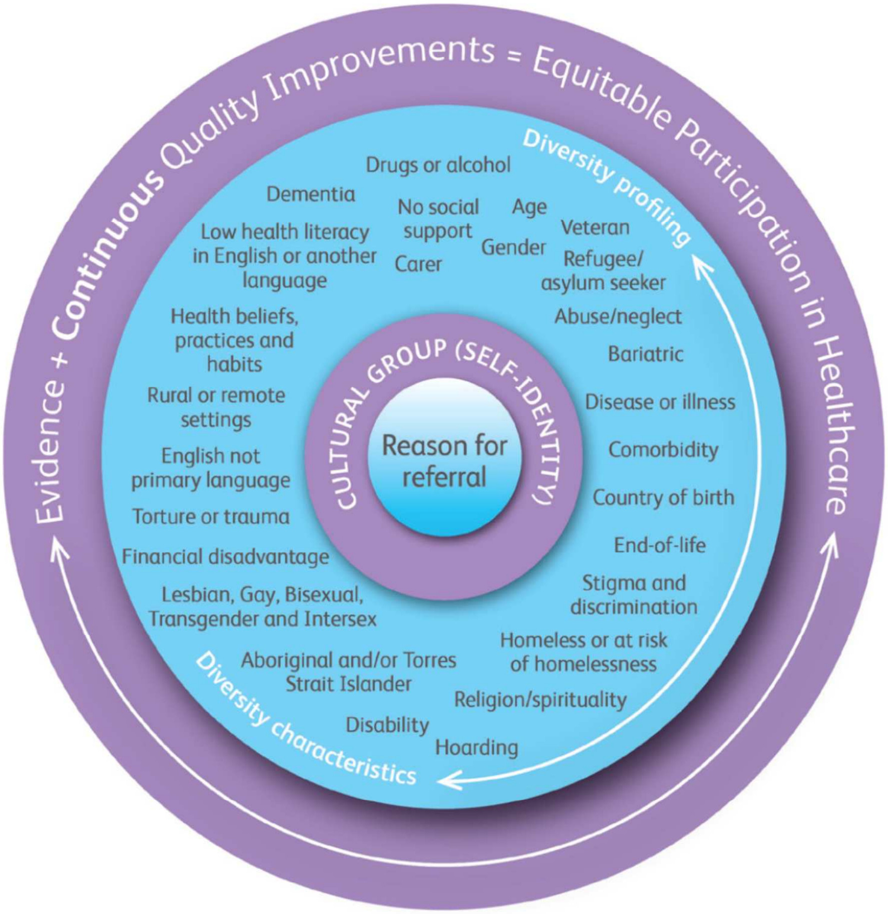
Some of the things that show they may be ready to exit from support:

- They have met all the goals they set out
- They are managing their goals without your assistance
- They feel they do not require further assistance
- Family and carers are happy and managing their situation well.

RDNS Diversity Conceptual Model

The Diversity Conceptual Model supports thinking about Diversity at RDNS. It assists RDNS to think, understand and solve problems associated with client and population diversity and possible associations with disadvantage.

The model encourages use of evidence and continuous quality improvements to inform and create opportunities for more equitable participation in healthcare and wellbeing through policy, planning and practice.



Further information and support

Further information and support

The below organisations may useful when working with clients from Culturally and Linguistically Diverse Communities.

Alzheimer's Australia **www.fightdementia.org.au**

Australian Multicultural Community Services
www.amcservices.org.au

Australian Multicultural Foundation **www.amf.net.au**

Carers Australia **www.carersaustralia.com.au**

Centre for Cultural Diversity in Ageing
www.culturaldiversity.com.au

Centre for Culture, Ethnicity & Health **www.ceh.org.au**

Centrelink **www.humanservices.org.au**

Cognitive Dementia and Memory Service
www.health.vic.gov.au/subacute/cdams.htm

Community Migrant Resource Centre **www.cmrc.com.au**

Council of the Ageing **www.cota.org.au**

Dementia Behaviour Management Advisory Service
www.dbmas.org.au

Department of Health **www.health.gov.au**

Federation of Ethnic Communities' Councils of Australia
www.fecca.org.au

Health Translations **www.healthtranslations.vic.gov.au**

My Aged Care **www.myagedcare.com.au**

Office of the Public Advocate Victoria
www.publicadvocate.vic.gov.au

RDNS **www.rdns.com.au**

Translating and Interpreting Service **www.tisnational.com.au**

BMJ Open

Development of a model of dementia support and pathway for culturally and linguistically diverse communities using co-creation and participatory action research

