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Journal article

Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals.

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Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals

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Abstract

Background: In order to provide improved care provision, integrated care services are being developed. However, little is known about how people living with dementia, their families and healthcare professionals experience integrated care. Therefore, the purpose of this review of the qualitative literature was to examine the experiences and perceptions of integrated dementia care.

Methods: This qualitative review synthesised findings from included studies identified from a comprehensive literature search. Searches included: five electronic databases, journal handsearching, and reference list searching of relevant literature reviews and the final included studies.

Findings: Three overarching themes were identified: 1) Ways of working which facilitate the delivery of integrated dementia care; 2) Informal carers as equal partners in care provision and decision making; and 3) Challenges leading to fragmented and disjointed integrated dementia care. For integrated care to be successful, communication and collaboration between healthcare professionals, and the involvement of informal carers is needed. Multidisciplinary teams and employing case managers to coordinate care provision can improve communication and collaboration. However, distrust between healthcare professionals and a lack of a central database to access and share information often hinders the development of integrated dementia care service provision.

Conclusion: Integrated dementia care can be successful and well received by people living with dementia and their families when certain conditions are met. However, given the negative consequences fragmented and disjointed care can have on people living with dementia and their families, action is needed to further support the development of integrated dementia care services.

Keywords: Dementia, integrated care, care homes, caregivers; healthcare professionals; evidence synthesis

Background

As of 2015, approximately 46.8 million people were living with dementia worldwide, which is predicted to increase to 131.5 million by 2050. Europe and North America accounted for just under one third of the 2015 total with 15.3 million diagnoses (Prince et al. 2015). In the United Kingdom (UK) there were almost 885,000 people living with dementia as of 2019, with 1.9 million projected to be living with the condition by 2040 (Wittenberg et al. 2019). With these increasing numbers, more people living with dementia and their informal carers will need to access various health and social care services, with integrated care an important facilitator in ensuring appropriate service delivery.

There are various definitions and concepts related to integrated care, with more than 70 terms and phrases relating to 175 definitions and concepts (Armitage et al. 2009). This lack of common terminology makes it challenging to compare and contrast experiences of integrated care, whether on a national or international level (Stein & Rieder 2009). Therefore, for clarity in this review when referring to integrated care, the definition provided by Shaw et al. (2011: page 7) will be used: *'Integrated care is an organising principle for care delivery with the aim of achieving improved patient care through better coordination of services provided'*. This interpretation, that it is the needs of those using the service at the centre of integrated care provision, has also been adopted by the English government which uses it to frame its integrated care strategies (World Health Organisation [WHO] 2016). The English government views integrated care as 'person-centred coordinated care' at its core (National Voices 2013).

Impact of fragmented integrated dementia care

People living with dementia and their informal carers need to access different health and social care services, often simultaneously. However, navigating and accessing these services can be challenging due to fragmentation, limited remit and inadequate cross partnership working (Peel & Harding 2014). The consequences of fragmented and underutilised care services are numerous, but often result in multiple and unnecessary visits from and to health and social care professionals; emergency hospital admissions; unreliable transitions through care pathways; and unreliable transfers from hospitals to a person's home (Department of Health & Social Care 2013). Fragmented service provision may also explain evidence showing that people living with dementia access fewer social care services than people living with other long-term conditions (Vecchio et al. 2016). It can also often lead people living with dementia to remain in hospital longer than necessary, negatively impacting on their quality of life (Kar 2015).

Whilst some studies have shown integrated dementia care offers improved outcomes for people living with dementia and their informal carers (Wolfs et al. 2008), the evidence for its effectiveness in this population remains mixed due to the numerous types of integration that can occur and barriers to implementing integrated care models. For example, aspects of

integrated care that can improve outcomes for service users can include: case management; care coordination; outreach teams for those living in rural areas; and multidisciplinary teams being involved in all aspects of patient care. Notable barriers which can inhibit integrated care include the various types of communication used by healthcare professionals and informal carers, such as telephone, internet messaging and video calling – some of which are impractical or poorly utilised, poor care continuity, and a lack of adequate funding and resources (Draper et al. 2019).

The importance of integrated care

That which constitutes integrated care is often described differently between people, with person-centred perspectives of what matters most to the person often being the main driver behind service delivery (Goodwin 2016), for example: *'The patient's perspective is at the heart of any discussion about integrated care. Achieving integrated care requires those involved with planning and providing services to impose the patient's perspective as the organising principle of service delivery'* (Lloyd & Wait 2005). A recent systematic review of the most commonly shared values of integrated care from various countries found seven common values: collaborative; co-ordinated; transparent; empowering; comprehensive; co-produced; and shared responsibility and accountability (Zonneveld et al. 2018). However, the majority of the included studies in the synthesis were from the perspectives of researchers or health professionals, with none of the participants involved in developing the seven common values being either informal carers or people (including people living with dementia) utilising services. It is therefore important to understand integrated care from their perspectives as well as healthcare professionals if the *'...patient's perspective as the organising principle of service delivery'* (Lloyd & Wait 2005) is to be accomplished.

Integrated dementia care can improve client satisfaction, increase use of appropriate community services and reduce the number of days spent in hospital (Low & Fletcher 2015). Integrating care was a key area for improvement in UK dementia policy documents, for example, the English National Dementia Strategy (Department of Health [DH], 2009). More recently, other European countries (e.g. Ireland, France, Italy, Denmark, and The Netherlands) have published National Dementia Strategies, with the aim of improving care services to support people living with dementia and their families. The development of integrated care services is also a priority for these countries, with both the Italian and Norwegian National Dementia Strategies reporting integrated care as a target area for improvement (Alzheimer Europe, 2017).

Frequently, models of integrated care enhance client satisfaction and perceived quality of care received (Baxter et al. 2018). However, whilst there is good evidence for the effectiveness of integrated care in older populations generally, such as a reduced need to transition into nursing

home care and fewer hospital visits, the evidence for its effectiveness in those with long-term conditions and complex needs, including those living with dementia, is mixed (Ham & Curry 2011). Therefore, there is a need to explore why this is the case from the perspectives of those who access integrated care services, their families and the healthcare professionals delivering integrated care.

Research question and aims

Research has shown that integrated care can offer improved outcomes for people living with dementia and their families, however their experiences remain poorly understood and the evidence currently available has not been synthesised. Therefore, the purpose of this review of the qualitative literature was to examine the experiences and perceptions of integrated care from the perspectives of people living with dementia, informal carers and healthcare professionals. The research questions were:

1. What are the experiences of integrated dementia care from the perspectives of people living with dementia, informal carers and healthcare professionals?
2. What do people living with dementia, informal carers and healthcare professionals perceive to be good quality integrated care?
3. What are the facilitators and barriers to receiving integrated dementia care?

