

## **Protocol Scoping Review**

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Title

1a Identification

**Factors related to the access to and use of formal care by people with dementia and their informal carers: protocol for a scoping review**

2 Registration

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4 Amendments

This updated version of the review protocol comprises the following changes:

- 10 Search strategy: a definition for community setting has been added.
- 13 Risk of bias of individual studies: The critical appraisal tool has been changed.

5 Support

5a Sources

5b Sponsors

5c Role of sponsor or funder

## Introduction

## 6 Background

Understanding the factors which may influence access to and use of formal care is the prerequisite for the further development of appropriate and timely professional support by the community on behalf of people with dementia and their informal carers. Carers for people with dementia experience more stress and depressive symptoms, lower levels of self-efficacy and subjective well-being (Pinquart & Sörensen, 2003). Despite this, only few people with dementia and their carers use community support services (Beeber et al., 2008). There are studies which have investigated the different aspects of and reasons for this low use of professional services, i.e. ethnicity, gender, region of residence, and attitudes or beliefs towards dementia and care for people with dementia. The influence of ethnicity on service use has been investigated in systematic reviews (Mukadam et al., 2011; Giebel et al., 2015), which gave as reasons the lack of knowledge about dementia and lack of awareness of appropriate services in minority ethnic groups. Two systematic reviews identified differences in service use between male and female carers (McDonnell & Ryan, 2011; Greenwood et al., 2015). Inner factors, e.g. understanding the caregiver role (McDonnell & Ryan, 2011) and personal experiences with support services (Greenwood et al., 2015) result in lower levels of service use by male carers of people with dementia. In contrast, other findings suggest that female carers tend to use fewer services than male carers (Pedlar & Biegel, 1999; Toseland et al., 2002; Robinson et al., 2005; Boersma et al., 1997). An international systematic review examined dementia care in rural and remote settings (Innes et al., 2011) and found that the use of formal support services is low, that there are gaps in service provision, and that the available services do not always meet the needs of people with dementia and their informal carers in these areas. The authors identified strategies for overcoming these barriers, e.g. increasing public awareness of dementia and its impact on carers, and improving the availability and accessibility of support services. Prorok et al. (2013) found that changing attitudes towards dementia could promote access to services. A systematic review of the factors associated with the non-use of respite care by carers of people with dementia identified health beliefs as being an influencing factor of service use (Phillipson et al., 2014). Further investigation of health beliefs of carers related to identity, target and leverage would therefore seem to be worthwhile.

### **Theoretical framework**

Prorok et al. (2013) and Phillipson et al. (2014) used for their review the Andersen Behavioural Model of Health Service Use as the theoretical framework, which has been applied in several studies of service use by people with dementia and their carers (Toseland et al., 2002; Robinson et al., 2005; Galvin et al., 2008; Thorpe et al., 2010). The Andersen

Behavioural Model (Andersen, 1995) is a theoretical framework for evaluation and understanding of access to and utilization of healthcare services, by identifying the predisposing, enabling and need factors. Predisposing factors imply that some individuals have the propensity to use services more often than others do. The propensity to use might be predicted by individual characteristics. Enabling factors influence the availability of a health service for an individual. Needs or illness factors are assessed as the most immediate reason for health service use (Andersen & Newman, 2005). The Andersen Model was first developed for acute care settings, where need factors were identified that had the most important influence on the use of a service. A systematic review, which tried to explain the use and non-use of community-based long-term care services by carers of people with dementia, was used to test the Andersen Model (Markle-Reid & Browne, 2001). An alternative theoretical framework has consequently been suggested, which considers the complex and dynamic interplay between people with dementia, carers and contextual factors. The updated Andersen model by Bradley et al. (2002) reflected some of the identified limitations of the first version of the model and further developed the model for the special situation of people in long-term care settings. Bradley et al. (2002) recognised predisposing factors, especially psychosocial aspects, as having considerable influences on service use in these settings, and defined attitudes, knowledge, social norms and perceived control as psychological aspects. Several studies suggest the exceptional role of psychosocial aspects (Collins et al., 1991; Kelley et al., Kosloski et al., 2002; Bond et al., 2005; Dilworth-Anderson et al., 2012). However, the updated Model by Bradley et al. (2002) has so far not been applied in studies.

In summary, many systematic reviews published in the last ten years dealt with service use by people with dementia and their carers. Each of these reviews focused on special influencing factors or reasons for use or non-use. However, a scoping review providing an overview of influencing factors on the access to and use of diverse types of formal care has not been done before.

