Everyday Decision Making in Individuals with Early-Stage Alzheimer's Disease

An Integrative Review of the Literature

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ABSTRACT

Individuals with Alzheimer's disease (AD) demonstrate fluctuation in cognitive abilities that can affect their ability to make decisions. Everyday decision making encompasses the types of decisions about typical daily activities, such as what to eat, what to do, and what to wear. Everyday decisions are encountered many times per day by individuals with AD/dementia and their caregivers. However, not much is known about the ability of individuals with AD/dementia to make these types of decisions. The purpose of the current literature review was to synthesize the evidence regarding everyday decision making in individuals with early-stage AD/dementia. Findings from the review indicate there is beginning evidence that individuals with early to moderate stages of AD/dementia desire to have input in daily decisions, have the ability to state their wishes consistently at times, and having input in decision making is important to their selfhood. The literature revealed few interventions to assist individuals with AD/dementia in everyday decision making. Findings from the review are discussed with implications for nursing practice and research.

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Alzheimer's disease (AD) is a frequent and devastating disease, currently affecting more than 5 million individuals in the United States (Alzheimer's Association, 2017). AD is the most common form of dementia, and accounts for 60% to 80% of all dementia cases (Alzheimer's Association, 2017). Symptoms of the disease include mild memory loss and other cognitive impairments in the early stages to complete functional dependence in the later stages of the disease (Alzheimer's Association, n.d.). The clinical trajectory of AD is thought to develop over years. During the preclinical phase, which can last years, the disease affects the brain but the individual does not have symptoms. The next phase, mild cognitive impairment (MCI), occurs when the patient begins to exhibit symptoms of the disease, such as memory impairment, but the symptoms do not impact daily functioning. The final state is dementia, whereby the patient experiences severe cognitive and functional problems that affect the ability to live independently (Sperling et al., 2011).

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The progressive nature of AD results in gradual cognitive and functional changes that can affect decision making ability. Although decision making is a form of autonomy that is embraced by most individuals, there are known impairments in the capacity to make decisions in the later stages of the disease (Miller, Whitlatch, & Lyons, 2016). However, individuals with AD gradually lose some cognitive abilities but retain others, making it difficult to determine when decision making ability has diminished to an extent that someone else must make decisions for them (Smeybe, Kirkevold, & Engedal, 2012). In addition, decision making ability depends on many types of factors related to the type of decision and the characteristics of individuals and their environment. For example, individuals with AD often have variable states of cognition, meaning that they may be confused at one moment and completely oriented at another (Trachsel, Hermann, & Biller-Andorno, 2015). High-stakes decisions that involve the weighing of risks and benefits, such as those about health care or legal matters, are known problems (van der Steen et al., 2014). Major decisions, such as those related to medical procedures or wishes concerning end-of-life care, are important to the well-being of individuals with AD, and there is a growing body of research on this topic (Hanson et al., 2011). Yet, less is known about another category of decision making called everyday decision making (EDDM).

EDDM is a concept that has been defined as a person's ability to "solve his or her own functional problems" (Lai & Karlawish, 2007, p. 102) or his or her ability to make decisions about activities of daily living (Lai et al., 2008). Menne, Tucke, Whitlatch, and Feinberg (2008) describe EDDM as the ability to have a say in daily decisions such as "what to wear, what to do" (p. 23) and decisions such as "what to spend money on, visiting with friends, when to go to bed, what to eat at meals, and choosing where to live" (p. 24). These decisions occur multiple times during a normal day and require an appraisal of an outcome related to a choice (Delazer, Sinz, Zamarian, & Benke, 2007) and as such are cognitively complex (Sinz, Zamarian, Benke, Wenning, & Delazer, 2008). Holm (2001) describes EDDM as a "situation when a person with dementia expresses a certain desire" (p. 153). Holm (2001) goes on to describe the fact that although individuals with dementia may not be legally competent to make certain decisions, it does not mean that they are incapable of making any decisions. Thus, EDDM is a concept that describes the daily decisions about what the individual has a desire to do, including such activities as eating, bathing, dressing, and engaging with others.