Methods

This review of qualitative evidence aimed to synthesise the experiences of integrated dementia care from all key stakeholders (Booth et al. 2016). The nine steps of qualitative evidence synthesis reported in Booth (2017) were followed: 1) development of clearly formulated review question; 2) scoping the literature; 3) formal identification of the relevant literature; 4) initial assessment of study reports; 5) analysis and synthesis; 6) preliminary synthesis; 7) full synthesis; 8) dissemination; 9) throughout an iterative process. These steps are not linear and review authors can move between stages as necessary.

The review was reported using the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong et al. 2012). This guideline consists of 21 items grouped into five main domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings. The research questions and search strategy were developed using the population, interest and context (PICO) process, which is often used in qualitative literature reviews (Centre for Reviews and Dissemination [CRD] 2009).

Inclusion criteria

1. Qualitative evidence exploring the experiences of integrated dementia care

2. Primary research exploring the experiences of people living with dementia, informal carers and healthcare professionals
3. Peer reviewed and grey literature
4. Published in English
5. There were no date restrictions

Exclusion criteria

1. Opinion pieces, letters, commentaries or editorials
2. Conference abstracts
3. Literature reviews

Electronic search strategy

The following five electronic databases were searched from their first records: MEDLINE (1948 to 6th July 2020); PsycINFO (1967 to 6th July 2020); Social Policy and Practice (SPP – 1981 to 6th July 2020); Social Science Citation Index (SSCI – 1900 to 6th July 2020) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL – 1937 to 6th July 2020).

Comprehensive pre-planned search strategies similar to that in Table 1 were designed dependent on the electronic databases listed above and their individual MeSH terms. All key words and combinations were the same throughout the database searching.

Table 1: Example electronic search strategy conducted in MEDLINE

Concept	Search terms	
People living with dementia	<i>Alzheimer Disease, Dementia</i> ; Alzheimer\$; dement\$	OR
AND		
Integrated care	<i>Delivery of Health Care; Integrated</i> ; integrat\$ care; integrat\$ health; integrat\$ framework\$; integrat\$ model\$; integrat\$ system\$; integrat\$ pathway\$; integrat\$ program\$; integrat\$ working; integrat\$ team\$; care integrat\$; case manage\$; care coordinat\$	OR
AND		
Experiences and perceptions	Experience\$; perception\$; perspective\$, facilitator\$; barrier\$; enabler\$; view\$; <i>patient satisfaction; personal satisfaction</i> ; satisfaction	OR

Note: \$ denotes truncation; italics denotes MeSH terms

Other sources searched

Grey literature was searched for using the Social Care Online database. The International Journal of Integrated Care was hand searched to find further relevant studies which may have been missed during the electronic database searches. Reference list searching of relevant literature reviews found during the electronic searches and the final included articles was conducted. Experts in the field of research were also contacted to identify other potentially relevant articles missed from the electronic searches.

Study screening and selection

Duplicate removal was conducted using Excel, one review author (RS) also hand searched the file for additional duplicates missed by the Excel duplicate removal process. Following duplicate removal, all review authors were involved in independently screening the titles and abstracts to identify studies fitting the inclusion criteria. Full texts of the selected articles were then scrutinised for inclusion. Where there was uncertainty about inclusion, consensus was achieved by discussion or the involvement of a third reviewer.

Data extraction and management

Data were extracted using standardised data extraction forms and subsequently entered into standardised tables. Data extracted included but was not limited to: author details; year of publication; publication type; participant demographic details; sample sizes; results, themes; key findings related to the experiences of integrated dementia care; and the study authors' conclusions.

Quality appraisal

The quality of included studies was assessed independently by at least two members of the research team using the qualitative research appraisal tool developed by Greenwood et al. (2009). This tool consists of 11 questions with 'yes' (one point) or 'no' (zero points) answers. Quality scores were not used to exclude studies, but to identify their strengths and weaknesses. Evidence has shown that excluding poor quality studies from qualitative reviews has little meaningful effect on the evidence synthesis (Carroll et al. 2012).

Synthesis

Data was synthesised using the four-stage approach for thematic synthesis as described by Thomas and Harden (2008). These four stages overlap to some degree but are described as follows - stage 1) extract data; 2) code text; 3) develop descriptive themes; and 4) generate analytical themes. Data synthesis was conducted by two study authors (RS and AM) who agreed on the final themes and subtheme after collaboration.

Findings

Electronic searches of six databases revealed 727 articles before duplicate removal: MEDLINE -145; Social Policy and Practice – 170; PsycINFO – 126; Social Sciences Citation Index – 73; CINAHL – 127; and Social Care Online – 86. After duplicate removal, 415 individual studies were identified from the electronic searches. After screening titles and abstracts, 59 full-text articles were retrieved. A further 10 full-texts were retrieved from hand searching the International Journal of Integrated Care; 16 from reference list searches of relevant reviews identified from the electronic searches; and 13 from reference list searches of already included articles identified from the above searches. No further relevant studies were identified from contact with experts in the field of integrated care research. Of the 98 full-texts retrieved, 23 fitted the inclusion criteria and were included in the thematic synthesis. Full details of the process of including and excluding articles with reasons is available in Figure 1.

