

Role of Community Health Workers in Addressing Dementia: A Scoping Review and Global Perspective

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Abstract

The current increase in global dementia prevalence deserves public health intervention. While limited access to health care and a shortage of health care workers are significant shortcomings, utilizing community health workers (CHWs) could be a promising way to improve dementia care through cost-effective approaches. This scoping review synthesizes existing research on roles of CHWs in dementia-related services. PubMed, CINAHL, Scopus, CABI Global Health, Web of Science, PsycINFO, and Cochrane Library were searched from inception to October 2, 2019, and yielded 1,594 articles. Five broad areas emerged as potential roles of CHWs from 10 eligible articles: educational and community awareness, screening for dementia, screening for HIV-associated dementia, utilization of health care systems and other dementia-related resources by patients, and services to dementia caregivers. This scoping review sheds light on important contributions of CHWs in addressing dementia among vulnerable communities/groups around the world.

Keywords

community health workers, dementia, Alzheimer's disease, cognitive function, cognitive impairment, task-shifting, scoping review

Introduction

Dementia is a chronic condition which includes symptoms associated with cognitive decline, specifically in thinking and reasoning, to such a degree that it disrupts a person's regular activities (Qiu & Fratiglioni, 2018). This neurodegenerative disorder affects mostly older adults and constitutes a major factor in disability among this population (World Health Organization [WHO], 2019). The global prevalence of dementia is 46.80 million which is predicted to double every 20 years (Alzheimer's Association [AA], 2015). Worldwide, the incidence is estimated to be 9.90 million dementia cases per year, which results in one new case every 3.20 s. There has been an almost 13% increase in global dementia cases in the last 5 years (AA, 2015). Moreover, dementia poses a profound economic burden to countries worldwide with an estimated 1.09% of the global gross domestic product (GDP) which accounts for US\$818 billion in direct care costs (AA, 2015). These numbers are even greater as they do not account for informal care costs (Wimo et al., 2017). While early diagnosis is crucial for attenuating the risk of dementia and its consequences, lack of awareness by community members worldwide precipitates a delayed diagnosis (Fox et al., 2013; WHO and Alzheimer's

Disease International, 2012). This is especially a concern across minority communities that are disproportionately affected by dementia. Late diagnosis of dementia in diverse populations exacerbates existing health disparities (Chin et al., 2011). The less-than-optimal utilization of the health care system by the community is a significant shortcoming that inhibits early detection of dementia and care (Warshaw & Bragg, 2014; Phillipson et al., 2014). Dementia is a growing health concern worldwide, and many countries have already declared it as a public health priority (AA, 2015; WHO and Alzheimer's Disease International, 2012).

The global dementia epidemic requires public health attention and compels health professionals and policy makers to

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think about how best to address the problem. The concept of task-shifting has emerged as a strategy for bettering dementia awareness and care to ease the burden of caregiving costs. Task-shifting is described as the process of moving tasks assigned from highly trained health professionals to health workers with substantially less formal training (Joshi et al., 2014). Community health workers (CHWs) are identified as lay health workers who have little to no training and are able to establish a link between the community and the health care facility through health education and other support interventions (Olaniran et al., 2017; WHO, 2018). They have been recognized as a defined occupational group (ISCO 3253) and subcategorized as a distinct associate health professional category by the International Labour Organization (ILO, 2012). This occupational group is referred to not only as CHWs but also by other terms such as community health agents, health promoters, lay health workers, and village health workers depending on geographical areas (Bhutta et al., 2010). Adopting the CHW model in wide-ranging health programs has been an effective strategy for task-shifting, explicitly in resource constrained areas experiencing a shortage of health care specialists (Bhutta et al., 2010; Javanparast et al., 2018). These health workers come from the responding community, and thus, have a reasonable understanding of cultural practices and language (Olaniran et al., 2017). Hence, CHWs have the potential to address cultural misbeliefs which is particularly important for dementia diagnosis and treatment through gaining trust in minority communities as there are misconceptions and distrusts toward clinical research, health care professionals, and the health care system (Chin et al., 2011). Therefore, adopting the cost-effective and culturally appropriate roles provided by CHWs might improve dementia care and health inequity related to dementia. Due to limited research in this area, the understanding of CHWs' contributions toward dementia services is limited. Therefore, this scoping review sought to identify studies which utilized CHWs in different dementia-related services throughout the world and examined their effectiveness.

Method

Nature of Review

A scoping review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009). The scoping review process systematically searches, selects, and synthesizes knowledge in a certain field (Arksey & O'Malley, 2005; Mialke-Lye et al., 2016). The nature of the scoping review addresses a broader research question in comparison with more systematic literature reviews and therefore was chosen for this article (Haby et al., 2016). Given the lack of research in this area, the scoping review allowed us to elucidate the scope of utilizing CHWs in a variety of dementia-related services globally and to identify gaps in the literature.

