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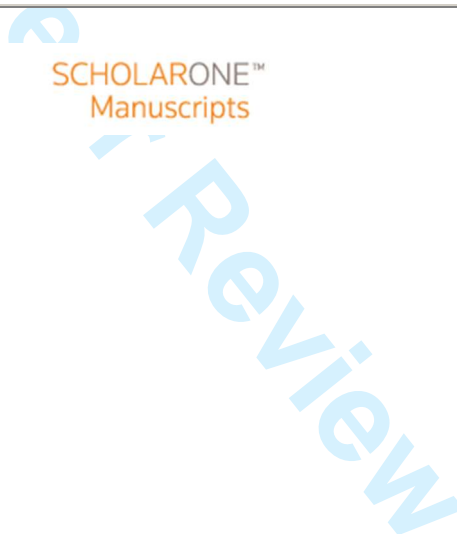
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Carer engagement in the hospital care of older people: An integrative review

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CARER ENGAGEMENT IN THE HOSPITAL CARE OF OLDER PEOPLE: AN INTEGRATIVE LITERATURE REVIEW

ABSTRACT

Background: Carer engagement can help to improve the delivery and continuity of care provided to older people in hospital. However definitions, guidance and structures for carer engagement in hospitals are lacking and there can be tensions and conflicts about the role of carers in hospitals.

Aim: The aim of this review was to explore the concept of carer engagement in the hospital care of older people and to build theory to inform future research and practice.

Method: Integrative literature review. Literature searches identified 2,745 peer-reviewed articles and studies published between January 1990 and November 2015 in the following databases: PubMed, Cochrane, Medline, EMBASE, and CINHALL. After applying inclusion/exclusion criteria the sample (103 articles) was subject to thematic analysis.

Results: Current evidence on carer engagement is dispersed across different research literatures on clinical conditions and contexts. Six distinct components of carer engagement were identified: patient caregiving, information sharing, shared decision making, carer support and education, carer feedback and patient care transitions.

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3 **Conclusion:** Hospitals can adopt a more consistent and comprehensive approach to carer
4 engagement for older people by developing and supporting the different components of carer
5 engagement identified.
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11 **Implications for practice:** The integrated model of carer engagement developed here could
12 help staff and hospitals to develop strategies, staff training and resources that work with
13 rather than against carers. The findings can inform future research on carer engagement
14 interventions and associated outcomes for patients, carers and staff.
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22 **Key words:** Carer engagement, carer involvement, family caregivers, older people, acute
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IMPLICATIONS FOR PRACTICE

What does this research add to existing knowledge in gerontology?

- Carer engagement in the hospital care of older people is an important health care issue internationally yet theory and evidence to inform hospital practice is lacking.
- An integrative review of the research literature on carer engagement in the hospital care of older people identified six distinct components of the construct which inform an integrated model of carer engagement.

What are the implications of this new knowledge for nursing care with older people?

- Carer engagement concerns all inpatient areas caring for older people, it should not be limited to specialist services for older people.

How could the findings be used to influence policy or practice or research or education?

- These findings can inform carer engagement policy, research and practice which could help to ensure patients and carers are satisfied with their care, improve health outcomes and enable hospitals to meet the care needs of an ageing population.

BACKGROUND

The United Kingdom (UK) National Health Service (NHS), like many other health care systems internationally, is currently facing some considerable challenges to deliver and improve the hospital care provided to an aging population (Ferlie and Shortell, 2001; Lindhardt et al., 2006; Oliver et al., 2014;). Most people (65 per cent) admitted to NHS hospitals are older than 65 years (Cornwell et al., 2012). Older people are often living with multiple long term conditions, requiring a focus on both the presenting acute event and their ongoing bio-psycho-social needs during an admission (Cornwell et al., 2012). The challenges include providing continuity of care, with dignity and compassion (Levenson, 2007; Firth-Cozens and Cornwell, 2009; Abraham, 2011; Care Quality Commission, 2011; Francis, 2013). Breakdowns in continuity of care put patients at risk of functional decline (Hartgerink et al., 2015) and add avoidable costs to both health and social care (JRF, 2012b). This paper focuses on carer engagement as a possible way to address some of the challenges of delivering hospital care to older people.

The research literature suggests that carers can provide a range of support to older patients during their hospital care (Nolan et al., 2004; Patterson et al., 2011), which may help to overcome some of the challenges of care delivery. “Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management” (NICE, 2004, p. 155). Carer engagement can support the continuation of a person’s activities of daily living (Laitinen, 1993) and provide personalised support (Lindhardt et al., 2006). Although the role of carers is now recognised in the NHS Constitution (2013) and The Care Act (2014) carer engagement is poorly defined and there is very little relevant guidance for hospitals (NICE

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3 Clinical Guidance 161, 2013; NICE Quality Standard 13, 2011; NICE Quality Standard 15,
4
5 2013;). Carer engagement is often seen as an extension of patient involvement in health care
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7 (Coulter, 2011; Barello et al., 2012; Tobiano et al., 2015) or as being covered by Patient and
8
9 Public Involvement (PPI); which refers to activities to enable the direct and active
10
11 participation of patients in decisions about healthcare delivery, service development or
12
13 research (Fotaki, 2011; Barnes and Cotterell, 2011). However patient involvement and PPI
14
15 are not only much broader concepts, supported by more formal structures (such as Patient
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17 Advice and Liaison services), they are more likely to involve non-clinical staff (e.g. managers
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19 or researchers), wider patient or community groups who may or may not be receiving
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21 hospital care. Furthermore, patient involvement in research or service development and
22
23 delivery doesn't relate to a specific health event but to wider processes or experiences of
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25 patients and the public.
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32 The definition of carer engagement used in this review is informed by existing research (in
33
34 particular Barnes & Cotterell, 2011; Cornwell et al., 2012; and Carers Trust, 2014) and our
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36 own research with carers, patients and staff in NHS hospitals. Here we draw on these sources
37
38 to suggest that "Carer engagement means the direct and active involvement of carers in older
39
40 people's hospital care and attention to the caregiving relationships between carers, patients
41
42 and clinical staff". There are some overlaps with family collaboration, which focuses on
43
44 relationships between relatives and nurses, where relatives are seen as competent
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46 collaborative partners in care in decision making rather than passive recipients of information
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48 (Lindhardt et al., 2008a; 2008b; 2008c). However carer engagement is not limited to relatives
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50 and it may not be feasible or acceptable for carers to take on a collaborative role in patient
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52 care, particularly if carers have a non-familial relationship with the patient.
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5 The role of carers in hospitals is predominantly controlled by professional priorities (Allen,
6 2000; Hancock et al., 2003; Porter et al., 2011) and practices (Nolan et al., 2004; Patterson et
7 al., 2011; JRF, 2012a) rather than evidence of what works. There can be tensions associated
8 with carer roles, such as staff/carer conflicts over care activities (Laitinen and Isola, 1996;
9 Walker and Dewar, 2001; Nolan et al., 2004; Lindhardt, et al. 2008b; Jurgens et al., 2012).
10 Very little is known about carer preferences, or how carer health or stress (Whittamore et al.,
11 2014; Carers Trust, 2014; Oliver et al., 2014), cultural differences, age or gender might affect
12 carer engagement (Li et al., 2004; Sandberg and Eriksson, 2009; Baider and Surbone, 2014).
13 Existing models of family-centred care and relationship-centred care have shown to be
14 helpful frameworks for practice, leading to better patient outcomes and carer satisfaction
15 (Nolan et al., 2004; Hudson and Payne, 2009; Patterson et al., 2011). For example the notion
16 of a Triangle of Care, developed in mental health, has been applied in dementia care to
17 emphasise a more ongoing and interactive relationship between patient, carer and
18 professionals (Carers Trust, 2014).
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Little is known about carer engagement and research is needed to examine different aspects and perspectives of the issues to inform hospital practice. Carers can provide a range of support to older patients which could help to meet the challenges of providing continuity of care in hospitals, with dignity and compassion. However, there is a lack of clear definitions, evidence and guidance about carer engagement in hospitals. Greater understanding of the concept of carer engagement is a possibly effective way to identify and develop components of carer engagement in hospital care. Therefore, the purpose of this integrative review was to search for relevant literature and to develop understanding of the concept of carer engagement to inform future research and practice.

AIM

The aim of this review was to explore the concept of carer engagement in the hospital care of older people and to build theory to inform future research and practice. Specifically, the paper seeks to address the following research question: What are the components of carer engagement in hospital care for older people?

METHOD

Approach

An integrative review was chosen as it is the broadest type of research review method, allowing for exploration of concepts, theory building and the simultaneous inclusion of experimental and non-experimental research in order to more fully understand carer engagement (Cooper, 1984; Broome, 1993; Whitemore and Knafl, 2005). For rigour and validity it is important to be clear about the approach taken in this integrative review (Gough et al., 2012). One researcher (EM) undertook the literature searches as part of a much larger study on older people's hospital care led by CN. Our experiences of research in NHS hospitals tells us that carer engagement exists but it is poorly defined and developed in health care practice. It is our view that some or all of the components of carer engagement are already present in the research literature (e.g. in accounts of carer interventions and observational studies) but have yet to be identified and defined in a way that is useful for research and practice. Review and interpretation of the data followed the logics and strategies of a structured literature review capable of identifying different components and distinguishing carer engagement from other information in the review process. The aim was

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2
3 to find sufficient cases to explore patterns and so not necessarily attempting to be exhaustive
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5 in the searches (Gough et al., 2012). Implications for the searches were to achieve a degree of
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7 homogeneity of data around the concept of carer engagement using iteration in the review
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9 method, for example development of inclusion criteria over time and refinement of themes.
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14 Cooper (1998) has delineated the process of conducting a research review as encompassing a
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16 problem formulation stage (explained in the background), a literature search stage, a data
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18 evaluation stage, a data analysis stage, and a presentation stage. This framework is used
19
20 below to explain the review method, illustrated by figure 1 (Figure 1).
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25 [FIGURE 1 TO GO NEAR HERE]
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28 29 *Literature search*