Nurses and informal caregivers must often facilitate decision making for individuals with AD; yet, this can be a complex process. There are times when supporting the everyday decisions of individuals with dementia may result in a negative effect, such as injury or embarrassment. An individual with AD may decide to cook a meal, but may not remember to turn off the stove (Tudor Car et al., 2017). In a circumstance such as this, the caregiver may decide to usurp the decision of the individual with AD to maintain safety; autonomy is then limited so that beneficence can be maintained. Because there are many times daily when individuals with AD make relatively minor decisions (Lai & Karlawish, 2007), the ways in which families and care providers support or do not support everyday decisions may have important ramifications for quality of life.

REVIEW

Aim

Nurses assess a patients' abilities and needs, provide a plan of care, and work with the care team to facilitate patients' goals of care. Nursing or interprofessional interventions that support autonomous decision making for everyday decisions are important to consider. Many research studies have examined medical decision making (Kim, Karlawish, & Caine, 2002) and informed consent for treatment and research (Karlawish et al., 2008; Kim, Caine, Currier, Leibovici, & Ryan, 2001) in individuals with AD. However, little is known about EDDM, which affects all individuals with AD throughout the progression of the disease. In fact, the authors of the current review found no systematic or integrative reviews that have examined EDDM in dementia except for one review on the topic of shared decision making in dementia (Miller et al., 2016). Miller et al.'s (2016) review focused on all types of decisions, including those related to medical care and transitional care placement. One section of their review included everyday decisions from the aspect of shared decision making; however, the central focus of the research was not on the individual with dementia but rather on the patterns of shared decision making regarding multiple types of decisions.

Thus, the aim of the current literature review is to synthesize the evidence in regard to EDDM in individuals with early-stage AD/dementia. The specific objectives are to analyze the literature regarding: (a) the meaning (perceived personal value) of decision making to individuals with AD/dementia; (b) the ability of individuals with early-stage AD/dementia to make everyday decisions; and (c) evidence-based ways in which to support EDDM ability of individuals with AD/dementia.

Search Method

A review of the literature included articles published between January 2000 and November 2016. These dates were chosen after a cursory look at the literature, which showed that most articles on this topic were published after 2000. Databases used in the search included CINAHL, PubMed, and Google Scholar. These databases were chosen to capture the interdisciplinary nature of the topic. Reference articles cited in the studies appraised were also explored for inclusion in the current review. The search terms used were combinations of: *dementia*, *early stage*, *Alzheimer's disease*, *decision making*, and *everyday*. Inclusion criteria were: research studies (qualitative or quantitative) addressing EDDM in early-stage AD or MCI (or those that would apply to this population); human studies; and those written in English. Exclusion criteria were: articles specifically analyzing EDDM in individuals with dementias other than the Alzheimer's type (unless they applied to individuals with AD); studies about individuals with later stage dementia, unless they also applied to early-stage AD; articles specifically about the caregiver's role in decision making; articles about singular, major types of decision making such as those surrounding advanced directives, financial decision making, and consent for medical treatment and research; and other types of literature or systematic reviews. Only primary sources were included.

Search Outcome and Quality Appraisal

The initial search yielded 2,778 articles. The abstracts of the articles were scanned by two reviewers (R.D., M.K.Z.) to determine applicability to this review and eligibility based on the inclusion and exclusion criteria. This scanning yielded a total of 12 articles that were included in the current review. Fisher and King's (2013) quality appraisal was used to determine the quality of the studies (**Table A**, available in the online version of this article). This quality appraisal method was selected because it allowed for inclusion of qualitative and quantitative studies. This method required evaluation of each study using nine criteria to assess the quality of the design, sampling, methods, results, limitations, and contribution to the literature. The review includes qualitative and quantitative studies with a variety of methods. Most studies exhibited the following strengths: they had methods that supported the study aims, the analyses of the data were clear, human research ethics were addressed sufficiently, and results were clearly described with a description of the limitations. The most common weaknesses were that the sample sizes were not justified and internal and external validity were not addressed in the quantitative studies.

RESULTS

Following the appraisal by the reviewers, studies were summarized in tables and categories were identified based on the specific objectives of the literature review. These main categories included: (a) the meaning (personal value) of EDDM to the individual with AD/dementia; (b) the ability of the individual with AD/dementia to make everyday decisions, with subcategories including assessment of decision making ability, factors related to decision making ability, and how individuals with AD/dementia make decisions; and (c) evidence-based ways to support EDDM in individuals with AD/dementia. The results are described in **Table B** (available in the online version of this article) and synthesized below.