Inclusion and Exclusion Criteria

The study selection criteria were developed using the PICOS (participants, intervention, context, outcome, and study design) framework (O'Connor et al., 2008). Studies were included according to the following criteria: (a) study design: randomized control trial, cross-sectional, pre-post, longitudinal, case-control, qualitative, mixed-method; (b) geographical location: global; (c) participants: CHWs (defined by ILO); (d) intervention and outcome: delivery of any dementia care-related services; (e) article type: peer-reviewed publications; and (g) language: English. Studies were not included if they met any of the following criteria: (a) CHWs delivering services not including dementia care, (b) dementia care interventions conducted by health professionals other than CHWs (e.g., primary care providers, community nurses, allied health professionals), (c) dementia care services provided by dementia caregivers, (d) non-English articles, (e) non-peer-reviewed publications, (f) non-empirical research, and (g) reviews, commentaries, protocols, position papers, case-studies, or editorials.

Search Strategy

A comprehensive search was conducted by a health science librarian in seven electronic bibliographic databases ranging from their inception to October 2, 2019: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), SCOPUS, CABI Global Health, Web of Science, PsycINFO, and Cochrane Library. The search terms included all possible synonyms and combinations of "Community Health Worker" and "Dementia." The complete search algorithm for each database is listed in the Supplemental Appendix. Two authors reviewed the articles for title and abstract against the study selection criteria independently and retrieved potential articles for full-text evaluation. Afterward, a cited reference search (e.g., forward reference search) and reference list search (e.g., backward reference search) were conducted and repeated to verify the availability of any additional articles. Two authors jointly determined the articles to be included in the scoping review after full-text reading. Any discordance was settled by face-to-face meeting or with the help of a third reviewer if needed. Cohen's kappa statistics ($\kappa = 84.71\%$) was used to measure the level of agreement.

Data Extraction and Synthesis

A standardized form was created for data extraction to record the following information from the included studies: first author, year of publication, objectives, study design, location, demographics (sample size, age, sex, education) of the community individuals served (Table 1), demographics (number, age, sex, education, experience,

Table 1. Basic Characteristics of the Included Studies and Their Participants.

Study ID	First author (year)	Location	Primary objectives	Individuals served (n)	Female (%)	Age (years)	Education	Study design
1	Shaji et al. (2002)	Kerala, India	To identify the possible cases of dementia by CHWs	1,979	NR	≥60 ^a	NR	Cross-sectional
2	Ramos-Cerqueira et al. (2005)	Piraju, San Paulo, Brazil	To identify dementia cases by CHWs with an easy, low-cost technique	2,222	58.1	≥65 ^a	Illiteracy rate 9%	Cross-sectional
3	Jacob et al. (2007)	Velore, India	To assess the potential of CHWs to determine dementia cases	1,000	54.6	≥65 ^a 72.7 ^b	Illiteracy rate 73.3%	Cross-sectional
4	Kvalsund et al. (2009)	Kalingalinga, Lusaka, Zambia	To employ CHWs to identify HIV-D for early treatment and prevent neurologic disability	48	62.5	≥18 ^a 34.7 ^b	7.2 years (mean) of education	Cross-sectional
5	Souder and Terry (2009)	Arkansas, the United States	To link Black community with health research to ensure dementia care	135	NR	NR	NR	Longitudinal
6	Boughtwood et al. (2013)	Southwestern Sydney, Australia	To know the contribution of bilingual CHWs and barriers in dementia education and services to CALD families	NR	NR	NR	NR	Qualitative
7	Robbins et al. (2011)	South Africa	To determine possible HIV-D rate and its risk factors among HIV-positive individuals on ART	65	65	18–68 ^c 38.5 ^b	59% high school (not completed)	Cross-sectional
8	Han et al. (2013)	Baltimore–Washington metropolitan area, the United States	To compare the diagnosis of dementia by the CHWs and the physicians among Korean Americans	90	77.8	≥60 ^a 75.7 ^b	64.4% high school (not completed)	Cross-sectional
9	Litzelman et al. (2017)	Indianapolis, IN, the United States	To assess an ACP intervention by CHWs to the elderly with chronic conditions including demented	818 (22.4% dementia cases)	78	≥65 ^a 74.2 ^b	NR	Pre-post
10	Askari et al. (2018)	East Palo Alto, CA, the United States	To promote dementia awareness by developing a curriculum using CBPR model and training CHWs	15–25 by each CHW	NR	NR	NR	Pre-post

Note. CHW = community health worker; NR = not reported; HIV-D = HIV-associated dementia; CALD = culturally and linguistically diverse; ART = antiretroviral therapy; ACP = advance care planning; CBPR = community-based participatory research.