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31 Multiple literature searches were undertaken based on keywords derived from our definition
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33 of carer engagement set out in the introduction (Gough, 2012). Having a specific focus on
34
35 carer engagement in the hospital care of older people facilitated a structured search strategy
36
37 based on the target group (carers of older people), the concept, and the hospital context. The
38
39 validity of key terms was tested using preliminary searches and was considered suitably
40
41 broad to capture articles on carer engagement. In addition to keyword searches the PubMed
42
43 database was used to search for the most recent literature using MeSH (Medical Subject
44
45 Headings) (Table 1). Functional limits applied in the searches were: English language and
46
47 years 1990 to 2015. A theoretical approach to sampling was used to identify a sufficient and
48
49 appropriate range of studies based on the existing body of literature (Gough et al., 2012)
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51 (akin to purposive sampling in primary research). The database searches identified 2,745
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53 articles. In the first stage of screening EM read all returned article titles and abstracts, and
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3 where necessary the full article to gain further detail about article content. A broad age
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5 category (60 years and over) was used to include articles about the young-old and the old-old,
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7 and to include patients on elderly care wards as well as general adult inpatient settings
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9 (Cornwell et al., 2012). EM and CN discussed the relevance of specific articles where it was
10
11 not clear whether articles should be included or not. This initial reading was followed by
12
13 further familiarisation with the returned articles by both authors, sharing information and
14
15 reflecting together on article content to develop a framework of inclusion/exclusion criteria.
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17 As screening progressed the criteria were further refined in an iterative process of reading,
18
19 modifying the criteria and screening to reduce the number of articles to the most relevant
20
21 (Table 2). The validity of the draft inclusion/exclusion framework was tested through
22
23 discussions with two project supervisors and with members of the study advisory group
24
25 (including NHS staff and carers of older people) for resonance with lay and professional
26
27 understandings of carer engagement. A further 30 articles were collected through manual
28
29 searches of reference lists of the included articles. After screening the final sample was 103
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31 articles.
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42 [TABLE 2 TO GO NEAR HERE]
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46 47 *Data evaluation*

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49 The final sample included empirical and theoretical articles. Empirical reports included a
50
51 wide variety of methods: case study, cross-sectional, grounded theory, phenomenology, and
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53 instrument development designs. Review studies were included as well as primary sources
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55 where these provided a distinct contribution or theoretical perspective about carer
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3 engagement. Due to the diversity of primary sources articles were considered according to
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5 two criteria: data relevance and methodological/theoretical rigour. Judgements about data
6
7 relevance were based on the focus of articles on carer engagement for older people in the
8
9 hospital context (High/Moderate/Low) (illustrated in column two of table 2). Judgements
10
11 about the quality of the evidence were informed by Grading of Recommendations
12
13 Assessment, Development and Evaluation (GRADE) (Balshem et al., 2011). The GRADE
14
15 approach specifies four levels of quality (High I- Very low IV) based on methodology:
16
17 randomized trials or double-upgraded observational studies (I: High), downgraded
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19 randomized trials or upgraded observational studies (II: Moderate), double-downgraded
20
21 randomized trials or observational studies (III: Low), triple-downgraded randomized trials or
22
23 downgraded observational studies or case series/case reports (IV: Very low). As the focus
24
25 was to explore carer engagement rather than to review evidence of effectiveness, no article
26
27 was excluded based on methodological criteria alone. However in general, articles of high
28
29 rigour and relevance were given more attention in the analysis and contributed more to the
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31 results.
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38 *Data analysis*

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40 The focus of the analysis was on identification and integration of information about carer
41
42 engagement, rather than meta-analysis of the findings of studies (Denzin and Lincoln, 2000).
43
44 Data were extracted from primary sources using a structured table in Microsoft Word (Table
45
46 3). CN and EM developed headings of the data extraction tables suitable to capture
47
48 information about the context (patient/carers group, country, research methods and clinical
49
50 context) and content relating to carer engagement (definitions of carer engagement, aspects of
51
52 the process of carer engagement, antecedents, consequences, and impact/how the findings
53
54 facilitate carer engagement). EM extracted the data from each article and CN checked the
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3 extraction process by reviewing a sample of extracted articles, as detailed in Noyes et al.
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5 (2011). A code framework was developed from the data to define patterns in the data and to
6
7 distinguish between various components of carer engagement. Codes were then grouped
8
9 together into potential themes which were reviewed to ensure that the overall code
10
11 framework reflected the research question and the content of the data set (Braun and Clarke,
12
13 2006). Data tables were used to display the coded data from each article by category and
14
15 were iteratively compared. The reviewers discussed their decisions and interpretations with
16
17 one another throughout the process.
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23 [TABLE 3 NEAR HERE]
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26 27 *Presentation*

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29 A synthesis in the form of a model was developed to comprehensively portray carer
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31 engagement in the hospital care of older people. Descriptions for each component of carer
32
33 engagement were developed and relevant data from primary sources was summarized to
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35 create an overview of the included literature.
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43 **RESULTS**

44 45 46 47 *Overview of the findings*

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49 Current evidence on carer engagement is dispersed across different research literatures on
50
51 clinical groups, clinical contexts and countries, summarized in table 4 (Table 4). The
52
53 underpinning research uses a range of qualitative (case study, interview, grounded theory,
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55 ethnography), quantitative (cross-sectional, quasi-experimental), review (meta-analysis,
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3 literature review) and action research methods. The overall quality of the body of evidence is
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5 moderate according to GRADE criteria (downgraded randomized trials or upgraded
6
7 observational studies). The relevance of all of the included articles were judged as being High
8
9 or Moderate, adding validity to the literature search process and our use of the
10
11 inclusion/exclusion framework. Over a third of the articles related to older patients generally,
12
13 with the remainder relating to specific groups/clinical conditions of which dementia, frailty
14
15 and palliative/end-of-life were the most common. Topics addressed in the articles related to
16
17 six major themes (Table 4) which concern different components of carer engagement: patient
18
19 caregiving, shared decision making, information sharing, support and education, carer
20
21 feedback, and patient care transitions. These components of carer engagement are explained
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23 in turn below.
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29 [TABLE 4 TO GO NEAR HERE]
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34 *(i) Patient caregiving*

