


**REVIEW**

# Hospital discharge processes involving older adults living with dementia: An integrated literature review

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**Aims and objectives:** To identify barriers and facilitators to engagement of people with dementia and family carers in planning for discharge from hospital.

**Background:** Hospital discharge can be particularly challenging for older people with dementia. To assist in the development of bespoke discharge processes that address the unique needs of older people with dementia, an integrated review of the literature was undertaken.

**Design and methods:** A four-stage integrative review framework guided the review. Three search strategies were employed: a computerised database search, a hand search of reference lists and forward citation searching. Paired members of the research team reviewed eligible full-text papers. The methodological quality of each paper was assessed using the Mixed-Methods Assessment Tool, followed by data extraction and completion of summary tables. Within and across study analysis and synthesis of study findings was undertaken using thematic synthesis.

**Results:** Fifteen papers were included in the review. Most identified barriers to collaborative discharge processes related to distributed responsibility for discharge, risk averse approaches to discharge, limited family carer confidence, and limited validation of assumptions about family competency to manage at home. Facilitators included supported clinician and family carer engagement, and maintaining independence for activities of daily living.

**Relevance to clinical practice:** Reflective analysis of discharge decisions, focused on risk and possible risk aversion, can assist teams to evaluate the quality of their discharge decisions. The use of formal communication strategies such as a patient/family-held journal of the hospital experience and a structured family meeting early in the hospital admission can enhance family engagement in discharge planning. Prevention of functional and cognitive decline is emerging as critical to improving hospital discharge outcomes.

**KEYWORDS**

acute care, dementia, discharge planning, family carers, transitions in care

## 1 | INTRODUCTION PURPOSE TO THE REVIEW

There are significant patient safety and quality challenges in relation to the transfer of care between inpatient and community settings (Snow et al., 2009). Discharge planning is defined as, “the process of identifying and preparing for a patient’s anticipated healthcare needs on discharge from an inpatient facility” (Maramba, Richards, Myers, & Larrabee, 2004, p. 123). The aim of discharge planning is to reduce hospital length of stay and unplanned hospital readmission by providing the patient with condition-specific information and, if required, organising postdischarge support (Gonçalves-Bradley, Lannin, Clemson, Cameron, & Shepperd, 2016). Ideally, discharge planning involves consultation between healthcare professionals and the patient and/or their family regarding their social circumstances and home environment, and the provision of support and education to meet postdischarge care needs (Coleman & Boulton, 2003; Mabire, Coffey, & Weiss, 2015; Moyle, Bramble, Bauer, Smyth, & Beattie, 2016). When the discharge planning process commences early in the hospital admission and is conducted in partnership with the patient and their family it supports a seamless transition from hospital to community settings that can be maintained (Ohta, Mola, Rosenfeld, & Ford, 2016).

Hospital discharge can be particularly challenging for older people with dementia. Older people with dementia have twice the length of hospital stay compared to those without dementia, and higher rates of emergency representation (Draper, Karmel, Gibson, Peut, & Anderson, 2011). They are more likely to experience a decline in functional ability during hospitalisation (Hoogerduijn, Grobbee, & Schuurmans, 2014), which can result in them being unable to return home (Grealish et al., 2013; Handley, Bunn, & Goodman, 2015). Older people with dementia frequently have complex healthcare and social care needs and require additional support and resources to facilitate their discharge (Department of Health UK, 2003). They are at high risk of adverse events when moving from hospital to home, including difficulty with medication management and delays or lack of community support or follow-up medical care (Masters & Brown, 2016).

In an earlier investigation into discharge planning for older people from a geriatric rehabilitation service, Bull and Roberts (2001) found that specific characteristics for discharge, included the need for a multidisciplinary team and for communication between the multidisciplinary team and the patient and family caregiver(s). However, engaging older people with dementia in discharge planning is difficult due to the impact of declining cognition on communication and/or understanding (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). Relatives or friends (family carers) are well positioned to provide valuable knowledge about the health and functional ability of the person with dementia (Emmett, Poole, Bond, & Hughes, 2014; Jurgens, Clissett, Gladman, & Harwood, 2012; Mortenson & Bishop, 2016). Where cognitive impairment is high and/or fluctuating, family

### What does this paper contribute to the wider clinical community?

- There is a need for a more balanced hospital discharge discourse that includes both patient and family outcomes as well as efficient resource utilisation;
- Formal communication strategies that focus on engagement with families in real time and through a journal may improve the quality of discharge; and
- Strategies to actively prevent functional and cognitive decline in hospital are required to improve discharge outcomes.

carers take on the crucial role of authorised advocate or substitute decision maker (Poole et al., 2014).

Systematic literature reviews of hospital discharge planning for older people (Popejoy, Moylan, & Galambos, 2009) and for older people with dementia (Chenoweth, Kable, & Pond, 2015) describe patient and family involvement in discharge planning as rare. For people with dementia, the significant role that family carers should play in healthcare and social care decision-making has been reinforced through national clinical guidelines in the United Kingdom (National Institute for Health and Care Excellence, 2006), the United States of America (American Psychiatric Association, 2007), Asia (Ministry of Health Singapore, 2013) and Australia (National Health and Medical Research Council, 2016). While Bull and Roberts (2001) attribute reduced patient and family involvement to the paternalistic attitudes of health professionals, the reason for reduced family involvement is not well described in recent reviews and specific strategies to support such engagement have not been explored.

