# The Nature of Decision-Making in People Living with Dementia: A Systematic Review

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## Abstract

***Objective:*** The objectives of this systematic review were to: 1) understand how people living with dementia are involved in making decisions; 2) explore the different decisional styles and domains of decision-making that people living with dementia experience and 3) identify what influences the level of decisional involvement of people living with dementia.

***Methods:*** A systematic review of literature identified studies from Medline, PsycINFO, HAPI and CINAHL databases. Search terms related to decision-making and dementia. Qualitative and quantitative research designs were included. Appraisal of included studies was done using quality ratings. All studies focused on how decision-making took place. Extracted findings were synthesised narratively with concept mapping, conceptualisation and an exploration of connections between studies to develop an overall model of decision-making involvement

***Results*:** Fifteen studies fully met the eligibility criteria (thirteen qualitative and two quantitative). All studies had moderate (n=10) to high (n=5) quality ratings. Participants were predominantly people living with dementia (n=13), Parkinson's disease and stroke. The model of decision-making encompasses four decisional styles (managed autonomy, and delegated) determined by different degrees of involvement from the person living with dementia and their supporter. The decisional style implemented is influenced by the presence or absence of background (the Freedom of Choice framework) and contextual factors (risk, relationships and resources).

***Conclusion*:** Decision-making in dementia is complex and influenced by many factors beyond cognitive impairment alone. This review indicates that decision-making in dementia takes place through decisional styles, determined by unique levels of involvement from people living with dementia and their carers.

Key words: dementia, autonomy, decision-making, narrative synthesis, systematic review

## Introduction

The ability to make decisions is an important exercise of a person's independence, control and autonomy. Decision-making allows the application of personal, social, professional and legal control over one's life. The consequences of impaired decision-making have been investigated in populations of Parkinson's disease (Mark & Sampson, 2013; Poletti et al., 2009; Witt, 2007), stroke and brain injury (Foster, Tisle & Fleming, 2004; Iaquinta, 2007; Kelly, McDonald & Kellett, 2014; Wood & McHugh, 2013) and dementia (Dahan & Eth, 2009; Davis et al., 2017; Whitlatch & Menne, 2009).

The ability to make decisions is critical for maintaining autonomy, well-being and the identity of people with dementia and their supporters (Davis et al., 2017; Menne, Tucke, Whitlatch & Feinberg, 2008; Whitlatch & Menne, 2009). Decision-making is also an important aspect of 'recovery' in dementia, which is defined here as the ability to live an independent life in the presence of dementia symptoms (Hammond & Debney, 2017; Martin, 2009; [National Institute for Mental Health in England] NIMHE, 2004).

The difficulties experienced by people living with dementia during decision-making have been typically attributed to a decline in and ultimately a loss of cognitive functioning (Derse, 1999; Jiménez, Chung Jaén, Vigara García & Barahona-Alvarez, 2013). Several facets of decision-making have been empirically explored in dementia research such as advanced care planning (Elliot, Gessert & Peden-McAlpine, 2009; Mitchell, 2015), medical treatment (Appel, 2012) and everyday decision-making (Davis et al., 2017). However, the decisional involvement of people living with dementia may not always be attributable to disease related factors such as cognitive impairment. Despite having the capacity to make decisions (Appel, 2012; Dahan & Eth, 2010; Derse, 1999), people living with dementia may still be excluded (Taghizadeh Larsson & Osterholm, 2014) or overridden by supporters (Livingston et al., 2010; Piffaretti, 2012).

The emphasis in previous research has been on shared decision-making between the person living with dementia and their carer (usually spousal). This is a collective or systems approach where carers (e.g. spouses, family members) and the person living with dementia, are informed about the available options and contribute to an overall decisional outcome (Mariani et al, 2016; Miller et al., 2016; Whitlatch & Menne, 2009). There is typically a distinction between the extent to which people living with dementia prefer to be involved and how much involvement occurs (Whitlatch & Menne, 2009).

There has been a shift in dementia discourses, away from the medical model where an individual is a diagnostic label, toward a psychosocial approach, where the experience of the individual is central (Kitwood, 1997; Pratt & Wilkinson, 2003). However, there are no person-centred models of how decision-making takes place in dementia. Medical decision-making models for joint clinician-patient dyads outline trajectories. These range from the clinician leading decisions to clinicians facilitating patient involvement (Murray, Charles & Gafni 2006; Whitney, 2003).

A recent review by Davis, Ziomkowski and Veltkamp (2017) focussed on the ability of individuals living with Alzheimer's disease to perform everyday decision-making. It concluded that decision-making in dementia is complex and multi-facetted but that people living with Alzheimer's disease are able to meaningfully contribute to the decisional process in everyday decision-making. To the authors' knowledge, there is no review of decision-making across dementias, decisional types (individual and shared decision-making) and domains (diagnosis, daily living, respite, residential, financial decisions) nor any systematic review of factors that influence decision-making in dementia or the involvement of people living with dementia through decisions they may make with their supporters. The unique complexity of capacity in dementia gives rise to a series of decision-making challenges that current models of generic decision-making do not cover.

The aim of this review was to understand the nature of decision-making in people living with dementia through the following objectives to:

1) Understand how people living with dementia are involved in decisions.

2) Explore the different decisional styles and domains of decision-making people living with dementia experience.

3) Identify what influences the level of decisional involvement of people living with dementia.

## Methods

PRISMA-P guidance was used to develop a protocol for this systematic review (Moher et al., 2015).

### *Eligibility criteria*

- *Study design*: studies reporting qualitative or quantitative findings with observational designs
- *Publication language*: studies published in the English language
- *Publication year*: peer reviewed studies published in academic journals between 1997-2017
- *Types of participants*: people living with dementia or other conditions where decision-making capacity is affected (e.g. acquired cognitive impairment, Parkinson's disease, stroke or brain injury)
- *Review focus*: studies reporting how decision making is conducted by people living with dementia or other conditions where decision making capacity is affected and can be compared to dementia

### *Search strategy*

Two platforms were used to conduct a database search. Ovid (Medline, PsycINFO, Health And Psychological Interventions; HAPI) and EBSCOHost (CINAHL) were searched using the medical subject heading (MeSH) term "dementia" in combination with "decision-making" and "decision-making support". Database filters were set such that only peer-reviewed full text articles in English, published between 1997 to 2017 in human populations appeared. Further MeSH terms were used to incorporate cross-disciplinary findings from conditions related to dementia such as "acquired cognitive impairment", "Parkinson's", "stroke" and "brain injury". Additional articles were identified from an updated database search, recommendations by experts, reference lists of reviews, included full texts and articles that had cited these.