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36 Patient caregiving relates to such terms and practices as – “looking after the person”,
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38 “personal care”, “preventing loneliness”, “helping patients to cope and feel in control”,
39
40 “maintaining function”, “helping with rehabilitation”, “dementia support”, and “delirium
41
42 prevention” , all of which describe situations in which patients are supported by carers to
43
44 various degrees, in their treatment or care. This theme includes research about carer
45
46 expectations and preferences about their role in patient caregiving, staff working with carers
47
48 in the delivery of patient care, and the quality of caregiving. Studies have examined carer
49
50 engagement in the physical and emotional care of the patient, including supporting nutrition
51
52 (Marshall et al., 2013), personal care (Walter-Ginzburg et al., 2001), mobility (Nahm et al.,
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54 2010) and daily-living while in hospital (Clissett et al., 2013). While the role of informal
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3 carer appears to be understood internationally, cultural norms concerning caregiving, systems
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5 of health care funding, and the availability of support have an impact on carer engagement
6
7 (Yang and Kirschling, 1992; Cho and Kim, 2006; Baider and Surbone, 2014). For all
8
9 patients, hospitalization is a time of disruption from normal routine and carers may respond
10
11 to disruption proactively by trying to make sense of the situation and attempting to gain
12
13 control for themselves or the patient (Lane et al., 2003; Lindhardt et al 2008c). As a result
14
15 carers can value the support of hospital staff and services or be highly critical of the care
16
17 provided (Clissett et al., 2013). Carers' behaviours to prevent the patient from feeling alone
18
19 (Berthelsen et al., 2014) include providing loving and respectful support, practical and
20
21 cognitive support. Carers may, unprompted by staff, adopt practices to manage nutrition
22
23 (Marshall et al., 2013), provide cognitive stimulation (Yunhas et al., 2006; Health Quality
24
25 Ontario, 2008; Woods et al., 2012), support physical recovery (Small et al., 2009; de Vos et
26
27 al., 2012; Boltz et al., 2014) or prevent falls (Avila et al., 2015). Studies of caregiving have
28
29 focused on improving partnership working between carers and staff generally in elder care
30
31 environments (Laitinen, 1996; Bridges and Fuller, 2014) and specifically in relation to
32
33 communication support (Carers Trust, 2014). An intervention study of Creating Avenues for
34
35 Relative Empowerment (CARE) (Li et al., 2003) showed positive effects on carer
36
37 participation in care and patient outcomes (confusion, incontinence and depression). Another
38
39 intervention study where family carers were encouraged to room-in with patients overnight
40
41 helped to decrease confusion, complications, and length of stay (Wells and Baggs, 1999).
42
43 However, an 'activation programme' in Finland to involve carers during the hospital stay did
44
45 not show any measurable effects (Laitinen-Junkkari, et al. 2001). Research on the quality of
46
47 informal caregiving has identified the risk profile for potentially harmful caregiver behaviour
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49 (Beach et al., 2005) and generated guidance about assessment (COPE-Index) of caregiver
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51 support (McKee et al., 2003).
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4 (ii) *Shared decision making*
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6 Shared decision making relates to such terms and practices as – “being involved in treatment
7 choices”, “care planning” and “best care decisions”, which describe situations in which
8 patients are supported by carers to understand or make decisions about their treatment or
9 care. This theme includes research about negotiation of decision making (Allen, 2000), carer
10 participation in professional meetings (Griffith et al., 2004), advanced care planning (Ng et
11 al., 2013), and staff/carer decision making relationships (Karlsson et al., 2015). Carer
12 engagement in shared decision making becomes a necessity in the case of patients that are not
13 able to make decisions about their care, for example due to dementia (Milte et al., 2013;
14 Karlsson et al. 2015). Carer engagement in shared decision making can challenge established
15 cultures of professional control over caring processes (Allen, 2000; Jacelon, 2006) and
16 expectations about the roles of staff and carers (Walker and Dewar, 2001). It can require
17 extra time and modification of technical language (Milte, et al. 2013). Hence, research in this
18 area has sought to create tools and guidance to support staff to involve carers in decision
19 making about patient care (Walker and Dewar, 2001; Firth-Cozens and Cornwell, 2009; JRF
20 2012b; Brief Encounters, 2014) and to open up professional decision making spaces to carers,
21 such as multidisciplinary team meetings or best interest meetings (Griffith et al., 2004). Carer
22 reported markers of satisfactory involvement in decision making include: feeling that
23 information is shared; feeling included in decisions; feeling that there is someone you can
24 contact when you need to; and feeling that the service is responsive to your needs (Walker
25 and Dewar, 2001).
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51 (iii) *Information sharing*
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53 Information sharing relates to such terms and practices as – “sharing information about the
54 patient’s condition or history”, “helping staff to see the patient as a person”, “supporting
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3 communication between the patient and staff” and “carers feeling informed and involved”,
4
5 which describe situations in which patients are supported by carers communicating
6
7 information with staff. This theme includes research about carer knowledge of patient’s
8
9 health and journey through care, carer involvement in patient assessment and carer/staff
10
11 communication. Information sharing between carers and staff is effective if carers are
12
13 actively involved in formal patient assessments, such as Comprehensive Geriatric
14
15 Assessment (Ellis et al., 2011) and readiness for discharge to home (Pennbrant, 2013).
16
17 Structured patient information tools can help staff to share information between staff and to
18
19 see the person they are working with, by understanding their interests, preferences, likes and
20
21 dislikes (Bradway and Hirschman, 2008; Goodrich and Cornwell, 2008; Alzheimer’s Society,
22
23 2014). Life story work involving people with dementia, carers and staff has been shown to
24
25 enhance care through sharing information about a patient’s personal history, relationships and
26
27 interests (Mckeown et al., 2010; Thompson, 2011). There is an association between staff
28
29 communication with carers and the patient’s perceptions of care quality (Cornwell et al.,
30
31 2012; Robben et al., 2012). The negative impact of poor communication of information by
32
33 staff has also been observed, for example qualitative research with a small sample of family
34
35 carers of older patients undergoing haemodialysis in Norway revealed carer feelings of
36
37 powerlessness because of a lack of dialogue with staff (Aasen et al., 2011). Simple
38
39 communication strategies focused on sharing information can improve carer and staff
40
41 experiences with potential safety benefits (e.g. reduced falls risk) for patients with dementia
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43 (Bradway and Hirschman, 2008; Luxford et al. 2015). However, interview research with frail
44
45 older people and their carers (Robben et al., 2012) shows individuals vary in their
46
47 information needs but participants generally preferred verbal information from staff
48
49 accompanied by brief, clearly written information leaflets. Survey research of families with a
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51 hospitalized older relative who had delirium (Toye et al., 2014) suggests the need for
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3 informational support outside of delirium-specific units and targeted information for male
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5 relatives. Other research reveals poor uptake of family communication tools and family
6
7 conferences by providers, use of electronic checklists, and provision of staff education
8
9 despite staff buy-in (Kodali et al., 2015).
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14 *(iv) Carer support & education*
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16 Carer support and education relates to terms and practices including “becoming a carer”,
17
18 “coping with caring and stress”, “learning about the condition”, and “knowing how to help
19
20 the patient” all of which describe situations in which carers are enabled through support and
21
22 education. This theme includes research about staff recognition and valuing of the carer role
23
24 (Morris and Thomas, 2001; Nolan, 2004; Patterson et al., 2011), carer support needs (Li
25
26 2005; Toye et al., 2014), interventions to reduce carer stress (Li et al., 2004; Lin and Lu,
27
28 2005; Given and Sherwood 2006), carer education about the patient’s condition (Li et al.,
29
30 2004), and carer training for caregiving skills (Hendrix et al., 2011: 2013a). A pilot study
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32 using qualitative research on family caregivers of hospitalized elders shows carers may need
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34 support from staff (e.g. information about the patient's condition, care received, and their role
35
36 in future care and finances) (Li, 2005). A feature of research within this theme is that carers
37
38 of older people tend to be older themselves, with their own health problems and support
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40 needs. For example, interview research with 41 carers of frail older people found 85% had
41
42 health problems that affected their caregiving, suggesting that differential planning based on
43
44 each of the caregivers' needs can maximize the care they provide (Abraham and Berry, 1992).
45
46 The Self-Care TALK resource guide, developed in the US, supports and extends older
47
48 caregivers' self-care skills and abilities (Leenerts et al., 2007). Qualitative studies of carers of
49
50 people with dementia (Douglas-Dunbar and Gardiner, 2007; Rosenbloom et al., 2010;
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52 Rosenbloom and Fick, 2014) and motor neurone disease (Hornsey, 1994) also conclude the
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3 need for hospital staff to develop a therapeutic relationship with the carer, for the benefit of
4
5 both patient and carer. Questionnaire-based interviews with 98 patients with hip fracture and
6
7 their caregivers in Taiwan (Lin and Lu, 2005) found that caregivers who are unable to access
8
9 support experienced higher burden (Lockery et al., 1994; Slatyer et al., 2013). Older carers
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11 caring for older patients require accessible support. An evaluation of teleconferencing support
12
13 (McHugh et al., 2012) provided to carers (n=8) of people with dementia in the United States
14
15 (US) found important issues were group processes, external facilitation and barriers to
16
17 communication (the need for user-friendly technologies). While a pilot intervention study
18
19 providing an individualized training program to carers of hospitalized older veterans in the
20
21 US (Hendrix et al., 2011), found carer participation in training is associated with increased
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23 self-efficacy and caregiving preparedness.
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30 *(v) Carer feedback*

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32 Carer feedback relates to terms and practices including “explaining concerns to staff”,
33
34 “telling staff how you are coping”, “views about care being provided”, and “cause for
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36 complaint or dissatisfaction”, all of which describe situations in which carers give feedback
37
38 to staff about patient care or their experience of caring. Carer feedback may extend beyond
39
40 carer engagement as it is defined here (see background) to include research about carer views
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42 and perspectives about caring beyond hospitals (Laitinen, 1993; Yeh and Bull, 2012), views
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44 about carer engagement in health care, satisfaction with coherence or quality of patient care
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46 (Mackenzie et al., 2007; Andrén and Elmståhl, 2008), and experiences of transitions between
47
48 care environments (Digby and Bloomer, 2014). Accordingly many different methods of carer
49
50 feedback exist and range to include carer engagement in clinical assessment of carer needs
51
52 (Yeh and Bull, 2011), carer surveys (Andrén and Elmståhl, 2008; Laitinen, 1993),
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54 participation in research or evaluation studies (Rose et al., 2000; Mackenzie et al., 2007;
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3 Matson, 1994), development of tools or resources in palliative care (Hudson and Payne 2009;
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5 Thomas and Moore, 2014) and contributing to professional education for dementia (Ellis,
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7 2008). This theme focuses on carer engagement in feedback at the patient/ward level, but
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9 these activities may be linked to, or part of, carer engagement at the hospital level not
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11 included here.
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16 *(vi) Patient care transitions*
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18 Patient care transitions relates to terms and practices including “hospital admission”
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20 “discharge planning”, “moving wards” and “support for patients near end-of-life”, all of
21
22 which describe situations in which carers support patients in their journey of care. This theme
23
24 includes research about carer engagement in patient admission to hospital (Bowman et al.,
25
26 1998), hospital discharge (to home or other care settings) (Bauer et al., 2009), and transitions
27
28 from general medical or surgical care to specialist palliative or end-of-life care. Carer
29
30 engagement in discharge planning has received considerable research attention and has
31
32 shown the importance of family inclusion and education, communication between health care
33
34 workers and family, interdisciplinary communication and ongoing support after discharge
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36 (Bowman et al., 1998; Shyu et al., 2000; Holzhausen, 2001; Walker et al., 2007; Popejoy,
37
38 2011; Giosa et al., 2014; Bragstad et al., 2014a; 2014b; 2008; Lundh and Williams, 1997).
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40 Intervention studies on discharge planning have combined teaching, assessment and home
41
42 follow-ups (Naylor et al., 1994; Naylor et al., 1999; Lenz and Perkins, 2000; Mant et al.,
43
44 2000; Bull et al. 2000) to engage carers and improve patient outcomes. In contrast a review of
45
46 evidence on hospital discharge planning for frail older people (Bauer et al., 2009) shows a
47
48 direct correlation between inadequate practices and adverse outcomes and an increased risk
49
50 of readmission. Furthermore, interviews with carers (n=12) of patients over 75 years (Knight
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52 et al., 2013) show inadequate explanations about medicines at discharge can lead to omission
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3 of medicines or incorrect dosage. Challenges for carers can also include preparing the home,
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5 organising care at home, coping with emotional concerns (Neiterman et al., 2015) and delays
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7 in outpatient review (Mudge et al., 2013). Patient transitions may also refer to carer
8
9 engagement in supporting patients through transitions in care delivery across settings
10
11 (Coleman et al., 2004) or provision of specialist/end-of-life care (Hanratty et al., 2014).
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13 Intervention studies (Coleman et al., 2004; Ellins et al., 2012; Hendrix et al., 2013b) and
14
15 action research (Cotter et al., 1998) to improve patient transitions in care show that staff and
16
17 carer communication and support through intra hospital or cross-site patient transfers are
18
19 important for patient and carer outcomes. For example, the Care Transitions Intervention
20
21 developed in the US (Coleman et al., 2004) includes tools to promote cross-site
22
23 communication, patient and carer encouragement to take a more active role in their care and
24
25 assert their preferences, and continuity across settings and guidance from a transition coach.
26
27 Also developed in the US, a nurse practitioner-led interprofessional care model, called
28
29 Transitional Care (TLC) Partners, supports the transition from hospital to home of older
30
31 veterans and reduces rehospitalization (Hendrix et al., 2013b). Research within an integrated
32
33 health and social care system in the UK (Baillie et al., 2014) shows transitions from acute
34
35 hospital wards can be improved by removal of organisational barriers but family and carer
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37 involvement in care transitions was a major issue, alongside service integration and staff
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39 education.
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49 **DISCUSSION**