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-013064.R1
Article Type:	Research
Date Submitted by the Author:	05-Oct-2016
Complete List of Authors:	Goeman, Dianne; Royal District Nursing Service, RDNS Research Institute King, Jordan; Royal District Nursing Service, RDNS Institute Koch, Susan; La Trobe University, Division of Research, Faculty of Health Sciences; University of Sydney, Medical School
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health services research
Keywords:	Dementia < NEUROLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PRIMARY CARE, PUBLIC HEALTH

Development of a model of dementia support and pathway for culturally and linguistically diverse communities using co-creation and participatory action research

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Abstract

Objective

To develop an inclusive model of culturally sensitive support, utilising a specialist dementia nurse (SDN), to assist people with dementia from Culturally and Linguistically Diverse (CALD) communities and their carers to overcome barriers to accessing health and social care services.

Design

Co-creation and participatory action research, based on reflection, data collection, interaction and feedback from participants and stakeholders.

Setting

A SDN support model embedded within a home nursing service in Melbourne, Australia was implemented between October 2013 and October 2015.

Participants

People experiencing memory loss or with a diagnosis of dementia from CALD backgrounds and their carers and family living in the community setting and expert stakeholders.

Data collection and analysis

Reflections from the SDN on interactions with participants and expert stakeholder opinion informed the CALD dementia support model and pathway.

Results

Interaction with sixty-two people living with memory loss or dementia from CALD backgrounds, carers or family members receiving support from the SDN and feedback from 13 expert stakeholders from community aged-care services, consumer advocacy organisations and ethnic community group representatives informed the development and refinement of the CALD dementia model of care and pathway. We delineate the three components of the ‘SDN’ model: the organisational support; a description of the role; and the competencies needed. Additionally,

we provide an accompanying pathway for use by health professionals delivering care to consumers with dementia from CALD backgrounds.

Conclusions

Our culturally sensitive model of dementia care and accompanying pathway allows for the tailoring of health and social support to assist people from CALD backgrounds their carers and families to adjust to living with memory loss and remain living in the community as long as possible. The model and accompanying pathway also have the potential to be rolled out nationally for use by health professionals across a variety of health services.

Strengths and limitations of the study

- A co-design approach, utilising feedback from people with dementia, their carers and families and experts in the field, was used to influence the development of a model of support for people experiencing memory loss or with dementia from CALD backgrounds and their carers and families living in the community, to ensure that it addressed their needs.
- We outline the resources required for an organisation to provide culturally sensitive dementia care, what the specific role of the specialist dementia nurse involves and the attributes and skills required to fulfil the role.
- We also provide a detailed CALD dementia pathway quick reference guide for health professionals.
- Despite the development of a CALD model of dementia support and pathway barriers to culturally appropriate home support services and planned activity groups meant that in some cases available services and activities were not always compatible with need.
- While this indepth qualitative study led to the development of a model of support for people experiencing memory loss or with dementia from CALD backgrounds, in order to provide a strong evidence base we recommend that our model be further tested by a wider scale evaluation utilising a randomised controlled trial design.

Background

With a rapidly ageing Australian population and a strong preference for older Australians to remain living in their own homes for as long as possible the development of strong systems of support for all community members are vital [1]. In 2011, it was estimated that there were approximately 200,000 informal carers of people with dementia, in Australia, living in the community [2]. In recognition of the need to relieve the burden on carers both Federal and State Governments provide Home and Community Care (HACC) services to assist with the activities of daily living (ADLs). ADLs can be described as bathing, eating, shopping, toileting, home medication management and home maintenance [3].

Despite the existence of these services, however, there is often a failure to access them [4]. In 2014, Phillipson et al. reported that despite formal community based services being available the use of these services by carers is quite low [5]. In the case of respite this was attributed to the services not meeting carer or care recipient needs or the belief that the service would result in negative outcomes [5]. People from Culturally and Linguistically Diverse Communities (CALD) are particularly at risk of not utilising services due to the numerous barriers they face accessing healthcare services [6]. Often this is due to difficulties with language, approximately 16% of the Australian population speak a language other than English at home [6], and a lack of knowledge of healthcare service systems. Currently, in Australia, there are limited language and culture specific supports for people with dementia and their carers and a shortage of culturally appropriate assessments [7]. This deficit is a major impediment to the accurate diagnosis and treatment of dementia; consequently, diagnosis of dementia in CALD communities often occurs in the later stages of the disease as first contact with health professionals most often happens at crisis point [4][8]. Factors that have been identified as impacting on early detection of dementia in older people from Asian backgrounds in addition to a lack of CALD appropriate diagnosis tools and services, is the level of dementia literacy, symptom interpretation and dementia related stigma [9]. It has been also been purported that health services need to consider language, religious belief and observance, cultural practices (including food handling and personal care practices), social support and coping mechanisms during service provision [10]. Studies have also found that perceived cultural sensitivity in relation to healthcare leads to greater satisfaction with health care providers and also influences adherence to treatment and better health outcomes [4].