### *Identification of articles*

For all articles, three screening stages were carried out. Firstly, article titles were screened. Titles that did not reflect the focus of this review were excluded. Secondly, abstracts of included articles were screened by two reviewers independently (JB, CS). Finally, all remaining full texts were screened for eligibility by two reviewers independently (JB, GC). Any disagreements over eligibility were discussed between authors until an agreement was reached.

### ***Quality Assessment***

A tool kit established by Mukadam, Copper and Livingston (2011) was used, which comprises of shortened versions of both qualitative (Critical Appraisal Skills Programme, 2006) and quantitative (Boyle, 1998) checklists. Two authors (JB and HW) independently assessed the quality of articles. Articles were assigned a score of 0 (criterion not met) or 1 (criterion met) for each item, resulting in a quality score out of six. Discrepancies were discussed and consensus was reached. Quality of studies were categorised as low quality (0-2), moderate quality (3-4) or high quality (5-6).

### ***Narrative Synthesis***

A narrative approach allowed both qualitative and quantitative evidence to be synthesised into a model of decision-making in dementia (Dixon-Woods et al., 2005). In line with guidance from Popay et al (2006), the narrative approach outlined four stages within the general framework of conducting a narrative synthesis: (1) developing a theory, (2) developing a preliminary synthesis, (3) exploring relationships and (4) assessing the robustness of the synthesis.

#### *Stage 1: Developing a theory*

The aims of this review and eligibility criteria were constructed through scoping existing literature and consulting a researcher leading on PPI and qualitative methodology in the Promoting Independence in DEmentia (PRIDE) study. This suggested the factors influencing decisional involvement of people living with dementia may include: kinship of supporter (Miller et al., 2016), history of decision-making within a dyad (Harrison-Dening, King, Jones & Sampson 2017), familial restrictions (Groen-van de Ven et al., 2016) and cognitive ability (Mariani et al., 2017; Mitchell, 2015). In this review, the term involvement refers to the extent to which a person contributes to the outcome of the decision through participation in the decision-making process.

#### *Stage 2: Developing a preliminary synthesis*

A preliminary synthesis was developed with eligible full text articles, which was the starting point for exploring patterns across included studies in line with the review question. Initial descriptions for included studies were tabulated into the following categories: author, year, peer reviewed journal, country, study aim/research question, decision-making type, decision-making domain, design, participant, measures and analysis and summary of study findings. Clustering of studies in this stage was based on the nature of results that were reported.

*Stage 3: Exploring relationships*

A visual diagram of the synthesis was then developed by conceptualising and exploring connections within clusters. To understand how decision-making may take place in dementia, the heterogeneity of the methods used in the included articles was explored. From stage two, the patterns across studies were clustered and these relationships were then developed into a synthesis. Concept mapping was used to link pieces of qualitative and quantitative evidence across individual studies to construct a model (Mulrow, Langhorne & Grimshaw, 1997). Articles which identified frameworks of decisional styles were used as a skeleton to map the concepts of cross sectional articles. A synthesis model was then developed.

*Stage 4: Assessing the robustness of the synthesis*

In addition to the quality assessment of individual studies, a critical reflection on the synthesis process took place. This involved exploring the strengths and limitations of the process as implemented, assumptions made and the evidence used, in line with guidance outlined by Popay et al (2006).

## Results

### *Study identification*

A total of 558 articles were identified (see Figure 1). After duplicate removal (n=282), 237 articles were excluded by screening the title (n= 194) and abstract (n = 43). The reference list of the remaining 39 articles was checked for relevant references (n = 16) and forward citations (n = 5), articles were also added from an updated database search (n = 6), references from relevant reviews n = 2, expert recommendations n = 1). Of the remaining 69 references, 54 were excluded. Studies that did not focus on how decision making was conducted by the person living with dementia (or other conditions where decision making is affected) were excluded (n = 30), as were studies that reported findings that did not relate to a decision making situation that people living with dementia would be in (n = 6). Studies that did not report qualitative and quantitative findings in observational designs were excluded (n = 7). Studies that were review articles were also excluded (n = 11).

### Study Characteristics

Fifteen studies fully met the eligibility criteria for this review of which, 13 used qualitative and two quantitative methods. The majority of qualitative studies were cross sectional (n= 9) whilst some were longitudinal (n=4); both quantitative studies were of a cross sectional design. Qualitative designs comprised of structured/semi-structured-open ended interviews (n= 8), interviews and observations (n= 4) and focus group interviews (n =1). Qualitative studies were analysed through grounded theory (n= 4), thematic analysis (n = 4), interpretative or interpretative phenomenological analysis (n= 2), phenomenological analysis (n= 1) and mixed qualitative methods (n= 2). The two quantitative studies used correlations (both), hierarchical multiple regression (n=1) and multilevel modelling to analyse data (n=1). Studies were from the United States (n =5), United Kingdom (n =4), Australia (n =3), with one each from Norway, France and China.

Participants were predominantly people with dementia, Parkinson's disease (n=1) and stroke (n=1). Within the included studies, some only collected data from those living with dementia or a related condition (n=2) whilst others included carers (n=13). Of the studies that included carers (n=13), carers were spouses, a mixture of family carers and friends (n=6), and a mixture of family and paid carers (e.g. nurses, physiotherapists, acupuncturists, n = 2). Sample sizes for qualitative and quantitative studies varied from 6 – 85 and 84 - 430 participants respectively. The mean age of participants was 68.38 years (n=10) whilst the other studies did not report this data (n= 5).

### Decision-making domains

A decision-making domain refers to the category of a decision (summarised in Table 1). Decision-making domains were everyday (n= 4), general (n = 4), health and social care planning (n= 3), driving, financial management, research participation, and exercise

### Quality Assessment

Quality appraisal scores were not used to exclude studies but to assess the robustness of the synthesis. Ten qualitative studies were rated as of moderate quality and three as of high quality (a score of five). Both quantitative studies were of high quality (a score of five, see Table 1).

[Table 1 here]

## ***How do people living with dementia make decisions?***

### *Decisional Styles*

Five studies referred to the term ‘shared decision making’ (SDM) across driving, every day, healthcare and general decisions. In some studies, SDM referred generally, to the joint involvement of a person living with dementia and carer (Fetherstonhaugh et al., 2016; Harrison-Denning et al., 2017). However the term was also used to refer to the decisions made by carers and professionals (e.g. healthcare workers) for or with the person living with dementia without their active participation (Adler, 2010; Horton-Deutsch, Twigg, & Evans, 2007). In one study, SDM also referred to reminding a person living with dementia of past joint decision-making on a particular topic, such that a repetition of the process was not necessary (Smebye, Kirkevold, & Engedal, 2012). Across these examples, ‘SDM’ lacked operational consistency, with the term describing an array of decision-makers outside the typical carer-person living with dementia dyad. In some instances, SDM was used as a term of reference when the person living-with dementia was not involved in making the decision.