^aCutoff for age. ^bMean age. ^cAge range.

type of employment) of CHWs, their training procedures (Table 2), roles, instruments used for screening dementia, methods of intervention, and key findings of the program (Table 3). A WHO guideline was adapted as a framework to create the results (WHO, 2018). We used descriptive statistics to classify the common areas and broad roles of CHWs synthesized from the studies (Table 4).

Results

Study Selection

A detailed screening process for the eligible studies has been provided as a flowchart in Figure 1. A total of 1,594 articles were identified from the database search and imported to EndNote. After removing duplicates, 919 articles were reviewed by title and abstract; 19 articles were selected for full-text review. After a thorough assessment, eight articles were excluded in accordance with the exclusion criteria and the reasons for exclusion have been listed in Figure 1. One additional article was excluded with the help of third reviewer

due to insufficient details about methodology. Finally, 10 articles were selected to be included in this review (Askari et al., 2018; Boughtwood et al., 2013; Han et al., 2013; Jacob et al., 2007; Kvalsund et al., 2009; Litzelman et al., 2017; Ramos-Cerqueira et al., 2005; Robbins et al., 2011; Shaji et al., 2002; Souder & Terry, 2009). No additional articles were found meeting the eligibility criteria in the forward and backward search.

Basic Characteristics of Included Studies

Table 1 describes the basic characteristics of the studies and their participants. All the studies were published between 2002 and 2018. Six of them were cross-sectional, two pre-post, one longitudinal, and one qualitative. The studies were conducted in different regions of the world (the United States = 4, India = 2, Australia = 1, South Africa = 1, Brazil = 1, Zambia = 1). The number of community individuals served by the CHWs varied from 48 to 2,222. Three studies set the minimum age for inclusion at 65 years, two studies at 60 years, and two studies at 18 years. Six studies reported the

Table 2. Basic Characteristics of CHWs in the Studies Included in the Review.

Study ID	Number of CHWs	Age (years)	Female (%)	Education and experience	Employment type	Training
1	19	NR	100	Educated	Employed by ICDS national government health program	Introductory 90-min session and advanced 60-min session
2	25	25–40 ^a	100	8–11 years of education	Employed by government	Preliminary 3-hr training session and another 3-hr group conversation and case review
3	4	44.5 ^b	100	Class 10 and 16.1 years of experience	NR	Interactive 2-hr session based on a guideline of 10/66 dementia research group for CHWs
4	7	NR	NR	3 years of secondary school education	NR	Trained in locally adapted screening instruments
5	3	No criteria	NR	Educated	Paid as consultants	3 months training included Six 2-hr sessions, homework, presentations, and watching videos
6	24	NR	91.67	NR	Employed by public or private organizations	NR
7	2	NR	NR	Minimum Grade 10 education and 3 years of counseling skill	Hired for the project	Trained by the professionals to apply the instrument needed (e.g., IHDS).
8	6	NR	83.33	College degree	NR	8–9 hr online CDR training, psychiatrist-led 4-hr group session and two supervised CHW-led interviews
9	20	NR	NR	NR	Employed at Aging Brain Care Program of Indiana University	ACP training comprised 4 workshops, 2 simulation sessions, EHR assistance, weekly case conference, and monthly review
10	20	27–65 ^a 43 ^b	95	Trained annually after the recruitment	Volunteers of Nuestra Casa, a community-based organization	Two 6-hr sessions on dementia education, program goal, interactive video class, and using instruments

Note. CHW = community health worker; NR = not reported; ICDS = Integrated Child Development Scheme; IHDS = International HIV Dementia Scale; CDR = Clinical Dementia Rating; ACP = advance care planning; EHR = Electronic Health Record.

^aAge range. ^bMean age.

number of female participants with a percentage ranging from 54.60% to 78%. All studies shared a common goal of improving dementia awareness and care by employing CHWs in a variety of ways.

Characteristics of CHWs

Table 2 shows the general attributes of CHWs along with their training. Five studies employed between 19 and 25 CHWs and the other five studies involved less than 10 CHWs for community interventions. The CHWs were predominantly female in the studies that reported sex with percentages of 83.30%, 91.67%, and 95% in Han et al. (2013), Boughtwood et al. (2013), and Askari et al. (2018), respectively, and 100% in Shaji et al. (2002), Ramos-Cerqueira et al. (2005), and Jacob et al. (2007). The majority of the CHWs had secondary school education to college degrees (Han et al., 2013; Jacob et al., 2007; Kvalsund et al., 2009; Ramos-Cerqueira et al., 2005; Robbins et al., 2011). Five

studies identified the CHWs as paid employees of public or private agencies or by a particular project (Boughtwood et al., 2013; Litzelman et al., 2017; Ramos-Cerqueira et al., 2005; Shaji et al., 2002; Souder & Terry, 2009). All the CHWs received dementia-related structured training for specific interventions.

