Master Thesis

Associated and reported determinants and experiences affecting the decision-making for nursing home placements of informal caregivers and individuals with dementia: A Meta-Ethnography

submitted by

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Graz, 26.07.2024 …………………………..

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Zusammenfassung

Hintergrund: Die Versorgung von Menschen mit Demenz erfolgt hauptsächlich zu Hause und wird überwiegend von weiblichen, informellen Pflegenden übernommen. Dies stellt erhebliche Herausforderungen dar. Oft führt die Überlastung der Pflegekräfte dazu, dass die Betroffenen in ein Pflegeheim umziehen müssen. Dies kann ihre Lebensqualität verschlechtern, die Gesundheitskosten erhöhen und zu mehr körperlichen, psychischen und familiären Belastungen führen. Um zu verstehen welche Faktoren und Erfahrungen bei der Entscheidungsfindung für einen Umzug eine Rolle spielen, wurde ein meta-ethnografischer Ansatz gewählt, um Einblicke in diesen komplexen Prozess zu gewinnen.

Ziel: Ergebnisse der Meta-Ethnographie sollen Erklärungen finden, wie zukünftige Interventionen und politische Maßnahmen die häusliche Pflege von Menschen mit Demenz fördern können. Ebenso sollen Ergebnisse daraus verwendet werden, um den Entscheidungsfindungsprozess besser betreuen zu können, damit emotionale und körperliche Belastungen aller Beteiligten verringert werden.

Methoden: Es wurde eine systematische Suche und strukturierte Selektion von relevanten Studien durchgeführt. Die inkludierten Studien wurden in sieben Schritten synthetisiert. Dieses Vorgehen richtete sich nach den PRISMA-Statement- und den eMERGE-Empfehlungen. Die Syntheseschritte lieferten gemeinsame Themen und Konzepte, die den belastenden Entscheidungsfindungsprozess beschreiben und erklären.

Ergebnisse: Durch den strukturierten meta-ethnografischen Ansatz konnten 13 relevante Artikel synthetisiert und dadurch dreizehn übergeordnete neue Interpreationen zusammengefasst werden. Diese Interpretationen beschreiben und erklären die Schlüsselfaktoren und Erlebnisse, die zu einem umfassenden Verständnis des Entscheidungsfindungsprozesses beitragen.

Schlussfolgerung: Durch ein Verständnis dieser dreizehn synthetisierten Schlüsselfaktoren, dieser Meta-Ethnographie, können Stakeholder bessere Unterstützungsangebote und Interventionen entwickeln, die auf die einzigartigen Bedürfnisse von informellen Pflegenden und Menschen mit Demenz zugeschnitten sind, was letztlich ihr Wohlbefinden und die Qualität der Betreuung für beide verbessert.

Abstract

Background: The care for individuals with dementia, primarily provided at home mostly by female informal caregivers, poses significant challenges. In many cases caregiver overburden leads to a nursing home transmission, which can result in poor quality of life, expants healthcare costs and increases physical, psychological and family strains. In an effort to understand which factors and experiences during the decision-making process may modulate the decision, a meta-ethnography approach was used to gain insight in this complex process.

Aim: To find explanations on how future interventions and policy making can support home care for individuals with dementia and how the decision making process can effectively supported to decrease emotionally and physically burdens.

Methods: Following a systematic search and selection process guided by PRISMA statement and eMERGE guidance, relevant studies were synthesized in seven phases to identify common themes and constructs explaining the burdensome decision-making.

Findings: The structured process of the meta-ethnography approach synthesized 13 eligible articles into thirteen new interpretations, which describe, explain and provide a comprehensive understanding of the key factors and experiences influencing the decision making process.

Conclusion: By understanding these thirteen key factors identified in this synthesis, stakeholders can develop better support systems and interventions tailored to the unique needs of informal caregivers and people with dementia, ultimately improving their well-being and the quality of care for both.

Table of Contents

Glossary VI
List of Figures VII
List of Tables VII
1 Introduction 1
1.1 Informal carers 1
1.2 Theoretical Background and Rational 3
1.3 Objective 5
2 Methods 6
2.1 Phase 1 Selecting meta-ethnography and getting started 7
2.2 Phase 2: Deciding what is relevant 7
2.3 Quality appraisal of included studies 9
2.4 Phase 3: Reading included studies 10
2.5 Phase 4—Determining how studies are related 10
2.6 Phase 5—Translating studies into one another 11
2.7 Phase 6 & 7 —Synthesizing the translations & expressing the synthesis 11
3 Findings 13
3.1 Identification and selection of studies 13
3.2 Characteristics of included studies and quality appraisal 15
3.3 How studies are related to each other 24
3.4 Outcome of translation 26
3.5 Outcome of synthesis process 28
3.5.1 Critical dementia related behaviors and incidents 29
3.5.2 Impact on caregivers' physical and psychological health 30
3.5.3 Damaged family relations 31
3.5.4 Informal help and coping strategies: useful if possible 32
3.5.5 Formal support: relief or frustration 33
3.5.6 Actively seeking for information and advice or being trapped in hopelessness 35
3.5.7 The placement decision: a complex and multidimensional effort 37
3.5.8 Drastic experiences and struggles in decision- making 39
3.5.9 Weighting up pros and cons in the decision-making process 42
3.5.10 Harmonious decision-making 44
3.5.11 Conflict-ridden decision-making 45
3.5.12 Outsourced or enforced decision-making 47
3.5.13 Refusal of relocation 49
3.6 A lines of argument synthesis of the third order constructs 50
4 Discussion 52
4.1 Implication for policymakers, health professionals and future research 55
4.2 Strengths, limitations and reflection 56
4.3 Conclusion 57
5 References 58
6 Appendix 64

Glossary

Caregiver burden: Is defined as the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time (Liu et al., 2020)

Interprofessional shared decision making: This is a collaborative approach that ensures healthcare decisions are made with input from professionals, care recipients and their family, leading to more personalized and effective care (Légaré et al., 2011b)

Qualitative synthesis: Is defined as any methodology whereby study findings are systematically interpreted through a series of expert judgements to represent the meaning of the collected work and where findings of qualitative studies are pooled (Bearman et al., 2013)

Meta-Ethnography: This approach facilitates a systematic and comprehensive understanding of the relationships between studies by comparing their findings both within individual studies and across multiple studies. The results are then coded and condensed into themes, which collectively offer an interpretation of the entire body of research (Noblit & Hare, 1988)

Theme: This term is not generally defined and depend on the researcher being referred to. Though, the underlying meaning remains the same: themes are abstract and nuanced expressions, patterns, or processes that help to explain a phenomenon (Mishra & Dey, 2022)

Concept: This term is defined as an abstract idea or a general notion that represents a category of phenomena or constructs. Concepts are used to describe, understand, and explain various aspects of the social world. They help researchers to identify, organize, and communicate key elements of their study (Miles et al., 2014)

Metaphor: This term means figures of speech where a term or phrase is applied to something to which it is not literally applicable, in order to suggest a resemblance and to provide deeper insight into a concept, situation, or phenomenon. Metaphors are used to convey complex ideas in more relatable and understandable terms by linking them to familiar experiences or concepts (Lakoff & Johnson, 1980)

Construct: This term is defined as an abstract concept or theoretical idea that is specifically devised to understand and explain a particular phenomenon. Constructs are used to form hypotheses, develop theories, and structure research questions. They provide a framework for the collection and interpretation of qualitative data (Miles et al., 2014)

List of Figures

Figure 1. Theoretical Framework on Interprofessional Shared Decision Making (Légaré et al., 2011b) 4
Figure 2. Seven-Phase Process of the eMERGe Reporting Guidance (France et al., 2019) . 6
Figure 3. PRISMA Flowchart (Page et al., 2021) 14
Figure 4. Example of Primary Data Synthesis of the Primary Authors Interpretations...... 27
Figure 5. Simplified Model of a Lines of Argument Synthesis.......... 51

List of Tables

Table 1. Components of SPIDER.......... 8
Table 2. Example Search Strategy PubMed 9
Table 3. Critical Appraisal of Primary Studies.......... 16
Table 4. Summary of Main Study Characteristics.......... 18
Table 5. Sample List of Key Concepts of Each Study and Categorization* Into Relevant Themes 25
Table 6. Reciprocal & Refutational Synthesis - Third Order Constructs Developed by the Review Author.......... 64

1 Introduction

Dementia is described as a syndrome of chronic progression. This condition primarily affects older adults but should not be seen as a natural part of the aging process (World Health Organization [WHO], 2023), as it also impacts individuals under 65 years of age (Holdsworth & McCabe, 2017). According to the WHO (2023), dementia encompasses a range of diseases that impair cognitive functions such as memory, orientation, behaviour, and communication. The most common form of dementia is Alzheimer's disease, but other types include vascular dementia and various diseases that contribute to the syndrome. Dementia is one of the leading causes of care dependency globally, resulting in significant loss of autonomy and impaired daily living for those affected (Alzheimer's Association, 2023).

Approximately 50 million people worldwide are living with dementia, and about 130,000 individuals with dementia reside in Austria. This number is expected to double over the next 30 years (WHO, 2023; Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz [Federal Ministry for Social Affairs, Health Care, and Consumer Protection], 2023a). A systematic review and meta-analysis on dementia prevalence in the European Union revealed a prevalence rate of 7.1% among 18,263 participants, standardized for age and sex (Bacigalupo et al., 2018). The pooled estimate for individuals 65 years and older is 12.4% (95% CI: 7.6%-17.2%). The prevalence of dementia increases with age and tends to manifest earlier in women than in men (women: 80-84 years vs. men: 85-89 years).

The demographic trend, coupled with the rising prevalence of dementia, has significant implications for health care systems globally and nationally. In 2015, global dementia-related medical and healthcare costs amounted to €750 billion, nearly 1% of the global gross domestic product (WHO, 2023). In Austria, the average annual expenses related to dementia are estimated at €2 billion. Additionally, there is substantial burden on informal caregivers (Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz, 2023b).

1.1 Informal carers

In this review, the term 'informal carers' refers to individuals such as family members, friends, or neighbours who provide support for a person with dementia.

According to a global report from Alzheimer's Disease International (2018), over 90% of affected individuals in low-income countries (e.g., Afghanistan and Ethiopia(Our

World in Data, 2024)) are cared for at home, compared to over 60% in high-income countries (e.g., Australia and Germany (Our World in Data, 2024)). Of these, 40% of informal carers are spouses, and worldwide, women constitute 55% to 91% of informal carers for people with dementia. In Austria, approximately 80% of the 130,000 individuals affected by dementia are cared for at home, with about 20% residing in nursing homes (Competence Center Integrierte Versorgung, 2020). Pertl et al. (2019) highlight that informal carers are a valuable and cost-saving resource in healthcare.

Home care for people with dementia is often a long-term commitment. For instance, in Great Britain, 30% of caregivers have been caring for their relatives with dementia for five to ten years (NHS Digital, 2017). Despite the demanding nature of caregiving, many people are willing to care for someone with dementia (Klie, 2014; Greenwood & Smith, 2019). Relatives feel a sense of obligation and are motivated by long-standing family relationships, personal affection, filial piety, duty, and sometimes guilt (Greenwood & Smith, 2019). However, demographic shifts and occupational mobility can challenge this willingness (Trukeschitz & Schneider, 2015).

Franke et al. (2019) found that distance caregiving can lead to perceived loss of control over the local caregiving situation. A recent systematic review (Lindt et al., 2020) on the burden experienced by informal caregivers of individuals with dementia highlights various stressors, including cognitive decline and behavioral problems of the care recipient, contributing to caregiver stress. The review emphasizes that the number of caregiving hours can lead to role conflict and overload, further exacerbating caregiver stress.

As dementia progresses, the increasing care dependency, safety concerns, neuro-geriatric symptoms, or the inability of informal carers to continue due to psychological, practical, economic, and health-related burdens often necessitate nursing home placement (Benedetti et al. 2013; Ducharme et al., 2012). A systematic review and meta-analysis by Toot et al. (2017) identified factors associated with nursing home placement, including poorer cognition, increased functional dependence, hip fractures, reduced mobility, multimorbidity, and caregiver burden.

1.2 Theoretical Background and Rational

One goal of caring for individuals with dementia is to enable them to stay at home or return home quickly after episodic institutionalized care (Alzheimer Society of Canada, 2016). Given that most people with dementia are cared for at home and there is currently no treatment to cure or slow the progression of the disease (WHO, 2023), informal carers must consider what is best for their situation, focusing on person-centered choices and preferences.

Abrupt, unplanned, and uninformed transitions to nursing homes can hinder older individuals from aging in their preferred environment and lead to anxiety, distress, and frustration (Sussman et al., 2018). Poor quality of life can result for nursing home residents, while better-supported caregivers with more options and information can make more reflective decisions, understanding that most people prefer to stay at home (Caron et al., 2006).

To facilitate healthcare services and involve all relevant actors in the care of individuals with dementia, shared decision-making has become crucial (Kuzel, 2009). Charles et al. (1999) describe shared decision-making as a collaborative process between health professionals and patients. However, common shared decision-making models focus on the patient-health professional relationship and are not always applicable in the interprofessional home care setting (Légaré et al., 2011a). Therefore, an interprofessional shared decision-making model (IP-SDM) can be useful as informal caregivers are often restricted in their autonomy and decision-making (Légaré et al., 2011a).

This review utilizes the theoretical framework of interprofessional shared decision-making as described by Légaré et al. (2011b) and illustrated in Figure 1. Interprofessional shared decision-making involves a process where healthcare providers identify a health problem requiring decision-making, clarify it with the person at the center of the process, their informal caregivers, and involved health professionals. Evidence-based options are presented, wishes and ideas of all parties are considered, and a consensus is reached on the best option for the person concerned. Légaré et al. (2011b) recommend that informal caregivers participate as decision-makers when those affected cannot be actively involved.

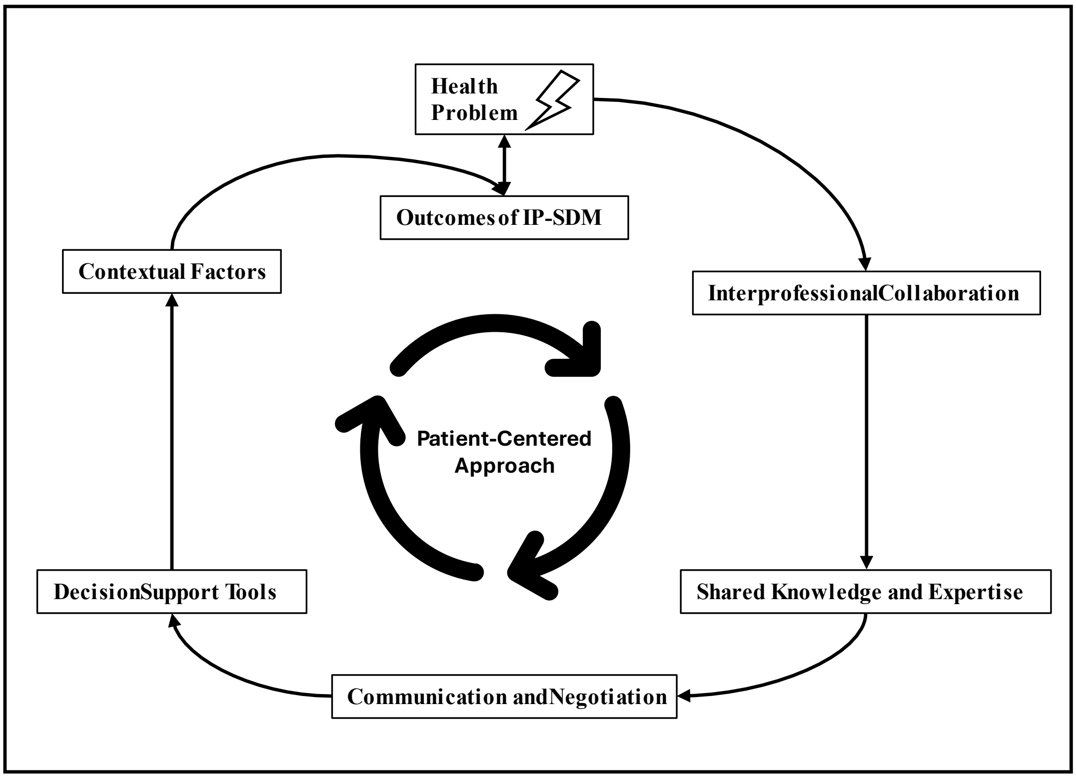


Figure 1. Theoretical Framework on Interprofessional Shared Decision Making (Légaré et al., 2011b)

Research shows that informal carers need more support in decision-making and opportunities to participate in housing decisions for their care recipients. However, support and guidance from health professionals are often lacking (Lord et al., 2015; Competence Center Integrierte Versorgung, 2020). Additionally, more evidence on different perspectives of the decision-making process of people with dementia and their informal caregivers regarding nursing home placement is needed (Lord et al., 2016; Couture et al., 2020). A deeper understanding of this process can aid in developing interventions to assist informal carers and people with dementia, allowing them to remain at home longer (Low et al., 2017).

1.3 Objective

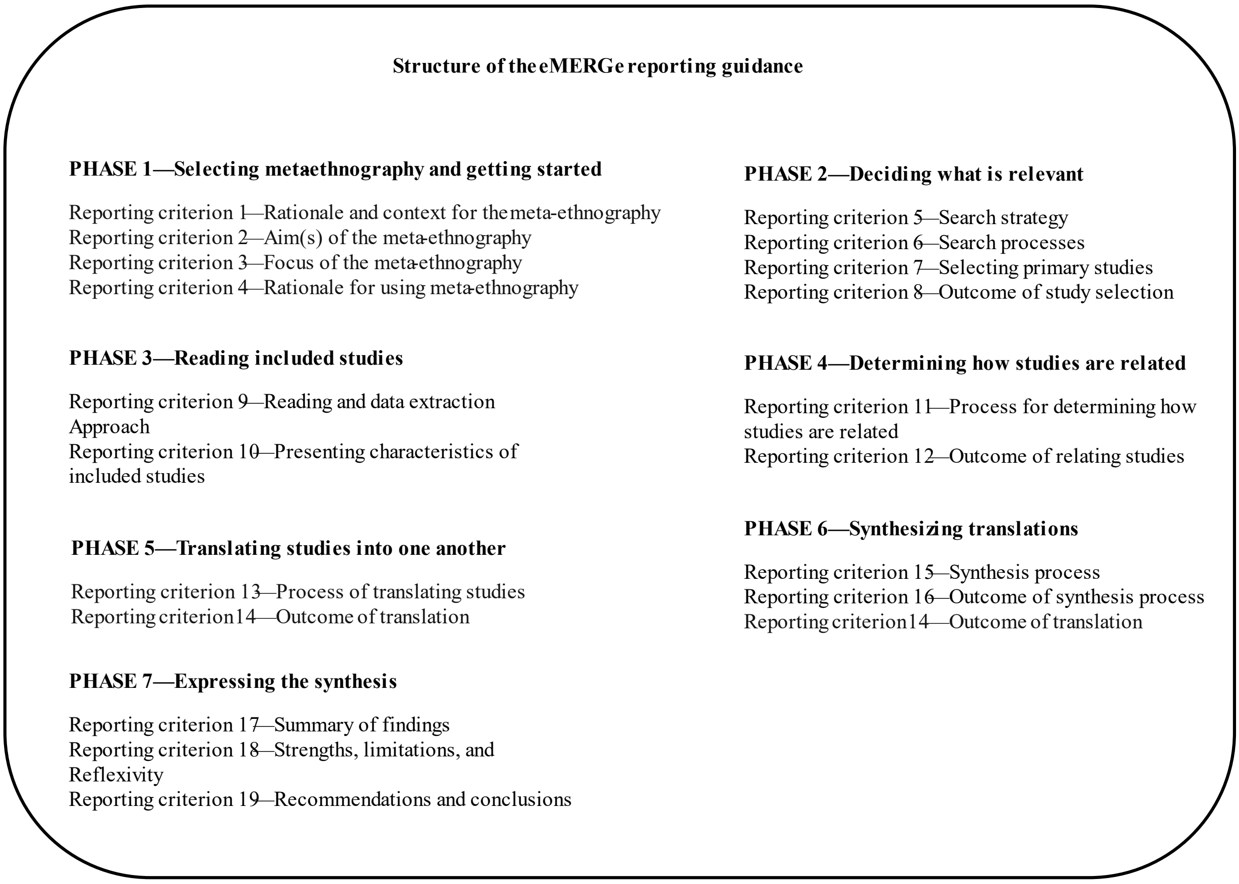
The principal objective of this qualitative review is to systematically review and synthesize literature regarding the experiences and determinants influencing both, informal caregivers and people with dementia, during the decision-making process to move the person with dementia to a nursing home. Findings of personal views and experiences in this decision-making process may support the planning and creation of recommendations to better support this population. The research questions are:

- Which determinants can be identified from the literature that influence the decision of informal carers to move their relatives with dementia to a nursing home?

- What is the evidence in the literature on how informal carers of people with dementia experience the decision-making phase for moving to a nursing home?

2 Methods

To conduct this qualitative review a meta-ethnographic approach has been chosen and the synthesis approach of Noblit & Hare (1988) was employed as reported in Frances´ et al. (2019) eMERGe guidance of meta-ethnography. To increase the transparency and completeness of conducting and reporting a meta-ethnography, the eMERGe reporting guidance was developed (France et al., 2019). The eMERGe guidance involves a seven-phase process (Figure 2) and reaches beyond the summery of qualitative evidence and towards generating new understandings and meanings.



Structure of the eMERGe reporting guidance

PHASE 1—Selecting metaethnography and getting started

Reporting criterion 1—Rationale and context for the meta-ethnography
Reporting criterion 2—Aim(s) of the meta-ethnography
Reporting criterion 3—Focus of the meta-ethnography
Reporting criterion 4—Rationale for using meta-ethnography

PHASE 2—Deciding what is relevant

Reporting criterion 5—Search strategy
Reporting criterion 6—Search processes
Reporting criterion 7—Selecting primary studies
Reporting criterion 8—Outcome of study selection

PHASE 3—Reading included studies

Reporting criterion 9—Reading and data extraction
Approach
Reporting criterion 10—Presenting characteristics of
included studies

PHASE 4—Determining how studies are related

Reporting criterion 11—Process for determining how
studies are related
Reporting criterion 12—Outcome of relating studies

PHASE 5—Translating studies into one another

Reporting criterion 13—Process of translating studies
Reporting criterion 14—Outcome of translation

PHASE 6—Synthesizing translations

Reporting criterion 15—Synthesis process
Reporting criterion 16—Outcome of synthesis process
Reporting criterion 14—Outcome of translation

PHASE 7—Expressing the synthesis

Reporting criterion 17—Summary of findings
Reporting criterion 18—Strengths, limitations, and
Reflexivity
Reporting criterion 19—Recommendations and conclusions

Figure 2. Seven-Phase Process of the eMERGe Reporting Guidance (France et al., 2019)

2.1 Phase 1 Selecting meta-ethnography and getting started

In the light of the introduction, theoretical background and rational of the current work, findings from recent research indicate that qualitative evidence of determinants and experiences on the decision-making process of informal caregivers and people with dementia before a decision on relocation is made is lacking (Greenwood & Smith, 2019; Franke et al., 2019; Lindt et al., 2020; Lord et al., 2015; Competence Center Integrierte Versorgung, 2020). To plan future support interventions and to address adequately needs and preferences of informal caregivers and people with dementia, evidence on the experiences and influencing factors in the decision-making process is crucial.

