


# Stigma Reduction Interventions of Dementia: A Scoping Review

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## Article

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## Résumé

Malgré l'impact de la démence au niveau mondial et sa reconnaissance en tant que priorité internationale en santé publique, les interventions visant à réduire la stigmatisation associée à la démence constituent un domaine en émergence et relativement nouveau. L'objectif de la présente étude était de synthétiser les publications existantes et d'identifier les éléments clés des interventions axées sur la réduction de la stigmatisation de la démence. Nous avons suivi le processus d'examen de la portée d'Arksey et O'Malley afin d'examiner les publications révisées par des pairs portant sur les interventions ayant pour cible la réduction de la stigmatisation liée à la démence. Les interventions ont été classées en fonction de dimensions d'un cadre théorique de la réduction de la stigmatisation : éducation (utiliser les faits pour dissiper des mythes), contact (interagir avec des personnes atteintes de démence), mixte (éducation et contact) et contestation (défier les attitudes négatives). Parmi les 732 références identifiées initialement, 21 ont été retenues. Nous avons repéré une variété d'interventions éducatives, de contact et mixtes, allant de films culturellement adaptés aux chorales intergénérationnelles. Les résultats de notre analyse pourront contribuer à l'élaboration d'interventions visant à soutenir les politiques, les programmes et les pratiques axés sur la réduction de la stigmatisation et l'amélioration de la qualité de vie des personnes atteintes de démence.

## Abstract

Despite its global importance and the recognition of dementia as an international public health priority, interventions to reduce stigma of dementia are a relatively new and emerging field. The purpose of this review was to synthesize the existing literature and identify key components of interventions to reduce stigma of dementia. We followed Arksey and O'Malley's scoping review process to examine peer-reviewed literature of interventions to reduce dementia-related stigma. A stigma-reduction framework was used for classifying the interventions: education (dispel myths with facts), contact (interact with people with dementia), mixed (education and contact), and protest (challenge negative attitudes). From the initial 732 references, 21 studies were identified for inclusion. We found a variety of education, contact, and mixed interventions ranging from culturally tailored films to intergenerational choirs. Findings from our review can inform the development of interventions to support policies, programs, and practices to reduce stigma and improve the quality of life for people with dementia.

## Introduction

Despite its global importance and the recognition of dementia as an international public health priority, interventions to reduce stigma of dementia are a relatively new and emerging field (Alzheimer's Disease International, 2019). "Stigma" refers to an attribute or characteristic which is socially discrediting and involves negative beliefs (stereotypes/prejudice), lack of knowledge (ignorance), and discriminatory behavior (discrimination) that results in unjustifiable or unequal treatment (Goffman, 1963; Thornicroft, Rose, Kassam, & Sartorius, 2007). The stigma

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of dementia may detrimentally impact interactions with health care providers, health service utilization, and experiences in acute care settings, and can lead to social isolation, feelings of shame, and suicide (Public Health Agency of Canada, 2019).

Over the past 10 years, a growing number of organizations have identified the increasing need for research to address stigma of dementia (Canadian Academy of Health Sciences, 2019; Centers for Disease Control, 2015). The World Health Organization (2012) created, *Dementia: A public health priority* which sheds light on the growing need for global action to raise awareness and reduce dementia-related stigma. Following this report, Alzheimer's Disease International (2019) released an independent report which emphasized that dementia-related stigma often prevents people from seeking dementia diagnosis, treatment, and support.

Despite this increasing awareness, there is a paucity of research focusing on interventions to reduce stigma of dementia. Rather, researchers have focused on identifying and documenting stigmatizing attitudes among various groups of people such as nurses (Hanssen & Tran, 2018); general practitioners (Gove, Downs, Vernooij-Dassen, & Small, 2016; Gove, Small, Downs, & Vernooij-Dassen, 2017; Low, McGrath, Swaffer, & Brodaty, 2018); dementia care workers (Kane, Murphy, & Kelly, 2018); family members (Abojabel & Werner, 2019); family caregivers (Mkhonto & Hanssen, 2018); minority and ethnic groups (Nielsen & Waldemar, 2016; Woo, 2017); and the general public (Stites *et al.*, 2018). A recent systematic review identified more than 50 articles reporting stigma-related attitudes towards people living with dementia (Herrmann *et al.*, 2018b). Although negative attitudes of dementia are well documented, there is a dearth of knowledge on interventions to reduce dementia-related stigma.

The purpose of this review was to summarize the existing literature and identify key components of interventions to reduce the stigma of dementia. We used Corrigan and Penn's (1999) stigma reduction framework to classify interventions into three categories: education (to dispel myths with facts and accurate information), contact (to provide interaction with persons with dementia), and protest (publicizing and speaking out against instances of prejudice or discrimination to suppress negative attitudes and challenge stereotypes of dementia). Findings from our study can inform the development of interventions to support programs, policies, and practices to reduce stigma and improve the quality of life for people with dementia.