Meaning of Everyday Decision Making

Three qualitative studies examined the meaning of decision making to individuals with dementia. These studies found that autonomy and independence with EDDM are factors in determining quality of life. For individuals experiencing mild cognitive changes associated with early-stage Alzheimer's dementia, the essence of quality of life is the feeling of being present and autonomous with decision making (Fetherstonhaugh, Tarzia, & Nay, 2013). Being able to make autonomous daily decisions was found to be important for individuals with dementia, as it promotes an increased sense of self-worth and confidence. Fetherstonhaugh et al. (2013) described the true meaning for many individuals with dementia in the early stage of AD as the feeling that "I am still here!" (p. 149). Maintaining a sense of control was an important aspect of these individuals' lives. Contributing to daily decisions allowed these individuals to feel productive, useful, and active. Participants described their decision making experiences as "autonomy with back-up" (Fetherstonhaugh et al., 2013, p. 146).

In a multi-case study, Smebye et al. (2012) conducted interviews and observations of 30 participants with dementia, their family caregiver, and a professional caregiver. The authors reported that individuals with dementia were more autonomous in making decisions about daily activities rather than other types of high-stakes decisions, such as medical treatment or living arrangements. Smebye et al. (2012) also found that retaining this ability was considered by individuals with dementia to be important for well-being. Similarly, Samsi and Manthorpe (2013), in a longitudinal study using interviews of 12 individuals with dementia and their caregivers, identified that most individuals with dementia accentuated the significance of making independent choices and wished to preserve the

right to make everyday decisions such as what to wear, what and when to eat, what activities to participate in, and what holidays to plan. Thus, in these three studies, being allowed to participate in daily decisions was found to be important for the well-being and quality of life for individuals with dementia.

Ability of Individuals with Dementia to Make Everyday Decisions

The literature review revealed eight studies that discussed the ability of individuals with dementia to make everyday decisions. The studies included for this theme are arranged by the following subcategories: tools that assess the ability for individuals with dementia to make everyday decisions; cognitive, psychological, social, and demographic factors related to EDDM; and how individuals with dementia make decisions.

Tools that Assess Ability in EDDM. The literature review yielded two tools that could be used in the assessment of EDDM. Lai et al. (2008) developed a tool for assessing capacity for EDDM called the Assessment of Capacity for Everyday Decision Making (ACED). This tool was developed based on commonly used criteria to assess capacity for medical decision making, including the abilities of "understanding, appreciation, reasoning, and expressing a choice" (Lai & Karlawish, 2007, p. 106). The ACED uses semi-structured interviews to address the individual's ability to make choices about a functional problem. Lai et al. (2008) conducted a study to establish the reliability and validity of the instrument in a sample of individuals with mild to moderate cognitive impairment. Results suggested there was suitable reliability for the tool and sound predictive validity. A translated version of the ACED was shown to be a valid tool for use in Chinese individuals with MCI and AD (Lam et al., 2013).

Another tool developed to assess EDDM is called the Decision Making Involvement Scale (DMI). In this 15-item scale, individuals with dementia rate themselves as to how involved they are in everyday decisions, such as what to spend money on and what to wear (Menne et al., 2008). There is also a caregiver version of the DMI, and results between caregivers and care receivers can be compared to determine congruence. Menne et al. (2008) conducted a factor analysis on the DMI and found that the tool for caregivers and care receivers had satisfactory reliability and validity.

The ACED and DMI tools assess differing aspects of EDDM in individuals with dementia. The ACED measures the individual's capacity to make specific decisions; this instrument can be useful in the clinical arena to determine when assistance is needed and when autonomy can be maintained. The DMI measures the individual's (and caregiver's) perception of the care receiver's involvement in everyday decisions; this instrument is especially useful in helping individuals with dementia and their caregivers understand the values regarding EDDM.

Factors Related to Decision Making. Three studies examined the types of demographic, social, and cognitive factors related to EDDM in individuals with dementia. Menne and Whitlatch (2007) found that cognitive and physical impairment, including more impairment on cognitive testing scores, activities of daily living abilities, and depression scores, were related to less decision making involvement by individuals with dementia. Thus, not surprisingly, as the disease progresses, individuals with dementia exhibit less involvement in decision making.

