Empowering Informal Carers of People with Dementia During Hospitalisation Events – a meta ethnographic literature review

Subject: Project in Ageing

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Task 3 – Research Report

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Affirmation

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Abstract

Hospitalisation is an area of concern for people with dementia and the informal carers who support them because there are increased risks for poorer outcomes for the patient during the process. While person centred care is considered best practice for people with dementia in an acute environment, a lack of consistent implementation can lead to high levels of carer dissatisfaction. This review examines relevant literature to identify gaps in current research relating to informal carers and hospitalisation events, to examine where informal carers are disempowered during this process, and identify ways in which they can mitigate that disempowerment.

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INTRODUCTION

1.1 Background

Dementia is a progressive, degenerative, and ultimately terminal illness, which predominantly affects individuals aged above 65 years, and is usually accompanied by comorbidities, making it challenging to manage (Alzheimer's Australia, 2018; World Health Organization, 2018). Due to these accompanying comorbidities, such as diabetes, hypertension, or frailty, people with dementia more commonly experience issues which often result in periods of hospitalisation (Kipfer & Pihet, 2019; Konno, Inoue, Schultz, & Wiechula, 2019; Ragg, Ragg, Milnes, Bailey, & Orford, 2019). Dementia has been recognised as both a global area of concern by the World Health Organisation and a domestic concern for Australia, where there are approximately half a million people currently living with dementia, with this number predicted to double by 2050 (Patterson, 2018; Downs, & Lord, 2019).

1.2 Hospitalisation as an area of concern

Hospitalisation is a significant area of concern for people with dementia (Barber, 2015; Kable, Chenoweth, Pond, & Hullick, 2015; Petry, Ernst, Steinbruchel-Boesch, Altherr, & Naef, 2019; Richardson, Blenkinsopp, Downs, & Lord, 2019). Once admitted to an acute care environment, patients with dementia have poorer outcomes than their peers without cognitive impairment. (Alzheimer's Australia, 2016; Flanagan & Fick 2010; World Health Organisation, 2019). The built environment of the hospital contributes to this as it is often confusing, bright, and difficult to navigate. (Faulkner, 2001; Huang, Larente, & Morais, 2011; Robinson et al., 2018). A lack of staff training in supporting and managing patients with dementia is also a contributing factor. (Greenwood & Smith, 2019; Kelley, Godfrey, & Young, 2019; Ouchi et al., 2019). In addition to this, most people with dementia have significant comorbidities that become more difficult to manage and treat due to their cognitive impairment (Watkin, Blanchard, Tookman, & Sampson, 2012).

1.3 Informal Carers in Australia

Currently, the majority of people with dementia in Australia remain in the community, supported by informal carers, usually family members or friends (Dementia Australia, 2018). A study conducted in 2011 by the Australian Institute of Health and Welfare (AIHW) identified that caregivers are primarily spouses (44%) or adult children (42%) (Australian Institute of Health and Welfare, 2011). These informal carers often reduce the strain on an overburdened residential aged care sector by allowing the person they care for to remain in their own home environment far longer than otherwise possible. (Australian Institute of Health and Welfare, 2018; Brooks & Ross, 2015) “Most people with dementia rely on informal carers to supplement formal care; as often the hours available even at the highest level of home care package are simply not sufficient to support a person with dementia to stay at home.” (Brooks & Ross, 2015). This would suggest that supporting informal carers to continue to provide this type of care is vitally important in the current Australian health and aged care system. Informal dementia carers provide assistance in a variety of ways, from fundamental activities of daily living (ADLs), such as getting in and out of bed, eating meals, and personal care to the instrumental activities of daily living (IADLs) such as household chores, shopping, and preparing meals (Carers Australia, 2017). There are also less tangible or definable care requirements, such as managing changes in behaviour and psychological symptoms (Cooper, Selwood, & Livingston, 2008).

Unfortunately, caring for someone with dementia takes a significant toll on the physical and mental health of the carer (Carers Australia, 2012). Due to the nature of the often slow decline in function of the person with dementia, informal care relationships can be quite lengthy, impacting the carers health, as well as their social and financial wellbeing (Gainey & Payne, 2006). Depression rates in carers of people with dementia are estimated to be between 15 and 30 percent. (Dementia Australia, 2018) High levels of ongoing and relentless stress for carers are especially stark during transitions between care environments and during hospitalisation events (Brodaty & Donkin, 2009; Gainey & Payne, 2006).

1.4 The Role of Informal Carers during Hospitalisation

For informal carers of people with dementia, the hospital environment and systems can also be challenging (Ouchi et al., 2019; Palmer, 2018; Watkin et al., 2012). This is in part due to the necessary relinquishing of control to the hospital systems and staff, as well as the logistical complexities inherent in providing care in a different environment to their usual day to day care (Douglas-Dunbar & Gardiner, 2007; Fitzgerald, Bauer, Koch, & King, 2011; Jamieson, Grealish, Brown, & Draper, 2016). Carers often feel overwhelmed, ignored, uninformed, disconnected, and confused during a hospitalisation event (Haikio, Sagbakken, & Rugkasa, 2019; Jacobsohn et al., 2019). Many feel that the patient’s personhood is not respected during such events, and that staff fail to provide person centred care. (Allen Christensen, Lund, & Thuesen, 2019; Kogan, Wilber, & Mosqueda, 2016) All three components of hospitalisation, these being admittance, stay, and discharge, have been criticised by informal carers (Beardon, Patel, Davies, & Ward, 2018). A sense of disappointment prevails among informal carers. The decision to use the word empowered in the research question was therefore a deliberate one, as hospital environments are frequently the opposite (Faulkner, 2001; Ouchi et al., 2019; Watkin et al., 2012). They can be a confusing and challenging environmental space generally for patients and their families to navigate (Huang et al., 2011). There is also a level of disempowerment inherent in the human dynamic, with the positioning of patients and loved ones as subordinate, passively receiving care, information, and instructions from the doctors and nurses (Kable et al., 2015; Robertshaw & Cross, 2019). For many informal carers, who are the ‘expert’ on their particular person, and who make care decisions daily, this is a dual loss of both physical and emotional autonomy (Kelley et al., 2019). The choice to use the word empowered in the research question therefore reflects the inherent power imbalance in the hospital environment.

1.5 Context In Australia - Royal Commission into Aged Care Quality & Safety

At the time of authoring this report the Royal Commission into Aged Care Quality & Safety had delivered its Interim Report. While it does not specifically speak to hospitalisation events in respect to those with dementia, The Commission has identified that there are systemic problems in aged care, inter alia, for instance that ‘the system’ is currently designed around transactions, rather than the human relations and care (Royal Commission into Aged Care Quality & Safety, 2019). While the current Morrison Government has recently allocated a relatively small amount of additional funding to the aged care sector and has flagged dementia care training as one of the targeted areas, increased support for both systemic change and further research is still required.

