Making clinical care decisions with people living with dementia in hospital: an integrative literature review

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Abstract

Background: As our population ages, the percentage of hospitalised patients diagnosed with dementia is expected to rise. However, there is emerging evidence that people living with dementia may experience discrimination and exclusion from decisions about their clinical care. Although dementia affects cognition, many patients living with dementia want to participate in decision-making processes relating to their clinical care in hospital.

Objective: Identify the processes associated with making decisions about clinical care with people living with dementia in hospital.

Design: An integrative literature review.

Data sources: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Scopus, EMBASE (Ovid), MEDLINE (PubMED), PsycINFO and HeinOnline.

Review method: One author conducted the initial screening of titles, and two authors screened in subsequent rounds for abstracts and full text. The process of making clinical decisions was the outcome of interest. Articles about people with cognitive impairment that did not include dementia, or decisions such as discharge planning or end of life care were excluded. An inductive synthesis of the findings was undertaken.

Results: Nine articles were identified for review and included expert opinion or hypothetical discussion (n=5), cross-sectional survey research (n=3), and qualitative research (n=1). Three themes were identified: capacity for decision-making is conceptualised as ‘all or nothing’; there are no universal principles for including people living with dementia in decision-making in acute care settings; and autonomy is recognised but superseded by beneficence.

Conclusions: Contemporary hospital practice is focused on determining capacity for decisions, with an all or nothing attitude to capacity, effectively excluding many people living with dementia from participation in decisions. While there is limited evidence to guide
clinicians in this complex and situated process of making clinical decisions, emerging models of supported decision-making require further evaluation in the hospital setting.

**What is already known about the topic?**

- The numbers of people living with dementia who use acute health services is expected to rise as the population ages.
- People living with dementia may be excluded from making decisions when they are in hospital.

**What this paper adds**

- The evidence on how to support people living with dementia participate in clinical care decision-making in hospital is limited to assessment of capacity.
- Ideally, making decisions about clinical care is a process to consider the (sometimes competing) interests of the patient living with dementia, their family and carers and the institution requiring resolution.
- Research into decision-making models for decisions about clinical care for people living with dementia in hospital care is required to assist clinicians to address the perpetual tensions between beneficence and autonomy.

**Keywords**

Autonomy, beneficence, decision-making, dementia, hospital
**Introduction**

Decision-making in healthcare is an area complicated by innovations in science and technology, cultural norms and societal values (Grady, 2015). For people aged from approximately 65 years and older, participation in decision-making can be confounded by declining cognitive function, most commonly associated with dementia. Dementia is a progressive neurodegenerative syndrome, which is typified by difficulties in memory and other accompanying cognitive deficits (Gale, Acar & Daffner, 2018). As of 2019, there are over 50 million people living with dementia worldwide and this number is estimated to increase to upwards of 152 million by 2050 (Alzheimer’s Disease International [ADI], 2019). A recent meta-analysis demonstrated an increased rate of hospitalisation for people living with dementia compared to their counterparts without a dementia diagnosis (RR = 1.42, 95% CI 1.21–1.66; Shepherd et al., 2019). Collectively, this suggests that people living with dementia are, and will continue to, increasingly engage with and use hospital services.

In hospital, people living with dementia experience more medical complications than people without dementia (Bail et al., 2013), intimating that their medical care is different in some way. Possibly associated with this phenomenon, there is an emerging body of evidence to suggest that discrimination against people living with dementia is embedded in hospital systems and processes (Dewing & Dijk, 2016; Moyle et al., 2010; Nilsson et al., 2012; Nilsson et al., 2013). The involvement of a person living with dementia in the decision-making process appears to be limited (Kelley, Godfrey & Young, 2021; Miller, Whitlatch & Lyons, 2016; Pecanac et al., 2018), and very little research has focused on the perspective of the person living with dementia in making decisions about their care in hospital (Kelley et al., 2021). It is timely to investigate how hospitalised people living with dementia participate in decisions about their clinical care, including how they provide consent for treatment.
Background

The process of making decisions about clinical care involves the individual right to choose to accept a medical treatment, which is widely recognised in Western medicine as a key principle to guide practice (Haberstroh, 2015). When recommending health care options, clinicians undertake the cognitive act of balancing what is ‘best’ for the patient’s health and wellbeing (beneficence) and limiting harm (non-maleficence) with the person’s right to choose (autonomy). As such, the right to choose is often enacted in hospitals as consent (Battard Menendez, 2013). Consent is a decision-making process whereby the patient is provided with information about a proposed treatment or dealing and based on that information makes an un-coerced decision to either accept or reject the proposed treatment or dealing (Faden & Beauchamp, 1986; Maclean, 2009).

While many clinicians deem that patient consent is only required for invasive procedures, it is required for all touchings (Lamont, Stewart & Chiarella, 2019). This is especially important for nurses, who conduct many procedures that require physical contact (touching). For many clinical procedures conducted by nurses, consent is implied (Seaman & Erlen, 2013), and only assent is sought to conduct the procedure. For example, applying a band-aid to a small cut will be assumed to have consent, and at the time of application assent will be apparent by the patient’s accepting or refusing the application. In this realm, clinicians enact patient consent as a ‘fait accompli’, based on patients’ admission to hospital for treatment, and do not necessarily present the patient with a choice (Redley et al., 2011).