Two studies examined the ability of individuals with mild to moderate dementia to state consistent choices about preferences for everyday activities, involvement in everyday living, and the individual's ability to give accurate responses about his/her demographics (e.g., age, address). Feinberg and Whitlatch (2001) tested dyads comprising individuals with early-stage dementia and their caregivers to determine how accurately and reliably individuals with dementia could answer factual questions. Individuals with dementia were asked questions that assessed self-knowledge, such as number of children and age in Sansone, Schmitt, and Nichol's (1996; as cited in Feinberg & Whitlatch, 2001) Correct Scale along with a demographics questionnaire. In addition, Sansone, Schmitt, and Nichol's Preference Scale (1996; as cited in Feinberg & Whitlatch, 2001) was used to determine the individual with dementia's preferences for various factors. Individuals with dementia were tested again on these measures within 1 week. Findings revealed that individuals with mild to moderate stages of dementia were able to give consistent and accurate responses to the measures (Feinberg & Whitlatch, 2001). Feinberg and Whitlatch (2002) also interviewed individuals with dementia to determine their decision making preferences for personal care and attitudes toward receiving assistance with personal care. They administered their Decision Control Inventory (DCI), a survey that examines the individual with dementia's perceived level of involvement in EDDM. Results of the study showed that individuals with dementia were able to state their specific preferences for everyday care, such as what to wear and what to do, and to share who they wished to help them with care needs. These studies provide beginning evidence

that individuals with mild to moderate dementia are able to demonstrate consistent and accurate responses about their wishes for daily activities.

How Individuals With Dementia Make Decisions. To assist individuals with dementia and their caregivers in decision making, it is important to determine how individuals with dementia and families make decisions on a daily basis. Three qualitative studies that investigated the meaning of EDDM in individuals with dementia (discussed earlier) also examined the patterns of decision making in individuals with dementia and their caregivers. Findings from these studies indicate that individuals with mild to moderate dementia and their caregivers are capable of making many everyday decisions (Reamy, Kim, Zarit, & Whitlatch, 2011; Samsi & Manthorpe, 2013). EDDM shifts and individuals with dementia at varying times may be capable of making some choices but not others (Samsi & Manthorpe, 2013; Smebye et al., 2012). Samsi and Manthorpe (2013) described decision making ability as nonlinear and nonabsolute; individuals with dementia may vacillate between the ability to make fairly independent decisions and yet at other times require variable levels of supported decision making. Everyday decisions are made in the context of daily life, and each decision is distinct and often embedded in natural routine or conversation (Samsi & Manthorpe, 2013). Thus, EDDM may occur without conscious effort.

Usually, everyday decisions are made together by caregivers and individuals with dementia (Samsi & Manthorpe, 2013; Smebye et al., 2012). Caregivers evaluate how capable the individual with dementia is in making each decision in the context of each day. Frequently, when the individual with dementia is not able to make the decision, the caregiver makes a choice based on the best interest of the individual with dementia. Caregivers may also make decisions grounded on their own preferences (Samsi & Manthorpe, 2013). Smebye et al. (2012) identified that at times, caregivers made decisions for individuals with dementia based on pseudo-autonomous decision making, a false confidence that the caregivers knew the values of the individuals with dementia. Although decisions are often made in collaboration with the individual with dementia, the caregiver is not always the best judge of, and often underestimates, the values or preferences that the individual with dementia holds about autonomy, burden, control, family, and safety (Reamy et al., 2011).

These studies afford important information about EDDM in individuals with dementia. Although the current review focused on how individuals with dementia make decisions, articles that discussed the complex relationship between individuals with dementia and their carers in EDDM were included because they illuminate how decisions are made by individuals with dementia (either independently or with a carer). The studies gave evidence that individuals with dementia are capable of stating consistent information about their values and preferences for activities and everyday care. However, they are highly reliant on caregivers, as many decisions are made together with or by caregivers. Caregivers may not perceive the values of individuals with dementia; thus, they are at risk for making decisions that are not in alignment with the values and beliefs of individuals with dementia.