Therefore, meta-ethnography is a dynamic method for synthesizing qualitative research and is gaining prominence in healthcare research (Cahill et al., 2018). A meta-ethnographic approach provides a more detailed description of methods and offers higher-order interpretation, what Atkins et al. (2008) name an overarching explanation of a phenomenon that extends beyond the implications of individual study components, compared to a conventional narrative literature review. Sattar et al. (2021) stated that this approach can help generate evidence for healthcare staff, researchers, and policymakers. Despite its increasing use by many reviewers, there remains a lack of transparency and clarity on how each stage should be conducted and the specific steps reviewers take to achieve their final synthesis. The primary goal of qualitative research synthesis in healthcare is to enhance patient care and experience while also improving the processes for healthcare professionals (France et al., 2019).

Primarily, the intention to choose a meta-ethnographic approach in this work was that it would allow the researcher to get a deeper understanding and to generate a conceptual model of informal carers´ and people with dementia subjective experiences and factors, which arise in the decision-making process to move a relative with dementia to a nursing home.

2.2 Phase 2: Deciding what is relevant

As stated by Toye et al. (2014), consensus concerning the number of possible studies needed to be searched is lacking. For that reason, a comprehensive systematic search strategy was completed for this meta-ethnography. To support transparency on reporting of the search strategy and procedures, recommendation followed the developed Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement by Page et al. (2021).

To generate a thorough search string, the components of the research questions were transferred into the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research Type) search strategy tool. According to Cooke et al. (2012) this helps to structure all contextual criteria for defining key elements of this review, to select applicable keywords and to support study selection due to explicit inclusion and exclusion criteria. Table 1 outlines eligibility criteria and search terms based on SPIDER.

Table 1. Components of SPIDER

	Inclusion Criteria	**Exclusion Criteria**	**Search Terms**
Sample	Informal carers and people with dementia in the home care setting	Studies that examine health care worker´s views and experiences	(“informal car*” OR spouse OR relativ* OR member* OR famil* OR care* OR lay*) AND (“cognitive impair*” OR dement*”)
Phenomenon of Interest	Associated and reported determinants and experiences on the decision making process of informal carers to move their relatives with dementia to a long-term inpatient care facility	Where the decision is already made or the qualitative data cannot be identified	(decision* OR “decision making” OR choic*) AND (“place of care” OR move* OR reloc*)
Design	Qualitative studies reporting primary qualitative data, through interviews or focus groups	Studies without a description of qualitative method	(interview* OR focus group*)
Evaluation	Qualitative analysis of affected people´s views, experiences, opinions, attitudes, perceptions, beliefs, feelings, knowledge and understandings in the decision making process towards the movement of their relatives	Studies without explicit qualitative data concerning the review questions	(view* OR experienc* OR opinion* OR attitude* OR perce* OR belie* OR feel* OR know* OR understand*)
Research Type	Qualitative articles published between no date limit – March 2024 in English and German language	Systematic reviews, protocols, theoretical work and editorials	(qualitative*)

The author considers it necessary to detect an extensive range of qualitative information to obtain enough data on the topic and to enable meaningful and rigorous conceptual categories as stated by Toye et al. (2014). Therefore, a comprehensive systematic search strategy derived from the SPIDER components was performed in six databases, Public Medicine (PubMed), Excerpta Medica dataBASE (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubPsych, BibNet and Gerontologische Literatur

(GeroLit). To cover a wide range of potential studies, the search strategy was extended to an open search in online search engines such as GoogleScholar, MetaGer and DuckDuckGo, as well as searching for grey literature via an open search in GreyLit and OpenGrey and a hand search of references. Also, only one limitation was used in databases and search engines, namely language (English & German), to gain as many qualitative articles as possible. As an example, the used search strategy in PubMed is presented in Table 2.

Table 2. Example Search Strategy PubMed

S1	**(“informal car*” OR spouse OR relativ* OR member* OR famil* OR care* OR lay*) AND (“cognitive impair*” OR “dement*”)**
S2	(decision* OR “decision making” OR choic*) AND (“place of care” OR move* OR reloc*)
S3	(interview* OR focus group*)
S4	(view* OR experienc* OR opinion* OR attitude* OR perce* OR belie* OR feel* OR know* OR understand*)
S5	(qualitative*)
S6	S1 AND S2 AND S3 AND S4 AND S5

For the study screening, the a priori defined in- and exclusion criteria (Table 1) were applied. Primary in title and abstract screening, and secondary by full-text of generated studies. All search results of the database were uploaded to Endnote software (EndNote 20, 2013) and duplicates were removed. All remaining citations were exported to Rayyan software (Ouzzani et al., 2016), which supports the screening of articles and was one of the most popular and high in usability scored tools in a survey by Harrison et al. (2020). Title and abstracts were screened by the author of this meta-ethnography (TF). If there appeared any dubiety, the study full text was read. Two reviewers (TF and YG) independently used the eligibility criteria to screen included full-text articles and the supervisor of this work (MH) screened 10% of eligible articles, by screening every eighth paper. Where dissent emerged this was dissolved through consensus by MH who helped to facilitate a final decision. Results of included and excluded studies at each stage of screening is presented as suggested by Page et al. (2021) in the PRIMSA flowchart (figure 3) in the findings section.

2.3 Quality appraisal of included studies

The critical appraisal and quality assessment of primary studies in qualitative systematic reviews was discussed by Carroll & Booth (2015). They showed, that excluding weak or poor-quality studies can lead to a constricted generalisability of the synthesis. They suggest to critically appraise primary studies based on a priori appraisal criteria, to use these findings in terms of a post- hoc sensitivity analysis. In the current synthesis included studies with weak methodological and theoretical rigor are going to be excluded post synthesis and the synthesis findings from both, primary synthesis and the post- hoc excluded one are going to be compared. To select appropriate studies for the post- hoc sensitivity analysis, criteria can include for instance, if adequate or appropriate sampling and data collection methods were used (Carrol & Booth, 2015). Therefore, the Joanna Briggs Institute Checklist for Qualitative Research was chosen (Lockwood et al., 2015), because this is known to be the most sensitive tool to critically assess methodological validity to attempt congruity (Hannes et al., 2010).

Two independent reviews (TF and YG) critically appraised included studies, using the before mentioned appraisal tool. In this stage, sensitivity regarding primary study context and the research questions of this meta-ethnography has been checked, as recommended by Carroll & Booth (2015). Studies were excluded only by the preassigned eligibility criteria (Table 1) or where there was no insight in the decision-making process of informal carers to move their relatives with dementia to a nursing home. The two reviewers compared the outcomes of the critical appraisals and variances has been discussed with MH if any appeared.

However, according to Garside (2014) no study will be excluded due to quality assessment. Hence, the results of the quality appraisal will be used within the synthesis and interpretations of the included studies (Carroll & Booth, 2015).

2.4 Phase 3: Reading included studies

As mentioned by Noblit & Hare (1988) the analytical and synthesis process in meta-ethnography is based on reading and re-reading all included studies in depth to get familiar with their content. This is crucial for data extraction and synthesis, as perceptions, opinions, experiences or conceptual theories in results of primary literature are seen as raw data of meta-ethnography (Toye et al., 2014). These raw data of expressions of study participants are called first order constructs (Atkins et al., 2008). Many authors of meta-ethnographies used Schutz's (1971) definition of "second order constructs", which are the researcher´s results of the included studies. Following France et al. (2019) guidance, also phase 3 was performed by two reviews independently (TF and YG). Each one used a standardised data extraction form and collected data concerning `article citation´, `country´, `setting´, `sample & participant characteristics´, `study aims´, `data collection and analysis´ and `main themes´. All first- and second order constructs of primary studies were extracted.

2.5 Phase 4—Determining how studies are related

In phase four of meta-ethnography, relation between each study is going to be determined (Noblit & Hare, 1988; France et al., 2019). In this process, first and second order constructs were discussed and compared in context of emerging concepts and how the first and second order constructs from the included studies relate to each other and to the review questions (France et al., 2019). TF generated codes that explained descriptive themes of each study. YG also independently coded explanations of descriptive themes from a selection of studies to compare findings with TF and if the understanding of generated descriptive themes from included studies was similar. Discrepancies were solved in discussion. Both TF and YG met regularly and discussed their interpretations of concepts across the included studies and by reference to the original context (Atkins et al., 2008). The interpretation and synthesis process of first and second order constructs was leading to new descriptive themes. This helped to identify similarities and differences between included studies, and this can be seen as a pre – stage that informs the translation process in phase five as outlined by Noblit and Hare (1988).

2.6 Phase 5—Translating studies into one another

In this phase the translation from one study into another was performed (Noblit & Hare, 1988; France et al., 2019). Authors of meta-ethnography use different approaches of translating studies into each other (France et al., 2019). In this review the approach described by Atkins et al. (2008) was followed, in which the included studies are arranged chronologically by publication date. Thereafter, first and second-order constructs grouped in new descriptive themes of the first study were translated reciprocal and where necessary refutational with the first and second order constructs of study two. This synthesis was compared with study three and leaded to a next new synthesis and was compared with study four and so forth, until all papers were synthesized and concluded in a synthesis of the primary author interpretations for each descriptive theme.

2.7 Phase 6 & 7 —Synthesizing the translations & expressing the synthesis

In the final process of meta-ethnography, in phase six and seven, the synthesised primary author interpretations for each descriptive theme were crosschecked and compared between all studies and their primary first and second order interpretations. By constantly comparing all relevant key concepts and metaphors within and across the included papers, new third order constructs emerged. From this third order constructs a lines of argument synthesis were performed and the key components of the lines of argument synthesis were illustrated in a simplified model, in which a deeper understanding on experiences and determinants in the decision-making process of informal carers to move their relatives with dementia to a nursing home will be presented as a whole. As stated by France et al. (2019) one synthesis can lead to more than one product. Therefore, the lines of argument synthesis can be interpreted as product for both initial research questions, given that experiences and determinants in the decision-making process may appear simultaneously (Lord et al., 2015). Conceptual categories and lines of argument synthesis were summarized narratively. Coded concepts, tables and figures were used to support narrative findings and to increase credibility.

3 Findings

The presentation of findings of the current meta-ethnography follows the structure of the eMERGe reporting guidance from France et al. (2019), given in Figure 2 of the methodology section. The following chapters represent the reporting outcomes of all relevant phases of meta-ethnography and show step by step the synthesis processes with additional methodological explanations.

3.1 Identification and selection of studies

Through the electronic search 6.525 references were identified. After removing duplicates 4495 remained and from these references titles and abstracts were screened by means of Rayyan software (Ouzzani et al., 2016). 4269 references were excluded in the screening of titles and abstracts. The full text of the remaining 226 references were retrieved and 176 were excluded after full-text screening, resulting in 50 papers, from which two papers were identified through other sources. The 50 papers were re-read and their suitability for inclusion to synthesize the primary data regarding to the review questions were checked again. 37 papers were excluded at this stage and reasoning is presented in a supplementary file which can be provided by the author of this review. Finally, 13 papers were included in the synthesis, whereas one study represents two papers (Chang et al., 2010; Chang et al., 2011). The process of the identification and selection of studies is shown in a PRISMA flow chart (Figure 3).

As the review process developed, some studies due to the eligibility criteria were critically discussed again because they included experiences and sights of family care givers, views from people with dementia and partially insights from health professionals. Also, single studies reported either on the decision-making process before and after applying their care recipient to a waiting list for a long-time care facility. Nonetheless, as the original research focus of this studies aimed the context of the review questions of this meta-ethnography, it was decided to include all relevant studies. To ensure trustworthiness, all information on the associated and reported determinants and experiences on the decision-making process of informal caregivers and people with dementia before a decision was made were analyzed to the same extent.

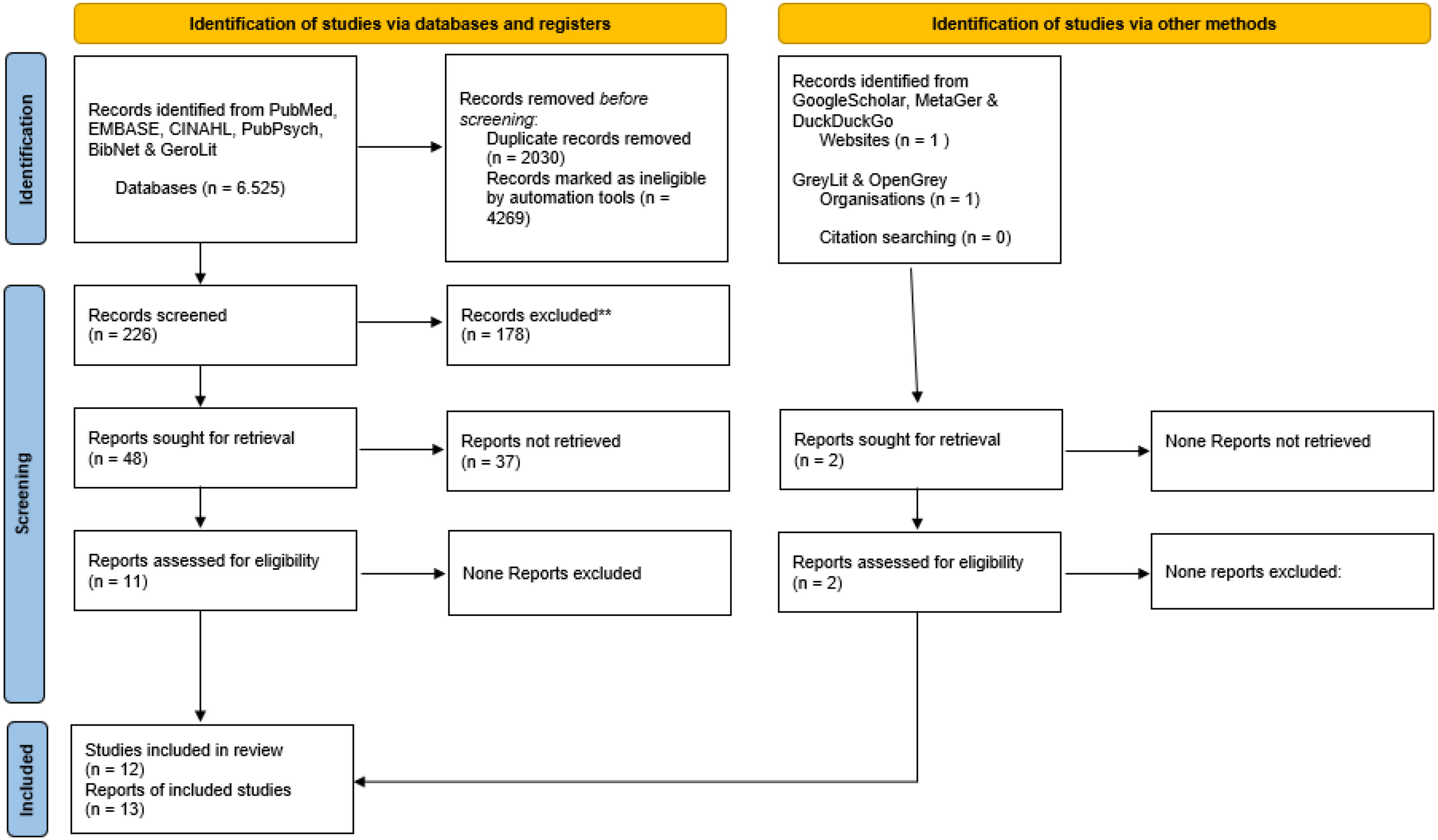


Figure 3. PRISMA Flowchart (Page et al., 2021)

3.2 Characteristics of included studies and quality appraisal

Table 4 provides a summary of the main characteristics of the 13 included papers, representing 12 studies. The papers were arranged chronologically from 1 to 13 according to their publication date (see table 4). Five (41.66%) of the studies were undertaken in European Countries and seven (58.34%) of the studies in non-European Countries. The studies which were conducted in Europe, three (60.0%) were from the United Kingdome, one (20%) from Norway and one (20%) from the Netherlands. Studies from non-European Counties were three (42.86%) from Canada, two (28.57%) from Australia, one (14.28%) from USA, and one (14,28%) from Taiwan. The studies were published between 2006 and 2023, with four (33.34%) published in the last seven years.

The 12 studies included 277 participating caregivers and 58 people living with dementia. In 11 studies most informal caregivers were female (57% to 83.3%), and the mean age ranged from 49.3 to 78.8 years. In four studies participating people with dementia were included and 33%-60% were female and the mean age ranged from 65 to 83.7 years. There was information on the housing situation in six studies, which reported that 60 caregivers lived with the person with dementia in the same household and that 23 people with dementia lived alone. Six studies did not mention any information on the housing situation. None of the studies specified a type of dementia.

Nine studies sampled participants from specialist services (e.g., community agencies, general practitioners, voluntary organizations & research advertisement) and three studies from inpatient services (e.g., longtime care facility administration, aged care psychiatry units &herontic-psychiatric units). Eleven studies used a purposive sample strategy and one study a consecutive sample. All included studies used data collected by semi-structured or narrative face to face interviews. Seven studies analyzed data in a thematical manner, one ethnographical, one interpretative, one on basis of grounded theory, one with iterative inductive quality analyses and one study did not mention any analytical method at all.

All in all, the studies had an acceptable methodological quality, with only one study being limited due to missing information about methodological design, analysis, researcher reflexivity and ethically considerations. The author of the study was contacted and asked for further details but did not respond. Overall quality appraisal is presented in Table 3

Table 3. Critical Appraisal of Primary Studies

First Author/ Year	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice- versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Chene 2006	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Unclear	Yes	No	Yes
Strang et al. 2006	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Chang et al. 2010	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Chang et al. 2011	Yes	Unclear	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Drennan et al. 2011	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes
Thein et al. 2011	Not applicable	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Ducharme et al. 2012	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
St. Amant et al. 2012	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Caldwell et al. 2014	Yes	Unclear	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Cole et al. 2017	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Larsen et al. 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Van Wijngaarden et al. 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Taylor et al. 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

The most severe limitations in five studies concerned the researchers culturally and theoretically context and how researchers could have influenced research outcomes in seven studies.

Interestingly, no linkage between the study methodological quality and the usefulness of their findings to the synthesis process was found. A post- hoc sensitivity analyses from the study interpretations at phase 6 and 7 showed that there are no other synthesis findings, when poor quality studies are excluded during the synthesis process. According to Atkin et al. (2008) this indicates a mainly thick nature of qualitative data and that the primary studies thickness, respectively their texture of descriptions can be synthesized in third order constructs with rich meaning.

By reporting methods and findings systematically, and describing comprehensively the analyses and interpretations, poorer quality studies also had impact on the understanding on the associated and reported determinants and experiences on the decision-making process of informal caregivers and people living with dementia.

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Table 4. Summary of Main Study Characteristics

Study Reference, country & arrangement	**Aim**	**Sampling & Recruiting**	**Participant characteristics**	**Data Collection**	**Analysis & Data Saturation**	**Main themes**	**Sub themes**
Chene 2006 **Australia** **1**	To find out what carers' lived experiences are when they are making the difficult decision of relinquishing full-time care of their relative who´s located in an Aged Care/Aged Psychiatric setting	Consecutive sampling via gatekeepers in aged care/psychiatry Units	N = 20 caregivers Mean carer age: 64a Mean carer spousal age:71a 75% female 11 caregivers lived with person with dementia, 5 persons with dementia lived alone	Face to face in-depth interviews with opened ended questions (Ø 1h)	No analytical method stated Data saturation not mentioned	**a)** Care Recipient Problem Behaviours **b)** Use of Informal Supports by Family Caregivers **c)** Use of Formal Supports by Family Caregivers **d)** Traumatic Admissions to the Unit **e)** Complex Admissions **f)** Caregiver Grief: Loss, Sadness and Resignation **g)** Caregiver Anxiety: Guilt, Worry and Uncertainty	None
Strang et al. 2006 **Canada** **2**	To present selected findings of a study that explored the experience of family caregivers while they awaited placement of their family members with dementia and how they coped during this period of waiting and transition	Purposive sample via gatekeepers through the Central Assessment Placement Services branch of the Capital Health Authority.	N = 29 caregivers Mean age: ~ 60.4a 75.86% female Housing situation not mentioned	Face to face open ended interviews with guiding questions and field notes of observations (Ø 60 min)	Descriptive interpretative analysis (Thorne et al., 1997). Data categories were coded in a higher level of conceptual complexity (Strauss & Corbin, 1998) Data saturation not mentioned	**a)** Crisis as initiator **b)** Need for synchronicity **c)** Control **d)** Reciprocity	None
Chang et al. 2010* **Taiwan** **3**	To understand the Chinese family caregivers' decision-making process of nursing home placement	Purposive sampling via gatekeepers in one nursing home & geropsychiatric clinic	N = 30 caregivers Mean age: 49.3a (± 11.1) 63.3% female 29 lived with person with dementia, 1 living in separate household 11 with nursing home placement, 19 with no nursing home placement	Face to face in –depth interviews with semi-structured interview guide (Ø 45-120min)	Data analysis steps of open, axial, and selective coding for developing a theory according to Strauss & Corbin (1998) Data saturation was reached	**a)** Stage I: Initiating the Placement Decision **b)** Stage II: Assessing and Weighing the Decision **c)** Stage III: Finalizing the Decision **d)** Stage IV: Evaluating the Decision	**a1)** Deteriorating Dementia-Related Behaviors. **a2)** Worsening Caregivers' Health Status. **a3)** Disturbing Family Life and Family Relationships. **a4)** Lacking Family Assistance and Seeking Professional Assistance.