1.6 What does this review add?

Given that hospitalisation is a critical event for people with dementia and a significant concern for informal carers who provide dementia care in the community, research examining the experience of informal carers during hospitalisation is a necessity. However, this area is little explored (Bradway & Hirschman, 2008; Douglas-Dunbar & Gardiner, 2007; Kelley et al., 2019; Timmons et al., 2016). This review brings together diverse studies sharing the experiences and observations of carers of people with dementia during hospitalisation. It attempts to distil these observations into broad conceptual areas of concern, to use the findings to determine whether there is a disempowering of carers during hospitalisation events, and, based on this, provide recommendations.

1.7 Dementia Language Guidelines

All terminology used in this review follows the Dementia Language Guidelines published by Dementia Australia to ensure that the terms used are respectful and inclusive. The publication endorses the preferred descriptor of a ‘person/people with dementia’ which has been used in this review.

1.8 Definitions

1.8.1 Dementia

For the purpose of this review the common definition of ‘Dementia’ is accepted as an umbrella term for a group of illnesses which cause progressive decline in a person’s functioning across a variety of areas. (Alzheimer’s Australia, 2017; Dementia Australia, 2019). There are many types of dementia including Alzheimer’s Disease, Vascular Dementia, Frontotemporal Dementia and Lewy Body Disease, and symptoms are generally chronic or progressive, affecting memory, intellect, rationality, social skills and physical functioning (Alzheimer’s Australia, 2017).

1.8.2 Informal Care

Informal care was defined as unpaid care provided in the context of a pre-existing social relationship (Australian Institute of Health and Welfare, 2015). Throughout this review, informal carers will be referred to by the terms informal carers, carers, and caregivers. Any reference to formal care providers will clearly make the distinction between the two.

1.8.3 Hospitalisation

Hospitalisation, for the purpose of this review, was defined as an episode of hospital care that starts with a formal admission process and ends with a clear mechanism of completion. An episode of care can be considered complete by the patient being discharged, transferred to another facility or type of care, or passing away.

1.9 Clarifying Note – Relationships in Informal Care

Prior to the discussion and analysis of these studies it must be made clear that an assumption has been made, for the purposes of this review, that the relationship between the carer/person with dementia is a healthy one unless specifically flagged otherwise in the source material. The issues, trauma, and dysfunction that can sometimes exist in this dynamic (Greenwood & Smith, 2019; Rippon et al., 2019; Vernon et al., 2019) are not the focus of this review, and were not the focus of any of the studies reviewed. However, it is important to acknowledge that not all care relationships are positive or productive, and that any statements made that imply the desirability of prioritising carers' involvement in the hospital environment should be interpreted with this corollary in mind. As always, professionals involved in the care of older people should be aware of the signs and indicators of Elder Abuse (Cooper et al., 2008; Gainey & Payne, 2006).

2

RESEARCH QUESTION

2.1 Objectives

The starting objectives of this review were threefold. Firstly, to identify gaps in the existing literature on supporting carers during hospitalisation of a person with dementia. Secondly, to identify ways in which these carers could be empowered to better support their person with dementia during this time. Thirdly, if possible, to provide recommendations for informal carers that could be implemented on an individual level.

2.2 Unpacking the Research Question

The research question was developed from a preliminary broad examination of information surrounding people with dementia (Alzheimer's Disease International, 2019; Dementia Australia, 2019) during which it emerged that outcomes for them were generally poorer in acute care environments (Ambrosi et al., 2017; Clissett, Porock, Harwood, & Gladman, 2013; Digby, Lee, & Williams, 2017; Kable et al., 2015). From this a series of questions emerged, which coalesced into the final form of the research question.

These questions were:-

1. What is the lived experience of people with dementia in hospital environments?
2. What role do informal carers play during these hospital admissions?
3. Do informal carers feel capable and supported in this role at those times?
4. How can informal carers best equip themselves to fulfil this role?

2.3 Review Overview

The 30 studies reviewed for this project showed broad conceptual consistency across four areas of Identity, Connection, Collaboration, and Communication. The studies chosen were selected by an iterative search process, in which synthesis was based on a meta ethnographic approach, with cautious consideration to exclusions. The studies were coded manually using a reciprocal translational analysis to identify the key themes or concepts in each study, which were subsequently narrowed down to four overarching themes. From this, the nature of each of these four themes was examined in detail and the identified information from each of these thematic coded areas in the papers were synthesised. Communication was identified as the most consistently raised issue, and the area in which informal carers could most effectively empower themselves when supporting a person with dementia.

3

METHODS

3.1 Refining the Question – PICO v SPIDER

The initial scoping search process for the formation of the review question began via a PICO (Population/problem, Intervention/exposure, Comparison, and Outcome) analysis which helped identify people with dementia, their informal carers, and poorer outcomes for dementia patients in acute care environments as an area of interest. However, during this process it became increasingly obvious the majority of the literature in this particular area was qualitative rather than quantitative, and an alternative search identifying strategy was required. The PICO analysis has been identified as a suboptimal strategy for the synthesis of predominantly qualitative evidence (Cooke, Smith & Booth, 2012) due to a focus on Intervention and Comparison, both of which can be absent or presented differently in qualitative studies.

The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type), developed by Cooke, Smith, and Booth in 2012, was chosen as a more appropriate analysis tool for this review for three reasons. Firstly, many of the qualitative studies had much smaller sample sizes and were not necessarily intended to be extrapolated out to a more general population. Secondly, the concept of Phenomenon of Interest was much more representative of the approach taken. Thirdly, the evaluation process, as opposed to the PICO category of Outcomes, was much more applicable to the predominantly interview based studies, in which the end results are not based on comparative or measurable interventions but on observations and more subjective constructs.

3.2 Meta-Ethnographic Approach – Conceptual Collation

The lack of quantitative data relating to the review question presented a significant challenge in terms of synthesising the information via a more conventional review process. Having moved away from a search protocol suited to quantitative studies (PICO), to one more suitable for qualitative studies (SPIDER), a similar approach to a review process was sought, and synthesis was subsequently completed using a more conceptual and interpretive meta-ethnographic approach, seeking common themes across the studies. Meta-ethnography is a technique used to synthesise data across multiple qualitative studies, with the goal of achieving insights or understandings not necessarily apparent in the initial research. (France et al., 2019) For a review of literature surrounding the highly subjective experiences of informal carers and people with dementia in acute care environments this allowed a broader and more interrogative approach.