To assist in the development of bespoke discharge processes that address the unique needs of older people with dementia, an integrated review of the literature was undertaken.

## 2 | DESIGN AND METHODS

A four-stage integrative review framework developed by Whittemore and Knafl (2005) guided the review.

### 3.1 | Problem identification

While there is evidence of the value of engaging older people with dementia and their family carers in the process of discharge planning, there are no specific strategies to support such engagement. The aim of the review was to identify barriers and facilitators to engagement of older people with dementia and family carers in planning for discharge from hospital. The objective is to recommend strategies, tools and resources that support family inclusion in discharge planning.

## 2.2 | Selection

Three search strategies were employed. First, a computerised database search of MEDLINE (MeSH), PubMed, AustHealth, Cochrane, Cumulative Index to Nursing and Allied Health (CINAHL), Psycinfo, SocIndex and the Health Policy Reference Center was undertaken. Second, a hand search of reference lists of retrieved articles to find relevant literature was conducted. Third, Scopus was used to forward search for citations of retrieved articles, which met the inclusion criteria, to identify subsequent publications.

The search was limited to empirical, full-text studies, published in English from 2006–2015. The search period acknowledges international policy directives on the quality and safety benefits of integrated care (in improving transitions between hospital and community care services for older people, including those with dementia [National Institute for Health and Care Excellence, 2006; National Health and Hospitals Reform Commission, 2010; National Institute for Health and Care Excellence, 2015]).

Inclusion and exclusion criteria were based on the concepts studied, target population, healthcare problem and sampling frame (Whittemore & Knafl, 2005). To be included, studies had to meet the following criteria. First, the included concepts were derived from the research aim. The included concepts are found in Table 1. Second, the studies had to focus on older people with cognitive impairment and family carers. Third, we aimed to capture discharge planning processes and practices. Finally, the studies had to be conducted in acute or subacute hospital settings. Studies were excluded if they described a quality improvement project/activity without a research methodology or if they were published in the grey literature (except for academic doctoral theses retrieved through electronic databases or hand searching).

A reference management system, EndNote X7 (Clarivate Analytics, 2016), was used to track the search results, eliminate duplicate publications and share the library between the team. Once duplicate publications were removed, members of the research team (AA, KL, ON, YS) independently reviewed the titles and abstracts against the inclusion and exclusion criteria. Figure 1 describes the process of study identification and screening, with 15 articles identified for this review.

## 2.3 | Data extraction and evaluation

Paired members of the research team (AA, LB, SH, KL, ON, YS, E S-M-J) reviewed eligible full-text papers. The methodological quality of each paper was assessed using the Mixed-Methods Assessment Tool (MMAT) (Pace et al., 2012). The MMAT is recognised as a reliable and efficient tool with which to appraise qualitative, quantitative and mixed-methods studies (Pace et al., 2012). Data from the studies were extracted into a data template, according to study design and objective(s), intervention(s) under study, methodological approach, main findings and quality assessment. Reviewers consulted throughout the review period to discuss discrepancies as well as the overall strengths and limitations of the studies. Discrepancies were

**TABLE 1** Search concepts and keywords

Concept	Controlled and natural keywords
Cognitive impairment	"Dementia (exp)", "Delirium" AND "Alzheimer's disease," "dement*" AND "delirium"
Consumer participation	"patient engagement," "patient* AND engag*," "carer AND engag*," "consumer* AND engage*," "patient* AND consult*," "consumer* AND consult*," "carer* AND consult*," "Aged+"
Discharge	"Patient discharge (exp)," "discharge plan*," "Hospital discharge (exp)" were paired with "patient* AND discharg*," and "patient AND plan*"
Discharge care	"community care plan*," hospital* AND care AND plan*, patient AND plan*
Barriers/ Facilitators	Barrier*/obstacle*/difficult*/Enabl*/facilitat*, Tool*, Resource*, Strateg*/method*/approach*/process*/technique*
<b>Databases</b>	
<ul style="list-style-type: none"> <li>• MEDLINE (Ovid)</li> <li>• PubMed</li> <li>• AustHealth</li> <li>• CINAHL (Cumulative Index to Nursing and Allied Health)</li> </ul>	<ul style="list-style-type: none"> <li>• Cochrane Library</li> <li>• Psycinfo</li> <li>• SocIndex</li> <li>• Health Policy Reference Center</li> </ul>
<b>Limits</b>	
2006–2015; English	