Global Perspectives

From an overall contextual viewpoint, nine of the 10 studies (90%) targeted underserved populations. Even though the studies were conducted in different regions of the world, the demographics of CHWs and community individuals did not differ significantly (Tables 1 and 2). However, engagement of male CHWs was evidenced in studies in high-income countries, whereas the interventions in low-income countries were delivered only by female CHWs. Moreover, the roles of CHWs differed with the income categories of the countries. Dementia screening was the only focus of CHWs in India,

Table 3. Role of CHWs, Instruments Used by CHWs, Method of Intervention, and Key Findings of the Studies Included in the Review.

Study ID	Role of CHWs	Instruments	Method of intervention	Main findings
1	Screening possible dementia cases	No	CHWs categorized cases, probable cases, and non-cases after first training session. The list was reassessed after advanced training. Individuals in final list were examined by a psychiatrist using <i>DSM-IV</i> criteria.	Among 51 dementia cases identified by CHWs, 33 cases were confirmed by the psychiatrist. PPV was 64.7%.
2	Screening possible dementia cases	No	CHWs listed dementia cases after preliminary training which was updated after final training. Cases were assessed by a psychiatrist using <i>DSM-IV</i> and CDR criteria.	72 identified cases by CHWs were clinically examined by a psychiatrist and confirmed 45 cases. PPV was 62.5%.
3	Screening possible dementia cases	No	CHWs listed cases from local participants based on their understanding and available information. Result was compared with education adjusted diagnosis protocol by 10/66 dementia research group.	9 dementia cases were diagnosed. Sensitivity was 3.8%, specificity 99.4%, false positive rate 55.6%, PPV 44.4%, false negative rate 10.3%, and NPV 89.7%.
4	Screening HIV-D in persons living with PLWAs	MMSE, HDS, CT I	A structured interview was conducted for demographic data and previous medical history. Then the instruments were applied on the study group and comparison group.	PLWAs scored 21.39 in MMSE and 2.4 in HDS (mean). Comparison group scored 28.20 in MMSE and 4.20 in HDS.
5	Educating on dementia to link Black community with health research and finding participation barriers	N/A	A pre-formed committee let CHWs deliver presentations in community settings. Recruitment of CHWs, number of presentations, and Black community involvement in research were evaluated.	The number of presentations were increasing and reached to 73 over 5 years. Number of Black participants increased from 12% to 30%. CHWs determined some barriers.
6	Providing dementia education, support, and care to CALD families and explore barriers	N/A	The CHWs were interviewed for an insight of their roles and challenges in dementia care and educational support toward the CALD families.	CHWs stressed on involving family, serving caregivers, link them to health care facilities, gaining trust and understanding culture.
7	Screening potential HIV-D cases in HIV-positive individuals	IHDS	Participants provided their demographics and medical history using a questionnaire and were screened for psychiatric disorders through a structured interview. IHDS was applied by the CHWs to determine HIV-D.	HIV-D was found positive among 80% participants and found associated significantly with poor immunity and alcohol dependence disorder in bivariate analysis.
8	Screening possible cases of mild cognitive dysfunction and/or dementia	CDR	Semi-structured interviews were conducted with the patients and caregivers to identify cases. The degree of cognitive impairment was categorized according to CDR scale.	CHWs and physicians identified mild dysfunction and dementia of 61.1% and 56.7%, respectively. Sensitivity was 85.5% and specificity was 88.6%.
9	Assessing dementia cases as an initial step and conducting ACP conversations with them to help prioritizing their needs	MMSE	The CHWs payed multiple home visits for long time to develop trust with the clients and families and know their priorities. An EHR was used as ACP CDS tool to evaluate the approach.	ACP conversation increased from 3.4% to 47.9%. Rate of hospitalization decreased to 34% after adjusting for history of hospital and ED admission.
10	Educating on dementia and raising awareness to seek assistance for early diagnosis	Mini-cog, PHQ-2	The CHWs propagated the education by speaking with the community members and delivering presentations. The outcome was evaluated by a survey after 1 year.	Pre–post training evaluation noted an improvement in expertise of CHWs. Number of presentations increased and conveyed to other communities.

Note. CHW = community health worker; *DSM-IV* = *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; American Psychiatric Association, 1994); PPV = positive predictive value; CDR = Clinical Dementia Rating; NPV = negative predictive value; HIV-D = HIV-associated dementia; PLWAs = persons living with AIDS; MMSE = Mini-Mental State Examination; HDS = HIV Dementia Scale; CT I = Color Trail I; CALD = culturally and linguistically diverse; IHDS = International HIV Dementia Scale; ACP = advance care planning; EHR = electronic health record; CDS = clinical decision support tool; ED = Emergency Department; PHQ-9 = Patient Health Questionnaire–9.