3.3 Quality Appraisal - Critical Interpretive Synthesis

A Critical Interpretive Synthesis (Woods et al, 2006) method was used in the assessment of quality of the included studies, prioritising relevance over study design or rigor. This method was utilised to facilitate the interpretive meta-ethnographical approach used in this review. Focussing not on data aggregation and summaries of evidence but rather the concepts which emerge from an exploration of the literature, a critical interpretive synthesis method allowed the inclusion of less rigorous studies which ultimately had valuable conceptual contributions to the review. It also allowed the inclusion of studies which did not meet the specific search criteria initially used but which contributed generally to the emerging narrative. Studies were therefore excluded or included based predominantly on relevance rather than a strict exclusionary quality appraisal framework.

3.4 Search Process

Literature relevant to this review was sourced via an electronic search of online database PubMed, using a combination of MeSH terms and keyword searches relating to dementia, hospitalisation, and carers. Additional literature was sourced via searching the reference lists of relevant papers.

3.4.1 Key Words

The following key words were used in the initial search process.

‘Dementia’; ‘Hospital*’; ‘Care*’; ‘Alzheimer’; ‘Hospitalisation’; ‘Carer’; ‘Geriatric’; ‘Hospitalization’; ‘Informal care*’; ‘Community’; ‘Patient-centred care’; ‘Acute care’; ‘Caregivers’; ‘Liaison’ ; ‘Education’; ‘Training’; ‘Continuity’; ‘Pathways’; ‘Support*’; ‘Empower*’; ‘Interventions’; ‘Champion’; ‘Awareness’; ‘Friendly’.

3.4.2 Inclusions

Initial inclusions were based on a fairly small criteria to ensure that studies were published no earlier than 2007, written in or available in English, and from developed countries with a comparable health care system to Australia.

3.4.3 Exclusions

Studies which dealt with populations based in residential aged care or similar formal care environments were excluded, as the focus of the review was on the lived experience of informal carers during hospitalisation and acute care episodes.

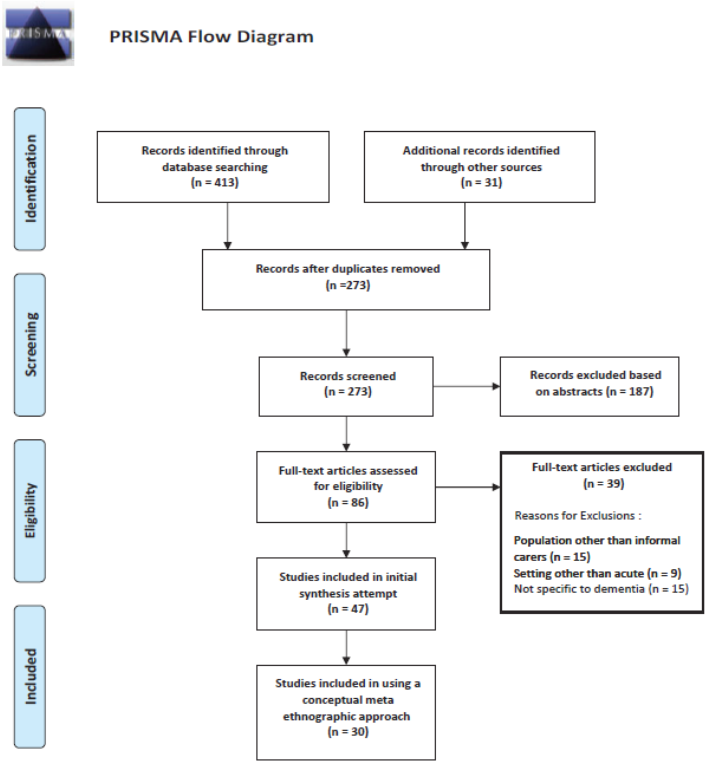
3.4.3.1 Palliative/End of Life Care

Further to the initial criteria, the decision was made to exclude studies which focused on end of life care. The experience of patients, loved ones, and informal carers during palliative care, while an important area for examination, is a situation quite different to hospitalisation for a period of time with the expectation of discharge.

3.4.3.2 Hospitalisation sans Cognitive Impairment

Studies which focussed on the hospitalisation of elderly people without cognitive impairment were also excluded, as the care of a person with dementia adds a level of complexity to hospitalisation events.

3.5 PRISMA Flow Chart



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

3.6 Table of Literature Reviewed

The following is a section of the larger table located in Appendix A, detailing the thematic commonalities between papers reviewed.

No.	Title	Thematic Commonalities			
		Identity	Connection	Collaboration	Communication
1	'And so I took up residence': The experiences of family members of people with dementia during admission to an acute hospital unit.	☑	☑	☑	☑
2	The experience of family carers of people with dementia who are hospitalised.	☒	☑	☑	☑
3	Older people's and relatives' experiences in acute care settings: systematic review and synthesis of qualitative studies.	☑	☑	☑	☑
4	Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services.	☑	☒	☑	☑
5	The impacts of family involvement on general hospital care experiences for people living with dementia: An ethnographic study.	☒	☑	☑	☒
6	Carers: The navigators of the maze of care for people with dementia-A qualitative study.	☑	☑	☑	☑
7	Experiences of family carers of older people with mental health problems in the acute general	☒	☒	☑	☑

	hospital: a qualitative study.				
8	Informal carers' perspectives on the delivery of acute hospital care for patients with dementia: a systematic review.	☑	☑	☑	☑
9	Stakeholder perspectives of care for people living with dementia moving from hospital to care facilities in the community: a systematic review.	☒	☒	☑	☑
10	The acute care experience of older persons with cognitive impairment and their families: A qualitative study.	☑	☑	☑	☑
11	(In-)formal caregivers' and general practitioners' views on hospitalizations of people with dementia - an exploratory qualitative interview study.	☑	☒	☑	☑
12	Working with families of hospitalized older adults with dementia: caregivers are useful resources and should be part of the care team.	☑	☑	☑	☑
13	Factors affecting in-hospital informal caregiving as decided by families: findings from a longitudinal study conducted in acute medical units.	☒	☒	☑	☑

14	The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families.	☑	☑	☑	☑
15	Support for carers of people with dementia during hospital admission.	☑	☑	☑	☑
16	Health professional perspectives on systems failures in transitional care for patients with dementia and their carers: a qualitative descriptive study.	☒	☒	☑	☑
17	Experiences of Integrated Care for Dementia from Family and Carer Perspectives: A Framework Analysis of Massive Open Online Course Discussion Board Posts.	☑	☑	☑	☑
18	Inclusion of carers when confused relatives are admitted to hospital.	☑	☒	☑	☑
19	Obtaining information from family caregivers to inform hospital care for people with dementia	☑	☑	☑	☑
20	Factors Influencing Emergency Care by Persons With Dementia: Stakeholder Perceptions and Unmet Needs.	☑	☑	☑	☑
21	The experience of people with dementia and nurses in hospital: an integrative review.	☑	☒	☑	☑