Furthermore, it remains unclear whether the investigated psychosocial aspects correspond with the Andersen Model by Bradley et al. (2002). A scoping review might help to fill these gaps.

## 7 Objectives

The objective of this scoping review is to gain an overview of influencing factors on the access to and use of formal care by people with dementia and their carers.

The research questions of the scoping review are:

1. Which influencing factors can be identified?

2. Which formal care services were investigated?
3. How can these factors be categorized according to the Andersen Model by Bradley et al. (2002)?
4. Do the identified psychosocial factors correspond with the Andersen Behavioral Model by Bradley et al. (2002)?

## Methods

### 8 Methodological framework

The scoping review is guided by Arksey and O'Melley's methodological framework (Arksey & O'Melley, 2005), and recommendations by Levac et al. (2010). A scoping review is conducted in five steps: identifying the research question, searching for relevant studies, selecting studies, charting and collating the data, summarizing and reporting the results. Expert consultation is recommended as a facultative step. This is not part of this review, because of the methodological uncertainties of evaluating the statements and opinions of stakeholders in the field, as described by Levac et al. (2010).

### 9 Information sources

- PubMed
- CINAHL
- Social Science Citation Index
- PsychInfo
- Reports by the World Health Organisation, the Organisation for Economic, Co-Operation and Development, and the Alzheimer's Disease International

### 10 Search strategy

#### Inclusion criteria

- Study types: all types including systematic reviews, randomised controlled trials, controlled studies, observational studies, qualitative studies
- Topics: investigation of factors influencing the access to and use of professional formal care by people with dementia and informal carers. Formal care is defined as

community care, which includes health care and social care services, e.g. home care services, day care, counselling, respite care.

- Population: people with dementia and informal carers
- Setting: community care, which is defined as health and social care services offered for people who live at home. That includes institutional respite care services, but excluded hospital care and care in nursing homes or institutions for palliative care.
- Publications in the English language
- Publications between 1995-2016

#### Exclusion criteria

- Studies relating exclusively to medical care, e.g. physicians visits for outpatient care, specialist visits for outpatient care, hospitalizations, emergency room visits

#### Search terms

Concept/complex	Search Terms		MeSH Terms (PubMed)
<b>Dementia</b>	Dement* OR Alzheimer*	<b>OR</b>	dementia
AND			
<b>Formal dementia care</b>	“professional care” OR “care giving” OR “home care” OR “community care” OR “care” OR “formal care” OR “long-term care” OR “informal care” OR “long-term support” OR “formal support” OR ...	<b>OR</b>	“Home care services” OR “health services for the aged” OR “long-term care” OR “community health services” OR “community mental health services”
AND			

<b>Utilization/accessibility</b>	Utilisation/ utilization OR access* OR “service use” OR “service non-use” OR “help-seeking” OR “help seeking”	OR	Health care quality access, and evaluation OR Health service accessibility OR Health Services for the Aged/utilization* OR Long- Term Care/utilization OR Community Health Services/utilization* OR Community Mental Health Services/utilization OR Health Services for the Aged/utilization*
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## 11 Data management, selection process, and data extraction process

Two researchers will independently review the retrieved titles and abstracts (screen 1) and check whether they are eligible. Bibliographic data will be downloaded to Citavi bibliographic software and duplicates deleted. The full text of those citations deemed relevant by both reviewers will be obtained. Two researchers will independently assess the full texts (screen 2) to determine whether they meet the inclusion criteria. Any disagreements will be solved by consensus or by discussion with a third researcher.

If studies were reported in more than one publication, these publications will be grouped together and the publication with the most complete data will be used as the primary reference; the other publications describing the same study will be classified as associated papers.

Reviews were screened towards their included studies, and these studies will be included, which fulfil the inclusion criteria.

For quality assurance purposes, the data extraction process will be pilot tested by two researchers, discussed between the researchers, and modified if necessary. A data extraction form was developed (Appendix 1), which will be modified after the testing phase if necessary. Five quantitative, five qualitative and five mixed-method studies will be analysed independently by two or three reviewers using the data extraction form. The testing phase will be evaluated carefully.

## 12 Outcomes

Extracted factors influencing service use will be classified according to the Andersen Behavioral Model of Health Service Use by Bradley et al. (2002). This includes the classification of factors in psychosocial factors as an extension of predisposing factors, enabling, and need factors. The factors with domains and major themes are summarized in Table 1.