Table 4. Descriptive Statistics of the Five Areas Representing the Roles of CHWs.

Areas	Roles of CHWs	Study ID, and authors (year)	Article frequency n (%)
Education and building awareness on dementia	Educating on dementia and raising awareness to seek assistance for early diagnosis	5, Souder and Terry (2009) 6, Boughtwood et al. (2013) 10, Askari et al. (2018)	3 (30%)
Screening for dementia	Screening possible dementia cases	1, Shaji et al. (2002) 2, Ramos-Cerqueira et al. (2005) 3, Jacob et al. (2007) 8, Han et al. (2013)	4 (40%)
Screening for HIV-associated dementia (HIV-D)	Screening HIV-D in persons living with PLWAs	4, Kvalsund et al. (2009) 7, Robbins et al. (2011)	2 (20%)
Assistance to utilize health care facilities and other resources	Reporting the accessible resources and benefits, conducting ACP conversations to increase access to available health care and social services	6, Boughtwood et al. (2013) 9, Litzelman et al. (2017)	2 (20%)
Services to dementia caregivers	Helping dementia caregivers to access information and services related to dementia and patient care and caregivers' psychological wellness and benefits.	6, Boughtwood et al. (2013)	1 (10%)

Note. CHW = community health worker; HIV-D = HIV-associated dementia; PLWAs = persons living with AIDS; ACP = advance care planning.

Brazil, South Africa, and Zambia; in contrast, services of CHWs in the United States and Australia were more diverse.

Role of CHWs

Table 3 displays the role of CHWs in each study and summarizes the results. Overall, nine of the 10 studies (90%) reported positive outcomes associated with the inclusion of CHWs in programs or interventions. The multifaceted roles of CHWs identified in the articles (Table 4) were classified into the following five areas: (a) education and building awareness on dementia, (b) screening for dementia, (c) screening for HIV-associated dementia (HIV-D), (d) assistance to utilize health care facilities and other resources, and (e) services to dementia caregivers.

Education and building awareness on dementia. Three studies focused on disseminating dementia education to minority communities through a variety of approaches with a goal of improving dementia knowledge and care, and eventually to establish a linkage with health care facilities (Askari et al., 2018; Boughtwood et al., 2013; Souder & Terry, 2009). Research by Souder and Terry (2009) describes an educational intervention conducted in the Black community through an Alzheimer's Disease Center program. The CHWs delivered presentations in community settings and the number of presentations increased from 12% to 30% over 5 years. Boughtwood et al. (2013) interviewed bilingual CHWs about their roles in four culturally and linguistically diverse (CALD) communities: Arabic, Chinese, Italian, and Spanish-speaking communities living in Australia which included educational interventions in non-English languages. The

CHWs not only serve the person with dementia but also addressed family issues and challenges. The article also stated that the people often did not reach out to medical facilities due to lack of knowledge, language barriers, and incompatible cultural conceptions (Boughtwood et al., 2013). Another study delivered a dementia awareness campaign through community-based participatory research (CBPR) approach (Wallerstein et al., 2008) for publicizing dementia knowledge among the Latino communities (Askari et al., 2018). The CHWs perceived the dementia training received as a productive opportunity to raise awareness of this important health issue in the community.

Screening for dementia. Four studies reported that CHWs participated in dementia screening to identify possible dementia cases after receiving a comprehensive training on basic and advanced knowledge on dementia (Han et al., 2013; Jacob et al., 2007; Ramos-Cerqueira et al., 2005; Shaji et al., 2002). In the first two studies, CHWs used the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; DSM-IV; American Psychiatric Association, 1994) criteria to screen dementia cases and the results were compared with a highly trained health care worker's (e.g., psychiatrists) diagnosis using the same instrument (Ramos-Cerqueira et al., 2005; Shaji et al., 2002). The studies reported a positive predictive value (PPV) of 64.70% and 62.50% for the CHWs' screening, respectively (Ramos-Cerqueira et al., 2005; Shaji et al., 2002). Likewise, in a third study, CHWs administered the Clinical Dementia Rating (CDR) instrument to screen dementia cases (61.10%) which was compared with a physician's diagnosis using the same scale (56.70%; Han et al., 2013). The sensitivity and specificity of diagnoses were

