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Treatment decision making involving patients with dementia in acute care: A scoping review

Kristen E. Pecanac^a, Mary Wyman^{b,c}, Amy J.H. Kind^{b,d}, and Corrine I. Voils^{b,e}

^aSchool of Nursing, University of Wisconsin, Madison, USA

^bWilliam S. Middleton Memorial Veterans Hospital, Madison, USA

^cDepartment of Psychiatry, University of Wisconsin, School of Medicine and Public Health, Madison, USA

^dDepartment of Medicine, University of Wisconsin, School of Medicine & Public Health, Madison, USA

^eDepartment of Surgery, University of Wisconsin, School of Medicine and Public Health, Madison, USA

Abstract

Objective: To summarize the evidence regarding the factors and processes of treatment decision making involving a person with dementia (PWD) in the acute care setting.

Methods: We conducted a scoping review, searching 4 databases (PubMed, CINAHL, Web of Science, & PsychINFO) for articles that contained primary data from a quantitative or qualitative study involving treatment decision making in the acute care setting for PWD and were published in English. We categorized the factors and processes of decision making identified in each article using inductive content analysis. We also consulted with healthcare practitioners to receive stakeholder input on our findings.

Results: Our search initially revealed 12,478 articles, of which 28 were included in the review. We identified 5 categories of factors that influence the decision-making process: knowing the patient, culture and systems, role clarity, appropriateness of palliative care in dementia, and caregiver need for support.

Conclusion: Our findings highlight the complexities of the decision-making process and the importance of attending to the needs of the caregiver, healthcare practitioners, and the patient.

Practice Implications: It is important to address beliefs of involving palliative care for a PWD and the role of each healthcare discipline.

Corresponding Author at: Kristen E. Pecanac, 4167 Signe Skott Cooper Hall, UW-Madison, School of Nursing, 701 Highland Ave, Madison, WI 53075 USA, (608) 262-1938, Lund2@wisc.edu, mfwyman@wisc.edu, ajk@medicine.wisc.edu, voils@surgery.wisc.edu

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story

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Keywords

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1. Introduction

Older persons with dementia (PWD) are frequently treated in acute care settings, with prevalence estimates of up to 40% [1], where they may receive aggressive, nonbeneficial care [2, 3]. About 10% of nursing home residents with advanced cognitive impairment, including dementia, are admitted to the intensive care unit (ICU) [2] and half of patients with advanced dementia who receive mechanical ventilation die within 30 days of admission [3]. Decisions about initiating or limiting certain treatments or care (a “treatment decision”) occur frequently at the end of life but may occur at any stage of the disease. Advance care planning allows a PWD to anticipate decisions about aggressive treatment. However, a review on advance care planning for PWD revealed that patient preferences may differ from those of caregivers who may ultimately make the decision [4]. In a review of proxy decision making of multiple decisions for PWD—from placement in long-term care to end-of-life decisions—Lord and colleagues [5] reported that proxies felt excluded from decision-making that occurred in the hospital. To determine how to minimize unwanted or burdensome treatment among hospitalized PWD, it is important to synthesize what is known regarding decision making in the acute care setting.

One method used for synthesis is a scoping review: a narrative summary of the evidence to summarize and disseminate research findings [6]. We undertook a scoping review of the literature that summarizes the evidence regarding the factors and processes of treatment decision making involving a PWD in the acute care setting.

2. Methods

We followed the 6-step framework for conducting a scoping review developed by Arksey and O’Malley [7] and later refined by Levac and colleagues [6]: 1) Identifying the research question, 2) Identifying relevant studies, 3) Study selection, 4) Charting the data, 5) Collating, summarizing, and reporting the results and 6) Consultation.

2.1. Identifying the Research Question

The primary research question is to determine what is known in the literature about treatment decision making involving PWD in the acute care setting. The sub-questions “What is the process by which treatment decisions involving PWD are made?” and “What factors influence decision-making?” helped to guide data extraction.