Patient consent is often taken for granted and is exposed only in situations when patients do not provide assent, they refuse the clinical procedure. For people living with dementia, refusal (lack of assent) raises the issue of competence to consent, revealing the legal, as well as the clinical, nature of the process of consent.
Consent as a legal process is often understood as a contract, with risks of harm to the patient made explicit. Consent transforms an unsanctioned act into a permitted act (Faden & Beauchamp, 1986; Maclean, 2009). Unsanctioned acts are those that would be considered negligent (a failure to take reasonable care to avoid causing injury or loss) or criminal (an action or omission that is an offence at law). The process of consent is assumed to be free of influences, prior to the treatment or dealing and informed about the benefits and detriments of the proposed treatment or dealing as an expression of the patient’s right to choose (autonomy).

Competence to consent is commonly used to describe a person’s ability to make a decision; to consider information, understand and appreciate the competing alternatives and make a decision about their best interests. Competence to make decisions is generally a question of law decided by the courts, determining a person is either competent to make a decision or not (Buchanan, 2004). For example, a child is often incompetent as a matter of law because they are assumed to be unable to make certain decisions, and therefore require a competent parent or guardian as a substitute decision maker to make those decisions.

A person’s capacity to make a decision is a key consideration in competence determinations. Decision-making capacity is an assessment of the facts about a person’s ability to make a decision. In a health context, capacity to make a decision is a clinical judgement relevant to specific decisions (Ganzini, Volicer, Nelson, Fox & Derse, 2005). Decision-making capacity is dimensional, context dependent and can change over time (Haberstroh, 2015; Peisah, Sorinmade, Mitchell & Hertogh, 2013; Wade et al., 2019). Assessment of a person’s capacity, to satisfy legal standard of competence, usually requires the ability to: 1) express a choice; 2) understand the information to make a choice; 3) appreciate the medical consequences of the choice; and 4) reason properly about their treatment choices (Appelbaum, 2007). Capacity assessments can also be used to determine
what level of support is required for involvement in decision-making, in order to promote autonomy for the person living with a disability, rather than merely to delineate capacity (Peisah et al., 2013).

Numerous tools are available to assess capacity, however there is currently no universally accepted gold standard (Pennington et al., 2018). The tools used to assess treatment decision-making capacity in people living with dementia include but are not limited to the MacArthur Competence Assessment Tool for Treatment (Grisso & Appelbaum, 1998), Hopemont Capacity Assessment Interview (Edelstein, 1999) and Capacity to Consent to Treatment Instrument (Marson et al., 1995). Assessment of capacity is complex, coupled with a formal assessment tool and expert opinion, due consideration of the patients’ emotions, values and experiences is essential (Pennington et al., 2018).

For people living with dementia, the assessment of capacity for the purpose of a legal competence determination can also provide an indication of the support required for involvement in decision-making. People living with dementia generally want to participate in decisions that relate directly to their medical treatment and care (Miller et al., 2016). Moreover, research into the experiences of people living with dementia suggests that involvement in decision-making adds to good quality of life and a sense of personhood (Fetherstonhaugh, Tarzia & Nay, 2013). Making ones’ own choices, big or small, is every person’s right rather than a privilege, withholding a choice or not respecting a choice may be considered a form of abuse (Flavin, 2020).

In the community setting, models based on shared decision-making for people living with dementia are being developed. A systematic review of shared decision-making between persons living with dementia and their carers led to a model of graduated decisions, from managed autonomy (low carer – high person living with dementia involvement) to delegation (high carer – low person living with dementia involvement) (Bhatt, Walton, Stoner, Scior &
The idea of a spectrum for supporting decision-making for people living with dementia would require varying levels and types of support, dependent on the type of decision and the degree and nature of the person’s cognitive impairment (Sinclair et al., 2019).

In the acute care setting, where decisions usually require relatively immediate consent, the processes are more complex (Pecanac et al., 2018). For in-hospital patients living with dementia, a focus on personhood requires maintenance of dignity, supported autonomy, and respect of their decisions (Edvardsson, Winblad & Sandman, 2008) and preferences (Fetherstonhaugh et al., 2013). Although knowing the patient and their values and desires is considered essential in the decision process, there is limited evidence to guide clinicians on how to involve patients living with dementia and their family/carers in decision-making about clinical care (Pecanac et al., 2018). Pecanac and colleague’s (2018) review emphasised the importance of nurses as intermediaries between clinicians, and advocates for patients during the decision-making process, although most articles included were focused on family/carers making decisions for the person living with dementia.

While balancing the principles of beneficence, non-maleficence and autonomy is widely agreed to be important in healthcare decisions, the process for decision-making with people living with dementia in hospital remains less clear. Issues of competence, capacity and consent are embedded in the clinical decision-making process. When making decisions about clinical care with people living with dementia, clinicians require additional support to ensure that their legal and ethical responsibilities to the patient are met. The aim of this review is to identify the processes used to make decisions about clinical care with people living with dementia in hospital settings.
Methods

Design

The study was guided by the five stages of the Whittemore and Knafl (2005) framework for conducting integrative literature reviews. This framework was selected due to its flexibility to include diverse primary sources whilst providing a systematic approach to conducting the review. In this case, the aim was to explore the processes used to make decisions about clinical care with people living with dementia.