## Methods

Our study was guided by Arksey and O'Malley's (2005) five-stage scoping review process: (1) identifying the research question, (2) searching for relevant studies, (3) identifying studies, (4) charting the data, and (5) summarizing and reporting the results. Scoping reviews are appropriate for studying new topics that are complex in nature and have not been previously reviewed, such as interventions to reduce stigma of dementia. Scoping reviews are also useful because they provide a rigorous and transparent method for mapping and synthesizing areas of research in terms of volume, characteristics, and findings.

## Research Question

Drawing on Corrigan and Penn's (1999) stigma-reduction framework, our research questions for this scoping review included: (1) What education, contact, and protest-based interventions have been developed to reduce stigma towards people with dementia?

(2) What are the key components of the different types of interventions?

## Data Sources and Search Strategy

We searched seven health and social science databases including: PubMed, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, PsycInfo, Google Scholar, and Social Services Abstracts. Combinations of search terms included: dementia, OR Alzheimer's disease (AD), OR Alzheimer's, OR cognitive impairment, AND stigma, OR dementia-related stigma, OR anti-stigma, OR stigma reduction, OR negative attitudes, OR stereotypes, OR discrimination, AND actions, OR strategies, OR interventions, OR programs.

## Inclusion and Exclusion Criteria

Predefined inclusion and exclusion criteria were developed to support the identification of relevant studies. The inclusion criteria included: (1) publication in English, (2) full text, peer-reviewed journal articles, (3) reported findings on interventions to reduce the stigma of dementia, and (4) having been published between January 2008 and January 2019. In 2008, a number of groups such as the Alzheimer's Society (United Kingdom), Alzheimer's Association (United States), and the Scottish government launched campaigns to increase public awareness, negate stigma, and improve knowledge of dementia (Alzheimer's Disease International, 2012). Given these events, 2008 was selected as the starting point for this review. The exclusion criteria included: (1) articles that did not report research results (e.g., commentaries/editorials), (2) articles on describing stigma-related attitudes rather than stigma-reduction interventions, and (3) research on interventions to address cognition rather than stigma.

## Screening and Study Selection

Each of the databases was searched separately by two independent reviewers in order to support reliability and rigour, and to ensure that no relevant articles were overlooked. We imported the search findings into bibliographic management software, followed by a systematic de-duplication. The two researchers independently screened the titles and abstracts of the articles based on the defined criteria. Full-text articles were assessed against inclusion and exclusion criteria. Any discrepancies related to article inclusion were discussed between the two reviewers.

A total of 732 citations were identified in the electronic databases, and 12 additional studies were found by hand-checking relevant reference lists. After 28 duplicates were removed, 716 articles remained. Following the title and abstract review, 682 articles were excluded as they did not meet the inclusion criteria. After reviewing the full text of the remaining 34 articles, 13 studies were excluded for the following reasons (Figure 1): commentary or review rather than research article (Hand, 2018; Lundquist & Ready, 2015; Mukadam & Livingston, 2009; Swinnen, 2012); interventions focused on addressing timely dementia diagnosis not stigma (Brooker, La Fontaine, Evans, Bray, & Saad, 2014; Devoy & Simpson, 2017; Edwards, Voss & Iliffe, 2014); interventions to address education not stigma (Palmer *et al.*, 2014); interventions focused on the benefits for people living with dementia not on reducing stigma (Beard, Knauss, & Moyer, 2009; Bienvenu & Hanna, 2017; Greenwood, Gordon, Pavlou, & Bolton, 2018; Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016); and not

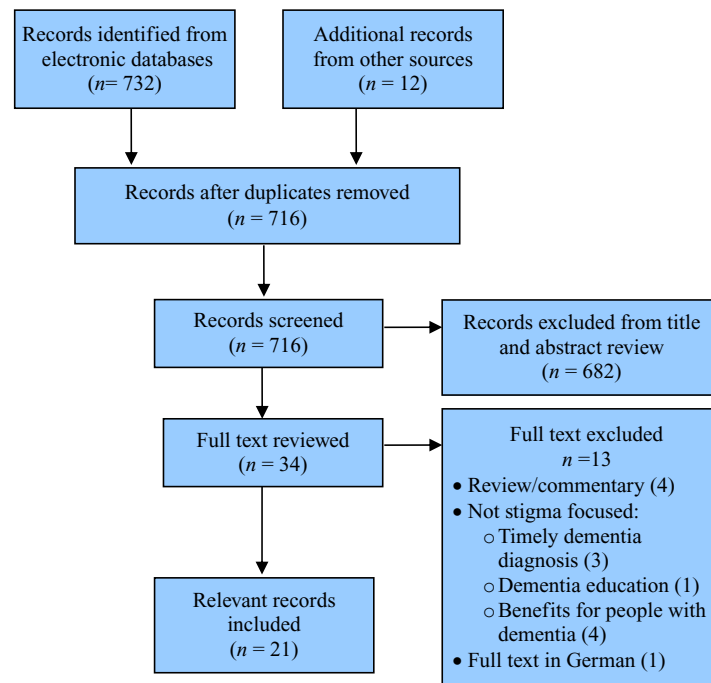


Figure 1. Study flow chart

available in the English language (Kaduszkiewicz, Rontgen, Mosakowski, & van den Bussche, 2009). After the full text review, 21 articles were included in the scoping review (see Figure 1).