2.2. Identifying Relevant Studies

We searched four databases—PubMed, CINAHLWeb of Science, and PsychInfo—for articles published from January 1991 until May 2017. We consulted an academic librarian

about appropriate search terms and strategies based on our definition of terms (Table 1). In addition, we reviewed reference lists of included articles to identify additional sources.

2.3. Study Selection

Studies were included in the review if they 1) contained primary data from a quantitative or qualitative study, 2) occurred in the acute care setting, 3) involved patients with Alzheimer's disease or other dementias, 4) examined the process of decision making, factors affecting the decision, experiences with making decisions, or interventions that influenced the decision-making process, and 5) were published in English. Studies that only reported outcomes of decisions (e.g., rates of certain interventions) and studies that used a hypothetical vignette were excluded to ensure we were capturing real experiences of decision making. We excluded studies that examined decision making solely in settings outside of the hospital, such as in long-term care; however, we included studies encompassing multiple settings if the hospital setting was involved. Lastly, we excluded studies of patients with acute or sudden cognitive impairment (e.g., delirium).

Selection of inclusion and exclusion criteria was an iterative process; we started with broad criteria that were refined while reading and discussing abstracts and articles. One member of the research team (KP) reviewed the titles and/or abstracts of the articles extracted from the database searches. Next, two team members (KP and MW) reviewed abstracts and full texts independently to assess appropriateness for inclusion and then compared assessments at three time points. When there were discrepancies about an article, both team members independently read the full text of the article again and discussed their decisions until consensus was reached.

2.4. Charting the Data

Two members of the study team (KP & MW) abstracted data from the articles using a data extraction table with the following variables: the article citation, country of data collection, study design and methods, sample and sample characteristics, factors that influence decision making and process of decision making..

2.5. Collating, Summarizing, and Reporting the Results

We discussed the findings of the data extraction for all articles, focusing on the factors and processes of decision making identified in each article. We used inductive content analysis to compare the factors and processes to each other to determine which "belonged" together in higher-order categories [8]. After developing the categories, we returned to the data extraction tables to ensure that all important factors and processes were included in the categories and to expound upon each category based on the findings from the articles.

To provide consistency in reporting the results, we have chosen certain terms to represent similar terms used across the articles. For example, while the articles used different terms to describe the informal support person involved in decision-making for the patient (surrogate, caregiver, carer, care partner, family member), we use *caregiver*. Similarly, when referencing a member of the healthcare team, the term *healthcare practitioner* is used, unless a specific discipline was described in the article (e.g., nurse or physician).

2.6. Consultation

During consultation, stakeholders provide input into the scoping review findings and comment on their own experiences not captured in the review. As part of a regularly scheduled geriatric medicine didactics series, hospital-based clinicians with experience working with PWD were invited to attend a brief overview of the results of the review, followed by a 35-minute focus group discussion. Focus group attendees were 6 healthcare practitioners representing nursing, medicine, and psychology. Two members of the research team were present and took notes during the focus group. The research protocol for consultation was granted an exemption by the university Institutional Review Board and approved by the local VA Research & Development Committee.

3. Results

Our search initially revealed 12,478 articles (see Figure 1). We included 28 articles from 26 studies. Studies took place in the United States (13), the United Kingdom (5), Japan (2), Australia (2), Belgium (1), Canada (1), Israel (1), and Netherlands/Australia (1). Fifteen were reports of qualitative studies, involving individual interviews or focus groups of caregivers (8), healthcare practitioners (5), or a combination of both (2). Thirteen were reports of quantitative studies, including 7 that tested an intervention (a decision aid [1] or involvement of palliative care [6]) and 6 studies that reviewed medical records or surveyed caregivers or healthcare practitioners. Nine studies focused exclusively on artificial nutrition and hydration, 10 discussed other medical decisions in the hospital (such as surgery, DNR orders, and ventilators), 5 focused on the provision of end-of-life care or palliative care, and 2 involved care planning.

We identified five categories of factors that influence the decision-making process: knowing the patient, culture and systems, role clarity, appropriateness of palliative care in dementia, and caregiver need for support (Table 2).

