

Appendix ‘Stability of home-based care arrangements for people living with dementia: Research protocol of a meta-study on mixed research’

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Appendix A – Systematic database searches

Aim of the systematic database searches is to identify a comprehensive set of published research that contributes to the conceptualisation of the complex phenomenon of ‘stability of home-based care arrangements for people living with dementia’. Databases to be searched are PubMed, CINAHL and PsycINFO. We will systematically search nine separate search strands:

1. search strand stability
2. search strand (self-)caring actions
3. search strand needs & demands
4. search strand crises
5. search strand positive aspects
6. search strand end-of-life-care
7. search strand institutionalization
8. search strand burden
9. search strand interventions

Each search strand will be searched by a combination of a syntax describing the specific phenomenon/concept of the strand and five standardised search domains:

- a) search domain dementia (to identify the population of persons living with dementia)
- b) search domain informal carer (to identify the population of informal carers)
- c) search domain community setting (to identify the community care/home-based care setting)
- d) search domain stability (to identify the phenomenon/outcome stability)
- e) search domain institutionalization (to identify the phenomenon/outcome instability).

In general the search for each strand will be combined in the following way.

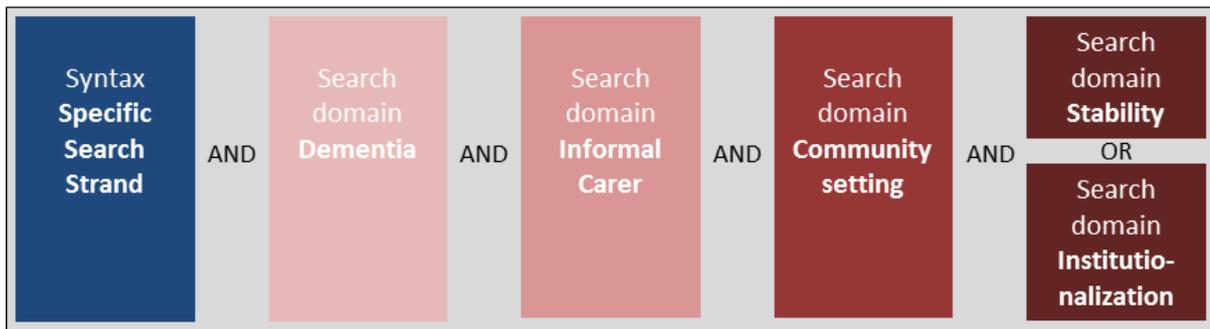


Figure 1: combination of search strands and search domains

Subsequent the syntaxes of the specific search strands and the standardised search domains are presented.

1. Search strand Stability

Syntax: Stability	1	stability
	2	stable
	3	maintain*
	4	sustain*
	5	(#1 OR #2 OR #3 OR #4)

2. Search strand (Self-)caring actions

Syntax: (Self-)caring actions	1	care manag*
	2	care coordination
	3	care strateg*
	4	supportive strateg*
	5	caregiv* style
	6	caregiv* career
	7	trajectory
	8	adjustment
	9	social support
	10	decision making
	11	service utilization
	12	service utilisation
	13	service use
	14	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13)

3. Search strand Needs & demands

Syntax: Needs & demands	1	need
	2	needs
	3	demand
	4	demands
	5	needs assessment
	6	health services needs and demands
	7	personal satisfaction
	8	patient satisfaction
	9	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8)

4. Search strand crises

Syntax: Crises	1	crisis
	2	crises
	3	critical incident*
	4	(#1 OR #2 OR #3)

5. Search strand positive aspects

Syntax: Positive aspects	1	positive aspect*
	2	gain
	3	uplift*
	4	*esteem
	5	satisfaction
	6	meaning
	7	(#1 OR #2 OR #3 OR #4 OR #5 OR #6)

6. Search strand end-of-life-care

Syntax: End-of-life-care	1	end of life
	2	palliative care
	3	palliative
	4	terminal care
	5	death
	6	dying
	7	hospice
	8	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7)

7. Search strand institutionalization

Syntax: Institutionalization	1	institutionalization
	2	institutionalisation
	3	nursing home placement
	4	nursing home admission
	5	institutional placement
	6	(#1 OR #2 OR #3 OR #4 OR #5)

8. Search strand burden

Syntax: Burden	1	stress
	2	burden
	3	strain
	4	(#1 OR #2 OR #3)