Models of support utilising a 'support worker' have been developed and implemented both in Australia and overseas to assist people and their carers to adjust to living with memory loss and functional decline [11,12]. Support workers are workers who are usually skilled in assessment and able to provide ongoing support to someone with a cognitive impairment and their families and carers. The support worker role also provides assistance with navigation of the health and aged-care system, accessing of services, information and support, and advocating between health professionals, services and service users [11,12]. However, few support worker models address the needs of those from culturally and linguistically diverse (CALD) communities [12].

Culturally sensitive health care has previously been described as 'the ability to be appropriately responsive to the attitudes, feelings, or circumstances of groups that share a common and distinctive racial, national, religious, linguistic or cultural heritage' [13] in a manner that is relevant to clients' needs and their expectations [14]. This project aimed to establish and refine a culturally sensitive model of dementia support and accompanying pathway through the implementation of a Specialist Dementia Nurse (SDN) role to act as an advocate, navigator and strategist for the culturally and linguistically diverse (CALD) person with cognitive impairment living in the community and their family or carer and most at risk of adverse dementia outcomes.

Methods

We developed an inclusive model of consumer-directed community-based dementia care and dementia care pathway (see figures 1 and 2) that uses culturally appropriate assessment tools [15] and reaches individuals, the family and carers from CALD backgrounds.

Study design

Theoretical framework

Our qualitative study utilised a co-creation and participatory action research (PAR) approach [16]. PAR is an approach to research that includes the involvement of the community that is being researched in order to understand their world and to ensure that research outcomes are appropriate to identified needs [16]. The increasing move to re-design healthcare systems around patients' needs influenced the choice to use a co-creation and participatory action approach to developing an effective clinical model of support and pathway based on patients' experiences and expert stakeholder opinion [17][18]. PAR in this instance was based on reflection, data collection, interaction with participants and feedback from stakeholders in a cyclical manner throughout the duration of the study [16].

Participant and stakeholder selection

Stakeholders representing clinical and community aged-care services (Senior Clinical Dementia Nurses, Occupational Therapist/Manager - Cognitive Decline Memory Clinic, Home Nursing Service Site Managers, Aged Care Assessors, Diversity) government, consumer advocacy and ethnic community groups were selected purposively to ensure the inclusion of adequate expertise in the delivery of high quality dementia care and CALD appropriateness. People from CALD backgrounds, experiencing difficulties with memory loss or with a formal diagnosis of dementia over 65 years of age who were living in the community, and their families and carers were eligible. Community nurses providing care to people with dementia from CALD backgrounds made referrals to the SDN and details of the service were also disseminated through other health services, ethnic communities, local government, radio announcements and advertisements were placed in Ethnic specific newsletters. Information about the service was also made available when presenting the study at dementia related conferences. Participants who were unable to speak English were not excluded from the study and interpreters were made available to anyone who needed this service. People with cognitive impairment undergoing palliative care or experiencing psychiatric issues that the SDN identified as impacting on their ability to provide consent were excluded. The SDN used a capacity checklist together with expert knowledge and assessment skills to determine the ability to consent to participation.

Settings

The SDN role was embedded within a not-for-profit home nursing service, that provides support to a large number of community-dwelling people with cognitive impairment from CALD backgrounds in Melbourne, Victoria. The SDN was integrated into normal services and was available for all clients from a CALD background experiencing memory problems or dementia and/or their carers and family members. The program was not, however, limited to the organisations' clients and any one fitting the criteria was able to access it. The intervention was conducted over a two year period between October 2013 and October 2015.

Data Collection and Analysis

Asessment and Care Planning

The SDN undertook assessment and care planning activities with each participant in line with the usual home nursing service current best practice model. The SDN also recorded case notes, describing interactions with each participant and using reflective practice methods [19] to document experiences and observations following each client visit.

Expert reference group meetings

The expert stakeholder reference group members met together with the research team on four occasions throughout the duration of the study. Initially, to contribute to a proposed model of dementia care that would address current service delivery gaps, review functions and establish competencies and then thereafter to provide feedback on the implementation of the new model, identify any remaining gaps in service delivery and contribute to the CALD dementia pathway (see figure 3).