Problem identification

The review was guided by the research question: What processes are used to include people living with dementia in decisions about their clinical care while in hospital? Three works relevant to making decisions about clinical care for people living with dementia were published in 1999: shared decision-making in clinical medicine (Frosch & Kaplan, 1999); person-centred care in people living with dementia (Kitwood & Benson, 1999); and the role of agency in dementia and decision-making (Jaworkska, 1999). As such, we limited our search to 1999 and later to capture any work published subsequent to these articles.

The focus of the review was determined using the Sample, Phenomenon of Interest, Design, Evaluation, Research Type (SPIDER) framework (Cooke, Smith & Booth, 2012). Studies that focus on decisions being made with people living with dementia in acute care settings were included. To ensure that no studies were inadvertently excluded, the initial search terms included ‘cognitive impairment’. The type of health professionals making the decisions was inclusive, given that nurses work closely with doctors and other professionals in the process of clinical care decision-making. The phenomenon of interest was ‘clinical care’ decision-making in hospital settings. The design was inclusive, with empirical and theoretical literature included (Whittemore & Knafl, 2005, p.548). The outcome of interest
was the process of making decisions. There were no restrictions on the study
design or research type.

Literature search

Following Whittemore and Knafll (2005), multiple search strategies were used to
enhance the quality of this review, with each strategy informing subsequent searches. The
initial search was associated to the phenomenon of interest, ‘making clinical care decisions in
hospital settings’. Search terms included decision-making (e.g., decision-making, shared-
decision, pseudo-decision, surrogate-decision, consent, and assent). Other search terms
associated with decision-making, such as ‘treatment compliance’, ‘treatment refusal’, and
‘treatment withholding’ were also included. Subsequent searches identified the sample, being
(2) dementia, Alzheimer’s, cognitive impairment and (3) nurse, doctor, carer, family, care-
giver, caregiver, care giver and (4) acute, hospital. Search terms were applied to titles,
abstracts, key words and full texts. A combination of MeSH (Medical Subject Headings)
terms using ‘or’ and ‘and’ Boolean operators as per database specifications were used. With
the support of a health librarian, a computerised database search of the Cumulative Index of
Nursing and Allied Health Literature (CINAHL), Scopus, EMBASE (Ovid), MEDLINE
(PubMED), and PsycINFO was conducted. A later search of the legal database, HeinOnline
was conducted to ensure that no articles published in this field were missed. A pilot search
was performed in PsycINFO to test the search strategy and refine the search terms before the
full search was undertaken. The reference lists of retrieved articles were hand searched to
find any relevant literature not identified in the initial search.

The initial search and screening of title and abstract for inclusion eligibility was
undertaken by one author (JT). Full text articles retrieved and reviewed by two authors for
inclusion (JT, LG). Articles were excluded if the participants had cognitive impairment other
than dementia, if the setting was non-acute hospital or psychiatric, or the decision under
interest was not about a clinical treatment conducted in hospital i.e., discharge planning, or an ethical decision such as end-of-life.

**Data evaluation**

Due to the diversity of the primary sources, two authors (JT, LG) reviewed articles for methodological or theoretical rigour, using a 2-point scale (see Table 1). The criteria used was based Johanna Briggs Institute Critical Appraisal Tools (https://jbi.global/critical-appraisal-tools). Given the nature of the articles, they were also ranked based on the John Hopkins Nursing evidence-based practice levels of evidence (Dang & Dearholt, 2017).

[Insert Table 1 here]

The data evaluation rating system was not used to exclude any articles. However, the quality of the articles was considered during the analysis stage, with findings from articles with low rigour contributing less to the analytical process.

**Data extraction and analysis**

The data from the eligible articles was extracted and recorded in a template in accordance with research design, aim, setting, sample and findings. Data reduction strategies were employed and focused on three key questions: 1) the type of decision; 2) the process used for the decision; and 3) how the person living with dementia was included in the decision. The study authors worked in pairs to independently extract information from each article and recorded the data in a spreadsheet.

An inductive process was then employed to analyse the extracted data. Two members of the research team (JT, LG) independently reviewed the data extraction tables. The focus was on initially and independently summarising and collating the evidence into conceptual categories, which were then reviewed with all three authors. Areas of disagreement were
resolved through consensus. Once the conceptual categories were agreed, two researchers then worked independently to develop themes based on the significance of the patterns and their broader meanings and implications (Braun & Clarke, 2006). These themes were integrated and finalised with the conclusions endorsed by all team members. As a way to establish rigour in the inductive process, each article was then reviewed to confirm that the final themes aligned with the contents of the source articles.

**Presentation**

The findings were synthesised with what is known to present a model for making clinical care decisions with people living with dementia in hospital.