9. Search strand interventions

Syntax: Interventions	1	"clinical trials as topic"
	2	intervention*
	3	case reports
	4	controlled before-after studies
	5	crisis intervention
	6	clinical trial
	7	cohort studies
	8	longitudinal studies
	9	mixed methods
	10	clinical trials as topic
	11	experimental study
	12	treatment outcome
	13	outcome*
	14	program
	15	therapy
	16	treatment
	17	psychoeducation
	18	information
	19	education
	20	counseling
	21	counselling
	22	support
	23	training
	24	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 # OR #20 OR #21 OR #22 OR #23)

Subsequent the syntax of the five standardised search domains are presented.

a. Search domain Dementia

Search domain: Dementia	1	dementia
	2	Alzheimer*
	3	demented
	4	(#1 OR #2 OR #3)

b. Search domain Informal carer

Search domain: Informal carer	1	caregivers
	2	caregiv*
	3	carer*
	4	informal care*
	5	(#1 OR #2 OR #3 OR #4)

c. Search domain Community setting

Search domain: Community setting	1	home nursing
	2	community living
	3	home care
	4	domestic
	5	community dwelling
	6	home dwelling
	7	(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7)

d. Search domain Stability

Search domain: Stability	1	stability
	2	stable
	3	maintain*
	4	sustain*
	5	(#1 OR #2 OR #3 OR #4)

e. Search domain Institutionalization

Search domain: Institutionalization	1	institutionalization
	2	institutionalisation
	3	nursing home placement
	4	nursing home admission
	5	institutional placement
	6	(#1 OR #2 OR #3 OR #4 OR #5)

This is the basic database searching plan. In line with the iterative and hermeneutic setting of our meta-study project, the strand syntaxes and search domains may be adapted in the process and on different levels (e.g. requirements of each database, searches of keywords, headings, title-abstract, title, addition of meaningful terms, variation of combination with regard to each strand etc.). It is not the aim of the systematic database searches to identify all published research in the field. The aim is to identify a likewise comprehensive and manageable set of published research that informs our research questions. In general we will be open to any meaningful adaptations of all searches during the whole meta-study process.