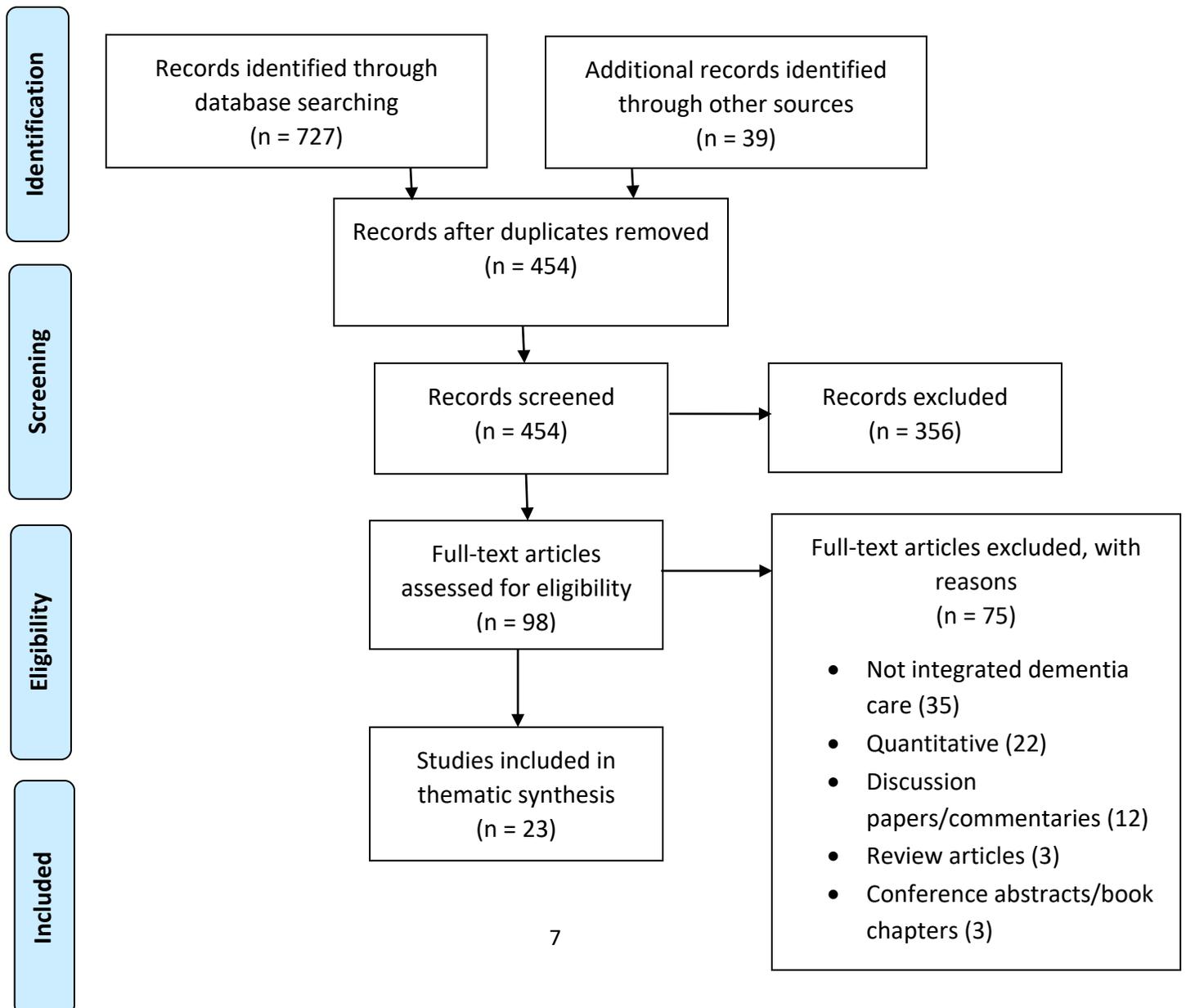


Figure 1. PRISMA flow diagram (Moher et al. 2009) showing the process of article identification and selection.

Study details and participant characteristics

The 23 included studies were published between 2006 and 2019, with the majority (17) published after 2014. Twelve were conducted in the United Kingdom (Bamford et al. 2014; Bunn et al. 2017; Carter et al. 2017; Davis et al. 2014; Gage et al. 2012; Kumpers et al. 2006; Kupeli et al. 2016; Piercy et al. 2018; Robertshaw & Cross 2017; Robertshaw & Cross 2018; Smith 2016; Woolrych & Sixsmith 2013); three in Australia (Bauer et al. 2011; Lockett et al. 2017; Robinson et al. 2009); three in the Netherlands (de Lange et al. 2016; Minkman et al. 2009; van Mierlo et al. 2014); two in Canada (Heckman et al. 2018; Kosteniuk et al. 2014); two in Japan (Hirakawa et al. 2017; Hirakawa et al. 2019); and one in Spain (Risco et al. 2014). Apart from two mixed methods studies (Gage et al. 2012; Piercy et al. 2018), all were qualitative. Types of analysis varied, but was most often reported as thematic, content or framework analysis. All but four studies used face-to-face interviews, telephone interviews or focus groups for data collection, with the other four using internet forum posts (Robertshaw & Cross 2017; Robertshaw & Cross 2018) online focus groups (de Lange et al. 2016) or free text responses to a survey (Gage et al. 2012).

Care settings for the studies were primary community based, however three (Gage et al. 2012; Kupeli et al. 2016; Lockett et al. 2017) focussed on care provision in care homes. Twelve investigated the experiences and perceptions of health care professionals (e.g. GPs; nurses; social workers), care workers or programme managers (Bamford et al. 2014; Carter et al. 2017; Davis et al. 2014; de Lange et al. 2016; Gage et al. 2012; Heckman et al. 2018; Hirakawa et al. 2017; Hirakawa et al. 2019; Kosteniuk et al. 2014; Kupeli et al. 2016; Lockett et al. 2017; Minkman et al. 2009; Piercy et al. 2018; Smith 2016; van Mierlo et al. 2014; Woolrych & Sixsmith 2013); five included a combination of health care professionals and informal carers (Bunn et al. 2017; Kumpers et al. 2006; Risco et al. 2014; Robertshaw & Cross 2017; Robertshaw & Cross 2018) and two exclusively on informal carers (Bauer et al. 2011; Robinson et al. 2009). Three studies also included the perceptions of people living with dementia (Bamford et al. 2014; Bunn et al. 2017; Risco et al. 2014). Full details of the study details are available in Table 2.

Quality scores

Study quality was generally high, ranging from 6 (Smith 2016) to 12 (Davis et al. 2014) out of a possible score of 12 using the Greenwood et al. (2009) quality assessment tool for qualitative studies. Sixteen studies were scored as nine or higher (Table 3). Most often lower scores (<8) were given where studies had not adequately described the methods used; provided enough detail of the analysis performed; the study participants were not adequately described (e.g. lack of demographic information); and a lack of evidence that more than one researcher was involved in the data analysis.