Evidence-Based Ways to Support Decision Making in Individuals with Dementia

Despite the frequency and importance of EDDM, few studies have examined methods to support individuals with dementia in making everyday decisions. Only two studies were found that examined methods to support EDDM in individuals with dementia. One study examined the effect of Talking Mats, a type of communication tool, on the engagement of individuals with dementia and their caregivers (Murphy & Oliver, 2013). Using Talking Mats, the individual with dementia and caregiver work together using symbols reflecting everyday activities on a visual continuum representing "managing," "needing assistance," or "not managing" the activity (Murphy & Oliver, 2013, p. 175). Interviews revealed that individuals with dementia and caregivers felt more involvement with decision making and increased well-being when using Talking Mats as compared to usual methods of communication.

Although there were no studies that tested a nursing intervention to enhance EDDM in individuals with dementia, one descriptive study examined the ways in which nursing assistants facilitated decision making for individuals with dementia living in an assisted living setting (Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2016). The results showed that care providers used strategies such as negotiating a compromise, making choices more simple, using visual aids, giving more time, and knowing the person to assist with decision making. Thus, improving communication and deeper understanding are promising methods that can be used to enhance decision making in individuals with dementia.

DISCUSSION

The current literature review focused on early-stage dementia, the period in which the cognitive abilities of individuals are highly variable (Alzheimer's Association,

n.d.). In a discussion of the capacity for individuals with AD to make decisions, Sabat (2005) states, "It cannot be assumed tacitly, even in the moderate to severe stages of probably AD, that a person lacks meaning-making ability; for doing so may well be incorrect and result in the infliction of further harm" (p. 1035). Thus, the ability or rights of individuals to make decisions about everyday activities is closely linked with the meaning of self-hood and identity; and to take measures that deter autonomy has the potential to inflict harm.

Overall, the most salient finding from the current literature review is beginning evidence that individuals with AD/dementia value the ability to make everyday decisions. In addition, individuals with dementia can make some decisions about everyday activities and at times can report their desires consistently and accurately (Feinberg & Whitlatch, 2001, 2002). However, decision making about many activities occurs in collaboration with the caregiver and is variable related to the types of decisions and ability of the individual with dementia (Reamy et al., 2011; Samsi & Manthorpe, 2013; Smebye et al., 2012).

Two tools assess aspects of EDDM in individuals with dementia. One tool, the ACED, may be especially suited in the clinical environment because it assesses the capacity for an individual to make specific decisions (Lai et al., 2008; Lai & Karlawish, 2007). However, there is an absence of studies that examine the use of tools such as this to facilitate decision making in individuals with dementia. In fact, there was surprisingly little research found on EDDM and minimal evidence supporting ways to promote EDDM for this population. Only one study examined an intervention to promote EDDM (Murphy & Oliver, 2013). One qualitative study examined perceptions of caregivers about their communication methods to promote EDDM (Fetherstonhaugh et al., 2016). No randomized controlled trials were found that provide evidence for interventions to assist with EDDM.

There are several possible reasons for the lack of research on EDDM. It is possible that there is an underlying assumption that individuals with dementia cannot make decisions. Boyle (2014) states that agency has been neglected in individuals with dementia due to a "focus on the negative impact of dementia on self-identity" (p. 1131). Boyle (2014) further proposes that limiting agency in individuals with dementia by not facilitating their expression of decisions prohibits these individuals from being equal to others.

Perhaps another explanation for the lack of research related to EDDM (especially intervention studies) is that the topic may not be considered important. Decisions such as those regarding end-of-life care, health care, finances and money management, and living arrangements, have important and long-term ramifications regarding safety and well-being. Everyday decisions, such as what to wear and what to do, are less crucial and may be considered to have fewer consequences. However, the current literature review offers beginning evidence that suggests these types of everyday decisions are important to individuals with dementia, and may indicate that quality of life is associated with participation in these types of decisions. Individuals with dementia state that being able to participate in decision making is desirable and that being excluded from decision induces feelings of being marginalized (Fetherstonhaugh et al., 2013).

A final argument for the paucity of systematic research related to EDDM in dementia may be due to a lack of a clear theoretical foundation regarding EDDM. A central definition of EDDM comes from work conducted to develop tools to assess decision making and functional ability (Menne et al., 2008). However, the types of decisions that individuals with dementia must make on a daily basis have not been systematically explored. Additional clarification of the types of decisions individuals with dementia make on a daily basis, and how these decisions differ from high-stakes decisions, is imperative to provide a foundation for future interventions.