22	Hospital discharge processes involving older adults living with dementia: An integrated literature review.	☒	☒	☑	☑
23	How collaboration is improving acute hospital admission for people with dementia.	☒	☑	☑	☑
24	Improving acute care for patients with dementia.	☑	☒	☑	☑
25	Acute hospital dementia care: results from a national audit.	☑	☒	☑	☑
26	Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study	☑	☑	☑	☑
27	The experiences and perceptions of care in acute settings for patients living with dementia: A qualitative evidence synthesis	☒	☑	☑	☑
28	Hospital discharge: recommendations for performance improvement for family carers of people with dementia	☑	☒	☑	☑
29	Empowerment, environment and person-centred care: A qualitative study exploring the hospital experience for adults with cognitive impairment.	☑	☑	☒	☑

30	A systematic review of the impact of Person-Centred Care interventions on the behaviour of staff working in dementia care.	☑	☑	☒	☑

4

FINDINGS AND DISCUSSION

The 30 studies reviewed for this project showed broad conceptual consistency across four areas of Identity, Connection, Collaboration, and Communication. Below is a summary of each of these areas, examining each concept in depth, the consistencies between studies for each particular theme, and further discussion providing observations and analysis on these findings. Also included is a section discussing person centred care and relationships in care to provide further context for the studies reviewed.

4.1 Person Centred Care – Best Practice not Practised

There is general consensus (Allen Christensen et al., 2019; Blake, Berry, & Brown, 2019; Ernst, Petry, Luethi, & Naef, 2019) that person centred care is best practice for patients with dementia. "Person-centred care is a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment." (Alzheimer Society of Canada, 2017). At the core of this practice is the individual. It is a way of recognising and respecting the 'self' and responding to a person's care needs on that individual basis. For people with dementia, this type of care has been shown to reduce many of the behavioural symptoms often associated with dementia (Sloane et al., 2004). Literature reviews conducted in 2013 by Levy-Storms and in 2016 by Kogan, Wilber, & Mosqueda both explored the core concepts and definitions of person centric care, identifying individualised care, dignity, and self-determination as a key parts of the philosophy. This can be seen to underpin many of the areas in which informal carers felt unhappy with their experiences during hospitalisation events (Clissett et al., 2013; Digby et al., 2017; Pohontsch, Scherer, & Eisele, 2017; Richardson et al., 2019). Fundamentally, they were expressing a desire for their person with dementia to be treated as an individual, irrespective of their cognitive abilities. Informal carers provide a level of person centred care that is virtually impossible in a hospital environment, tailoring their care based on a deep and intimate knowledge of their person with dementia (Allen Christensen et al., 2019; Kogan et al., 2016). Examining the shared experiences of carers during hospitalisation events identified a significant gap between what is recommended and what is executed on a daily basis (Fitzgerald et al., 2011; Kelley et al., 2019; Timmons et al., 2016; Wood, Cairns, & Sharp, 2017). A key finding of this report is that while person centred care is considered best practice for patients with dementia, it does not seem to be implemented consistently in any of the environments experienced by the informal carers in the studies included in this review. In fact, the core tenants of person-centred care are strongly reflected in the thematic findings of this review (Pohontsch et al., 2017; Richardson et al., 2019; Robertshaw & Cross, 2019). The expressed desires of the carer to ensure that their person with dementia is treated with dignity, respected as an individual, included in care decisions when practicable, and supported based on their individual characteristics and needs are at the very basis of person centred care. (Simpson, 2016; Stockwell-Smith et al., 2018) Extending this style of care to incorporate the informal carer as part of the triad could possibly address many of the issues raised in these included studies.

4.2 Theme One - Identity

4.2.1 Clarification

Identity deals with the personhood of the patient, and the desire of their carer to protect their dignity and individual needs during hospitalisation. It is a key component of person-centred care that the patient is treated as an individual, and that their dignity is maintained as much as practicable in an acute care environment. "… failure to acknowledge personhood is often the root cause of patient and family dissatisfaction, and the reason why medicine is sometimes perceived as uncaring or emotionally abrasive." (Chochinov et al., 2015). Hospital environments can be very disempowering for both the patient and their carer (Faulkner, 2001; Prato, Lindley, Boyles, Robinson, & Abley, 2018). In this context being disempowered can be related to a loss of control over how the person with dementia is both perceived and treated. The shift in status from person with dementia to generic patient is echoed in the shift for the informal carer from caregiver to visitor.

4.2.2 Identity in the Literature

As per the table in appendix A, in 22 out of the 30 studies reviewed, the concept of identity or individual dignity was clearly raised as a separate issue, with the remainder raising it indirectly or as part of another issue. Many of the respondents in the studies directly flagged circumstances under which the personhood of the patient with dementia was ignored or minimised (Bloomer, Digby, Tan, Crawford, & Williams, 2016; Fitzgerald et al., 2011; Prato et al., 2018; Robertshaw & Cross, 2019). In the New Zealand study titled 'And so I took up residence' (de Vries et al, 2019), they identified "One of the greatest anxieties expressed by all participants was how much they wanted to ensure that the dignity of the person with dementia was maintained." (de Vries, Drury-Ruddlesden, & Gaul, 2019). This was echoed in Haiko's et al's work in 2019, which also identified consistency across all participants in their desire to ensure there was the same level of respect given, regardless of cognitive impairment (Haikio et al., 2019). Informal carers' perspectives on the delivery of acute hospital care for patients with dementia: a systematic review highlights the distress experienced by carers observing a lack of empathy and compassion in staff treatment of patients with cognitive impairment (Beardon et al., 2018). Also flagged were some of the ways in which a person's dignity might be compromised in the hospital environment. Examples given related to the person with dementia being spoken over while trying to communicate or being discussed without inclusion while present (Bridges, Flatley, & Meyer, 2010). Additional examples presented related to physical dignity, such as inappropriate or revealing clothing, "humiliating" toileting or other medical interventions completed without concern for privacy, and a lack of proactive management of these issues by staff. (Bloomer et al., 2016; de Vries et al., 2019; Digby et al., 2017)

4.2.3 Further Discussion

While carers reported experiencing or observing person centred care at times, (Bradway & Hirschman, 2008; Bridges et al., 2010; Douglas-Dunbar & Gardiner, 2007) this is significantly different to encountering a system wide culture of person and family centric care (Petry et al., 2019). Whether it is to do with physical or emotional dignity or the treatment of the person with dementia as more than a collection of symptoms, recognition of their personhood is a vital part of their care (Chochinov et al., 2015; Faulkner, 2001).