							b1) Gathering and Comparing the Information on Care Options. **b2)** Negotiating with Families. **c1)** A consensual decision: **c2)** Partially consensual decision: **c3)** Reluctant decision: **d1)** Visiting the Elderly Frequently. **d2)** Adjusting expectations. **d3)** Reconciling Family Relationships
Chang et al. 2011* **Taiwan** **4**	To describe factors influencing decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia	Purposive sampling via gatekeepers in one nursing home & geropsychiatric clinic	N = 30 caregivers Mean age: 49.3a (± 11.1) 63.3% female 29 lived with person with dementia, 1 living in separate household 11 with nursing home placement, 19 with no nursing home placement	Face to face in –depth interviews with semi-structured interview guide (Ø 45-120min)	Thematic analysis (Braun & Clarke, 2006) Data saturation was reached	**a)** The decision-making period **b)** Chinese value of filial piety **c)** limited financial resources and information **d)** placement willingness of the older adult **e)** family disagreement **f)** distrust of nursing home care quality **g)** limited nursing home availability	None
Drennan et al. 2011 **United Kingdom** **5**	To explore the perspective of the carers on the range of problems in toileting and incontinence they deal with and the strategies for managing them	Purposive sample combined with snowball sampling through general practice, specialist community mental health services and voluntary organisations	N = 32 caregivers 21 were spouses Age (n.a.) 59.4% female Housing situation not mentioned	Face to face semi-structured interviews (n = 21) or by telephone (n =11) (Ø n.a.)	Thematic analysis (Boyatzis, 1998) Data saturation was reached	**a)** Carer developed strategies and issues of acceptability **b)** Seeking help from health professionals **c)** Consequences for carers and the need to contain excreta	None
Thein et al. 2011 **United Kingdom**	To explore the subjective experience of people with dementia of the move, including home situation before	Purposive sample via gatekeepers by the current clients of old age psychiatry services of the city	N = 18 people with dementia aged 65a or older 61.11% female	Face to face semi-structured interviews and use of filed notes for reference and clarification (Ø n.a.)	Systematically coding in major codes, emerging themes (Crabtree & Miller, 1999) and re-grouped	**a)** The realization of own difficulties **b)** Hopes and fears about the home they were moving into	None

6	the move, reasons for moving into care, expectations about the home, any pre-move visit and preparation		Housing situation not mentioned		new themes after final analysis. Data saturation untested by means of the sample size calculations based on quantitative outcomes	**c)** Their role in preparation for the move.	
Ducharme et al. 2012 Canada **7**	To build an explanatory model of the decision-making process by carrying out a prospective qualitative follow-up of family caregivers having thought about placing an elderly relative	Purposive sample through two strategies. One on basis of a five - year longitudinal study (Hébert, Dubois, Raîche, Dubuc, & the PRISMA-Estrie Group, 2008) and one of referrals from Alzheimer Society	N = 18 caregivers Mean age: 61.4a (± 13.3) 83.3 % female 7 cognitively impaired people lived alone and 11 in a retirement residence	Face to face semi-structured interviews with an interview guide comprising open-ended questions (Ø = 60-90 min)	Data analysis according to the coding paradigm developed by Strauss (1987) Data saturation was reached	**a)** Activation of Decision-Making Process **b)** Significant interactions in Decision-Making Process **c)** Identifying and Weighing Reasons For and Against Placement **d)** Longitudinal Trajectories: Activation and Cessation of Decision-Making Process	**a)** Possibility of placing elderly relative introduced by members of the social networks **a1)** Possibility of placing elderly relative introduced by caregiver **b)** Elderly person **b1)** Family/ Friends/ Neighbors **b2)** Health care professionals **b3)** Directors of elderly relative´s retirement residence (when applicable) **b4)** Visits and quality assessment of prospective living environments **d)** Cessation of decision – making process without re-activation **d1)** Switching between cessation and re-activation of Decision-Making Process **d2)** Ongoing activation of Decision-Making Process
St-Amant et al. 2012 Canada **8**	To explore both major care decisions such as institutionalization	Purposive sample via gatekeepers in community agencies and care provider agencies, identifying	N = 9 people with dementia, N = 25 family caregivers, N = 10 formal health care providers and	Face to face semi-structured interviews with open-ended questions and field notes after each	Critical ethnography (Thomas, 1993) analysis guided by Lofland et al. (2006)	**a)** Accommodating clinically defined incompetence **b)** Making untimely decisions **c)** Reinforcing exclusion in decision making	

	as well as everyday decisions for families providing care to people with dementia	potential research participants within their roster of clients	N = 7 community case mangers Mean people with dementia age: 83.7a Mean caregiver age: 50.1 Mean spouse caregiver age: 78.8a 55.56 % female people with dementia 68% female family caregivers Formal healthcare providers and community case managers were predominantly female Housing situation not mentioned	session (Ø not mentioned)	Data saturation not mentioned		
Caldwell et al. 2014 Australia **9**	(1) The decision-making process for placing a person with dementia on a waiting list for a nursing home (2) Why offers of a place in a nursing home are accepted or declined (3) The influence of cultural factors in this decision, in people living in Australia from a Chinese background compared with those from an English-speaking background	Purposive sampling via gatekeepers in nursing homes	N = 27 caregivers, 20 Chinese background and 7 English-speaking background; Mean age: Chinese 55a ± 9 English-speaking: 65a ± 16; 70.4% female; 11 lived with person with dementia, 9 persons on waiting list for nursing home placement	Face to face semi-structured interviews; three interviewed with assistance of a Chinese interpreter (Ø 1h)	Thematic analysis (Braun & Clarke, 2006) Data saturation was reached	**a)** When caregivers apply for a waiting list **b)** Reasons why caregivers apply **c)** Reasons against placement **d)** Weighting up the decision	**a1**) Not ready, so did not apply **a2)** Waiting list as first step **a3)** Ready for placement **a4)** Critical decision from hospital **b1)** Anticipated a long wait and wanted to be prepared **b2)** The caregiver could not manage **b3)** Factors of person with dementia **b4)** The facility was good **c1)** Still managing at home **c2)** person with dementia objected **c3)** Family relationships **c4)** No suitable facility **d1)** Seeking help and considering alternatives **d2)** Choosing a facility

							d3) Expectations **d4)** Emotions
Cole et al. 2017 United Kingdom **10**	To investigate the experiences of people with dementia who had incontinence problems including difficulties with using the toilet	Purposive sampling combined with snowball sampling alongside a study on family carer perceptions of supporting a person with dementia experiencing incontinence, through voluntary organisations, family carer meetings, health and social care organisations and eight general practices	N = 7 people with mild-to-moderate dementia 3 interviewed with family support Age 76a – 90a 57% female 3 lived alone and 4 with a spouse	Face to face guided conversation with an aide-memoire of the topic areas of interest and field notes (Ø not mentioned)	Thematic analysis (Boyatzis, 1998) Data saturation not reached	**a)** the type of difficulties experienced and associated feelings **b)** strategies to manage difficulties with using the toilet and incontinence **c)** help in managing incontinence	None
Larsen et al. 2018 Norway **11**	To explore family caregivers' experiences with involvement in and influence on nursing home decision-making processes for persons with dementia	Purposive sample among participants in a survey study in northern Norway, exploring family caregivers caring for people with dementia	N = 12 caregivers Mean age: ~ 60a 58% female 5 caregivers lived with person with dementia, 4 lived in the neighbourhood and 3 in a 10min driving distance.	Face to face semi-structured interviews with an interview guide including open-ended questions and field notes after each session (Ø = 56-176 min)	Interpretative coding (Tjora, 2012) Data saturation not mentioned	**a)** Self-condemning determiner position **b)** Dominant position **c)** Proponent position **d)** Saluting position **e)** Pending position **f)** Prisoner position **g)** Stooge positions	None
Van Wijngaarden et al. 2018 Netherlands **12**	Two folded aims: first, to develop an in-depth insight of what it means to live with dementia from the perspective of family members who were–to a greater or lesser extent–involved in the care of their loved one. Second, to gain insight into what constitutes the art of living with dementia.	Purposive sample with maximum variation cases through research advertisement	N = 47 caregivers Age: 20a - 80a 43.24% female Housing situation not mentioned	Face to face semi-structured in- depth interviews with an interview guide (n = 47), focus group interviews (n = 10) and observational field notes (Ø n.a. for face to face interviews; Ø 1:52h focus group amount)	Inductive & thematic analysis (Finlay, 2011; Braun & Clarke, 2006) Data saturation not reached	**a)** Before the diagnosis: A growing uneasy feeling that something is amiss **b)** The diagnostic disclosure: An uncertain and upsetting relief **c)** Dementia at home: Entangled in an isolated and exhausting life **d)** Capitulation to relocation: Torn between relief and guilt **e)** The art of living with dementia	**a)** Growing suspicions and doubts. **a1)** A growing sense of disharmony **b)** A paradox of give and take **b1)** Feeling trapped in by a prospectless future **c)** A hidden and uncomprehended world **c1)** Loss of equality and reciprocity **c2)** Imprisoned in your own home **d)** The inability to keep your promise

							d1) Letting go and maintaining grip **e)** The ability to face tragedy **e1)** The discovery of meaning and dignity **e2)** Retaining a sense of connection **e3)** The primacy of attention and recognition by others
Taylor et al. 2023 **USA** **13**	To understand the lived experiences of persons with dementia and caregivers and to center the voices of persons with dementia on key decisions made and crosscutting themes related to decisions to seek more supportive care from the perspective of persons with dementia and caregivers	Purposive sample from the Alzheimer´s Disease Research Center, and from community partner organizations (i.g. assisted living facilities, senior centers, memory care facilities)	N = 24 people with mild to moderate dementia N = 37 caregivers Mean people with dementia age: 75 (65 – 88)a Mean caregiver age: 65 (42 – 88)a. 33% female people with dementia 73% female family caregivers Housing situation not mentioned	Face to face (Zoom or phone) interviews with an interview guide and hired Spanish-speaking interviewer (Ø = 45-60 min)	Iterative inductive qualitative analysis (Leavy, 2020) Data saturation not mentioned	**a)** Seeking a diagnosis **b)** Shifting of responsibility for everyday tasks **c)** Increasing safeguards and supportive care at home **d)** Increasing care **e)** Increasing and expanding informal care: **f)** Bringing in Formal Support **g)** Moving to supportive care environment **h)** Unknowns and uncertainty **i)** Maintaining life as you know it **j)** There’s no place like home **k)** Challenges of resource constraints	none

* Chang et al. 2010 & 2011 represent one study

3.3 How studies are related to each other

Focusing on the review questions of this meta-ethnography, all 13 included papers related to the prespecified aspects of the experiences and determinants about the decision-making process of informal caregivers caring for people living with dementia. To some extent all 13 papers reported on determinants that have influence on the decision-making process and some give insight in personal experiences and perceptions about the decision-making process from caregivers and people living with dementia. Table 5 presents an example list of key concepts from the 13 included studies. The original list of key concepts of each study and how they were categorized into relevant themes can be requested by the author of this review.

According to the principals of meta-ethnography, the formatting of the list of key concepts allowed to keep track of the relationships between themes or concepts of each paper (Erasmus, 2014). By juxtaposing similar key concepts through each paper, five relevant themes emerged. Namely "problems, difficulties and crisis", "help, strategies and support", "thinking about placement", "weighting up pros and cons, and struggles in decision making" and "reaching the decision, willingness, capitulation, or reasons against placement". Within the categorization process of key concepts into relevant themes according to the research questions, some concepts between the papers were found reciprocally translatable, whereas single concepts appeared to be refutational. For instance, when seeking help from health professionals, findings from paper 5 indicated that informal caregivers made negative experiences and became frustrated, but findings from paper 7 showed a beneficial aspect. Furthermore, single concepts went beyond reciprocal translation and explored different aspects of the same topic. For example, key concepts grouped under the theme "problems, difficulties and crisis" added a variety of determinants which had influence on the informal caregiver's ability to take properly care of the person with dementia. Although experiences and views of participating informal caregivers and people with dementia differed, the same determinants seemed to have influence on their caring and housing situation that affected or modulated the decision-making process for the relocation to a longtime care facility. Caregivers and people with dementia appeared as dyads, with the suffering of one increasing the distress of the other. Consolidated in the first relevant key concept, the included papers 1, 2, 3, 5, 6, 7, 10, 12 & 13 describe how care recipient behavioral problems, deteriorating caregivers´ health and damaged family relationships influence the starting point of the decision-making process, in which daily living situations become more and more burdensome for both, the caregivers and people with dementia. Due to these burdensome situations, concerned people searched for help or used strategies to manage

Table 5. Sample List of Key Concepts of Each Study and Categorization* Into Relevant Themes

Chene 2006	Strang et al. 2006	Chang et al. 2010	Chang et al. 2011	Drennan et al. 2011	Thein et al. 2011	Ducharme et al. 2012	St. Amant et al. 2012	Caldwell et al. 2014	Cole et al. 2017	Larsen et al. 2018	Van Wijngaarden et al. 2018	Taylor et al. 2023
Care Recipient Problem Behaviours	crisis as initiator	Deteriorating Dementia-Related Behaviours	The decision-making period	Carer developed strategies and issues of acceptability	the realization of own difficulties	Activation of Decision-Making Process a) Possibility of placing elderly relative introduced by members of the social networks a1) Possibility of placing elderly relative introduced by caregiver	accommodating clinically defined incompetence	When caregivers apply for a waiting list	the type of difficulties experienced and associated feelings	Self-condemning determiner position	Before the diagnosis: A growing uneasy feeling that something is amiss	Seeking a diagnosis
Use of Informal Supports by Family Caregivers	need for synchronicity	Worsening Caregivers' Health Status	Chinese value of filial piety	Seeking help from health professionals	hopes and fears about the home they were moving into	Significant interactions in Decision-Making Process b) Elderly person b1) Family/ Friends/ Neighbors b2) Health care professionals b3) Directors of elderly relative´s retirement residence (when applicable) b4) Visits and quality assessment of prospective living environments	making untimely decisions	Reasons why caregivers apply	strategies to manage difficulties with using the toilet and incontinence	Dominant position	The diagnostic disclosure: An uncertain and upsetting relief	Shifting of responsibility for everyday tasks

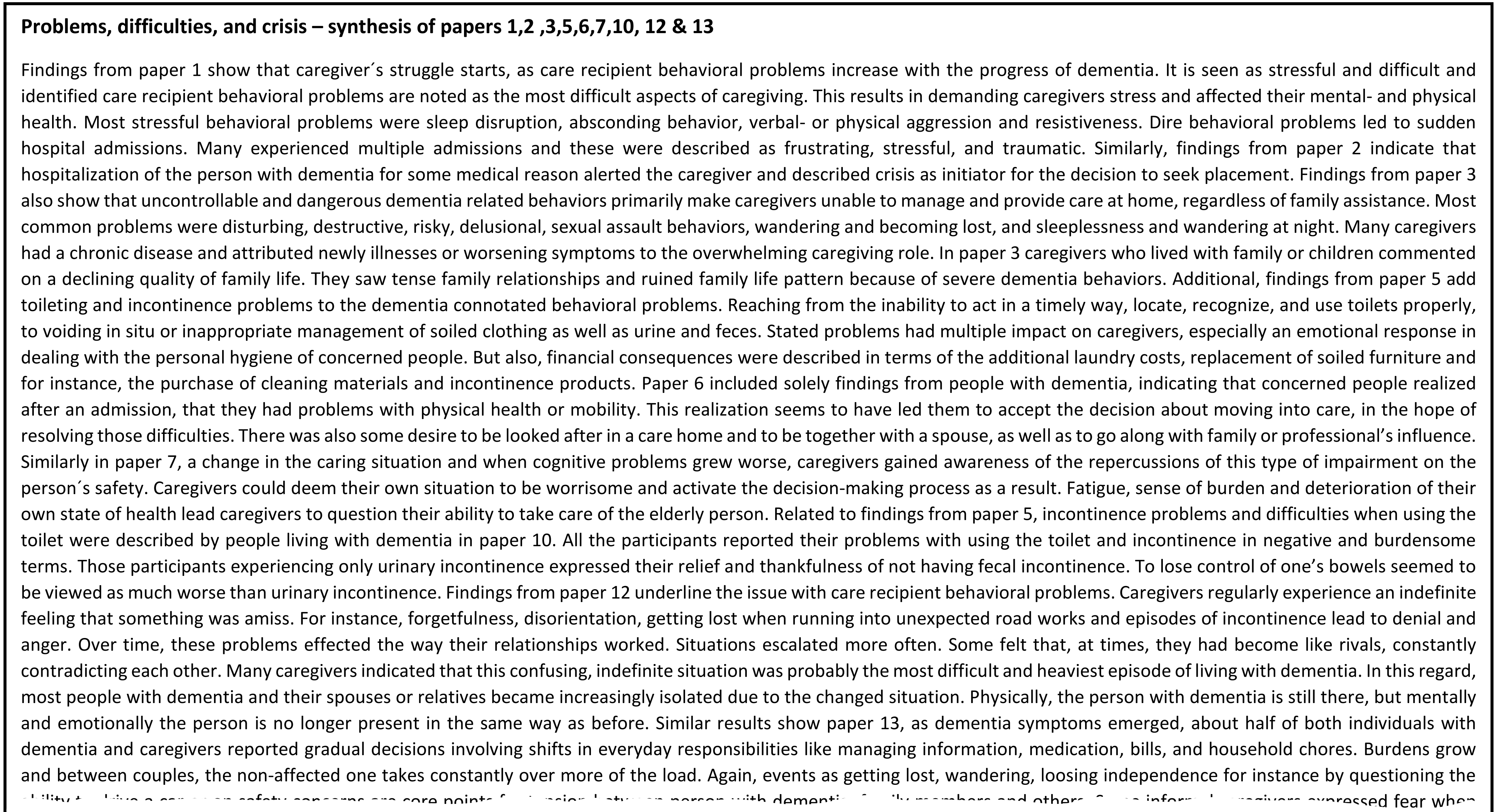
* Similar relevant concepts coded in same color

everyday problems in their living situation. Papers 1,2,3,5,6,7,9,10, 12 & 13 show how informal caregivers and people with dementia seeking for help from informal and formal support or using strategies to manage daily challenges. As mentioned before, single findings refute the experiences which were made. At some point critical incidents or the realization that formal or informal support were insufficient lead to the phase where thinking about the placement to a longtime care facility become apparent. Papers 4, 7, 8, 9 and 11 report on experiences, considerations, and forces which informal caregivers and people with dementia expressed. Once, the thought about placement developed, informal caregivers and people with dementia weighted up the impact of the decision and expressed their struggles in the decision-making process. Papers 1, 2, 3, 4, 6, 7, 8, 9 & 13 show their considerations and feelings during this stage. When juxtaposing of the key concepts developed, it appeared clearer that the decision-making process cannot be seen as a circular reasoning. Refuting expressions of papers 3, 4, 7, 8, 9, 11, 12 & 13 show that results of the decision-making process can lead to different circumstances which were stated by participants.

3.4 Outcome of translation

The translation from one study into another was based on the suggestion from Noblit & Hare (1988). This stage involved the comparison from original metaphors or concepts from one study with the metaphors or concepts from all other studies. This was done by using a translation table where all relevant first and second order constructs from original papers were compared to check for commonalities or disparities. Table 6 in appendix A presents the chronologically summarized translation from reciprocal and refutational comparisons. First and second order constructs of columns four and three are jointed in the relevant themes of the first column. With the objective of remaining faithful to the original metaphors and concepts of all papers, the terminology used in them is preserved in the translation table.

As recommended by Sattar et al. (2021) to support the translation from one paper into the others, all relevant themes were summarized and compared from one paper to the other papers. By considering where commonalities are or what one paper adds to the information given in others, this process continued until all papers were synthesized and concluded a synthesis of the primary author interpretations. Overall, the five relevant themes mentioned above were summarized in primary authors interpretations. For this purpose, primary data from first and second order constructs were synthesized. An example of a synthesis of the primary author interpretations is given in Figure 4.



Problems, difficulties, and crisis – synthesis of papers 1,2 ,3,5,6,7,10, 12 & 13

Findings from paper 1 show that caregiver´s struggle starts, as care recipient behavioral problems increase with the progress of dementia. It is seen as stressful and difficult and identified care recipient behavioral problems are noted as the most difficult aspects of caregiving. This results in demanding caregivers stress and affected their mental- and physical health. Most stressful behavioral problems were sleep disruption, absconding behavior, verbal- or physical aggression and resistiveness. Dire behavioral problems led to sudden hospital admissions. Many experienced multiple admissions and these were described as frustrating, stressful, and traumatic. Similarly, findings from paper 2 indicate that hospitalization of the person with dementia for some medical reason alerted the caregiver and described crisis as initiator for the decision to seek placement. Findings from paper 3 also show that uncontrollable and dangerous dementia related behaviors primarily make caregivers unable to manage and provide care at home, regardless of family assistance. Most common problems were disturbing, destructive, risky, delusional, sexual assault behaviors, wandering and becoming lost, and sleeplessness and wandering at night. Many caregivers had a chronic disease and attributed newly illnesses or worsening symptoms to the overwhelming caregiving role. In paper 3 caregivers who lived with family or children commented on a declining quality of family life. They saw tense family relationships and ruined family life pattern because of severe dementia behaviors. Additional, findings from paper 5 add toileting and incontinence problems to the dementia connotated behavioral problems. Reaching from the inability to act in a timely way, locate, recognize, and use toilets properly, to voiding in situ or inappropriate management of soiled clothing as well as urine and feces. Stated problems had multiple impact on caregivers, especially an emotional response in dealing with the personal hygiene of concerned people. But also, financial consequences were described in terms of the additional laundry costs, replacement of soiled furniture and for instance, the purchase of cleaning materials and incontinence products. Paper 6 included solely findings from people with dementia, indicating that concerned people realized after an admission, that they had problems with physical health or mobility. This realization seems to have led them to accept the decision about moving into care, in the hope of resolving those difficulties. There was also some desire to be looked after in a care home and to be together with a spouse, as well as to go along with family or professional's influence. Similarly in paper 7, a change in the caring situation and when cognitive problems grew worse, caregivers gained awareness of the repercussions of this type of impairment on the person´s safety. Caregivers could deem their own situation to be worrisome and activate the decision-making process as a result. Fatigue, sense of burden and deterioration of their own state of health lead caregivers to question their ability to take care of the elderly person. Related to findings from paper 5, incontinence problems and difficulties when using the toilet were described by people living with dementia in paper 10. All the participants reported their problems with using the toilet and incontinence in negative and burdensome terms. Those participants experiencing only urinary incontinence expressed their relief and thankfulness of not having fecal incontinence. To lose control of one's bowels seemed to be viewed as much worse than urinary incontinence. Findings from paper 12 underline the issue with care recipient behavioral problems. Caregivers regularly experience an indefinite feeling that something was amiss. For instance, forgetfulness, disorientation, getting lost when running into unexpected road works and episodes of incontinence lead to denial and anger. Over time, these problems effected the way their relationships worked. Situations escalated more often. Some felt that, at times, they had become like rivals, constantly contradicting each other. Many caregivers indicated that this confusing, indefinite situation was probably the most difficult and heaviest episode of living with dementia. In this regard, most people with dementia and their spouses or relatives became increasingly isolated due to the changed situation. Physically, the person with dementia is still there, but mentally and emotionally the person is no longer present in the same way as before. Similar results show paper 13, as dementia symptoms emerged, about half of both individuals with dementia and caregivers reported gradual decisions involving shifts in everyday responsibilities like managing information, medication, bills, and household chores. Burdens grow and between couples, the non-affected one takes constantly over more of the load. Again, events as getting lost, wandering, loosing independence for instance by questioning the

Figure 4. Example of Primary Data Synthesis of the Primary Authors Interpretations

The original synthesis of primary author interpretations can be requested by the author of this review. This primary data synthesis was helpful in the development of the third order constructs in the next stage.

