Healthcare professionals' dementia knowledge and attitudes towards dementia care and family carers' perceptions of dementia care in China: An integrative review

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- **Author Contributions**

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Being involved in drafting the manuscript or revising it critically for important intellectual content;	WZ, CJ, M-LW, WM
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Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	WZ, CJ, M-LW, WM

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Abstract

Aims and objectives: To establish an understanding of healthcare professionals' dementia knowledge and attitudes towards dementia care, and family carers' perceptions of dementia care in China.

Background: Healthcare professionals and family carers of people with dementia deliver most of the dementia care in China. However, little research on healthcare professionals' dementia knowledge and attitudes towards dementia care, and family carers' dementia care perceptions has been conducted in China.

Methods: An integrative review was conducted and reported based on the PRISMA guidelines and Whittemore and Knafl's framework. Eight English databases were searched without date restriction: CINAHL Plus with Full Text, MEDLINE, PubMed, Web of Science, Cochrane Library, Embase, PsycINFO and Scopus; and three Chinese databases: China National Knowledge Infrastructure, Chongqing Weipu and Wanfang, plus a manual search of reference lists.

Results: Thirty-eight primary research papers were included in the review. Three themes were identified from the synthesis: 1) knowledge and competency; 2) attitudes towards dementia care; and 3) carers' burden and unmet needs. Healthcare professionals' dementia knowledge ranged from low to moderate levels and attitudes towards dementia care were generally negative. With low levels of knowledge of dementia and negative attitudes including stigma, family carers were

under stress with insufficient support, and they expected more support from community nurses.

Conclusions: There is an apparent need for a national policy on healthcare professional education and training to improve dementia care practice in China. Such a policy may improve support services for family carers.

Relevance to clinical practice: Nurses, and particularly community nurses, are well-positioned to support family carers in China. However, healthcare professionals in China are not prepared for this. Therefore, education and training on dementia care should be integrated into medical and nursing undergraduate programs and provided for healthcare professionals after commencing employment, and strategies to reduce stigma are needed.

KEYWORDS: attitude, caregivers, dementia, education, healthcare professionals, integrative review, knowledge, nurses

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

- Deficits in the dementia education and training of healthcare professionals in China and lack of support for family carers are highlighted.
- A national dementia education and care policy is needed to address dementia knowledge and training deficiencies among healthcare professionals and support carers in China.
- Community nurses have the opportunity to support family carers in providing dementia care for care recipients.

1. INTRODUCTION

Dementia is a significant neurological condition that is more common among older people. In 2016, China had 149 million people aged 65 years and older, accounting for 10.8 percent of the total 1.382 billion population (National Bureau of Statistics of China, 2018). Furthermore, in 2015, there were more than 9.5 million people with dementia in China, which contributes to nearly 20 percent of the total number of people with dementia worldwide (World Alzheimer Report, 2018). The rapidly increasing prevalence of dementia in older adults suggests that this health issue is significant for the Chinese healthcare system.

More than 90% of people with dementia are underdiagnosed and undertreated due to a reduced awareness of dementia among the public in China (Chen et al., 2013). Approximately 85% of people with dementia in China are cared for by family carers (Jia et al., 2020). Perceptions of dementia care amongst family carers have been explored in countries such as the United Kingdom and United States (Lethin et al., 2019; Watkins, Murphy, Kennedy, Dewar, & Graham, 2019). However, there is limited research examining family carers' perceptions of dementia care in China, which is of concern given that family carers' perceptions can influence dementia care. Furthermore, healthcare professionals are the primary resources that people with dementia and their family carers rely on for dementia diagnosis and treatment (Hsiao, Liu, Xu, Huang, & Chi, 2016). An examination of healthcare professionals' dementia knowledge and attitudes towards dementia care and family carers' perceptions of dementia care will help us to understand the current status of dementia care in China.

To date, most research literature from China has focused on summarising the prevalence and incidence of dementia, as well as the risk factors, the challenges of dementia care in rural China and the economic costs associated with dementia (Chen et al., 2013; Wang et al., 2019). This integrative review, will instead, focus on healthcare professionals' dementia knowledge and attitudes towards dementia care and family carers' perceptions of dementia care in China. These are important areas to explore as healthcare professionals' knowledge can influence the way they treat people with dementia, and their attitudes can contribute to the stigmatisation of people with dementia and, as a result, negatively influence care provision (Hsiao et

al., 2016). Furthermore, the perceptions of family carers can determine how they care for people with dementia and their expectations of care, and these perceptions can also influence dementia care quality. Furthermore, growth in the numbers of people with dementia, particularly in China, adds to the significance of this research topic.

2 AIMS

This review addresses a significant gap in the literature. This review aims to describe, evaluate and synthesise both qualitative and quantitative studies on dementia care in China and to identify the influencers of this care. The research questions include:

1. What is healthcare professionals' knowledge of dementia and their attitudes towards dementia care in China?
2. What are the perceptions of Chinese family carers of people with dementia towards dementia care?

3 METHODS

This review was conducted and reported based on the guidelines for Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA guidelines; see Supplementary File 1) (Moher, Liberati, Tetzlaff, & Altman, 2009), and Whittemore and Knalf's five-stage method, which includes problem identification, literature search, data evaluation, data analysis and presentation (Whittemore & Knafl, 2005). An integrative review approach was undertaken to integrate a variety of methodologies and data to promote a holistic understanding of the research topic (Whittemore & Knafl, 2005). This approach was considered appropriate as it allows for a comprehensive understanding of the phenomenon (Whittemore & Knafl, 2005). The review was registered on the International Prospective Register of Systematic Reviews PROSPERO website https://www.crd.york.ac.uk/PROSPERO/ (ID: CRD42019108789).

3.1 Eligibility criteria

3.1.1 Inclusion criteria

- Primary studies conducted in mainland China
- Studies that contained qualitative and/or quantitative descriptions of healthcare professional-related knowledge and/or attitudes and/or family carers' perceptions towards dementia care

3.1.2 Exclusion criteria

- Studies on the biochemistry of dementia
- Trial registration materials
- Studies conducted in Hong Kong and/or Taiwan
- Studies of Chinese people living in other countries
- Studies investigating or developing assessment tools
- Secondary sources such as literature reviews, and "grey" literature such as theses, newsletters, editorials and commentaries and discussion documents, notes and conference proceedings.

3.2 Information sources and search

Eight English electronic databases including CINAHL Plus with Full Text, MEDLINE, PubMed, Web of Science, Cochrane Library, Embase, PsycINFO and Scopus; and three Chinese databases: China National Knowledge Infrastructure (CNKI), Chongqing Weipu (VIP), and Wanfang, were searched without date restrictions in July 2019. Search terms included synonyms and derivates of: "knowledge", "attitude", "perception", "healthcare professional", "family carer", "dementia", and "China" (For more search details, please refer to Supplementary File 2). The reference lists of eligible articles and systematic reviews pertinent to this research area were searched manually.

3.3 Study selection and data collection

There were 1211 articles identified from English databases and 166 articles from Chinese databases. After removing duplicates, the screening of titles and abstracts was independently conducted by three reviewers (WZ, CJ and M-LW) according to

the inclusion and exclusion criteria. Full-texts of eligible studies (14 from English databases and 22 from Chinese databases, and another two articles retrieved from reference lists) were retrieved and assessed by three reviewers (WZ, CJ and M-LW). Disagreements were resolved via discussion with another reviewer (WM). In total, thirty-eight studies were included in this review. A PRISMA flow diagram outlines the study selection (Figure 1).

Data were extracted into an Excel spreadsheet by two reviewers individually (WZ and CJ). The contents of data extraction included author, year of publication, city, study aim, study design, setting, sample, data collection method, and main findings. Emails were sent to the corresponding authors of two articles (Fan & Shen, 2016; Zou et al., 2017) to seek further clarification on information reported in the articles regarding the samples and family carers' relationship with the care recipient. However, only one author (Fan & Shen, 2016) responded about their sample. Extracted data is presented in Table 1.

3.4 Quality appraisal

The quality of 38 included studies was evaluated using the Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong, Gonzalez-Reyes, & Pluye, 2018) by three reviewers who can read and write Chinese and English (WZ, CJ and M-LW). The tool consists of an evaluation of qualitative studies, quantitative randomised controlled trials, quantitative non-randomised studies, quantitative descriptive studies and mixed methods studies (Hong et al., 2018). The 2018 version of the MMAT encourages quality appraisal rather than a scoring of the articles. Therefore, there are no item-level appraisal scores for the studies included in this review. Two reviewers (WZ and CJ) assessed quality independently. Any discrepancies between them were resolved by discussion with the third reviewer (M-LW).