The extent to which a person living with dementia was involved, if at all, is unclear from the term SDM. Some studies emphasised the decline in decision-making ability due to dementia however still made use of the term SDM. The results of this systematic review have avoided SDM as a decisional style, as the actual amount of involvement from the person living with dementia or in fact the parties whom are involved in the process is unclear from previous research. More specific terminology was developed in this review in order to reduce ambiguity and clarify who is involved in the decision-making processes and how.

Decision-making led by the person with dementia was defined as autonomous typically, when decisions had no serious consequences and were seen as minor decisions (Smebye, Kirkevold & Engedal, 2012). This was the least common form of decision-making as only a few studies reported the person with dementia being the ultimate decision maker (Black et al., 2013; Horton-Deutsch, Twigg & Evans, 2007; Smebye et al., 2012).

***Managed Autonomy.*** Managed autonomy was decision-making with support from both formal and informal carers (Smebye et al., 2012). Spousal carers implemented support strategies (discussion around choices, dialogue about consequences, understanding the person, negotiation and listening) to facilitate the person with dementia's autonomy in everyday decision-making (Boyle, 2013; Fetherstonhaugh, Rayner & Tarzia, 2016). The strategies employed by carers included: reinforcing the person with dementia's opinions, exchanging information through consultation and dialogue, encouraging questioning, and supporting reasoning and understanding (Boyle, 2013; Fetherstonhaugh et al., 2016; Smebye et al., 2012).

***Mutual.*** In mutual decision-making, carers had increased responsibility for contributing to the overall outcome (Harrison-Dening et al., 2016). For this approach, carers were theorised to be compensating for the loss of abilities of the person with dementia whilst respecting boundaries by acknowledging the importance of autonomy to the person with dementia (Samsi & Manthorpe, 2013; Smebye et al., 2012).

***Reductive.*** This was defined by carers taking on a larger share of decisional responsibility due to the increasing impact of dementia symptoms (Samsi & Manthorpe, 2013). The strategy employed by carers therefore, was to uphold and facilitate the remaining capacity of the person with dementia irrespective of the loss of abilities (Boyle, 2013a). Evidence supporting this form of decision-making in dementia suggests that the person living with dementia appreciated even trivial involvement in decision-making (Fetherstonghaugh et al., 2016).

***Delegated.*** Delegated decision-making was the conscious act by the person with dementia of placing decision-making responsibility in the hands of others (Smebye et al., 2012). This decisional style was common in situations where consequences were major and of high risk. The supporter chosen to take on responsibility for making decisions was based on accumulated family bonds and social capital over a period of time (Smebye et al., 2012). As a consequence, decision-making responsibility was often deferred to the spousal carer and depended on the previous decision-making history and roles within the dyad (Horton-Deutsch et al 2007).

### *What factors influence the involvement of people living with dementia in decision-making?*

*Background Factors: Freedom of Choice Framework*

Background factors are those that should be present regardless of context and should run in the background for meaningful decision-making involvement. Tyrrell et al. (2006) suggest that people living with dementia are capable of expressing meaningful decisions but are often unheard in the decisional process. According to the freedom of choice framework, a person with dementia is in a better position to contribute to the decisional process if the freedom of choice dimensions are in place: being informed, being listened to, ability to express opinion, time for reflection and reversibility of choice.

The components of the framework were implemented over various decision styles in the literature identified in this review. Carers managed the autonomy and expression of the person living with dementia in decision-making by upholding the necessary background factors (Boyle, 2013; Fetherstonhaugh et al., 2016; Smebye et al., 2012). The framework was upheld by carers through supervision, guidance, emotional support and facilitating communication where carers played a resourceful role (Boyle, 2013; Fetherstonhaugh et al., 2016; Horton- Deutsch et al 2006). Background factors created a ‘space’ in which a person living with dementia’s voice could be meaningfully heard. This concept of having space to decide, led people living with dementia to feel central to decisions. This was seen as a way of combatting dementia symptoms and conquering challenges such as negotiating support from carers whilst still remaining involved in the decision –making process (Fetherstonhaugh et al., 2013).

The freedom of choice framework therefore can be seen as way of adapting in the face of symptomatic changes in chronic conditions, where decisional involvement contributed to an overall sense of empowerment (Fetherstonghaugh et al., 2016; Menne & Whitlatch, 2007; Miller et al., 2017; O'Brien, Clemson & Canning, 2016). When these background factors were not in place, there was lack of opportunity, marginalisation and exclusion of people living with dementia due to others (Boyle 2013a; Fetherstonhaugh et al., 2016; Smebye et al., 2012). There were examples of decisional styles that violated the freedom of choice framework, suppressing involvement sometimes irrespective of decisional capacity. These decisional styles fell outside the freedom of choice framework and were not included in the final synthesis model as the person living with dementia was not involved in the process hence did not contribute to the outcome. These were styles such as pseudo-autonomous ("people talk about me, around me but not to me", Fetherstonhaugh et al., 2013) and non-involvement (the product of either loss of decision-making ability or lack of opportunity, Smebye et al., 2012; Boyle, 2013a). Along with other carer-led styles such as retrospective (carers make decisions about a person based on accumulated knowledge, Samsi & Manthorpe, 2013) and best interest or substitute (completely carer led decision- making regardless of consent from the person living with dementia Samsi & Manthorpe, 2013).

### *Contextual Factors: Risk, Relationships and Resources*

Contextual factors are transient and unique to certain types of decisions within particular domains. The freedom of choice made up background factors that created the figurative space for people living with dementia to be involved in decision-making, however the contextual factors influences this involvement.

***Risk.*** Authors of included papers illustrated the tensions experienced by carers of people living with dementia between supporting autonomy and maximising safety. In the presence of risk, some carers were able to facilitate activities such as driving in the face of deteriorating ability, upholding the freedom of choice framework ("[wife] we've discussed this issue about him losing his license eventually because his brother had a stroke and he eventually had to give up his license. So . . . one of these days it will come to that . . . and I think if we keep educating him and keep telling him [it will help]", Adler, 2010). However, sometimes the factor of risk led to decision-making occurring outside the freedom of choice framework and synthesis model as the person living with dementia was excluded from contributing to the outcome ("[carer speaking to a professional] I want you to tell him to stop driving", Adler, 2010). High risk lowered levels of decisional involvement from the person living with dementia, and where a particular conclusion was deemed necessary (e.g. for the person living with dementia to discontinue driving), it became difficult for a carer to stay in a supportive role (Adler 2010; Fetherstonhaugh et al. 2016; Smebye 2012). To maintain risk aversion, spousal carers made decisions based on their own beliefs overriding those of the person living with dementia, justifying their involvement as for the person's "own good" (Fetherstonhaugh et al., 2016).