3.5 Outcome of synthesis process

By examining all relevant key concepts and metaphors within and across the included papers, this process is described by Cahill et al. (2018) as like the method of constant comparison. During this phase the study characteristics and the full papers were considered. Each of the five relevant themes was synthesized separately by constantly compare the single papers´ key concepts or metaphors and the summarized synthesis of the primary author interpretations. To assure trustworthiness the summery and the developed third order constructs have been constantly crosschecked against the translation table. This approach also helped to ensure the consistency with the original context and data. Developed third order constructs are presented in table 6 in appendix A with illustrated quotes of the included papers.

Thirteen third order constructs contributed decisively on the associated and reported determinants and experiences on the decision-making process of informal caregivers and people living with dementia: “Critical dementia related behaviors and incidents”, “impact on caregivers’ physical and psychological health”, “damaged family relations”, “informal help and coping strategies: useful if possible”, “formal support: relief or frustration”, “actively seeking for information and experiences or being trapped in hopelessness”, “the placement decision: a complex and multidimensional effort”, “drastic experiences and struggles in decision- making”, “weighting up pros and cons in the decision-making process”, “harmonious decision-making”, “conflict-ridden decision-making”, “outsourced or enforced decision-making” and “refusal of relocation”.

These findings cannot be seen as a linear process by one effecting or inducing another, but rather sheds light into the complexity of a burdensome process many informal caregivers and people with dementia must experience. Each single third order construct can bear a different meaning to some distinct or even be irrelevant to an individual. Furthermore, informal caregivers, and people living with dementia experience similar burden in different extent or antithetical. There is selective disclosure in the way in which informal caregivers and people with dementia express the information on how they manage their housing situation and experience on the decision-making process of relocation. Thus, the different experiences and perceptions are most likely informed by their own cultural meanings and social standings. Participating people in the primary studies have different living circumstances and underwent diverse socialization. Therefore, the decision-making process can differ from case to case. However, the synthesized third order constructs were derived from all included papers and describe commonalities or disparities expressed by all participants.

3.5.1 Critical dementia related behaviors and incidents

A common perception described by informal caregivers and people living with dementia was the time when they realized something suspicious in the behavior or in everyday living situations. It can be described as a struggle´s starting point, as care recipient behavioral problems increase with the progress of dementia. Stressful behavioral problems stated were sleep disruption due to sleeplessness or wandering at night, absconding behavior, verbal- or physical aggression, resistiveness, sexual assault, wandering and becoming lost, getting difficulties driving vehicles, incontinence problems or difficulties when using the toilet and general disturbing, destructive and risky behaviors. If these behaviors can be excused and managed, both, informal caregivers and people living with dementia find ways to get along with each other. At some point, when the behavior offends informal caregivers or strangers or for instance becomes problematic especially with emotional response in dealing with the personal hygiene according to incontinence problems, the caring or housing situation becomes unbearable, as illustrated by the following quotes:

> *"She was always calling out. I had to check the locks, as she always wanted to leave. I always had to go to bed when she's in bed and I would get up 4 to 5 times at night" (Mr D, an 82-year-old carer for his wife who has a dementia)* (Paper 1)
>
> *"I don't think I can manage at home anymore. You see I live alone and it can get quite difficult sometimes. I've been on my own for a few years now" (Elsie: 88 year-old woman)* (Paper 6)
>
> *"I don't know how to take care of my wife because she always tosses and turns from side to side. She can't control urination and bowel movement. Last time, she got a big bedsore on the buttock. So, I need their [professional] help to take care of her" (husband)* (Paper 3)

Even though when critical dementia related behaviors can be managed, incidents like accidental falls, self-medication with a wrong dosage or overdose or dangerous behaviors induce an admission in hospitals or other institutions such as psychiatric or geropsychiatric clinics. Unpredictable admissions were therefore identified as one of the core mechanisms of action, enabling informal caregivers to think about relocation, as illustrated by the following quotes:

> *"Of course, after the fall, there and then, it was clear that she would not be going back to where she had been living" (F07 T3)* (Paper 7)
>
> "*…as well as over medication such as the person with dementia self-medicating with laxatives unbeknown to the carer"* (Paper 5)
>
> *"I'd have to lock her into the house, otherwise she would run away. One day her son came down and said I should put her away. I couldn't and I wouldn't. He rang the police and they brought her to a psychiatric hospital" (Mr R, an 80- year-old husband explaining the circumstances of his wife's admission to an Aged Psychiatry Unit)* (Paper 1)

In turn, as housing or caring situations become affected by dementia related behaviors and unpredictable admissions to inpatient institutions take place, informal caregivers and people living with dementia can get an indefinite felling that something is amiss. If then coping strategies are not present, informal caregivers could lose control of caring properly for their care recipients. From this point they can be overwhelmed and exhausted. Such a crisis can be an initiator for the decision to seek placement.

3.5.2 Impact on caregivers' physical and psychological health

Due to changes in used living and caring situations informal caregivers see their circumstances as stressful and difficult. Experienced care recipient behavioral problems are the most difficult aspects of caregiving and result in demanding informal caregivers stress and have impact on their physical and psychological health. As the following quote illustrates, many informal caregivers have besides the caring aspect of the person with dementia other liabilities they´ve to manage.

> *"I was very healthy but I was diagnosed with hypertension that has lasted several months. My mother has been so non-compliant. . . . I get mad at her easily. I worry about myself. I still need to raise two kids" (son)* (Paper 3)

Therefore, liabilities such as raising children, full-time or part-time employment to save the backstop or solely housekeeping are identified as components which can increase informal caregiver´s distress and have directly impact on their physical or psychological health.

Another factor which increases informal caregiver´s distress and has influence on their physical and psychological health is the outsider's perspective. People who are not involved in the caring of the person with dementia often get the impression, that everything is fine and works out well. They have no sight behind the curtain and superficially experience the tragedy´s extent. As the following quotes show, probably informal caregivers often become isolated and feel discarded from their surroundings.

> *"While these remarks might be well-intentioned, caregivers often felt misunderstood, unrecognized, and deprived of the opportunity to share their struggles: "They simply*

> *have no clue". Others were just mainly frustrated: "They just don't understand. Actually, I think they don't want to understand"* (Paper 12)

Again, care recipient behavioral problems frame the point of action, where outsiders are overstrained and cannot find the right attitude. For instance, people become reluctant for visits, feel embarrassed by deviant behavior, or have no idea how to talk or to cope with informal caregivers. Such uncertainties would result to a more explicit misunderstanding and drives informal caregivers more into frustration. Which in turn increases the insecurity of outsiders and thus accelerates the isolation of informal caregivers.

One common perception indicates a realization of informal caregiver´s deteriorating health by members of the social network. It seems that informal caregivers often don´t have the capacity of discernment over their situation. Key persons of the social network can act as advisors and give suggestions from a differentiated overview. As the following quote underlines, members of the social network observe the trajectory informal caregivers are in and try to guide them to reasonable decisions.

> *"I'd prefer to keep her a little while longer in order to get her into a place like that. But the doctor would like me to place her because he says: `A lot of your energy is being spent taking care of her. It's taking a toll on you. Sooner or later, you're the one who's going to need help getting up. You can't afford to ruin your own health´" (H18 T2)* (Paper 7)

All given aspects show that informal caregivers could deem their own situation to be worrisome and activate the decision-making process as a result. Fatigue, sense of burden and deterioration of their own state of health lead caregivers to question their ability to take care of the elderly person with dementia.

3.5.3 Damaged family relations

One common expression was, that many families experienced a gradually loss of their family relationship due to aspects of dementia behavioral induced problems and difficulties in everyday living situations. Converse attitudes towards the caring situation and a lack of knowledge about dementia connotated symptoms and behavioral aspects create a disturbing family relation and end up in disharmony as the following quotes illustrates.

> *"My husband could not understand [her behaviors] by knowing that she is sick. We argued . . . my family had conflict. Also, my kids felt strange about her behaviors. They could not understand why grandmother acted like this. She shouted to the kids. I think it was a bad influence on the kids" (daughter)* (Paper 3)

> *"My wife isn't my wife any longer. Basically, she has become a toddler with speech difficulties. We don't make love anymore. I'm really losing the desire. Just because she's not my wife anymore"(Husband i_6)* (Paper 12)

Many informal caregivers felt that this is probably their most difficult and heaviest time in life living with a person with dementia. Progressively dementia floated their lives and enlaced them, leaving a feeling of being powerless and helpless. In single cases the combination of hopelessness and solitude ended in a secretly wish about a partner´s death. On one side to end their partner´s suffering and on the other side to end their own misery, as the following quote illustrates.

> *"I don't have a husband anymore. I'm not allowed to say it out loud, but it would be better if he dies. It may sound sad, but a widow is better off than me" (Wife I_10)* (Paper 12)

It seems to be a threat on the socially acquired attitude on piety. Spouses, children, and relatives feel socially induced the importance to care for their care recipients with dementia and simultaneously experience a gradually increasing feeling of grief and loss. Similarly, as mentioned before by getting isolated by their surroundings, informal caregivers feel isolated in their own home because they lose perspectives and family relationships. Some respondents compare this situation to a prison. With informal caregivers as inmates and the person with dementia as the jailor by using comments as the following.

> *"I became a prisoner in my own home"* (Paper 12)

3.5.4 Informal help and coping strategies: useful if possible

Informal help from friends and family members is expressed as beneficial. Some expect more help but feel this help to be far away. If informal support was felt insufficient, this could result in a tough feeling of being overwhelmed and a great burden for informal caregivers, regardless of the severity of dementia related behaviors.

Regarding the respondents of the included papers, all appreciated informal help if possible as the following quotes represents.

> *"Sometimes I would call my son, but when he was away it was difficult" (Mrs.C)* and *Mr D related how his "son was a consultant, lived interstate and travelled a lot"* (Paper 1)

Informal help concerned for instance caring for children, housekeeping, grocery shopping or if manageable looking for the person with dementia while informal caregivers are out of home for a short period of time.

A common theme informal caregivers and people with dementia stated was dealing with incontinence. The presence of incontinence regardless of type is one major dementia connotated problem. Reaching from the inability to act in a timely way, locate, recognize, and use toilets properly, to voiding in situ or the inappropriate management of soiled clothing. Stated problems had multiple impact on caregivers, especially an emotional response in dealing with the personal hygiene of concerned people. This problem also has financial consequences described in terms of the additional laundry costs, replacement of soiled furniture and for instance, the purchase of cleaning materials and incontinence products. The following quotes underline a humiliating and embarrassing feeling which caregivers experience, although they developed coping strategies.

> "*I didn't want people to know about her not managing and incontinence. Not for what I did [cleaning her after voiding], I felt her dignity, you know. I felt I didn't want anybody to know. She was so in herself a very dignified lady, you know, and to suddenly be like that. If she'd have known she'd have been horrified, and I didn't want people to know that either" (Husband)* (Paper 5)
>
> *"The problem is she doesn't like people touching her. She knows she wants to go to the toilet, you get her there, then she doesn't want to pull her trousers down, so you have to start, you have to do it, so she's going to fight......If she gets your fingers she'll try and break them" (Daughter)* (Paper 5)

Informal caregiver´s problem solving strategies vary and mirror the trajectory of dementia. They consider mechanism for day and night-time and inside and outside the house. Firstly, the acceptability of prompts and aids; secondly, whether such intimate assistance was acceptable to the person with dementia, and thirdly, issues related to gender and the acceptability of men helping women in the intimate act of toileting. The following four quotes illustrate how informal caregivers and people with dementia manage incontinence.

> *"Yeh I take precautions and making sure when I set off, set off from here, I make sure which, which route I can take" [where there are public toilets] (Man living with wife, 03)* (Paper 10)
>
> *"I limit the amount of drink towards the end of the day and that works" (Man living alone, 05)* (Paper 10)
>
> *"Oh they're good they [the incontinence pads] are, they're very nice because they're just nice and small, they're not big, big ones like the other ones I had, these are smaller ones" (Woman living alone, 02)* (Paper 10)
>
> *Person with dementia: "Look, I take what I need, I don't take too much, so. . .." Son: "Mother! You take more than you need" Husband: "You should take only two a day, it's on the, on the box" Person with dementia: "Mm, that I know" (Woman living with her husband, 06)* (Paper 10)

A lack of informal help and insufficient strategies to manage incontinence were therefore identified as further core mechanisms of informal caregivers to seek placement.

3.5.5 Formal support: relief or frustration

The use of formal support along with healthcare professionals is perceived positive and negative in the included papers. Some experienced frustrating situations when seeking help from health professionals. A common experience was that the health professional failed to understand the impact and consequences of the problems and transmitted informal caregivers to another professional or service who similarly was unable to help. The following quotes illustrate the frustration informal caregivers experience.

> *"So I talk to the doctor, right; he was the first person I spoke to, he was his family doctor. . . . So I say to him: "Listen. What do we do now then?" And he says: "I know he's sick. He needs to be cared for all the time" (F12 T3)* (Paper 7)

> *"My most dreadful day was Boxing Day when my mother emerged from the lavatory carrying a pile of faeces which she dumped on the little social services trolley she ate from. After this I managed to get a visit from the consultant geriatric psychiatrist, a copy of whose letter the GP sent me. It says something about the daughter expressing concerns about hygiene but no help or advice" (Daughter)* (Paper 5)

Contrary, other informal caregivers felt that seeking formal support would be a good way for the care-recipient to receive better care. Especially for those who have physical conditions that require professional care. Healthcare professionals can be involved in evaluation of the present living environment and the future environment´s potential to meet particular needs of the person with dementia and those of the informal caregivers. They can assess the current health status of the person with dementia and how acceptable placement is to the informal caregivers. Positive perceptions are illustrated by the following quotes.

> *"I got a Care Package from Villa Maria which is excellent as they helped my uncle until he needed to enter hospital and now they are helping my aunt who lives alone" (Mr E, nephew and carer for his aunt and uncle)* (Paper 1)

> *"The social worker said that, based on all the data he had entered into the computer system, my mother more than met the eligibility criteria for long-term care" [She no longer really belonged in a retirement residence?] "No, that's right, I think what you just said is true as well" (F04 T1)* (Paper 7)

Another upsetting experience with formal support was that the extent of informal caregiver´s problems was only revealed to healthcare professionals as part of a crisis, such as an admission to a hospital. Despite that, some reported that admissions led to iatrogenic consequences with the person with dementia previously continent but discharged incontinent and using incontinence products, as illustrated by the following quote.

> *"So we are managing, he is dry because I help him and then he has to go into hospital and that's it - 7 days and he comes back out using pads. No one has even tried to help him - bam! Straight into pads. It takes me weeks to get him to use the toilet again" (Wife) (Paper 5)*

Nonetheless, important at this stage is a diagnostic disclosure which can be helpful and give a sense of relief. On one side weird behaviors and the frustration informal caregivers experience can then be explained and increase their understanding and strengthen their resilience. On the other side a continuum of uncertainty starts, as informal caregivers slip into a new role without knowing what to expect and what course the disease will take. Both sides are illustrated by the following quotes.

> *"The clarity it brings is really appreciated and valued!" Respondent (i_54)* (Paper 12)

> *"I wished the doctor would have given us a calendar, or at least a description of the process, something to hold on to, something that might provide a little steadiness" Respondent (i_49)* (Paper 12)

Even though informal caregivers are willing to use formal support, dementia related behavioral problems are factors that inhibit the utilization of services. Some informal caregivers were resistive to use formal support and were isolating themselves as illustrated by the following quotes.

> *"My mother would not let anyone come inside the house. My mother did not want to see anyone"* (*Mrs Q)* (Paper 1)

> *Mr D: "I have been approached for help by others. I thanked them but I could not accept as my wife is vicious and aggressive"* (Paper 1)

Use of formal support with insufficient advice or suggestions, intermediate hospitalization with iatrogenic adverse events and dementia related behaviors that inhibit formal support are therefore identified as further core mechanisms, which can promote informal caregivers to seek placement.

3.5.6 Actively seeking for information and advice or being trapped in hopelessness

At the point where informal caregivers and people with dementia experience a feeling that something is amiss, and their current living and caring situation changes rapidly, some informal caregivers start to obtain information. In their situation they want to keep control and are afraid of losing it, as the following quote shows.

> *"It's [caregiving] a burden . . . it gives me many sleepless nights because I don't know how to get him out of the house . . . it's awful. Now I'm, you know, I'm kind of floating, I don't know whether I am doing the right [thing] or not"* (Paper 2)

Informal caregivers try to gain information from different sources, for instance asking their physician, friends, or family members, searching the internet, touring nursing homes, or searching for written information. Thereby they unexpectedly learn that there are several services available for the care of people with dementia besides a nursing home (e.g., dementia day care centers, respite care, home care services or hiring foreign workers to support home care). The following quotes illustrate their effort.

> *"Hiring a foreign worker would make it easier for my mother to take care of my father but she disagreed. We used respite care twice but they only allowed you to use the service twice a year. I also used a home assistance program several times. They came to help with some physical care for my father for only a couple of hours at a time. My mother is old and not really healthy. Perhaps, nursing home is the best choice for us but it is very expensive for a good one. I do not have enough money to pay for [it] because I have my own family" (son)* (Paper 3)
>
> *"We came up with other things like to bring in a carer for her, but she wouldn't like that…Another one was for her to stay with one of the children but she objected to that…And then…it would be a fulltime care if she had come in and stayed with one of the children" (CR13)* (Paper 9)
>
> *"I told them that I was not able to care [for] my aunt at home. I told them the nursing home I found was very nice and near our town. I learned about this home from a friend of mine who is a health professional. She said this nursing home has good quality of care and provides many activities for older adults" (nephew)* (Paper 3)

When informal caregivers obtained information or advice, they fully assess pros and cons of alternatives in terms of quality of care, level of assistance, informal caregivers´ health status and financial burden. For instance, if a service is expensive or the acquisition is extensive and an informal caregiver perceives his or her health status as not too bad, they will continue to care for the person with dementia on their own. Hiring a foreign caregiver or a full-time maid is considered too expensive by some informal caregivers and by some foreign informal caregivers.

One positive aspect several informal caregivers and people with dementia experience is the chance of a scouting visit to the future environment. Of those who make a scouting visit, some will like it, and some not. Informal caregivers and people with dementia can interact with the prospective living environment and assess the quality of care it could offer. Informal caregivers can experience the care recipient´s reaction and prepare them for the future change. A scouting visit can also be useful to actively involve the person with dementia in the decision on this major life event. Besides a scouting visit, also contacting or visiting directors or managers of services can be helpful, especially to determine the right time for the transfer of services or relocation. The following quotes show this positive impact.

> *"Well, I have various other places I should go. I was there for a matter of a whole day. It was lovely. yes, yes, there for a full day and you liked it. Very nice, lovely." (Brian: 83 year-old man)* (Paper 6)
>
> *"The place I liked most was. . . . So then I checked it out in November along with my husband, so he could see the place for himself" (F17 T2)* (Paper 7)

In single cases informal caregivers fell out of control, not knowing what to do next or where to seek for help. Mostly they are aware that their circumstances are overwhelming, as the following quotes show.

> *"Who did I call first? I talked so many people . . . to see what they could do to help me with this [situation]"* (Paper 2)
>
> *"It's a silent killer, there is no cure or stop"* (Paper 12)

If the misery gets perceptible for informal caregivers and people living with dementia and they experience a loss of control, seeking for information and advice appears as an anchor to not loose one´s footing. As described among the third order constructs above, if informal and formal support does not fit the needs of informal caregivers and obtaining information and advice from different sources fails to clarify the prospective living and caring situation, informal caregivers and people with dementia feel being trapped in hopelessness.

3.5.7 The placement decision: a complex and multidimensional effort

The triggers of the placement decision were described by informal caregivers and people with dementia through the included papers. As mentioned above, indicating that either informal caregivers, people from the social network, the person with dementia or health professionals realized that caregivers are overwhelmed with the caregiving situation. Also, specific incidents such as accidents, falls or unpredictable hospital admissions can introduce the decision-making process. Another reason is a decline in person´s with dementia or informal caregiver´s health. Some informal caregivers express their discernment as the following quotes reveal.

> *"'We're only able to provide so much care here. We've taken it as far as we can, but we've now reached our limit" (F05 T5)* (Paper 7)
>
> "*My dad had a fall at home last December so I said even at home they are not really safe. So I check with my sister and we better start to enrol them in nursing home" (CW1)* (Paper 9)

Involved people experience the beginning of the decision-making process as difficult, painful, conflict ridden and powerless. A mixture of complex emotions and various thoughts are involved, especially when weighting up the needs and preferences of oneself, the person living with dementia and other family members. Respondents speak about this phase in the following manner.

> *"It was so painful to make the placement decision. There are too many things I need to consider. Sometimes, I was confused about how to deal with those issues. Making this decision was a torment to my husband and me"* (Paper 4)

> *"It's getting so that I'm too tired and down. I used to cry so much I was down. They say that a lot of people become depressed if they live for too long with a person who has Alzheimer's disease. You know, I'm made pretty tough, but I'm not made of steel" (F17 T1)* (Paper 7)
>
> *One wife (ID8) noted, "My conscience bothers me even though I realize this is the only way to make life worth living for both parties"* (Paper 11)

One fascinating component of the incipient decision-making process is the combative negotiation of the rights of people with dementia and their informal carers. When authorities (e.g., case managers, healthcare professionals…) have the tendency to dichotomize a person with dementia as competent or incompetent, this can result in positive or negative perceptions. Some informal caregivers are forced to struggle when their care recipients are declared incompetent. One´s a person with dementia is defined incompetent and the decision for placement is structurally induced, it becomes problematic for family members who are left without authority in the decision-making process. In those cases, they feel removed from the process, powerless and helpless, as the following quote illustrates.

> *Granddaughter: "It was the decision that grandpa made that put those people in charge of his life, if he ever were to become incompetent". Then she [mother of granddaughter] said: "It's out of your hands, you know? I know you feel bad for him and you don't want that [admission to LTC] to happen, but it's just going make things worse if you try to fight it. ... And uh… it's not my decision. There's nothing I can do. All we can do is help them [people with dementia] feel as comfortable as we can while they're at home, visit them at the nursing home, and whatever it takes. Those specific decisions weren't up to us"* (Paper 8)

Other informal caregivers feel a relief of their decisional burden when authorities declare their care recipients as incompetent. In their point of view people with dementia are positioned as confused and not to blame for the disease. Therefore, the disease is interpreted as a socially accepted reason for relocation and can decrease the perceived decisional burden when placement is structurally induced. The next two quotes are expressions of informal caregivers who can accept the dichotomization as incompetent.