**Findings**

The search strategy revealed 586 articles, nine of which met the inclusion criteria. Figure 1 outlines the process for selecting the final articles. A summary of the nine articles included in the review is provided in Table 2. Five of the articles were from Europe, three from the United States, and one from Australia. The articles primarily included narratives expressed as expert opinion ($n=3$) (Appel, 2012; Appelbaum, 2007; Kabelka, 2017) and discussion ($n=2$) (Khizar & Harwood, 2017; Nazarko, 2008). One qualitative research study was included, which focused on the views of carers of people living with dementia in hospital (Bloomer et al., 2016). For the three cross-sectional surveys, the samples included physicians (Eisemann et al., 1999; Volicer & Ganzini, 2003), nurses (Richter & Eisemann, 2001) and other professionals (Volicer & Ganzini, 2003). Of these, two studies used the same case study for physicians (Eisemann et al., 1999) and nurses (Richter & Eisemann, 2001).

[Insert Figure 1 here]
There was diversity in the quality of the included literature, with no intervention studies found. Four articles ranked as Level III (non-experimental cross-sectional surveys and qualitative designs) and five articles ranked as Level V (expert opinion) evidence. Of the expert opinion and discussion articles, three were rated as low quality (Appel, 2012; Kabelka, 2017; Nazarko, 2008). The primary critique of these articles was the lack of literature to support their claims. The one qualitative article demonstrated clear logic between theory and methodology, and the findings and conclusions consistent with the data collected. The quality of the quantitative literature was rated low on the grounds of lack of clear criteria for sample inclusion and lack of reported reliability and validity of the surveys. In summary, the quality of evidence to inform our understanding of making clinical care decisions with people living with dementia in hospital is limited.

[Insert Table 2 here]

There were three themes identified from the articles: 1) capacity for decision-making is conceptualised as ‘all or nothing’; 2) there are no universal principles for including people living with dementia in decision-making in acute care settings; and 3) autonomy is recognised but superseded by beneficence.

*Capacity for decision-making is conceptualised as ‘all or nothing’*

The discourse across the articles on decision-making with people living with dementia focused on whether the patient had capacity (or not) to make the decision. Capacity was considered in the process of making a decision (Appelbaum, 2007; Khizar & Harwood, 2017; Nazarko, 2008; Volicer & Ganzini, 2003). A person’s capacity was most often queried when the person disagreed with the clinician’s treatment decision (e.g., Eisemann et al., 1999; Khizar & Harwood, 2017).
In principle, most authors agree that capacity can vary and should be decision specific, and several required a confirmation of capacity (yes or no) for those decisions (Appel et al., 2013; Appelbaum, 2007; Khizar & Harwood, 2017; Nazarko, 2008). In the US survey (Volicer & Ganzini, 2003), the assessment of risk was found to be a consideration in deciding on the criteria used to judge capacity, with more stringent criteria used for procedures with higher risk for the patient (Volicer & Ganzini, 2003). In one of the hypothetical cases, likelihood of risk of harm to the patient was considered important during the process of determining capacity (Khizar & Harwood, 2017).

The application of capacity assessments was subject to the expertise of medical clinicians (Appelbaum, 2007; Khizar & Harwood, 2017; Volicer & Ganzini, 2013), with limited evidence of formal assessment approaches to determine capacity. One article suggested using the MacArthur Competence Assessment Tool for Treatment (Grisso & Appelbaum, 1998, cited in Appelbaum, 2007). Researchers conducting the largest cross-sectional survey study concluded that there appeared to be no uniform standard in the determination of capacity (Volicer & Ganzini, 2003). The authors identified the Hopkins Competency Assessment Test (Janofsky, McCarthy & Folstein, 1992, cited in Volicer & Ganzini, 2003) as a formal assessment tool of general capacity, and state there are also tools to assess capacity relative to specific decisions (e.g., consent to hospitalisation, medical treatment, emergency care). They conclude there is no evidence of use of these assessment tools in clinical practice (Volicer & Ganzini, 2003). In summary, clinicians were aware that the capacity to make decisions was dependent upon the context of the situation and the nature of the decision. However, capacity was consistently deemed as being present or not, all or nothing.

No universal process or principles for including person living with dementia in decision-making
Respecting the rights and dignity of a person living with dementia in the decision-making process was consistently identified as essential by experts (Kabelka, 2017; Khizar & Harwood, 2017; Nazarko, 2008), health professionals (Eisemann et al., 1999; Richter & Eisemann, 2001), and carers (Bloomer et al., 2016). However, including the person living with dementia in the decision-making process was not consistently addressed. In the accounts of carer’s experiences, participation of the person living with dementia in decisions was not addressed; the focus was on carer participation (Bloomer et al., 2016). Conflict (personal and ethical) between the person living with dementia, family members and/or clinicians further complicated the decision-making process in the study of carers (Bloomer et al., 2016) and is also raised as an issue by one expert (Appel, 2012).

However, family was considered important in several ways. First, as a source of information during the process of assessing capacity for consent (Appelbaum, 2007). Secondly, family was identified as an important source of information about a person’s needs and preferences (Nazarko, 2008). Finally, family members perceived themselves as experts on the care of the person living with dementia and expected to be included in clinical care decisions (Bloomer et al., 2016).