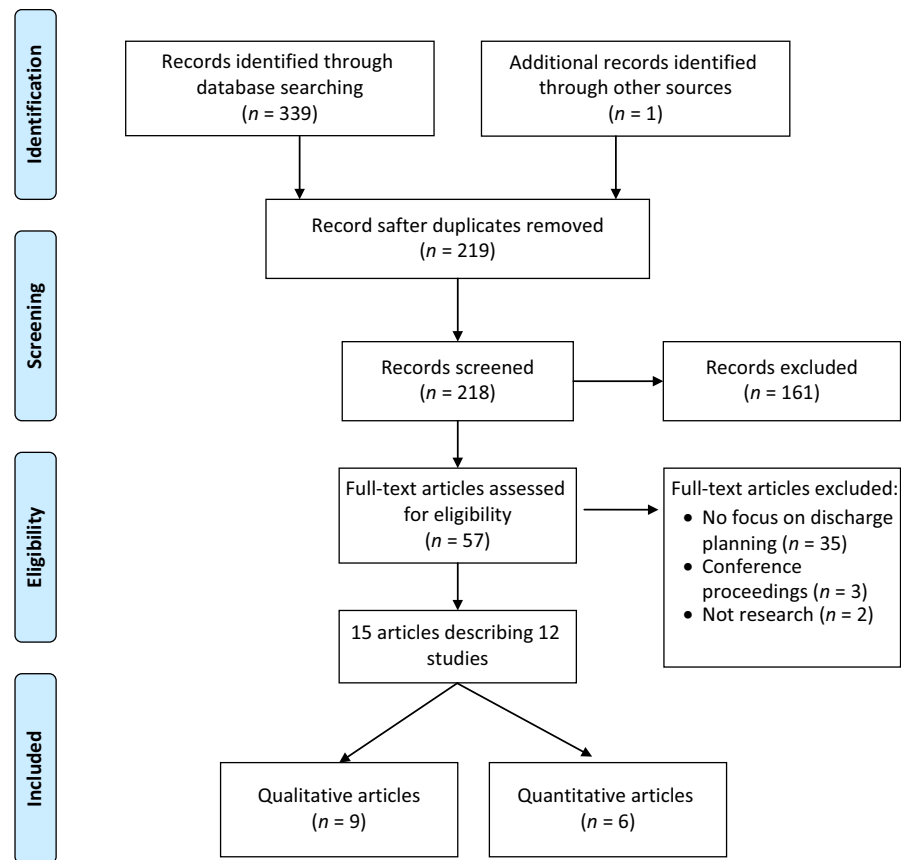
overcome through consensus within the reviewer pairs or a third reviewer (GSS) adjudicated the matter.

## 2.4 | Data analysis

Two research team members (GSS, LG) conducted a content and thematic analysis of the papers selected for analysis. The focus was on summarising the qualitative and quantitative evidence from the selected publications. The review synthesis commenced with an aggregation of findings from the literature, during which key concepts were defined and formed the categories under which data extracted from the studies were summarised (Munn, Tufanaru, & Aromataris, 2014). Data from the articles were ordered, categorised and summarised into a unified and integrated conclusion. Conclusion drawing and verification completed the data analysis.

## 3 | RESULTS

There were 15 articles describing 11 studies included in this review. The review included three articles from one study conducted in Australia (Bauer, Fitzgerald, & Koch, 2011; Bauer, Fitzgerald, Koch, & King, 2011; Fitzgerald, Bauer, Koch, & King, 2011) and three articles



**FIGURE 1** Publication flow chart

from one study conducted in the UK (Emmett, Poole, Bond, & Hughes, 2013; Emmett et al., 2014; Poole et al., 2014). These studies were included because they reported on distinct aspects of multi-site studies (see Table 2).

The quality of the research evidence was high, with 13 of the 15 papers meeting the highest four-star rating on the MMAT and the remaining rated three-star. Four of the 11 studies were conducted in the UK, three in Australia, three in Europe and one in Canada. Most studies were conducted in acute hospital settings, drawing their participants from more than one site. One study was conducted in a dementia-specific long-term care facility (Mortenson & Bishop, 2016).

Six studies used quantitative designs. One was retrospective (Astell, Clark, & Hartley, 2008), three were cross-sectional (Lindhardt, Nyberg, & Hallberg, 2008; Mabire, Büla, Morin, & Goulet, 2015; Mabire, Coffey et al., 2015; Mortenson & Bishop, 2016), one was prospective observational (Rozzini et al., 2006), and one was mixed methods, combining cross-sectional and time series designs (Luxford et al., 2015). The five studies using qualitative methodology demonstrated research rigour through their descriptions of comprehensive development and application of data collection methods (interviews, focus group discussions and observations) and interpretation of results. Only one qualitative article addressed data saturation in sample size (Bauer, Fitzgerald, Koch, King, 2011). Sample sizes varied considerably, from 16 case studies (Emmett et al., 2014)–798 health professionals in a survey (Luxford et al., 2015). The samples were appropriately dependent on the research methodology and the

number of research sites, with qualitative studies typically having smaller sample sizes.

The studies predominantly focused on discharge in relation to frail older people (65 years and older), including those identified as having dementia or lacking decision-making capacity. Information on the older people was often obtained from secondary sources; hospital-acquired data, family carers or health professionals (predominantly nurses, doctors and to a lesser extent allied health; physiotherapists, occupational therapists, social workers). Only one study involved an intervention (Luxford et al., 2015), and this was not specifically related to the discharge process.

The analysis identified four themes strongly associated with barriers to collaborative discharge planning: (i) distributed responsibility for discharge limits clarity of process or intended outcomes; (ii) risk-focused decisions, where discharge decisions aimed to manage risk with limited assessment of family and community support; (iii) limited family participation, influenced by their lack of knowledge and confidence; and (iv) family competency and interests, in which staff assumptions are seldom validated through consultation (Figure 2). The two final themes related to the facilitation of discharge: (v) engagement and communication and (vi) maintaining/improving functional capacity.