***Relationship.*** Research in healthcare decision-making suggested that people with dementia did not feel well informed, listened to, able to express their opinions, or reflect on decisions enough when supported by adult children compared to spousal carers (Tyrrell et al., 2006). For minor decisions, female compared to male spouses were better at ensuring background factors were in place as highlighted by the freedom of choice framework (Boyle, 2013; Tyrrell et al., 2006). However, this gender difference was not apparent for major decisions, where background factors were not incorporated into the decision making process irrespective of gender. Domineering behaviours left the person with dementia feeling marginalised and excluded from decisions, even in the presence of decisional capacity (Boyle, 2013; Fetherstonhaugh et al., 2013). This behaviour from the carer was often viewed negatively by the person with dementia, causing them frustration and reducing their sense of control and opportunity (Fetherstonhaugh et al., 2013).

Married dyads had habituated roles (e.g. financial management), which had been established over time and provided an infrastructure for decision-making. In the face of dementia symptoms, men were more likely to resist financial management by their female spouses (Boyle 2013a). In contrast, evidence from advanced health care planning suggests that regardless of prior history, dyads did not initiate decision-making until a crisis situation occurred (Harrison-Dening et al., 2017). This suggests that the relationship history within a dyad may contribute to the domain specific decisional involvement of a person living with dementia.

***Resources.*** A carer's ability to perform a supportive role within the decisional process (employ support strategies) influenced the decisional style used. For example, carers who dominated the conversation diminished the opportunity for the person with dementia to express their views (Boyle 2013). Wang and Nolan (2016) outlined 'hiding' behaviours (failing to disclose negative information or tailoring the truth) performed by a sample of Chinese carers (formal and informal) that served the purpose of upholding cultural values but precluded individuals with stroke from difficult decisions, all together reducing their decisional involvement. On the other hand, when carers provided guidance, emotional support and dialogue around choices they were seen as a resource to help the person living with dementia negotiate decisions (Boyle 2013; Fetherstonhaugh et al., 2016; Horton-Deutsch et al., 2006).

The presence of cognitive impairment was seen, by some, as a precluding factor for decision making and could lead to the conclusion that the person living with dementia was unable to contribute to the decision-making process (Boyle 2013a; Fetherstonhaugh et al., 2013). However, when a carer performed a supportive role implemented the aforementioned support strategies it was still possible for the person living with dementia to meaningfully engage in the decision-making process (Tyrrell et al 2006).

### ***The synthesis model***

The synthesis model (Figure 2) is a representation of two dynamic transitions; the lesser involvement from the person living with dementia across decisional styles and the greater involvement from the carer. Involvement is defined as the extent to which a person contributes to a decisional outcome. This model is a reflection of evidence from research studies where the majority of participants were able to give written informed consent and had mild or moderate dementia. A key message arising from the model is that the involvement of a person living with dementia in decision-making is not always dictated by cognitive impairment or capacity and other factors that contribute were explored through two lenses. Firstly, background factors (being informed, listened to, expression of opinion, time for reflection and reversibility of choice) placed a person living with dementia in a better position to participate in active and meaningful decision-making. Secondly, three domains (contextual factors) influenced the decisional style implemented. The involvement of a carer in the decision-making process, according to such contextual factors, gave rise to a spectrum whereby carers were placed as having a supportive to suppressive role.

[Figure 2 here]

## Discussion

This systematic review draws together four styles of decision-making that people living with dementia use with varying levels of involvement from carers. Shared decision-making as a decision-making style lacks definitional specificity, as it refers to ambiguous and undefined levels of involvement from a person living with dementia and a carer (usually spousal). For this reason, this systematic review referred to other decision-making styles that people living with dementia use to encourage greater definitional specificity such as managed autonomy, mutual, reductive and delegated decision-making. According to this review, factors other than cognitive impairment contribute to the way in which people living with dementia make decisions. Factors that influence decisional involvement include background (freedom of choice framework) and contextual factors (risk, relationships and resources).

### *Summary of Model*

Narrative synthesis methodology allowed the findings of both qualitative and quantitative studies to be brought together in a synthesis model. The model represents how people living with dementia make decisions based on their level of involvement across decisional styles, rather than over cognitive decline or time.

The synthesis model comprises of managed autonomy, mutual, reductive and delegated decisional styles that are implemented based on the presence or absence of background and contextual factors. Findings suggest that cognitive impairment is not always the key dimension through which the decisional involvement of a person living with dementia is determined. A plethora of factors such as background factors and contextual factors also contribute.

This review provides support for previous research on the importance of decision-making to the ongoing autonomy of people living with dementia (Davis et al., 2017; Menne, Tucke, Whitlatch & Feinberg, 2008; Whitlatch & Menne, 2009). The findings suggest that preservation of autonomy and decisional involvement are related objectives (Fetherstonhaugh et al 2013; Miller, Lee, Whitlatch & Lyons, 2017; Samsi & Manthorpe, 2013). This review has successfully linked these objectives through the presence of background and contextual factors.

### *Critical Reflection of Robustness of Synthesis*

The review had well defined inclusion and exclusion criteria that were developed in a protocol with the aim of capturing as many relevant studies in line with the research question. Further, the identification and selection process was conducted over a number of pre-specified stages with two independent reviewers during two critical stages, namely, abstract screening and quality appraisal of studies, greatly reducing the impact of bias.

A narrative approach allowed for the synthesis of both qualitative and quantitative literature to construct a model of decision-making in dementia. Although suitable for the evidence base in this review, a narrative synthesis does pose methodological limitations. The range of techniques that can be implemented in a narrative synthesis may cause the same evidence to synthesise in different ways. In addition, there is limited guidance on the synthesis of both qualitative and quantitative research designs (Dixon-Woods et al., 2005). Regardless of these limitations, this review was conducted in line with guidance from Popay et al. (2006) for methodological consistency. The final synthesis model was discussed with a small group of carers who validated the decisional styles and factors through personal experiences with their spouses living with dementia. Further, the qualitative and quantitative quality appraisal tools used were standardised and comparable between study designs. The latter suited the nature of this review as the evidence reviewed was of both a qualitative and quantitative nature.

### *Limitations*

The chosen databases were based on the authors' previous knowledge, recommendations from experts and published reviews. Only peer-reviewed, published full text studies in the English language were eligible for inclusion. Therefore, some relevant material may not have been included, for example non-academic literature. This review also contained a small number of studies from predominantly Western parts of the world, restricting the generalisability of findings to other cultural backgrounds.

### *Implications*

It is both an ethical and moral obligation for research to understand how decision-making occurs in dementia. This can be used to improve the decision-making process such that legislation can actively ensure the independence and autonomy of those living with dementia rather than having the opposite effect. This review contributes to this understanding by illustrating the optimal conditions for people living with dementia to meaningfully engage in the decisional process whilst also encompassing contextual factors that may cause supporters of the person to become barriers to their decisional involvement, irrespective of cognitive decline.