> *"We could tell that she was more confused. Often, she had burn marks on her arms. She had these marks and she didn't know how she got them" (H03 T1)* (Paper 7)
>
> *One daughter (ID5) said, "Luckily, he was too physically sick to be aware of the move"* (Paper 11)

Another important component to mention is the applying for waiting lists, using of dementia services or respite care as a first step in the decision-making process. On one hand informal caregivers and people living with dementia can take this step, although some are not necessarily ready for the relocation at this stage. Ones applied does not mean the decision is finally made. However, some apply or use services and are not ready, knowing the person with dementia can deteriorate. Others do not apply, are not ready and do not want to think about relocation. Some use services or respite care as a step for the person with dementia to adjust and single informal caregivers apply when they are ready, because they want to relocate the person with dementia. The following quotes underpin the described approaches.

> *"If I made the decision for myself, it would be much easier. However, I am making the decision for my family. I have to think of every aspect of our family. I cannot imagine his life in the nursing home. Also, my brothers would disagree with placement"* (Paper 4)
>
> *"In the future …maybe my parents have to go to some nursing home… But like, until now, everything is still good, so I stop thinking about something in the future. You know that make me worry, I stop thinking about those" (CW20)* (Paper 9)
>
> *"I didn't have a hard feeling making this decision because I think it's like step by step…if I don't put my mum in a queue at an earlier stage…when she's not in a good condition and then still has to wait, that's no good" (CW2)* (Paper 9)

At the early stage of the decision-making process, informal caregivers and people with dementia are in a dilemma of attending to the needs of all involved persons in addition to legitimize their decisions. As the ongoing decision-making process continues, efforts, circumstances and attitudes can change. If the possibility of placement is considered, informal caregivers and people with dementia find themselves in recurrent dilemma and contradictions.

3.5.8 Drastic experiences and struggles in decision- making

Experiences and struggles in the decision-making process of informal caregivers and people living with dementia are affected by interpersonal, timely, financial, and structural reasons. A satisfying decision for all parties with minor burdens can be achieved, if the potential of prospective living environments meets the needs of the care-recipients and their relatives, the timing of relocation for all stakeholders is feasible and the availability of a potential place in a long-time care facility is given. This, a sound decision-making, is illustrated by the following quotes:

> *[When you decided together with your brother to send your mother to the residence, how did she take it? Did she say "no, no, no"?] "No," she said: Yeah, I know—she said—"I can't live on my own anymore." She accepted the fact. (F06 T3)* (Paper 7)
>
> *Jane: "I think I will feel safer. I would like to have the company of other people and my own room" (88 year-old woman)* (Paper 6)

Nonetheless, informal caregivers experience feelings of guilt, worry and uncertainty during the decision-making process. Those feelings are linked to the consequences which the decision entails, regardless of the distinctive burdens.

If interpersonal, timely, financial, and structural reasons are conflicting, involved people make drastic experiences and have diverse struggles in the decision-making. One important interpersonal aspect lies in the notion of filial piety. In this case, most informal caregivers perceive the placement decision as a violation of filial piety and therefore must negotiate with other family members. Informal caregivers reported that the decision primarily caused opposing family values and authority problems concerning the practice of filial piety, because it is the family´s duty to take care of their relatives with dementia, as the following quotes show:

> *"My older sister disagreed with nursing home placement. She had a more traditional concept. She felt that it is not practicing filial piety to place our mother to the nursing home. We had a big argument. Our relationship got worse after that. ... Finally, I got all siblings together to vote on this (the placement decision)"* (Paper 4)
>
> *"I don't even want to go there, because I can't talk to her about it; I mean, if I bring it up, she'll say: 'You just want to get rid of me'" (H18 T2)* (Paper 7)

Some informal caregivers must negotiate with their families and have to justify their decision by expressing their overwhelmed burden of caregiving. These informal caregivers try to legitimate the placement decision by highlighting positive aspects of long-time care.

Another interpersonal aspect lies on family members and how they expect the decision making to be done. Many informal caregivers state that involved people expected the decision making to be more collectively, although mostly informal caregivers feel alone in making this decision. Probably of reason that the person living with dementia can not participate in the decision-making process due to their dementia related conditions, as shown in the following quotes:

> *"The whole family sat down together to decide what to do. We didn't want to decide for everyone. So we all met and we could see that she had reached that point" (T1 H03)* (Paper 7)
>
> *"I am responsible for his [father-in-law's] care. I stay with him all the time. Unfortunately, I cannot say I want him to be in a nursing home because I am sick, and I am not able to care for him. I cannot say that directly to my husband because I am the daughter-in-law. My husband is the oldest son so he can make the final decision. However, he disagreed with the decision. So, we had argued several times and had to talk to other relatives for more opinions. ... After two years, they finally agreed with me"* (Paper 4)

Further interpersonal stressors are a denial of a long-time care placement if a vacancy opened by the person living with dementia or dealing with threats of self-harm from care recipients if there was no possibility to fully discuss the planned relocation, as the following quotes mention:

> *Mr R: "That's what worries me. How will she cope in there? Because she swears to me if she goes into a home she will kill herself, by hanging" Mrs Q: "No she is not aware, as if she knows, she says she will kill herself, put herself under a train"* (Paper 1)
>
> *Ivy: "To be quite honest I don't have high hopes about it. Like I'm quite sure the people concerned will do everything they can but I don't think I will love it. And so long as it is in a condition of the house and that it is reasonably good I can cope with it" (86 year-old woman)* (Paper 6)

When timely, financial and structural issues accrue, the decision-making process can become problematic for informal caregivers. In some cases, informal caregivers have to apply for a waiting list up to six months in advance and many apply for several long-time care waiting lists simultaneously. In many cases informal caregivers refuse to do so, because the physical- and cognitive status of their care-recipients is not indicating a move. Problematic when circumstances or health related concerns changes within this time span.

Another challenge experienced by many informal caregivers is a limit on financial resources. Financial burdens have a high impact on the choice to select a good quality long-time care facility. Some informal caregivers describe how limited financial resources have a negative effect on the placement decision. This makes the decision for them more challenging and frustrating. Also long-time care system structures influences the timing actively. It is noteworthy to recognize system´s structural use of positional power to privilege single caregivers and to force compliance with the waiting list approach. In some cases, hospitalization was accepted as an alternative to the relocation or seen as a loophole in the waiting list approach that would enable the family to cope with the system structural time constrains. The following quotes highlight these issues:

> *"I have to provide the living expenses for my own family. My wife does not work because she needs to take care of the children. I know it would be better for my father to live in a good nursing home but I do not think I would be able to pay for it"* (Paper 4)
>
> *"My sister and I brought her to visit the place. She was willing to go but not right away. It was always later with her . . . she felt she was still too young to go there" (H03 T1)* (Paper 7)
>
> *Spouse: "I don't know how it worked. Whether he was on his last time to deny that [i.e., turn down the offer of a bed in LTC when his name was at the top of the wait list] ... it was still an option. So I'm thinking "well, you know what the problem is, if it comes to the point where you can't deal with it, then it's a hospitalization that has to come first before that [LTC]" ... It might take a little bit longer to get him in [to LTC] now that he's off that" [wait list]* (Paper 8)
>
> *Case manager: "Is it a crisis or not? And where is that? Sometimes our conversation has to be, "You might have to accept a bed anywhere in Ontario", and that usually*

> *backs them off really quick [that is, forces them to make a decision in the moment for the potential eventuality of having to place the person with dementia into"[LTC]* (Paper 8)

To some extent, those experiences and struggles drive informal caregivers and people with dementia who make the difficult decision, to feel the painful emotions of loss, sadness, and resignation. The interaction of interpersonal, timely, financial, and structural reasons can lead to major distress while going through the decision-making process. Before involved people arrive at a final decision, they start to weight up pros and cons.

3.5.9 Weighting up pros and cons in the decision-making process

When weighting up pros and cons in the decision-making process, informal caregivers, people living with dementia and other family members are discussing and debating through the reasons explained in the third order construct `drastic experiences and struggles in decision- making´ before. Interpersonal, timely, financial, and structural reasons are not only aspects for negative experiences during the decision-making process, but they are also key components when weighting up the decision. When informal caregivers think about their decision, they mention the experience of viewing long-time care facilities as depressing and were shocked about the conditions they found by scouting visits. This forces them to overthink the decision. Also thoughts of placing their relatives for the last time or where they would remain until death to come are factors for overthinking the decision. The following quotes illustrate these concerns:

> *"I asked some of my friends. They said some bad things about the care in nursing homes such as bad smells, small space, restraint, neglect, abuse…. Those nursing homes do not really provide good care. I decided to look for myself. The nursing home I went to was okay, but I do not think they showed me how they are actually caring for those patients"* (Paper 4)

> *"What I worry is if she feel depressed or she doesn't like, you know, one of the staff there or one of the residents there, what's going on affect her health. From emotional, from psychological to physical" (CW1)* (Paper 9)

Alongside with those concerns, informal caregivers and people living with dementia have fears and expectation values regarding the future living environment which bring them to weighting up the decision. Additionally, to the distrust of long-time care facilities, involved people have concerns about the care quality and doubts on structural reasons. Many mention concerns on eventually limited care place availability when they are prepared to a move and limited specialization to people´s needs with dementia. Also, negative perceptions about worries and concerns on overall quality of care provided are mentioned. In detail, insufficient nutrition, poor hygiene, risk of falls, lack of activity, pressure ulcers, loss of autonomy and fear to lose one's independence. Informal caregivers and people living with dementia expect long-time care facilities to provide concerned people with company, to facilitate a feeling of safety, to care for them, and relieve them from day- to day housework. Therefore, they are looking for a clean and commodious environment that does not smell bad. Foreign informal caregivers consider a culturally appropriate facility, mainly because of language and food. Further wishes from informal caregivers are a place nearby, so that they can easily do visits and where the general practitioner can continue the medical care of the person living with dementia. The following quotes underpin the described distrust and concerns:

> *"Those residents were just waiting for death. In the daytime, they [staff] placed patients with wheelchairs outside in rows and let them just look around without paying attention to them, and then, about 11 a.m., they pushed them inside for lunch. There was only one lady cooking for more than 70 patients. She cooked in a huge pot that was just like pigswill. My idea is that sending him here [this nursing home] is waiting for death…. [Cries.]"* (Paper 4)
>
> *"Deep down, ideally, he should be in a nursing home, period. That's where he should be and he should go of his own volition. Ideally, that's how I see it. There would be people there round the clock, he wouldn't be alone" (F09 T3)* (Paper 7)
>
> *"Some of them are dirty, and the conditions no good, and so they won't choose that kind of residential care. And the one they finally got her…is neat and tidy, brand new, good looking" (CR6)* (Paper 9)
>
> *"I told them sending her to this home is good to a family like us who cannot care for the older adult at home. Those nurses are very nice. It does not smell weird. It is the best one among those I toured" (daughter-in-law)* (Paper 3)

Opposing, but stated by many informal caregivers is, when a sound decision-making can be achieved and the viewing of long-time care facilities is positive, they still start to overthink a placement. This seems also to be influenced by family concerns of filial piety and the perceived feelings of guilt, sadness and fear of loss. Many informal caregivers are of the mind that caring for their loved ones with dementia as long as possible is the best way they can chose. Regardless of all negative impacts this can have on their family relationships, their physical- and psychological health and the outsider's perspective from a community point of view. Whilst informal caregivers' wish to care for their relatives with dementia at home as long as possible, they think of reasons against placement as the following quotes show:

> *When a place in a well-situated institution became available the daughter, however refused placement because "she wasn't that bad, if you know what I mean ...I broke down and said no, we won't do it"* (Paper 2)

> *In one mother daughter situation, the caregiver daughter stated, "I don't want to [use services] because Mom's memory is still good enough that she would be upset if I wasn't doing it [caregiving] and if somebody else was taking care of her while I went away, so I can't"* (Paper 2)

Before a final or sound decision can be achieved, informal caregivers, people living with dementia and other family members overthink potential pros and cons and this results mainly in the constant effort to take care at home as long as possible. When the boundary of homecare is pushed and involved people must finalise the decision-making process, some feel guilty or sad that their loved one cannot stay at home, while others, although difficult, mention the decision as quite a matter of fact and necessity. At least, when a placement occurs, either informal caregivers feel rushed to make the decision, were lucky and relieved that this vacancy opened, or refused to relocate the person with dementia.

3.5.10 Harmonious decision-making

A harmonious decision-making can be achieved, if consensus between informal caregivers, the person living with dementia and family members is given on the decision that a long-time care placement is the best choice. Also, when the before mentioned interpersonal, timely, financial, and structural reasons are no points of great concerns. Some informal caregivers have to spend more time to overcome barriers such as financial issues or quality of care concerns than others. Open communication and support from family members is helpful to reach this agreement. Specially in situations when informal caregivers have to apply for a waiting list because they anticipate a long waiting time and want to be prepared for the relocation, when they were overwhelmed by the care of the person with dementia. Many informal caregivers are warned about long waiting times by authorities such as doctors, social workers, and long-time care nursing stuff.

Similar reasons concern the readiness for the relocation and why a long-time care placement will be refused. Informal caregivers and people living with dementia accept the decision when both come to the stage where they felt ready to accept the fact for relocation. Often informal caregivers and people living with dementia are ready if there is a sudden deterioration in health.

Typically for a harmonious decision-making is the effort to actively involve the person living with dementia in the decision-making process. Informal caregivers put varying effort to achieve an involvement without fights or additional decisional burden. In cases where placement is rejected by local services, informal caregivers conspire with their general practitioner while pointing out that they were caring for their own needs. Some informal caregivers express their feelings of not being listened or recognized by healthcare services, in hope to facilitate the process of relocation.

One special form of harmonious decision-making is associated with older informal caregivers. Those distinguish their role as being the main duty of caring for the person living with dementia, but place the responsibility for the decision of placement to healthcare services. This effort appears to reduce decisional burden and the loss of social reputation.

The following quotes highlight a harmonious decision-making:

> *"We all agreed with the placement decision after discussion and consideration. My brother and sister were very supportive" (daughter)* (Paper 3)
>
> *"It was a new nursing home that opened up, it was Cantonese…they said he could have his own room, and it was so close to home as well" (CR9)* (Paper 9)
>
> *One wife (ID8) said, "I got him admitted to the nursing home because my GP knows the doctor who is in charge of the nursing home, and they both backed me up. I was lucky" (*Paper 11)

If a harmonious decision-making of interpersonal, timely, financial, and structural reasons cannot be achieved, informal caregivers and people living with dementia run through a more burdensome decision-making process.

3.5.11 Conflict-ridden decision-making

Some informal caregivers and people living with dementia describe a dynamic within the decision-making process and what influences have impact on either the activation or the ending of the decision-making process. They mention activities on temporary changes in interpersonal, relational, and contextual factors in care delivery to the person living with dementia and between other family members. The decision-making process is actively influenced by changes in the state of health, by interactions within the family, tense family relationships, and by changing sources of help and support. Mainly informal caregivers reflect on the decision by the following three components – `Person with dementia´s progressive deterioration´, `deterioration of the caregiver´s physical or psychological health´ and `external pressure from service providers who deem the home-caring situation to be too heavy for the dyad to bear and recommend relocation´, as the following quotes show:

> "*We looked into it, I think it was this past winter, but now it's back on ice. We don't know, we didn't look into how much it would cost [You thought you could just send her there?] Yeah, that's right" (H03 T1)* (Paper 7)
>
> *"I am not hard hearted enough to send [care-recipient] to the nursing home. I asked him about placement and he said "no". Therefore, we just delayed [the placement decision] until we could not stand his behaviors anymore…. Because we asked, and*

> *he said he did not want to go….he got used to staying at home….So….it was very difficult to make the decision"* (Paper 4)
>
> *"Finally we believe we have no alternative because we are so tired to taking of her for almost three years, and me and my wife…we are start to suffer from a bit of hell because of the stress of taking care of her" (CR8)* (Paper 9)

One vexing issue informal caregivers express is to decide whether to involve the person living with dementia in the decision-making process or not. Further, they have issues when informing the person living with dementia when the placement decision is made. This is a difficult and painful experience because the decision knowingly is done against their wishes. Greater burdens are associated in the decision-making when the main informal caregiver does not obtain fully approval and support from family members. Those informal caregivers experience criticism due to family disagreement on the decision. This often appears when the main informal caregiver has the most authority or financial power. The following quotes outline these experiences:

> *"It is a painful decision. I know my grandfather does not want to go to the nursing home. Although he is demented now and forgets almost everything, he still can decide what he wants or does not want. He still has autonomy. I eventually ignored him and took him to the nursing home. This makes me feel sad and worried. I feel heartache. The feeling is just like "tight tightness"* (Paper 4)
>
> *"Those good Asian ones, they always have a long queue…late last year I decided to put my mum in the queue. But I actually don't want her to go even if a position is available... But end up you know we say "Ok we put her on the queue." Just in case…Because we understand she's already 86, things may drop at any time" (CW2)* (Paper 9)
>
> *"Me, too, I'm not what I used to be. So, when you see that the situation is deteriorating. . . . If it's for their own good, between you and me, even though they don't see it that way at first. Maybe in the beginning she'll say: "No, I'm not going." But I think she'll come around in time" (F05 T4)* (Paper 7)
>
> *One husband (ID3) related, "I have managed this company for many years; so, I mostly take care of the big decisions at home"* (Paper 11)

Other conflict-ridden decision-making experiences emerge when the main informal caregiver disagrees with the relocation but is convinced by family members to do it anyway. Their reluctance to make the decision is based on still focusing on the possibility of taking care of the person living with dementia at home, as the following quote illustrates:

> *"I insistently disagreed with the placement but they tried to persuade me and even forced me to make the decision. I really reluctantly made the decision. I think we are non-filial children" (daughter-in-law)* (Paper 3)

Another conflict-ridden experience which informal caregivers mention is reluctance to accept the decision on relocation by family members or the person living with dementia. Also, many informal caregivers tend to postpone the relocation to the last feasible moment because of earlier naive promises to never allow the person living with dementia to end up in a long-time care facility, as the following quotes show:

> *"I spent the most time taking care of her and paid the most money for her. If they did not agree, they should do more. I had tried very hard but they still said that I did not treat her well. I had nothing more to explain and I just decided to send her to the nursing home" (nephew)* (Paper 3)

> *One brother (ID10) noted, "It is tough, but the family caregivers must accept the burden of the anger of the person with dementia" (*Paper 11)

> *Respondent (i_54) talked about her inability to keep her promise: "All these years he asked, please don't let me down. That's the theme of his life, feeling abandoned. And with my hand on my heart I promised him: 'Of course, I will never let you down.' And look what I'm doing. . .".* (Paper 12)

Through many experiences from informal caregivers and people living with dementia, a common perception goes beyond the familial decisional conflict and explains how home care structures dictate the involvement of people living with dementia in the decision-making. Perceived social locations such as age, gender, and class influence the inclusion in decision making, following by giving primacy to one individual instead of all involved family members. Therefore, family decisional conflicts result from familial, and societal values and beliefs, and from usage of valuing someone as competent or not and ranking people hierarchically based on social standings. To choose a family spokesperson may be helpful to address conflicts but cannot compensate a collectively decision-making demand.

When a conflict-ridden decision-making process cannot achieve a final decision, many caregivers mention that it can bring them deep relief after a healthcare professional takes over the decision that relocation has become inevitable. Otherwise, some felt guilty when they must give up and call themselves egoists who put their own rest before the welfare of the person living with dementia.

3.5.12 Outsourced or enforced decision-making

In many cases informal caregivers describe their torn between relief and guilt when their decisional burden is taken over by health care services. They mention that after years or an intensive period of caring duty, they reach a point that they cannot longer handle the situation. Those informal caregivers feel of an increasing strain in disrupted day and night rhythm, family clashes, and conflicts, and domestic accidents. Completely overburdening them physically and emotionally. In this stage, informal caregivers express that health care services are either at behalf of the duty to take care of the person living with dementia and that they should promote decisions. Or that informal caregivers feel that the position of caring was imposed upon. Therein they experience frustration, non-involvement, and societal isolation. Those informal caregivers position the person living with dementia as the jailor who is omnipresent and all-dominant. Informal caregivers expect that healthcare services would take initiative and free them from their present situation. The following quotes illustrate these expressions:

> *A daughter (ID1) described how she proceeded to make the HcP change their mind as follows: "In a humouring manner, I praised them and further explained why my father needed to be admitted to a nursing home"* (Paper 11)
>
> *"It was probably someone working there who detected us and observed that I was not able to do all the care work myself; so, we have been lucky after all" (ID5)* (Paper 11)

Contemporaneous, informal caregivers can experience an enforced decision-making by health care providers. Even though they hold that they are taking care properly, they feel that they are exploited and helpless. Many informal caregivers seem to be treated unfair by health care services. On one side some complain that they have been waiting for as long as possible to apply for a nursing home admission, but mostly the first attempt was rejected. On the other side, when the caring situation at home is questionable and informal care givers are exhausted, they experience the enforced decision making by health care services either as a relief or an assignment of guilt, as the following quotes show:

> *One husband (ID9) said, "I take it as a matter of course that healthcare service providers tell us if it is time for my wife to move"* (Paper 11)
>
> *"It was not about me! The healthcare service providers decided that he should be in a nursing home. It was the house that was the problem. It's not built for old people" (ID8)* (Paper 11)
>
> *"…And then they asked who was going to be the power of attorney for personal care, and I think there was kind of a general discussion. And they said, "Well, Kim's a nurse." They put her down. And then they put myself down as well" (Son)* (Paper 8)

Despite all the attempts who lead to a final decision, in some cases informal caregivers and / or the person living with dementia refuse to move to a nursing home, due to several reasons.

3.5.13 Refusal of relocation

Some informal caregivers mention that one of the most difficult experiences during the decision-making process was a refusal of placement by the person with dementia. This happens when reasons in favor of the relocation did not weigh heavily enough, and the relevance of a placement was questioned by family members or the person living with dementia. A Placement was also refused when informal caregivers and people living with dementia were still managing at home or when the person living with dementia objected to move to a nursing home. Many informal caregivers and people living with dementia see a nursing home placement as a last resort and are happy to continue caring at home as long as they can manage the situation.

Further refusal reasons are fears of poor quality of care, and fear induced by negative histories about nursing homes and experiences of other family members. Additionally, disturbed family relationships which emerged during the decision-making process are a reason to refuse. Also, the non-availability of a suitable facility is a reason against the placement, as the following quotes outline:

> *The way he is now is all right. If something else were to happen, I'm not saying we might not have to place him, but other than that, I think he's fine in his own home" (F11 T1)* (Paper 7)
>
> *"The last resort is nursing home…nobody likes to be admitted to nursing home. We hang on until we have no choice" (CR19)* (Paper 9)
>
> *"It's a long waiting process as well. Especially for the low care period, I think that was very hard…it's almost like oh, you know, let's let them deteriorate until they're high care and then let them in" (CR16)* (Paper 9)

The synthesis process involves reciprocal translation, where similar concepts across studies are compared and integrated, and refutational synthesis, where conflicting findings are examined. In this context, the experiences of caregivers, though varied, reveal common patterns of struggle, coping strategies, and decision-making processes. Divergent findings, such as varying experiences with professional support, highlight the need for more personalized and flexible support systems.