3.1. Knowing the Patient

Caregivers used what they knew about the PWD, while healthcare practitioners attempted to gather evidence to get to know the patient, to guide treatment decision making.

3.1.1. Caregivers—Many caregivers incorporated the patient's wishes into their decision making, either previously stated in written documents such as an advance directive [9, 10], or in prior verbal discussions with the patient [9, 11, 12]. In one study, 80% of caregivers reported that a written advance directive "helped a great deal" in making treatment decisions [10]. Caregivers who knew what the patient wanted could effectively engage in substituted decision making [13]. When patient wishes were not known, caregivers tried to make decisions based on knowing the patient's values, preferences and routines [9] or considering the patient's current best interest [13].

However, caregivers struggled when attempting to balance the patient's previously expressed wishes with what they believed was currently in the patient's best interest [9, 13]. Caregivers reported having good knowledge of the patient's baseline health status or normal behavior [14]. Caregivers' concerns about the prospect of poor quality of life, compared to that

baseline, was often related to a subsequent decision to withhold treatment [9, 15, 16,]. Caregivers' perceptions of the PWD's quality of life usually changed significantly after a "pivotal event," such as an acute hospitalization of the patient [15].

There were also instances when caregivers pursued more aggressive treatment than what the patient had wanted. Some caregivers explained that even when the wishes were known, they had a reluctance to "let the person go," [9] or they experienced uncertainty, which contributed to the weight of those decisions [12].

3.1.2. Healthcare practitioners—Three articles from the same data set [17, 18, 19] highlighted how nurses developed a "holistic picture" that influenced their conceptualization of "good care" for that patient [17]. Nurses gathered information about the physical, cognitive, mental, and social condition of the PWD and tried to imagine the world as experienced by that person [17]. Nurses verified their perceptions with caregivers to improve their understanding of the patient [19]. Both nurses and physicians interpreted patient behaviors, such as rejecting food/fluids or defensive behavior, as indicators of patient preferences [18, 20]. Physicians also emphasized the importance of getting to know the PWD through attempts to understand the patient's wishes, such as by accessing written documents and having discussions with caregivers [20].

3.2. Culture and Systems

The articles highlighted many levels—patient/caregiver, professional, institutional, state and national—where culture and systems influenced how treatment decisions were made for a hospitalized PWD.

3.2.1. Patient/caregiver—Religious beliefs were a factor in treatment decisions for some caregivers [21, 22] but not all [16]. Patient race was also a factor in decisions: patients with feeding tubes were more likely to be black or Hispanic [22] and caregivers who chose to avoid aggressive care tended to be white [16]. Different types of treatments and treatment decisions also had different cultural meanings. For example, withdrawing treatment was described as more emotionally difficult than withholding treatment [20]. In addition, providing nutrition and hydration represented love and caring for many caregivers and healthcare staff, and other treatments may not hold such strong symbolic meaning [19].

3.2.2. Professional—Healthcare practitioners from different specialties had varying perceptions about artificial nutrition and hydration. When a specialist was the attending physician or part of the attending team, there was increased likelihood that the PWD would receive a feeding tube [23]. There were different views of the impact of a percutaneous endoscopic gastrostomy (PEG), a type of feeding tube, on quality of life. In one study, about 39% of hospital physicians and nurses expected improved quality of life from a (PEG) [24] and in another, 85% of physicians referred a patient for a PEG to improve quality of life [25]; however, 60% of gastroenterologists did not feel PEG tubes improved quality of life [25]. Notably, Buiting and colleagues [20] found that physicians had different opinions of what constituted the provision of "artificial nutrition and hydration," with responses ranging from tube feeding to offering spoon feeding and hydration.

3.2.3. Institutional—A lack of care coordination and resources made it more difficult for physicians working off-hours to get to know the PWD in order to guide treatment decisions, specifically to characterize the current stage of dementia [26]. Some physicians expressed concern about a lack of resources of already limited local palliative care services to accept PWD [27]. Staff time may be limited, leading to primarily task-focused care, and staff may not be able to meet all the care needs of the PWD; this shortfall may impact subsequent treatment decisions [28]. In Japan, some nursing homes require that PWD have a PEG to reduce staff burden [29].