### *Future research*

Future research should seek to implement the proposed model to inform interventions that facilitate the decisional involvement of people living with dementia within the carer relationship. Further, there are implications for practice as often clinicians work with dyads (person living with dementia and their carer), rather than a person living with dementia in isolation. The proposed model provides clinicians with a tool that may better assist decisional involvement of all parties by understanding unique characteristics that may act as facilitators or barriers.

### *Conclusion*

People living with dementia are involved in decision-making within the context of four different types of decisional styles. These styles are distinguishable based on the decisional involvement of the person living with dementia and their supporter. The factors that influence decisional involvement can be grouped into two categories; (1) background factors (being informed, being listened to, ability to express opinion, time for reflection and reversibility of choice), and (2) contextual factors (risk, relationship and resources). This review provides evidence that cognitive impairment is not always the key dimension that determines the decisional involvement of a person living with dementia. Future research, clinical practice and policy should aim to use the proposed model to ensure the meaningful contribution of people living with dementia in decisions that affect them.

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## Conflict of interest

The authors report no conflict of interest

## References

*Adler, G. (2010). Driving decision-making in older adults with dementia. *Dementia*, *9*(1), 45–60. https://doi.org/10.1177/1471301209350289

Appel, J. M. (2012). Medical decision-making in dementia patients. *Psychiatric Annals*. SLACK. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc9&NEWS=N&AN=2014-31815-006

*Black, B. S., Wechsler, M., & Fogarty, L. (2013). Decision making for participation in dementia research. *The American Journal of Geriatric Psychiatry : Official Journal of the American Association for Geriatric Psychiatry*, *21*(4), 355–363. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=23498382

*Boyle, G. (2013a). “She”s usually quicker than the calculator’: financial management and decision-making in couples living with dementia. *Health & Social Care in the Community*, *21*(5), 554–562. https://doi.org/10.1111/hsc.12044

*Boyle, G. (2013). Facilitating decision-making by people with dementia: Is spousal support gendered? *Journal of Social Welfare and Family Law*, *35*(2), 227–243. https://doi.org/10.1080/09649069.2013.800290

Boyle, M. H. (1998). Guidelines for evaluating prevalence studies. *Evidence-Based Mental Health*, *1*(2), 37–39. https://doi.org/10.1136/ebmh.1.2.37

Dahan, A., & Eth, S. (2009). Medical decision-making capacity of patients with dementia: four criteria must be met. *Psychiatric Times*, *26*(12), 1–7. Retrieved from https://search.proquest.com/docview/204590397?accountid=14511

Davis, R., Ziomkowski, M. K., & Veltkamp, A. (2017). Everyday Decision Making in Individuals with Early-Stage Alzheimer’s Disease: An Integrative Review of the Literature. *Research in Gerontological Nursing*, *10*(5), 240–247. https://doi.org/10.3928/19404921-20170831-05

Derse, A. R. (1999). Making decisions about life-sustaining medical treatment in patients with dementia. The problem of patient decision-making capacity. *Theoretical Medicine and Bioethics*, *20*(1), 55–67. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=10442054

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy*, *10*(1), 45–53. https://doi.org/10.1258/1355819052801804

*Fetherstonhaugh, D., Rayner, J. A., & Tarzia, L. (2016). Hanging on to some autonomy in decision-making: How do spouse carers support this? Dementia: The International Journal of Social Research and Practice. Advance online publication. DOI: 10.1177/1471301216678104.

*Fetherstonhaugh, D., Tarzia, L., & Nay, R. (2013). Being central to decision making means I am still here!: the essence of decision making for people with dementia. *Journal of Aging Studies*, *27*(2), 143–150. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=23561279

Foster, M., Tilse, C., & Fleming, J. (2004). Referral to rehabilitation following traumatic brain injury: practitioners and the process of decision-making. *Social Science & Medicine (1982)*, *59*(9), 1867–1878. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=15312921

Groen-van de Ven, L., Smits, C., Oldewarris, K., Span, M., Jukema, J., Eefsting, J., & Vernooij-Dassen, M. (2017). Decision trajectories in dementia care networks: decisions and related key events. *Research on aging*, *39*(9), 1039-1071. https://doi.org/10.1177/0164027516656741

Hammond, L. L., & Debney, C. (2017). Recovery and dementia: promoting choice and challenging controversy. *Mental Health and Social Inclusion*, *21*(5), 297–303. https://doi.org/10.1108/MHSI-06-2017-0025

*Harrison Dening, K., King, M., Jones, L., Sampson, E. L., Harrison Dening, K., King, M., … Sampson, E. L. (2017). Healthcare decision-making: past present and future, in light of a diagnosis of dementia. *International Journal of Palliative Nursing*, *23*(1), 4–11. https://doi.org/10.12968/ijpn.2017.23.1.4

Harrison Dening, K. King, M. Jones, L. , Vickerstaff, V. & Sampson, E. (2016) Advance Care Planning in Dementia: Do family carers know the treatment preferences of people with early dementia? Plos One. 11(8): e0161142. DOI: 10.1371/journal.pone.0159056

*Horton-Deutsch, S., Twigg, P., & Evans, R. (2007). Health care decision-making of persons with dementia. *Dementia*, *6*(1), 105–120. https://doi.org/10.1177/1471301207075643

Iaquinta, M. (2007). The experience and meaning of career decision-making as lived by women with brain injury. *Dissertation Abstracts International Section A: Humanities and Social Sciences*.

Kelly, M., McDonald, S., & Kellett, D. (2014). Development of a novel task for investigating decision making in a social context following traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, *36*(October 2014), 897–913. https://doi.org/10.1080/13803395.2014.955784

Kitwood, T. (1997). The experience of dementia. *Aging and Mental Health*, *1*(1), 13–22. https://doi.org/10.1080/13607869757344

Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., … Cooper, C. (2010). Making decisions for people with dementia who lack capacity: Qualitative study of family carers in UK. *BMJ (Online)*, *341*(7771), 494. https://doi.org/10.1136/bmj.c4184

Mariani, E., Vernooij-Dassen, M., Koopmans, R., Engels, Y., & Chattat, R. (2017). Shared decision-making in dementia care planning: barriers and facilitators in two European countries. *Aging & Mental Health*, *21*(1), 31–39. https://doi.org/10.1080/13607863.2016.1255715

Martin, G. (2009). Recovery approach to the care of people with dementia: Decision making and “best interests” concerns. *Journal of Psychiatric and Mental Health Nursing*, *16*(7), 654–660. https://doi.org/10.1111/j.1365-2850.2009.01446.x

*Menne, H. L., & Whitlatch, C. J. (2007). Decision-making involvement of individuals with dementia. *Gerontologist*, *47*(6), 810–819. https://doi.org/10.1093/geront/47.6.810

Menne, H. L., Tucke, S. S., Whitlatch, C. J., & Feinberg, L. F. (2008). Decision-making involvement scale for individuals with dementia and family carers. *American Journal of Alzheimer’s Disease and Other Dementias*, *23*(1), 23–29. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med6&NEWS=N&AN=18276955

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, *15*(5), 1141–1157. https://doi.org/10.1177/1471301214555542

*Miller, L. M., Lee, C. S., Whitlatch, C. J., & Lyons, K. S. (2017). OUP accepted manuscript. *The Gerontologist*, *00*(00), 1–10. https://doi.org/10.1093/geront/gnw265

Ministry of Justice (2007) Code of Practice of the Mental Capacity Act 2005. London: Department for Constitutional Affairs, Ministry of Justice.