The hypothetical cases proposed in the narratives suggested that people living with dementia should be offered meaningful information (Appel, 2012; Applebaum, 2007; Kabelka, 2017), have their preferences considered (Kabelka, 2017; Khizar & Harwood, 2017), and for this to be communicated with attention to background noise, clear language, and aligning body language with words (Nazarko, 2008). This was supported by the findings in the two cross sectional surveys where European physicians (Eisemann et al., 1999) and nurses (Richter & Eisemann, 2001) considered the patient’s wishes. However, the inclusion of the person living with dementia in decision-making is not articulated in the hypothetical
example used in the US cross-sectional survey study, which was solely focused on determining capacity (Volicer & Ganzini, 2003).

The absence of clear processes or procedures for including people living with dementia in decision-making was evident. When the clinical determination is lack of capacity, how the person living with dementia can be included in the decisions appears to be overridden by family concerns and clinician expertise.

*Autonomy is recognised but superseded by beneficence*

A patient-centred approach to decision-making for people living with dementia was highlighted as important. For example, Appel (2012) suggested ‘meaningful understanding’ of the ‘patient’s wishes’ and Nazako (2008) suggests ‘care that reflects who she is as a person when she is unable to make decisions.’ In theory, respecting autonomy was recognised as fundamental to the decision-making process and maintaining autonomy was recommended if possible (e.g., Khizar & Harwood, 2017).

In the survey findings, factors attributed to privileging beneficence over autonomy included: stage in the disease progress (Eisemann et al., 1999), clinician’s experience (Eisemann et al., 1999) and clinician’s attitudes, beliefs and perceptions of the person’s quality of life or lack thereof (Richter & Eisemann, 2001). When making clinical decisions with people living with dementia, clinicians may privilege their view of beneficence as most important. When the person living with dementia is not included in the decision-making process, this approach may work to the detriment of patient autonomy.

**Discussion**

This review focused on how clinical decisions were made with people living with dementia in hospital and illustrates the complexity of the process. Three themes emerged around the assessment of capacity to make a decision, lack of universal processes or principles for including people living with dementia in decisions, and a deference to
beneficence despite acknowledgement of the importance of autonomy. These themes are synthesised with available evidence on the process of making clinical care decisions to develop a framework for making the processes of a clinical care decision explicit. The essential elements of a clinical care decision are outlined in Table 3.

[Insert Table 3 here]

Much literature reviewed focused on the assessment of capacity as central to engaging people living with dementia in clinical care decisions. While many of the decisions in the articles were those decisions about invasive procedures made with a physician, the process for making decisions is also relevant for nurses. Under the law, consent is required for all touchings (Lamont et al., 2019) and given the intimate nature of nursing work, consent is required many times per day. Before capacity is considered, nurses must consider whether the proposed treatment requires more than mere implied consent and whether they are authorised to take that consent.

The criteria used to assess capacity was related to the risks associated with the procedure, with the use of cognitive measures recommended for decisions about surgical treatment (Appelbaum, 2007; Volicer & Ganzini, 2003). Otherwise, there was reliance on clinician judgement about capacity, which was informed by collecting information from family members. How capacity should be assessed and determining whether the patient has capacity for comprehension and understanding are key elements in the process for making a clinical decision.

In this review, capacity was deemed present or absent, ‘all or nothing’. To address the limitations of the ‘all or nothing’ approach to capacity, and therefore competence to make decisions, researchers are exploring conceptual tools such as ‘agency’ (Boyle, 2014) and
‘patients own preferences’ (Wasserman & Navin, 2018) to enable people living with dementia to engage in decision-making. Agency is the ability to be an active participant in decision-making or at least influence their personal circumstances (Boyle, 2014). Patients own preferences posits that a patient’s preferences should be an additional source of guidance for decisions about patients who lack decision-making capacity (Wasserman & Navin, 2018). When people living with dementia are assumed to have agency, even with limited capacity, the requirement for providing information in a way that can be understood by the person is an essential element to the process of clinical care decisions.

While no universal process or principles for making a clinical care decision with a person living with dementia were found, respecting the rights and dignity of the person was identified as essential. The most important element to maintaining agency is collaboration between the carer and the person living with dementia (Fetherstonhaugh et al., 2013). In this review, family members were considered important to providing information about the person’s preferences and should be engaged in the process of making a decision. While not explored in the reviewed articles, the inclusion of others, possibly legal guardians, may need to be considered (Gil, 2018). Identification of others that can be engaged in the process for decisions is a critical step.

The context of clinical decision-making was not addressed in any of the reviewed articles. The healthcare institutional setting carries a matrix of rules, policies and epistemic practices that determine patient competence to make decisions (such as delegated authority to bind the institution). Further, these occur within a financial framework that regulates resources, spending commitments and budgets. Specific social, economic and cultural norms should be explored in the process of making decisions. Further research is required to understand how social elements should be incorporated into the process of making a clinical decision.
The autonomy of the person living with dementia was often found to be superseded by clinician perspectives of beneficence. Using a patient’s own preferences is promoted for patients with compromised decision-making (Wasserman & Navin, 2018), which would include people living with dementia. This concept of preferences is drawn from values-based health literature focused on personhood for people living with dementia (Edvardsson et al., 2008). Rather than framing the main question as whether a person has the capacity to make the decision, how clinicians can help the person living with dementia attain and exercise autonomy becomes more important (Haberstoh, 2015). In hospital settings, nurses have the most interactions with the patient and their families, positioning them as advocates for the person.