3.5 Data synthesis

An integrative synthesis of both qualitative and quantitative studies was undertaken. To avoid the risk of bias, data analysis consisting of data reduction, data display, data comparison and conclusion drawing and verification was conducted by two reviewers independently (WZ and CJ) (Whittemore & Knafl, 2005). Data reduction was completed by subgroup classifications of the studies. Next, an iterative process of examination of the displayed data (Table 1) was used to identify themes, and data

comparison was undertaken by two reviewers (WZ and CJ) independently (Whittemore & Knafl, 2005). Conclusions were drawn, and finally, a summary of the evidence in the review was integrated into three themes.

4 RESULTS

4.1 Study characteristics and participants

Of the 38 included articles conducted in mainland China, the earliest study was published in 2008. The majority of studies were conducted in Hunan Province, Beijing, Shanghai. As reflected in Table 1, there were 26 quantitative studies (19 survey studies, five descriptive cross-sectional studies and two randomised controlled trial (RCT) studies), 11 qualitative studies (five qualitative description studies, three phenomenology, one grounded theory, one interpretive study and a double hermeneutic approach), and one concurrent mixed-method study. Healthcare professionals and family carers were recruited in 23 and 12 studies, respectively. There were three studies that included both healthcare professionals and family carers as participants. Family carers were mostly the spouse or adult children of the people with dementia. Most studies (n=30) were conducted in a single setting, such as a hospital. The remaining studies (n=8) were conducted across multiple settings.

4.2 Quality appraisal

All studies met the first two screening questions of the MMAT, with clear research questions and collected data allowing the authors to address the research questions. Most qualitative studies (n=9) met all five criteria except for two studies. One study by Wu et al. (2016) presented insufficient data for the authors to determine if the reported findings and interpretation are appropriate. Additionally, reported findings by Lang (2019) were not adequately derived from the data, and the data insufficiently substantiated interpretation of results. A summary of the quality assessment can be found in Table 1.

Among the 38 studies, only 19 reported sampling methods: five studies used purposive sampling (Dai et al., 2015; He, Yu, Pang, Zhou, & Sun, 2013; Hsiao et al., 2016; Shi, Song, & Du, 2016; Xu, Hsiao, Denq, & Chi, 2018), five studies used random sampling (He, Yu, Jing, Sun, & Gao, 2012; Ma & Guo, 2015; Ma, Ma, &

Guo, 2015; Wang et al., 2018c; Zhang & Fu, 2013), five used convenience sampling (Gu & Wang, 2017; Lang, 2019; Li et al., 2019; Wang, Wang, Tang, & Yang, 2017a; Xiao et al., 2014) and four used cluster sampling methods (Fu, 2019; Luo, Wang, Li, & He, 2017; Wang, Wang, Tang, & Yang, 2016; Zheng, Li, & Chen, 2014).

Sample sizes for the qualitative studies ranged between 10 and 46 participants, while quantitative studies reported samples ranging from 63 to 1333 participants with the largest sample size coming from a descriptive cross-sectional study of healthcare professionals. The only concurrent mixed-method study reported 148 primary family carers. The small sample size was noted as a methodological weakness in one quantitative study (Xiao et al., 2014) and one qualitative study (Dai et al., 2015). Six qualitative studies (Dai et al., 2015; Hsiao et al., 2016; Li et al., 2019; Wang, Xiao, He, & Bellis, 2014a; Wang, Xiao, & Li, 2018b; Xu et al., 2018) and one concurrent mixed-method study (Xiao et al., 2014) recognised the limited representativeness of their sample.

Four out of 24 quantitative descriptive studies (Du, Li, & Shi, 2014; Wang, 2014; Wang, Jiang, Chen, & Tang, 2014b; Yu et al., 2013) and one mixed-method study (Xiao et al., 2014) did not provide details on response rate. Response rates of surveys ranged from 74.1% to 100%. Low response rate was acknowledged in one qualitative study where only 23 out of 45 invited carers participated in an interview (Wang et al., 2014a). One qualitative study and the one concurrent mixed-method study reported that their theoretical frameworks restricted the analysis of issues outside the study theory (Wang et al., 2014a; Xiao et al., 2014). Among all studies retrieved from the Chinese databases, only one RCT study discussed ethical considerations (Hu et al., 2015). Eleven studies from English databases simply reported the receipt of ethical approvals (Dai et al., 2015; Hsiao et al., 2016; Sun, 2014; Wang et al., 2014a; Wang et al., 2018b; Wang et al., 2018c; Wang, Xiao, Ullah, He, & De Bellis, 2017b; Wu, Gao, Chen, & Dong, 2016; Xiao et al., 2014; Xu et al., 2018; Zou et al., 2017).

One RCT, which examined the effect of training on the early detection of Alzheimer's disease (AD) for community doctors, had a risk of bias for not blinding the outcome assessors to the intervention (Hu et al., 2015). Blinding of outcome evaluators and participants' adherence to the intervention were unclear in another cluster RCT exploring the effectiveness of a nurse-led dementia education and

knowledge translation programme for community healthcare professionals (Wang et al., 2017b).

4.3 Theme 1: Knowledge and competency

Theme 1 identified that care providers' (formal and informal) dementia knowledge and confidence in providing care were generally perceived as poor. Healthcare professionals and carers ruminated that there were limited focused dementia education and training opportunities available to them. This theme was identified from 22 studies related to healthcare professionals (Fan & Shen, 2016; Fu, 2019; He et al., 2012; He et al., 2013; Hsiao et al., 2016; Hu et al., 2015; Jiang, Shan, Zhang, & Wang, 2009; Li et al., 2019; Lu, Wu, & Zhu, 2016; Luo et al., 2017; Ma & Guo, 2015; Ma et al., 2015; Wang et al., 2016; Wang et al., 2017a; Wang et al., 2018b; Wang et al., 2018c; Wang et al., 2017b; Wu et al., 2016; Wu, Yu, Liao, & Qiu, 2013; Xu et al., 2018; Yu et al., 2013; Zhang & Fu, 2013), six studies associated with family carers (He et al., 2013; Lang, 2019; Wang et al., 2014a; Xiao et al., 2014; Xu et al., 2018; Zhong, Zou, & Yang, 2010), and from a combined study of healthcare professionals and family carers (He et al., 2013). Two sub-themes were further identified: "insufficient knowledge and education", and "perceived needs related to dementia care."

4.3.1 Insufficient knowledge and education

This sub-theme was reported in 20 studies related to healthcare professionals (Fan & Shen, 2016; Fu, 2019; He et al., 2012; He et al., 2013; Hsiao et al., 2016; Hu et al., 2015; Jiang et al., 2009; Li et al., 2019; Luo et al., 2017; Ma & Guo, 2015; Ma et al., 2015; Wang et al., 2016; Wang et al., 2017a; Wang et al., 2018b; Wang et al., 2018c; Wang et al., 2017b; Wu et al., 2016; Xu et al., 2018; Yu et al., 2013; Zhang & Fu, 2013), three studies associated with family carers (He et al., 2013; Wang et al., 2014a; Xiao et al., 2014), and in a combined study of healthcare professionals and family carers (He et al., 2013). The majority of these studies were conducted in urban areas.

Healthcare professionals showed relatively low to moderate levels of knowledge about dementia in both hospital and community settings (Fan & Shen, 2016; Fu, 2019; He et al., 2012; He et al., 2013; Hu et al., 2015; Ma & Guo, 2015;

Ma et al., 2015; Wang et al., 2017a; Wang et al., 2018c; Wang et al., 2017b). For example, healthcare professionals' knowledge of dementia was assessed by the Alzheimer's Disease Knowledge Scale (ADKS) with a total score of 30 (Fan & Shen, 2016; Fu, 2019; He et al., 2012; He et al., 2013; Ma & Guo, 2015; Ma et al., 2015; Wang et al., 2017a; Wang et al., 2018c; Wang et al., 2017b). The overall reported scores ranged from 16.14 to 20.77 in hospital settings (Fan & Shen, 2016; Fu, 2019; He et al., 2012; He et al., 2013; Ma & Guo, 2015; Ma et al., 2015; Wang et al., 2017a; Wang et al., 2017b); and 19.33 to 19.70 in community settings (Wang et al., 2018c; Wang et al., 2017b).

There were several variables significantly influencing healthcare professionals' knowledge scores. Healthcare professionals with higher levels of education, previous experience of caring for people with dementia, who were older, who received dementia training and worked in hospital neurology departments, and who had higher income had significantly greater dementia knowledge (Fu, 2019; Luo et al., 2017; Ma et al., 2015; Wang et al., 2017a; Wang et al., 2018c). In terms of the professional groups working in the community, general practitioners (GPs) showed significantly higher dementia knowledge compared to nurses (Wang et al., 2016; Wang et al., 2018c). However, nurses working in acute care settings in hospitals were found to possess significantly higher knowledge in dementia assessment and diagnosis compared to doctors (He et al., 2012).