The SDN reflections and case note data were presented to the expert stakeholders for discussion at each reference group meeting. The SDN and the research team worked closely with members of the expert reference group throughout the study to develop and refine the CALD dementia care model and accompanying pathway quick reference cards (see figure 1 and 2).

Ethics approval

Ethics approval to conduct the study was obtained from the Royal District Nursing Service Human Research Ethics Committee.

Results

Participants

Thirteen stakeholders representing community aged-care services, government, consumers, consumer advocacy and ethnic community groups were engaged as members of an expert reference group.

Sixty-two people (41 female, 21 male) received support from the SDN. The average age of participants was 69 ± 14 years. The majority of participants(n = 36/62) were people from CALD backgrounds living with dementia or memory loss. Fifteen were family members and 11 identified themselves as carers (table 1). Fourteen participants were from Italian backgrounds. Other ethnicities were Maltese (n = 8), Vietnamese (n = 7), Turkish (n=7), Greek (n=6), German (n=6), Burmese (n=4), Chinese (n= 3), Iraqi (n=2), Dutch (n=2), Australian (n=2) Hungarian (n=1) and Nepalese (n=1) (see table 1).

Specialist Dementia Nurse assessment and care plan: reflections on the type and frequency of support needed

The SDN identified that many participants lacked the confidence or knowledge to overcome barriers or may have had bad experiences in the past when accessing health care services and recognised that advocating for the client, their family and carers was paramount to the success of them achieving their goals and enabling them to live well at home. The SDN implemented a variety of interventions tailored to meet individual needs of CALD consumers. Interventions included: brochures translated into their own language; information on Forward Planning; accessing local council home care and personal hygiene services; incontinence advice; referral to consumer and carer advocacy groups; community assessment services; behavioural management services; music therapy; assistance in accessing financial reimbursements; aids and assistive technology. While all participants were provided with information brochures in their own language, 33 participants were provided referrals to Alzheimer's Australia Victoria and 25 to Carers Victoria for further information. The SDN provided in-home strategies or advice to 34 participants including advice on incontinence and resolving unmet needs. The overall number of interactions between the SDN and the 62 participants was 406 (see table 1 for details on interventions and interactions). Interactions consisted of a combination of face to face visits and telephone contact. Support from the SDN was provided on an 'as needs based service' and participants could step in and out of the service as required. There was no time or length of service restrictions. No participants exited the service due to dissatisfaction or their needs not being met.

Components of the Specialist Dementia Nurse Model

The SDN and the expert stakeholders identified an overarching framework and three components of the SDN model based on analysis of case notes and the SDN's self-reflections, as being required to facilitate the implementation of a culturally sensitive SDN model. The over arching framework consists of culturally appropriate assessments, referral and linking; a diversity framework with guidelines, policies and education and understanding and acceptance of difference cultures [20].

The three components of the model that were identified are: organisational support needed, the detail of the support worker role and the competencies required to undertake the role ie. attributes, skills and knowledge (see figure 1). Each component of the model is discussed in turn below.

1. *Organisational Support required to support the SDN model?*

Resources required to support the implementation of the SDN model for CALD communities include access to office space, a mobile telephone, computer, a dedicated vehicle and interpreters. Facilitation of access to specialised services and other organisations with expert dementia knowledge and skills, ongoing professional development and education opportunities including attendance at conferences, seminars and relevant education is also essential as is the availability of debriefing and counselling (see figure 1).

2. *What does the Specialist Dementia Nurse Role entail?*

The SDN role needs to have sufficient autonomy and flexibility to allow for the tailoring of support to assist people from CALD backgrounds their carers and families. The SDN provides assistance to navigate the aged and health care service systems, provides culturally appropriate information to assist people with dementia and their caring unit to adjust to living with memory loss by increasing their understanding of dementia and the need for forward care planning, identify unmet needs and provide in-home strategies to manage change in behaviour to improve the quality of life of people with dementia and reduce carer strain, obtain culturally appropriate assessment and diagnosis and act as an advocate when necessary (see figure 1).

3. *What knowledge, skills and attributes does a Specialist Dementia Nurse need?*

Implementation of the Specialist Dementia Nurse role revealed that in order to meet the needs of consumers and provide person-centred care the SDN role required the ability to build trusting professional relationships, excellent assessment abilities, an in-depth knowledge of dementia, excellent interpersonal, listening skills, and advocacy skills and an acceptance and understanding of different cultures and strong leadership skills (see figure 1).