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., ... & Stewart, L. A. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic reviews*, *4*(1), 1.

Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, *26*(1), 12–20. https://doi.org/10.1002/gps.2484

Murray, E., Charles, C., & Gafni, A. (2006). Shared decision-making in primary care: Tailoring the Charles et al. model to fit the context of general practice. *Patient Education and Counseling*, *62*(2), 205–211. https://doi.org/10.1016/j.pec.2005.07.003

National Institute for Mental Health in England (2004) Emerging Best Practices in Mental Health Recovery, UK Version 1. NIMHE, London. Available at: http://www.nimhe.org.uk

*O’Brien, C., Clemson, L., & Canning, C. G. (2016). Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson’s disease: a qualitative enquiry. *Disability and Rehabilitation*, *38*(5), 472–481. https://doi.org/10.3109/09638288.2015.1055377

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. *A Product from the ESRC Methods Programme*. https://doi.org/10.1177/1356389008097871

Pratt, R., & Wilkinson, H. (2003). A Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia. *Dementia*, *2*(2), 181–199. https://doi.org/10.1177/1471301203002002004

*Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics*, *25*(6), 949–961. https://doi.org/10.1017/S1041610213000306

*Smebye, K. L., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? a multi-case study. *BMC Health Services Research*, *12*, 241. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med7&NEWS=N&AN=22870952

Taghizadeh Larsson, A., & Österholm, J. H. (2014). How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings. *International Psychogeriatrics*, *26*(11), 1849–1862. https://doi.org/10.1017/S104161021400132X

*Tyrrell, J., Genin, N., & Myslinski, M. (2006). Freedom of choice and decision-making in health and social care: views of older patients with early-stage dementia and their carers. *Dementia (14713012)*, *5*(4), 479–502. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=jlh&AN=106146192&site=ehost-live&scope=site

*Wang, Y., & Nolan, M. (2016). Older people and decision-making following acute stroke in China: “hiding” as a barrier to active involvement. *Ageing & Society*, *36*(7), 1526–1554. https://doi.org/10.1017/S0144686X15000549

Whitlatch, C., & Menne, H. (2009). Don’t forget about me! Decision making by people with dementia. *Journal of the American Society on Aging*, *33*(1), 66–73. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=jlh&AN=105426997&site=ehost-live&scope=site

Whitney, S. N. (2003). A new model of medical decisions: Exploring the limits of shared decision making. *Medical Decision Making*, *23*(4), 275–280. https://doi.org/10.1177/0272989X03256006

Wilkinson, H. (2001). Empowerment and decision-making for people with dementia: the use of legal interventions in Scotland. *Aging & Mental Health*, *5*(4), 322–328. https://doi.org/10.1080/13607860120080260

Wood, R. L., & McHugh, L. (2013). Decision making after traumatic brain injury: a temporal discounting paradigm. *Journal of the International Neuropsychological Society : JINS*, *19*(2), 181–188. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=23298735