Determining how the person’s choice can be considered voluntary may be addressed using the concept of agency. When agency is used, three possible decision-making pathways emerge: autonomous decision-making, shared decision-making, and pseudo-autonomous decision-making (Bosco et al., 2019). Rather than focus only on cognitive decline (Bhatt et al., 2020), decision-making pathways for agency are time-bound processes, influenced by cognitive decline and the meta-cognitive processes of self-awareness, self-reflection and self-monitoring to appraise the situation, combined with the quality of the care environment, including the level of support from the carer (Bosco et al., 2019). Nurses making many clinical care decisions each day should be aware of patient autonomy and record how this is honoured in their daily care reports.

In their analysis of preferences as a way to guide supportive decision-making for people with cognitive impairment, Wasserman and Navin (2018) suggest that clinicians ‘still tend to disregard the preferences of a patient who lacks decision-making capacity as psychopathological noise’ (p 34). Peisah and colleagues (2013) suggests using a practical
model to guide decision-making in a way that values autonomy. The acronym ASK ME is used for the process of:

- Assessing a person’s cognitive strengths such as recalling information, weighing alternatives, planning or communicating;
- Simplify the task to core elements, avoiding jargon;
- Know the person in order to find common ground to work together;
- Maximise the ability to understand by managing environment i.e. quiet room and use of visual aids; and
- Enable participation by tailoring support to the complexity of the decision and seriousness of consequences of the decision (Peisah et al., 2013).

Finally, once consent is gained, it is important to appreciate that consent can be withdrawn at any time. For nurses, the concept of assent guides most clinical care work, whereby consent is implied (Seaman & Erlen, 2013) and lack of assent corresponds with withdrawn consent. For busy clinicians, supporting the process of clinical decision-making requires an understanding of dementia and how different areas of the brain, and therefore meta-cognition, are affected. Unfortunately, clinician knowledge of dementia tends to be limited (Annear 2020), highlighting the problem of determining withdrawal of consent. Any model for clinical care decisions with people living with dementia must address withdrawal of consent and assent.

Making clinical decisions with people living with dementia is also particularly problematic for healthcare providers because of the temporal assessments of consent (and assent). Healthcare providers must gain consent to a proposed treatment or dealing without being sure the person living with dementia necessarily has the relevant capacity and competence. While the temporal process of the healthcare provider gaining consent precedes the proposed treatment or dealing, the actual lawfulness of the consent decision is adjudicated
in the future. When clinical care decisions are reviewed, the healthcare professional must reach back in time to the how, where, when and why of the consent decision. As such, healthcare providers, such as the nurse, presumes there is sufficient consent when administering the treatment or dealing *but can never* be certain. To gain satisfactory consent essentially involves a process of determining what to disclose, assessing comprehension, confirming a voluntary choice and then confirming the authorization. With this complexity, reaching back through the consent process that is embedded within the sociocultural context and the competing priorities at the time of treatment is complicated, and made yet more complex for people living with dementia.

**Implications for nursing**

While the evidence to support clinical care decision-making with people living with dementia in hospital was limited, integrating what was found with what is already known provides an outline for nurses to follow in their day-to-day work, which consists of intimate care involving *touchings*. The concept of agency and the value of shared decision-making emerge as critical to enacting the process of making decisions about clinical care with people living with dementia. How to include families in a shared decision-making process requires specialised skills. Family nursing theory (Wright & Leahey, 2013) may offer new insights into how families of people living with dementia could be included in care decisions.

Nurses’ have an important role in helping the person living with dementia attain and exercise autonomy. The 24-hour presence of nurses in the hospital setting ideally positions nurses in the role of advocate for people living with dementia. In order to advocate, nurses must have improved knowledge of dementia and meta-cognition. How to incorporate the care of people living with dementia in nursing education requires further development.

The lack of high-quality evidence around the process of making clinical care decisions with people living with dementia must be addressed. Well-designed studies that
investigate different decision-making models to enact agency in people living with dementia are urgently required. While the evidence is not adequate for the development of universal principles, the 13 elements for clinical care decisions (Table 3) identify a preliminary framework to guide practice. How this might be operationalised now requires research attention.

Limitations

The authors acknowledge that laws evolve and change over time, as such this review is limited to the selected timeframe. In this study, we used an integrated review process to identify evidence-based processes for clinical decision-making. There were few research studies found in the search, and as such, we are unable to make evidence-based recommendations about how to make clinical decisions with people living with dementia. However, through this review, we have been able to raise the need for a more nuanced approach to making clinical decisions for the patient, thereby respecting their dignity as human beings.