Development of the CALD Dementia Care Pathway

A set of quick reference cards, to be used in conjunction with a consumer directed care approach to care and based on the SDN model, was designed to be used as a point of reference for health professionals undertaking a support worker type role in CALD communities (see figure 2).

The CALD dementia care pathway quick reference cards provide an outline of steps to consider prior to meeting with the client, engaging with the client, taking the client's history in a culturally appropriate manner, culturally appropriate assessment tools, goal setting and care planning, monitoring and review, exit planning, details of the diversity model and where to find further information, support and resources (see figure 2).

Discussion

This study delineates a framework for providing support to people with dementia, from CALD backgrounds, and their families and carers. The inclusion of consumers and expert stakeholders in the co-creation of a culturally sensitive model of dementia support and accompanying pathway has provided a means by which to appropriately respond to the attitudes, feelings and circumstances that are relevant to client needs and expectations and address the inequities currently faced by CALD communities.

The effectiveness of our person-centred inclusive model of community based health and social care for CALD communities was demonstrated by the uptake of numerous community support services including aged-care assessments, planned activity groups and respite care, an area previously reported as having low uptake [5].

Additionally, our model of support developed for people with dementia from CALD backgrounds and their families and carers is innovative. A systematic review of support worker interventions for people with dementia and or their carers undertaken by the study authors, revealed that out of 36 models of support for people with dementia and or their carers, only four of the models were provided to people from CALD backgrounds [12]. As three of the four models identified provided support to Chinese people with dementia and /or their caregivers living in Hong Kong they cannot be considered as culturally or linguistically diverse models of care [21-23]. Therefore, only one of the papers, by Boughtwood et al, actually reported on a CALD model of support for people with dementia and their families/caregivers living in the community setting in the Australia [24]. This model reported on by Boughtwood et al. however, focused on the experiences and perceptions regarding workers perspectives on the dynamics and management of family care-giving for dementia in CALD communities and how this influenced decisions made about family care-giving [24]. Three main themes: cultural and familial norms pertaining to illness and older people; understanding and naming the term carer and patterns in family care giving were identified [24]. A number of sub-themes were also identified these included: keeping dementia in the family; being judged by the community; women as carers; children carers; spousal carers and family sharing care which demonstrated the expectations that elderly people would be cared for by one or more family members [24].

Our novel model of dementia support provides a significant contribution to the literature as it is the first such model specifically developed for people with dementia from CALD backgrounds living in the community setting. The accompanying CALD Dementia Care Pathways quick reference cards also provide a valuable reference for health professionals providing care to people with dementia from CALD backgrounds.

Conclusions

The Specialist Dementia Nurse model of care and CALD dementia care pathway addresses current healthcare system service gaps by providing culturally and linguistically diverse communities with health and social care services that are culturally appropriate. There is potential for this consumer directed model to improve the wellbeing of persons with dementia and their carers and family members from minority, vulnerable groups and assist them to adjust to living with memory loss. Embedding this persons-centred culturally appropriate model of care into health services nationally would provide equitable access to vital services that enables CALD communities members across Australia to remain living at home as long as possible.

Funding:

Funding for this project was proudly provided by the Lord Mayors Charitable Foundation

Acknowledgments

We would like to acknowledge the contribution of participants, all members of the expert reference group and Senior Dementia Advisor Ms Fleur O'Keefe.

Authors contributions

DG & SK conceived and initiated the study. JK undertook the role of the Specialist Dementia Nurse. DG,JK undertook the data collection, DG, JK & SK undertook the data analysis and the final drafting of the article and revised it for critical content, approved the final version of the paper and accept accountability for all aspects of the work. JK and DG developed and refined the CALD Dementia Care Pathway.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Data sharing

No additional data available

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Table 1: Participant Characteristics number of interactions and interventions