Some existing theories may provide a foundation for nursing interventions. Adams and Gardiner (2005) have extended Kitwood's (1993) theory on person-centered care to include the triadic communication styles among health care providers, individuals with dementia, and their informal caregivers. Adams and Gardiner (2005) assert that enabling communication occurs when "informal carers or health and social care professionals either help the person with dementia express their thoughts, feelings and wishes or represent the person with dementia as someone who is able to make decisions about their own care" (p. 190). Enabling behaviors include activities such as ensuring individuals with dementia are positioned optimally in the conversation, are encouraged to verbalize their views, and their contributions are acknowledged and valued. Conversely, disabling communications are those actions that discount the individual with dementia's contributions in the triadic relationship. Behaviors such as interrupting or representing individuals with dementia (instead of letting them represent themselves) are disabling (Adams & Gardiner, 2005). This type of communication has not been studied in terms of EDDM, but would provide a founda-

tion for interventions in which nurses could facilitate the individual with dementia's abilities.

LIMITATIONS AND STRENGTHS

The primary limitation of the current review is related to the scarcity of research investigating EDDM; few high-quality studies were identified that explored EDDM. Of those that were included in the review, most did not sufficiently quantify the etiology or stage of dementia. Although the inclusion criteria specified studies were to include individuals with early-stage AD, studies that did not illuminate the participants' etiology of dementia were included because it was believed that these studies applied to the AD population. However, there may be differences in how individuals with AD can make decisions when compared to individuals with other diseases that cause dementia. In addition, it was the decision of the current authors to exclude studies that were primarily focused on shared decision making, as there has been a recent literature review on this topic and because the authors were predominantly interested in determining ways in which to enhance autonomy in individuals with dementia. This decision may have limited the review, in that decision making may often be made in collaboration with caregivers (Samsi & Manthorpe, 2013). Another limitation was that there were no studies that examined how nurses support the decision-making ability of individuals with dementia.

The major strength of the review is that it included qualitative and quantitative studies. Due to the aims of the review, both types of articles were important to understand the phenomenon of EDDM. In addition, this review had clear inclusion and exclusion criteria, and evaluated the quality of the literature, which has been identified as a means to enhance rigor (Whittemore & Knafl, 2005).

IMPLICATIONS FOR NURSING

Nurses hold as their highest ethical value the desire to maintain the dignity and self-determination of their patients (American Nurses Association, 2015). As such, measures to enhance participating in all types of decision making are important for practice. Although none of the studies that were included in the current review were from the perspective of nursing, there are several practice implications for nursing:

- Nurses should encourage individuals with dementia to have input into daily decisions as this ability is highly valued (Fetherstonhaugh et al., 2013; Samsi & Manthorpe, 2013).
- Nurses should recognize that individuals with early-stage dementia may be able to provide consistent and accurate information about their wishes and thus can be trusted in terms of their decisions (Feinberg & Whitlatch, 2001, 2002).
- Nurses can use tools to assess EDDM ability including the ACED (Lai et al., 2008) or DMI (Menne et al., 2008).

SUGGESTIONS FOR FUTURE RESEARCH

The current authors have several suggestions for future research. Currently, the science about EDDM is in the beginning stages of development. A theoretical background is needed for the phenomenon of EDDM in dementia. Qualitative studies would be informative in understanding how families and caregivers adapt to the cognitive changes associated with dementia in terms of EDDM. In addition, studies should include a more in-depth analysis of the type and stage of dementia, as well as the cognitive abilities of the individuals in the studies. An understanding of the types of everyday decisions that are commonly made by individuals with dementia, in addition to those that are considered problematic by caregivers, needs to be explored. Finally, studies that examine how individuals with dementia who live alone (or do not have any caregivers) make daily decisions are of great interest. Based on this work, intervention studies aimed at facilitating EDDM would contribute greatly to the literature.

CONCLUSION

The current literature review shows the complex nature of EDDM in individuals with dementia. There is more work to be done in developing an understanding of this complex phenomenon. EDDM is of great concern to nurses who care for individuals with dementia. Individuals with dementia want to be involved in daily decisions and consider EDDM essential to their personhood. Further research must be performed to clearly define the phenomenon of EDDM so that theoretical-based interventions can be developed.