3.2.4. State and national—Regional and national policies and customs influence decision-making. Within some cultures, the physician is expected to make final decisions, whereas in others, it is the family's role to do so [21, 17]. Ryan and colleagues [27] noted the influence of the 2005 U.K. Mental Capacity Act in prompting healthcare practitioners to conduct capacity assessments and engage in partnerships with family. Anronhelm and colleagues [30] shared that stringent state laws may also influence the decision-making process, leading physicians to be reluctant to forgo life-sustaining treatments without advance directives.

3.3. Role Clarity

Caregivers, nurses, and physicians demonstrated uncertainty or inconsistency in their perceived role in the decision-making process.

3.3.1. Caregivers—Caregivers consistently reported limited involvement in planning the hospital care, and they did not receive the communication they felt was necessary to fulfill their role [14]. It was also evident that families had variable desire for involvement in decision-making for the PWD. While some caregivers stated they lacked the medical expertise to make a decision (leaving that task solely to the medical team), others talked about advocating to be involved in the decision-making process [15]. One intervention explicitly addressed this lack of role clarity: a decision aid for feeding tube placement included a summary of the principles of substituted decision making [29], presumably to assist caregivers to understand their role in making treatment decisions for the patient.

While most studies reported on caregiver uncertainty in their role vis-à-vis healthcare practitioners, Elliott and colleagues [11] found that caregivers of PWD also have uncertainty amongst members of their families. Some families experienced conflict as certain members transitioned to taking primary responsibility for treatment decisions, or from having multiple family members involved in that process. In other families, decision-making sharing or delegation functioned well and ultimately strengthened family ties [11].

3.3.2. Nurses—Nurses were often in conflict about their role, as they wanted to protect and support the PWD's well-being [19], yet felt excluded from the decision-making process [18]. Nurses took on the roles of conversation initiator, go-betweens, and facilitators to enhance physician-family communication [17]. Nurses attempted to delay a feeding tube decision by stimulating the patient to eat or drink, through tempting them with their favorite foods or adapting the food consistency to facilitate eating [17]. When physicians made

decisions that nurses did not agree with, nurses either privately discussed their concerns with physicians, or more indirectly resisted the treatment decision by attempting to involve the palliative care team or convincing the caregivers to pursue a different treatment plan [17]. When nurses disagreed with caregivers on a treatment choice, nurses were “touched by the family’s suffering,” [18] yet felt the patient was “wronged” by this decision [17, 18].

3.3.3. Physicians—Physicians’ self-defined roles varied significantly, ranging from “laying the seeds” of the patient’s health status and prognosis with caregivers [21], to actively guiding or advising caregivers in consideration of decisions [20], to making the final decisions themselves [20]. Physicians reported having assumptions about the role of other involved physicians. For example, primary care physicians relied on the acute care hospital physician to supply caregivers with information regarding the PWD’s health status and care [21], and emergency department physicians often chose not to initiate a palliative care consult because they presumed the admitting physician would do so [31].

3.4. Appropriateness of Palliative Care in Dementia

While some articles evaluated interventions incorporating palliative care into the decision-making process, others revealed healthcare practitioners’ misperceptions of dementia and/or palliative care.

3.4.1. Defining palliative care—Different definitions of palliative care emerged across studies. Sampson and colleagues [32] reported that in consultations with caregivers, nurses clarified that palliative care was an appropriate, active care option and “NOT withdrawal of treatment” (p. 199). However, Anronheim and colleagues [30] used the following definition: “A treatment plan guided by the goal of maximizing patient comfort and *avoidance* [emphasis added] of painful or invasive treatments, including hospital admission, diagnostic tests, and invasive procedures, unless needed for symptom control” (p. 267). This disagreement regarding what palliative care is—whether patients can receive any treatment or procedures beyond what is needed for symptom control—may influence healthcare practitioner and caregiver perceptions of the appropriateness of palliative care for PWD.