Table 2: Aims and participant demographic characteristics

Authors (Year published) [Country]	Aims	Care setting	Participant type and numbers	Age in years Mean [median] (range)	Gender (%)	Ethnicity (%)
Bamford et al. (2014) [UK]	To explore the views and experiences of patients, carers, case managers, health and social care professionals of case management.	Community based – GP practices	49 (10 informal carers; 9 case managers; 6 PLWD; 6 GPs; 5 admin staff; 4 case manager mentors; 3 volunteers; 2 researchers; 2 community mental health team; 2 commissioners)	NR	NR	NR
Bauer et al. (2011) [Australia]	To explore whether hospital discharge practices meets the needs of the family carer of a person living with dementia.	Hospital discharge	25 informal carers	NR	NR	NR
Bunn et al. (2017) [UK]	To explore the impact of dementia on access to nondementia services and identify ways of improving service delivery for this population.	Community based	56 HCPs (18 nurses; 13 consultants; 10 GPs; 9 therapists; 4 'other'; 2 managers); 33 informal carers 28 PLWD	PLWD: NR [82.5] (59-94) Informal carers: NR [65] (46-90)	PLWD: 36% female Informal carers: 82% female	PLWD: 85% White British Informal carers: 85% white British
Carter et al. (2017) [UK]	To elicit GPs' perceptions of the potential barriers and solutions to the provision of good quality palliative care in dementia in their practices.	Community based – GP practices	138 GPs	NR	NR	NR
Davis et al. (2014)	To explore professional perspectives on barriers to the	Various (community and	39 HCPs (18 clinical practitioners, including	NR	NR	NR

[UK]	delivery of high-quality palliative care for people with dementia.	care home setting)	GPs, nurses and old age psychiatrists; 13 care home managers/directors; 6 senior managers; 2 researchers)			
de Lange et al. (2016) [The Netherlands]	To obtain insight into facilitating factors for case management in dementia care.	Community based	99 HCPs (42 case managers; 17 nurses; 14 neurologists; 9 general practitioners; 9 project leaders; 3 managers; 2 psychologists; 1 nursing assistant; 1 policy maker; 1 lobbyist)	NR	NR	NR
Gage et al. (2012) [UK]	To establish the current extent of integrated working that exists between care homes and primary and community health and social services.	Care homes	89 care home managers	NR	NR	NR
Heckman et al. (2018) [Canada]	To understand physicians' and specialists' perspectives on an integrated dementia care system and identify barriers to its implementation.	Community based	10 primary care doctors	NR	NR	NR
Hirakawa et al. (2017) [Japan]	To identify the barriers to achieving efficient cooperation and coordination among HCPs.	Community based	13 HCPs (4 directors; 4 social workers; 3 nurses; 2 care managers)	NR	NR	NR
Hirakawa et al. (2019) [Japan]	To identify key challenges to successful community-based integrated team approach to the management of older adults with dementia.	Community based	13 informal carers; 24 HCPs (8 doctors; 8 nurses; 6 social workers; 1 pharmacist; 1 nursing home manager)	NR	23 females; 14 males	NR
Kosteniuk et	To explore family doctors' views	Community based	15 family doctors/general	NR	13 males;	NR

al. (2014) [Canada]	regarding this issue, their role in providing dementia care, and the implications of providing dementia care in a rural setting.		practitioners		2 females	
Kumpers et al. (2006) [UK & The Netherlands]	To explore the importance of knowledge transfer between specialist and generic services in improving health care.	Community based	29 HCPs (e.g. nurses; social workers and therapists); 20 HCPs in management positions; 20 informal carers; 19 medical doctors; 12 managers	NR	NR	NR
Kupeli et al. (2016) [UK]	To identify the barriers to providing integrated care as understood by care professionals working with people with advanced dementia residing in care homes.	Care homes for people with advanced dementia	14 HCPs (5 nurses; 3 healthcare assistants; 2 care home managers; 2 commissioners; 1 clinical manager; 1 occupational therapist)	NR	NR	NR
Lockett et al. (2017) [Australia]	To explore Palliative Care Planning Coordinators and health professional perceptions of the benefits of facilitated case conferencing and identify factors influencing implementation.	Care homes	40 HCPs (18 nurses; 11 palliative care planning coordinators; 8 allied health workers; 3 medical doctors)	NR	NR	NR
Minkman et al. (2009) [The Netherlands]	To describe and analyse a new approach in extensive case management programmes concerned with long-term dementia care in The Netherlands.	Community based	16 programme managers	NR	NR	NR
Piercy et al. (2018) [UK]	To assess how well an integrated service for post diagnostic dementia care had performed in providing support to PWD and	Community based	17 (7 dementia advisers; 6 partner organisation representatives; 3 Admiral nurses; 1 service	NR	NR	NR

	their family/carers.		administrator)			
Risco et al. (2014) [Spain]	To identify the barriers and facilitators in dementia care with respect to information provision, communication, and collaboration from the perspectives of the person with dementia, family caregivers, and health care professionals	Various (care homes; hospitals and community settings)	19 HCPs (10 medical doctors; 5 nurses; 4 social workers) 11 informal carers 7 PLWD	PLWD: 74.2 [NR] (63-81) Informal carers: 78.3 [NR] (65-92) HCPs: 41.2 [NR] (31-53)	NR	NR
Robertshaw & Cross (2017) [UK]	To understand the views and experiences of integrated health and social care for dementia from the perspective of carers, families, healthcare professionals and researchers.	Various (Internet forum and training module for those providing care to PLWD)	Informal carers, care workers and researchers (3058 participants took part in the training course, NR how many provided the 847 forum posts)	NR	NR (83% female)	NR
Robertshaw & Cross (2018) [UK]	To characterise roles and responsibilities in relation to integrated care from the perspective of massive open online course (MOOC) participants	Various (Internet forum and training module for those providing care to PLWD)	3058 informal carers, care workers and researchers (same participants as above – participant numbers not counted twice in reporting this review)	NR	NR (83% female)	NR
Robinson et al. (2009) [Australia]	To identify and describe the experiences of family carers of people with dementia in accessing relevant information and services in Southern Tasmania, Australia.	Community based	15 informal carers	NR (ages are ranked; unable to separate out)	10 females; 5 males	NR
Smith	To explore the experiences of	Community based	10 HCPs (7 pharmacists; 2	NR	NR	NR

(2016) [UK]	community pharmacies delivering services to people affected by dementia, and the facilitators and barriers to these services.		technicians; 1 nurse)			
van Mierlo et al. (2014) (The Netherlands]	To provide insight into facilitators and barriers to the delivery of community-based personalised dementia care of two different case management models.	Community based	22 HCPs (5 care co-ordinators; 3 Alzheimer Netherlands workers; 3 stakeholders from municipalities; 2 case managers; 2 GPs; 2 health insurance workers; 2 mental health professionals; 2 day care centre co-ordinators; 1 informal carer support worker).	NR	NR	NR
Woolrych & Sixsmith (2013) [UK]	To understand the experiences of formal carers working with the context of an integrated dementia service.	Community based	15 care workers	NR	NR	NR

NR = not reported; PLWD = people living with dementia; HCPs = healthcare professionals; GPs = general practitioners