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54 This review shows that a range of types of carer engagement have been used internationally
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56 in hospital care but this tends to be limited to specific clinical or service problems (such as
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3 hospital discharge). Identifying six different components of carer engagement helps to further
4
5 define care engagement as a multifaceted element of hospital care. Although carer
6
7 engagement manifested in quite different practices and actions in hospitals, there was a
8
9 common theme to the underlying rationale – supporting the physical and emotional wellbeing
10
11 of patients.
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16 The findings echo reports in the literature that carer engagement can improve continuity of
17
18 care by providing a consistent relationship for patients through the multiple and complex
19
20 transitions in care older people are likely to experience (Ellins et al., 2012). Our findings
21
22 suggest that an integrative model of care exists (Figure 2) and establishes carer engagement
23
24 as a distinct element of hospital practice, with its own theory and evidence base, rather than
25
26 an extension of patient involvement. Drawing on the idea of a triangle of care (Carers Trust,
27
28 2014) figure 2 illustrates the interrelationships between carer engagement and interactions
29
30 between patient, carers and staff. This perspective acknowledges the ongoing and interactive
31
32 contribution of the carer alongside the patient in their journey of care, rather than specifying a
33
34 set role for carers in hospital settings. Unlike some previous interpretations of family-centred
35
36 and relationship-centred care (Nolan et al., 2004; Hudson and Payne, 2009; Patterson et al.,
37
38 2011), this perspective is sufficiently broad to inform carer engagement throughout all
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40 inpatient areas caring for older people, rather than being limited to specialist services for
41
42 older people. It could encourage hospital staff to look beyond seeing families as the only
43
44 providers of informal care: in most models there is limited understanding of the network of
45
46 social relationships within which older people live their lives. This perspective addresses the
47
48 need for a model that moves beyond family relatives or one named carer to multiple carers
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50 and dynamic engagement over time and place.
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8 *Strengths and limitations*

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10 The perspective taken in this integrative review influences the findings about what is known
11 and not known from within those perspectives. The review focused on components of carer
12 engagement rather than other perspectives, such as health care processes or effectiveness for
13 example. The review focused on the hospital inpatient context and did not include evidence
14 from research about carer engagement in outpatient contexts, long term care facilities or
15 community settings, which would require further research. The searches were in the English
16 language, so that evidence reported in other languages was not included. All articles were
17 identified through peer reviewed journals or research reports, some grey literature (e.g.
18 organisational reports and web-based information) was picked up through reference checking
19 but there was not sufficient time search for grey literature searches or to contact authors about
20 their articles. The main consequences of these limitations are that the study findings are
21 limited to interventions reported in the academic literature which could exclude unpublished
22 initiatives or ongoing improvements in hospital practice.
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41 *Implications for practice and further research*

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43 Developing carer engagement is not only about freeing up staff time in busy hospital
44 environments (Patterson et al., 2011), it also concerns developing cultures of care that value
45 and enable carer engagement (Lane et al., 2003). Indeed, carer engagement may offer a
46 means to defend professional values – such as compassion and dignity – in pressurised
47 hospital environments. There are significant implications for staff training and education,
48 including developing carer engagement as a distinct element of healthcare course curricula
49 and student assessment. Carer engagement could also be developed as a theme within staff
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3 reflective practice and continuing professional development. Future research could test the
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5 integrated model with carers of different age, gender and ethnicity in the UK and
6
7 internationally to see if it makes sense to them and to observe the effects of carer
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9 engagement. Such research should include development and testing of outcome measures in
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11 order to generate reliable evidence of the effects of carer engagement on patient outcomes,
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13 patient and carer experiences of care, and staff awareness and skills to meet older patients'
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15 needs.
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23 CONCLUSION

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27 This review supplements and extends knowledge of carer engagement by providing an
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29 overview of the existing evidence and presenting an integrated model to inform more
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31 consistent and comprehensive approaches to carer engagement in hospital care. Six
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33 components of carer engagement in hospital contexts are identified: patient caregiving,
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35 shared decision making, information sharing, carer support and education, carer feedback,
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37 and patient care transitions. Creation of a culture of carer engagement is an opportunity that
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39 hospital staff can use to improve continuity within existing structures and systems of care.
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2
3 **REFERENCES**
4
5
6

- 7 Aasen, E., Kvangarsnes, M., Wold, B. & Heggen, K. (2012) The next of kin of older people
8 undergoing haemodialysis: a discursive perspective on perceptions of participation.
9
10 *Journal of Advanced Nursing* 68(8), 1716-25.
11
12
13
14 Abraham, A. (2011) Care and Compassion? Report of the Health Service Ombudsman on ten
15 investigations into NHS care of older people. Fourth report of the Health Service
16 Commissioner for England; session 2010–2011. The Stationery Office, London.
17
18
19
20
21 Abraham, P. & Berry, M. (1992) Needs of the family caregivers of frail elderly. *Canadian*
22 *Journal of Public Health* 83(2), 147-9.
23
24
25 Allen, D. (2000). Negotiating the role of expert carers on an adult hospital ward. *Sociology of*
26 *Health & Illness* 22(2), 149-171.
27
28
29
30 Alzheimer's Society (2014) 'This is me' tool for people with dementia receiving professional
31 care. <https://www.alzheimers.org.uk/thisisme> (Accessed 3 Dec 2015)
32
33
34 Andrén, S. & Elmståhl, S. (2008) The relationship between caregiver burden, caregivers'
35 perceived health and their sense of coherence in caring for elders with dementia. *Journal*
36 *of Clinical Nursing* 17(6), 790-9.
37
38
39
40 Avila, M., Pereira, G. & Bocchi, S. (2015) Informal caregivers of older people recovering
41 from surgery for hip fractures caused by a fall: fall prevention. *Cien Saude Colet* 20(6),
42 1901-7.
43
44
45
46
47 Baidar, L. & Surbone, A. (2014) Universality of aging: carers for elderly cancer patients.
48 *Front Psychol* 5(5), 744.
49
50
51
52 Baillie, L., Gallini, A., Corser, R., Elworthy, G., Scotcher, A., & Barrand, A. (2014) Care
53 transitions for frail, older people from acute hospital wards within an integrated
54
55
56
57
58
59
60

- 1
2
3 healthcare system in England: a qualitative case study. *International Journal of Integrated*
4
5 *Care* 14 (1), e009.
6
7 Balshem, H., Helfand, M., Schünemann, H., Oxman, A., Kunz, R., Brozek, J., Vist, G.,
8
9 Falck-Ytter, Y., Meerpohl, J., Norris, S. & Guyatt, G. (2011) GRADE guidelines: 3.
10
11 Rating the quality of evidence. *Journal of Clinical Epidemiology*, 64(4), 401-406.
12
13 Barello, S., Graffigna, G., & Vegni, E. (2012) Patient engagement as an emerging challenge
14
15 for healthcare services: mapping the literature. *Nursing Research and Practice*, e905934,
16
17 7 pages.
18
19 Barnes, M., & Cotterell, P. (eds.) (2011) *Critical Perspectives on User Involvement*. The
20
21 Policy Press. University of Bristol, Bristol.
22
23 Bauer, M., Fitzgerald, L., Haesler, E. & Manfrin, M. (2009) Hospital discharge planning for
24
25 frail older people and their family. Are we delivering best practice? A review of the
26
27 evidence. *Journal of Clinical Nursing* 18(18):2539-46.
28
29
30
31 Beach, S., Schulz, R., Williamson, G., Miller, L., Weiner, M. & Lance, C. (2005) Risk
32
33 factors for potentially harmful informal caregiver behavior. *Journal of the American*
34
35 *Geriatric Society* 53(2): 255-61.
36
37
38 Berthelsen, C., Lindhardt, T. & Frederiksen, K. (2014) Maintaining Unity - relatives in older
39
40 patients' fast-track treatment programmes. A grounded theory study. *Journal of*
41
42 *Advanced Nursing* 70(12), 2746-56.
43
44
45 Boltz, M., Resnick, B., Chippendale, T. & Galvin, J. (2014) Testing a family-centered
46
47 intervention to promote functional and cognitive recovery in hospitalized older adults.
48
49 *Journal of the American Geriatric Society* 62(12), 2398-407.
50
51
52 Bowman, K., Rose, J., Kresevic, D. (1998) Family caregiving of hospitalized patients.
53
54 Caregiver and nurse perceptions at admission and discharge. *Journal of Gerontological*
55
56 *Nursing* 24(8), 8-16.
57
58
59
60

- 1
2
3 Bradway, C., & Hirschman, K. (2008) Working with families of hospitalized older adults
4
5 with dementia: caregivers are useful resources and should be part of the care team. The
6
7 American Journal of Nursing, 108(10), 52-60.
8
9
10 Bragstad, L., Kirkevold, M. & Foss, C. (2014a) The indispensable intermediaries: a
11
12 qualitative study of informal caregivers' struggle to achieve influence at and after
13
14 hospital discharge. BMC Health Service Research 30; 14:331.
15
16 Bragstad, L., Kirkevold, M., Hofoss, D. & Foss C. (2014b) Informal caregivers' participation
17
18 when older adults in Norway are discharged from the hospital. Health & Social Care in
19
20 the Community 22(2), 155-68.
21
22
23 Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research
24
25 in Psychology 3, 2, 77-101.
26
27
28 Bridges, J. & Fuller, A. (2014) Creating learning environments for compassionate care: a
29
30 programme to promote compassionate care by health and social care teams. International
31
32 Journal of Older People Nursing 10(1), 48-58.
33
34
35 Broome, M. (1993) Integrative literature reviews for the development of concepts. In
36
37 Concept Development in Nursing, 2nd edition Rodgers, B. & Knafl K. (eds), W.B.
38
39 Saunders Co., Philadelphia, PA, pp. 231–250.
40
41 Brief Encounters (2014) (www.brief-encounters.org). Cambridge Hospitals NHS Trust.
42
43 (Accessed 3 Dec 2015)
44
45
46 Bull, M., Hansen, H. & Gross, C. (2000). A professional-patient partnership model of
47
48 discharge planning with elders hospitalized with heart failure. Applied Nursing Research
49
50 13(1), 19-28.
51
52 Care Quality Commission (2011). Dignity and Nutrition Inspection Programme: National
53
54 overview. Care Quality Commission, Newcastle upon Tyne.
55
56
57
58
59
60