### 3.1 | Barriers

*Responsibility for discharge was distributed* among many different health professionals, with limited individual accountability. While it

**TABLE 2** Included studies

Study (country)	Research aim	Setting/Design	Participants	Sample size	Key findings in relation to the present review	Quality appraisal <sup>a</sup>
Astell et al. (2008) (UK)	To examine the factors that predicted discharge destinations of patients ( $\geq 65$ years) admitted to a combined geriatric medicine/old age psychiatry unit	Geriatric medicine-psychiatry unit/Case-control study	Patients	234	Independence for activities of daily living (ADL) in combination with the number of active medical problems was the key predictor of discharge destination (home, nursing home or died in hospital). Patients discharged home were characterised by relative independence for ADL and few active medical problems. Behavioural problems and dementia severity were not predictive of discharge destination. The findings suggest that although the key precipitants of admission to specialist geriatric units are behavioural and psychiatric they can be successfully treated in an appropriate environment and therefore did not play a major role in determining discharge outcome	4
<sup>b</sup> Bauer, Fitzgerald, Koch (2011) (Australia)	To explore family carers perceptions of hospital discharge planning and preparation for a person with dementia	Three hospitals/Qualitative constructivist (interview)	FC	25	There was limited engagement of family by health professionals in planning both hospital care and postdischarge care. The family carers' expectations of communication by nurses and other health professionals about both the care received in hospital and the care needed after discharge frequently fell short of what they considered necessary to meet their caregiver role	4
<sup>b</sup> Bauer, Fitzgerald, Koch, King (2011) (Australia)	To explore whether hospital discharge practices meet the needs of the family carer of a person with dementia	Three hospitals/Qualitative constructivist (interview)	FC	25	Common issues about discharge planning and execution raised by family carers include the lack of involvement in the process, the difficulty obtaining information, and inadequate communication about in-hospital and postdischarge medical treatment and care	4
Bloomer et al. (2014) (Australia)	Explore the experience of carers of people with dementia through hospitalisation, rehabilitation and transitioning into residential care	60 bed geriatric rehabilitation facility/Qualitative descriptive (interview)	FC	20	The carers found admission of the person with dementia to hospital a highly emotive and challenging experience in relation to (a) feeling helpless and lost; (b) losing control; (c) family support and conflict; (d) feeling undervalued. They also suggested opportunities for improvement. The study highlighted that the emotional health of carers is generally not well supported by the health service. The inpatient care process must consider the dyad of carer and patient, as they are often tightly entwined	3

(Continues)

TABLE 2 (Continued)

Study (country)	Research aim	Setting/Design	Participants	Sample size	Key findings in relation to the present review	Quality appraisal <sup>a</sup>
Connolly et al. (2009) (UK)	To understand the perspective of hospital-based health professionals with regard to preparing patients for discharge	Adult wards in one university-affiliated hospital/Qualitative thematic (focus group)	HCP	32	A number of issues were found to have an impact on discharge planning especially when treating patients with complicated psychosocial needs. Verbal and written communication between professionals and with patients/relatives was compromised at times because of the pressures associated with discharge. An emphasis on a swift discharge was felt to overlook people's unique circumstances and prevented the establishment of an individual discharge path	4
<sup>c</sup> Emmett et al. (2013) (UK)	To comment on how assessments of residence capacity are actually performed on general hospital wards compared with legal standards for the assessment of capacity set out in the UK Mental Capacity Act, 2005 (MCA)	Three care of the elderly wards in two hospitals/Constructionist comparative case studies (ethnographic)	Cases	29	The findings suggest that while health professionals profess to be familiar with broad legal standards governing the assessment of capacity, they do not routinely apply the standards when assessing capacity to decide place of residence on discharge from hospital	4
<sup>c</sup> Emmett et al. (2014) (UK)	Explore the informal role of relatives and the extent to which they fulfil a effective safeguard role when decisions are made to discharge PWD from hospital	Three care of the elderly wards in two hospitals/Constructionist comparative case studies (ethnographic)	Cases	16	Relatives struggled to safeguard the rights of incapacitated patients with dementia and were often ill-equipped or unsuitable to make best-interests decisions about their living arrangements. Decisions about hospital discharge and living arrangements are also linked with diminishing community services and finite hospital resources	3
<sup>b</sup> Fitzgerald et al. (2011) (Australia)	To explore family carers perceptions of hospital discharge planning and preparation for a person with dementia	Three hospitals/Qualitative constructivist	FC	25	It is recommended that health professionals be educated on the needs of family carers as it relates to communication and consultation. The primary carer is involved in discussions and decisions about in-hospital and posthospital treatment regimens and is in agreement with, and competent in, postdischarge treatments, therapies and support services	4

(Continues)