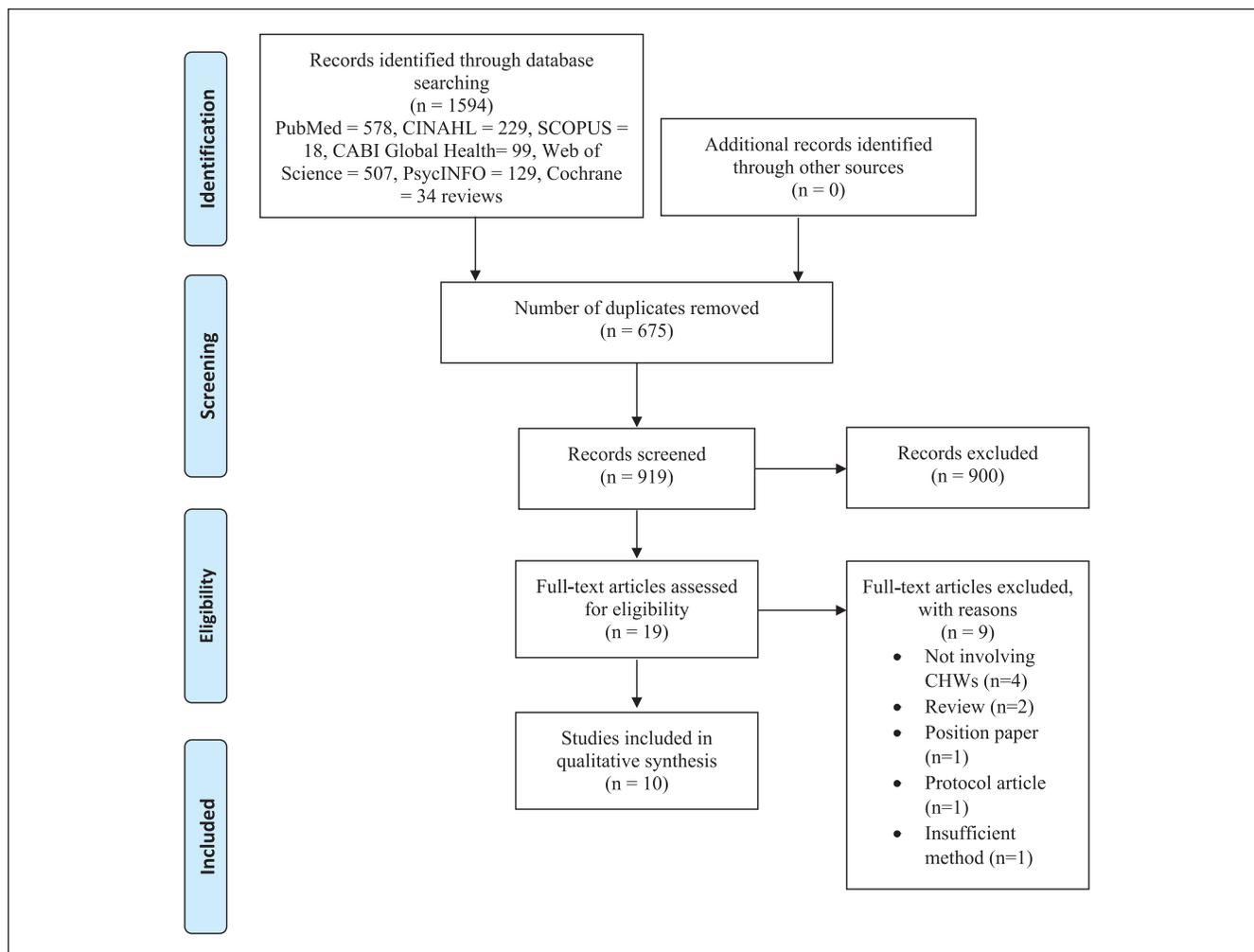


Figure 1. PRISMA 2009 flow diagram for study selection.

Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analysis; CHW = community health workers.

found to be 85.50% and 88.60%, respectively. All three studies suggested that training CHWs for screening dementia cases is a cost-effective approach, especially in communities with limited resources. In contrast, screening procedures in a fourth study turned out to be ineffective with a low agreement of screening results from CHWs when compared with *DSM-IV* criteria. Sensitivity and specificity were 3.80% and 99.40%, respectively (Jacob et al., 2007).

Screening for HIV-D. Based on the fact that the human HIV-1 infection can act on the nervous system and trigger dementia, the coexistence of these two diseases is described as HIV-D (Kaul et al., 2001). Persons with HIV-D experience more difficulties in everyday life and have poor medication compliance which supports the need for early detection and intervention (Gorman et al., 2009). Therefore, in a combined effort to optimize resources and reach, in Zambia and South Africa, CHWs were trained to administer specific instruments for HIV-D in existing HIV-focused programs (Kvalsund et al.,

2009; Robbins et al., 2011). The first study was conducted on persons living with acquired immunodeficiency syndrome (PLWAs) and included three dementia and cognition-related tests assessed by the CHWs (Mini-Mental State Examination [MMSE], HIV Dementia Scale [HDS], Color Trail 1; Kvalsund et al., 2009). The CHWs found that 25 PLWAs (52.10%) had memory loss and 16 (33.30%) had reasoning problems when compared with a control group without PLWA. All the PLWAs scored significantly lower in MMSE and HDS (Kvalsund et al., 2009). In a later study, the CHWs assessed HIV-positive patients on antiretroviral therapy (ART) using the International HIV Dementia Scale (IHDS) and 80% of them were found to be HIV-D positive (Robbins et al., 2011). The study revealed a strong association between cognitive performance and receiving ART.