- 1
2
3 Carers Trust (2014) Triangle of Care. [http://professionals.carers.org/health/articles/triangle-](http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html)
4 [of-care,6802,PR.html](http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html)- I (Accessed 3 Dec 2015)
5
6
7
8 Cho, S. & Kim, H. (2006) Family and paid caregivers of hospitalized patients in Korea.
9
10 *Journal of Clinical Nursing* 15(8), 946-53.
11
12 Clissett, P., Porock, D., Harwood, R. & Gladman, J. (2013) Experiences of family carers of
13
14 older people with mental health problems in the acute general hospital: a qualitative
15
16 study. *Journal of Advanced Nursing* 69 (12), 2707-16.
17
18
19 Coleman, E., Smith, J., Frank, J., Min, S., Parry, C. & Kramer, A. (2004) Preparing patients
20
21 and caregivers to participate in care delivered across settings: The Care Transitions
22
23 Intervention. *Journal of the American Geriatrics Society* 52:1817–1825.
24
25
26 Cooper, H. (1998) *Synthesizing Research: A Guide for Literature Reviews*, 3rd edn. Sage
27
28 Publications, Thousand Oaks, CA.
29
30
31 Cooper, H. (1984) *The Integrative Research Review: A Systematic Approach*. Beverly Hills,
32
33 CA. Sage.
34
35
36 Cornwell, J., Levenson, R., Sonola, L., Poteliakhoff, E., & King's Fund (2012) Continuity of
37
38 care for older hospital patients: a call for action. King's Fund, London.
39
40
41 Cotter, A., Meyer, J. & Roberts, S. (1998) The transition from hospital to long-term
42
43 institutional care. *Nursin Times* 1, 94 (34) 54-6.
44
45
46 Coulter A. (2011) *Engaging patients in healthcare*. Berkshire, England: Open University
47
48 Press, pp 1-201.
49
50
51 de Vos, A., Asmus-Szepesi, K., Bakker, T., de Vreede, P., van Wijngaarden, J., Steyerberg,
52
53 E., Mackenbach, J. & Nieboer, (2012) An Integrated approach to prevent functional
54
55 decline in hospitalized elderly: the Prevention and Reactivation Care Program (PReCaP).
56
57
58
59
60 *BMC Geriatrics* 12:7.

- 1
2
3 Denzin N., Lincoln Y. (2000) (Eds.) Handbook of Qualitative Research (2nd ed). Sage,
4
5 Thousand Oaks, CA.
6
7
8 Digby, R. & Bloomer, M. (2014) People with dementia and the hospital environment: the
9
10 view of patients and family carers. *International Journal of Older People Nursing* 9, 34–
11
12 43.
13
14 Douglas-Dunbar, M. & Gardiner, P. (2007) Support for carers of people with dementia
15
16 during hospital admission. *Nursing Older People*, 19(8), 27-30.
17
18
19 Ellins, J., Glasby, J., Tanner, D., McIver, S., Davidson, D., Littlechild, R., & Spence, K.
20
21 (2012). Understanding and improving transitions of older people: a user and carer
22
23 centred approach. Final report. UK: NHR Service Delivery and Organisation
24
25 Programme. Birmingham University, Birmingham.
26
27
28 Ellis, G., Whitehead, M., Robinson, D., O'Neill, D. & Langhorne P (2011) Comprehensive
29
30 geriatric assessment for older adults admitted to hospital: meta-analysis of randomised
31
32 controlled trials. *British Medical Journal*, 343, d6553.
33
34
35 Ellis, J. (2008) Carer-driven dementia education for professionals. *Nursing Older People*
36
37 20(2), 35-9.
38
39
40 Ferlie, E. & Shortell, S. (2001) Improving the quality of health care in the United Kingdom
41
42 and the United States: a framework for change. *Milbank Quarterly* 79(2), 281-315.
43
44
45 Firth-Cozens, J. & Cornwell, J. (2009) *The Point of Care: Enabling compassionate care in*
46
47 acute hospital settings. London: The King's Fund, London.
48
49
50 Fotaki, M. (2011) Towards developing new partnerships in public services: Users as
51
52 consumers, citizens and/or co-producers in health and social care in England and
53
54 Sweden. *Public Administration* 89 (3), 933-955.
55
56
57 Francis, R. (2013) Report of the Mid Staffordshire NHS Foundation Trust public inquiry:
58
59 executive summary (Vol. 947) The Stationery Office, London.
60

- 1
2
3 Giosa, J., Stolee, P., Dupuis, S., Mock, S. & Santi, S (2014)). An examination of family
4
5 caregiver experiences during care transitions of older adults. *Canadian Journal of Aging*
6
7 33(2), 137-53.
8
9
10 Given, B. & Sherwood, P. (2006) Family care for the older person with cancer. *Seminars in*
11
12 *Oncology Nursing* 22(1), 43-50.
13
14 Godfrey, M., Smith, J., Green, J., Cheater, F., Inouye, S. & Young, J. (2013) Developing and
15
16 implementing an integrated delirium prevention system of care: a theory driven,
17
18 participatory research study. *BMC Health Serv Res.* 13:341.
19
20
21 Goodrich, J. & Cornwell, J. (2008). *Seeing the Person in the Patient: The Point of Care*
22
23 review paper. The King's Fund, London.
24
25 Gough, D., Thomas, J., & Oliver, S. (2012) Clarifying differences between review designs
26
27 and methods. *Systematic Reviews* 1, 1-28.
28
29
30 Griffith, J., Brosnan, M., Lacey, K., Keeling, S. & Wilkinson, T. (2004) Family meetings - a
31
32 qualitative exploration of improving care planning with older people and their families.
33
34 *Age & Ageing* 33(6), 577-81.
35
36 Hancock, K., Chang, E., Chenoweth, L., Clarke, M., Carroll, A. & Jeon, Y. (2003) Nursing
37
38 needs of acutely ill older people. *Journal of Advanced Nursing* 44(5), 507-16.
39
40
41 Hanratty, B., Lowson, E., Grande, G., Payne, S., Addington-Hall, J., Valtorta, N. & Seymour,
42
43 J. (2014) Transitions at the end of life for older adults – patient, carer and professional
44
45 perspectives: a mixed-methods study. *Health Services and Delivery Research* 2 (17).
46
47
48 Hartgerink, J., Cramm, J., Bakker, T., Mackenbach, J. & Nieboer, A. (2015) The importance
49
50 of older patients' experiences with care delivery for their quality of life after
51
52 hospitalization. *BMC Health Services Research*, 15, 311.
53
54
55 Health Quality Ontario. (2008) Caregiver- and patient-directed interventions for dementia: an
56
57 evidence-based analysis. *Ontario Health Technology Assessment Series* 8(4), 1-98.
58
59
60

- 1
2
3 Hendrix, C., Hastings, S., Van Houtven, C., Steinhauer, K., Chapman, J., Ervin, T., Sanders,
4
5 L. & Weinberger, M. (2011) Pilot study: individualized training for caregivers of
6
7 hospitalized older veterans. *Nursing Research* 60(6), 436-41.
8
9
10 Hendrix, C., Landerman, R. & Abernethy, A. (2013a) Effects of an individualized caregiver
11
12 training intervention on self-efficacy of cancer caregivers. *West Journal of Nursing*
13
14 *Research* 35(5), 590-610.
15
16
17 Hendrix, C., Tepfer, S., Forest, S., Ziegler, K., Fox, V., Stein, J., McConnell, E., Hastings, S.,
18
19 Schmader, K., & Colon-Emeric, C. (2013b) Transitional Care Partners: a hospital-to-
20
21 home support for older adults and their caregivers. *Journal of the American Association*
22
23 *of Nurse Practitioners* 25(8), 407-14.
24
25
26 Holzhausen, E. (2001) *You Can Take Him Home Now: Carers' experience of hospital*
27
28 *discharge*. Carers National Association: London.
29
30
31 Hornsey, J. (1994) Empowering patient and carer through terminal MND. *Nursing Times*
32
33 90(29), 37-9.
34
35
36 Hudson, P. & Payne, S. (2009) *Family carers in palliative care-a guide for health and social*
37
38 *care professionals*. Oxford University Press, Oxford.
39
40
41 Jacelon, C. (2006) Directive and supportive behaviors used by families of hospitalized older
42
43 adults to affect the process of hospitalization. *Journal of Family Nursing* 12(3), 234-50.
44
45
46 JRF (2012a) *Improving decision making in the care and support of older people*. Joseph
47
48 Rowntree Foundation, York.
49
50
51 JRF (2012b) *Continuity of care for older hospital patients: A call to action*. Joseph Rowntree
52
53 *Foundation, York*.
54
55
56 Jurgens, F., Clissett, P., Gladman, J., Harwood, R. (2012) Why are family carers of people
57
58 with dementia dissatisfied with general hospital care? A qualitative study. *BMC*
59
60 *Geriatrics* 24, 12:57.

- 1
2
3 Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M., Stephan, A., Suhonen, R.,
4
5 Zabalegui, A., Hallberg, I. (2015) Dementia care in European countries, from the
6
7 perspective of people with dementia and their caregivers. *Journal of Advanced Nursing*
8
9 71 (6), 1405-16.
10
11
12 Knight, D., Thompson, D., Mathie, E. & Dickinson, A. (2013) 'Seamless care? Just a list
13
14 would have helped!' Older people and their carer's experiences of support with
15
16 medication on discharge home from hospital. *Health Expectations* 16(3), 277-91.
17
18
19 Kodali, S., Stametz, R., Clarke, D., Bengier, A., Sun, H., Layon, A. & Darer, J. (2015)
20
21 Implementing family communication pathway in neurosurgical patients in an intensive
22
23 care unit. *Palliative & Supportive Care* 13 (4), 961-967.
24
25
26 Laitinen, P. (1993) Participation of caregivers in elderly-patient hospital care: informal
27
28 caregiver approach. *Journal of Advanced Nursing* 18(9), 1480-7.
29
30
31 Laitinen, P. & Isola, A. (1996) Promoting participation of informal caregivers in the hospital
32
33 care of the elderly patient: informal caregivers' perceptions. *Journal of Advanced Nursing*
34
35 23(5), 942-7.
36
37
38 Laitinen-Junkkari, P., Merilainen, P. & Sinkkonen, S. (2001) Informal participation in
39
40 elderly-patient care: An interrupted time-series study. *International Journal of Nursing*
41
42 *Practice* 7, 199-213.
43
44
45 Lane, P., McKenna, H., Ryan, A. & Fleming, P. (2003) The experience of the carers' role: a
46
47 qualitative study. *Research & Theory for Nursing Practice* 17(2), 137-51.
48
49
50 Leenerts, M., Teel, C. & Shafton, G. (2007) Designing a Resource Guide to help promote
51
52 health in caregiving. *International Journal of Older People Nursing*. 2(3), 189-97.
53
54
55 Lenz, E. & Perkins, S. (2000) Coronary artery bypass graft surgery patients and their family
56
57 member caregivers: Outcomes of a family focused staged psycho-educational
58
59 intervention. *Applied Nursing Research* 13(3), 142-150.
60