Most healthcare professionals received little formal training about dementia care after commencing employment (Hsiao et al., 2016; Li et al., 2019; Xu et al., 2018). Furthermore, where training was provided, it focused on assessment and treatment of severe mental disorders such as schizophrenia rather than dementia (Hsiao et al., 2016). Consequently, healthcare professionals had difficulty in detecting and diagnosing dementia, and had limited knowledge of risk factors, treatment and management concerning dementia care (Hsiao et al., 2016; Li et al., 2019; Wang et al., 2016). These resulted in reported low confidence in clinical practice (Hsiao et al., 2016; Li et al., 2019; Yu et al., 2013) as well as when communicating with patients and family carers (Jiang et al., 2009).

Due to healthcare professionals' limited knowledge and training in dementia care, health education and information provided for family carers was thus limited (Hsiao et al., 2016; Li et al., 2019; Zhang & Fu, 2013) given that healthcare professionals were the main sources from whom carers obtain information related to

dementia in China (Hsiao et al., 2016). Although some carers learned about dementia through their own experience, or heard about it from others (Wang et al., 2014a; Xiao et al., 2014), they could not obtain adequate relevant information (Xiao et al., 2014). As a result, family carers had low levels of dementia knowledge (He et al., 2013; Wang et al., 2014a; Xiao et al., 2014).

Interestingly, He et al. (2013) study, which compared the difference in dementia knowledge of family carers and hospital healthcare professionals, reported that the mean ADKS scores of healthcare professionals' and family carers' were similar at 16.61, and 16.70 respectively. However, it was noted that healthcare professionals scored significantly lower than family carers in three domains of the ADKS: symptoms, assessment and diagnosis, and life impact (He et al., 2013).

4.3.2 Perceived needs related to dementia care

Six studies related to healthcare professionals (Jiang et al., 2009; Li et al., 2019; Lu et al., 2016; Wang et al., 2018b; Wu et al., 2013; Xu et al., 2018) reported findings related to this sub-theme. Realising their inadequate knowledge of dementia, most healthcare professionals expressed a strong need for training in dementia care (Jiang et al., 2009; Li et al., 2019; Lu et al., 2016; Wang et al., 2018b; Wu et al., 2013; Xu et al., 2018). For example, there were reported requests for training on early diagnosis, prevention, and treatment of dementia among community healthcare professionals (Lu et al., 2016; Wu et al., 2013), and on prevention and pathogenesis among hospital healthcare professionals (Xu et al., 2018).

4.4 Theme 2: Attitudes towards dementia care

This theme identified the impact of widespread negative attitudes towards dementia and dementia care on healthcare professionals' and carers' behaviour and care options. This theme was identified in nine studies associated with healthcare professionals (Du et al., 2014; Fan & Shen, 2016; Hsiao et al., 2016; Hu et al., 2015; Shi et al., 2016; Wang et al., 2017a; Wang et al., 2018c; Wang et al., 2017b; Wu et al., 2016) and six studies related to family carers (Dai et al., 2015; Hsiao et al., 2016; Sun, 2014; Wang et al., 2014a; Xiao et al., 2014; Zou et al., 2017). The findings highlighted that there was an overall negative attitude towards dementia care among healthcare professionals and carers.

Four quantitative studies used a variety of instruments to assess healthcare professionals' attitudes towards dementia care in urban areas (Fan & Shen, 2016; Hu et al., 2015; Wang et al., 2017a; Wang et al., 2018c), and the results illustrated their negative attitudes regarding dementia care (Fan & Shen, 2016; Hu et al., 2015; Wang et al., 2017a; Wang et al., 2018c) (See Table 1). Similar findings were also found in qualitative studies conducted in both urban and rural areas (Hsiao et al., 2016; Wu et al., 2016). For example, doctors in rural areas had negative impressions about people with dementia, and thought it was a waste of money to diagnose and treat people with dementia, as dementia could not be cured (Wu et al., 2016). Two studies conducted in hospital neurology and geriatric departments focused on healthcare professionals' attitudes towards palliative care for people with advanced dementia (Du et al., 2014; Shi et al., 2016), and found that approximately 80% expressed negative attitudes towards specific palliative care measures (i.e. admission to ICU, application of CPR) for these patients. (Shi et al., 2016). No clarification of the reasons for these attitudes was provided. Nurses tended to have more positive attitudes than doctors regarding palliative care as nurses were closer to patients and were regularly exposed to the reported pain experience of patients with dementia (Du et al., 2014; Shi et al., 2016).

Attitudes towards dementia were significantly influenced by age, gender, professional group, dementia care training, and experience of caring for people with dementia (Wang et al., 2017a; Wang et al., 2018c). Healthcare professionals who were female, GPs, with prior dementia care training, and with experience of caring for people with dementia demonstrated positive attitudes towards dementia care (Wang et al., 2017a; Wang et al., 2018c). There were different conclusions about age influencing attitudes. One study found that older community healthcare professionals displayed more positive attitudes towards people with dementia (Wang et al., 2018c). Conversely, another study reported that younger nurses had better attitudes towards dementia care (Wang et al., 2017a).

Family carers' negative attitudes were concluded in six studies (Dai et al., 2015; Hsiao et al., 2016; Sun, 2014; Wang et al., 2014a; Xiao et al., 2014; Zou et al., 2017). The negative attitudes of carers may be related to their low level of health literacy (Wang et al., 2014a; Xiao et al., 2014) which, in turn, contributed to the stigmatisation of both family carers and people with dementia. For example, patients with dementia faced discrimination because of the Chinese terminology of

"*laonianchidai"* (Dai et al., 2015), which means 'stupid, idiot', and beliefs that having a family member with dementia could be a shame to the family (Sun, 2014). As a result, the majority of carers would not disclose the condition to neighbours and friends (Sun, 2014; Zou et al., 2017). Furthermore, some carers in rural areas reported keeping their relatives with dementia, who were displaying aggressive behaviours, at home to avoid embarrassment in the community (Hsiao et al., 2016).

In addition, both healthcare professionals and family carers revealed ageist attitudes in the context of dementia care (Dai et al., 2015; Hsiao et al., 2016; Wu et al., 2016). For example, memory loss, which is a common symptom in people with dementia (World Alzheimer Report, 2018), is considered by some healthcare professionals and carers as a normal disabling phenomenon of ageing rather than a sign or symptom of dementia (Dai et al., 2015; Hsiao et al., 2016; Wu et al., 2016). Consequently, early detection and diagnosis could be impeded (Hsiao et al., 2016).

4.5 Theme 3: Carers' burden and unmet needs

This theme highlights high emotional, physical, and financial stresses experienced by Chinese family carers and the limited availability of specialised services to address them. This theme was identified across nine articles related to family carers (Dai et al., 2015; Lang, 2019; Sun, 2014; Wang, Guo, & Lü, 2018a; Wang et al., 2014a; Wang et al., 2014b; Xiao et al., 2014; Zhang, Yang, Wang, & Li, 2008; Zou et al., 2017). This comprised two sub-themes: "stress" and "carers' unmet needs".

4.5.1 Stress

Seven studies identified this sub-theme (Lang, 2019; Sun, 2014; Wang et al., 2014a; Wang et al., 2014b; Xiao et al., 2014; Zhang et al., 2008). Family carers of people with dementia experienced stress in three ways: exhaustion, financial burden, and social restriction. They felt physically and mentally exhausted while providing care in daily activities of living for people with dementia (Lang, 2019; Sun, 2014; Wang et al., 2014a; Wang et al., 2014b; Xiao et al., 2014), especially for those with late stage dementia (Sun, 2014; Zhang et al., 2008). Additionally, financial costs pertinent to treatment and healthcare services, including medical examination, hospitalisation bills, and prescribed medication, further contributed to carers' stress (Sun, 2014; Xiao et al., 2014). In addition, many family carers experienced social restriction as

they spent most of the time with their relatives with dementia and had no much time for themselves or engaging in social and leisure activities (Sun, 2014; Wang et al., 2014a). Nevertheless, there were positive experiences reported by carers, who felt that people with dementia needed them and that their efforts were appreciated by other family members (Zhang et al., 2008).

4.5.2 Carers' unmet needs

Eight studies identified family carers' unmet needs in dementia care (Dai et al., 2015; Lang, 2019; Sun, 2014; Wang et al., 2018a; Wang et al., 2014a; Xiao et al., 2014; Zhong et al., 2010; Zou et al., 2017), including inadequate support in their dementia care provision (Dai et al., 2015; Sun, 2014; Wang et al., 2018a; Wang et al., 2014a). This included the unavailability or lack of supportive healthcare services, such as formal services (Dai et al., 2015), specialist teams (Sun, 2014; Wang et al., 2018a), and poor coordination within the healthcare system (Wang et al., 2014a). Specifically, there was little coordination between primary and specialist care services for people with dementia, which resulted in frequent hospitalisation, especially for people with dementia who had comorbidities (Wang et al., 2014a).