**TABLE 2** (Continued)

Study (country)	Research aim	Setting/Design	Participants	Sample size	Key findings in relation to the present review	Quality appraisal <sup>a</sup>
Jurgens et al. (2012) (UK)	To study the views of carers who expressed dissatisfaction with hospital care.	12 general or geriatric medical or trauma orthopaedic wards of one hospital/Grounded theory	FC	35	The family caregivers' experience of hospital care was variable but often negative, and their expectations were influenced by prior experiences. A cycle of discontent is proposed. Events (or "crises") are associated with expectations. When these are unmet, carers become uncertain or suspicious, which leads to a period of "hyper vigilant monitoring" during which carers seek out evidence of poor care, culminating in challenge, conflict with staff, or withdrawal, itself a crisis. Considering the person with dementia and their family carer together as a unit and respecting their perspective may reduce dissatisfaction or conflict	4
Lindhardt et al. (2008) (Denmark)	To investigate collaboration between relatives and nurses among those relatives reporting high vs low satisfaction with the hospital care trajectory	Three medical and one geriatric ward/ Cross-sectional design	FC	156	The overall satisfaction with the hospital care trajectory was high although lower at discharge than at admission. Relatives who are more involved in collaboration with nurses are seemingly more satisfied with the hospital care trajectory than those who are not. Low satisfaction was significantly related to low level of collaboration. Other predictors for low satisfaction were as follows: feelings of guilt and powerlessness, having provided help for less than a year and not providing psychosocial help	3
Luxford et al. (2015) (Australia)	To examine the impact of implementing a clinician-carer communication tool for hospitalised patients with dementia	17 public and five private hospitals/ Cross-sectional survey and time series analysis	HCP FC Local liaison staff	798 240 21	TOP 5 is a simple and useful communication tool to assist clinicians in engaging with carers and formalising personalised care delivery. Following the introduction of TOP 5, clinicians rated their confidence in caring for patients with dementia significantly higher than prior to its introduction. The findings indicate that the use of TOP 5 is associated with improvements in carer and clinician experience, with early indications of potential benefits for patient safety and potential cost savings to health services	4

(Continues)

TABLE 2 (Continued)

Study (country)	Research aim	Setting/Design	Participants	Sample size	Key findings in relation to the present review	Quality appraisal <sup>a</sup>
Mabire, Büla et al. (2015), Mabire, Coffey et al. (2015) (Switzerland)	Investigating the association between nursing discharge planning components in older medical inpatients, patients' readiness for hospital discharge and unplanned healthcare utilisation during the following 30 days	Medical units of four hospitals/Cross-sectional	Patients 65+ years	235	Information, assessments, interventions, and outcomes are essential to the implementation and monitoring of comprehensive discharge planning. The results indicated that no patients benefited from comprehensive discharge planning but most benefited from some of the discharge planning components. These findings suggest that discharge planning is not yet an established and mature process in current clinical practice. Successful hospital discharge of frail older patients should be part of a multidisciplinary and coordinated process involving all health professionals	4
Mortenson and Bishop (2016) (Canada)	To describe current admission criteria, discharge criteria and services to support discharge	30 specialised dementia care units (DCU)/Cross-sectional	Unit Managers	45	Most DCU did not have discharge criteria as the facility supported ageing-in-place. One discharge criteria recommended by participants, a resident's inability to function in a regular long-term care environment and a lack of socially appropriate behaviours. DCUs were established to meet the specialised needs of this population, so this study raises concerns about their ability to handle challenging behaviours. Respondents believed that the discharge process could be improved with better communication and higher staffing levels to address resident needs during relocation	4
Poole et al. (2014) (UK)	To understand how residence capacity and consequent best interests for people with dementia are decided in acute and rehabilitation hospital settings	Three care of the elderly wards in two hospitals/ Constructionist comparative case studies (ethnographic)	Cases	29	The study highlights the complexity of judgements about capacity and best interests in relation to decisions about place of residence for people with dementia facing discharge from hospital. Recommendations include better support and training for practitioners, as well as support for patients and families; clarity about the information to be imparted to the person with dementia; more advocacy for people with dementia; appropriate assessments embedded in routine clinical practice; the patient with dementia to be centre stage; and properly resourced step-down or rehabilitation units to facilitate timely and good decision-making about place of residence	4

(Continues)

TABLE 2 (Continued)

Study (country)	Research aim	Setting/Design	Participants	Sample size	Key findings in relation to the present review	Quality appraisal <sup>a</sup>
Rozzini et al. (2006) (Italy)	To identify patient's and caregiver's characteristics that influence discharge destination	Rehabilitation Unit for Dementia/ Prospective observational	PWD	214	Living alone, patient functional impairment, severity of dementia and caregiver burden were independent predictors of institutionalisation. The interaction between a patient's and a caregiver's characteristics had an important effect on the rate of nursing home placement in patients with dementia	4

FC, family carer; PWD, person with dementia; HCP, healthcare professional.

<sup>a</sup>MMAT: low = 1; high = 4.

<sup>b</sup>One Australian study.