*included systematic review articles

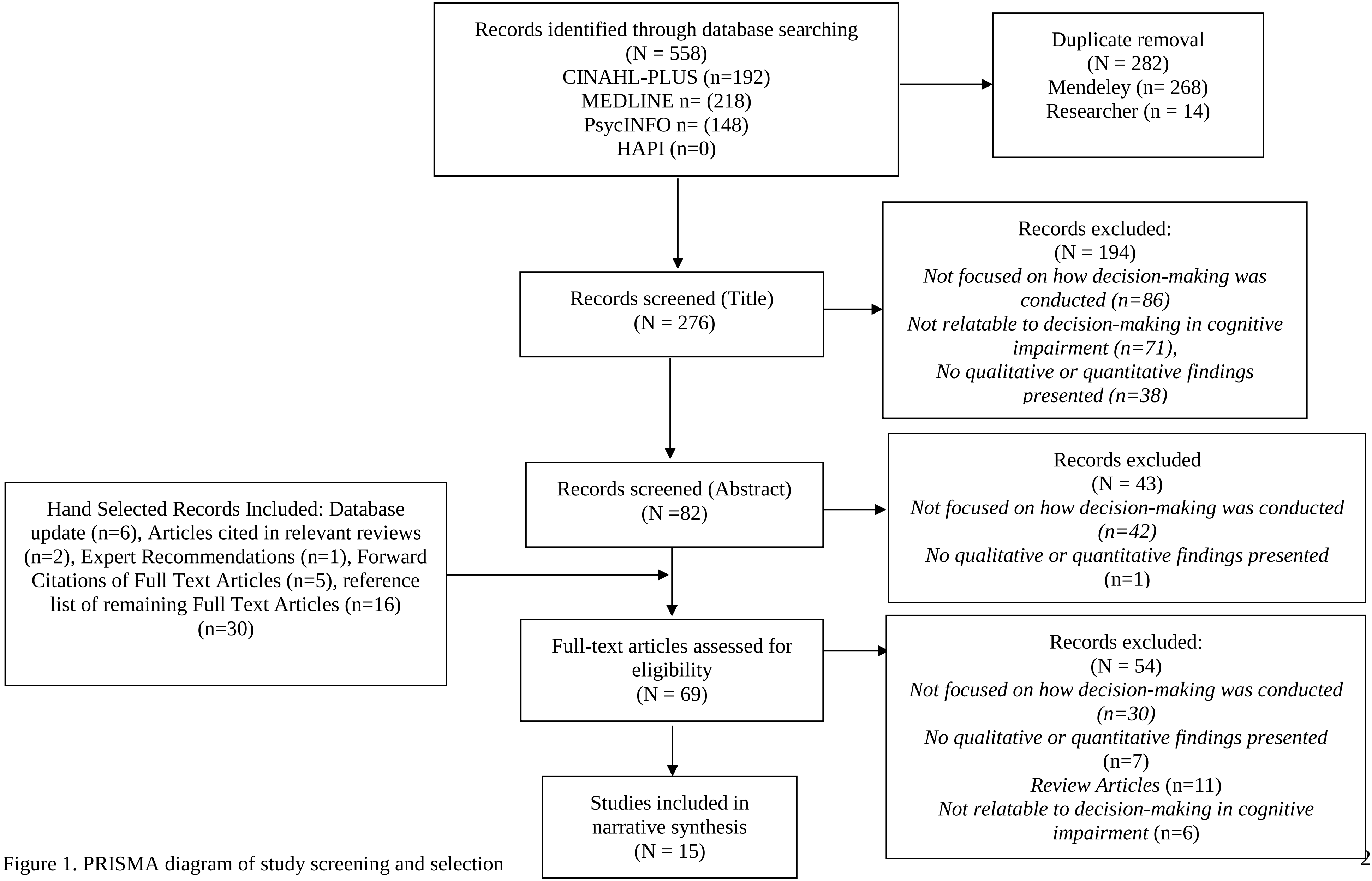

Figure 1. PRISMA diagram of study screening and selection

Table 1. Summary of included studies

Qualitative Studies

| Author | Year/ Country | Decision-making type/domain | Participants | Data collection | Analysis | Main Findings | Quality Score |
|---|---|---|---|---|---|---|---|
| Adler | 2010/US | Shared/Driving | Plwd with licenses (n=20, male = 75%, Age range = 53-83, M=69.9 SD= 8.9)<br>Spouses of current drivers (n=20, Female = 75%, Age range = 49-82, M=68.0, SD= 9.5)<br>Spouses of former drivers (n=25, Female = 92%, Age range = 54-85, M=70.6, SD=7.7) | Early stage support group meetings<br>13 Focus Groups of 2 - 8 | Thematic analysis | Driving decisions are a responsibility shared between families and professionals, and showed that diagnostic delays hamper families in making long-term plans. | 4 |
| Black, Wechsler, Fogarty | 2013/US | Shared/ Research Participation | Plwd (N=39, Female = 51.3%, Age M= 74.2, SD=8.8) | Semi-structured interviews | Grounded Theory | Ultimate decision-making involvement of plwd depends on cognitive impairment. | 3 |

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| | | | Surrogates (defined as the study partner or proxy decision maker, N=46, Female = 73.9%, Age M= 63.1, SD= 12.6, Spousal = 60.9%) | | | ‘Best interest’ decision-making was the ethical standard for future proxy research decision-making | |
| Boyle | 2013/UK | Shared/ Everyday | 21 married dyads Plwd (n = 21, Female=12, Range= 40-80) | Interview and observation *(longitudinal)* | Thematic analysis | Spouses assist the autonomy of plwd facilitating everyday decisions (e.g. communication) so that they have a say. Assisted autonomy however is mediated by gender for *minor* decision-making where females are more facilitative spouses | 5 |
| Boyle | 2013a/UK | Shared/ Financial | 21 married dyads Plwd (n = 21, Female=12, Range= 40-80) | Interview and observation *(longitudinal)* | Thematic and comparative analysis | Individual roles in decision-making are habituated through a marriage. Spousal carers undertook decision-making | 5 |

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| | | | | | | when plwd had limited capacity but in some cases plwd were marginalised and unable to exercise their capacity when they were able. | |
| Fetherstonhaugh, Rayner, Tarzia | 2016/Australia | Shared/Everyday | 7 married dyads and 2 spousal carers<br>Plwd (n =7, Age Range = 56-79, Median =75, Time since diagnosis Median = 2 years, Range (2-6 years)<br>Spousal carers (n=9, Age Range=57-80, Median =72.5) | Semi-structured interviews | Interpretive phenomenological approach | The caregiving relationship was the essence of decision-making where carers supporting and facilitating decision-making for plwd through understanding the importance of their autonomy, facilitating their autonomy but knowing when to override beliefs should decisions carry major consequences | 3 |
| Fetherstonhaugh, Tarzia, Nay | 2013/Australia | Shared-individual/Everyday | Plwd (n=6, Age Range= 54-78), Time since diagnosis 1.5 - 16 years | Interviews | Phenomenological Analysis | The essence of decision-making for plwd is a feeling that "I am still here" | 3 |

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| | | | | | | facilitated through support, pragmatism and feeling central. These three domains however, can be disrupted having the opposite impact on decisional involvement of plwd | |
| Harrison Dening, King, Jones, Sampson | 2017/UK | Shared/Healthcare planning | 6 married dyads and 1 additional carer (adult child)<br>Plwd (n=6, Female = 3, Age Range = 70-88, M= 77.6)<br>Carers (n=7, Female = 3, Age Range= 49-85, M=73.4) | Semi-structured interview | Content thematic analysis | Level of cognitive impairment and characteristics of the relationship between the plwd and carers impact decisional involvement | 4 |
| Horton-Deutsch, Twigg, Evans | 2007/USA | Shared/Healthcare | 20 dyads | Semi-structured interview | Constant comparative method | A plwd's symptoms, resources, function and | 4 |

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|---|---|---|---|---|---|---|---|
|  |  |  | Plwd (n=20, Age Range = 55 - 85 Females = 11, M= 72.6 SD = 9.1)<br>Carers, (n=20, Age Range = 44 - 83, M= 69.6 SD = 11.4, 2 were non-spousal: *son/daughter*) |  |  | normality affects their health care decision-making |  |
| O'Brien, Clemson, Canning | 2016/Australia | Individual/Exercise | 8 individuals with Parkinson's disease (N=8, Females =2, Age Range 64 - 82, M= 71.38). Disease duration 3-11 years | Interview | Grounded Theory | Adapting to loss and change, the influence of others and making sense of the exercise experience influence decisions regarding exercise participation in Parkinson's disease. | 4 |
| Samsi & Manthorpe | 2013/UK | Shared/Everyday | 12 dyads<br>Plwd (n=12, Female = 6, Age M= 81.5, Range 72-92), Time since | Topic guided interviews *(longitudinal)* | Thematic analysis | A continuum representing decision-making discourse, where the carer gradually makes a transition from | 5 |

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| | | | diagnosis = 3 – 11 months<br>Carers (n=12, Female = 8, Age Range 49-88, M= 70.08), 7 spousal, 4 adult children/relative, 1 friend | | | "supported decision-making" to "substitute decision-making" in their engagement of the plwd | |
| Smebye, Kirkevold, Engedal | 2012/Norway | Shared /General | 10 triads<br>Plwd (n=10)<br>Carers (n=10): spouse, adult children (in-law), sibling,<br>Professionals (n=10): registered, enrolled or aid nurse. | Semi-structured interviews | Framework analysis and interpretive approach | Five types of decision-making outlined, autonomous, pseudo-autonomous, delegating, shared and non-involvement where decision-making involvement of the plwd and carer differs from each type | 4 |
| Tyrrell, Genin, Myslinski | 2006/France | Shared/ Health and social care | 21 dyads<br>Plwd (n=21, Female= 16, Age Range 74-91, M= 84) | Semi-structured interviews | Framework Analysis | Highlight conditions of decision-making to for the involvement of plwd: being informed, listened to, | 3 |

