

## **What is the Effectiveness of the Support Worker Role for People with Dementia and their Carers/Family living in the Community?**

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### **Background**

As dementia is usually gradual, irreversible and progressive in nature, functional decline inevitably leads to increasing dependence on others in areas of daily living. A variety of roles and models of support have been developed and implemented worldwide to assist people and their carers to: adjust to living with memory loss; navigate the health and aged care system; and access services, information and support. These roles include: key workers; support workers; case managers; care managers; Admiral Nurses; dementia advisors; and team-based integrated care roles. Currently, there is a lack of evidence of the efficacy of the support worker roles for people with dementia, their carers and family within the Australian context.

This two phased project, funded through the Cognitive Decline Partnership Centre, included a systematic review of international and national literature focusing on dementia support worker roles and a qualitative evaluation of dementia support worker type roles currently in operation across Australia. The aims of this CDPC activity were to:

- Assess how the support worker role can best be utilised to assist community-dwelling people with dementia and their carers/family;
- Develop recommendations to inform policy and practice change and provide a framework for further implementation of the support worker models within different organisations such as Primary Health Networks, advocacy organisations, community groups and other partner organisations.

The project is timely, given the considerable reform currently underway in the Australian health, aged and disability sectors, including the new Primary Health Networks and the move to consumer directed care.

### **Phase One Systematic Review: Support Worker Roles for People with Dementia and their Carers/Family**

#### **Method**

Academic papers and government reports and unpublished work (grey literature) focusing on support worker roles for people with dementia, their carers and family were identified by searching scientific databases, Google scholar and a variety of dementia and aged care websites. An eligibility

instrument was used to determine whether the identified articles were included in the review. Criteria for inclusion included: written in the English language; published between 2003 and December 2014; the utilisation or discussion of a support worker role; participants of the study having a diagnosis of dementia/cognitive decline or being carers of people with dementia; and research conducted in a community setting only. Once an article was deemed eligible two researchers critically appraised and assessed the articles in order to determine the quality of evidence and how well the studies were conducted in order to eliminate bias. This included how the subjects were selected, allocated to groups, managed and followed up and how the study outcomes were measured. Validated tools were used to assess the quality of the articles according to study design (e.g. randomised controlled trials<sup>1</sup>, experimental and observational studies<sup>2</sup>, qualitative evaluations<sup>3</sup>).

## Results

Fifty-eight papers on models of support for people with dementia and their carers were evaluated in this review. This included 46 academic papers and 12 grey literature papers. The models of support identified and study designs utilised are shown in table one.

**Table 1: Roles identified and Study Designs Utilised**

	Case Manager	Care Manager	Counselling Roles	Team-based/ multi-agency/ integrated support models	Support Worker Roles	Total
Randomised Controlled Trials	4	4	15	3	-	<b>26</b>
Non-Randomised, Quasi-Experimental	2	-	-	-	-	<b>2</b>
Observational Analytic/Cohort Design	5	-	-	-	1	<b>6</b>
Observational Case Report/ Case Series Design	1	-	-	1	-	<b>2</b>
Academic Mixed Method Design	2	-	-	-	-	<b>2</b>
Academic Qualitative Design	1	-	-	1	6	<b>8</b>
Grey Literature Mixed Method Design	2	-	-	-	7	<b>9</b>
Grey Literature Qualitative Design	2	-	-	-	1	<b>3</b>
<b>Total</b>	<b>19</b>	<b>4</b>	<b>15</b>	<b>5</b>	<b>15</b>	<b>58 papers</b>

The inconsistencies in results between the studies identified in this systematic review were notable. The heterogeneity in inclusion criteria, study design, study populations, recruitment strategies, methods of delivery, role implemented, outcomes measured and the health and social care systems in which they are conducted made it difficult to synthesis results and draw conclusions. The

<sup>1</sup> Cochrane Risk of Bias Tool

<sup>2</sup> Critical Appraisal Skills Programme Checklists

<sup>3</sup> Greenhalgh & Taylor's (1997) paper and Britten & Pope's (2006) work on synthesising qualitative studies

interventions and role of the support workers were often not described in sufficient detail which made it difficult to assess and draw out how the support worker role was best utilised to assist community-dwelling people with dementia and their carers/family. It should also be noted that the methodological quality of the majority of the studies included in this review was quite low. Only four randomised controlled trials were rated as having high quality according to the quality criteria.