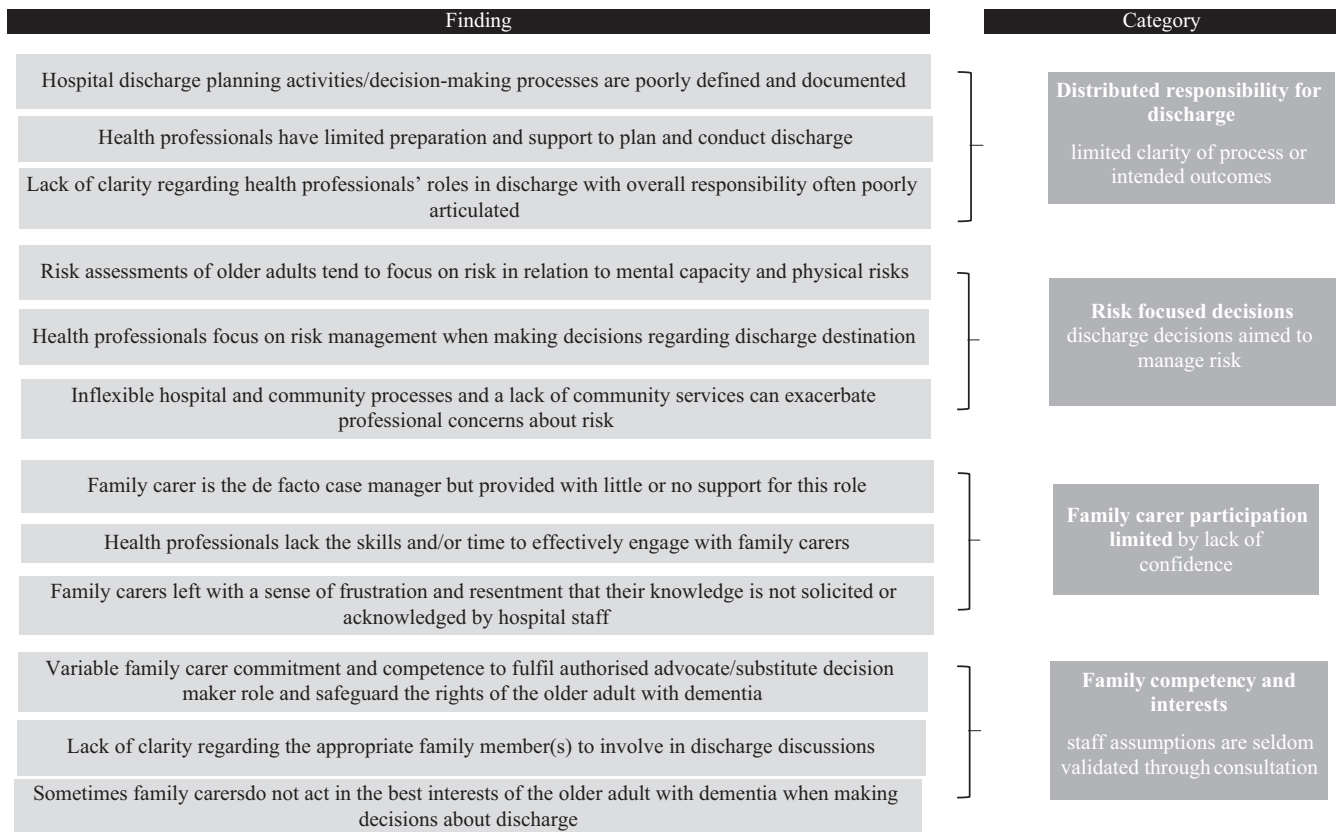
<sup>c</sup>One UK study.

was generally agreed that all staff were responsible for discharge, there was a lack of clarity regarding individual's roles, or accountabilities, resulting in poorly defined and documented discharge processes (Mabire, Büla et al., 2015; Mabire, Coffey et al., 2015; Poole et al., 2014). Several studies confirmed that individual accountability was hindered by poor preparation and support to conduct discharge planning (Bauer, Fitzgerald, Koch, King, 2011; Emmett et al., 2014; Mabire, Monod, Dwyer, & Pellet, 2013). The lack of accountability for specific processes for discharge appears to be related to limited formal training, with acute care health professionals describing discharge preparation as something that is learnt "on the job" (Connolly et al., 2009).

A focus on risk influenced discharge processes and decisions for older people with dementia, with health professionals generally exhibiting a risk averse tendency (Bloomer, Digby, Tan, Crawford, & Williams, 2014; Emmett et al., 2013; Poole et al., 2014). Risk assessments of older people commonly focus on risk in relation to mental capacity and physical risks, and related to concerns regarding professional or organisational liability if things go wrong postdischarge (Astell et al., 2008; Rozzini et al., 2006). In some cases, health professionals privileged their duty of care over supporting or enabling greater choice and control in regard to preferred discharge destination (Emmett et al., 2013). Functional and cognitive capacity influenced decisions for placement in a long-term care facility, regardless of the older people or their family carers' preferences (Astell et al., 2008; Emmett et al., 2013). Consequently, older patients with low cognitive and functional levels and high levels of behavioural and psychological symptoms of dementia (BPSD) are consistently discharged to long-term care (Astell et al., 2008; Han et al., 2011; Rozzini et al., 2006).

Inflexible hospital and community processes and a lack of community support can exacerbate professional concerns about risk in regard to discharge destination (Mabire, Büla et al., 2015; Mabire, Coffey et al., 2015). The current organisational imperative to reduce hospital length of stay can mean that decisions about older patients' capacity to return home are made when they are still unwell and/or vulnerable (Connolly et al., 2009). As a result, clinicians are balancing the risks of early discharge with inadequate community support against the organisational imperative to reduce hospital length of stay.