3.4.2. Understanding dementia trajectory—Ryan and colleagues [27] found that many healthcare practitioners held the misperception that dementia is not a terminal disease or may not reflect a disease process at all, but rather a normal part of aging. Another study found that healthcare practitioners and caregivers did not attribute physical symptoms to advanced dementia and instead presumed they were the result of another pathology [21]. Healthcare practitioners noted the challenge of determining when dementia could be considered terminal [26]. In addition, both healthcare practitioners and caregivers expressed wanting more information about advanced dementia symptoms and treatment options so that they can more effectively plan ahead (of note, however, some caregivers found this information stressful) [21]. Furthermore, some geriatricians or general practitioners did not consult palliative care specialists because of an assumption that the palliative care teams lacked experience with and important knowledge of PWD [20, 27].

3.4.3. Involvement of palliative care—Six studies reported on an intervention involving palliative care with the goal of influencing treatment decision making for PWD, yet four reported negative findings. Ouchi and colleagues [31] provided training to emergency department physicians on how to initiate palliative care consultation, along with education on the identification of patients with advanced dementia, yet this did not significantly increase palliative care consultations. Anrohnhelm and colleagues [30] found that when a palliative care team met with both healthcare practitioners and caregivers to make recommendations, patients were more likely to receive a palliative care plan; however, this plan was usually not adopted until after hospital discharge. Providing a palliative care consulting team along with an educational program for medical residents led to a significant decrease in feeding tube placement, yet there was no significant reduction in feeding tube placement among PWD with an advance directive specifically refusing artificial nutrition [33]. Having a nurse trained in palliative care provide an advanced care planning discussion with the caregiver, resulted in only a few completing an advance care plan [32].

However, Campbell and Guzman [34] found that when a palliative care service proactively provided consultation to ICU staff, PWD had significantly reduced hospital and ICU length of stay and all PWDs received a DNR order. In a smaller study, a multidisciplinary effort to encourage palliative care consultations, explicitly identify patients with advanced dementia, and provide specific information about the non-benefit of a PEG tube placement for patients with advanced dementia resulted in no PWDs receiving a PEG tube [35].

3.5. Caregiver Need for Support

It was apparent from many articles that the decision-making process was stressful and difficult for caregivers, who acutely felt the enormous responsibility of making treatment decisions for their loved one [9]. Even when the patient had severe dementia, many caregivers felt it was difficult to limit treatment [10]. There were several sources identified that contributed to or hindered support for caregivers in making their decision.

3.5.1. Family—Caregiver uncertainty about the decision led to consulting other family members, which could strengthen family bonds and be a positive experience [9, 11]. Engaging in discussions with family and receiving support for and trust in their decision was helpful for many caregivers [36]. However, consulting family members also led to disagreements about the decision, and invited criticism from family members, which added to caregiver stress [9, 36]. At times, having several decision makers and subsequent conflict about the decision led to caregivers not following the patient's wishes [11].

3.5.2. Healthcare practitioners—Being involved in treatment discussions with the healthcare team was very important to caregivers, although many reported that this communication and caregiver involvement was “largely absent” in hospitals [28]. Indeed, one study found that only 63% of caregivers felt included in the decision-making process [23]. Almost 14% of caregivers stated there had been no discussion with healthcare practitioners before the insertion of a feeding tube, although 91% of these caregivers believed a discussion should have occurred [22]. Caregivers who reported that feeding-tube discussions took place, stated they did not cover important aspects such as risk or the

alternative possibility of hand feeding [22]. Caregivers sometimes felt pressured to consent to treatments suggested by the healthcare team [22, 25], with just over half feeling they had enough time to make a decision [25]. In contrast, caregivers felt supported by physicians when they sensed their opinions were heard and valued, and when physicians respected the patients' wishes, if known, when making treatment recommendations [36]. Only about a third of caregivers received support when they expressed their reservations about a treatment decision to the healthcare practitioner [25].