In addition, most family carers expressed needs in more accessible and affordable services within the community, such as day care services and rehabilitation centres (Lang, 2019; Wang et al., 2014a; Xiao et al., 2014; Zhong et al., 2010), and in training related to knowledge of dementia and home-based skills to help them with care provision (Wang et al., 2014a). Additionally, carers would like community nurses to have a leading role in supporting them (Wang et al., 2014a; Zhong et al., 2010).

5 DISCUSSION

This is the first known integrative review to summarise current evidence on healthcare professionals' dementia knowledge and attitudes towards dementia care, and family carers' perceptions of dementia care in China. This review is significant as it provides the international community with an overarching understanding of dementia care in China beyond a focus on the prevalence and risk factors of dementia. It identified deficiencies in dementia education and training and

negative attitudes towards dementia care among healthcare professionals and family carers who reported lack of support. These are key factors that can influence dementia care quality as healthcare professionals' knowledge and attitudes can determine what health information is provided to people with dementia and their family carers, and perceptions of family carers can influence dementia care provision. It is recommended that a national policy for education and training as well as an integrated healthcare and social care system be developed to improve dementia knowledge and attitudes of healthcare professionals and carers as well as the quality of dementia care and social support for both people with dementia and their carers.

5.1 Knowledge and competency

This review indicates that mediocre dementia knowledge amongst healthcare professionals is associated with limited professional training and inadequate education since dementia care has not been integrated into medical or nursing curricula in China (Hsiao et al., 2016; Li et al., 2019; Wang et al., 2018c; Yu et al., 2013). These findings are consistent with studies reporting inadequate knowledge of dementia of healthcare professionals from developing countries such as Africa (Brooke & Ojo, 2020). Although compared with this review, healthcare professionals working in long-term care facilities from developed countries tend to possess greater knowledge of dementia (Evripidou, Charalambous, Middleton, & Papastavrou, 2019; Jones, Moyle, & Stockwell-Smith, 2013). Similar findings to the review were found in hospital healthcare professionals from developed countries who reported a lack of knowledge and skills, insufficient training and great uncertainty in dementia care (Dewing & Dijk, 2016; Houghton, Murphy, Brooker, & Casey, 2016; Hynninen, Saarnio, & Isola, 2015; Pinkert et al., 2018).

Consequently, healthcare professionals' insufficient knowledge and training have led to a lack of confidence in clinical practice, especially in their communication with people with dementia (Jiang et al., 2009; Shi et al., 2016). These findings were consistent with studies in the US and Sweden, which identified that nurses reported little knowledge of strategies to communicate with patients with dementia (Evripidou et al., 2019; Moonga & Likupe, 2016). As a result, nurses' clinical practice in dementia care provision was adversely impacted where nurses reported avoiding interaction with patients with dementia and prioritising the care of others (Moonga &

Likupe, 2016). However, a study in acute hospitals in Germany and Austria showed that communication training in dementia care for nurses could increase their awareness of needs of people with dementia and provide them with appropriate care and support (Pinkert et al., 2018).

Similarly, family carers were reported to have inadequate knowledge of dementia (He et al., 2013; Wang et al., 2014a) due to the limited access to useful information (Hsiao et al., 2016). This is unlike carers in other countries such as Australia where they can seek information on dementia from peak body organisations such as Alzheimer's Australia (Xiao et al., 2014). Additionally, carers in China have a low level of health literacy and experience difficulties in providing dementia care, especially when behavioural and psychological symptoms of dementia are displayed (Wang et al., 2014a; Xiao et al., 2014). Therefore, the delivery of quality dementia care could be hindered (Wang et al., 2014a).

Dementia has become a national heath priority in some developed countries (Australian Government, 2019; Macaden, 2016). For example, in the UK, the first national dementia strategy was established in 2009 to raise awareness of dementia (Thomas Powell & Baker, 2019), which was followed by the integration of a dementia curriculum within nurse education in Scotland in 2014 (Macaden, 2016). The Australian government also has invested funding into dementia education and training, including via the National Dementia Support Program (NDSP) for people with dementia, their families, healthcare professionals, volunteers and community contacts (Australian Government, 2019). Furthermore, allied healthcare professionals are involved in the dementia support system in countries, such as Scotland and Australia (Alzheimer Scotland, 2020; Australian Government, 2019). However, this is not the case in China where there is a lack of studies on allied healthcare professionals identified from this review. Integrated programmes including the involvement of allied healthcare professionals may help to develop a better healthcare system and to improve dementia education and training in China.

Educational interventions have been effective in improving dementia knowledge for healthcare professionals and family carers in several countries (Chen, Huang, Yeh, Huang, & Chen, 2015; Gonge & Buus, 2015; Murphy et al., 2016). Limited evidence; however, is found in China. Only two RCT studies included in this review examined educational interventions for healthcare professionals (Hu et al., 2015;

Wang et al., 2017b). Therefore, further exploration of educational interventions is essential for future research in China.

5.2 Healthcare professionals and family carers' attitudes

Generally, healthcare professionals and family carers in China possess negative attitudes towards dementia care (Du et al., 2014; Hsiao et al., 2016; Wu et al., 2016). Similar negative attitudes towards dementia care by healthcare professionals and carers were found in countries in Europe and Africa (Brooke & Ojo, 2020; Evripidou et al., 2019). Stigma associated with dementia can negatively affect the attitudes of healthcare professionals, as well as the perceptions and health-seeking behaviours of carers (Brooke & Ojo, 2020), which can delay diagnosis and treatment and thus, impede quality care for people with dementia (Herrmann et al., 2018). Attitudes towards dementia care by healthcare professionals and family carers were more negative in rural China compared with urban China, where there was more stigma and lower health literacy (Wu et al., 2016). This is different to findings of a US study where stigma towards people with dementia was more prevalent in urban than rural areas, which was attributed to a greater sense of community in rural areas (Herrmann et al., 2018). Another reason for reported negative attitudes may be the media's portrayal of dementia (Hsiao et al., 2016), which can be based on stereotypes that promote ageism (Stites et al., 2018). To modify negative attitudes and promote help-seeking, measures and approaches that are effective in reducing stigma associated with dementia are needed (Herrmann et al., 2018).

5.3 Carers' burden and unmet needs

This review revealed that family carers were under stress with unmet needs in dementia care. For example, family carers had fewer opportunities for social interaction with other carers, which is consistent with the findings of studies internationally (Lethin et al., 2019; Livingston et al., 2017). For example, family carers in Europe reported a desire to share care experiences with other dementia carers (Lethin et al., 2019). Addressing these issues requires more policy and financial support from government insurance schemes, the establishment of a supportive network for carers as well as resource investment in the community sector.

In addition, this review identified poor dementia care coordination among different healthcare settings, which supported previous studies where insufficient cooperation within the healthcare system was reported (Brooke & Ojo, 2020; Pinkert et al., 2018). Currently, the Chinese government has carried out some reforms among public hospitals to optimise medical care resources between primary care and acute care systems (The State Council of the PRC, 2019). However, these reforms are non-dementia specific, and not likely to be utilised by people with dementia from rural areas due to low health literacy and poor awareness and understanding of dementia (Chen et al., 2013). To address this issue, technologies, such as telemedicine may be an option for people with dementia and their carers in rural areas of China to connect with healthcare professionals via video conferencing. Telemedicine has been well accepted by rural patients with dementia and their carers in the US (Dang, Gomez-Orozco, van Zuilen, & Levis, 2018).

Family carers would like more training and support from community nurses (Wang et al., 2014a). Nurses were also expected to support family carers in dementia care in Europe and Africa (Brooke & Ojo, 2020; Lethin et al., 2019). Nurses constitute the majority of healthcare professionals in the community health service centres and have more contact and closer relationships with patients compared with other healthcare professionals (Wang et al., 2014a; Zhong et al., 2010). Therefore, nurses have the opportunity to engage in education and training on dementia care to improve dementia care practice and to support carers in community settings.

The findings of the review recommend several areas for development in this field. The majority of the included studies were conducted in urban China. Further exploration is needed in rural China. The included literature provided a limited exploration of healthcare professionals' specific learning needs concerning dementia care. Therefore, future research should explore the learning needs of healthcare professionals as a means of developing dementia curricula for undergraduate programs and exploring evidence-based educational interventions on dementia care. This review noted that family carers' expectations on dementia care were mainly focused within the community setting. Therefore, a broader exploration of family carers' expectations about dementia care along the stages of one's dementia journey in acute and long-term care is also needed to ensure that care needs are met.