4.3 Theme 2 - Connection

4.3.1 Clarification

Connection, defined as the forming of a reciprocal or empathetic bond, is what emerges where there are more than just transactional interactions during the care process (Kelley et al., 2019). This overlaps with the thematic concept of Identity as genuine connection with someone in this environment requires acknowledging their individuality (Ernst et al., 2019). When a person with dementia and their carer form a rapport with staff in hospitals, they are more likely to feel that they are listened to and rate the level of care more highly. (Bloomer et al., 2016).

4.3.2 Connection in the Literature

Identity affirming behaviours are acknowledged to facilitate greater connection between health care professionals and patients. (Ambrosi et al., 2017; Barber, 2015) When patients are unable to communicate, family members' knowledge of their interests, wishes and values becomes crucial in facilitating and expressing connections. (Haikio, Sagbakken, & Rugkasa,2019). Methods of connection can take many forms such as allowing use of personal possessions, accommodating individual preferences or routines, asking and learning about personal; preferences, asking about their non-medical history or life stories, and reacting empathetically to challenging behaviours (Bloomer et al., 2016). Connection between staff and the patient may be considered either genuine or performative by the observing carers. However, the perception that they are proactively attempting to engage on an individual level often reassures them and reconciles the informal carer to a 'less than perfect' level of care (Clissett et al., 2013; Jamieson et al., 2016).

4.4 Theme 3 - Collaboration

4.4.1 Clarification

Collaboration is defined as the process of two or more people or organizations cooperating to complete a task or achieve a goal (Pesonen, Remes, & Isola, 2011). In this context it refers to the triadic relationship between health professional, patient, and carer, and their capacity to work together (Monroe, Herr, Mion, & Cowan, 2013; Rippon et al., 2019; Watkin et al., 2012). It requires involving both the carer and the patient in discussions with health professionals around care needs and about utilising a combined pool of knowledge to achieve the highest level of person-centred care possible (Fortinsky, 2001; Kogan et al., 2016).

4.4.2 Collaboration in the Literature

Collaboration was identified as an issue especially relevant while navigating the care required/expected during the span of the hospital stay and during discharge planning (Beardon et al., 2018; Bloomer et al., 2016; Bradway & Hirschman, 2008; Bridges et al., 2010; Clissett et al., 2013). Many carers prior to undergoing a hospitalisation event believe that there are specialised systems in place for patients with dementia, and experience increased stress and disappointment when they find that in most facilities this is not the case (Jurgens, Clissett, Gladman, & Harwood, 2012; Kelley et al., 2019; Petry et al., 2019). Lack of specialised staff and environments means that carers simultaneously feel the need to fill the gaps in care while often feeling unrecognised as a reliable or credible resource in the care of their person with dementia. (Robertshaw & Cross, 2019; Simpson, 2016; Wood et al., 2017)

4.4.2.1 Discharge Planning

The process of working together is crucial during transitions between care environments, such as discharge planning, an area previously known to be associated with significant dissatisfaction amongst carers. (Bauer, Fitzgerald, & Koch, 2011; Fitzgerald et al., 2011; Richardson et al., 2019; Stockwell-Smith et al., 2018). Many participants in the literature reviewed expressed that a lack of knowledge, empathy, and logistical coordination led to highly negative experiences such as midnight discharges (Wood et al., 2017), unplanned or uncoordinated discharges which put the person with dementia at risk (Jamieson et al., 2016), and a lack of consultation with carers surrounding medication and community services

(Stockwell-Smith et al., 2018). “For one family this abrupt process had a near disastrous outcome, the staff having told the person that he was going home, and packed him up, to await a family member to arrive. In the interim, the person left the hospital, and was found wandering and lost several kilometres away later in the day.” (Jamieson, Grealish, Brown, & Draper, 2016). Most family carers did not consider the process of discharge as collaborative, consultative, or informative. (Haikio et al., 2019; Stockwell-Smith et al., 2018; Timmons et al., 2016)

4.4.2.2 Paradox of Care

Although not discussed specifically in the reviewed studies other than ‘Carers: The navigators of the maze of care for people with dementia - A qualitative study’ (2016) the concept of the paradox of care is also worth raising in the context of collaboration (Jamieson et al., 2016). The paradox of care is the expectation that carers will simultaneously maintain their caring role and perform caregiving tasks while being excluded from care decisions. “While it is vital to build relationships with carers and involve them if they want to be involved, it is not acceptable to expect them to deliver the care that is the responsibility of the nursing team.” (Simpson, 2016).

4.4.3 Further Discussion

“Usual care-giving roles, and control over these, were taken away as care ‘ownership’ transferred to the hospital, leaving many families to transition to the much less active role of visitor.” (Haikio, Sagbakken, & Rugkasa,2019). Recognising carers as a source of information regarding the person with dementia, and an important contributor to the ongoing care process is vital in both the provision of individualised care, and the ability of the informal carers to make informed decisions (Haikio et al., 2019).

4.5 Theme 4 - Communication

4.5.1 Clarification

Communication is the process of transmitting and sharing information, ideas, opinions, facts, and values between two or more people (Fortinsky, 2001). In the hospital environment, there are often limits to the level of communication between staff, carers, and patients (Chochinov et al., 2015). This can be a product of the hospital processes, in which scheduling and staffing levels can impact directly on the logistics of communication (Prato et al., 2018). It can also be a product of staff training and attitudes, or part of the overall culture of the facility. (Blake et al., 2019; Ernst et al., 2019)

4.5.2 Communication in the Literature

Communication was the issue most consistently raised by carers as problematic during a hospitalisation event. From the process of admission to the process of discharge and the duration of stay between the two, carers consistently reported communication as a significant issue. (Bloomer et al., 2016; Bridges et al., 2010; Douglas-Dunbar & Gardiner, 2007; Fitzgerald et al., 2011; Jamieson et al., 2016; Jurgens et al., 2012; Richardson et al., 2019; Simpson, 2016; Stockwell-Smith et al., 2018; Toye et al., 2019). A lack of comprehensive, systematic, and documented interactions between health professionals, carers, and patients to inform safe person-centred hospital care for people with dementia was identified. (Bloomer et al., 2016; Bridges et al., 2010; Jurgens et al., 2012). This lack of communication was identified during the admission process (Fitzgerald et al., 2011) in which incomplete or incorrect information was given or received by carers, as well as during the stay, and the discharge process (Richardson et al., 2019). During hospitalisation events carers experienced a variety of communication issues, such as the person with dementia being given information about their care that they were expected to retain (Jamieson et al., 2016), the person with dementia being talked over or ignored (Bloomer et al., 2016), no information being given to the carer regarding medication choices or what side effects the carer should expect, (Stockwell-Smith et al., 2018), and a lack of access or clear lines of communication between staff and carer when the carer was seeking specific information. (Bloomer et al., 2016; Bridges et al., 2010; Jurgens et al., 2012). Carers expressed the belief that many staff lacked experience or knowledge in communicating with people with dementia, which impacted the triadic flow of information (Simpson, 2016).