*Family carer participation was often limited by lack of confidence.* Most family carers want to be acknowledged as a resource to benefit care delivery, but were intimidated by the decision-making process and the "expert" knowledge exhibited by health professionals (Bloomer et al., 2014; Emmett et al., 2014; Lindhardt et al., 2008; Mockford, 2015). Three studies highlighted that health professionals lack the skills and/or time to effectively engage with family carers of older people with dementia and therefore families' knowledge of the person's health and social circumstances was not used (Emmett et al., 2014; Jurgens et al., 2012; Mortenson & Bishop, 2016). Consequently, family carers were often left with a sense of frustration and resentment that their knowledge was not solicited or acknowledged by hospital staff (Fitzgerald et al., 2011; Lindhardt et al.,



**FIGURE 2** Meta-aggregation—discharge planning barriers

2008; Luxford et al., 2015). Family carers in several studies reported feeling excluded from key discharge decisions to the extent they were unaware that discharge was imminent until (or in some cases after) it occurred (Bauer, Fitzgerald, Koch, King, 2011; Emmett et al., 2014; Jurgens et al., 2012; Poole et al., 2014). In some instances, family carers find they have agreed to their relative being discharged to permanent long-term care, referred to euphemistically as “a bit more care” during postdischarge case management meetings, but lack the confidence to challenge professional views to resolve the issue otherwise (Emmett et al., 2013, 2014).

The final barrier was the lack of validation of assumptions about *family carer competency and interests*. Where cognitive impairment is high and/or fluctuating, it is not uncommon to require the assistance of an authorised advocate or substitute decision maker (Poole et al., 2014). This role is generally filled by a family member, who it is presumed will have the best interests of the person with dementia in mind and will therefore safeguard their rights (Emmett et al., 2014). However, some doubt exists regarding the extent to which family carers are equipped to fulfil this critical safeguarding role and contribute objectively to discharge decisions that are in the best interests of the cognitively impaired adult (Emmett et al., 2014). Conflicts of interest can arise if the older patient's family and close friends hold divergent views to hospital staff (or each other), and if they wish to assert their own personal agendas (Bloomer et al., 2014; Poole et al., 2014).

### 3.2 | Facilitators

Although not directly focused on improving discharge outcomes, one single intervention study (Luxford et al., 2015) provided evidence of a simple intervention to *support clinician and family carer engagement*. In this Australian study, the intervention “TOP 5,” a clinician–carer communication tool for patients with dementia, was developed and trialled (Luxford et al., 2015). Clinical staff used the tool to engage with family carers and identify up to five important nonclinical communications “tips” and management strategies that were recorded and kept at the patient's bedside for easy reference. The essential elements of “TOP 5” are frequency and quality of communication, clinician accessibility and relationship qualities such as trust, respect and understanding (Luxford et al., 2015). Following the introduction of TOP 5, the majority of clinicians reported being more satisfied with their work in caring for patients with dementia, and carers appreciated the opportunity to share information (Luxford et al., 2015). A Swedish study also found family carers who were included as collaborators in care and discharge planning expressed greater satisfaction with care (Lindhardt et al., 2008).

An Australian study, with family carers of people with dementia recently discharged from hospital, recommended the early identification of a principal family carer as the person to be involved in the discharge process and their incorporation as an equal partner in discharge planning activities (Bauer, Fitzgerald, Koch, King, 2011). This

recommendation is supported by Mabire, Büla et al. (2015), Mabire, Coffey et al. (2015) and Jurgens et al. (2012), who both emphasise that the patient and their family carer must be at the centre of discharge decision-making to improve outcomes for patients with dementia. Further, when carers are committed to a shared vision, collaborative discharge to home can be promoted (Emmett et al., 2014).

Although not explored in many of the studies, *functional capacity*, and specifically independence for activities of daily living, was found to be a predictor for discharge destination in a study of 234 patients in one geriatric acute care unit (Astell et al., 2008). A cross-sectional analysis of 214 patients with dementia in northern Italy found that higher functional capacity through a period of rehabilitation resulted in more admissions to home, rather than a nursing home (Rozzini et al., 2006).

## 4 | DISCUSSION

The purpose of this review was to describe the barriers and facilitators to discharge planning for older people with dementia and their families. While we found more barriers than facilitators, there is emerging evidence that specific practices that focus on engagement with the family (Luxford et al., 2015) and prevention of functional decline have the potential to promote discharge home (Rozzini et al., 2006).

Consistent with earlier reviews (Chenoweth et al., 2015; Popejoy et al., 2009), our review found that a multidisciplinary team was responsible for discharge planning. However, we found that poor discharge planning was associated with limited individual clinician accountability. For example, Connolly et al. (2009) found that individual staff accountability was not clearly proscribed, with many staff learning about discharge planning "on the job." "On the job" learning or "knowing in practice" is a complex social and cultural process that requires clear communication between clinicians (Gherardi, 2012). While not arising in our review, Chenoweth et al. (2015) concluded that communication between clinicians during discharge planning is often not effective. Ineffective communication would limit "on the job" or learning through practice. To clarify individual accountability for discharge, improved understanding of how discharge planning is learnt and continually improved in practice is required.