Table 3: Methods and quality scores

Authors (Year published) [Country]	Study type and design	Sampling	Data collection	Data analysis	Quality scores
Bamford et al. (2014) [UK]	Qualitative; cross-sectional	Purposive	Ethnographic methods (in-depth interviews; informal discussion and observations)	Constant comparative approach and Normalisation Process Theory	9
Bauer et al. (2011) [Australia]	Qualitative; cross-sectional	Purposive	Semi-structured face-to-face interviews	Comparative method of thematic analysis	11
Bunn et al. (2017) [UK]	Qualitative; cross-sectional	Purposive	In-depth semi-structured interviews and focus groups	Thematic content analysis	9
Carter et al. (2017) [UK]	Qualitative; cross-sectional	Convenience	Postal survey with free-text qualitative responses	Thematic analysis	9
Davis et al. (2014) [UK]	Qualitative; cross-sectional	Purposive and snowballing	Semi-structured face-to-face interviews, telephone interviews, focus groups	Thematic analysis	12
de Lange et al. (2016) [The Netherlands]	Qualitative; cross-sectional	Purposive	Online focus groups	Eclectic inductive method	11
Gage et al. (2012) [UK]	Mixed methods	Convenience national sample of care homes	Online survey with free-text responses for qualitative data	Thematically coded	10
Heckman et al. (2018) [Canada]	Qualitative; cross-sectional	Random (random number generator)	Telephone interviews	Naturalistic enquiry approach	8
Hirakawa et al. (2017) [Japan]	Qualitative; cross-sectional	Purposive	Focus groups	Content analysis	9
Hirakawa et	Qualitative;	Purposive	Face-to-face	Content analysis	11

al. (2019) [Japan]	cross-sectional		interviews		
Kosteniuk et al. (2014) [Canada]	Qualitative; cross-sectional	Purposive	Telephone interviews	'Coded by identifying themes'	8
Kumpers et al. (2006) [UK & The Netherlands]	Qualitative; cross-sectional	Purposive	Semi-structured in-depth interviews	Data summarised into main topics and then coded	10
Kupeli et al. (2016) [UK]	Qualitative; cross-sectional	Purposive	Interactive interviews	Thematic analysis	9
Lockett et al. (2017) [Australia]	Qualitative (sub-study); cross-sectional	Purposive and snowballing	Face-to-face semi-structured and telephone interviews	Thematic framework approach	10
Minkman et al. (2009) [The Netherlands]	Qualitative; multiple case studies	Purposive	Face-to-face Semi-structured interviews	Construction of tables of core characteristics. Structured overviews	8
Piercy et al. (2018) [UK]	Mixed methods	Purposive	Focus groups and face-to-face semi-structured interviews	Framework analysis	11
Risco et al. (2014) [Spain]	Qualitative; cross-sectional	Purposive	Focus groups	Content analysis	11
Robertshaw & Cross (2017) [UK]	Qualitative; cross-sectional	Convenience	Internet forum responses	Framework analysis	8
Robertshaw & Cross (2018) [UK]	Qualitative; cross-sectional	Convenience	Internet forum responses	Framework analysis	9
Robinson et al. (2009) [Australia]	Qualitative; cross-sectional	Purposive	Focus groups	Iterative/thematic analysis	8
Smith (2016) [UK]	Qualitative; cross-sectional	Purposive	Semi-structured interviews	NR	6
Van Mierlo et	Qualitative;	Purposive	Semi-structured	Directed content	11

al. (2014) (The Netherlands]	cross-sectional		interviews	analysis	
Woolrych & Sixsmith (2013) [UK]	Qualitative; cross-sectional	Purposive	Face-to-face semi-structured interviews and focus groups	Thematic analysis	8

NR = not reported.

Themes

Three overarching themes were identified: 1) Ways of working which facilitate the delivery of integrated dementia care; 2) Informal carers as equal partners in care provision and decision making; and 3) Challenges leading to fragmented and disjointed integrated dementia care. The themes with associated subthemes are presented Table 4 along with example quotations demonstrating each theme.

Theme 1: Ways of working which facilitate the delivery of integrated dementia care

1.1. The importance of interprofessional communication and collaboration

Thematic synthesis of the findings suggests that close cooperation and team working between case managers, other healthcare professionals and community organisations promotes integrated care and better meets the needs of people living with dementia and their families (de Lange et al. 2016; Robertshaw & Cross 2017; van Mierlo et al. 2014; Woolrych & Sixsmith 2013). Open and transparent communication and knowledge transfer were viewed as important for facilitating integrated care and allow healthcare professionals to effectively support people living with dementia with the limited resources available to them (de Lange et al. 2016; Kumpers et al. 2006). However, breakdowns in communication between healthcare professionals and community support services, results in a lack of team approach to care provision, poor knowledge transfer and inadequate integrated care (Carter et al. 2017; Risco et al. 2014).

Whilst some care home managers and care workers reported good working relationships with National Health Service (NHS) and other external healthcare professionals, communication difficulties were often reported when working with secondary care services, such as: poor information sharing; lack of care planning; and little follow up of people living with dementia who have recently left hospital (Gage et al. 2012; Kupeli et al. 2016). Professional hierarchies between specialists and generalists were described as barriers to effective communication (Kumpers et al. 2006).

To overcome challenges associated with interprofessional communication and collaboration, health and social care services need to be seamlessly joined up, allowing close working relationships between healthcare professionals for integrated care to develop (Bunn et al. 2017; Davis et al. 2014; Kosteniuk et al. 2014; Piercy et al. 2018). Some healthcare professionals and specialists were proactively developing working arrangements which promoted collaboration and approaches to integrate care (Heckman et al. 2018). Healthcare professionals meeting either face-to-face or via case conferencing to discuss clients' needs has been shown to increase knowledge transfer, improve integrated care and highlighted changing care needs for people living with dementia (Kumpers et al. 2006; Lockett et al. 2017; Piercy et al. 2018). A way of improving communication and collaboration among healthcare professionals was through the development of multidisciplinary teams.

1.2. Working together in multidisciplinary teams

Bringing together multidisciplinary teams (e.g. geriatricians, dementia special nurses, social workers, case managers, etc.) to provide care for people living with dementia, both in care homes and living in the community, was an important factor in providing good quality integrated care. Comprehensive input from a wide range of specialists, care workers, people living with dementia and their families, was described as offering the best outcomes for people living with dementia with regards to decision making surrounding care provision (Hirakawa et al. 2017; Kosteniuk et al. 2014). It also enabled healthcare workers to develop a holistic understanding of the person living with dementia as a whole and what their needs were, as opposed to just treating their symptoms (Robertshaw & Cross 2017). Where multidisciplinary teams did not exist, care was described as chaotic, disorganised and fragmented (Davis et al. 2014).