4.5.3 Further Discussion

Communication is made difficult when it is prioritised more highly by one side of a dynamic, and many medical professionals see this dynamic as dyadic, between the patient and themselves, rather than triadic, which would incorporate informal carers and/or family members as well. (Bloomer et al., 2016; Fitzgerald et al., 2011; Jamieson et al., 2016) “Despite evidence to state the standard patient-professional relationship needs to be replaced by a ‘triad’ relationship that includes the carer of people with dementia this is not always the case.” (Bloomer et al, 2014)

Person centric care is difficult to achieve, if not impossible, if medical professionals are not aware of a patient’s individual needs and, are not open to a collaborative method of care. (Chochinov et al., 2015; Huang et al., 2011; Kelley et al., 2019).

4.6 Limitations/Weaknesses

4.6.1 Limitations of the studies reviewed

This review has revealed that the majority of the literature surrounding the topic remains descriptive. Much of the literature reviewed focussed on single locations, self-selected participants, and do not elaborate on any confounding variables, such as demographics, cultural differences, stage of disease, nature of family relationships, or additional stressors in the life of the carer. Due to the large number of variables involved, this topic may not be well understood via cross-sectional research designs. Instead, longitudinal observational designs may more fully capture the needs and responsibilities of informal caregivers during the disease trajectory.

4.6.2 Limitations of this Review

- Limiting this review to academic papers and excluding grey literature may have resulted in overlooking current recommendations for informal carers in this context. A thorough examination of the informative literature provided by community and government bodies may reveal areas for further academic study.
- Restricting the review to studies written in English was a necessary constraint but one which most likely has impacted providing a comprehensive global picture of the issue.
- Additionally, the choice to prioritise studies taking place in comparable health care systems to Australia facilitated more identifiable commonalties but once again may not present the full picture.
- It also must be noted that the studies reviewed focused almost exclusively on the experiences of informal carers and were not inclusive of the views of health professionals or of the person with dementia.

4.7 Areas Not Reviewed But Noteworthy

4.7.1 Knowledge & Skills of Staff

Some studies have shown that the experience and training of staff in working with people with dementia in acute settings have been suboptimal. Concerns were present in a number of studies that staff were inadequately trained or inexperienced in caring for patients with dementia in an acute care environment (Jacobsohn et al., 2019; Kable et al., 2015; Kelley et al., 2019; Petry et al., 2019; Simpson, 2016). When this is combined with the lack of genuine person-centred care expressed in many of the studies reviewed, the reasons for carer dissatisfaction unfold. (Ambrosi et al., 2017; Bloomer et al., 2016; Clissett et al., 2013; de Vries et al., 2019). Much of the additional literature examined focusses on reforming processes from a top down perspective, suggesting that outcomes for patients could be improved via staff training, education, and hospital or community-based initiatives. (Chochinov et al., 2015; Faulkner, 2001; Watkin et al., 2012). These are important areas for research, and refining hospital processes and environments to better accommodate people with dementia is crucial.

4.7.2 The Built Environment

Additional criticism was raised by informal carers in the literature reviewed regarding the physical environment of hospitals failing to accommodate those with cognitive impairment. (Fitzgerald et al., 2011; Petry et al., 2019; Robertshaw & Cross, 2019; Timmons et al., 2016) Factors such as lighting, signage, and access to bathrooms and toilets amongst others all play a role in the usability and friendliness of the environment. (Huang et al., 2011) Age friendly environments are generally more accessible and usable for all who need to engage with them, and progress towards this would be valuable. Additionally, the spouses of patients with dementia are also likely to be in the same or comparable age groups. The sophisticated built environment of the hospitals often does not provide a carer friendly or easily accessible milieu.

5

CONCLUSIONS & RECOMMENDATIONS

5.1 Conclusions

One of the key takeaways from this literature review is that informal carers may be able to better support patients with dementia during hospitalisation by acting as efficient providers, receivers, and curators of information. (Beardon et al., 2018; Pohontsch et al., 2017; Prato et al., 2018). While ideally there would be consistent and reliable accommodations made for people with dementia when admitted to hospital, this is not currently the case. Many of the criticisms raised by informal carers in the literature reviewed centred around gaps and flaws in both communication and engagement. A focus on pre-prepared comprehensive and informative documentation could conceivably mitigate some of these issues by reducing the burden on carers to provide correct and coherent information under high levels of stress. The reliance on informal carers in Australia to enable people with dementia to remain living in the community suggests interventions or programs that utilise a reduction in caregiver stress as a metric should also be considered, even if there is neutral impact on outcomes for patients.

5.2 Recommendations Relating to Aims

What has emerged from this process is a reiteration of the clear and consistent feedback from informal carers across a broad range of studies regarding key issues that should be taken seriously, and key areas that need to be further explored. The following sections discuss the recommendations in the context of the stated aims of this review, which were to identify gaps in the existing research, to identify ways of empowering informal carers by identifying where they are disempowered, and to provide recommendations on this basis.

5.2.1 Aim 1 – To identify gaps in existing research

While there has been significant research into acute care best practices for elderly patients (Ouchi et al., 2019; Rippon et al., 2019; Vernon et al., 2019) there is a clear gap in the examination of this review question. With hospitalisation an area of concern for people with dementia and Australia's health and aged care systems heavily relying on the work done by informal carers, this should be rectified (Fitzgerald et al., 2011; Haikio et al., 2019; Jacobsohn et al., 2019; Jamieson et al., 2016). Within the search parameters of this review, there was no quantitative data revealed or identified that dealt with the research question directly. From an analysis of the limitations of the studies reviewed, a more longitudinal approach with stricter cohort restrictions and narrower scope may be better suited to produce the data required. However, it must be acknowledged that research involving dementia patients has a high number of confounding variables and ethical issues (Jenkins, Smythe, Galant-Miecznikowska, Bentham, & Oyebode, 2016; Monroe et al., 2013; Pesonen et al., 2011). An important observation from this review is that despite a triadic care relationship involving staff-patient-family being considered best practise this does not necessarily occur consistently and may contribute significantly to carer dissatisfaction.

5.2.2 Aim 2 – Empowering the carer – where are they disempowered?

Carers are often not recognised as an information resource, not included in care decisions, not kept informed, and feel at the mercy of the hospital when it comes to admission and discharge (Bloomer et al., 2016; Bradway & Hirschman, 2008; Bridges et al., 2010). Generally, hospitalisation events are considered extremely stressful for carers (Prato et al., 2018; Richardson et al., 2019). Therefore, even if there was a neutral or negligibly positive impact on patient outcomes, interventions which reduce carer stress during this time should be considered worthwhile.