5.4 Limitations

This review did not include grey literature, so some studies pertinent to this topic may have been missed. However, this review searched through both English and Chinese databases to ensure studies relevant to this topic were identified and to avoid missing any non-English literature. Some studies, particularly those published in Chinese, demonstrated poor methodology, such as small sample size, sampling bias and reliance on self-reporting measures, which suggests a need for caution in the interpretation of findings.

6 CONCLUSIONS

This integrative review provides a synthesis of research examining healthcare professionals' dementia knowledge and attitudes towards dementia care and family carers' perceptions of dementia care, helping to establish an understanding of dementia care in China. Healthcare professionals' dementia knowledge ranged from low to moderate levels, and their attitudes towards dementia care were generally negative. Dementia education and training can increase dementia knowledge for healthcare professionals. However, specific learning needs are not known, and this requires further investigation. A national dementia strategy and a framework for dementia education and training programmes is required to meet healthcare professionals' and family carers' learning needs and thus improve dementia care practice as knowledge and attitudes can influence practice. Furthermore, an integrated dementia healthcare system is required to meet carers' needs. Nurses, particularly those in the community, are well-positioned to support family carers in China.

7 RELEVANCE TO CLINICAL PRACTICE

Nurses are well-positioned to support family carers within the community in China. However, this review identified insufficient knowledge of dementia and negative attitudes among healthcare professionals and carers in China. Therefore, dementia care education and training should be integrated into medical and nursing undergraduate programs and continuously provided for healthcare professionals

after commencing employment. In addition, new approaches that could reduce stigma are needed. A national dementia strategy and framework to improve public awareness of dementia and reduce stigma, as well as education on dementia are essential. In addition, robust evidence-based educational interventions on dementia care are needed to improve healthcare professionals' and carers' knowledge in the Chinese context.

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Table 1 Summary of included studies

Author (Year), City	Study Aim	Study Design	Setting	Sample	Data Collection Method	Main findings	Quality assessment
Quantitative studies (n=26)							
Healthcare professionals (n=19)							
Du, Li, and Shi (2014), Jinan in Shandong Province	To explore medical and nursing staff's attitudes towards palliative care and provide scientific basis for palliative care practice	Survey	Neurology departments and Geriatric departments of four hospitals	107 healthcare professionals (79 nurses and 28 doctors)	Chinese version of Bradley attitudes about care at the end of life among clinicians and questionnaire on perceptions of palliative care	1) 5.6% of respondents believed that they had sufficient knowledge to discuss palliative care with patients and their family carers. 2) Bradley attitudes total mean score was 3.12±0.32, with the lowest scoring recorded for communication between nurses and patients. 3) Age, gender, occupation role and titles were found to influence attitudes. Respondents who were female, older, in a nursing role with greater experienced roles possessed better attitudes.	Concerns: can't tell risk of nonresponse bias

Fan and Shen (2016), Chongqing, Zunyi and Guiyang in Guizhou Province	To identify carers' knowledge and attitudes towards dementia care	Survey	Three hospitals and three nursing homes	297 carers including 144 healthcare professionals and 153 carers in nursing homes	Chinese version of ADKS and modified questionnaire on attitudes towards people with dementia	1) Knowledge mean score of healthcare professionals was 20.77±2.24 (out of a total score of 30) and significantly influenced by level of education, age, income and relationship with care recipient. 2) Respondents with more positive views of people living with dementia, caring perceptions and greater knowledge were found to possess better attitudes about dementia care. 3) Attitude scores of healthcare professionals ranged from 1.41 to 3.18 out of a total score of 4.	Concerns: none
He, Yu, Jing, Sun, and Gao (2012), Taiyuan in Shanxi Province	To assess medical personnel knowledge on AD	Survey	Three hospitals	100 nurses and 100 doctors	Chinese version of ADKS	1) The mean percentage score of ADKS knowledge was 60.20±11.94. 2) The respondents with higher level of education had significantly greater knowledge of AD. 3) Nurses had significantly higher	Concerns: none

						knowledge of AD assessment and diagnosis compared to doctors. 4) There were significant differences of AD knowledge among different departments of nurses and doctors. 5) Understanding of risk factors and the impact of dementia on daily living varied significantly among respondents with different titles. 6) Respondents who have received education on AD scored significantly higher in 4 dimensions: (a) risk factors, (b) symptoms, (c) treatment and management, and (d) process of the disease.	
Jiang, Shan, Zhang, and Wang (2009), Beijing	To explore and compare self-perceived dementia knowledge between	Survey	One hospital	418 healthcare professionals (257 doctors and 161 nurses)	Self-designed questionnaire	1) Only 5% of doctors and 3.1% of nurses felt that they knew dementia very well with doctors reporting greater knowledge in the diagnosis of dementia in comparison to nurses.	Concerns: none

	nurses and doctors					2) Majority of doctors and nurses (>65%) expressed interests and concerns about dementia. 3) Doctors and nurses reported mediocre confidence in their management of dementia management (>65%) but over half indicated a lack of dementia care knowledge. 4) Doctors (42.9%) and nurses (36.6%) indicated their awareness of dementia prevention. 5) There is no statistical significance difference in self-perceived awareness of symptoms, preventive knowledge or treatment confidence between nurses and doctors.	
Ma, Ma, and Guo (2015), a city in Henan	To compare Alzheimer's disease knowledge of nurses from	Survey	Three hospitals	130 nurses	Chinese version of ADKS	1) The overall knowledge score of AD was relatively low, with mean score of 16.59±2.12 in neurology department and 16.14±3.62 in other departments.	Concerns: none

Province	different hospital departments					2) Overall, there are significant differences between nurses in neurology department and other departments in relation to knowledge, symptoms, treatment and management, as well as care of people with AD.	
Ma, Ma, and Guo (2015), a city in Henan Province	To investigate the Alzheimer's disease knowledge of nurses and the influencing factors	Survey	Three hospitals	130 nurses	Chinese version of ADKS	1) The overall knowledge score of AD was relatively low, with a mean score of 17.21±2.47. 2) Titles, level of education, and years of employment influenced nurses' knowledge of AD. 3) There was no statistical significance difference in AD scores between departments. There were no significant differences between nurses in neurology department and other departments in relation to knowledge of AD.	Concerns: none

Shi, Song, and Du (2016), Jinan in Shandong Province	To explore the attitudes of medical staff on advance directives for people with dementia	Survey	Neurology departments in three hospitals	63 medical staff (45 nurses and 18 doctors)	Self-designed questionnaire	1) 76. 2% of medical staff supported the preparation of advance directives for dementia patients. 2) 77.8% of medical staff agreed that palliative care was necessary for people with late-stage dementia. 3) All medical staff felt that it was very important to learn about patients' life intention. 4) 80% of medical staff showed negative attitudes towards specific palliative care measures such as admission into ICU, application of CPR, use of antibiotics and nasogastric intubation.	Concerns: none
Wang, Wang, Tang, and Yang (2016), Chongqing	To explore community medical staff's knowledge, risk management and associated factors for	Survey	22 community health service centres	717 medical staff (393 nurses and 324 doctors)	Self-designed questionnaire	1) The mean score for dementia knowledge was 2.68±1.82 (out of a total score of 9), with 29.8% of the questions correctly answered. Dementia knowledge was significantly influenced by respondents' occupation type and title, presence of cardiovascular	Concerns: none

	dementia care					disease, prior dementia training and care experience with people with dementia. 2) The mean score of knowledge on risk management was 35.47±4.26 (out of a total score of 40). Risk management knowledge was significantly related to respondents' title, level of education, prior dementia training, care experience with people with dementia, perception towards dementia as well as likelihood of experiencing dementia in the future.	
Wang, Wang, Tang, and Yang (2017), Chongqing	To examine the knowledge and attitudes of clinical nurses towards dementia	Survey	Hospitals	223 nurses	Chinese version of ADKS and DAS	1) The average knowledge score on the ADKS was 19.17±2.63 (out of a total score of 30). Correct responses ranged from 54% to 76.6% in each scale dimension. Knowledge was influenced by title, age and prior dementia training experience.	Concerns: none