A lack of general practitioner (GP) integration with specialist support services, as well as patients being treated by generalists as opposed to specialist clinicians, was viewed as disjointed and a hindrance in providing integrated care (Carter et al. 2017; Davis et al. 2014). However, where GPs and other specialists were involved in decision making within multidisciplinary teams, medical concerns could be actioned quicker (Lockett et al. 2017). Further, where case managers were part of multidisciplinary teams, they could inform clinicians of challenges, thereby facilitating discussion and resolving issues (Minkman et al. 2009). Developing multidisciplinary teams with one person designated for co-ordinating dementia care (e.g. case managers) was regarded as a way of improving integrated care and better meeting the needs of those being cared for (Carter et al. 2017; Davis et al. 2014).

1.3. Case managers: a point of contact and facilitating access to services

Case managers (also known as: care managers; care navigators and care coordinators) often acted as the first point of contact for informal carers and people living with dementia, facilitating access to various services and healthcare professionals, reducing the need for them

to contact multiple service providers (Bamford et al. 2014; Bunn et al. 2017; Robertshaw & Cross 2017; Robertshaw & Cross 2018; van Mierlo et al. 2014). They had an important role in overseeing the care for people living with dementia. Making sure they were receiving the services they needed and identifying any changing needs (Kosteniuk et al. 2014). Advanced levels of education, adequate training in understanding the needs of people living with dementia, communication skills and knowledge of appropriate local services were identified as important skills for case managers to have to be effective in their role (de Lange et al. 2016; Minkman et al. 2009; van Mierlo et al. 2014; Woolrych & Sixsmith 2013).

Case managers having regular contact with GPs and other health care professionals helped with speeding up referrals and identifying the changing needs of people living with dementia (de Lange et al. 2016). Ideally case managers would be imbedded into GP surgeries to be most effective in their role through communicating with other clinicians, but this rarely happened in practice (Bamford et al. 2014; de Lange et al. 2016). For the long-term success of case managers, strong collaboration and communication between them and other health care professionals was critical (van Mierlo et al. 2014). However, a lack of clarity and confusion was discussed over how the case manager role is different from other clinical roles which require caring for people living with dementia, for example: Admiral Nurses and mental health nurses (Bamford et al. 2014; van Mierlo et al. 2014).

Case management was often most effective if offered to informal carers and people living with dementia soon after diagnosis (Bamford et al. 2014). This can be for various reasons, notably for assisting informal carers navigate complicated care systems and being one point of contact for people living with dementia and their families.

Theme 2: Informal carers as equal partners in care provision and decision making

2.1. Involving informal carers in decision making for improved care integration

Involving informal carers in decision making and the care of the person living with dementia was described as an integral part of providing good quality integrated care. Healthcare professionals needed to take adequate time to listen to their concerns and understand their needs (Bamford et al. 2014). This was especially important given the active role informal carers have in facilitating care, for example; keeping records of medical tests and transferring records and information between different service providers (Bunn et al. 2017). However, informal carers were often not informed of changes in care provision due to a breakdown in communication, which not only caused stress, but could also make them feel undervalued, excluded from decision making and necessitated them searching out information by themselves (Bauer et al. 2011; Bunn et al. 2017; Risco et al. 2014; Robinson et al. 2009). Informal carer stress can be compounded by difficulties they experience in accessing services (e.g. having to

repeat the same information to various service providers) and the perception that services are poorly organised and confusing to access (Hirakawa et al. 2019; Robinson et al. 2009; van Mierlo et al. 2014; Woolrych & Sixsmith 2013).

In addition to telephone and face-to-face meetings, conference calling was shown to provide a person-centred approach to improving communication between nursing home staff and informal carers, allowing informal carers to be more involved with decision making (Luckett et al. 2017). Healthcare professionals communicating effectively and sharing information with informal carers has been shown to facilitate high quality integrated care for people living with dementia in the community (Hirakawa et al. 2017). Supporting informal carers and involving them with decision making can also positively impact on continuity of care for people living with dementia through improved care integration and coordination.

2.2. Coordinating care to ensure continuity: reducing stress on informal carers and people living with dementia

Seamless continuity of care, whereby the sharing of patient information between healthcare professionals, people living with dementia and their informal carers, was found to be essential for effective service coordination and the provision of good quality integrated dementia care (Robertshaw & Cross 2017). The ability to have one point of contact, as opposed to informal carers or people living with dementia having to contact numerous services, was highly valued (Bamford et al. 2014; Piercy et al. 2018; Robinson et al. 2009). Providing multiple care services (e.g. respite; day care; outreach) within one integrated service was viewed by care workers to offer clients better continuity of care and provide more flexibility when referring clients from one service to another (Woolrych & Sixsmith 2013). Where a lack of care continuity was discussed, it often led to the perception of poor organisation and coordination on the part of the care providers and could negatively impact on the health and wellbeing of people living with dementia and their families (Bauer et al. 2011; Bunn et al. 2017). This lack of coordination to care provision was likely to be more pronounced in rural areas due to fragmented services, leading to poor integrated care and health inequalities (Hirakawa et al. 2019; Kosteniuk et al. 2014). In care homes, having staff specifically assigned to providing care for certain residents was described as a way of improving care continuity (Kupeli et al. 2016). This was also found in the community, with healthcare staff able to build up trusting relationships with people living with dementia and informal carers (Piercy et al. 2018). However, high staff turnover could negatively affect this, especially with regards to loss of relationships and knowledge transfer between healthcare professionals (Kumpers et al. 2006; Kupeli et al. 2016). Subsequently, fragmented and lack of care continuity could lead to confusion, conflict and frustration for people living with dementia and their carers (Risco et al. 2014; Robertshaw & Cross 2018).

Theme 3: Challenges leading to fragmented and disjointed integrated dementia care

3.1. Distrust amongst health care professionals

General practitioners perceived that a poor interdisciplinary team approach was a barrier to providing good quality integrated dementia care (Carter et al. 2017). However, this view was also shared by clinicians from other disciplines, in that it could be difficult to collaborate with GPs. Those healthcare professionals working in care homes reported finding it challenging to engage with GPs and described difficulty having them visit residents in the care home, subsequently affecting the frequency of necessary medication changes (Gage et al. 2012). Further, some care home employees held a general view that it was difficult to work with some external healthcare professionals as they did not fully understand the workings of care homes, leading to distrust and a breakdown of working relationships (Gage et al. 2012; Kupeli et al. 2016). The importance of developing strong working relationships were also described in other settings, for example, memory clinics. However, a lack of understanding, a perceived poor attitude of some specialists, and GPs having too little time to fully engage in dementia care acted as barriers to adequately integrating care (Heckman et al. 2018; Kosteniuk et al. 2014; Minkman et al. 2009; van Mierlo et al. 2014).