- 1
2
3 Levenson, R. (2007) *The Challenge of Dignity in Care: Upholding the rights of the*
4
5 individual. *Help the Aged*: London.
6
- 7 Li, H., Melnyk, B. & McCann, R. (2004) Review of intervention studies of families with
8
9 hospitalized elderly relatives. *Journal of Nursing Scholarship* 36 (1), 54-9.
10
- 11 Li, H. (2005) Hospitalized elders and family caregivers: a typology of family worry. *Journal*
12
13 of *Clinical Nursing* 14(1), 3-8.
14
- 15 Li, H., Melnyk, B., McCann, R., Chatcheydang, J., Koukouglioti, C., Nichols, L., Lee, M. &
16
17 Ghassemi, A. (2003) *Creating Avenues for Relative Empowerment (CARE): A pilot test*
18
19 of an intervention to improve outcomes of hospitalized elders and family caregivers.
20
21 *Research in Nursing and Health*, 26, 284-299.
22
- 23 Lin, P. & Lu, C. (2005) Hip fracture: family caregivers' burden and related factors for older
24
25 people in Taiwan. *Journal of Clinical Nursing* 14(6), 719-26.
26
27
- 28 Lindhardt, T., Bolmsjö, I. & Hallberg, I. (2006) Standing guard – being a relative to a
29
30 hospitalised, elderly person. *Journal of Aging Studies* 20(2), 133-149.
31
- 32 Lindhardt, T., Hallberg, I., & Poulsen, I. (2008a) Nurses' experience of collaboration with
33
34 relatives of frail elderly patients in acute hospital wards: A qualitative study.
35
36 *International Journal of Nursing Studies*, 45(5), 668-681.
37
- 38 Lindhardt, T., Nyberg, P. & Hallberg, I. (2008b). Collaboration between relatives of elderly
39
40 patients and nurses and its relation to satisfaction with the hospital care trajectory.
41
42 *Scandinavian Journal of Caring Sciences*, 22(4), 507-519.
43
- 44 Lindhardt, T., Nyberg, P. & Hallberg, I. R. (2008c) Relatives' view on collaboration with
45
46 nurses in acute wards: Development and testing of a new measure. *International Journal*
47
48 of *Nursing Studies* 45(9), 1329-1343.
49
- 50 Lockery, S., Dunkle, R., Kart, C. & Coulton, C. (1994) Factors contributing to the early
51
52 rehospitalization of elderly people. *Health & Social Work*, 19(3), 182-91.
53
54
55
56
57
58
59
60

- 1
2
3 Lundh, U. & Williams, S. (1997) The challenges of improving discharge planning in Sweden
4 and the UK: different but the same. *Journal of Clinical Nursing*, 6(6), 435-42.
5
6
7 Luxford, K., Axam, A., Hasnip, F., Dobrohotoff, J., Strudwick, M., Reeve, R., Hou, C., &
8
9 Viney, R. (2015) Improving clinician-carer communication for safer hospital care: a
10 study of the 'TOP 5' strategy in patients with dementia. *International Journal of Quality*
11 *in Health Care*. 27(3), 175-82.
12
13
14 Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G., & Mann, H. (2007) Family
15 carers of stroke survivors: needs, knowledge, satisfaction and competence in caring.
16 *Disability & Rehabilitation*, 29(2), 111-121.
17
18
19 Mant, J., Carter, J., Wade, D. & Winner, S. (2000). Family support for stroke: A randomized
20 controlled trial. *Lancet* 356, 808-813.
21
22
23 Marshall, S., Bauer, J., Capra, S. & Isenring E. (2013) Are informal carers and community
24 care workers effective in managing malnutrition in the older adult community? A
25 systematic review of current evidence. *Journal of Nutrition Health & Aging* 17(8), 645-
26 51.
27
28
29 Matson, N. (1994) Coping, caring and stress: a study of stroke carers and carers of older
30 confused people. *British Journal of Clinical Psychology* 33(3), 333-44.
31
32
33 McHugh, J., Wherton, J., Prendergast, D., Lawlor, B. (2012) Teleconferencing as a source of
34 social support for older spousal caregivers: initial explorations and recommendations for
35 future research. *American Journal of Alzheimer's Disease & Other Dementias* 27(6),
36 381-7.
37
38
39 McKee, K., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., Spazzafumo, L.,
40 Bień, B., Parker, C., Nolan, M., & Szczerbinska, K. (2003) The COPE index- a first
41 stage assessment of negative impact, positive value and quality of support of caregiving
42 in informal carers of older people. *Aging & Mental Health* 7(1):39-52.
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 Mckeown, J., Clarke, A., Ingleton, C., Ryan, T. & Repper, J. (2010) The use of life story
4
5 work with people with dementia to enhance person-centred care. *International Journal of*
6
7 *Older People Nursing* 5, 148–158.
8
9
10 Milte, C., Ratcliffe, J., Davies, O., Whitehead, C., Masters, S. & Crotty, M. (2013) Family
11
12 meetings for older adults in intermediate care settings: the impact of patient cognitive
13
14 impairment and other characteristics on shared decision making. *Health Expectations* 18
15
16 (5), 1030-40.
17
18
19 Morris, S. & Thomas, C. (2001) The carer's place in the cancer situation: where does the
20
21 carer stand in the medical setting? *European Journal of Cancer Care* 10(2), 87-95.
22
23
24 Mudge, A., Shakhovskoy, R. & Karrasch, A. (2013) Quality of transitions in older medical
25
26 patients with frequent readmissions: opportunities for improvement. *European Journal of*
27
28 *Internal Medicine* 24(8), 779-83.
29
30
31 Nahm, E., Resnick, B., Orwig, D., Magaziner, J. & Degrazia, M. (2010) Exploration of
32
33 informal caregiving following hip fracture. *Geriatric Nursing*, 31(4), 254-62.
34
35
36 NICE (2004) Improving supportive and palliative care for adults with cancer. The manual.
37
38 National Institute for Health and Care Excellence, London.
39
40
41 NICE (2013) Clinical Guidance 161, Assessment and prevention of falls in older people.
42
43 Section 1.1.10: Education and information giving. National Institute for Health and Care
44
45 Excellence, London.
46
47
48 NICE (2012) Quality Standard 15, Patient experience in adult NHS services . Quality
49
50 Statement 13: Sharing information with partners, family members and carers. National
51
52 Institute for Health and Care Excellence, London.
53
54
55 NICE (2011) Quality Standard 13, End of life care for adults. Quality Statement 7: Holistic
56
57 support families and carers. National Institute for Health and Care Excellence, London.
58
59
60

- 1
2
3 Naylor, M., Brooten, D., Campbell, R., Jacobsen, B., Mezey, M., Pauly, M. & Schwartz, J.
4
5 (1999) Comprehensive discharge planning and home follow-up of hospitalized elders: A
6
7 randomized clinical trial. *Journal of the American Medical Association* 181(7), 613-620.
8
9
10 Naylor, M., Brooten, D., Johnes, R., Lavizzo-Mourey, R., Mezey, M., & Pauly, M. (1994)
11
12 Comprehensive discharge planning for the hospitalized elderly: A randomized clinical
13
14 trial. *American College of Physicians* 120(12), 999-1006.
15
16 Neiterman, E., Wodchis, W. & Bourgeault, I. (2015) Experiences of older adults in transition
17
18 from hospital to community. *Canadian Journal of Aging* 34(1), 90-9.
19
20
21 Ng, R., Chan, S., Ng, T., Chiam, A. & Lim, S. (2013) An exploratory study of the
22
23 knowledge, attitudes and perceptions of advance care planning in family caregivers of
24
25 patients with advanced illness in Singapore. *BMJ Supportive & Palliative Care* 3(3), 343-
26
27 8.
28
29
30 Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004) Beyond 'person-centred'
31
32 care: a new vision for gerontological nursing. *Journal of Clinical Nursing* 13(s1), 45-53.
33
34
35 Noyes, J. & Lewin, S. (2011) Chapter 5: Extracting qualitative evidence. In: Noyes, J.,
36
37 Booth, A., Hannes, K., Harden, A., Harris, J., Lewin, S., Lockwood, C. (editors)
38
39 Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic
40
41 Reviews of Interventions. Cochrane Collaboration Qualitative Methods Group.
42
43
44 Oliver, D., Foot, C. & Humphries, R. (2014) Making our health and care systems fit for an
45
46 ageing population. The King's Fund: London.
47
48
49 Patterson, M., Nolan, M., Rick, J., Brown, J., Adams, R., & Musson, G. (2011) From metrics
50
51 to meaning: culture change and quality of acute hospital care for older people. National
52
53 Institute for Health Research Service Delivery & Organisation programme project,
54
55 3(1501), 93.
56
57
58
59
60

- 1
2
3 Pennbrant, S. (2013) A trustful relationship-the importance for relatives to actively
4 participate in the meeting with the physician. *Int J Qual Stud Health Well-being*.
5 8:20608.
6
7
8
9
10 Popejoy, L. (2011) Complexity of family caregiving and discharge planning. *Journal of*
11 *Family Nursing* 17(1), 61-81.
12
13
14 Porter, S., O'Halloran, P., & Morrow, E. (2011) Bringing values back into evidence-based
15 nursing: the role of patients in resisting empiricism. *Advances in Nursing Science* 34(2),
16 106-118.
17
18
19
20 Robben, S., van Kempen, J., Heinen, M., Zuidema, S., Olde Rikkert, M., Schers, H. & Melis,
21 R. (2012) Preferences for receiving information among frail older adults and their
22 informal caregivers: a qualitative study. *Family Practice* 29(6), 742-7.
23
24
25
26
27 Rose, J., Bowman, K. & Kresevic, D. (2000) Nurse versus family caregiver perspectives on
28 hospitalized older patients: an exploratory study of agreement at admission and
29 discharge. *Health Communication* 12(1), 63-80.
30
31
32
33
34 Rosenbloom, D. & Fick, D. (2014) Nurse/family caregiver intervention for delirium increases
35 delirium knowledge and improves attitudes toward partnership. *Geriatric Nursing* 35(3),
36 175-81.
37
38
39
40
41 Rosenbloom-Brunton, D., Henneman, E. & Inouye, S. (2010) Feasibility of family
42 participation in a delirium prevention program for hospitalized older adults. *Journal of*
43 *Gerontology Nursing* 36(9), 22-33.
44
45
46
47 Sandberg, J. & Eriksson, H. (2009) From alert commander to passive spectator: older male
48 carers' experience of receiving formal support. *International Journal of Older People*
49 *Nursing* 4, 33-40.
50
51
52
53
54
55
56
57
58
59
60