Table1: Summary of Factors, Domains, and Major Themes

<b>Factors</b>	<b>Domains</b>	<b>Major themes (and their dimensions)</b>
Psychosocial	Attitudes	Care Providers (Technical expertise, Interpersonal skill) Affordability (Perceived expense, Home ownership) Social environment (Social interaction, Activity level, Familiarity, Diversity) Self-determination (Privacy, Dignity, Independence)
	Knowledge	Content and Amount of Information (Service types provided, Eligibility rules, Legal issues, Financial coverage) Sources of Information (Family/ friends; Lawyers, Healthcare Professionals) Accessibility of Information (Attainability, Comprehensibility)
	Social Norms	Referents (Spouse, Children, Friends, Neighbours, Social workers, Clergy, Doctors, Lawyers) Relevant Norms (Family burden, Caregiving expectations)
	Perceived Control	Role of Choice (Decision maker, Alternatives) Planning for Future Needs (Financial planning, psychosocial planning)
Enabling	Availability of Support	Formal services (Openings at facilities/ waiting lists, Hours of operation, Proximity) Informal support (Willingness to provide support, Ability to provide support proximity)
	Financial Resources	Financial Well-being (Income, Assets) Protection against risk

Need	Objective/ Perceived	(Insurance) Degree of disability (Physical, Cognitive) Duration of disability (Physical, Cognitive)
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### 13 Risk of bias in individual studies

Critical appraisal is not originally suggested by Arksey and O-Melley (2005); however, several authors who have performed scoping reviews request critical appraisal (Levac et al., 2010 & Daudt et al., 2013).

We will adhere to the PRISMA Statement and therefore to critical appraisal as an indispensable methodological aspect (Moher et al. 2009). We will use the Mixed Method Appraisal Tool (MMAT) by Pluye et al. (2011), which has been designed for the appraisal stage of complex systematic literature reviews that include qualitative, quantitative and mixed methods studies. The MMAT is a reliable and practical critical appraisal tool (Pace et al., 2012; Souto et al., 2016); and will be used in another scoping review too (Puts et al., 2016).

### 15 Data synthesis

In accordance with Levac et al. (2010), data synthesis will include three steps to increase the consistency of the scoping review: 1) analysis of data, 2) reporting of results, and 3) applying meaning to the results. The analysis step will cover a descriptive numerical summary and a thematic analysis. The thematic analysis will be conducted using qualitative content analytic techniques. Results will be reported narratively, and will consider the meaning of the scoping study results and the broader implications for research, policy, and practice.

### References

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## Appendix 1 Data extraction form

	Description	Location in text
<b>Author(s)</b>		
<b>Title</b>		
<b>Year of publication</b>		
<b>Study location</b>		
<b>Study population</b>		
<b>Aims of the study</b>		
<b>Methods</b>		
<b>Sample</b>		
<b>Data Collection</b>		
<b>Analysis</b>		
<b>Important results</b>		
<b>Outcome measures</b> 1.Which influencing factors can be identified?		
<b>Outcome measures</b> 2.Which formal care services were investigated?		

### Outcome measures

3. How can the identified influencing factors be categorized according to the Andersen Model by Bradley et al. (2002)?

Factors	Domains	Major themes (and their dimensions)	Findings
Psychosocial	Attitudes	Care Providers (Technical expertise, Interpersonal skill)	
		Affordability (Perceived expense, Home ownership)	

		Social environment (Social interaction, Activity level, Familiarity, Diversity)	
		Self-determination (Privacy, Dignity, Independence)	
	Knowledge	Content and Amount of Information (Service types provided, Eligibility rules, Legal issues, Financial coverage)	
		Sources of Information (Family/ friends; Lawyers, Healthcare Professionals)	
		Accessibility of Information (Attainability, Comprehensibility)	
	Social Norms	Referents (Spouse, Children, Friends, Neighbours, Social workers, Clergy, Doctors, Lawyers)	
		Relevant Norms (Family burden, Caregiving expectations)	
	Perceived Control	Role of Choice (Decision maker, Alternatives)	
		Planning for Future Needs (Financial planning, psychosocial planning)	
Enabling	Availability of Support	Formal services (Openings at facilities/ waiting lists, Hours of operation, Proximity)	
		Informal support (Willingness to provide support, Ability to provide support proximity)	
	Financial Resources	Financial Well-being (Income, Assets)	
		Protection against risk (Insurance)	
Need	Objective/ Perceived	Degree of disability (Physical, Cognitive)	
		Duration of disability (Physical, Cognitive)	

### Outcome measures

4. Do the identified psychosocial factors correspond with the Andersen Model by Bradley et al. (2002)?

4.1 Were psychosocial factors investigated? Yes/no	
4.2 Which psychosocial factors were investigated?	
4.3. Are there correlations? Which?	