### Data Extraction and Analysis

After a review of the relevant articles, the data were extracted and charted using a standardized template developed by the research team. The extracted data included the study's aims, interventions, sample, research designs, findings, and key components (see Table 1). A preliminary pilot test was independently conducted by two of the reviewers, who extracted data from four of the included articles. Any data extraction concerns were discussed between the reviewers before they reached a final decision. Following the data extraction, the research team reviewed the data extraction tables to ensure clarity and consistency in the reporting of the data.

## Results

### Descriptive Analysis

From the 21 articles identified, 11 were qualitative, 8 quantitative, and 2 were mixed methods (Table 2). Nineteen of the studies included an evaluation component to assess the effectiveness of the intervention in reducing stigma of dementia, while the other two articles focused on informing the development of an intervention. The majority of the articles were exploratory in nature and were small-scale pilot studies. The articles were from 4 countries: 10 from the United States, 6 from Canada, 4 from the United Kingdom, and 1 from Australia.

### Interventions

Eleven articles focused on reporting education interventions to improve dementia knowledge and reduce stigma. Eight of the articles used contact interventions, and two studies used mixed (e.g.,

education and contact) interventions. No studies were identified that addressed protest interventions. An overview of the key components for education, contact, and mixed interventions is provided in Table 3.

### Education interventions

#### Presentations

Two of the studies included interventions focused on education through presentations targeting students and/or the general public (Baillie, Beecraft, & Woods, 2015; Friedman et al., 2016). Baillie et al. (2015) Dementia Friends intervention consisted of a 1-hour presentation to 450 nursing students to learn five brief facts and dispel myths about dementia. The session was evaluated through students' voluntarily writing lessons learned and intended actions (e.g., to educate others) on sticky notes. The presentation was considered effective based on the 418 completed sticky notes, with 456 comments on knowledge learned and 369 on intended actions. A key component of this study was keeping the educational materials brief and accessible by focusing on five simple facts.

Un Cafe' por Alzheimer (Friedman et al., 2016) was a multi-component intervention using different media such as in-person educational sessions and a Facebook page to advance knowledge about AD. The educational sessions included basic information on AD risk factors, definition, diagnosis, and medications. After the session, people were invited to share stories, ask questions, and follow the Facebook page. The sessions were attended by 212 participants, and 51 participants completed the pre- and post-survey evaluations. Based on the 51 voluntary evaluations and the Facebook postings, the researchers found improved general knowledge of AD and its related risk factors. Key components associated with this study included that usage of different mediums (e.g., presentations and Facebook) to mobilize dementia knowledge and education.

#### Theatre and film

Six of the articles consisted of interventions using theatre-style plays about dementia (Burns et al., 2018; Jonas-Simpson et al.,