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| | | | Carer (n=21, Age Range 45-85, M= 62) Carers were 14 daughters, 6 sons 1 husband | | | expression of opinion, time for reflection and reversibility of choice. That contribute to involvement in care related decisions | |
| Wang & Nolan | 2016/China | Shared/General | People with stroke (n=19, Female = 5, Age Range 60-80)<br>Family members (n=28, female=17, Age Range 33-77,)<br>7-sons, 12- daughters, 3-husband, 5-wife, 1 son-in-law<br>Professionals (n=25, Age Range 24-46, 19 female)<br>15-doctors, 7-nurses, 2-physio, 1-accupuncturist | Interviews and observations *(longitudinal)* | Constant comparative analysis | Decision-making behaviours occurred in line with cultural ideals, hiding behaviours were employed to preclude the person who had had a stroke from full and active decisional involvement | 4 |

| Quantitative Studies | | | | | | | |
|---|---|---|---|---|---|---|---|
| Author | Year/Country | Decision-making type/domain | Participants | Data collection | Analysis | Main Findings | Quality Assessment |
| Menne & Whitlatch | 2007/US | Individual-Shared/General | 215 dyads<br>Plwd (n = 215, Female = 50% Age M= 75.89, SD = 9.26) Time since diagnosis M=33.63 *(39.93)* months<br>116 carers (approx.) were spousal | Psychometric scales: Decision making involvement scale, Memory and behavioural problem checklist, mini-mental state examination, dyadic relationship strain, values and preferences scale | Bivariate correlations, Hierarchical multiple regression | Plwd who report more decision-making involvement are younger, female, had more education, have non-spousal carers, have fewer months since diagnosis, have fewer depressive symptoms, exhibit fewer activity of daily living problems and place more importance on autonomy and self-identity. | 5 |
| Miller, Lee, Whitlatch & Lyons | 2017/US | Individual-Shared/General | 42 dyads<br>Plwd inpatients (n=21, Female = 45.24%, Age | Psychometric scales: Decision making | Correlations and multilevel modelling (HLM) | Cognitive impairment, care related strain, relationship strain and value of autonomy | 5 |

| | | | | |
|---|---|---|---|---|
| | Range 72-88, M= 79.81 SD= *7.76*)<br>Carers (n=21, Female = 75%, Age Range = 48-74, M= 61, SD=12.95) 70% adult children/in-law, 30% spousal | involvement scale, mini mental state examination, role overload scale, dyadic strain subscale of the dyadic relationship scale, care values scale scale | | were identified as being significantly affected the decision-making involvement of plwd |

Plwd – person living with dementia

1

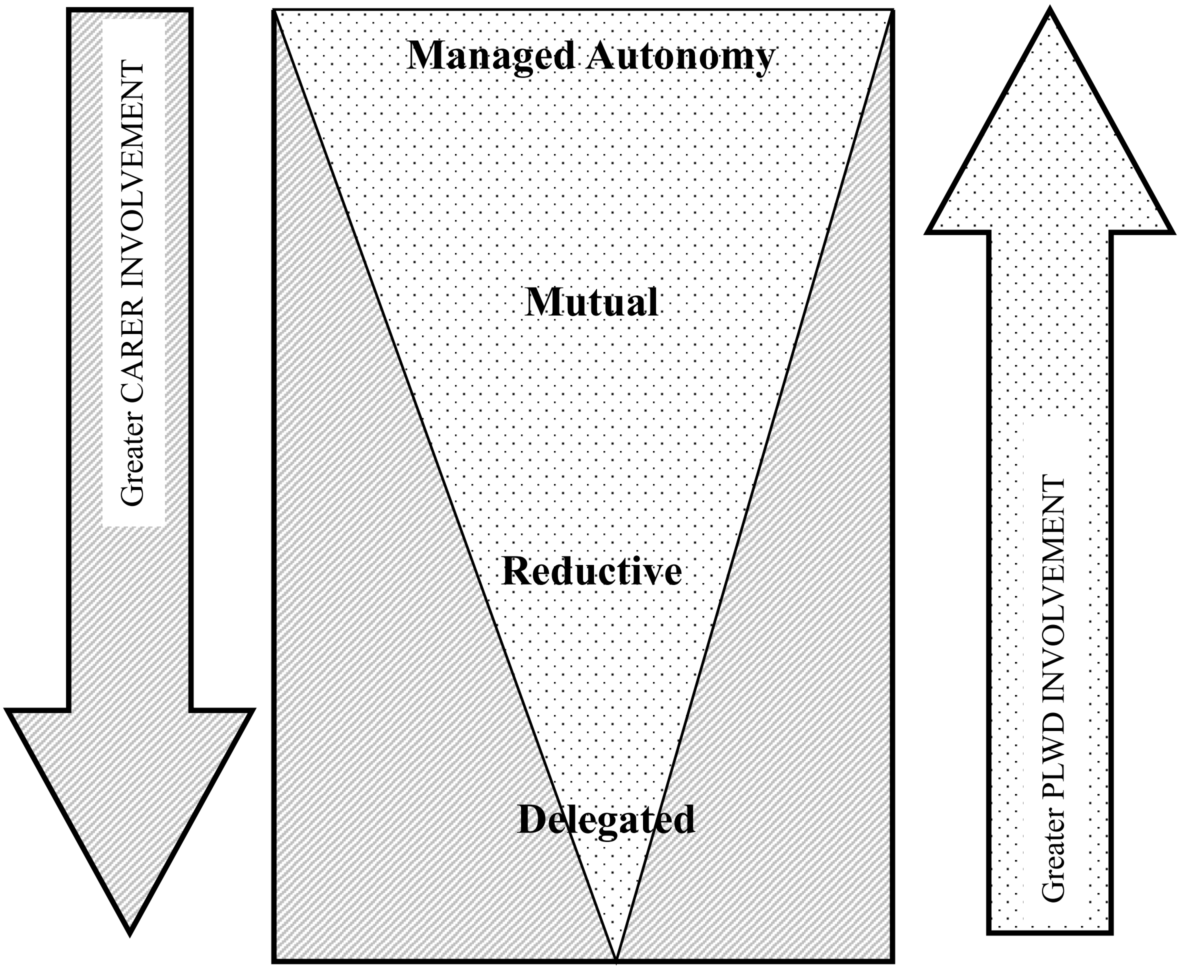

Figure 2. Narrative synthesis model representing the decision-making involvement of a person living with dementia (PLWD) and carer. Background factors make the space for these decisional styles (Freedom of Choice Framework[1]) which can be influenced by