						2) The average attitudes score (DAS) was 88.59±13.02 (out of a total score of 140). Attitudes were influenced by age and prior dementia care experience.	
Wu, Yu, Liao, and Qiu (2013), Hangzhou, Shaoxing and Jinhua in Zhejiang Province	To explore requirements of community physicians for the diagnosis and treatment techniques for depression and senile dementia	Survey	10 community health service centres	512 doctors	Self-designed questionnaire	1) Most community physicians expressed strong interest in common diagnostic and treatment techniques for patients with depression and senile dementia, with 62% to 80% of them expressing a strong need. 2) 73% community physicians did not know management techniques for patients with senile dementia.	Concerns: none
Yu et al. (2013), Shanghai	To explore the attitudes and confidence of general practitioners (GPs) in dementia management	Survey	14 hospitals and 59 community health service centres	287 GPs	Self-designed questionnaire	1) 75.3% of GPs thought they had good knowledge of dementia, with significantly higher self-reported knowledge in senior GPs (81.7%) compared to junior GPs (70.9%). 2) 58.1% of junior GPs and 68.7% of senior GPs indicated that they were confident in dementia	Concerns: can't tell risk of nonresponse bias

	and its associated problems.					diagnosis. 3) 78.4% of GPs reported that they had few interactions with people with dementia during their clinical practice. 4) 24.7% of GPs attended dementia related knowledge training courses. 5) Compared to junior GPs, senior GPs were significantly less enthusiastic and more likely to think that dementia should be diagnosed by a specialist. 6) Senior GPs in comparison to junior GPs felt that GPs had a limited role in dementia diagnosis and management.	
Zhang and Fu (2013), Hangzhou in Zhejiang Province	To examine the current health education capacity of community	Survey	12 community health service centres	353 nurses	Self-designed questionnaire	1) The health education capability of community nurses was found to be acceptable, with a higher score in implementation of health education and a lower score in assessment of health education.	Concerns: none

	nurses on dementia relating to preventive treatment of disease					2) 43.6% of community services had implemented health education on dementia. 3) 95.2% of nurses indicated that it was necessary for them to possess knowledge on dementia prevention. 4) 91.4% of nurses agreed that health education on dementia in the community was needed. 5) Top 3 factors influencing health education on dementia were patients' demands, nurses' knowledge and communication ability.	
Fu (2019), Shandong Province	To understand nurses′ cognition of Alzheimer ' s disease and improve their ability to care	Descriptive cross-sectional	Six hospitals	293 nurses	Chinese version of ADKS	1) Knowledge mean score for nurses was 17.71±3.15 (out of a total score of 30). Significantly influenced by age, level of education, years of employment, department, titles, experience of caring for people with dementia, and training experience of	Concerns: none

	for patients and improve patients′ quality of life.					dementia care. 2) Nurses aged ≥ 30, years of employment ≥ 10 and with higher titles had higher perceptions of dementia. 3) Nurses from neurology departments had significantly higher knowledge score than other departments as they had more access to people with dementia.	
Lu, Wu, and Zhu (2016), Shanghai	To explore community medical workers' dementia knowledge, training and education needs and challenges in dementia care provision.	Descriptive cross-sectional	12 community health service centres	98 medical workers (34 doctors and 64 nurses)	Self-designed questionnaire	1) 66.7% of respondents in the community could distinguish dementia cases correctly. 2) Medical workers require dementia education and training particularly on early diagnosis of dementia (3.83±1.10) and dementia prevention (3.61±1.33). 3) The biggest difficulty for medical workers with implementing dementia prevention related to their professional knowledge and the lack of available support.	Concerns: none

Luo, Wang, Li, and He (2017), Changsha in Hunan Province	To explore the knowledge of medical personnel on pain in people with dementia	Descriptive cross-sectional	Five hospitals and four primary health centres	1333 medical personnel (495 doctors and 838 nurses)	Self-designed questionnaire	1) The mean score for healthcare professionals' pain knowledge in people with dementia was 55.73 ±5.09. 2) 75.6% of medical personnel agreed that people with dementia could feel pain. 3) Medical personnel from primary health centres had significantly lower understanding of pain in people with dementia than those from hospitals. 4) Medical personnel who had previous experience of caring for people with dementia had significantly higher knowledge of pain than those with limited experience.	Concerns: none
Wang, Xiao, Luo, et al. (2018), Changsha	To assess dementia knowledge, attitudes and care approach	Descriptive cross-sectional	Community	390 healthcare professionals (212 GPs and 178 nurses)	Chinese version of ADKS, DCAS and ADCQ	1) Overall, dementia knowledge was poor with a mean score of 19.7±3.07 (out of a total score of 30). Knowledge scores were associated with age, gender,	Concerns: none

in Hunan Province	of community healthcare professionals					professional group and care experience. 2) The mean score of dementia attitudes was 28.5±3.20 (out of a total score of 40). Attitudes were generally positive and influenced by age, occupation, gender, and care experience. 3) The mean score reflecting care approach was 7.8±2.17 (out of a total score of 13) and positively associated with a person-centred care approach.	
Zheng, Li, and Chen (2014), Fujian Province	To investigate knowledge, attitude and behaviour of nurses towards feeding difficulty in patients with Alzheimer's	Descriptive cross-sectional	Neurology departments and Geriatric departments of three hospitals	221 nurses	Self-designed questionnaire	1) 36.6% of nurses believed they could manage feeding difficulties of patients with Alzheimer's disease in a timely and appropriate way. 2) 96.8% of nurses agreed that feeding difficulty in people with Alzheimer's disease can be fatal. 3) 38.9% of nurses misunderstood that the best way to solve feeding	Concerns: none

	disease					difficulty was nasogastric feeding. 4) There were significant differences in feeding difficulty knowledge amongst nurses of different ages, level of education, titles, years of working experience, and years working in neurology or geriatric departments.	
Hu et al. (2015), Beijing	To examine the training effectiveness for community doctors to improve their skills for early recognition of Alzheimer's disease	Randomised controlled trials	Seven community health service centres	63 doctors	Self-designed questionnaire	1) Baseline knowledge scores for participants in both the control and intervention groups were similar at 16.0±3.0 and 15.6±2.2 respectively (out of a total score of 25). 2) Baseline attitudes scores for participants in both the control and intervention groups were similar at 8.3±1.3 and 8.2±1.2 (out of a total score of 10).	Concerns: can't tell whether outcome assessors were blinded to the intervention or not
Wang et al., (2017), Hunan Province	To determine the effectiveness of a nurse-led dementia	Cluster RCT	14 community health service centres	170 healthcare professionals (102 GPs and 68 RNs)	Chinese version of ADKS and DCAS and ADCQ	1) Baseline knowledge scores for participants in both the control and intervention groups were similar at 19.29±2.72 and 19.36±3.05 respectively (out of a total score of	Concerns: can't tell whether outcome assessors

	education and knowledge translation programme for healthcare professionals in primary care; participants' satisfaction with the programme; and to understand participants' perceptions of and experiences in the programme					30). 2) Baseline attitude scores of DCAS-Heartfelt for participants in both the control and intervention groups were similar at 16.20±2.02 and 16.26±2.03 respectively (out of a total score of 20). 3) Baseline attitude scores of DCAS-Heartsink for participants in both the control and intervention groups were similar at 11.67±2.70 and 11.58±3.46 respectively (out of a total score of 20). 4) Baseline ADCQ scores for participants in both the control and intervention groups were similar at 5.12±2.05 and 5.33±2.37 respectively (out of a total score of 13).	were blinded to the intervention or not & whether participants adhere to the intervention or not
Family carers (n=5)							
Gu and Wang	To explore the attitudes of	Survey	One hospital	150 family carers	Self-designed	1) 76.0% family carers understood the usage of protective constraints.	Concerns: none

(2017), Nanjing, Jiangsu Province	family carers of people with dementia on the use of protective constraints				questionnaire	2) 75.3% family carers stated that informed consent should be obtained from them before the implementation of protective constraints. 3) 72.7%believed the need for hospital regulations in the use of protective constraints. 4) 42.3% family carers felt that the use of protective constraints might worsen their relatives' illness. 5) 36.7% family carers believed that psychological comfort could replace protective constraints reflecting their inadequate understanding the need for protective constraints. 6) Older carers with higher level of education demonstrated more understanding of the need in the use of protective constraints.	