Conclusions

The findings from the review highlight the complicated task of how to achieve a clinical decision involving a person living with dementia in hospital. The evidence for the process of clinical decision-making were limited to addressing the problems of determining capacity, the administrative and bureaucratic process for consent and the balance between autonomy and beneficence. While these remain unresolved, the concept of agency provides an opportunity to create new, family inclusive models for making clinical decisions. These models must be developed and evaluated in hospital settings to assist with the important balance of autonomy and beneficence.
Conflict of interest
The authors claim no conflict of interest

Funding sources
There was no external funding for this work.
References


Battard Menendez, J. (2013) Informed consent. Essential legal and ethical principles for nurses. JONA’s Healthcare Law, Ethics, and Regulation, 15, 140-144. DOI: 10.1097/NHL.0000000000000015


Records identified through database searching
\((n = 586)\)

Additional records identified through other sources
\((n = 1)\)

Records after duplicates removed
\((n = 530)\)

Records screened
\((n = 530)\)

Records excluded
\((n = 493)\)

Full-text articles assessed for eligibility
\((n = 37)\)

Full-text articles excluded, with reasons
\((n = 28)\)
- Cognitive impairment not dementia \((n = 12)\)
- Not acute care \((n = 10)\)
- Decision making not clinical \((n = 12)\)
  (Some articles met more than one criterion)

Studies included in integrated review
\((n = 9)\)

**Figure** PRISMA flow diagram

Table 1: Criteria Applied to Assess the Quality of the Literature included in the Review.

<table>
<thead>
<tr>
<th>Quality</th>
<th>Quantitative 1</th>
<th>Qualitative 2</th>
<th>Theoretical 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Cross-sectional Survey)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of Evidence 3</td>
<td>Level III 4</td>
<td>Level III 4</td>
<td>Level V 4</td>
</tr>
<tr>
<td>High</td>
<td>Clear criteria for sample inclusion. Detailed description of study and setting. Measures are objective and determine outcomes in valid &amp; reliable way. Confounding factors identified and managed. Statistical analysis is appropriate for the data.</td>
<td>Congruence between philosophy, methodology and methods. Researcher theoretical position is stated. The participants, and their voices, were adequately represented. The conclusions drawn in the research report flowed from the analysis, and/or interpretation, of the data.</td>
<td>Opinion source is clearly identified as an expert. The interests of the relevant population were the central. A logical argument, with evidence (from the literature) to support claims, is provided.</td>
</tr>
<tr>
<td>Low</td>
<td>Details of the sample, setting, measurement, confounding factors, outcomes, and statistical analysis were inconsistent or absent.</td>
<td>Incongruence evident between philosophy, methodology and methods. Researcher position is unclear. Absence or limited inclusion of participant voice. Conclusions are not clearly derived from the data.</td>
<td>Details of the source, expertise, relevant population, analytical processes and logic, and relevant literature were inconsistent or absent.</td>
</tr>
</tbody>
</table>

1 Critical Appraisal Checklist for Analytical Cross-Sectional Studies
2 Critical Appraisal Checklist for Qualitative Research
3 Critical Appraisal Checklist for Text and Opinion
Level III: Non-experimental study.
Level IV Opinion of respected authorities or nationally recognized expert committees or consensus panels based on scientific evidence.
Level V: Based on experiential and non-research evidence.
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<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Research Design/ Aim</th>
<th>Setting &amp; Sample</th>
<th>Findings</th>
<th>Rating</th>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appel (2012)</td>
<td>USA</td>
<td>Expert opinion Identify key considerations in medical decision-making for people living with dementia</td>
<td>Hypothetical 78-year-old female in a medical service in a community hospital</td>
<td>Type of decision: Medical treatment decision. Process for decision: Clinicians gather information about the patient’s history and circumstances to develop a meaningful understanding of the patient’s preferences. How person living with dementia included in decision: Clinicians are obliged to offer meaningful information about the procedure even if the person is unable to provide informed consent (proxy required).</td>
<td>Low</td>
<td>Level V</td>
</tr>
<tr>
<td>Appelbaum (2007)</td>
<td>USA</td>
<td>Expert Opinion Explore strategies that physicians use to determine patient’s competency to make decisions</td>
<td>Hypothetical 75-year-old female in a surgical ward in hospital</td>
<td>Type of decision: Decision about surgical treatment. Process for decision: Use a structured approach to assess capacity (e.g., MacArthur Competence Assessment Tool for Treatment’). At least two evaluations should be performed at different time points. Family and nursing staff are collateral informants for assessing capacity. How person living with dementia included in decision: Provide information relevant to making an informed decision to the person, regardless of their level of assessed competence to make a decision. Include substitute decision-maker if person deemed not competent to make a decision.</td>
<td>High</td>
<td>Level V</td>
</tr>
<tr>
<td>Bloomer et al. (2016)</td>
<td>Australia</td>
<td>Descriptive qualitative Explore carers’ experience when the person he/she cares for is a hospital inpatient</td>
<td>60-bed geriatric evaluation and management unit Family/caregivers of people living with dementia (n=20)</td>
<td>Type of decision: In hospital treatment decisions. Process for decision: Family/careers prefer to be recognised as experts about the care of the person living with dementia and included in the decision-making process. How person living with dementia included in decision. The inclusion of the person living with dementia was not detailed. In-hospital decisions were made by hospital staff and/or family in collaboration or conflict with other family members and hospital staff.</td>
<td>High</td>
<td>Level III</td>
</tr>
<tr>
<td>Study Authors</td>
<td>Country/Region</td>
<td>Research Design</td>
<td>Example Survey/Description</td>
<td>Type of Decision</td>
<td>Process for Decision</td>
<td>How Person Living with Dementia Included in Decision</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------------</td>
<td>--------------------------</td>
<td>-----------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Eisemann et al. (1999)</td>
<td>Austria, Germany, Sweden</td>
<td>Cross-sectional survey</td>
<td>Describe the extent to which the decision-making process is influenced by cultural and socio-political circumstances. Survey example: hypothetical 82-year-old male presenting in emergency department. Physicians from hospitals and general practice completed the survey (n=540).</td>
<td>Type of decision: Medical treatment decision about gastrointestinal bleeding. Process for decision: Physicians consider patient’s wishes (advanced directives) and ethical factors as more important than religious beliefs and hospital costs. Swedish doctors considered the level of dementia and recommended less aggressive treatment than doctors from Austria and Germany. How person living with dementia included in decision: Complying with patient’s wishes for treatment. 20% of physicians did not comply with the patient’s wishes about treatment.</td>
<td>Low Level III</td>
<td></td>
</tr>
</tbody>
</table>
### Nazarko (2008) UK