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Table A: Summary of critical appraisal

1. Is the chosen research method/methodology appropriate for addressing the aims of the study?
2. Is the achieved sample size sufficient for the study aims and to warrant conclusions drawn?
3. Are the chosen data collection strategies appropriate for the research question?
4. How adequate is the description of the data analysis?
5. Is there comprehensive evidence that ethical issues have been taken into consideration?
6. Does the study clearly demonstrate external and internal validity/ rigour?
7. Is there a clear statement of the study findings?
8. Are the limitations or weaknesses of the study acknowledged?
9. Is the research valuable (makes valuable contribution/ addresses clinical implications)?

Article	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Feinberg & Whitlatch (2001)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔
Feinberg & Whitlatch (2002)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔
Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie (2016)	✔	✔	✔	✔	✔	Moderate	✔	✔	✔
Fetherstonhaugh, Tarzia, & Nay (2013)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔
Lai et al. (2008)	✔	Limited	✔	Moderate	✔	Moderate	✔	Limited	✔
Lam et al. (2013)	✔	✔	✔	✔	✔	✔	✔	✔	✔
Menne, Tucke, Whitlatch, & Feinberg (2008)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔

Menne & Whitlatch (2007)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔
Murphy & Oliver (2013)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔
Reamy, Kim, Zarit, & Whitlatch (2011)	✔	Moderate	✔	✔	✔	Moderate	✔	✔	✔
Samsi & Manthorpe (2013)	✔	✔	✔	✔	✔	Moderate	✔	✔	✔
Smebye, Kirkevold, & Engedal (2012)	✔	✔	✔	✔	✔	✔	✔	✔	✔

Note: A check means that the item was addressed sufficiently.

Questions and method of critique were taken from the following publication: Fisher, D., & King, L. (2013)

Table B

Everyday Decision Making in Early-Stage Alzheimer's Disease

Citation	*Purpose*	*Sample*	*Measures*	*Findings*
Feinberg & Whitlatch (2001).	Examine the decision-making capacity of persons with cognitive impairment with respect to their everyday care preferences	51 pairs including a care receiver with cognitive impairment and his/her caregiver	MMSE, The Correct Scale, The Preference Scale, demographic data, Involvement in Everyday Living	Care receivers were able to provide significantly consistent answers to questions regarding daily living preferences and demographics.
Feinberg & Whitlatch (2002).	Explore the ability of persons with cognitive impairment to answer questions regarding daily care preferences and decision-making involvement	51 pairs including a care receiver with cognitive impairment and his/her caregiver	Interview data	Care receivers were able to consistently identify a surrogate decision maker. Care receivers believed they were more involved in decision-making than caregivers thought they were.
Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie (2016).	Address how staff in residential aged care facilities perceive they support decision making for persons with dementia within their everyday practice	80 direct care staff working in Australian nursing homes	Interview data	To facilitate decision making, the staff simplified questions; used visual aids; allowed more time; negotiated. Also must know person and their desires.
Fetherstonhaugh, Tarzia, & Nay (2013).	To illuminate the essence of decision making for PWD	6 persons with a diagnosis of dementia, less than 1.5 years since diagnosis	Interviews in person and on the phone. Phenomenological analysis.	Essence of EDDM is that "I am still here." Other attributes: subtle support versus taking over; hanging on versus letting go; being central versus being marginalized or excluded. They wished to hang on to their decision making as long as possible. Emphasized feeling central to decisions involving them and resented being ignored.
Lai et al. (2008).	To assess the reliability and validity of the Assessment for Everyday Decision Making (ACED) tool.	39 persons with mild-moderate dementia; 13 caregivers	Administered the ACED along with several cognitive tests and the MacArthur Competency Assessment Tool for Treatment (MacCAT-T)	ACED scores were correlated with similar item scores in the MacCAT-T and cognitive tests. The ACED also demonstrated sufficient reliability.