Nurses were also a unique source of support for caregivers. After caregivers were informed of the physician's decision (in a country where the physician makes the decision), nurses answered questions, listened to their concerns and provided both additional information and emotional support [17]. Having more frequent contact with nurses was associated with caregivers deciding not to provide tests or treatment—such as, x-rays or ventilators—to patients [16].

3.5.3. Other sources of support—Some caregivers attended support groups for dementia caregivers, either face-to-face or online [9]. Support group involvement was associated with reduced likelihood of aggressive treatment for the PWD [16]. Religiosity and spirituality provided hope and helped caregivers cope with the emotional burden [36]. However, caregivers felt conflicted when patient wishes did not coincide with the caregiver's religious beliefs, which at times led to caregivers making a decision against the patient's wishes but in keeping with religious tenets [36]. Lastly, a decision aid booklet for caregivers considering insertion of a feeding tube for the PWD increased knowledge and decreased decisional conflict, suggesting that this written information represented a source of support in making the treatment decision [29].

3.6. Consultation

The notion of “knowing the patient” resonated with the participants in the focus group. They described inpatient healthcare practitioners as eager for guidance from someone who knows the PWD, which sometimes led practitioners to contact primary care providers to obtain patient history and consultation. Physicians who had a relationship with the patient could act as a patient advocate; however, these physicians have been less present on inpatient units over time, with the spreading of the hospitalist model and increasing “compartmentalization of care.” Some practitioners noted that this factor can impact the effectiveness of palliative care; although palliative care teams have wonderful “scripts” for discussions, they still do not know the patient. Amidst the chaos of acute care, there can be a diffusion of responsibility regarding which practitioner should lead the decision-making process; this can contribute to confusion and lack of support experienced by caregivers. They noted that in their experience, caregivers can be caught in the gaps between healthcare settings and different care teams, and caregivers may search for the right practitioner to give them guidance.

Focus group participants also explained that not only is there not enough time to have conversations about treatment decisions, but also there is little value and priority placed on such conversations compared to other tasks. Quality metrics of an emergency department are

judged by patients with certain symptoms receiving certain interventions within a certain timeframe. For example, if a patient arrives with chest pain, a dementia diagnosis may be difficult to include in the decision algorithm, because interventions must be rapidly implemented to meet standard quality metrics. This point parallels articles that noted that emergency department physicians were too busy to consult palliative care [31] and perhaps limited by care that is “task-focused” [28]. This discussion provides context of the culture and systems contributing to suboptimal treatment decision making for PWD.

4. Discussion and Conclusions

4.1 Discussion

This scoping review illustrates the complexity of the factors and processes involved in treatment decision making for PWD in the acute care setting. Informal caregivers often felt burdened, uncertain, and unsupported in making treatment decisions for their loved ones. For healthcare practitioners, the many medical subspecialties and healthcare disciplines involved has led to lack of clarity about each provider’s role in the decision-making process. In addition, there appears to be confusion about whether palliative care is appropriate for a PWD and when best to involve these specialists. Overall, knowing the patient—including the course of dementia progression, patient values, and quality of life—appears critical to effective decision making. Nevertheless, strategies for involving the caregivers and healthcare practitioners who know the patient best in the decision-making process are perceived to be inadequate.

The process of decision making involving a PWD is unique in that a patient’s ability to make his or her own treatment decisions, and the need for caregiver involvement in the decision-making process, may change over the course of the disease. In our literature search, we chose not to specify patients with “*advanced dementia*” because we were interested in how decision making may change depending on the stage of illness. However, most of the articles focused on circumstances when the caregiver made the decision for a patient; the literature offered little insight on patient involvement in acute care treatment decision making. This gap in the literature is noteworthy, in part because incorporating knowledge of what the patient desires and values was the most frequently identified factor in our review. Similarly, the authors of a systematic review of 17 articles on decision aids for older patients at the end of life critiqued the decision aids as having “gaps in areas that matter to patients” such as “symptom burden, disruption to family and patient time, level of family involvement required in alternative care, consideration of the most difficult decision, quality of remaining life, and financial implications of relevant treatment choices” [37]. While caregivers and healthcare practitioners identified quality of life as an important factor in their decision, consideration of these other areas of importance to patients was not seen. Future studies should explore decision making in acute care *involving* patients with dementia.