1
2
3 Shyu, Y., Chen, M., Chen, S., Wang, H. & Shao, J. (2008) A family caregiver-oriented
4
5 discharge planning program for older stroke patients and their family caregivers. *Journal*
6
7 of *Clinical Nursing*. 17(18), 2497-508.
8

9
10 Shyu, Y. (2000) The needs of family caregivers of frail elders during the transition from
11
12 hospital to home: a Taiwanese sample. *Journal of Advanced Nursing* 32(3), 619-25.
13

14 Slatyer, S., Toye, C., Popescu, A., Young, J., Matthews, A., Hill, A. & Williamson, D. (2013)
15
16 Early re-presentation to hospital after discharge from an acute medical unit: perspectives
17
18 of older patients, their family caregivers and health professionals. *Journal of Clinical*
19
20 *Nursing* 22(3-4), 445-55.
21

22
23 Small, N., Green, J., Spink, J., Forster, A. & Young, J. (2009) Post-acute rehabilitation care
24
25 for older people in community hospitals and general hospitals-philosophies of care and
26
27 patients' and caregivers' reported experiences: a qualitative study. *Disability*
28
29 *Rehabilitation* 31(22), 1862-72.
30

31
32 The Care Act (2014) Part 1: Care and Support. UK Legislation.
33

34 Thomas, K. & Moore, G. (2014) The development and evaluation of a multimedia resource
35
36 for family carers of patients receiving palliative care: A consumer-led project. *Palliative*
37
38 and *Supportive Care* 13 (3), 417-23.
39

40 Thompson, R. (2011) Using life story work to enhance care. *Nursing Older People* 23(8), 16-
41
42 21.
43

44
45 Tobiano, G., Marshall, A., Bucknall T., Chaboyer W. (2015) Patient participation in nursing
46
47 care on medical wards: An integrative review. *Int J Nurs Stud*. 2015 Feb 19.
48

49 Toye, C., Matthews, A., Hill, A. & Maher, S. (2014) Experiences, understandings and
50
51 support needs of family carers of older patients with delirium: a descriptive mixed
52
53 methods study in a hospital delirium unit. *International Journal of Older People Nursing*
54
55 9 (3), 200-8.
56
57
58
59
60

- 1
2
3 Walker, C., Hogstel, M. & Curry, L. (2007) Hospital discharge of older adults. How nurses
4
5 can ease the transition. *American Journal of Nursing*, 107(6), 60-70.
6
7 Walker, E. & Dewar, B. (2001) How do we facilitate carers' involvement in decision
8
9 making? *Journal of Advanced Nursing* 34(3), 329-337.
10
11 Walter-Ginzburg, A., Guralnik, J., Blumstein, T., Gindin, J. & Modan, B. (2001) Assistance
12
13 with personal care activities among the old-old in Israel: a national epidemiological
14
15 study. *Journal of American Geriatric Society* 49(9), 1176-84.
16
17 Wells, N. & Baggs, J. (1997) Rooming-in for elderly surgical patients. *Applied Nursing*
18
19 *Research* 10 (2), 72-79.
20
21
22
23 Whittamore, K., Goldberg, S., Bradshaw, L., Harwood, R. (2014) Medical crises in older
24
25 people study group. Factors associated with family caregiver dissatisfaction with acute
26
27 hospital care of older cognitively impaired relatives. *Journal of American Geriatric*
28
29 *Society*. 62(12), 2252-60.
30
31
32 Whittemore, R., & Knafl, K. (2005) The integrative review: updated methodology. *Journal of*
33
34 *Advanced Nursing* 52(5), 546-553.
35
36 Woods, B., Aguirre, E., Spector, A. & Orrell, M. (2012) Cognitive stimulation to improve
37
38 cognitive functioning in people with dementia. *Cochrane Database of Systematic*
39
40 *Reviews*. 15, 2:CD005562.
41
42
43 Yang, C. & Kirschling, J. (1992) Exploration of factors related to direct care and outcomes of
44
45 caregiving. Caregivers of terminally ill older persons. *Cancer Nursing* 15 (3), 173-81.
46
47 Yeh, P. & Bull, M. (2012) Use of the resiliency model of family stress, adjustment and
48
49 adaptation in the analysis of family caregiver reaction among families of older people
50
51 with congestive heart failure. *International Journal of Older People Nursing* 7(2), 117-26.
52
53
54
55
56
57
58
59
60

1
2
3 Yuhas, N., McGowan, B., Fontaine, T., Czech, J., Gambrell-Jones, J. (2006) Psychosocial
4
5 interventions for disruptive symptoms of dementia. Journal of Psychosocial Nursing &
6
7 Mental Health Services 44 (11), 34-42.
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
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For Peer Review

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CONFLICTS OF INTEREST

None declared.

CONTRIBUTIONS TO THE MANUSCRIPT

Study design (CN, EM), data collection and analysis (EM, CN), and manuscript preparation (EM, CN).

Figure 1: Flow chart of integrative review method

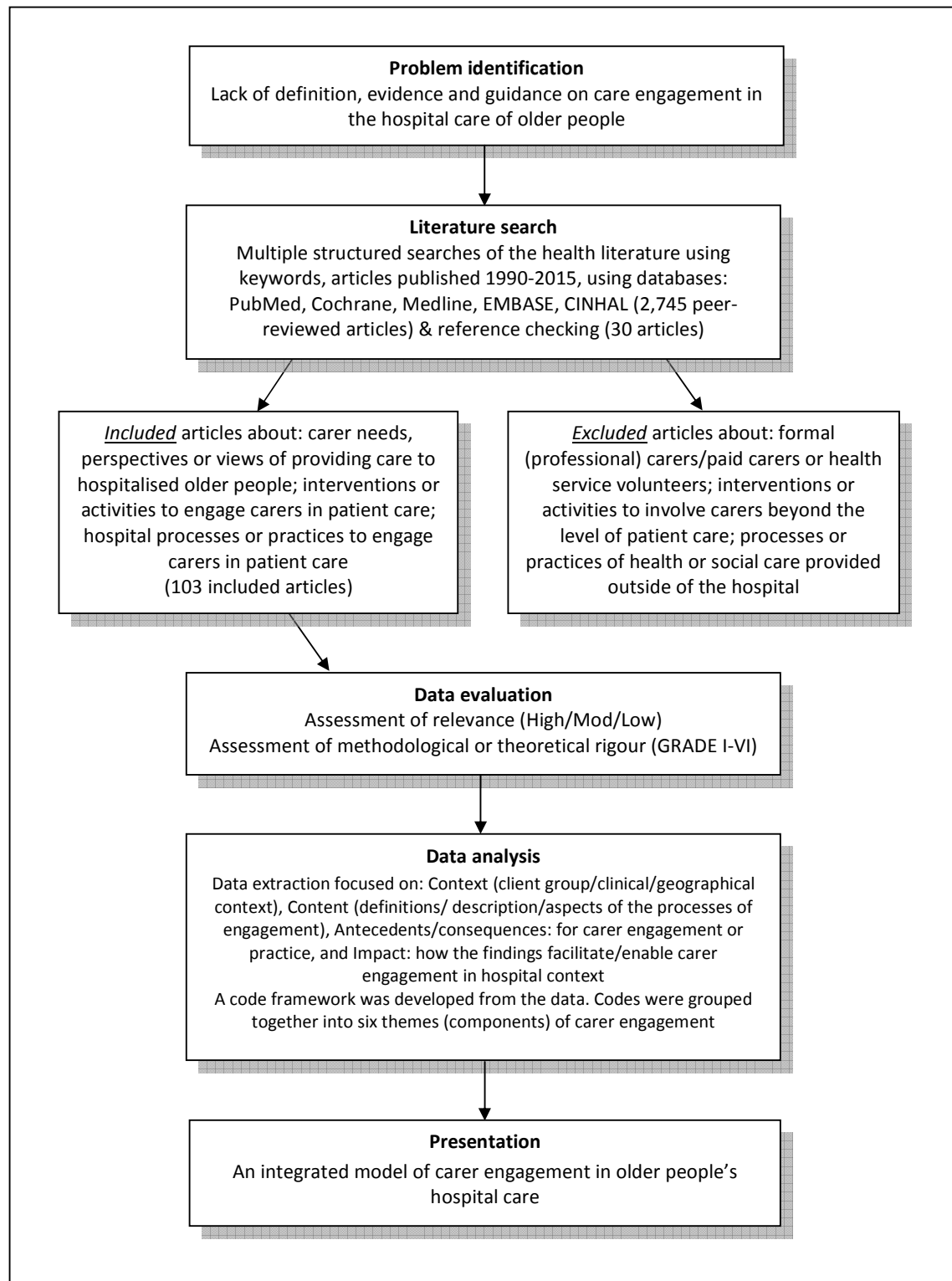


Table 1: Example search showing key words

Database:	
PubMed	
Search query:	
AND	((carer[Title] OR caregiver[Title] OR family[Title] OR relative[Title]) (engagement[Title/Abstract] OR involvement[Title/Abstract] OR collaboration[Title/Abstract] OR participation[Title/Abstract] OR partnership[Title/Abstract] OR decision-making[Title/Abstract] OR information[Title/Abstract] OR communication[Title/Abstract] OR education[Title/Abstract] OR training[Title/Abstract]))
AND	((older[All Fields]
AND	("patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields])) OR (older[All Fields]
AND	("persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields])) OR ("aged"[MeSH Terms] OR "aged"[All Fields] OR "elderly"[All Fields]) OR geriatric[All Fields])
AND	(("hospitals"[MeSH Terms] OR "hospitals"[All Fields] OR "hospital"[All Fields]) OR ("Acute Care"[Journal] OR "acute"[All Fields] AND "care"[All Fields]) OR "acute care"[All Fields]))
MeSH Terms:	
patient	"patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields]
person	"persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields]
elderly	"aged"[MeSH Terms] OR "aged"[All Fields] OR "elderly"[All Fields]
hospital	"hospitals"[MeSH Terms] OR "hospitals"[All Fields] OR "hospital"[All Fields]
acute care	"Acute Care"[Journal] OR ("acute"[All Fields] AND "care"[All Fields]) OR "acute care"[All Fields]
Filters:	
AND	("1990"[Date - Publication]: "2015"[Date - Publication]))
AND	English[Language]
Result:	
1466	

Table 2: Inclusion/exclusion criteria

- i. ***Included:*** articles about carer needs, perspectives or views of providing care to hospitalised older people, defined as “Informal caregivers, family members, friends, relatives, or neighbours who have experience of caring for an older person in hospital”. Carers may be caring for patients with multiple morbidities, cancer, stroke, elective or emergency medical or surgical treatment, renal, respiratory or palliative care, and/or dementia.