Studies that showed the highest quality evidence (statistically significant findings and a low risk of bias) were used to draw together some overall findings that describe how the dementia support role provided significant outcomes for people living with dementia and their families and carers in the community. The findings from these studies suggest that the essential components for support worker roles/interventions were:

- Having an intervention duration of at least 6-12 months in order to significantly impact on measures such as caregiver burden, general health or wellbeing measures or the person with dementia's symptom severity;
- Having a multi-disciplinary/inter-disciplinary team;
- Having collaborative input to determine what support is needed/provided (e.g. with the person with dementia, their caregiver and family);
- Inter-professional collaborations and a shared approach to care;
- Providing individualised support for each person based on a needs assessment;
- Ensuring the support worker has a skilled background (e.g. a nurse, occupational therapist, social worker, trained in dementia);
- Providing ongoing follow-up (home visits, telephone contact) that is based on needs;
- Providing individualised education based on needs;
- Investment in a strong provider network including linking with and having close contact with the physicians/GPs of the person with dementia and coordination and monitoring of care;
- Capacity to develop relationships.

## Conclusion

This review is the first to our knowledge to: include quantitative and qualitative academic, grey literature studies; assess all models of community support (case managers, care managers, counselling roles, team based/multi-agency/integrated care, support/key workers and Admiral Nurses); and analyse the essential components of the support worker role for people with dementia, their carers/family.

The results of this review have the potential to inform future research and practice through the incorporation of the identified essential features into future research trials or current dementia support worker roles operating in the community. However the evaluation also revealed poor evaluation design of the majority of studies published to date with insufficient detail provided on the intervention and role provided by the dementia support worker roles. High quality evaluations of holistic, tailored models of support are needed to identify which components of support produce the most valuable outcomes to assist people with dementia and their carers and families to continue to live meaningful lives.

## Phase Two Qualitative Evaluation: Australian Support Worker Roles for People with Dementia and their Carers

### Method

A qualitative evaluation utilising a co-creation approach was used to investigate Australian support worker models for people with dementia and their carers/family. This process of co-design and co-creation involved ongoing collaboration between the Cognitive Decline Partnership Centre reference and working group, consisting of members from Alzheimer's Australia Consumer Dementia Research Network, industry partners, policy makers and researchers, to develop a framework and subsequent interview questions that were used to evaluate the support worker models. This process ensured a commitment to implementing findings in the broader health service community creating real innovation. Consumers were involved in all stages of this evaluation from inception to completion which is a key strength and novelty of this report.

Support worker models were identified via: the systematic review completed in phase one; internet searches; and consultation with key dementia organisations and experts in the field. Interviews were conducted with organisations operating support worker type models, individual support workers and people with dementia and/or their carers/family members. All interviews were audio-recorded, professionally transcribed and then checked for accuracy against the original recording prior to being imported into NVivo 10 to aid analysis. Descriptive and topic coding was then undertaken. Following this the reference and working group met to map the interview results and determine how well the identified models matched up with the framework developed at the beginning of the evaluation.

### Results

Sixteen support worker type models were identified across Australia with 14 agreeing to participate in the evaluation. Overall 14 interviews were conducted with organisation managers, 19 with support workers and 15 with consumers. The models operated under a range of different organisational and geographical contexts. Although the models had similarities no one model had the same design, set-up, criterion for support or organisational constructs but each role was highly valued by the majority of respondents.

### *Framework for the Dementia Support Worker Role*

The support worker role was broad and varied; there was no day or client that was the same. Despite the diversity and changeability of the role, there were common components across the models evaluated. The main role aspects in all models included: building relationships; referral to services and navigating the service system; responding to individual needs; providing education/information to people with dementia/ their carers or family; listening and counselling; setting people up for the future and providing education and training to the community. Personal attributes, the ability to empathise and connect, a person-centred philosophy, ability to learn and change, professional warmth, common sense, work and life experience and willingness to seek information were seen as more important than a certain professional background. When discussing attributes needed in the role consumers also commented that it is important to look at personal attributes to ensure you get the right person in the role at the beginning.

Overall there was consensus on the skill areas of: capacity for interagency communication; ability to work as part of a multidisciplinary team; ability to provide education (to the person with dementia, carers, family and/or to the community and health professionals); ability to build and maintain relationships; communication and interpersonal skills; clinical skills; counselling/listening skills; assessment skills; advocacy skills; problem solving skills; and time management skills.