5.2.3 Aim 3 – Steps that can be taken on an individual level?

This review identifies the potential value of informal carers maintaining and curating a comprehensively detailed file relating to their person with dementia in preparation for unplanned hospitalisations. This would ideally incorporate personalised information regarding the patient, such as their preferred name, idiosyncratic behaviours, and calming techniques. A General Practitioner (GP) may be able to assist with the provision of medication lists and paperwork regarding diagnosis or previous treatments. Maintaining a record of pertinent aspects of the hospitalisation event may also be valuable, for example, identifying how long the wait was in the Emergency Room, staff names and roles, and visitor policies for future reference. Additionally, carers should ensure any legal documentation required, such as a Power of Attorney or an Advanced Health Directive, is in place. Being able to provide copies as needed is important, as health professionals are bound by laws relating to patient confidentiality, and may require formal confirmation of a carer's legal right to make decisions.

5.3 Areas for Future Research

- The following propositions emerged during this review as areas which may benefit from more rigorous or quantitative study.
- Value of assertiveness or advocacy training for informal carers.
- Value of standardising information exchange methods between carer and staff during a hospital admittance.

- Observations on the endorsement of person-centred care versus the level actually delivered in acute care environments.
- Age friendly hospital design and the impact on informal carers.

5.4 Final Statement

Dementia is a degenerative and terminal illness, implying the necessity of a more positive patient experience and increased satisfaction for family members surrounding care during the progression towards the end of life. While tangible results are extremely important for research into acute care best practices, the literature reviewed reveals a deep and profound unhappiness from a carer's perspective with regards to hospitalisations which should be addressed given the current reliance of the Australian health care system on informal care. Informal carers may be able to better support and to advocate for their person with dementia by curating and providing relevant information efficiently. However, hospitalisation for a person with dementia is a complex and multidimensional process that stretches from admission to discharge and efforts to enhance engagement with informal carers across the themes discussed in this review and the empowerment of informal carers should be considered essential in providing person centric care during this process.

What does this review add?

- Confirms that a person-centred mode of care is considered most desirable by informal carers of people with dementia.
- Highlights four thematic areas in which disempowerment of the carer can and does take place in the hospital environment.
- Provides a clear recommendation for the self-empowerment of informal carers using information curation.

6

APPENDIX A

No.	Title	Authors	Year	DOI	Country of Study	Design and Methods	Participants	Key Results/Conclusions	Thematic Commonalities			
									Identity	Connection	Collaboration	Communication
1	'And so I took up residence': The experiences of family members of people with dementia during admission to an acute hospital unit.	de Vries, Kay; Drury-Ruddlesden, Jenny; Gaul, Chris	2019	10.1177/1471301216656097	NZ	Interview based	Family members of people with dementia n = 26	Family members are an untapped resource during hospitalisation.	☑	☑	☑	☑
2	The experience of family carers of people with dementia who are hospitalised.	Bloomer, Melissa; Digby, Robin; Tan, Heather; Crawford, Kimberley; Williams, Allison	2016	10.1177/1471301214558308	Australia	Interview based	Informal carers of people with dementia n = 20	Hospital admission has a significant impact on family carers.	☒	☑	☑	☑

3	Older people's and relatives' experiences in acute care settings: systematic review and synthesis of qualitative studies.	Bridges, Jackie; Flatley, Mary; Meyer, Julienne	2010	10.1016/j.ijnurstu.2009.09.009	UK	Systematic Review	Studies n = 42	Relation centred approach necessary for positive experience during hospitalisation.	☑	☑	☑	☑
4	Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services.	Haikio, Kristin; Sagbakken, Mette; Rugkasa, Jorun	2019	10.1186/s12913-019-4478-2	Norway	Interview based	Informal carers of people with dementia n = 23	Family caregivers engage in a variety of protective practices surrounding their person with dementia.	☑	☒	☑	☑
5	The impacts of family involvement on general hospital care experiences for people living with dementia: An ethnographic study.	Kelley, Rachael; Godfrey, Mary; Young, John	2019	10.1016/j.ijnurstu.2019.04.004	UK	Observations and interviews	Informal carers of people with dementia n = 23	People living with dementia experience significant disconnection from a variety of areas during and surrounding hospitalisation.	☒	☑	☑	☒

6	Carers: The navigators of the maze of care for people with dementia-A qualitative study.	Jamieson, Maggie; Grealish, Laurie; Brown, Jo-Ann; Draper, Brian	2016	10.1177/1471301214554930	Australia	Interview based	Informal carers of people with dementia n = 30	Carers experience a paradox - expected to deliver care, but excluded from care decisions.	☑	☑	☑	☑
7	Experiences of family carers of older people with mental health problems in the acute general hospital: a qualitative study.	Clissett, Philip; Porock, Davina; Harwood, Rowan H; Gladman, John R F	2013	10.1111/jan.12159	UK	Interview based	Informal carers of people with dementia n = 32	Family members often respond to the disruption of hospitalisation by involving themselves in the care/support of their person with dementia.	☒	☒	☑	☑
8	Informal carers' perspectives on the delivery of acute hospital care for patients with dementia: a systematic review.	Beardon, Sarah; Patel, Kiran; Davies, Bethan; Ward, Helen	2018	10.1186/s12877-018-0710-x	UK	Systematic Review	Studies n = 44	Identifies common perspectives of informal carers.	☑	☑	☑	☑
9	Stakeholder perspectives of care for people living with dementia	Richardson, Angela; Blenkinsopp, Alison;	2019	10.1186/s12877-019-1220-1	UK	Systematic Review	Studies n = 88	Identifies issues during the discharge/transition process from stakeholder perceives.	☒	☒	☑	☑

	moving from hospital to care facilities in the community: a systematic review.	Downs, Murna; Lord, Kathryn									
10	The acute care experience of older persons with cognitive impairment and their families: A qualitative study.	Petry, Heidi; Ernst, Jutta; Steinbruchel-Boesch, Corinne; Altherr, Jeanine; Naef, Rahel	2019	10.1016/j.ijnurstu.2018.11.008	Switzerland	Interview based	Family members of people with dementia n = 19	Caregivers need to be recognized and involved in the acute care process.	☑	☑	☑	☑
11	(In-)formal caregivers' and general practitioners' views on hospitalizations of people with dementia - an exploratory qualitative interview study.	Pohontsch, Nadine Janis; Scherer, Martin; Eisele, Marion	2017	10.1186/s12913-017-2484-9	Germany	Interview based	Informal Carers n = 12	Hospitalisations of people with dementia cannot be completely avoided, therefore better trained staff are required.	☑	☒	☑	☑
12	Working with families of hospitalized older adults	Bradway, Christine; Hirschm	2008	10.1097/01.NAJ.0000336 9	USA	Interview based	Family members n = 10	Family members are an invaluable resource of information and should be recognised	☑	☑	☑	☑

	with dementia: caregivers are useful resources and should be part of the care team.	an, Karen B		67.324 62.2d				as such during hospitalisations.				
13	Factors affecting in-hospital informal caregiving as decided by families: findings from a longitudinal study conducted in acute medical units.	Ambrosi Et al,	2017	10.1111/scs.12321	Italy	Interview and observation based	Family members n = 48	Family carers contribute significant amounts of care during hospitalisation events.	☒	☒	☑	☑
14	The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families.	Clissett, Philip; Porock, Davina; Harwood, Rowan H; Gladman, John R F	2013	10.1016/j.ijnurstu.2013.03.001	UK	Interview based	Care dyads n = 29	Person centred care needs to be more highly valued in the acute care of a person with dementia.	☑	☑	☑	☑