Assistance to utilize health care facilities and other resources. In a study by Litzelman et al. (2017), CHWs were employed as a part of an interdisciplinary team in an innovative collaborative

care model developed by the researchers for providing an Advance Care Planning (ACP) service to older adults having chronic diseases, including dementia. Dementia cases were diagnosed by CHWs using MMSE before the ACP intervention. In the intervention, CHWs introduced palliative care services to patients with mild to moderate dementia and helped them to understand their needs to appropriately seek out health care services. CHWs used an electronic health record tool to enter patients' information related to topics such as their purpose in life, future care plan, advance health care directive, and referrals. Whereas the dementia cases were found to be associated with increased Emergency Department (ED) visits prior to the intervention (p value = .03), a significant increase in ACP conversations resulted in a 34% decreased rate of hospitalization when controlled for history of hospital and ED admission. Another study employed the bilingual CHWs to acquaint the CALD communities with accessible resources and benefits, thus increasing access to the conventional health care and social services (Boughtwood et al., 2013).

Services to dementia caregivers. Boughtwood et al. (2013) described the work of CHWs with dementia caregivers. Bilingual CHWs in this program directly supported the caregivers access dementia-related information and services, counseling about patient care, and following up their progress via phone calls or home visits. They also encouraged caregivers to seek out opportunities for personal wellness and developed a caregiver-network for socialization and mutual emotional support. The focus on caregivers also included information about pension benefits and other services available to them.

Discussion

This scoping review examined the roles of CHWs in community-based dementia programs and interventions around the world. Findings revealed important contributions of CHWs in dementia programs among vulnerable communities. CHWs have been involved in educational and community awareness programs on the topic of dementia. Some articles have documented the expanded scope of CHWs' role that combined dementia into existing HIV programs (HIV-D). Another possible role of CHWs is in screening for dementia. CHWs have also assisted both patients and dementia caregivers to locate and utilize health care systems and dementia-related resources. Nevertheless, CHWs were not widely employed in dementia care programs to meet the current increased need for dementia care and this scoping review highlights this as an under researched area.

Educational and community awareness programs seems to be a natural fit for CHWs. In addition to dementia, CHWs have contributed to increased education and community awareness of other programs related to communicable and non-communicable diseases. A systematic review by Norris and colleagues (2006) listed education as a key role of CHWs

in diabetic care, with roles similar to those described in this review. Another systematic review found CHWs to be valuable in the promotion of physical activity awareness (Costa et al., 2015). Another important role of CHWs in dementia found in this scoping review is their assistance to the community navigate the health care system and other resources. This is in agreement with studies that examined CHW-led programs across other health issues. For instance, Brownstein and colleagues (2007) published a systematic review on the roles of CHWs in hypertension programs and found benefits in improving self-care, use of health care services, patient adherence, and outcomes. In addition, CHWs successfully contributed to education, awareness, and service utilization of community programs which include topics such as maternal and child care, family planning, cancer screening, prevention of HIV, tuberculosis, malaria, and asthma (WHO, 2018). The studies included in this review support the fact that modestly trained CHWs can make a difference likewise in dementia care.

An area that needs further investigation is related to dementia screening. Although four studies in this scoping review reported that CHWs were successful in identifying dementia cases, one study (Jacob et al., 2007) showed opposite results. Authors in this study described dementia screening by CHWs in communities in India with high illiteracy rates (73.30%). It is possible that educational levels of intervention participants influenced the success of using screening tools (Noroozian et al., 2014). Two studies in this scoping review described successful efforts of CHWs in screening HIV-D in Zambia and South Africa (Kvalsund et al., 2009; Robbins et al., 2011). However, due to higher-than-expected positive cases, researchers expressed concerns about the influence of low education of participants on IHDS scores (Robbins et al., 2011). Nevertheless, while the CHWs serve in many HIV programs in the sub-Saharan Africa region, screening for the early detection of dementia-related problems in HIV-D is relatively new (Baldeweg et al., 1997; Mwai et al., 2013). Establishing a simple low-cost screening tool that can be effectively used by low-trained health care workers (e.g., CHWs) in underserved and low-literacy areas would be beneficial.