Appendix B – Flow-Diagram

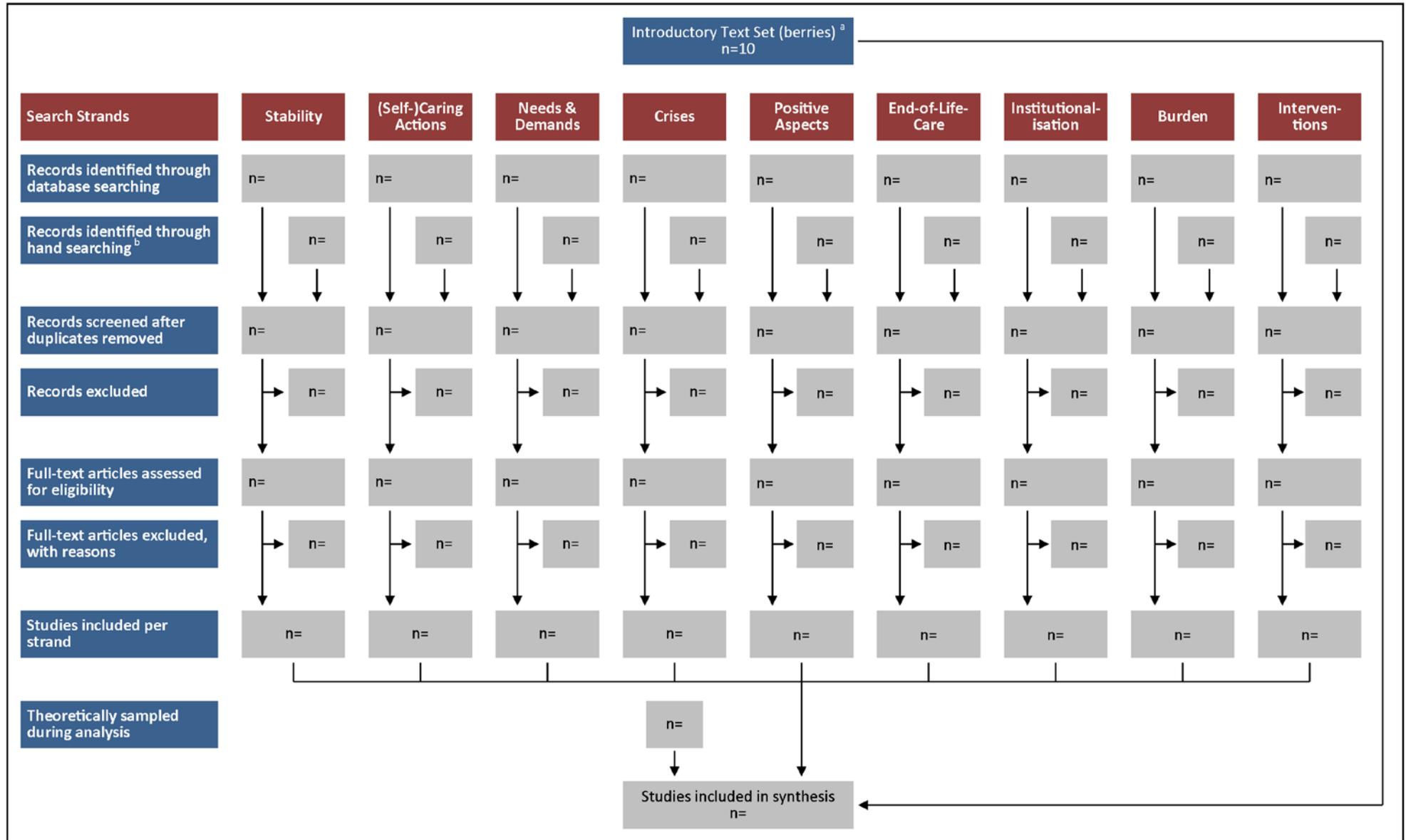


Figure 2: Flow-Diagram

Appendix C – Coding System

The following figures display the first draft of the codesystem for the analysis in MAXQDA. For better presentation the ‘descriptive codes’, ‘codes for meta-theory’, ‘codes for meta-method’ and ‘codes for meta-data-analysis’ are presented separately, but they all belong to the same codesystem. In the proceeding of the analysis the codesystem will be likely to change and will be inductively extended. Therefore this codesystem is preliminary.