Clien	Age	Gender	Ethnicity	Participant Ty	Number Interactions	Brochuresres	Forward Planning	Hygeine Assistance	Domstic Assistance	Alzheimer's Australia	Carer's Victoria	Respite Services	Music Therapy	Planned Activity Group	DBMAS	ACAS	CDMAS/ geriatrician	SDN in-home strategies	Centrelink
1	33	Female	Italian	Family	10	✓	✓			✓		✓		✓	✓			✓	
2	43	Male	Iraqi	Family	2	✓				✓	✓								
3	44	Female	Maltese	Family	6	✓	✓			✓	✓	✓		✓	✓		✓	✓	
4	46	Female	Italian	Carer	24	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓
5	46	Female	Vietnamese	Carer	7	✓				✓	✓			✓		✓	✓	✓	✓
6	47	Female	Turkish	Family	6	✓	✓	✓	✓	✓	✓	✓							
7	48	Female	Italian	Family	4	✓					✓		✓						
8	48	Female	Maltese	Family	6	✓	✓			✓	✓	✓		✓	✓		✓	✓	
9	51	Female	Burmese	Family	1	✓				✓	✓							✓	
10	52	Female	Maltese	Family	5	✓					✓								✓
11	52	Male	Maltese	Family	4	✓				✓	✓	✓						✓	✓
12	53	Female	Greek	Family	2	✓					✓							✓	
13	53	Female	Italian	Carer	2	✓					✓							✓	
14	54	Female	German	Family	5	✓	✓		✓	✓	✓	✓	✓	✓		✓		✓	
15	57	Female	Greek	Carer	3	✓					✓	✓							
16	61	Female	Turkish	Family	7	✓				✓									
17	61	Male	Turkish	Family	8	✓				✓	✓								
18	62	Female	Italian	Carer	48	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
19	65	Female	Burmese	Consumer	1	✓				✓									
20	65	Male	Vietnamese	Consumer	2	✓				✓									
21	66	Male	Italian	Consumer	47	✓	✓	✓		✓		✓	✓	✓		✓	✓	✓	
22	66	Female	Iraqi	Consumer	1	✓												✓	
23	66	Male	Australian	Family	4	✓				✓	✓								
24	69	Female	German	Consumer	4	✓				✓			✓	✓		✓		✓	
25	70	Male	German	Family	1	✓			✓	✓	✓		✓	✓		✓		✓	
26	72	Female	Italian	Carer	18	✓	✓				✓					✓		✓	
27	72	Female	German	Consumer	4	✓	✓				✓								
28	72	Female	Dutch	Consumer	6	✓												✓	
29	72	Female	Maltese	Consumer	7	✓				✓								✓	
30	72	Male	Italian	Consumer	3	✓				✓							✓		
31	73	Male	Hungarian	Consumer	4	✓										✓			
32	73	Female	Maltese	Carer	4	✓					✓							✓	
33	74	Female	Chinese	Consumer	5	✓	✓							✓				✓	
34	75	Female	Vietnamese	Carer	10	✓	✓			✓	✓	✓			✓		✓		
35	75	Female	Australian	Carer	8	✓	✓			✓	✓	✓						✓	
36	76	Male	Maltese	Consumer	4	✓				✓									
37	77	Female	Burmese	Consumer	2	✓												✓	
38	78	Female	Italian	Consumer	4	✓													
39	78	Male	Italian	Consumer	12	✓	✓	✓		✓						✓	✓	✓	
40	78	Male	German	Consumer	2	✓													
41	78	Male	Dutch	Consumer	8	✓	✓											✓	

42	78	Male	Maltese	Consumer	4	✓	✓												
43	78	Female	Nepalese	Consumer	3	✓								✓				✓	
44	80	Female	Greek	Consumer	3	✓				✓									
45	80	Male	Burmese	Consumer	2	✓												✓	
46	80	Female	Turkish	Consumer	3	✓				✓				✓				✓	
47	81	Female	Italian	Consumer	6	✓		✓											
48	81	Female	Chinese	Carer	8	✓	✓				✓	✓				✓			
49	81	Female	Vietnamese	Consumer	2	✓				✓									
50	82	Male	Italian	Consumer	4	✓												✓	
51	82	Female	Vietnamese	Consumer	6	✓	✓							✓					
52	83	Male	Greek	Consumer	3	✓												✓	
53	83	Female	Italian	Carer	6	✓				✓	✓	✓						✓	
54	84	Female	German	Consumer	7	✓			✓										
55	84	Male	Italian	Consumer	2	✓				✓									
56	84	Female	Vietnamese	Consumer	4	✓	✓												
57	84	Male	Turkish	Consumer	5	✓												✓	
58	85	Female	Greek	Consumer	4	✓				✓									
59	87	Male	Chinese	Consumer	8	✓	✓									✓		✓	
60	87	Female	Turkish	Consumer	4	✓				✓									
61	88	Female	Greek	Consumer	3	✓				✓								✓	
62	88	Male	Vietnamese	Consumer	8	✓	✓							✓				✓	
		Total				**62**	**21**	**5**	**5**	**33**	**25**	**14**	**6**	**15**	**6**	**12**	**9**	**34**	**5**

Legend:

A	Brochures	H	Music Therapy
B	Forward Planning	I	Planned Activity Groups
C	Local Council - Hygeine Assistance	J	Dementia Behaviour Management Services (DBMAS)
D	Local Council - Domestic Assistance	K	Aged Care Assessment Services (ACAS)
E	Alzheimer's Australia	L	Cognitive Decline & Memory Services (CDAMS) / Geriatrician
F	Carer's Victoria	M	SDN In-home strategies
G	Respite Services	N	Centrelink (Access to financial assistance/carer payment)

Fig 1: CALD Specialist Dementia Nurse Model

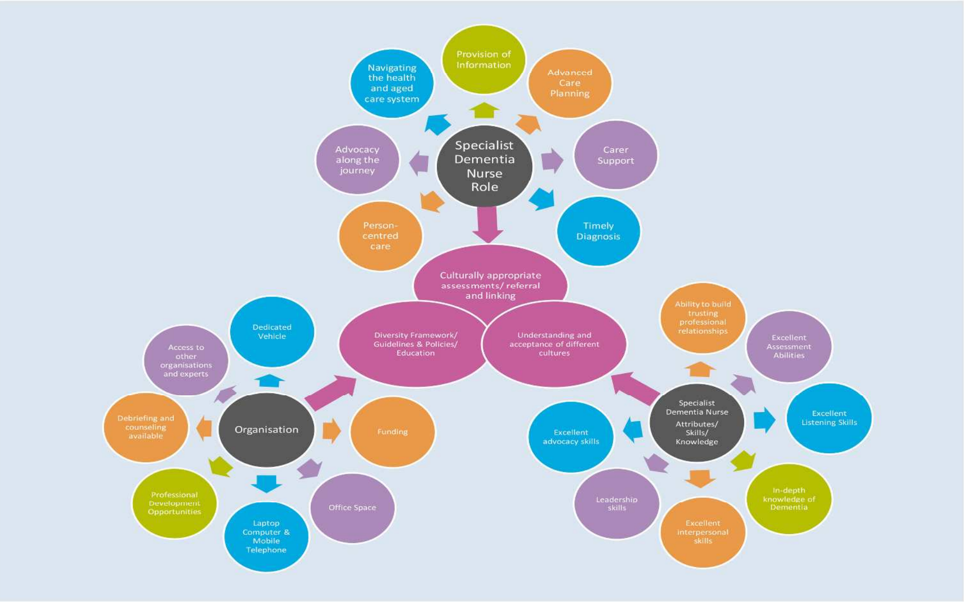
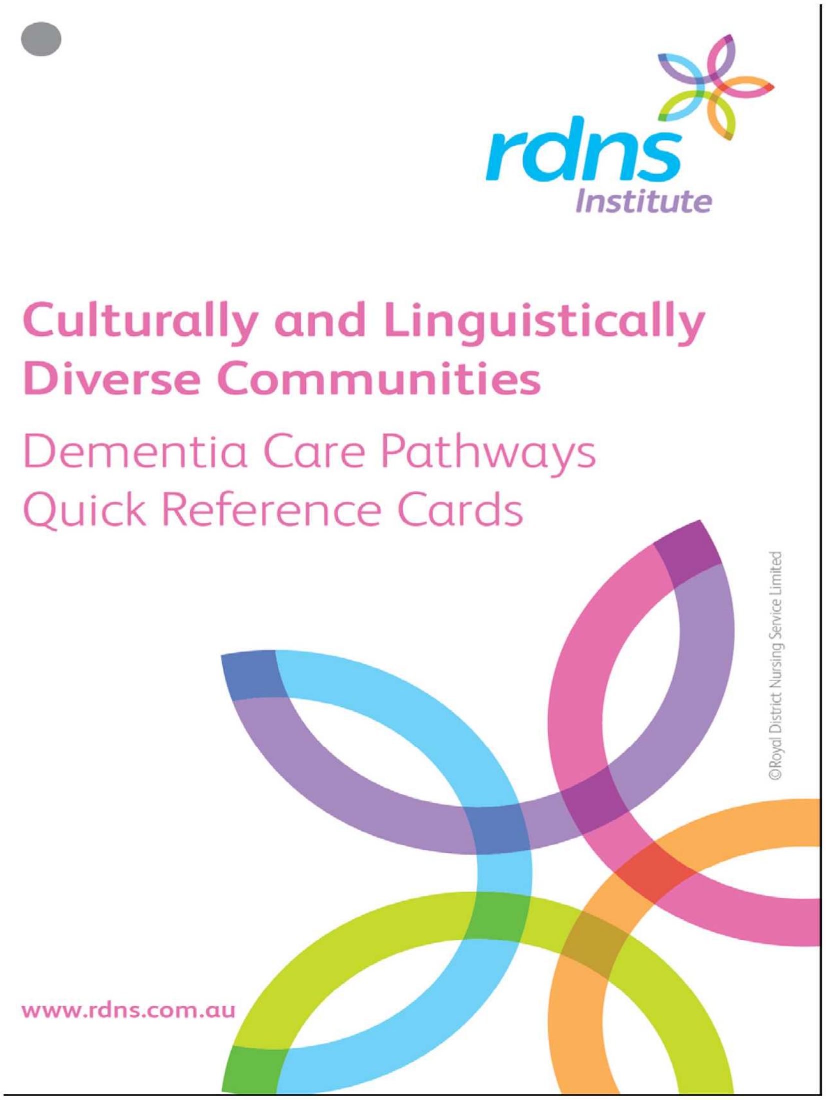