Wang (2014), Hengyang in Hunan Province	To examine knowledge of dementia safety among family carers	Survey	Emergency department of a hospital	84 family carers of people with dementia (30 spouses, 24 daughters or sons, 2 siblings, 28 others)	Self-designed questionnaire	1) There was no significant difference between level of education of family carers and their knowledge of dementia safety. 2) Family carers of people with dementia experienced high awareness on items placement, physical constraints and disease observation. 3) Family carers had low awareness on going out, water temperature, and pain experience of people with dementia. 4) Family carers with more than 10 years' experience in caring had significantly higher scores in safety awareness.	Concerns: can't tell risk of nonresponse bias
Wang, Guo, and Lü (2018), Beijing	To explore dementia caregivers' care status and influencing factors	Survey	Communities	245 carers including 172 family carers (76 spouses, 94 daughters or sons, 2	Self-designed questionnaire	1) Caring ability score of carers was 57.8±15.64 (out of a total score of 105). 2) Age, level of education, acceptance of dementia training and relationship with care recipient	Concerns: none

				relatives) and 73 paid cares of people with dementia		individually influenced the caring ability of family carers of people with dementia. 3) Caring ability was collectively influenced by care recipients' complications of other chronic diseases, caregivers' age, relationship between caregivers and care recipients as well as acceptance of dementia training.	
Wang, Jiang, Chen, and Tang (2014), Hunan Province	To explore memory loss in people with dementia and relative attitudes of their caregivers	Survey	Nine hospitals	153 people with dementia and their primary family caregivers (86 spouses, 55 daughters or sons,12 daughters-in-law or sons-in-law)	RMBPC	1) 99.3% of people with dementia had memory-related problems, 89.5% had depression and 88.9% had disruptive behaviours. 2) Caregivers reported significantly higher distress when caring for people with dementia exhibiting disruptive behaviours than those with depression or memory-related symptoms. 3) Family caregivers indicated that 'engaging in behaviour that is potentially dangerous to self or	Concerns: can't tell risk of nonresponse bias

						others', 'destruction of property' and 'waking up family members at night' were most distressful to them.	
Zou et al. (2017), Shanghai	To evaluate attitudes towards disclosing an AD diagnosis to patients with cognitive impairment from their carers' perspective, and factors that may affect their attitudes	Survey	Two hospital and a mental health centre	164 carers of people with dementia (96 adult children, 37 spouses, 8 other relatives, 5 sons-in-law or daughters-in-law, 4 grandchildren, 3 brothers or sisters, 1 mother)	Self-designed questionnaire	1) 95.7% of respondents wished to know their own diagnosis if diagnosed with AD, and 97.6% preferred the doctor to tell their family members about the diagnosis. 2) If a family member was diagnosed with AD, 82.9% carers preferred disclosure to patients by their doctors. 3) "Cognitive impairment" was considered the most accepted term by carers to convey the diagnosis in Chinese.	Concerns: none
Both healthcare professionals and family carers (n=2)							
He, Yu, Guifeng;, Zhou, and Sun	To explore and compare the knowledge of dementia	Survey	Three hospitals	590 respondents including 200 healthcare	Chinese version of ADKS	1) Knowledge mean scores of healthcare professionals, people with AD and carers were 16.61±2.59, 10.49±2.96 and	Concerns: none

(2013), Taiyuan in Shanxi Province	between healthcare professionals, people with AD and their carers			professionals, 195 family carers, and 195 people with AD		16.70±2.84 respectively (out of a total score of 30), reflecting relatively low level of dementia knowledge across all seven dimensions. 2) People with AD had significantly lower knowledge scores than their carers and healthcare professionals. 3) Healthcare professionals scored significantly lower than family carers in three domains of ADKS: symptoms, assessment and diagnosis, and life impact.	
Zhong, Zou, and Yang (2010), Shaoyang in Hunan Province	To examine the current nursing situation for people with dementia living in the community	Survey	15 community health centres	68 nurses & 283 people with dementia and their carers	Self-designed questionnaire	1) 57.1% of nurses were knowledgeable of dementia and aware of skills relating to the management of safety concerns, behavioural and psychological symptoms, relational concerns and care burden. 2) 75.6% of people with dementia and their carers would like to	Concerns: none

						receive assistance and support from community health centres, including home visit (59.5%) and day care centre (51.2%) services. 3) 76.8% of people with dementia and their carers hoped to receive health education on dementia care from healthcare professionals. 4) 41.8% of respondents indicated that the community provided relatively standard management for people with dementia.	
Qualitative studies (n=11)							
Family carers (n=6)							
Sun (2014), Shanghai	To identify caregiving stressors and coping strategies in family caregivers of people with dementia	Qualitative description	One mental health centre	18 family carers of people with dementia (14 spouses, 3 daughters, 1 daughter-in-law)	Semi-structured interviews	1) Stressors directly related to care included the progression of disease, burden due to recipients and limited physical, cognitive or behavioural functions, financial burden, social restrictions as well as poor caregivers' physical health. 2) Other stressors related to	Concerns: none

						caregiving role, family conflicts and social environment. 3) Carers demonstrated resilience by drawing on their coping resources from a variety of sources, including personal experience, family, technology and information, religion, and governmental support.	
Lang, (2019), Shenyang in Liaoning Province	To explore the mental experience of family carers in the process of taking care of cognitive impairment people with Alzheimer's disease, know the needs of carers and address the	Phenomenology	One hospital	12 family carers	Semi-structured interviews	Four themes: 1) Carers reported needs for treatment and rehabilitation knowledge. 2) Carers needed social support, and hoped to gain support and understanding from family members and the society. 3) Carers suffered from enormous physical and mental stress, and had experienced mental disorders. 4) Carers were worried about the future.	Concerns: findings were not adequately derived from the data & the interpretation of results were not sufficiently substantiated by data

	difficulties they have.						
Rao and Shen (2017), Chongqing	To explore the perception of carers of people with dementia on elder abuse	Phenomenology	One community and one nursing home	10 family carers of people with dementia (6 adult children, 1 spouse, 1 sibling, 2 daughters-in-law) and 8 carers from nursing homes	None	Four themes were generated: 1) limited understanding about elder abuse, specifically regarding intentional physical and verbal violence as well as neglect; 2) lack of filial piety and sense of responsibility; 3) need for self-discipline to reduce abuse; 4) limited awareness of the dangers of elder abuse particularly an erroneous belief that people with dementia do not experience abuse	Concerns: none
Zhang, Yang, Wang, and Li (2008), Beijing	To describe the care experiences of Chinese carers of people with dementia	Phenomenology	Neurology outpatient clinic of a hospital	10 family carers of people with dementia (5 spouses, 3 daughters, 2 sons)	Non-structured interviews	Five themes were found: 1) Enduring stress and frustration: Carers were physically and mentally exhausted with care provision, experienced communication difficulties with care recipients; and had limited	Concerns: none

						time for themselves. 2) Suffering through the losses: Carers were upset with the progressive change in their care recipients, disruption to their career and time spent with family and friends, as well as changes to their life plans. 3) Moving with continuous change: Carers emphasised the importance of keeping up with and accepting changes in care recipients, seeking help and support in knowledge and care provision; and embracing the unknown future. 4) Immersed in caregiving. 5) Establishing self-identify and acknowledging self-value from the caregiving process.	
Dai et al. (2015), Wuhan in Hubei	To examine the perception of Alzheimer's disease (AD)	Grounded theory	One hospital and one Dementia	46 participants including 22 family carers of individuals	Interviews	1) Most carers thought that cognitive function decline was the law of nature for older adults. 2) All family carers thought the	Concerns: none

Province and Beijing	and caregiving among family carers of individuals with mild cognitive impairment (MCI) and AD		Care & Research Centre	with mild cognitive impairment and 24 of individuals with mild AD (38 spouses, 7 children, 1 sibling)		Chinese terminology of AD "*laonianchidai*", brought discrimination to individuals with cognitive impairment. 3) Carers of individuals with AD experienced burden and desired an increasing of formal services. 4) Traditional beliefs of respecting elders and caring for extended family members were held among family carers of individuals with cognitive impairment.	
Wang, Xiao, He, and Bellis (2014), Changsha in Hunan Province	To examine social, cultural and political constructed factors affecting family caregiver practice in dementia care, and to identify possible	A double hermeneutic approach	Three hospitals	23 family caregivers of people with dementia (16 spouses, 7 adult children)	In-depth semi-structured interviews	1) Caregivers were unable to manage behavioural and psychological symptoms of dementia. 2) The burden on the primary caregivers was evident especially for older spousal caregivers and caregivers received limited support. 3) There was little coordination between primary and specialist care services for people with	Concerns: none

	changes in a country with undeveloped dementia services					dementia. 4) Family caregivers suggested that accessible and affordable dementia services, dementia education programmes and community care services were needed and should be improved. 5) Family caregivers suggested that community nurses had a leading role in coordinating dementia services and supporting caregivers. 6) Caregivers were keen to learn more about dementia care.	
Healthcare professionals (n=4)							
Hsiao, Liu, Xu, Huang, and Chi (2016), Beijing	To explore the similarities and differences in knowledge, attitudes, and clinical practices regarding	Qualitative description	Mental health community clinics and psychiatric hospitals	40 healthcare professionals (28 doctors and 12 nurses)	Focus groups	1) Regional disparities between cities and towns included knowledge of early diagnosis of dementia and competence in counselling by mental health providers. 2) Mental health providers in towns had little skill in communication, such as explaining diagnosis with	Concerns: none

	dementia and working with family carers from the perspectives of mental health providers between town and city					people with dementia or their family carers. 3) Both cities and towns lacked training and knowledge with mental health providers in towns reported experiencing more difficulty detecting or diagnosing dementia. 4) Mental health providers' attitudes towards dementia care included therapeutic nihilism, ageism and a need for specialist care in community. 5) Mental health providers reported poor awareness of dementia among family carers and discriminative attitudes towards people with dementia.	
Li, Wang, Shao, Liu, Xuxiao, and Du (2019),	To investigate general practitioners′ knowledge and attitudes	Qualitative description	14 community health service centres	20 general practitioners	Focus groups	Four themes: 1) GPs had very limited professional training on dementia care. 2) GPs felt that they had insufficient knowledge on dementia care and	Concerns: none