Figure 3: Descriptive Codes

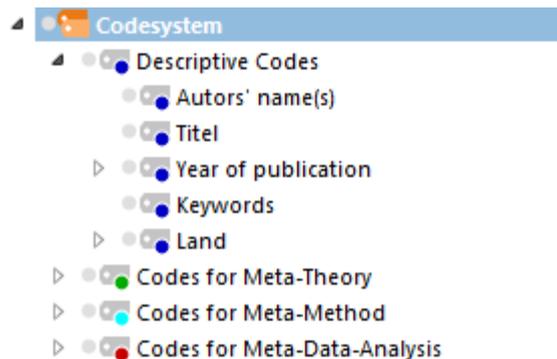


Figure 4: Codes for Meta-Theory

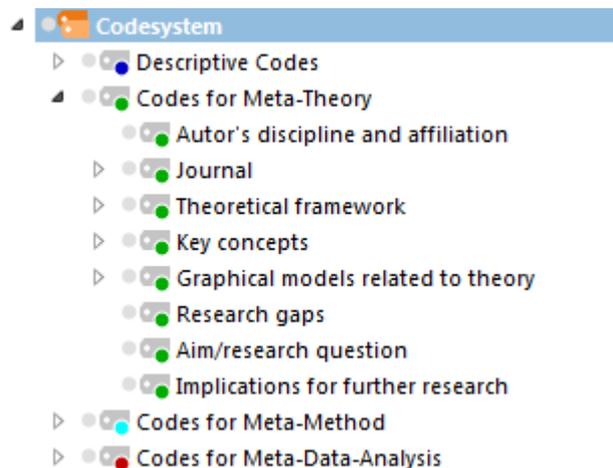


Figure 5: Codes for Meta-Method

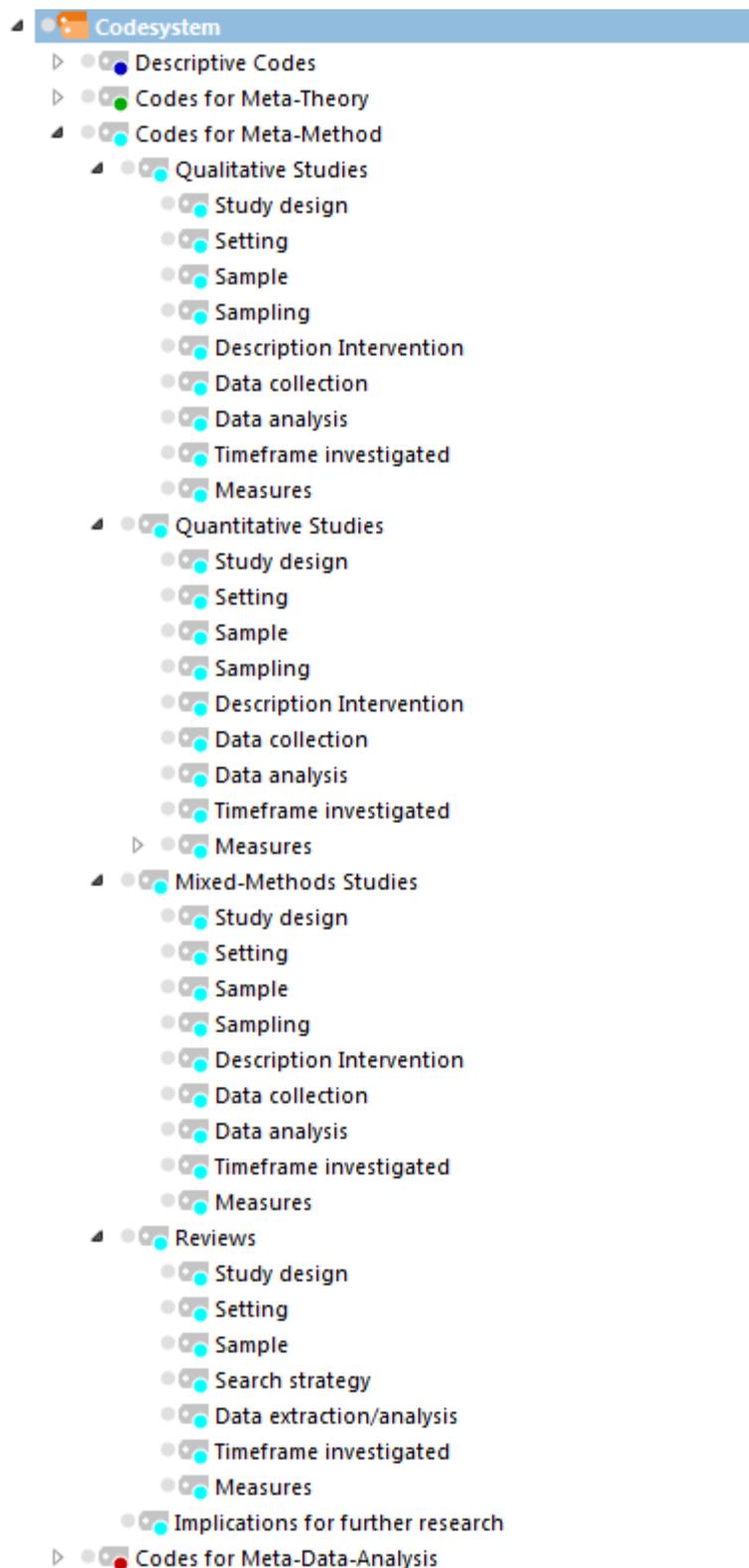


Figure 6: Codes for Meta-Data-Analysis

- ▲ Codesystem
 - ▷ Descriptive Codes
 - ▷ Codes for Meta-Theory
 - ▷ Codes for Meta-Method
 - ▲ Codes for Meta-Data-Analysis
 - ▲ Stability
 - ▷ Term stability and synonyms
 - ▷ Influencing factors on stability
 - ▲ Caring actions
 - ▷ Informal carer
 - ▷ Formal carer
 - ▲ Selfcaring actions
 - ▷ Person with dementia
 - ▷ Informal carer
 - ▲ Needs
 - ▷ Person with dementia
 - ▷ Informal carer
 - ▲ Demands
 - ▷ Person with dementia
 - ▷ Informal carer
 - ▷ Formal carer
 - ▷ Crises/Turning Points
 - ▷ Dynamic process/continuum
 - ▲ Institutionalization
 - ▷ Risk factors, predictors, reasons for institutionalization
 - ▷ Transition into another care setting (de facto)
 - ▲ Interventions
 - ▷ Stability promoting interventions
 - ▷ Suggested interventions
 - ▲ Phases of dementia
 - ▷ First symptoms
 - ▷ Diagnosis
 - ▷ Early
 - ▷ Middle/moderate
 - ▷ Late/advanced/severe
 - ▷ End-of-life/place of death
 - ▷ Early onset
 - ▷ Implications for further research