Minority populations are an at-risk group with a higher prevalence of dementia. Evidence suggests that U.S. African Americans and Hispanics have a higher likelihood of developing dementia than the non-Hispanic Whites (Tang et al., 2001). Along with some biological basis, additional risk factors have been indicated in the research, such as cultural factors, socio-economic factors, delayed diagnosis, and limited access to clinical research (Chin et al., 2011). CHWs have been employed in targeting ethnic and racial minority populations and achieved success. A notable improvement among African Americans having a family history of coronary heart disease risk has been shown in a CHW-delivered program (Becker et al., 2005). A systematic review describing 12 CHW-led interventions among Latinos with Type 2 diabetes

demonstrated significant impact on blood sugar levels in seven interventions (Little et al., 2014). In this scoping review, four studies targeted minority communities with positive outcomes (Askari et al., 2018; Boughtwood et al., 2013; Han et al., 2013; Souder & Terry, 2009). Two studies delivered educational interventions in African American and Latino communities, one delivered educational and other support interventions in CALD families (Arabic, Chinese, Italian, Spanish) and one identified dementia cases among Korean Americans (Askari et al., 2018; Boughtwood et al., 2013). Concepts of culture awareness have been underscored by CHWs while working in the communities (Askari et al., 2018; Boughtwood et al., 2013). Speaking the same language was found crucial to strengthen trust. Boughtwood and colleagues (2013) underscore that CHWs contribute to the delivery of dementia programs that are culturally and linguistically appropriate to minority groups and recommend focusing on important shortcomings, such as recruitment and retention of minority groups in research/programs, utilization of medical facilities, and diagnosis barriers due to lack of knowledge, cultural beliefs, and/or stigma.

Despite being a global problem, the greater proportion (63%) of dementia-affected individuals live in low- and middle-income countries where availability of resources is a challenge (WHO, 2015). Previous CHW-led interventions addressing different health problems in low-income contexts have been impactful (Gilmore & McAuliffe, 2013; Mutamba et al., 2013). Five of the 10 studies in this review were performed in low-income countries and four of them indicated promising outcomes. They particularly focused on screening, which indicates an emphasis on under-detection of dementia cases in low-income contexts (Lang et al., 2017). Studies in this review conducted in high-income countries found that CHWs perform educational, health care utilization, and caregiver-related services among minority populations which indicates the importance of addressing cultural misbeliefs, distrust toward health care providers, and racial disparities.

Another pressing issue in dementia care is the extreme caregiving burden and unique challenges experienced by informal caregivers (AA, 2020). Their responsibilities toward patients include, but are not limited to, health care, emotional support, medical, legal, or financial decision making, and long-term care planning (AA, 2015). The stressful nature of the work manifests itself in vulnerability to different negative health conditions and higher prevalence of mental disorders, particularly depression and anxiety (Kiecolt-Glaser et al., 2002; Sallim et al., 2015). Boughtwood and colleagues reported positive outcomes when it comes to CHWs assisting dementia caregivers. Future CHW-led programs should consider expanding their scope to focus on informal dementia caregivers, especially in the management of behavioral and emotional issues (Logsdon, 2008; Mittelman, 2013). Although this area is important, only one study in this scoping review engaged CHWs in addressing the needs of dementia caregivers (Boughtwood et al., 2013).

This scoping review underscored that CHWs are engaged in a variety of roles in community-based programs/interventions. Disease-specific systematic training is important to ensure effectiveness of these programs (Khetan et al., 2018). A WHO guideline presented a framework in 2018 to synthesize information on CHW-led interventions and effectiveness from the existing systematic reviews ($n = 137$). It provides a rationalized recommendation on recruitment and training strategies alongside supervision and evaluation, payment, and other important aspects related to CHW-led programs (WHO, 2018).

Limitations

There are some limitations worth noting that point to directions for future research. Due to the limited research in this field and our decision to include only articles published in English, only 10 studies met the selection criteria. However, the publication dates of the studies indicate that this area has drawn increased research attention over the past few years. Six studies were cross-sectional and able to portray the outcome at one point in time. Moreover, barriers experienced by the CHWs are rarely explored in the studies. As a result, we were not able to discuss barriers and challenges of CHWs in dementia programs/interventions. Also, a high percentage of female CHWs limited this scoping review to a predominantly female-oriented view of CHWs in dementia care. We acknowledge that despite the various search terms used to capture the different titles to describe CHWs, our review may have excluded articles describing the work of dementia caregivers and other groups that provide important dementia-related services to communities worldwide. Nonetheless, to the best of our knowledge, this is the first review mapping the scope of CHWs in dementia care and it offers new insights about the role of CHWs in dementia programs/interventions.

Conclusion

This review was able to identify important roles of CHWs in dementia programs/interventions and findings support the integration of CHWs in interdisciplinary teams working on preventing and managing dementia. Important roles identified include educational and community awareness, screening for dementia and HIV-D, as well as, both patients' and dementia caregivers' utilization of health care systems and other dementia-related resources. This scoping review sheds light on important perspectives related to CHWs in dementia, and their special contributions in addressing this growing health issue among vulnerable communities/groups around the world.

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Supplemental Material

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