3.6 A lines of argument synthesis of the third order constructs

The decision-making process for informal caregivers of people with dementia is complex and multifaceted. This synthesis, based on thirteen third-order constructs identified in the studies, provides a comprehensive understanding of the key factors influencing caregivers' decisions. The decision-making process for informal caregivers of people living with dementia is intricate and influenced by numerous interrelated factors. By understanding the core themes and constructs identified in this synthesis, stakeholders can develop better support systems and interventions tailored to the unique needs of caregivers, ultimately improving their well-being and the quality of care for people living with dementia. Figure 5 depicts the relationships between the synthesized third order constructs in a simplified conceptual model of the associated and reported determinants and experiences on the decision-making process of informal caregivers and people with dementia before a decision on relocation was made.

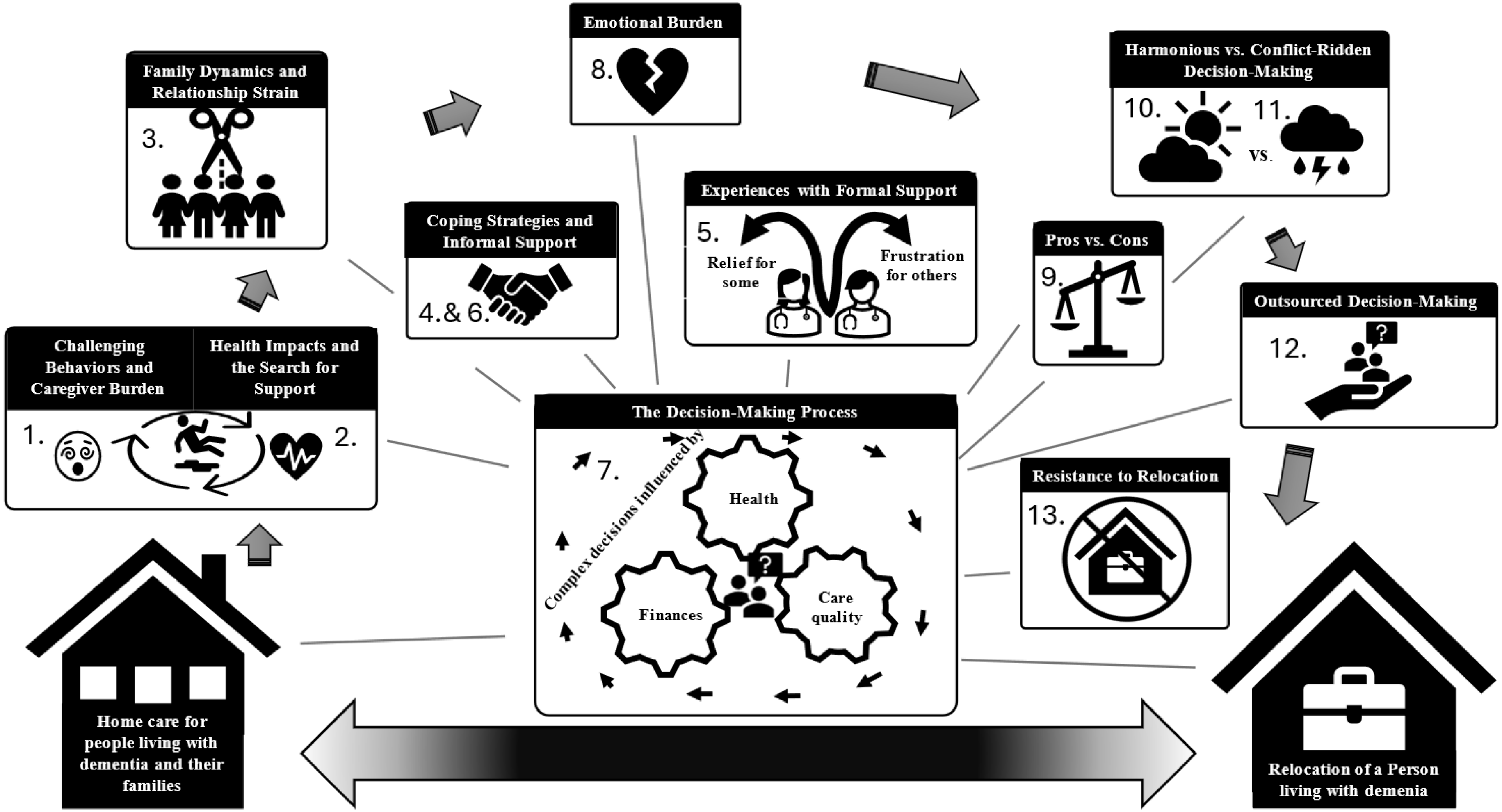


Figure 5. Simplified Model of a Lines of Argument Synthesis

4 Discussion

This review looked at existing qualitative research on the decision-making process of informal caregivers and people with dementia before deciding on relocation. The findings from the current meta-ethnography show that the decision-making process is complex and influenced by many factors. Following the approach suggested by France et al. (2019), an explanation using a lines-of-argument synthesis (Figure 5) should be provided in phase 7 to express the synthesis.

Thus, this meta-ethnography found evidence that (1) caregivers often face challenging behaviors and critical incidents related to dementia, such as aggression, wandering, or severe cognitive decline. These behaviors can escalate over time, making home care increasingly difficult and unsafe. Such incidents frequently act as tipping points, prompting caregivers to consider alternative care options. (2) that the physical and psychological toll on caregivers is profound. Many experience chronic stress, burnout, and health issues due to the demanding nature of caregiving. This deterioration in health often influences the decision to seek external support or long-term care for the care recipient. Further (3) the strain of caregiving can lead to damaged family relationships. Disagreements over care responsibilities, differing opinions on care decisions, and the emotional stress of the situation can create conflict among family members. These relational dynamics complicate the decision-making process and can lead to feelings of isolation and resentment for the primary caregiver. Informal caregivers and people living with dementia employ (4) various coping strategies and seek informal help from friends, family, and community networks. While such support can be beneficial, it is often inconsistent and insufficient to meet the escalating demands of dementia care. Effective coping strategies can delay the need for formal intervention, but they are not always sustainable in the long term. If formal support is necessity, (5) experiences with formal support services are mixed. Some caregivers find relief through professional assistance, which can provide much-needed respite and specialized care. However, others encounter frustration due to perceived inadequacies in the quality of care, lack of empathy from professionals, or bureaucratic obstacles. Caregivers often (6) actively seek information and share experiences with others in similar situations to make informed decisions. This proactive approach can provide a sense of control and hope. Conversely, some caregivers feel trapped in a cycle of hopelessness, overwhelmed by the challenges and uncertain about the future, which hinders effective decision-making.

When facing the decision-making, deciding to place a loved one in long-time care is (7) a multifaceted process influenced by numerous factors, including the caregiver's health, the care recipient's needs, financial considerations, and the quality of available facilities. This decision is rarely straightforward and involves careful deliberation of various practical and emotional aspects. Therefore, Caregivers often (8) undergo drastic experiences and significant struggles when making care decisions. The emotional burden, coupled with the pressure of making the "right" choice, creates a highly stressful environment. These experiences are marked by intense emotions, such as guilt, fear, and grief.

The decision-making process involves (9) weighing the pros and cons of different care options. Caregivers consider the benefits of continued home care, such as maintaining a familiar environment for the care recipient, against the advantages of professional care, including specialized services and reduced caregiver burden. This balancing act is crucial in reaching a final decision. In some cases, decision-making is (10) harmonious, with caregivers and family members reaching a consensus on the best course of action. Effective communication, shared values, and mutual support contribute to a smooth decision-making process, fostering a sense of unity and collaboration. Conversely, many decisions are (11) conflict-ridden, marked by disagreements and tension among family members. Differing opinions on care approaches, financial concerns, and emotional stress can lead to prolonged conflicts, complicating the decision-making process and potentially delaying necessary actions. Sometimes, decisions are (12) outsourced to or enforced by external parties, such as healthcare professionals or social services. This can occur when caregivers are unable to decide independently due to emotional or physical exhaustion. While this can relieve some of the decision-making burden, it can also lead to feelings of loss of control and autonomy.

In certain instances, caregivers or care recipients (13) refuse relocation to a care facility. This refusal is often driven by emotional attachments, cultural values, or negative perceptions of institutional care. Such resistance can prolong the caregiving challenges and delay the implementation of potentially beneficial care solutions.

The decision-making process for informal caregivers and people living with dementia is intricate and influenced by numerous interrelated factors as shown during the synthesis process in this meta-ethnography. Cole et al. (2018) and Couture et al. (2020) presented similar findings in their reviews on \`the optimal time to move to a care home´ and \`factors associated with informal caregivers´ decision-making for care setting placements´ for people living with dementia. Although most included participants in the reviews already made the decision and therefore retrospectively explained the decision-making process, factors such as dementia related behavior, planning and weighting up the decision, lack of support, decision drivers, emotional impact and ongoing reflection on the decision were identified. Findings of the present meta-ethnography probably suggest that people with similar conditions, resources, knowledge and support systems can have completely different experiences in identical situations.

However, Couture et al. (2020) explained findings between analytical and descriptive themes as the assessment of the current living environment and caregiving arrangements, caregivers consider the cognitive and physical condition of the person with dementia, safety concerns, their own physical and psychological capacities, and the availability of formal and informal support. A change in living environment occurs when caregivers determine that these factors are overburdening the current resources, respectively jeopardizing the safety of the person with dementia or others. Similar findings are expressed in the lines of argument synthesis 1, 2, 3, 4, 5, 9 & 10 (Figure 5) of this meta-ethnography. Therefore, the synthesis process described in the chapters above can offer a more detailed and straightforward insight into the associated and reported determinants and experiences on the decision-making process of informal caregivers and people living with dementia before a decision on relocation is made

To understand associated and reported determinants and experiences on the decision-making process of informal caregivers and people with dementia in the home care situation is crucial. By understanding the core themes and constructs identified in this synthesis, stakeholders can develop better support systems and interventions tailored to the unique needs of caregivers, ultimately improving their well-being and the quality of care for people living with dementia. This is supported by recent dementia research on urgent care for patients with dementia (Dooley et al., 2020) and shared decision-making (Mattos et al., 2023). Common topics in dementia research are improving and increasing community support, education of informal and formal caregivers and providing person-centered care to facilitate shared decision-making, to mitigate avoidable circumstances and empower those who are in need (Cole et al., 2020; Taghizadeh et al., 2014; Mattos et al., 2023). The lines of argument synthesis of the given meta-ethnography draw outlines on where support, education and empowerment thru interprofessional shared decision making can be applied (Figure 5). At every stage in which informal caregivers and people living with dementia express to be challenged, frustrated and emotionally burdened and where insufficient support leads to strain, actions can be enrolled, and health professionals can help to decrease the feeling of being decisional overburdened.

However, in a review of 2014 by Taghizadeh et al. most decisions concerning home dwelling people living with dementia were based on an opportunity to react on decisions made by others, and on the potential impact of these responses. The authors claimed that only a little number of participants expressed an active involvement in decision making by the person living with dementia. Thus, this meta-ethnography confirms that people with dementia are mostly not active involved in decisions and that findings suggest that uninformed, non-participating decisions and conflict-ridden decisions lead to more emotional burden. Notably, the majority of articles focused on shared decision-making are of a qualitative nature and methodological robust quantitative studies are lacking (Mattos et al., 2023).

4.1 Implication for policymakers, health professionals and future research

Policymakers should prioritize the development of comprehensive support systems for informal caregivers and people living with dementia. Including financial assistance, respite care, and access to mental health services, such as dementia day care services. By Implementing training programs for caregivers that focus on managing challenging behaviors and decision-making processes can empower them and improve homecare quality. Resources should also be made available to educate families about dementia and caregiving strategies. Given the diverse cultural backgrounds of caregivers, policies should reflect cultural sensitivities, as these families might experience the process differently because of conflicting cultural ideals (Taghizadeh et al., 2014) and address the unique challenges faced by different communities in caregiving contexts. This support can alleviate the burden on informal caregivers and people living with dementia and improve their well-being.

This meta-ethnography also adds to the evidence that health professionals and social services being involved by these populations should be aware of their fundamental role in influencing and modelling the informal caregiver burden and emotional stress. Since findings of this meta-ethnography indicate that negative experience with formal support causes elevated emotional and decisional burden. On basis of this knowledge, interprofessional shared decision-making might be a beneficial way to support informal caregivers and people with dementia. Through interprofessional shared decision-making including competent skillful communication, health professionals provide individualized care adapted to the family circumstances. Thus, enhancing feelings of normality at home. Skillful communication is a multidimensional intervention in itself (Spitzberg, 2013), combining listening to concerns openminded, acknowledging informal caregivers and people living with dementia as recipients and facilitating person centered decision-making. Further, by educating, teaching and giving anticipatory guidance. Therefore, a holistic approach that considers the physical, emotional, and social needs of both informal caregivers and individuals with dementia is essential. For instance, by implementing regular assessments of caregivers' mental and physical health can help identify those in need of additional support early. Allowing for timely interventions based on interprofessional shared decision-making.

Despite varying experiences and factors influencing the decision of informal caregivers and people living with dementia, cultural diversity in research is underrepresented (Couture et al., 2020; Mattos et al., 2023). In this meta-ethnography, some participants from primary studies did not come from the socio-cultural background of the country under study. It appears that even if the cultural context of the participants was different, problematic experiences and factors were very similar among all those examined. Future research should include diverse populations to better understand the varying experiences of caregivers across different cultural and socioeconomic backgrounds. Also, the efficacy and accessibility of supporting systems to reveal how high and low level services work should be considered, since evidence on effective strategies is unclear (Toot et al., 2017) and how social values, family values and filial piety influence the decision-making process (Taghizadeh et al., 2014; Couture et al., 2020).

4.2 Strengths, limitations and reflection

To enhance the meta-ethnography´s dependability and credibility, a systematic approach to search and screen for published and unpublished literature according to the recommendations of the PRISMA statement (Page et al., 2021) and the eMERGE reporting guidance (France et al., 2019) was used. The meta-ethnography feasibility and usefulness was considered by reading and re-reading similar research on this field and limitations on every synthesis step were addressed as suggested by Sattar et al. (2021). The current work shows transferability and confirmability, given that 12 studies originated from European and non- European countries reported similar experiences and factors on the decision-making process of informal caregivers and people living with dementia on relocation to a long time care facility.

Being a dynamic method for synthesizing qualitative research and successfully used before in healthcare research (Cahill et al., 2018), the meta-ethnographic method proved to be appropriate to meet the goal, guiding and structuring the interpretation of the findings, and allowing for adaptions between steps. Nevertheless, Cahill et al. (2018) stated that conducting a meta-ethnography is an ambitious methodology in all stages.

Although the constantly invaluable support from colleagues, tutors and attempts to contact authors, not all relevant data could be retrieved and some steps during the synthesis processes were taken by the author of the meta-ethnography himself. Also, some decisions concerning inclusion and exclusion were made later in the review process by the author himself, as stated earlier in this meta-ethnography. For instance, single papers (2, 8 & 9) were included in the synthesis process, although informal caregivers already chose to place their loved one with dementia on a waiting list, as the first step toward nursing home placement. Since the timing when a waiting list approach was considered was not given in the primary data, all available information to answer the research questions were analyzed to the same extent.

Due to the interpretative nature of the meta-ethnography, the findings of this review are subject to critique. Researchers with different philosophical perspectives and professional experiences might have arrived at a different synthesis (Atkins et al., 2008). One goal of the present meta-ethnography was that, by understanding the experiences and factors of the decision-making process of informal caregivers and people living with dementia on relocation, it would be able to identify which determinants had a huge impact on the outcome of the decision making process. To ensure that various perspectives were considered and that the interpretation accurately reflected the study results rather than the reviewers' opinions, two people independently synthesized the primary data and teamed up to discuss their findings and developed a final simplified conceptual model that encompasses the different interpretations and focused on the main findings of the synthesis process.

4.3 Conclusion

Synthesizing these findings provides a nuanced understanding of the decision-making process of informal caregivers and people living with dementia. The collective insights from multiple studies highlight the significant challenges faced by informal caregivers and people living with dementia, and the complex factors influencing their decisions. This synthesis, following the principles of meta-ethnography as outlined by France et al. (2019), underscores the importance of considering both shared and divergent experiences to inform supportive interventions and policies for formal and informal caregivers.

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6 Appendix

Table 6. Reciprocal & Refutational Synthesis - Third Order Constructs Developed by the Review Author

Relevant themes	Third order constructs	Second order constructs by primary authors	First order constructs (participant quotes)
Problems, difficulties, and crisis	**Critical dementia related behaviors and incidents**	▪ Care Recipient Problem Behaviours (Chene, 2006)	"She was always calling out. I had to check the locks, as she always wanted to leave. I always had to go to bed when she's in bed and I would get up 4 to 5 times at night" (Mr D, an 82-year-old carer for his wife who has a dementia; Chene, 2006) Mrs B: "After about 5 am he gets up again. I try to give him the medication but he no take it. He needs toileting, he no wants to shower" (Chene, 2006)
		▪ Traumatic Admissions to the Unit (Chene, 2006)	"I'd have to lock her into the house, otherwise she would run away. One day her son came down and said I should put her away. I couldn't and I wouldn't. He rang the police and they brought her to a psychiatric hospital" (Mr R, an 80- year-old husband explaining the circumstances of his wife's admission to an Aged Psychiatry Unit; Chene, 2006)
		▪ Complex Admissions (Chene, 2006)	Mrs S: "At the hostel Mum was needing more and more one-to-one attention, and they couldn't be bothered. They didn't even ring us up to let us know that Mum was in hospital" (Chene, 2006)
		▪ Crisis as initiator (Strang et al., 2006)	In one situation, "there have been several kinds of crises" said the caregiver as she related how each crisis jolted her into taking action (Strang et al, 2006) Caregivers said in different ways, "I don't know how much longer I can keep this up on my own" or "there is a problem if anything would happen to me" or "it's getting too much" (Strang et al, 2006)
		▪ Deteriorating Dementia-Related Behaviors (Chang et al., 2010)	"He is shouting very often. He yells when you cannot satisfy his needs immediately. My daughters need to go to school and go to work. They cannot tolerate it. We really cannot stand it in the long run" (wife) (Chang et al., 2010) "I don't know how to take care of my wife because she always tosses and turns from side to side. She can't control urination and bowel movement. Last time, she got a big bedsore on the buttock. So, I need

			their [professional] help to take care of her” (husband) (Chang et al., 2010)
		▪ Problems identified (Drennan et al., 2011)	“The carers described a wide range of problems: some as a result of the loss of cognition and memory, some from behavioural and psychological symptoms and some from the interplay of these with other co morbidities, as well as over medication such as the person with dementia self-medicating with laxatives unbeknown to the carer” (Drennan et al., 2011) “Toileting and incontinence problems described reached from the inability to act in a timely way, locate, recognize and use toilets properly, to voiding in situ or inappropriate management of soiled clothing as well as urine and feces. Stated problems had multiple impact on caregivers, especially an emotional response in dealing with the personal hygiene of concerned people” (Drennan et al., 2011)
		▪ Consequences for carers and the need to contain excreta (Drennan et al., 2011)	“I found the smell and trying to get rid of them [used continence pads] most distressing. I got to where I would take the rubbish bags with the soiled pads to the shared bins in the middle of the night so I wouldn’t meet any of the neighbours” (Wife) (Drennan et al., 2011) “Even the district nurses and the incontinence service seemed unable to provide the kind of insight into managing incontinence in patients with dementia which I required” (Wife) (Drennan et al., 2011)
		▪ The realization of own difficulties (Thein et al., 2011) (People living with dementia)	“Well, I’ve got to look after it, isn’t it? Now I’m too old now to ... washing and that type of thing sort of. Because people come and tend to do it for you but it’s very expensive to pay for it” (John: 83 year-old man) (Thein et al., 2011) “I don’t think I can manage at home anymore. You see I live alone and it can get quite difficult sometimes. I’ve been on my own for a few years now” (Elsie: 88 year-old woman) (Thein et al., 2011)
		▪ Possibility of placing elderly relative introduced by caregiver (Ducharme et al., 2012)	“Of course, after the fall, there and then, it was clear that she would not be going back to where she had been living” (F07 T3) (Ducharme et al., 2012)
		▪ The type of difficulties experienced and associated feelings (Cole et al., 2017) (People living with dementia)	“. . and I now find that I can’t hold it physically and it does start and that is really hard from the point of view of making sure I’m near a loo because when I want to go, I want to go quickly and that’s really the problem

			on incontinence” (Man living with wife, 04) (Cole et al., 2017) [Following an episode of urinating while in bed] “It’s like a fire really, I mean with everything, we [he and his wife] have to get up, change the sheets, I’d be mortified you know and all that” (Man living with wife, 04) (Cole et al., 2017)
		▪ Growing suspicions and doubts (Van Wijngaarden et al., 2018)	They had regularly had an indefinite feeling that something was amiss: “Somehow, I knew that something was off, but I couldn’t put my finger on it.” Or: “I had a gut feeling that something was wrong” (Van Wijngaarden et al., 2018)
		▪ Shifting of responsibility for everyday tasks (Taylor et al. 2023) (including People living with dementia)	none
	Impact on caregivers’ physical and psychological health	▪ Worsening Caregivers’ Health Status (Chang et al., 2010)	“I was very healthy but I was diagnosed with hypertension that has lasted several months. My mother has been so non-compliant. . . . I get mad at her easily. I worry about myself. I still need to raise two kids” (son) (Chang et al., 2010)
		▪ Possibility of placing elderly relative introduced by members of the social networks (Ducharme et al., 2012)	“I’d prefer to keep her a little while longer in order to get her into a place like that. But the doctor would like me to place her because he says: `A lot of your energy is being spent taking care of her. It’s taking a toll on you. Sooner or later, you’re the one who’s going to need help getting up You can’t afford to ruin your own health´” (H18 T2) (Ducharme et al., 2012)
		▪ A hidden and uncomprehended world (Van Wijngaarden et al., 2018)	While these remarks might be well-intentioned, caregivers often felt misunderstood, unrecognized, and deprived of the opportunity to share their struggles: “They simply have no clue”. Others were just mainly frustrated: “They just don’t understand. Actually, I think they don’t want to understand” ((Van Wijngaarden et al., 2018)
	Damaged family relations	▪ Disturbing Family Life and Family Relationships (Chang et al., 2010)	“My husband could not understand [her behaviors] by knowing that she is sick. We argued . . . my family had conflict. Also, my kids felt strange about her behaviors. They could not understand why grandmother acted like this. She shouted to the kids. I think it was a bad influence on the kids” (daughter) (Chang et al., 2010)
		▪ A growing sense of disharmony (Van Wijngaarden et al., 2018)	Many respondents told us about the way their relationships gradually lost harmony. In retrospect, many respondents indicate that this confusing, indefinite situation was probably the most difficult and heaviest episode of living with