15	Support for carers of people with dementia during hospital admission.	Douglas-Dunbar, Maggi; Gardiner, Penny	2007	n/a	UK	Interview based	Carers n = 9	A therapeutic relationship needs to be developed with carers as well as the patient with dementia.	☑	☑	☑	☑
16	Health professional perspectives on systems failures in transitional care for patients with dementia and their carers: a qualitative descriptive study.	Kable, Ashley; Chenoweth, Lynnette; Pond, Dimity; Hullick, Carolyn	2015	10.1186/s12913-015-1227-z	Australia	Interview/focus discussion	Focus Group n = 33	Discharge planning for people with dementia is an area of high priority.	☒	☒	☑	☑
17	Experiences of Integrated Care for Dementia from Family and Carer Perspectives: A Framework Analysis of Massive Open Online Course Discussion Board Posts.	Robertshaw, David; Cross, Ainslea	2019	10.1177/1471301217719991	UK	Synthesis of discussion board posts	n/a	Care for people with dementia should be person centred and holistic	☑	☑	☑	☑

18	Inclusion of carers when confused relatives are admitted to hospital.	Barber, Jeanette	2015	10.7748/nop.27.5.23.e683	UK	Literature Review	Paper n = 12	Carers and family members provide valuable information about the patient with dementia and should be included in the care process.	☑	☒	☑	☑
19	Obtaining information from family caregivers to inform hospital care for people with dementia	Toye, Christine; Slatyer, Susan; Quested, Eleanor; Bronson, Mary; Hill, Andrew; Fountaine, Janet; Uren, Hannah V; Troeung, Lakkhina; Maher, Sean	2019	10.1111/opn.12219	Australia	Interview based	Carers n = 32	Communication initiatives are required to facilitate the flow of information between the carer and the health professionals in an acute setting.	☑	☑	☑	☑
20	Factors Influencing Emergency Care by Persons With Dementia: Stakeholder	Jacobsohn, Gwen Costa; Hollander, Matthew; Beck,	2019	10.1111/jgs.15737	USA	Interview based	Informal Carers n = 4	Identified numerous unmet needs amongst stakeholders.	☑	☑	☑	☑

	Perceptions and Unmet Needs.	Aaron P; Gilmore-Bykovskyi, Andrea; Werner, Nicole; Shah, Manish N										
21	The experience of people with dementia and nurses in hospital: an integrative review.	Digby, Robin; Lee, Susan; Williams, Allison	2017	10.1111/jocn.13429	Australia	Literature Review	Articles n = 24	Health professionals working with people with dementia need further training and support.	☑	☒	☑	☑
22	Hospital discharge processes involving older adults living with dementia: An integrated literature review.	Stockwell-Smith, Gillian; Moyle, Wendy; Marshall, Andrea P; Argo, Alison; Brown, Laura; Howe, Shelley; Layton, Keith; Naidoo, Ornissa; Santoso	2018	10.1111/jocn.14144	Australia	Literature Review	Studies n = 15	Formal communication processes need to be implemented during the discharge process.	☒	☒	☑	☑

		, Yuwati; Soleil-Moudiky-Joh, Elizabeth; Grealish, Laurie										
23	How collaboration is improving acute hospital admission for people with dementia.	Wood, Nicola; Cairns, Yvonne; Sharp, Barbara	2017	10.7748/nop.2017.e990	UK	Literature Review	Carers n = 34	Further collaboration between carers and health professionals required to improve outcomes for patients.	☒	☑	☑	☑
24	Improving acute care for patients with dementia.	Simpson, Kate	2016	n/a	UK	Literature Review	Informal carers n = 7	It is vital for the voices of carers to be heard in acute care environments.	☑	☒	☑	☑
25	Acute hospital dementia care: results from a national audit.	Timmons, Suzanne; O'Shea, Emma; O'Neill, Desmond; Gallagher, Paul; de Siun, Anna; McArdle, Denise;	2016	10.1186/s12877-016-0293-3	UK/Ireland	National Audit	35 Acute Hospital Data	Findings included a large number of unmet needs and issues, especially surrounding discharge planning.	☑	☒	☑	☑

		Gibbons, Patricia; Kennelly, Sean										
26	Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study	Jurgens, F. J., Clissett, P., Gladman, J. R., & Harwood, R. H.	2012	10.1186/1471-2318-12-57	UK	Interview based	Family carers n = 34	Carers reported widespread dissatisfaction with hospital care.	☑	☑	☑	☑
27	The experiences and perceptions of care in acute settings for patients living with dementia: A qualitative evidence synthesis	Reilly, J. C., & Houghton, C	2019	10.1016/j.ijnurstu.2019.04.018	UK	Evidence Synthesis	Papers n = 7	Further investigation into interventions to support person centred care for people with dementia in acute environments is required.	☒	☑	☑	☑
28	Hospital discharge: recommendations for performance improvement for family carers of	Fitzgerald, L. R., Bauer, M., Koch, S. H., & King, S. J.	2011	10.1071/ah09811	Australia	Interview based	Family carers n = 25	It is recommended that health professionals be further educated on communication, consultation and needs of family carers.	☑	☒	☑	☑

	people with dementia											
29	Empowerment, environment and person-centred care: A qualitative study exploring the hospital experience for adults with cognitive impairment.	Prato, L., Lindley, L., Boyles, M., Robinson, L., & Abley, C.	2018	10.1177/1471301218755878	UK	Interview based	Carers n = 8 People with cognitive impairment n = 6	Moves must be made towards care which explores measures to improve and expand relative involvement in hospital care.	☑	☑	☒	☑
30	A systematic review of the impact of Person-Centred Care interventions on the behaviour of staff working in dementia care.	Blake, D., Berry, K., & Brown, L. J. E	2019	10.1111/jan.14251	UK	Literature Review	Studies n = 33	A range of interventions and outcome measures that could potentially highlight different ways person centred behaviour can be implemented.	☑	☑	☒	☑

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