Lam et al. (2013).	This study aimed to develop a culturally appropriate Assessment of Capacity for Everyday Decision-Making (ACED) for Chinese older persons	97 cognitively intact; 99 MCI, 95 mild dementia	The ACED was translated and back translated into the Chinese language and modified to be culturally appropriate. Administered to persons with dementia; and recorded and rated by geriatric psychiatrists. Then the MacArthur Competence Assessment Tools for Treatment (MacCAT-T) and for Clinical Research was administered and rated.	The ACED correlated with other measures of decision making. The concurrent validity of the ACED was also supported by significant correlations between clinician ratings and the ability scores. Mental incapacity was higher in MD subjects. All areas correlated with cognitive testing.
Menne, Tucke, Whitlatch, & Feinberg (2008).	Development and psychometric properties of Decision Making Involvement Scale (DMI)	217 persons with dementia and their caregivers.	The DMI scale assesses 15 dimensions of the PWD's day to day decision making. A caregiver version of the scale was given to the caregivers. Also assessed MMSE, Quality of life-Alzheimer' disease scale.	The caregivers felt the person with dementia was less involved in decision making than the person with dementia. DMI has internal consistency, convergent and divergent validity, and the scale can work as a 1 factor solution. Length of time since diagnosis, depressive symptoms, ADL problems, and age were independent predictors of decision making involvement.
Menne & Whitlatch (2007).	Used conceptual framework that adapted key components of the Stress Process Model of Chronic Illness (SPMCI) to the experience of living with dementia (what are the stressors and strains associated with having cognitive impairment) and to understand which constructs within the framework contribute to the involvement of IWDs in EDDM	215 Family caregiver/persons with dementia dyads	Used SPMCI as a guide to choose measures from original study; most data based upon self-reports from IWDs; certain items based on CG reports. DMI scale, demographics, ADL's, MMSE, Dyadic Relationship Strain Scale and Values and Preferences Scale.	Persons with dementia who are older and male reported less decision-making involvement. Individuals without a technical diagnosis, those with fewer months since diagnosis, those with fewer depressive symptoms, and those with fewer ADL problems were more involved with decision-making. Higher levels of decision-making correlated with feelings of importance of being part of a family, wanting to avoid being a burden to family, and wanting to maintain autonomy and self-identity
Murphy & Oliver	Explore if Talking Mats (TM)	18 persons with	Personal interviews and a	Persons with dementia reported that TM

(2013).	can help people feel more involved in discussions about managing ADLs as compared with having a typical conversation without TM.	dementia/caregiver dyads; 3 were judged to be in the early stage, 13 in the moderate stage, and 2 in the late stage.	questionnaire which used plain English and visual cues (Talking Mats); qualitative analysis of discussions and questionnaire responses.	helped to clarify their thoughts and enabled them to express their views. Family caregivers reported the TM made them feel more listened to by the person with dementia.
Reamy, Kim, Zarit, & Whitlatch (2011).	Explore discrepancies in perceptions of values and care preferences between IWD and their family caregivers	266 dyads – mild-moderate dementia and their family caregivers.	Demographics, Values and Preferences Scale, Cognitive function, Best Interest scale, DMI scale, Dyadic Relationship Scale	Persons with dementia had higher preference for values than did caregivers. Caregivers reported that individuals with dementia had less involvement in EDDM than the care receivers. There was a discrepancy between the values of the persons with dementia and the caregiver's ratings of those values.
Samsi & Manthorpe (2013).	The focus of this study was on how EDDM occurs and changes among individuals with dementia and their caregivers.	12 persons with dementia and their caregivers.	Open-ended questions; thematic analysis was applied to the transcripts	Persons with dementia and caregivers described the importance of maintaining *autonomy* over decisions. Everyday decisions were made throughout the day with each decision evaluated in light of person with dementia's abilities. Decisions made for persons with dementia were made based on best interests of the person with dementia.
Smebye, Kirkevold, & Engedal (2012).	Explore how persons with dementia participated in making decisions about healthcare and how their family and professional caregivers influenced decision making.	30 participants: triads consisting of a person with mild – moderate dementia, a family caregiver, and a professional caregiver.	Semi-structured interviews were conducted of family and professional caregivers. Observation of individuals with dementia at a day center or during morning care, focusing on decision making.	Study findings indicated considerable variability in how persons with dementia were involved in their own decisions. Persons with dementia were more autonomous in EDDM than in medical treatment or in deciding to move to sheltered housing or a nursing home. Shared decision-making seemed to be the most typical pattern of decision-making. Decreased mental capacity, lack of available choices, or not being given the opportunity to be involved led to non-involvement.

Note: MMSE = Mini-Mental Status Examination; EDDM = everyday decision making;