Excluded: articles about formal (professional) carers/paid carers or health service volunteers.

- ii. ***Included:*** articles about interventions or activities to engage carers in patient care, including: participation, engagement or involvement in the delivery of hospital care to patients, carer participation in education, support or training provided within hospital settings, participation in research or interventions, engagement through carer feedback, collection of comments, surveys/ observations or feedback, consultation (e.g. focus groups, interviews, arts-based methods), health interventions or self-management programmes within the hospital setting.

Excluded: articles about interventions or activities to involve carers beyond the level of patient care, including hospital service development or quality improvement work, Patient and Public Involvement (PPI) in hospital design or management, national level service user groups/ networks, carer engagement in healthcare staff education or formal assessment outside of the hospital context, carer involvement in service-level quality monitoring and health service investigations.

- iii. ***Included:*** articles about hospital processes or practices to engage carers in patient care, including: patient or carer assessment, care planning or delivery of care, collection of patient information, delivery of basic or essential care (safety, nutrition, hygiene, dignity), communication, shared decision making, recognising and respond to changes in the patient, support for medicine management or self-care, best care or end-of-life care decisions, care planning and management of transitions in care, including discharge planning, helping to maintain independence or adjust to a level of need.

Excluded: articles about processes or practices of health or social care provided outside of the hospital (e.g. primary care, community or long term residential care).

Table 3: Data extraction table (extract)

Reference (date)	Relevance/Grade of evidence: REL (High/Mod/Low) GRADE (High I- low IV)	Context: client group/ clinical/ geographical context	Content: definitions/ description/ aspects of the processes of engagement	Antecedents/consequences: for carer engagement or practice	Impact: How the findings facilitate carer engagement in hospitals
Alzheimer's Society (2014)	'This is me' tool for carers. A downloadable leaflet, originally developed for people with dementia who were going into hospital, has now been updated and is relevant for people with dementia who are receiving professional care in any setting. (REL: High) (GRADE: IV)	A tool for people with dementia and their carers to complete that lets health and social care professionals know about their needs, interests, preferences, likes and dislikes. Relevant to carer engagement in a range of clinical contexts including hospitals. (UK)	Provides a central place for carers and patients to record patient personal information and preferences. It supports health and social care staff in the gathering of personal/ life history information from individuals with dementia, and in tailoring care more specifically to patient/carers needs.	'This is me' is about the person at the time the document is completed and needs to be revised and updated as necessary through patient care. carer literacy. Possible issues of literacy, language, ownership and confidentiality of document.	Provides an accessible way for carers and professionals to share information about patients and their care. Facilitates communication and shared decision making.
Bridges and Fuller (2014)	Creating Learning Environments for Compassionate Care (CLECC) uses workplace learning to promote change at unit/ward/team level by enabling the development of leadership and team relational practices which are also designed to enhance the capacity of individual team members to relate to older people. (REL: Mod) (GRADE III)	Aims to optimise relational capacity of individuals and teams to support the delivery of compassionate care to older people. A four month implementation programme designed for hospital ward nursing teams caring for older people, but relevant to other teams working with other client groups. (UK)	This evidence-based intervention is designed to develop and sustain the relational work required by managers and team members to support care delivery and has the potential to address widely documented variations in care quality. Describes importance of carer engagement and staff working in partnership with carers.	Little is known about the feasibility of the intervention in practice. Possible issues are identifying carers and how teams of staff communicate with carers and share information about patient care.	Novel implementation programme designed to improve and support the delivery of compassionate care by health and social care teams. Potential to engage carers in immediate improvement in patient care/ hospital environment.
Brief Encounters (2014)	Brief Encounters - A resource to promote effective communication between staff and patients/families in hospitals www.brief-encounters.org (REL: High) (GRADE IV)	Provides information about communication issues and explains staff needs and patient needs in relation to clinical relationships and communication in stressful situations, focusing on patients with dementia or cognitive impairment. (UK)	Draws on staff and carer perspectives of communication issues. Considers patient/carers relationships and implications for how staff communicate with patients.	Relies on staff willingness to engage with the resource and apply knowledge in practice. Staff may not recognise older people's mental health needs or the implications for caregiving.	This communication aid can help resolve tensions and support information sharing and relationship building between patients, carers and staff.
Carers Trust (2014)	The Triangle of Care is a project based on a guide developed by carers of people accessing mental health services. Six key standards to include, inform and support carers have been extended and adapted by health providers including hospitals. (REL: High) (GRADE III)	Guide designed for inpatient services with focus on mental health but has been revised and extended to other service contexts including carers of older people with dementia when the person they care for is admitted to hospital. (UK)	The UK RCN is using the guide as part of their Dignity in Dementia: Improving Care in Hospital Settings. A new guide: Triangle of Care, Carers Included – Best Practice in Dementia Care has been developed in partnership with carers, people with dementia and professionals to address this particular field of health care.	Staff need training and support to learn about key standards and how they apply to their practice. Management support is needed so that teams can implement the Triangle of Care consistently in practice.	Staff have a better understanding of ways of working with carers. Carers are included, informed and better supported when they are caring for someone with a serious mental health condition or impairment.

Table 4: Characteristics of included articles

Subjects		Study design	
Carers/caregivers	57	Qualitative	50
Family carers/relatives	45	Quantitative	27
Expert carers (established family carers)	1	Review	18
		Mixed-methods	7
		Action research	1
Location of authors		Condition/context	
UK	39	Older patients/unspecified	46
USA	30	Dementia/cognitive impairment	16
Australia	7	Frailty/multiple conditions	7
Canada	4	Palliative/end-of-life care	6
Taiwan	4	Hip or knee surgery	5
Sweden	4	Cancer	4
Norway	3	Delirium	4
Finland	3	Stroke	4
The Netherlands	2	Congestive heart failure	3
Israel	2	Elderly care wards	2
Brazil	1	Neurosurgical	1
Denmark	1	Haemodialysis	1
Korea	1	Alzheimer's disease	1
New Zealand	1	Harmful behaviour	1
Singapore	1	Emotional vulnerability	1
		Motor neurone disease	1
Components of carer engagement (themes)			
<p>Patient caregiving: Avila et al. 2015; Baider & Surbone 2014; Beach et al. 2005; Berthelsen et al. 2014; Boltz et al. 2014; Bridges & Fuller 2014; Carers Trust 2014; Cho & Kim 2006; Clissett et al. 2013; de Vos et al. 2012; Godfrey et al. 2013; Health Quality Ontario 2008; Lane et al. 2003; Laitinen & Isola 1996; Laitinen-Junkkari et al. 2001; Lindhardt et al. 2008; McKee et al. 2003; Marshall et al. 2013; Nahm et al. 2010; Small et al. 2009; Walter-Ginzburg et al. 2001; Wells & Baggs 1997; Woods et al. 2012; Yang & Kirschling 1992; Yuhas et al. 2006</p>			
<p>Information sharing: Aasen et al. 2012; Alzheimer's Society 2014; Bradway & Hirschman 2008; Cornwell et al. 2012; Ellis et al. 2011; Goodrich & Cornwell 2008; Kodali et al. 2015; Luxford et al. 2015; Mckeown et al. 2010; Pennbrant 2013; Robben et al. 2012; Thompson 2011; Toye et al. 2014</p>			
<p>Shared decision making: Allen 2000; Brief Encounters 2014; Firth-Cozens & Cornwell 2009; Griffith et al. 2004; Jacelon 2006; JRF 2012; Karlsson et al. 2015; Milte et al. 2013; Ng et al. 2013; Walker & Dewar 2001</p>			
<p>Carer support and education: Abraham & Berry 1992; Douglas-Dunbar & Gardiner 2007; Given & Sherwood 2006; Hendrix et al. 2011; Hendrix et al. 2013a; Hornsey 1994; Leenerts et al. 2007; Li 2005; Li 2004; Li et al. 2003; Lin & Lu 2005; Lockery et al. 1994; McHugh et al. 2012; Morris & Thomas 2001; Nolan et al. 2004; Patterson et al. 2011; Rosenbloom & Fick 2014; Rosenbloom-Brunton et al. 2010; Slatyer et al. 2013</p>			
<p>Carer feedback: Andrén & Elmståhl 2008; Digby & Bloomer 2014; Ellis 2008; Hudson and Payne 2009; Laitinen 1993; Mackenzie et al. 2007; Matson 1994; Rose et al. 2000; Thomas & Moore 2014; Yeh & Bull 2012</p>			
<p>Patient care transitions: Baillie et al. 2014; Bauer et al. 2009; Bowman et al. 1998; Bragstad et al. 2014a; Bragstad et al. 2014b; Bull et al. 2000; Coleman et al. 2004; Cotter et al. 1998; Ellins et al. 2012; Giosa et al. 2014; Hanratty et al. 2014; Hendrix et al. 2013b; Holzhausen 2001; Knight et al. 2013; Lenz & Perkins 2000; Lundh & Williams 1997; Mant et al. 2000; Mudge et al. 2013; Naylor et al. 1994; Naylor et al. 1999; Neiterman et al. 2015; Popejoy 2011; Shyu et al. 2008; Shyu 2000; Walker et al. 2007</p>			

Figure 2: Integrated model of carer engagement