			dementia. Gradually, the disease had slipped into their lives, entangling them, powerless, in this new phase of life (Van Wijngaarden et al., 2018)
		▪ Loss of equality and reciprocity (Van Wijngaarden et al. 2018)	Several respondents indicated that gradually they witnessed their loved ones drifting away from them. “It’s a sort of ongoing grieving process” (Van Wijngaarden et al. 2018) Using a child metaphor, she describes the change in their relationship: a child needs guidance and is dependent on its mother. It also illustrates the resulting distance. One man (i_6) put it quite bluntly: “My wife isn’t my wife any longer. Basically, she has become a toddler with speech difficulties. We don’t make love anymore. I’m really losing the desire. Just because she’s not my wife anymore” (Van Wijngaarden et al. 2018)
		▪ Imprisoned in your own home (Van Wijngaarden et al. 2018)	Most respondents felt absorbed by a project that lacked all perspective, using phrases like: "I became a prisoner in my own home" (Van Wijngaarden et al. 2018) Some respondents said that the combination of hopelessness and solitude resulted in them secretly ideating about their partner’s death. Partly to end their partner’s suffering, but also to end their own misery. One respondent (i_10) expressed herself in these words: "I don’t have a husband anymore. I’m not allowed to say it out loud, but it would be better if he dies. It may sound sad, but a widow is better off than me” (Van Wijngaarden et al. 2018)
Help, strategies, and support	**Informal help and coping strategies: useful if possible**	▪ Use of Informal Supports by Family Caregivers (Chene, 2006)	Mrs. C “Sometimes I would call my son, but when he was away it was difficult” (Chene, 2006) Mr D related how his “son was a consultant, lived interstate and travelled a lot” (Chene, 2006) Mrs L, who had two sons, said: “I don’t get that much help from my family” (Chene, 2006)
		▪ Carer developed strategies and issues of acceptability (Drennan et al., 2011)	“I didn’t want people to know about her not managing and incontinence. Not for what I did [cleaning her after voiding], I felt her dignity, you know. I felt I didn’t want anybody to know. She was so in herself a very dignified lady, you know, and to suddenly be like that. If she’d have known she’d have been horrified, and I didn’t want people to know that either” (Husband) (Drennan et al., 2011) “The problem is she doesn’t like people touching her. She knows she wants to go to the toilet, you get her there, then she doesn’t want to pull her trousers down, so you have to

			start, you have to do it, so she's going to fight......If she gets your fingers she'll try and break them " (Daughter) (Drennan et al., 2011)
		▪ Strategies to manage difficulties with using the toilet and incontinence (Cole et al., 2017) (People living with dementia)	"Yeh I take precautions and making sure when I set off, set off from here, I make sure which, which route I can take" [where there are public toilets] (Man living with wife, 03) (Cole et al., 2017) "I limit the amount of drink towards the end of the day and that works" (Man living alone, 05) (Cole et al., 2017) "I have an old towel that nobody would, if they've got any sense, because it does go to the wash. . .. Well I can pour like a tap or I can, don't run at all" (Woman living with husband, 07) (Cole et al., 2017) "Oh they're good they [the incontinence pads] are, they're very nice because they're just nice and small, they're not big, big ones like the other ones I had, these are smaller ones" (Woman living alone, 02) (Cole et al., 2017)
		▪ Help in managing incontinence (Cole et al., 2017) (People living with dementia)	"I couldn't even give her a quarter of what she wanted and then I would come out of the hospital place and I'd be wet but you know, to give on tap. . .. I couldn't do it, I went there three times and if I can't give her a decent sample she doesn't want to know and I just gave up" (Woman living alone, 01) (Cole et al., 2017) Person with dementia: "Look, I take what I need, I don't take too much, so. . .." Son: "Mother! You take more than you need" Husband: "You should take only two a day, it's on the, on the box" Person with dementia: "Mm, that I know" (Woman living with her husband, 06) (Cole et al., 2017)
		Increasing safeguards and supportive care at home (Taylor et al. 2023) (including People living with dementia)	"That's been a fear for me, that if he wandered away from the house, that something terrible would happen to him. So that's why my doors are the way they are and the yard's locked" (CG_105) (Taylor et al. 2023) "… all the things that were important to him are absolutely juxtaposed to what we needed to do to help keep him safe, and healthy, and all that. And yeah, big, big, big clash" (CG_141) (Taylor et al. 2023)
		Increasing and expanding informal care (Taylor et al. 2023) (including People living with dementia)	none
	Formal support: relief or frustration	▪ Use of Formal Supports by Family Caregivers (Chene, 2006)	"I got a Care Package from Villa Maria which is excellent as they helped my uncle until he needed to

			enter hospital and now they are helping my aunt who lives alone" (Mr E, nephew and carer for his aunt and uncle) (Chene, 2006) Mrs Q: "My mother would not let anyone come inside the house. My mother did not want to see anyone" (Chene, 2006) Mrs A: "My husband was too possessive to have someone else in the house" (Chene, 2006) Mr D: "I have been approached for help by others. I thanked them but I could not accept as my wife is vicious and aggressive" (Chene, 2006)
		▪ Seeking help from health professionals (Drennan et al., 2011)	"So we are managing, he is dry because I help him and then he has to go into hospital and that's it - 7 days and he comes back out using pads. No one has even tried to help him - bam! Straight into pads. It takes me weeks to get him to use the toilet again" (Wife) (Drennan et al., 2011) "My most dreadful day was Boxing Day when my mother emerged from the lavatory carrying a pile of faeces which she dumped on the little social services trolley she ate from. After this I managed to get a visit from the consultant geriatric psychiatrist, a copy of whose letter the GP sent me. It says something about the daughter expressing concerns about hygiene but no help or advice" (Daughter) (Drennan et al., 2011)
		▪ Health care professionals (Ducharme et al., 2012)	"So I talk to the doctor, right; he was the first person I spoke to, he was his family doctor. . . . So I say to him: "Listen. What do we do now then?" And he says: "I know he's sick. He needs to be cared for all the time" (F12 T3) (Ducharme et al., 2012) "The social worker said that, based on all the data he had entered into the computer system, my mother more than met the eligibility criteria for long-term care" [She no longer really belonged in a retirement residence?] "No, that's right, I think what you just said is true as well" (F04 T1) (Ducharme et al., 2012)
		▪ A paradox of give and take (Van Wijngaarden et al., 2018)	It gave them a sense of relief. Finally, a very uncertain and unexplainable episode had come to an end: "The clarity it brings is really appreciated and valued!" One respondent (i_54) said that she cried very hard when her husband's diagnosis was disclosed. The doctor asked whether she was shocked. "No," she replied, "I'm just so relieved . . ." Finally, she understood why her husband put nutmeg on his steak instead of pepper (Van Wijngaarden et al., 2018)

			On the other hand, most respondents felt they were left in a state of uncertainty, having no idea about the course of the disease and what they could expect of the future. One man (i_6) said irritably: he neurologist just announced: 'It's refractory so you don't have to come back.' And to me, he simply said: 'From now on, you can completely focus on the caring.' Well, I thought, that's nice. . . not! We both cried bitterly (Van Wijngaarden et al., 2018) Some presumed that the doctor had bitten his tongue in order not to upset them. One respondent (i_49) said: I wished the doctor would have given us a calendar, or at least a description of the process, something to hold on to, something that might provide a little steadiness (Van Wijngaarden et al., 2018) In some cases, respondents regret sharing the diagnosis too quickly with their network. One woman (i_57) told: "There was not much going on yet, and he was still saying very reasonable things. But immediately, he was no longer taken seriously by his friends and family." In the eyes of others, the diagnosis instantly took away his competence (Van Wijngaarden et al., 2018)
		Bringing in Formal Support (Taylor et al. 2023) (including People living with dementia)	none
	Actively seeking for information and advice or being trapped in hopelessness	▪ Control (Strang et al., 2006)	There was evidence that they felt out of control, not knowing what to do next or where to turn for help, just being aware that the circumstances were overwhelming. For example, one caregiver who cried throughout the interview said, " it's [caregiving] a burden . . . it gives me many sleepless nights because I don't know how to get him out of the house . . . it's awful. Now I'm, you know, I'm kind of floating, I don't know whether I am doing the right [thing] or not" (Strang et al., 2006) The desperate search for help so that they could maintain control in their situation; for example, "Who did I call first? I talked so many people . . . to see what they could do to help me with this [situation]" (Strang et al., 2006)
		▪ Gathering and Comparing the Information on Care Options (Chang et al., 2010)	"Hiring a foreign worker would make it easier for my mother to take care of my father but she disagreed. We used respite care twice but they only allowed you to use the service twice a year. I also used a home assistance

			program several times. They came to help with some physical care for my father for only a couple of hours at a time. My mother is old and not really healthy. Perhaps, nursing home is the best choice for us but it is very expensive for a good one. I do not have enough money to pay for [it] because I have my own family" (son) (Chang et al., 2010) "I told them that I was not able to care [for] my aunt at home. I told them the nursing home I found was very nice and near our town. I learned about this home from a friend of mine who is a health professional. She said this nursing home has good quality of care and provides many activities for older adults" (nephew) (Chang et al., 2010)
		▪ Their role in preparation for the move (Thein et al., 2011) (People living with dementia)	"Well, I have various other places I should go. I was there for a matter of a whole day. It was lovely. yes, yes, there for a full day and you liked it. Very nice, lovely." (Brian: 83 year-old man) (Thein et al., 2011)
		▪ Directors of elderly relative´s retirement residence (when applicable) (Ducharme et al., 2012)	"So I went down to talk to the owner and I asked him: "What does it mean when you say you won't be able to keep her past a certain point? What does it mean concretely?" Well, he explained to me that it was if she wasn't able to do things on her own anymore, like getting up, getting dressed, going to the bathroom on her own. . . . "(F05 T4) (Ducharme et al., 2012)
		▪ Visits and quality assessment of prospective living environments (Ducharme et al., 2012)	"So I called. The lady says: 'I'll let you know as soon as we have a vacancy.' And then I decided to check the place out. The rooms were a bit of a disappointment; they were really, really small" (F17 T2) (Ducharme et al., 2012) "The place I liked most was. . . . So then I checked it out in November along with my husband, so he could see the place for himself" (F17 T2) (Ducharme et al., 2012)
		▪ Seeking help and considering alternatives (Caldwell et al., 2014)	They asked for help and advice from family and friends, caregiver support groups, general practitioners, social workers, and aged care assessment teams. Although some received more help at home from community services or neighbors, most felt that the situation would reach at some point a stage, where that was not enough. Many foreign caregivers thought about employing a full time maid, however, this was generally considered too expensive (Caldwell et al., 2014) "We came up with other things like to bring in a carer for her, but she

			wouldn't like that…Another one was for her to stay with one of the children but she objected to that…And then…it would be a fulltime care if she had come in and stayed with one of the children" (CR13) (Caldwell et al., 2014)
		▪ Feeling trapped in by a prospectless future (Van Wijngaarden et al. 2018)	Some conceived the diagnosis as a death warrant: "It's a silent killer, there is no cure or stop" (Van Wijngaarden et al. 2018) Others had experienced the disclosure as an announcement of a forced relocation to a nursing home. A way to safeguard their loved ones–and allay their concerns about the future–was to promise them that they would never allow them to end up in a care home. One respondent (i_12) stated: "I remember, I reassured him: 'Absolutely, I will always take care of you, as long as I can.'" In retrospect, though, she (as well as others) realized that she had no idea of the intensity of the promise they made (Van Wijngaarden et al. 2018)
		Seeking a diagnosis (Taylor et al. 2023) (including People living with dementia)	none
Thinking about placement	**The placement decision: a complex and multidimensional effort**	▪ The decision-making period (Chang et al., 2011)	"It was so painful to make the placement decision. There are too many things I need to consider. Sometimes, I was confused about how to deal with those issues. Making this decision was a torment to my husband and me" (Chang et al., 2011) "If I made the decision for myself, it would be much easier. However, I am making the decision for my family. I have to think of every aspect of our family. I cannot imagine his life in the nursing home. Also, my brothers would disagree with placement" (Chang et al., 2011)
		▪ Activation of Decision-Making Process (Ducharme et al., 2012)	"The lady told us: 'We're only able to provide so much care here. We've taken it as far as we can, but we've now reached our limit" (F05 T5) (Ducharme et al., 2012) "We could tell that she was more confused. Often, she had burn marks on her arms. She had these marks and she didn't know how she got them" (H03 T1) (Ducharme et al., 2012) "It's getting so that I'm too tired and down. I used to cry so much I was down. They say that a lot of people become depressed if they live for too long with a person who has Alzheimer's disease. You know, I'm made pretty tough, but I'm not made of steel" (F17 T1) (Ducharme et al., 2012)

		▪ Accommodating clinically defined incompetence (St. Amant et al., 2012)	Case manager: “We are responsible [for] capacity, and there’s a legal aspect to that, an ethical aspect to that. A very difficult moral aspect occurs with some of these families [when] you are taking away someone’s right to make a decision for themselves. Rarely do I find … there isn’t tears and falling part in caregivers when they are doing that. There is also sometimes, depending on the way the dementia is exhibited … really severe anger and physical acting out at times and sometimes it’s so bad that the people completely withdraw, you know they completely give up. And then we’re back to meeting them at the beginning”[starting the process of reviewing the circumstances necessitating this decision all over again] (St. Amant et al., 2012) Granddaughter: “It was the decision that grandpa made that put those people in charge of his life, if he ever were to become incompetent”. Then she [mother of granddaughter] said: “It’s out of your hands, you know? I know you feel bad for him and you don’t want that [admission to LTC] to happen, but it’s just going make things worse if you try to fight it. … And uh… it’s not my decision. There’s nothing I can do. All we can do is help them [people with dementia] feel as comfortable as we can while they’re at home, visit them at the nursing home, and whatever it takes. Those specific decisions weren’t up to us” (St. Amant et al., 2012)
		▪ When caregivers apply for a waiting list (Caldwell et al., 2014)	“My dad had a fall at home last December so I said even at home they are not really safe. So I check with my sister and we better start to enrol them in nursing home” (CW1) (Caldwell et al., 2014) “In the future …maybe my parents have to go to some nursing home… But like, until now, everything is still good, so I stop thinking about something in the future. You know that make me worry, I stop thinking about those” (CW20) (Caldwell et al., 2014) “I didn’t have a hard feeling making this decision because I think it’s like step by step…if I don’t put my mum in a queue at an earlier stage…when she’s not in a good condition and then still has to wait, that’s no good” (CW2) (Caldwell et al., 2014) “We had to look for an alternate place, which is respite then because there was no nursing home where permanently straight you can take her in, because she wants a Chinese-

			speaking nursing home" (CR19) (Caldwell et al., 2014)
		- Self-condemning determiner position (Larsen et al., 2018)	One daughter (ID12) noted the following: "They are not dolls that I can put away in a drawer when I get tired" (Larsen et al., 2018) One wife (ID8) noted, "My conscience bothers me even though I realize this is the only way to make life worth living for both parties" (Larsen et al., 2018) One daughter (ID5) said, "Luckily, he was too physically sick to be aware of the move" (Larsen et al., 2018) A husband (ID3) said: "The most troublesome is that I build up a kind of suppression and have to restrain myself not to yell" (Larsen et al., 2018)
Weighting up pros and cons, and struggles in decision making	**Drastic experiences and struggles in decision- making**	- Caregiver Grief: Loss, Sadness and Resignation (Chene, 2006)	"It's a shock to the system to find that you haven't got your husband home with you, and you never will again. I am still sad as to the decision for a nursing home but I'll be 80 this year and I just can't manage it. I can't really cope with that, but I just have to try and bypass thinking about that" (Mrs A, commenting on the decision for residential placement) (Chene, 2006) Mrs F: "I was sad as we had spent 62 years married together" Mrs A: "I thought he would be coming home again" Mrs I: "I was sad, I cried a bit, as we had spent all that time together. I thought he was coming home initially" Mrs C: "I feel guilty you know, but it's not my fault" Mrs K: "I can't look after him anymore. I hope somebody will look after me. Nobody looks after me" Mrs A: "I'm not strong enough to do it on my own, I have to ask God to help me don't I?" (Chene, 2006)
		- Caregiver Anxiety: Guilt,Worry and Uncertainty (Chene, 2006)	"I didn't have the heart to explain it to her. If she realized it was a nursing home she would be very upset. Years ago she always said: 'never put me in a nursing home.' We made a promise that we can never keep" (Mrs M explains 'The Promise') (Chene, 2006) Mrs C: "He doesn't know he is going to a nursing home. He doesn't understand anymore" Mrs A explained how her husband "wants to go home but he doesn't know where home is" Similarly Mrs B explains that "because he wants to go home, I remember him everywhere now. With my eyes now I follow him everywhere" [starts crying] Mrs C: "who is not happy in Aged Care. He wants to leave, but he was the same at home.', Mrs H: her husband "wants to go home. He would escape to go

			home. I would feel better if he were at home” (Chene, 2006) Mr R: “That’s what worries me. How will she cope in there? Because she swears to me if she goes into a home she will kill herself, by hanging” Mrs Q: “No she is not aware, as if she knows, she says she will kill herself, put herself under a train” (Chene, 2006)
		▪ Chinese value of filial piety (Chang et al., 2011)	“We, Chinese people, value filial piety. We cannot just leave an older family member in the nursing home. We cannot abandon them in the nursing home. We (the family) need to think about this (nursing home placement)” (Chang et al., 2011) “I know my family is unable to take care of [care-recipient] but placing her to [nursing home] is a sin. Have you ever thought about the fact that she does not have the ability to take of herself, and we sent her here? That is not filial. I felt guilty” (Chang et al., 2011) “Last year, my daughter was getting married and we were very busy with the preparations for the wedding ceremony. Someone suggested that we should send [the carerecipient] to the nursing home. I thought it was a good idea but I was afraid to do so because all the relatives will come to the wedding ceremony and want to see [the carerecipient]. If they did not see her, some of them would say, “You must be un-filial because you sent her to a nursing home.” Although I really wanted to, I did not dare to do so” (Chang et al., 2011)
		▪ Limited financial resources and information (Chang et al., 2011)	“I have to provide the living expenses for my own family. My wife does not work because she needs to take care of the children. I know it would be better for my father to live in a good nursing home but I do not think I would be able to pay for it” (Chang et al., 2011) “When I was looking for a nursing home, no one talked to me about this [long-term care selection]. I did not have information about day care or respite care. I went online and searched myself….Finally, I found one [nursing home], but it was not a good one” (Chang et al., 2011)
		▪ Family disagreement (Chang et al., 2011)	“My older sister disagreed with nursing home placement. She had a more traditional concept. She felt that it is not practicing filial piety to place our mother to the nursing home. We had a big argument. Our relationship got worse after that. … Finally, I got all siblings together to vote on this (the placement decision)” (Chang et al., 2011)

			“I am responsible for his [father-in-law's] care. I stay with him all the time. Unfortunately, I cannot say I want him to be in a nursing home because I am sick, and I am not able to care for him. I cannot say that directly to my husband because I am the daughter-in-law. My husband is the oldest son so he can make the final decision. However, he disagreed with the decision. So, we had argued several times and had to talk to other relatives for more opinions. … After two years, they finally agreed with me” (Chang et al., 2011)
		▪ Limited nursing home availability (Chang et al., 2011)	“I went to visit a nursing home that had a nice and clean environment. I talked to their administrator but she refused to admit people with dementia. She said that it is their policy to not take care of people with dementia. They only take care of people with medical or surgical problems. Otherwise, it was the only nursing home that I was satisfied with” (Chang et al., 2011) Some residents' families reported “my father's violent behaviors to the nurses so we were asked to move out of the nursing home. We spent a lot of time finding another one that is able to take care of my father. It was very hard. As I knew, there is only one home that provides care to patients with dementia in X City, and it is always full of patients. You need to apply, and they will put your name on the waiting list. You never know when they will have a bed available” (Chang et al., 2011)
		▪ Hopes and fears about the home they were moving into (Thein et al., 2011) (People living with dementia)	Glenda: “I want to be with people, with somebody. Not with people. With somebody to care for me” (75 year-old woman) (Thein et al., 2011) Jane: “I think I will feel safer. I would like to have the company of other people and my own room” (88 year-old woman) (Thein et al., 2011) Ivy: “To be quite honest I don’t have high hopes about it. Like I’m quite sure the people concerned will do everything they can but I don’t think I will love it. And so long as it is in a condition of the house and that it is reasonably good I can cope with it” (86 year-old woman) (Thein et al., 2011) Eileen: “I don’t think I would want to go, to be honest with you… But er, well I, well, how can I think? You need care and you’d have to do what you were told, you know. You’d have to do all what, you couldn’t do what you liked. And you know, you’re not like your own boss kind of thing. You’d have somebody over you and

			so I’m not thinking about it” (84 year-old woman) (Thein et al., 2011)
		▪ Significant interactions in Decision-Making Process (Ducharme et al., 2012)	“I asked him: ‘What do you think of this place?’ And he said: ‘It’s all right’” (F17 T2) (Ducharme et al., 2012) [When you decided together with your brother to send your mother to the residence, how did she take it? Did she say “no, no, no”?] “No,” she said: Yeah, I know—she said—“I can’t live on my own anymore.” She accepted the fact. (F06 T3) (Ducharme et al., 2012) “My sister and I brought her to visit the place. She was willing to go but not right away. It was always later with her . . . she felt she was still too young to go there” (H03 T1) (Ducharme et al., 2012) “It took a while before agreeing because my mother didn’t want to move again. When she left her home, she found it hard. After that, we asked my parents to move into the retirement residence and my mother didn’t want to move. It took a long time before they came around” (F08 T1) (Ducharme et al., 2012) “I don’t even want to go there, because I can’t talk to her about it; I mean, if I bring it up, she’ll say: ‘You just want to get rid of me’” (H18 T2) (Ducharme et al., 2012) “My husband called them up. They all said: “Whatever you decide will be fine by us.” It was never brought up again because they know that my husband and I are the ones who take care of her all the time. Which is why they said: “You call it!” [So it’s clear now in the family that you’re the ones who make the decisions?] Yes, absolutely” (F16 T1) (Ducharme et al., 2012) “The whole family sat down together to decide what to do. We didn’t want to decide for everyone. So we all met and we could see that she had reached that point” (T1 H03) (Ducharme et al., 2012) “I called my sister and she, too, found it hard. We could see clearly that she wasn’t getting the care she needed. I mean, at the residence, they just left her there by herself’ (F04 T2) (Ducharme et al., 2012)
		▪ Making untimely decisions (St. Amant et al., 2012)	Spouse: **“**I don’t know how it worked. Whether he was on his last time to deny that [i.e., turn down the offer of a bed in LTC when his name was at the top of the wait list] … it was still an option. So I’m thinking “well, you know what the problem is, if it comes to the point where you can’t deal with it, then it’s a hospitalization that has to come first

			before that [LTC]” … It might take a little bit longer to get him in [to LTC] now that he’s off that” [wait list] (St. Amant et al., 2012) Case manager: “Is it a crisis or not? And where is that? Sometimes our conversation has to be, “You might have to accept a bed anywhere in Ontario”, and that usually backs them off really quick [that is, forces them to make a decision in the moment for the potential eventuality of having to place the person with dementia into”[LTC] (St. Amant et al., 2012)
		▪ Unknowns and uncertainty (Taylor et al. 2023) (including People living with dementia)	“So, I think that would be really helpful to some people, like a definition of what the illness is. I know they don’t want to scare people, but the inevitability of it with this particular disease is pretty…, people should know what they’re up against and prepare” (CG_129) (Taylor et al. 2023) “I feel like if I put her in a home, she’s going to be dead, and I’m not having that” (CG_120) (Taylor et al. 2023) “It’s almost impossible to plan adequately because, again, you just don’t know what you’re planning for. You’re planning for one year. You’re planning for 10 years” (CG_137) (Taylor et al. 2023) “But, that’s the kind of attitude that this kind of thing gives to not just me, but people in general that have to deal with that because you have so many hoops to jump through, basically, and you got to find the right ones and it’s just ... there is no direction, really” (CG_118) (Taylor et al. 2023) “I mean, we talked about certain things watching both of our parents kind of go through health situations, what kind of care they had or didn’t have. ... So you kind of talk about things hypothetically” (CG_123) (Taylor et al. 2023)
		▪ Challenges of resource constraints (Taylor et al. 2023) (including People living with dementia)	“I don’t really want him to go anywhere else. I mean, he’s built this house so that that doesn’t have to happen. So, it would be a matter of just the finances of having a caregiver and then there’s multiple caregivers because I know when you’re talking about one, you’re probably talking about five to seven.… between the hours and the availability and people calling in sick and things it’s a lot. (CG_103) (Taylor et al. 2023) “She wouldn’t want to be a problem to anybody, and she doesn’t want anyone to spend any money on her. … But to care for her, I would have to … hire someone” (CG_107) (Taylor et al. 2023)