Advance directives provide an avenue to involve patients in the decision-making process when they are no longer able to participate in the discussions. However, our findings revealed that advance directives were not followed in circumstances where the caregiver felt the wishes were inconsistent with personal religious or spiritual beliefs, when there was discord among family members about the “right” decision, or if the caregiver felt burdened

by the decision and unable to “let go.” A qualitative study of healthcare practitioners in nursing homes also noted that surrogate preference was the most significant influence on decisions to transfer advanced dementia residents to hospitals, despite advance directives or do not hospitalize orders [38]. Additionally, advance directive use is not consistent across countries; for PWD in nursing homes, about 40% have an advance directive in the United States [39], compared to 10% in Belgium [40]. Further study is needed to explore the use and benefit of advance directives.

This review has several limitations. First, only four databases were searched, which may have limited the number of articles for inclusion in the review. However, the databases were purposively chosen to promote a broad scope of articles from different disciplines. Second, only healthcare practitioners were included in the final step of consultation and other stakeholders, such as PWD and caregivers, were not included. This limited input on factors not experienced by healthcare practitioners, although it was noteworthy that focus group participants recognized and discussed caregiver need for support. Lastly, we included literature from multiple countries, but due to differences in models of decision making and availability of palliative care, our findings may not be generalizable across countries.

4.2 Conclusion

The findings of this scoping review, the first review of the literature on treatment decision-making for PWD in the acute care setting, contribute to an improved understanding of how these treatment decisions are made. Our findings highlight the complexities of this process and the importance of attending to the needs of the caregiver, the healthcare practitioners, and the patient. Our findings also demonstrate that the patient’s role is understudied and that treatment decision-making in the hospital for PWD in the mild or moderate stages, many of whom maintain involvement in treatment decision-making process, has been severely neglected in the literature.

4.3 Practice Implications

It is important to explore the institutional culture and address system barriers that may impede progress, particularly beliefs surrounding the benefit of involving palliative care for a PWD and the role of each healthcare discipline. For example, this review highlighted the nurse’s role in getting to know the patient, acting as an intermediary between the healthcare team and the caregiver, and advocating on behalf of the patient’s well-being. This finding is consistent with a discourse analysis of the nurse role as the patient advocate during treatment decision making that included getting to know the patient’s view of quality of life and preventing patient suffering when treatments are not enhancing well-being [41]. Healthcare practitioners in acute care should recognize the potential contributions of nurses and promote their involvement in the decision-making process. Healthcare practitioners should also negotiate a clear role for caregivers and provide them support in decision-making, work with caregivers to get to know the patient, and describe palliative care and how it can benefit PWD.

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Figure 1.
Flow diagram of identification, screen, and inclusion of articles

Table 1.

Definition of terms and corresponding search terms

Term	Definition	Search terms
Dementia	Chronic cognitive impairment resulting from Alzheimer's Disease or other dementias	Dementia, Alzheimer's disease, cognitive dysfunction, cognitive impairment, cognitive decline
Treatment decision making	A decision regarding whether to initiate, continue, withdraw, or withhold a medical treatment or procedure	Decision making, shared decision making, decision making process, treatment decision making, communication, communication strategies, communication skills, advance care planning, advance directives, advance care directive, living will, end of life wishes, palliative care, palliative medicine, terminal care, life support care, life-sustaining treatment, prolongation of life by medical means, end of life care, dying, professional-patient relations, professional-family relations, physician-patient relations, nurse-patient relations
Hospital setting	Includes inpatient units and the emergency department	None ^a

^aThe search was not specific to the hospital setting to be inclusive of studies that incorporated the hospital setting with other settings

Table 2.

Categories of factors influencing the decision-making process

Categories	% of articles in which factors contributed to the category
Knowing the patient	64%
Culture and systems	57%
Role clarity	50%
Appropriateness of palliative care in dementia	43%
Caregiver need for support	39%