All models agreed that ideally you would have a multidisciplinary dementia support team with a range of professions. Participants considered that inter-professional collaboration and strong links with all organisations involved in the care of people with dementia would reduce silos and isolated working groups. Multi-disciplinary support worker teams and working in a team environment with the ability to consult with people from different backgrounds and disciplines was thought by many to foster a high quality service for people with dementia, their family and carers.

Other key components identified for a successful model included: strong, collaborative links to other services, including primary care; the provision of proactive, flexible, relationship-centred care; holistic support that focuses on promoting independence and enablement, meets physical, emotional and social needs; and infrastructure support for staff wellbeing, skill development and clear performance support.

### *The Value of the Support Worker Role*

The support worker role was highly valued by the majority of respondents. Organisation managers, support workers and consumers reported that the support worker played a role in preventing or delaying crises and thus may have reduced the utilisation of other health and aged care services. Consumers highly valued: support that focused on promoting independence and enablement (practical support); emotional support; flexibility in the mode and frequency of support offered; and meeting in relaxed settings over office-type environments. All respondents agreed that in an ideal model the most important aspects of the support worker role would be: acting as a central point of contact; being someone to listen and discuss issues and concerns with; providing assistance with navigating the service system; providing individualised support; being a source of information and education; building-relationships; promoting enablement and independence; advocacy; and providing case management; early intervention and whole of journey support from diagnosis to death.

### *Current Limitations for the Support Worker Role and Services*

Issues raised were consistent across models. This included: not having enough support workers; not being able to properly support rural and regional areas; covering large distances; and support workers having high caseloads and workloads and being time poor. Service system limitations were also raised including the frequently raised issue of there being a lack of appropriate services available in the community to meet people's preferences and needs.

Overall the consumer's views on the limitations of the support worker services they were receiving fell into four main themes: turnover of staff; high case loads and not enough support workers; having a time-limited service; and being overloaded with information. Direct consultation with people with dementia and their carers about what services and programs they need and prefer was reported to be missing which was a key concern to consumers.

A poignant issue raised by a few support workers was the limited support provided for self-care, reflection type processes where they could debrief with counselors about tough, emotional situations. Support workers commonly reported that they had support within their team but from an organisational perspective there were no formal processes set up to assist them in seeking formal support for de-briefing. This was reported to lead to feelings of burn-out and also contribute to staff turnover.

A clear gap for the majority of models was a lack of evaluation for service improvement. None of the models interviewed had undertaken a cost-effectiveness analysis for their dementia support models or roles nor collected robust feedback to formally ascertain the benefits and gaps in the service, client satisfaction or reasons for withdrawal and disengagement with the services.

### *Suitability of Support Provided and Available Services*

Early intervention and crisis planning to minimise overall stress was viewed as essential by all respondents but wasn't always achieved mainly due to delays in diagnosis and lack of direct referrals from GPs and specialists. Consumers commented on the issue of time-limited services as they felt once they had been "discharged" they couldn't contact the service again if an issue arose. Supporting people with dementia and their carers/family was seen as an ongoing commitment as needs constantly change; therefore all respondents believed the person receiving support should have the ability to come in and out of the service when required. Support across the continuum of care was raised as one of the most important aspects of care from all perspectives and should be taken into consideration for organisations operating dementia support worker models.

Consumers strongly noted that there was a lack of appropriate services available in the community especially for people with younger onset dementia. All respondents noted that appropriate services that met needs were scarce and often had huge waitlists. The suitability of activities was also reported to be an issue by consumers. Services that focused on re-enablement and function were highly sought after by consumers but hard to find. Attending services and programs with people that were in the more advanced stages of dementia or with more complex health issues was also reported to be upsetting. Equally programs that were designed for carers and people with dementia did not always meet needs. This was reflected in comments from all perspectives regarding funding and support for diverse groups and rural and remote areas.

### **Conclusion**

This extensive qualitative evaluation of dementia models of support for community-dwelling people with dementia and their carers and family is the first to our knowledge to be conducted in Australia; to evaluate multiple model types; and to compare and contrast the role from three different perspectives. The value of the support worker role for people with dementia, their family and carers was strongly apparent. There is a need to ensure the continuation of this support role to allow people with dementia, their family and carers to have access to a worker that provides support that meets individualised needs. Important areas of value as well as limitations and gaps in services and models were identified that should be taken into account by those involved in policy, practice and consumer decision making.