Some healthcare professionals were reluctant to consult psychiatrists, despite their importance in a community based integrated dementia care system. This could be due to poor understanding of the role of psychiatrists in dementia care or through fear the people living with dementia might be prescribed strong antipsychotic medications (Hirakawa et al. 2019). Distrust between healthcare professionals from different clinical backgrounds could result in poor care integration through poor knowledge exchange. Clinicians who were reassuring and respectful to each other when describing the care of a person with dementia improved trust and interdisciplinary team working (Kumpers et al. 2006). Despite challenges to interprofessional working relationships, a major factor in inadequate information sharing and collaboration is due to challenges involved with accessing client information.

3.2. Challenges in accessing and sharing information

Healthcare professionals often described how current infrastructure did not support the sharing of information across different specialities, with some being unaware a person had a dementia diagnosis (Bunn et al. 2017). This lack of access to information on clients also prevented seamless team working and integration of care (Smith 2016). For example, care home staff reported finding it challenging to access and share information with NHS services (Gage et al. 2012), resulting in the duplication of work and increasing pressure on services already under strain due to capacity and time constraints (Piercy et al. 2018).

To overcome barriers to accessing and sharing information, there needs to be standardised electronic medical records stored in a central location which healthcare professionals, care

workers and specialists can access to ensure good quality person-centred care and integrated care (Heckman et al. 2018; Robertshaw & Cross 2018; Woolrych & Sixsmith 2013). However, legal barriers were identified as reasons for not sharing information with services and families which can inhibit early intervention (Hirakawa et al. 2019).

3.3. Lack of funding and limited resources

The lack of funding and resources available was described as the greatest barrier to providing good quality integrated care for people living with dementia (Robertshaw & Cross 2017). The lack of secure funding for case managers' roles led to uncertainty among healthcare professionals surrounding the ongoing service they could provide people living with dementia and their families (de Lange et al. 2016; Minkman et al. 2009).

Time restraints, a lack of resources, and poor access to specialists can negatively impact upon care integration and knowledge transfer between case managers and healthcare professionals (Heckman et al. 2018; Kumpers et al. 2006; Robertshaw & Cross 2018). With regards to care homes, some care workers felt they were driven by profit as opposed to providing optimal care, and that some are poorly equipped to provide integrated end of life care to people living with dementia (Kupeli et al. 2016).

Where integrated care has been successful, it should prevent the duplication of service provision by adequately allocating resources and providing consistent continuity of care (Robertshaw & Cross 2018). However, whilst integrated care was viewed as desirable by healthcare professionals, they suggested that it could only be provided within the boundaries and constraints of the current system, with little flexibility beyond that (Woolrych & Sixsmith 2013).

Table 4: Themes, subthemes and representative quotes from included articles

Themes	Subthemes	Representative quotes
1. Ways of working which facilitate the delivery of integrated dementia care	<p>1.1 The importance of interprofessional communication and collaboration</p> <p>1.2 Working together in multidisciplinary teams</p> <p>1.3 Case managers: a point of contact and facilitating access to services</p>	<p>1.1. <i>"We need clear collaboration agreements between care providers in the dementia care network, between general practitioner and case manager, but also between specialist in geriatric medicine or psychologist and case manager."</i> (de Lange et al. 2016) <i>"It's about joining it (health and social care teams) all up, isn't it?"</i> (Davis et al. 2014)</p> <p>1.2. <i>"I can ascertain that somebody doesn't know who the prime minister is, doesn't know what today is, and can't remember what they had for breakfast. I don't really need a neurologist to tell me that. I need a neurologist to help me with the subtleties and I think a team would be much better."</i> (Kosteniuk et al. 2014). <i>"True integrated care should involve a seamless flow between medical specialties, nursing teams, health and social care, along with associated administrative and managerial support. A service that has this structure will allow for a more holistic approach to caring for a patient, rather than silo working that is often commonplace."</i> (Robertshaw & Cross 2017)</p> <p>1.3. <i>"So that then when it gets to a stage when we really do need help, we've got the confidence in the person (case manager) you've been seeing all along."</i> (Bamford et al. 2014) <i>"Each service user should be appointed a care coordinator: an [intermediate] who could liaise between service users and service providers."</i> (Robertshaw & Cross 2017)</p>
2. Informal carers as equal partners in care provision and decision making	2.1 Involving informal carers in decision making for improved care integration	<p>2.1 <i>"You see one person one time and then you'd have, tell them what they need to know and then you see the next person and they don't know, do they. You have to go all through it yeah, you have to start again."</i> (Bunn et al. 2017) <i>"I went in there and her suitcase was packed and she was going home that day. I found out when I turned up. There was no discussion really."</i> (Bauer et al. 2011)</p>

	2.2 Coordinating care to ensure continuity: reducing stress on informal carers and people living with dementia	2.2. <i>“The fact that you know that you can be involved with somebody and it’s not time limited ...that helps you build the relationships with families....So you might see somebody on an intense level, and you might be seeing them two or three times a week if they’re going through a really difficult phase of the dementia. And then that gradually tapers off ... and then most of my families will be honest and say I’m OK at the minute, I don’t need you at the minute, I’ll ring you if I need you.”</i> (Piercy et al. 2018)
3. Challenges leading to fragmented and disjointed integrated dementia care	<p>3.1. Distrust amongst healthcare professionals</p> <p>3.2. Challenges in accessing and sharing information</p> <p>3.3. Lack of funding and limited resources</p>	<p>3.1. <i>“If somebody rings me up . . .They have a problem for about a week; “I can’t do it tomorrow, I’ve just too much on”, I say I will try on Friday, . . .they know that I will come whatever time, . . .I think that helps with the trust and the commitment, in terms of they are desperate for some help”</i> (Kumpers et al. 2006) <i>“I feel there is a mistrust and poor communication. Transferring a resident to hospital we send all details and then are phoned to ask for them again-poor discharge information to the home which involves possible re-admission to hospital for the resident.”</i> (Gage et al. 2012)</p> <p>3.2. <i>“I think that’s a key point I was going to make is one of the big stumbling blocks we have is the fact that services or parts of different Trusts so the Mental Health Services sit within the H Partnership Trust so they don’t use the same system as us so we can’t share notes, the GPs use a different system again so it makes it very difficult to communicate to even find out what services people are under, you know, if that could be improved, if we could all be on the same system that would be good [laughs]”</i> (Bunn et al. 2017).</p> <p>3.3. <i>“They’re pulling team members from other programs for the clinic and while [our organization] is committed to the memory clinic, the reality is that there are other programs, and can’t take staff away from those programs any longer than you need.”</i> (Heckman et al. 2018) <i>“It would be nice that you did not have to think about funding every time you are delivering care. As a professional you should offer the right care at the right time in the right place, independently of the right funding.”</i> (de Lange et al. 2016)</p>