Limited community-based resources continue to be a challenge for discharge planning for older people generally (Popejoy et al., 2009) and people with dementia specifically (Grealish et al., 2013). In this review, the lack of community-based resources underpinned a risk averse approach to discharge planning, with clinicians seeking to avoid professional or organisational liability for postdischarge harm (Astell et al., 2008; Rozzini et al., 2006) while also trying to support patient and family choice and control (Emmett et al., 2013). Some Australian researchers have argued for increased involvement of families of people with dementia in discharge planning (Bauer, Fitzgerald, Koch, King, 2011). One of the facilitators to family involvement found in our review was the use of the TOP 5 approach

(Luxford et al., 2015). Strategies such as TOP 5 and others that increase engagement between families and staff require further investigation in relation to the quality of discharge outcomes.

In our review, staff assumptions about family competency to manage at home were often not informed by families' health and socio-economic knowledge. The lack of consultation with families in discharge planning is consistent with earlier reviews (Chenoweth et al., 2015; Popejoy et al., 2009). Bull and Roberts (2001) attributed lack of consultation to the paternalistic attitudes of health professionals. In our review, lack of consultation with families appeared to be related to lack of skills or the time to effectively engage (Emmett et al., 2014; Jurgens et al., 2012; Mortenson & Bishop, 2016). It is possible that lack of consultation may be attributed to clinicians' avoidance of situations of potential conflict with families. Several studies identified conflict of interest between older person's family and close friends and hospital staff as an emerging challenge in discharge planning (Bloomer et al., 2014; Emmett et al., 2014; Poole et al., 2014). Given the success of the TOP 5 engagement strategy, there is a clear need for structured communication strategies that can enhance family engagement, and therefore include the important health and socio-economic knowledge of families in the discharge process.

Our review found that family carers had limited confidence in their ability to manage the older person with dementia at home posthospital discharge. This may be in relation to studies suggesting that family carers are intimidated by the expert knowledge of health professionals (Bloomer et al., 2014; Emmett et al., 2014; Lindhardt et al., 2008). However, while clinicians may have expert knowledge, this is not readily translated to meaningful information to prepare the person for discharge.

In their review of discharge for older people, Popejoy et al. (2009) suggested that a lack of cooperation of patient and family impeded the development of discharge plans. While the family can assist with discharge processes, the timing of family visits with medical or allied health rounds is often ad hoc and limits opportunities for information sharing. There are two strategies that may improve the translation of expert clinical knowledge to families. First, a formal family meeting could be conducted between clinicians and patients and family carers early in the hospitalisation. This meeting would have a clear agenda, focused on the current problem, establishing possible barriers to discharge home, and strategies to address those barriers as soon as possible. Second, a family-held journal of the hospital experience could be encouraged. A family-held journal of decisions can be shared with hospital staff and may open new lines of communication and add clarity to the planning process. These formal communication strategies would build on the TOP 5 and promote inclusion of the patient and family in the discharge process prescribed by national guidelines (American Psychiatric Association, 2007; Ministry of Health Singapore, 2013; National Health and Medical Research Council, 2016; National Institute for Health Care Excellence, 2006).

Finally, maintaining functional capacity of the older person with dementia has emerged as a critical element in quality discharge. It is

widely recognised that a decline in functional capacity is common during hospitalisation (Grealish et al., 2013; Handley et al., 2015; Hoogerduijn et al., 2014). There is emerging evidence that functional, as well as cognitive, decline of older patients in hospital may be reduced through fundamental nursing care (Bail & Grealish, 2016). Further attention to aspects of health care, such as an increased focus on fundamental nursing care that can prevent functional and cognitive decline may improve the quality of discharge outcomes.

## 5 | CONCLUSIONS

Discharge is a complex and multidimensional process, and preparation should start from admission and extend into the home postdischarge to enable the person and family carers to effectively manage the demands of care at home after an acute episode. For older people with dementia, the discharge journey is fraught with barriers, limiting opportunities to return home. Efforts to overcome known barriers, specifically efforts to enhance engagement with families, are critical to improved discharge planning.

## 6 | RELEVANCE FOR CLINICAL PRACTICE

For clinicians, awareness of the challenges confronted by patients with dementia, and their families, is essential. The transition home from hospital is an important first step in quality improvement. Assessing current systems for the potential barriers identified in the literature may promote stronger and more satisfying discharge processes. Possible considerations include the following: (i) critical analysis of current discharge approaches to determine whether the person's autonomy is limited by organisational concerns about safety and risk, (ii) encourage use of a patient and family journal to enhance in-hospital communication and planning for discharge and (iii) implement a regular family meeting or assessment whereby assumptions about family competency to manage at home are validated. Finally, a focus on strategies to prevent functional and cognitive decline in older hospitalised people with dementia appears to have significant potential to improve discharge outcomes.

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## CONTRIBUTIONS

Research protocol design: LG, GSS, AA, LB, SH, KL, ON, YS and E S-M-J; data collection and evaluation: GSS, AA, LB, SH, KL, ON, YS

and E S-M-J; critical review of draft papers: WM and AM, and analysis and drafting of the final manuscript: all authors.

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