Beijing	toward dementia care at community level in Beijing, so as to provide reference for future practice in dementia care at community level.					lack of confidence in dementia care in the community. 3) GPs were willing to provide people with dementia and their carers in the community with medical help as much as possible. 4) GPs had limited time and limited services and suggested to create the model of team management.	
Xu, Hsiao, Denq, and Chi (2018), Beijing	To understand training needs for dementia care from the perspective of mental health providers	Qualitative description	Community clinics and psychiatric hospitals	40 healthcare professionals (12 nurses and 28 doctors)	Focus group	1) There was a significant need to train both mental health providers and informal carers. 2) Mental health providers required training on clinical knowledge of dementia (i.e. pathogenesis, approaches for preventing dementia deterioration) and clinical practice skills (i.e. diagnostic, treatment, counselling, and communication skills).	Concerns: none

						3) Informal carers required training on basic dementia knowledge and home-based caring skills including safety, stress management and how to communicate with people with dementia. 4) Support from the government and community was crucial in delivering these trainings for formal and informal carers.	
Wang, Xiao, and Li (2018), Changsha in Hunan Province	To explore community healthcare professionals' perceptions of dementia service development using China as a case.	Interpretive study design	Seven community health centres	21 healthcare professionals (12 RNs and 9 GPs)	Focus group guided by semi-structured interviews	Three themes were: 1) Incorporating dementia components in government-subsidised primary care services that include (a) inclusion of dementia prevention in health education program; (b) early detection of dementia using screening tools; as well as (c) subsidising dementia management as part of the chronic disease management scheme. 2) An under-prepared workforce to	Concerns: none

						meet the demand for dementia care where there is a low ratio of healthcare professionals to the population; as well as inadequate education and training in dementia care were highlighted. 3) An enabling environment to sustain dementia care through a review of policies and funding for service development and the need for collaborations between community health centres and general hospital.	
Both healthcare professionals and family carers (n=1)							
Wu, Gao, Chen, and Dong (2016), Jinhua in Zhejiang Province	To determine the state of health and supportive services available to older adults with dementia and their	Qualitative description	Care facilities for older people	Three rural physicians, one urban geriatrician, seven directors of institutions for the care of the older people,	Observations and in-depth interviews	1) Physicians in the countryside thought that going to the doctor was a waste of money for people with dementia. 2) There was a lack of specialised services designed specifically to meet the needs of individuals with dementia and their family members.	Concerns: can't tell whether findings are adequately derived from the data or not & whether sufficient data

	families in rural Lanxi county, in the province of Zhejiang, China			three officials of the civil affairs bureau and five family carers of older people with dementia		3) Non-psychiatric medical services as well as the available facilities for institution care were insufficient. 4) The institution did not provide any formal training for staff in dementia care. 5) There were a shortage of clinical staff and standardised and evidence-based diagnosis, care, treatment and rehabilitation for people with dementia. 6) Institutions often refused to admit people with dementia, consequently, families were forced to care for relatives with dementia at home.	for interpretation of results
Mixed method study (n=1)							
Xiao et al. (2014), Not reported	To compare socially and culturally constructed enablers and barriers	Concurrent mixed method	Communities	148 primary caregivers of people with dementia (57 from Australia and 91 from	Caregiver Survey Questionnaire including questions about family	Three categories were found: 1) A higher objective burden in the Chinese cohort versus a higher subjective burden in the Australian cohort. 2) Unmet need for caregiver support	Concerns: can't tell risk of nonresponse bias

	pertinent to dementia caregivers in Australia and China			China) (87 spouses or partners, 61 children or relatives)	caregivers and care recipients, CBI, NPI-Q and the usage of community care services in Australian and Social Support Rating Scale in China. Focus groups and individual interviews	in Australia and China, including a need for ongoing learning for care provision. 3) Expectations for improving dementia services in Australia and for developing dementia services in China including affordable treatment for dementia, respite care, rehabilitation services and community care.	

Abbreviations: AD, Alzheimer's disease; ADCQ, Approach to Advanced Dementia Care Questionnaire; ADKS, Alzheimer's Disease Knowledge Scale; CBI, Caregiver Burden Inventory; DAS, Dementia Attitudes Scales; DCAS, Dementia Care Attitude Scale; NPI-Q, Neuropsychiatric Inventory Questionnaire; RMBPC, Revised Memory and Behavioral Problems Checklist

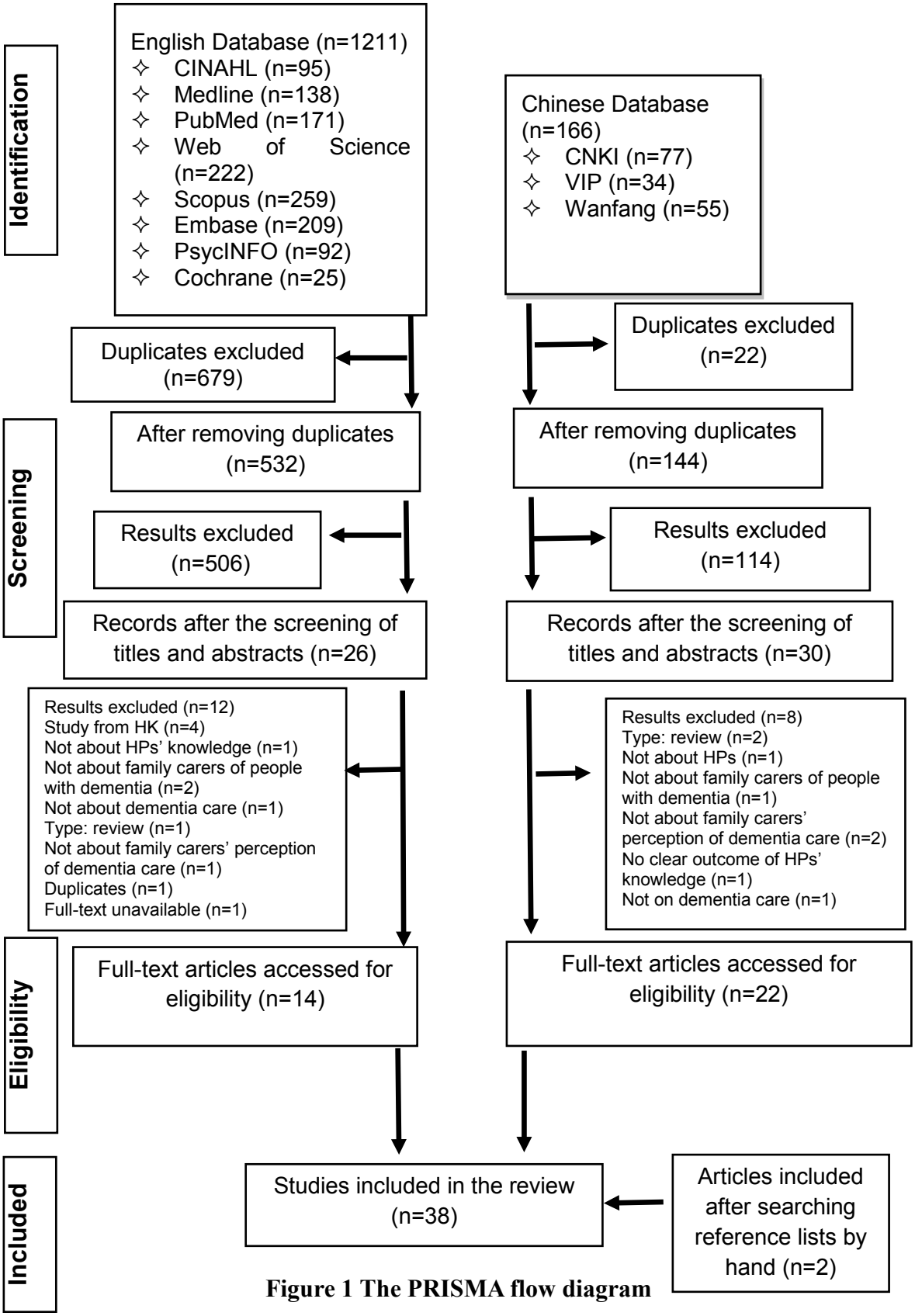

Figure 1 The PRISMA flow diagram