Discussion

This qualitative evidence synthesis set out to explore the experience of integrated dementia care from the perspectives of those accessing services and those providing them. Thematic synthesis of the included studies showed that for integrated care to be successful, communication and collaboration between healthcare professionals and the involvement of informal carers are crucial, particularly for providing long-term continuity of care for people living with dementia. Effective communication and collaboration can potentially be achieved through the use of multidisciplinary teams and employing case managers to oversee care provision. However, distrust between healthcare professionals from different clinical disciplines and pressures on time and resources often hinder the development of integrated dementia care. These, combined with poor access to a central database where information on clients can be stored and shared amongst healthcare professionals, often leads to fragmented and disjointed care provision, resulting in negative experiences for people living with dementia and their families.

The negative consequences of fragmented and disjointed integrated dementia care are numerous (Department of Health & Social Care 2013), including unnecessary health and social care professional visits, emergency hospital admissions, remaining in hospital longer than necessary, and unreliable transitions through care pathways (Kar 2015). It is, therefore, vital that 'joined up' ways of working between healthcare professionals from both health and social care services are encouraged and facilitated to enable reliable, person-centred care for people living with dementia. However, the barriers identified in this review, including distrust between healthcare professionals and a lack of resources, are likely to hinder the development of truly integrated service provision. Therefore, service managers and clinicians should seek to develop open, honest and respectful dialogue with those working in other services to build secure working relationships. These types of communication enablers have been found previously, with information sharing needing to be open, two-way and inclusive of all healthcare team members (Lawn et al. 2015).

With recent policy documents focusing on increasing and improving integrated dementia care in many European countries (Alzheimer Europe, 2017; DH 2009; Wright & O'Connor 2018), the findings of this review should prove useful for developing integrated services which improve client satisfaction. However, evidence exploring the experiences of people living with dementia and their involvement in decisions made about their care appears to be limited. Given previous studies describing integrated care as needing to be person-centred and the '*patient's perspective is at the heart of any discussion about integrated care*' (Lloyd & Wait 2005), exploratory studies with a focus on patient experience should be considered to develop a deeper understanding of what integrated dementia care means to those accessing services. Further, whilst quantitative studies exploring the impact of integrated dementia care interventions have shown some positive results, for example: improvements in memory; quality

of life; mental health of the person living with dementia; and reduced carer 'burden' (Ha et al. 2020; Zwingmann et al. 2018), future studies using a mixed-methods approach may provide a more robust understanding of why some interventions work well and others do not.

As most of the studies included in this review were cross-sectional, no inferences can be made surrounding how experiences and perceptions of integrated dementia care change over time. Longitudinal studies which interview all key stakeholder may highlight challenges which occur as the health of person living with dementia declines. For example, how continuity of care is maintained if a person transitions from living independently in the community to residential care. These studies should also seek to explore the experiences of informal carers overtime to examine if and how integrated dementia care affects their levels of stress and perceived caring burden. Informal carers in this review described anxiety and stress related to poor communication from some healthcare professionals, therefore, interventions which target improving informal carer and healthcare professional communication should be considered a priority.

Limitations

Despite a comprehensive literature search, all of the included studies were conducted in western countries with robust health and social care systems. The findings are also skewed to be more relevant to integrated dementia care in the United Kingdom, where 12 of the 23 studies were conducted. It is unclear if these findings will be applicable to developing countries or in cultures where people living with dementia are usually cared for by family members in their own homes with little outside assistance. Where studies included the experiences of people living with dementia and informal carers, ethnicity; religion; and sexuality were rarely described. It is therefore difficult to draw conclusion surrounding whether the findings presented in this review are applicable to those from minority groups.

Only research studies published in English were eligible for inclusion, which could have led to relevant papers being missed. This decision was taken for pragmatic purposes (CRD 2009), however the findings are therefore biased toward western English-speaking countries. Finally, only the International Journal of Integrated Care was hand searched. This choice was made as it was considered by the research team likely to contain more articles relevant to the research questions, compared to other journals. However, it should be noted that not hand searching other journals in the field of dementia care may have led to relevant papers being missed that were not indexed in the electronic databases.

Future directions

Future studies should investigate whether there are variations in the perceptions and experiences of integrated dementia care from the perspectives of informal carers and people living with dementia from minority groups. For example, only one study reported ethnicity of

informal carer participants (Bunn et al. 2017) and none reported sexual identities. Of the 23 included studies, just three included data from interviews from people living with dementia. It is important future research takes steps to include people living with dementia so that their perceptions and experiences of integrated care can contribute in developing services which they may be using. Further, studies exploring the experiences of those in rural areas, people living with dementia who live alone or without family assistance, and whether there are gender differences in the perceptions of integrated dementia care are needed to help develop policy initiatives to help those who may find it challenging to access integrated dementia care services.

As all included studies were published before 2020, the review findings reflect on experiences in the context of pre-COVID19 dementia care service provision. If and how the current pandemic has impacted on integrated care is currently unknown. Further research to explore if the pandemic has affected integrated dementia care from the experiences of people living with dementia, their families and healthcare professionals is warranted.

Conclusions

Integrated dementia care can be successful and well received by people living with dementia and their families when certain conditions are met. It relies on effective communication, professional collaboration and the involvement of informal carers in decision making. These can be achieved through employing multidisciplinary teams and case managers to oversee care for people living with dementia over the long term. However, distrust between healthcare professionals, poor interdisciplinary team working, and a lack of resources are barriers which may prevent care integration. Further research is needed to specifically explore the experiences of people living with dementia, their perceptions of integrated care, and whether the COVID-19 pandemic has impacted on integrated dementia care provision. Given the negative consequences fragmented care can have on people living with dementia and their carers, along with the increasing numbers of people being diagnosed with the condition worldwide, action is needed to further support the development of integrated dementia care services.

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