**Discussion**
Explore how staff can work with family and friends to provide care that meets the needs and aspirations of people who lack capacity.

**Hypothetical 85-year-old female in a hospital ward**

**Type of decision:** Fundamental care decision, shower.

**Process for decision:** Gather information to understand the person’s needs and preferences such as the:
- person’s family/friends can provide important information; and
- Mental Capacity Act (2005) can guide decision processes.

Level of cognitive assessment is dependent on the importance of the decision, e.g. a formal assessment of capacity is required for a surgical operation whereas ‘reasonable belief’ that the person lacks capacity is considered acceptable for less important decisions (e.g., bathing).

Decisions made based on providing care in the person’s best interest.

Document care provided to a person unable to consent.

**How person living with dementia included in decision:** Enhanced communication through elimination of background noise, use of simple clear language, and take time to explain – aligning unhurried body language with words.

### Richter & Eisemann (2001) Sweden & Germany

**Cross-sectional survey**
Explain the importance of conscious and unconscious factors in nurse decision-making.

**Convenience sample of nurses working in hospitals**

- Swedish nurses ($n=122$)
- German nurses ($n=182$)

**Type of decision:** Medical treatment decision about gastrointestinal bleeding.

**Process for decision:** Differed by country: Swedish nurses primarily considered the level of dementia; German nurses considered patient age, wishes and ethical concerns.

Nurses imposed their own attitudes and values in decision making regarding patient decisions.

**How person living with dementia included in decision:** Patient’s wishes were considered.

### Volicer & Ganzini (2003) USA

**Cross-sectional survey**
Determine the elements considered important for evaluation of decision-making capacity.

**Hypothetical 84-year-old female in a hospital**

- Physicians ($n=237$)
- Geriatricians ($n=103$)
- Psychologists ($n=46$)

**Type of decision:** Decision about surgical treatment.

**Process for decision:** The most important element in assessment of capacity was the person’s ability to appreciate the consequences of the decision.

Less than 50% of respondents in each category identified all five essential elements for capacity to make decisions.

Identify the Hopkins Competency Assessment Test designed to identify general capacity.

Other tools to evaluate capacity for specific decisions are available (e.g., consent to hospitalisation, medical treatment, emergency care).
How person living with dementia included in decision: The inclusion of the person living with dementia was not detailed.


Table 3. Elements of the clinical care decision by a proposed patient to a proposed treatment or dealing that requires consent.

<table>
<thead>
<tr>
<th>Element</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Is the proposed treatment or dealing lawful (noting that some treatments and dealings will be unlawful irrespective of consent)?</td>
</tr>
<tr>
<td>2.</td>
<td>Is this a proposed treatment or dealing that requires consent?</td>
</tr>
<tr>
<td>3.</td>
<td>Is the person taking the proposed consent able to take a consent (authorised or delegated)?</td>
</tr>
<tr>
<td>4.</td>
<td>How could and should the proposed patient’s capacity be assessed?</td>
</tr>
<tr>
<td>5.</td>
<td>Does the proposed patient have the capacity of comprehension and understanding?</td>
</tr>
<tr>
<td>6.</td>
<td>How much information needs to be provided to the proposed patient?</td>
</tr>
<tr>
<td>7.</td>
<td>How could and should the information be presented?</td>
</tr>
<tr>
<td>8.</td>
<td>Could and should others be engaged in the process, like family and advisers?</td>
</tr>
<tr>
<td>9.</td>
<td>How could and should others be engaged in the process?</td>
</tr>
<tr>
<td>10.</td>
<td>Is or are there specific social, economic and cultural norms that affect consent, like cultural decision making?</td>
</tr>
<tr>
<td>11.</td>
<td>How could and should the proposed patient’s choice(s) be considered (sufficiently) voluntary?</td>
</tr>
<tr>
<td>12.</td>
<td>How could and should the patient’s choice(s) be recorded and documented?</td>
</tr>
<tr>
<td>13.</td>
<td>Before conducting the proposed treatment or dealing, has consent been affirmed (assent)?</td>
</tr>
</tbody>
</table>