## Implications for Research

While the results from the comprehensive systematic review of support models for people with dementia and their carers provided evidence in regards to the value of models of support for community-dwelling people with dementia and their carers nationally and internationally gaps in regard to study designs, efficacy in the Australian setting and a lack of cost effectiveness evaluations were identified.

High quality randomised controlled trials of multi-disciplinary/collaborative holistic models of support are needed in the Australian setting. To ensure support models are appropriate to the needs of people with dementia and their carers and families in a variety of settings these trials should take place across several Australian states. High-quality trials will provide robust evidence in regard to cost-effectiveness and potential for cost savings of the support model as well as the emotional, physical and social benefits (quality of life, wellbeing, social support, reduction in symptoms and carer stress) for people with dementia, their carers and families.

It is vital that any future research in this area has sound methodology and that the interventions and trials are rigorous in design and delivery. The outcome measures need to be valid and reliable and the methodology clearly defined and well-documented to enable critical appraisal and interpretation of results. With clearly defined sound-methodology there is less risk that the results and outcomes will be subject to bias. In addition to quantitative outcome measures a qualitative component included in the evaluation would add richness to the data collection by providing direct information from the people with dementia, their carers and family about the real implications and effectiveness of the role which are often not captured in clinical tools.

The essential components for support worker roles/interventions identified in this review should be incorporated into the support worker model and role under investigation. It is essential that a full description of the support model and the support provided in both the intervention and control groups is provided in any further research. These clear descriptions will also be useful for others looking to replicate the trial or implement the support model in other settings.

## Implications for Australian Service Development and Policy

The value of a support worker for people with dementia, their family and carers came out strongly in both phases of the evaluation; the systematic review and qualitative evaluation.

The findings support the continuation and expansion of the dementia support worker role and further exploration of how the role can be incorporated within consumer directed care. Closer links with primary care was identified as important and the opportunity of aligning the role with the Primary Health Networks could be an important future direction. Despite the broad and varied roles, essential knowledge, skills and attributes of the role and key components of the models were identified that can guide further service design and development. The evaluation was qualitative and did not include a cost effective analysis of the model that, if undertaken, would be beneficial for service planning.

This evaluation validates gaps and emerging issues identified in the recent KPMG's analysis of dementia programmes funded by the Commonwealth Department of Social Services. In particular

the issue of accessibility and equality of programmes and services for rural, regional and remote areas and special needs groups and the need to ensure coverage is maximised; as well as the need to raise awareness and promote earlier detection in the primary care sector; and for a 'single entry point' for people with dementia and carers to access dementia support to improve access and efficiency.

The framework for an optimised model of support for people with dementia, their family and carers living in the community developed as part of this evaluation has the potential to assist organisations, services, governments and policy makers involved.

## Recommendations

In order to continue the provision of the dementia support worker role and to address the current limitations, the following recommendations relevant for service development, research and policy include:

1. Explore options for increasing access to the dementia support worker role within consumer directed care;
2. Trial and align the dementia support worker model with Primary Health Networks to encourage early intervention and increase geographic coverage, particularly rural and remote;
3. Address the issues of accessibility for diverse groups including younger onset dementia, CALD, Aboriginal and Torres Strait Islanders and LGBTI communities within existing and future service models;
4. Address the outcomes of the evaluation and provide opportunities to raise awareness of the dementia support worker services and what they are able to offer;
5. Undertake a cost effective analysis of dementia support models;
6. Ensure continuous service improvement for existing services and any new services including collecting feedback from consumers on satisfaction, and areas for improvement;
7. Investigate the reasons why people with dementia and/or their caring unit fail to seek help, fail to engage with services or withdraw from services as an important service improvement exercise for existing and future services;
8. Improve the options for emotional, physical and social care for both people with dementia and their carers, to enhance the enablement of people with dementia so that they can live as well as possible and meet the principles of consumer directed care;
9. Provide adaptable funding structures that allow support across the continuum;
10. Utilise the framework developed as part of this evaluation as a human resources recruitment, service review and service development tool;
11. Actively include people with dementia in service development.