			"I was anxious about the fact that I was learning that there isn't as much available in terms of housing for seniors, whether it just be an individual unit, that was within my financial range" (PWD_115) (Taylor et al. 2023) "My sister found what my mom could afford... She (mother) was single, she had a very small pension, she had Medicare and very limited resources. The facility was very substandard" (CG_121) (Taylor et al. 2023) "But, this is the only place I can live now. I have so much equity here that I can't move. And, I love this place, too. I wouldn't want to move unless I actually had to" (CG_118) (Taylor et al. 2023)
	Weighting up pros and cons in the decision-making process	▪ Need for synchronicity (Strang et al., 2006)	When a place in a well-situated institution became available the daughter, however refused placement because "she wasn't that bad, if you know what I mean ...I broke down and said no, we won't do it" (Strang et al., 2006)
		▪ Reciprocity (Strang et al., 2006)	Most significant, it was the caregiver perception of the relationship that seemed to affect the caregiving situation. In one mother daughter situation, the caregiver daughter stated, "I don't want to [use services] because Mom's memory is still good enough that she would be upset if I wasn't doing it [caregiving] and if somebody else was taking care of her while I went away, so I can't" (Strang et al., 2006) In another situation, by contrast, where there was greater congruence between the caregiver and person with dementia expectations, the caregiver talked of how easy it is to care for her mother: "It [caregiving] is not bothering me . . . Mom is very easy to care for" (Strang et al., 2006)
		▪ Negotiating with Families (Chang et al., 2010)	"I told them sending her to this home is good to a family like us who cannot care for the older adult at home. Those nurses are very nice. It does not smell weird. It is the best one among those I toured" (daughter-in-law) (Chang et al., 2010)
		▪ Distrust of nursing home care quality (Chang et al., 2011)	"I asked some of my friends. They said some bad things about the care in nursing homes such as bad smells, small space, restraint, neglect, abuse…. Those nursing homes do not really provide good care. I decided to look for myself. The nursing home I went to was okay, but I do not think they showed me how they are actually caring for those patients" (Chang et al., 2011) "Those residents were just waiting for death. In the daytime, they [staff]

			placed patients with wheelchairs outside in rows and let them just look around without paying attention to them, and then, about 11 a.m., they pushed them inside for lunch. There was only one lady cooking for more than 70 patients. She cooked in a huge pot that was just like pigswill. My idea is that sending him here [this nursing home] is waiting for death…. [Cries.]" (Chang et al., 2011) "If we call the staff to help with something, it takes about two hours to have them to come to the bedside. No one will pay attention to you even if you are crying or yelling. They do not care for patients attentively. If a diaper gets wet, they will not come to you to change it until a two hour period has elapsed. It is very inflexible. He was incontinent and used diapers. If his wet diaper did not get changed, he would get an infection. It is very dangerous, isn't it?" (Chang et al., 2011)
		▪ Identifying and Weighing Reasons For and Against Placement (Ducharme et la., 2012)	"Deep down, ideally, he should be in a nursing home, period. That's where he should be and he should go of his own volition. Ideally, that's how I see it. There would be people there round the clock, he wouldn't be alone" (F09 T3) (Ducharme et al., 2012) "I'd be more inclined to place him . . . but, on the other hand, I feel guilty just talking about it" (F09 T3) (Ducharme et al., 2012) "We knew deep down that she wouldn't be there long, it wasn't the right place for her, where she's now. But we didn't want to yank her from her environment. . .." (H03 T3) (Ducharme et al., 2012)
		▪ Weighting up the decision (Caldwell et al., 2014)	"Some of them are dirty, and the conditions no good, and so they won't choose that kind of residential care. And the one they finally got her…is neat and tidy, brand new, good looking" (CR6**)** (Caldwell et al., 2014) "I want that nursing home – Chinese food, Chinese TV, because my mum can't speak English, you know, only very basic, and the nurses speak Cantones" (CR11) (Caldwell et al., 2014) "What I worry is if she feel depressed or she doesn't like, you know, one of the staff there or one of the residents there, what's going on affect her health. From emotional, from psychological to physical" (CW1) (Caldwell et al., 2012) "I never had any concrete thoughts on it. All I wanted to know was that she was going to be looked after as good as I was going to look after her, or I

			was looking after her. I didn't want her to get any less than that but I think she needed more concentrated care that I obviously couldn't give her" (ER7) (Caldwell et al., 2012) "We had already prepared to put him in the nursing home, but once it happened…we still feel surprised. It happened too quickly" (CR12) (Caldwell et al., 2012) "Mother will go when we, for one reason or another, can't manage her, and then we have to relinquish. As long as we can manage, we will continue our community home care" (CW15) (Caldwell et al., 2012) "We make application beforehand for the nursing home. But this is just kind of, for the sake of just have her put into the waiting list…it's just an open choice that we can have more options for later. But we not very keen to send her to nursing home" (CR3) (Caldwell et al., 2012)
		▪ Maintaining life as you know it (Taylor et al. 2023) (including People living with dementia)	"It looks to me it's like we're on a path, or a road, and we haven't come to that bridge yet, so I haven't really thought about it that much" (PWD_113) (Taylor et al. 2023) "But we'll deal with that when we … get there" (CG_103) (Taylor et al. 2023) "If you ask [PWD_101], he thinks that he's got all that going on still…. He can totally be by himself without any problem. I feel there's a certain amount of unawareness, not self-awareness. I feel that's typical to a lot of folks if you're a person with dementia, trying to plan things out" (CG_101) (Taylor et al. 2023)
		▪ There's no place like home (Taylor et al. 2023) (including People living with dementia)	"No. I'm not leaving. I love our house" (PWD_104) (Taylor et al. 2023) "So culturally, I would say that we pretty much come from a family culture that does try to care for our elders as much as possible, in the home or in their home and not facilities, unless absolutely necessary" (CG_121) (Taylor et al. 2023) "There's a lot of things that you can do, but again, there's just that deep-down feeling like I just hate to have my family just having to spend all their time trying to care for me" (PWD_134) (Taylor et al. 2023) "I think the primary factor for [PWD_126] was family, was being able to be where family is and having that support. I would say that's the major factor for choosing to move" (CG_126) (Tylor et al. 2023)
Reaching the decision,	**Harmonious decision-making**	▪ A consensual decision (Chang et al., 2010)	"We all agreed with the placement decision after discussion and consideration. My brother and sister

willingness, capitulation, or reasons against placement			were very supportive” (daughter) (Chang et al., 2010) “I would like my father to live in a good nursing home. I think I am doing the right thing for him and for our whole family. It is a way to practice my filial piety. The old concept of filial piety should change to meet the modern society” (son) (Chang et al., 2010)
		▪ The facility was good (Caldwell et al., 2014)	“It was a new nursing home that opened up, it was Cantonese…they said he could have his own room, and it was so close to home as well” (CR9) (Caldwell et al., 2014)
		▪ Proponent position (Larsen et al., 2018)	One daughter (ID2) described, “She is still somewhat headstrong and discusses the process with me and the healthcare service providers; however, now, I am able to supervise her" (Larsen et al., 2018) “I refused to be the only one to force him . . . we had to agree among us siblings, at least” (ID5) (Larsen et al., 2018) One husband (ID11) described how he strategically acted familiar by asking the HcPs about their parents when they met at local stores. He said, “If it had not been for me, her (his wife’s) admission to the nursing home would not have been established as quickly as it did. It’s nice to know people” (Larsen et al., 2018) One wife (ID8) said, “I got him admitted to the nursing home because my GP knows the doctor who is in charge of the nursing home, and they both backed me up. I was lucky” (Larsen et al., 2018) “At the hospital, they acknowledged my needs as well, and they met my demands that they could not send him home” (ID2) (Larsen et al., 2018) One daughter (ID12) said, “The main reason that I participate in this study is that the politicians need to know how it feels for us” (Larsen et al., 2018)
	Conflict-ridden decision-making	▪ Partially consensual decision (Chang et al., 2010)	“I spent the most time taking care of her and paid the most money for her. If they did not agree, they should do more. I had tried very hard but they still said that I did not treat her well. I had nothing more to explain and I just decided to send her to the nursing home” (nephew) (Chang et al., 2010)
		▪ Reluctant decision (Chang et al., 2010)	“I insistently disagreed with the placement but they tried to persuade me and even forced me to make the decision. I really reluctantly made the decision. I think we are non-filial children” (daughter-in-law) (Chang et al., 2010)

		▪ Placement willingness of the older adult (Chang et al., 2011)	“It is a painful decision. I know my grandfather does not want to go to the nursing home. Although he is demented now and forgets almost everything, he still can decide what he wants or does not want. He still has autonomy. I eventually ignored him and took him to the nursing home. This makes me feel sad and worried. I feel heartache. The feeling is just like “tight tightness” (Chang et al., 2011) “I am not hard hearted enough to send [care-recipient] to the nursing home. I asked him about placement and he said “no”. Therefore, we just delayed [the placement decision] until we could not stand his behaviors anymore…. Because we asked, and he said he did not want to go….he got used to staying at home….So….it was very difficult to make the decision**”** (Chang et al., 2011)
		▪ Switching between cessation and re-activation of Decision-Making Process (Ducharme et al., 2012)	“We looked into it, I think it was this past winter, but now it’s back on ice. We don’t know, we didn’t look into how much it would cost [You thought you could just send her there?] Yeah, that’s right” (H03 T1) (Ducharme et al., 2012)
		▪ Ongoing activation of Decision-Making Process (Ducharme et al., 2012)	“Me, too, I’m not what I used to be. So, when you see that the situation is deteriorating. . . . If it’s for their own good, between you and me, even though they don’t see it that way at first. Maybe in the beginning she’ll say: “No, I’m not going.” But I think she’ll come around in time” (F05 T4) (Ducharme et al., 2012)
		▪ Anticipated a long wait and wanted to be prepared (Caldwell et al., 2014)	“Those good Asian ones, they always have a long queue…late last year I decided to put my mum in the queue. But I actually don’t want her to go even if a position is available… But end up you know we say “Ok we put her on the queue.” Just in case…Because we understand she’s already 86, things may drop at any time” (CW2) (Caldwell et al., 2014)
		▪ The caregiver could not manage (Caldwell et al., 2014)	“Finally we believe we have no alternative because we are so tired to taking of her for almost three years, and me and my wife…we are start to suffer from a bit of hell because of the stress of taking care of her” (CR8) (Caldwell et al., 2014) “I think the decision we make here is more like…if she is in care, would it be better off and I said I just couldn’t provide the care at home. There’s no way we could have done it” (CW10) (Caldwell et al., 2014) “It sort of becomes impossible, you know. I’ve got older and less mobile and she’s got a little bit harder to look

			after and you just can’t do it” (ER2) (Caldwell et al., 2014) “I just saw it as really necessary for her safety. You know, because I would have hated for anything to have happened to her and nobody being around” (ER3) (Caldwell et al., 2014)
		▪ Factors of person with dementia (Caldwell et al., 2014)	“It was mainly after she lost control of her feces and things that it just became pretty much impossible for me” (ER2) (Caldwell et al., 2014)
		▪ Dominant position (Larsen et al., (2018)	One wife (ID4) stated, “the one who still can reason has to decide” (Larsen et al., 2018) One brother (ID10) noted, “It is tough, but the family caregivers must accept the burden of the anger of the person with dementia” (Larsen et al., 2018) One sister (ID3) noted, “I have to say that she signed because of my strong influence on her” (Larsen et al., 2018) One husband (ID3) related, “I have managed this company for many years; so, I mostly take care of the big decisions at home” (Larsen et al., 2018) One brother (ID10) stated, “If the healthcare service providers disagree with me, I will start a fight and we’ll see (who wins)” (Larsen et al., 2018) Remarks of one wife (ID8): “He tried to explain that he could stay at home alone, but he cannot. I have to make the decision for both of us” (Larsen et al., 2018)
		▪ The inability to keep your promise (Van Wijngaarden et al., 2018)	Caregivers often felt guilty when they had to give up, calling themselves ‘egoists’ who put their own rest before the welfare of their partner or parent. Placement in the nursing home is considered ‘putting away’ or ‘abandoning’ their loved one. One respondent (i_33) said: “His whole life, he has worked very hard to support us. And now, when there’s practically nothing he can do anymore, I feel we are discarding him” (Larsen et al., 2018) Another respondent (i_54) talked about her inability to keep her promise: “All these years he asked, please don’t let me down. That's the theme of his life, feeling abandoned. And with my hand on my heart I promised him: ‘Of course, I will never let you down.’ And look what I’m doing. . .”. Some literally compared relocating to a divorce. The sense of distance and detachment in the relationship had now gained a spatial dimension as well (Van Wijngaarden et al., 2018)
			none

		▪ Moving to supportive care environment (Taylor et al. 2023) (including People living with dementia)	
	Outsourced or enforced decision-making	Reinforcing exclusion in decision making (St. Amant et al., 2012)	son: “I think maybe that I was a little bit more distant and a little bit more objective. And I would be fairer as to the administration of everything because I didn’t have any personal financial pressures myself. Like, I am independent of the family and have not had to ask for money for 50 years and so on. So they were saying, “Well, he knows what he’s doing”, and so on. And, “If someone is going to look after my affairs then … I’ll ask [my son] to do it, so”” (St. Amant et al., 2012) Caregiver: “My dad made his will, I think maybe when he was 85, relatively recently. I think they [the executors of his will] decided that he didn’t have an up-to-date will, or should have an up-to-date will. And I was there, my mother was there, my father was there, and I believe maybe one or two of my sisters as well, although I can’t remember who. They asked my dad, you know, “Who do you want to be the executor?” and he said “My son”, and they asked who they wanted to be the power of attorney. And then the lawyers said, “Well, somebody else should go on [the paperwork] as well.” And … I think it was Kim as well. It might be my sister, Sally, though, I’m not sure. And then they asked who was going to be the power of attorney for personal care, and I think there was kind of a general discussion. And they said, “Well, Kim’s a nurse.” They put her down. And then they put myself down as well“ (St. Amant et al., 2012)
		▪ Saluting position (Larsen et al., 2018)	A daughter (ID1) described how she proceeded to make the HcP change their mind as follows: “In a humouring manner, I praised them and further explained why my father needed to be admitted to a nursing home” (Larsen et al., 2018) One husband (ID9) said, “I emphasize that they do a great job and I often praise them. Then, it is much easier for me to ask for services when I need it, and I probably make it harder for them to reject my request” (Larsen et al., 2018)
		▪ Pending position (Larsen et al., 2018)	One husband (ID9) said, “I take it as a matter of course that healthcare service providers tell us if it is time for my wife to move” (Larsen et al., 2018) (ID3): “I told her that I would have taken care of her, but it was no longer my decision” (Larsen et al., 2014)

			"It was not about me! The healthcare service providers decided that he should be in a nursing home. It was the house that was the problem. It's not built for old people" (ID8) (Larsen et al., 2018) "It was probably someone working there who detected us and observed that I was not able to do all the care work myself; so, we have been lucky after all" (ID5) (Larsen et al., 2018)
		▪ Prisoner position (Larsen et al., 2018)	One daughter (ID1) stated, "I feel I am constantly on my toes and trapped in the caregiving role" (Larsen et al., 2018) One daughter (ID12) cried, "caring for my parent is a choice, but at the same time, it's not a real choice" (Larsen et al., 2018) One husband (ID9) noted, "Our biggest problem is the blurred lines for responsibility the moment I leave the house. Thus, I cannot leave" (Larsen et al., 2018) One husband (ID3) said, "We are plucked out of context, and I have no idea what to do about it" (Larsen et al., 2018) One wife (ID4) stated, "It is not right. He refused to apply, and thus, my life became more and more burdensome. I am exhausted, and whatever work tasks seem to drain me of energy" (Larsen et al., 2018) One husband (ID3) said, "I need to talk to nurses about potential services, but it is difficult when she (person with dementia) is always present" (Larsen et al., 2018)
		▪ Stooge positions (Larsen et al., 2018)	Several participants expressed sentiments similar to this daughter (ID1) as follows: "They rely on us to do care work in an effort to maintain the status quo" (Larsen et al., 2018) One nephew (ID7) described his uncle as "far more mentally healthy than the other patients at the nursing home" and noted, "His being all alone was an important part of the rapid intervention" (Larsen et al., 2018) One brother (ID10) stated, "I want to question the use of family caregivers. It's impossible for most people to do this much care work" (Larsen et al., 2018) One daughter (ID1) said, "My parents should have moved to the nursing home a long time ago. However, nobody in local healthcare services acknowledges our needs" (Larsen et al., 2018) Several family caregivers expressed sentiments similar to this daughter (ID1): "If he gets worse, I will just leave! [Long pause – crying] However, I know that I cannot leave him, and the healthcare service providers know that just as well as I

			do. I actually do not know what to do anymore” (Larsen et al., 2018) One husband (ID9) with a severe illness, who told the interviewer that he would not live much longer, said, “I could have helped her (wife with dementia) to make the decision, but there is no point when the nurses say that there is no capacity” (Larsen et al., 2018)
	Refusal of relocation	▪ Cessation of decision – making process without re-activation (Ducharme et al., 2012) ▪ Still managing at home (Caldwell et al., 2014) Person with dementia objected (Caldwell et al., 2014)	“The way he is now is all right. If something else were to happen, I’m not saying we might not have to place him, but other than that, I think he’s fine in his own home” (F11 T1) (Ducharme et al., 2012) “The last resort is nursing home…nobody likes to be admitted to nursing home. We hang on until we have no choice” (CR19) (Caldwell et al., 2014) “I think if you can keep them in their own home for as long as you can they’ll appreciate it a lot more” (ER4) (Caldwell et al. 2014) “It’s just too early stage to take her to the nursing home. Reason being that one, going to nursing home is just like going to jail…So food, she can enjoy good food, she can have the general basic living, what other people do, she does some little shopping for herself, and doing all this exercise, right, it helps her brain” (CW14) (Caldwell et al., 2014) “She put the fear of God in the three of us…that she is not going into any home, this is her home, she’s staying here and she doesn’t care. So I thought, yeah well I don’t want to upset you anymore” (ER4) (Caldwell et al. ,2014) “In Hong Kong and China…the general standard of nursing home in those places are not well. So the elder generation would believe that the service level would be similar. So they are afraid of been put in those places” (CR8) (Caldwell et al., 2014) “In my mother’s era, nursing homes were like institutions. And if you were to put your loved one there, it was like they were going mad. And they weren’t very, very nice, and they smelled. And people knew it. And there’s that fear” (EW1) (Caldwell et al., 2014) “The plan actually was to trial her and then if she gets used to all that…we know that next time the respite care can be extended. But that experience is a no go zone” (CW15) (Caldwell et al., 2014) “She liked her little room and she’d like her house and it was all her things around and they’re things that her and my dad strove for and built…

			she just likes her home and yeah that was where she wanted to be” (ER4) (Caldwell et al., 2014)
		▪ Family relationships (Caldwell et al., 2014)	“I had thought of it ages ago. It’s just that my brother was a lot more resistant to the idea. And I guess my mum wasn’t unwell enough . . . she was resistant to the idea as well” (CR16) (Caldwell et al., 2014) “As a Chinese, when you send your mum to a nursing home you don’t honor your mother” (CR11) (Caldwell et al., 2014) “If I put my mum in the nursing home, I’m the bad guy…I fail my duty” (CW5) (Caldwell et al., 2014) “My mum and dad will think, if the children…do not want to take good care of them, they find an excuse that is to send them to nursing home…So like they’re abandoned by their children” (CW20) (Caldwell et al., 2014) “I get benefits from it too. Because I think she’s a very good company…Because the doctor’s telling me one day, your mum will not remember me. That’s the sad part of it. And that has driven me – I don’t want mum to forget me” (CW14) (Caldwell et al., 2014) “In Chinese culture, relatives have to take care of each other. Husband and wife have to take care of each other too. You can’t put your husband or wife into a nursing home” (CR12) (Caldwell et al., 2014)
		▪ No suitable facility (Caldwell et la., 2014)	“For people not speaking English… a nursing home that can handle only Chinese, is not that many in Sydney. There are few but the queue is long” (CR8) (Caldwell et al., 2014) “It’s a long waiting process as well. Especially for the low care period, I think that was very hard…it’s almost like oh, you know, let’s let them deteriorate until they’re high care and then let them in” (CR16) (Caldwell et al., 2014)