Figure 1: CALD Specialist Dementia Nurse Model

245x157mm (300 x 300 DPI)

Figure 2: CALD Dementia Care pathway



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Dementia Care Pathways
Quick Reference Cards

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Figure 2: CALD Dementia Care pathway

166x229mm (300 x 300 DPI)

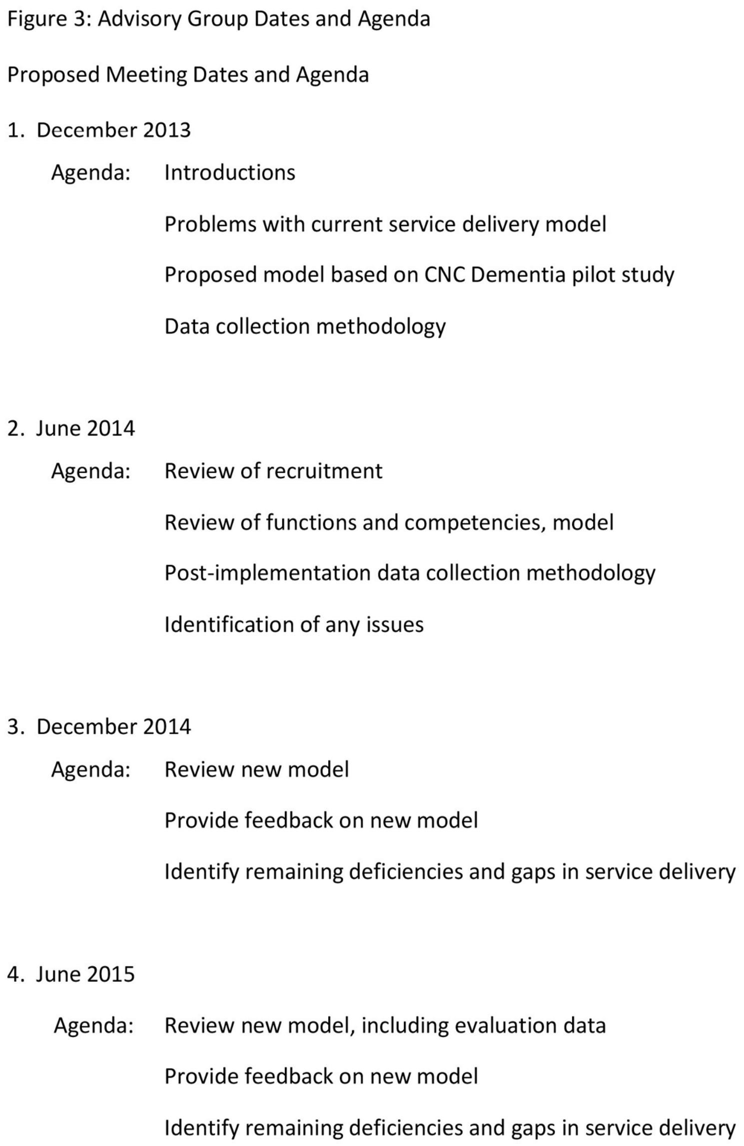

Figure 3: Advisory Group Dates and Agenda

Proposed Meeting Dates and Agenda

1. December 2013

Agenda: Introductions

Problems with current service delivery model

Proposed model based on CNC Dementia pilot study

Data collection methodology

2. June 2014

Agenda: Review of recruitment

Review of functions and competencies, model

Post-implementation data collection methodology

Identification of any issues

3. December 2014

Agenda: Review new model

Provide feedback on new model

Identify remaining deficiencies and gaps in service delivery

4. June 2015

Agenda: Review new model, including evaluation data

Provide feedback on new model

Identify remaining deficiencies and gaps in service delivery

Figure 3: Advisory Group Dates and Agenda

126x193mm (300 x 300 DPI)