**Table 1.** Descriptive characteristics of included studies

Authors	Title	Aim	Intervention	Sample	Research Design	Findings	Key Components
Baillie, Beecraft, & Woods (2015) UK	Dementia Friends sessions for nursing students	Address stigma and improve knowledge/perceptions of dementia	One-hour, introductory session to learn key facts and dispel dementia myths	450 nursing students	Qualitative, informal evaluation - voluntary sharing of knowledge learned and intended actions on sticky notes	Identification of knowledge gained and intended actions (educate others and share knowledge)	Use brief and simple facts to dispel dementia myths and stigma
Burns et al. (2018) USA	Impact of creative arts in AD and dementia public health education	Educate and reduce stigma of AD through theatre	Theatre play based on social relations and experiences of people affected by dementia	147 participants	Quantitative, pre- and post-performance questionnaires on beliefs about dementia and the arts for dementia care education	Attitude changes from an initial strong negative effect to slightly more positive and de-stigmatized views after performance	Theatre supports emotional transformation to elicit change in audience perception of disease realities
Canning, Gaetz, & Blakeborough (2018) Canada	It takes time: Building relationships and understanding through an intergenerational ballet programme	Foster intergenerational understandings to dispel stigma and improve dementia knowledge	Imagine Dance- children participated in ballet with long-term care residents for 1 hour a week over 6 months	Seven children, 7-9 years old and seniors with moderate to advanced dementia	Qualitative semi-structured interviews with children at baseline, and 3- and 6-month intervals	Children described residents more positively, highlighting their strengths rather than their previous notions of residents' being unable and unwell	Relationship building, partnering students with seniors, sharing stories, and purposeful learning with common goals (dance)
Di Bona, Kennedy, & Mountain (2017) UK	Adopt a care home: An intergenerational initiative bringing children into care homes	Educate and reduce stigma of dementia among children	Adopt a Care Home, linking children with people with dementia in a care home. Lifestory booklet used to encourage conversation and reinforce children's literacy skills	41 children, 10 people with dementia, and 8 school/care home staff	Mixed methods, questionnaires (pre-and post-intervention), observations, interviews, and focus groups	Initiative increased children's dementia knowledge	Intergenerational initiatives increase dementia awareness in children and the support well-being of people with dementia
Friedman et al. (2016) Puerto Rico	Increasing community awareness about AD in Puerto Rico through coffee shop education and social media	Improve knowledge and reduce myths of AD	Un Cafe por el Alzheimer program - shared education through 4 presentations and a Facebook page	212 participants (college students and public)	Quantitative, 51 completed pre- and post-surveys of education sessions	Participants reported improved understanding and knowledge of AD	Use different media to mobilize dementia knowledge (social media and Facebook)
George, Stuckey, Dillon, & Whitehead (2011) USA	Impact of participation in TimeSlips (TS), a creative group-based storytelling program, on medical student attitudes toward persons with dementia: A qualitative study	Improve medical student attitudes towards people with dementia	Narratives in Aging, elective course using TS, a creative group-based storytelling program held over a month, with persons affected by dementia and students	15 fourth-year medical students	Qualitative, course evaluations conducted at end of program	Study reported more positive attitudes toward persons with dementia	Importance of social interaction between students and people with dementia outside of clinical environment

(Continued)

Table 1. Continued

Authors	Title	Aim	Intervention	Sample	Research Design	Findings	Key Components
Harris & Caporella (2014) USA	An intergenerational choir formed to lessen AD stigma in college students and decrease social isolation of people with AD and their family members: A pilot study	Combat stigma of AD in students, and lessen social isolation of people affected by AD	Intergenerational choir, 8 weeks of rehearsals and the concluding performance	13 college students and 13 people with AD and a family member	Qualitative, semi-structured, open-ended interviews on attitudes and knowledge of AD, collected at 3 points over 8 weeks	Study found more positive attitudes such as recognizing capabilities, expanded understanding, and reduced stigma and social discomfort	Give people with dementia a voice, educate the public, and involve people with dementia
Harris & Caporella (2018) USA	Making a university community more dementia friendly through participation in an intergenerational choir	Address stigma and develop a dementia-friendly community	Intergenerational choir, 10 weeks of rehearsals	Four cohorts, including 62 college students and 43 people with dementia and family members over 4 years	Qualitative - students completed semi-structured interviews, at 3 points over 10 weeks, focus groups conducted with people affected by dementia	Students showed an increased understanding of dementia, reduced stigma, and increased awareness of capabilities of people with dementia	Regular interaction, using humor, people as equals, teamwork, and shared goals (concert performance)
Herrmann et al. (2018b) USA	A new curriculum to address dementia-related stigma: Preliminary experience with Alzheimer's Association staff	Develop and test a stigma education curriculum	Curriculum included a definition, types and domains of stigma, effects of stigma, stigma evaluation, tips to address dementia-related stigma, and real life scenarios	21 Alzheimer's Association chapter staff	Pre- and post- curriculum surveys	Staff showed an improved ability to identify AD stigma, felt more comfortable talking about stigma, and would change the way they interacted with people impacted by AD	Keep dementia education brief and accessible
Jonas-Simpson et al. (2012) Canada	Phenomenological shifts for health care professionals after experiencing a research-based drama on living with dementia	Reduce dementia-related stigma to diminish unnecessary suffering of persons affected by dementia	I'm Still Here, an ethnodrama based on six studies, created to change understandings and views of dementia	50 health professionals and 8 nursing students	Qualitative, pre- and post-intervention focus groups with health professionals to test "immediate" impact of the play	Study found improvements in attitude and intended actions towards persons with dementia after the play	Power of sharing study findings through performance
Kimzey, Mastel-Smith, & Alfred (2016) USA	Impact of educational experiences on nursing students' knowledge of and attitudes towards people with AD: A mixed-method study	Examine different educational interventions of knowledge of and attitudes towards people with AD and their caregivers	Three groups - AD clinical experience, online learning module, and no dementia-specific intervention	94 senior level nursing students	Mixed methods, pre- and post- surveys which included AD Knowledge Scale, Dementia Attitudes Scale, and demographic questionnaire, and a focus group	Clinical placements improved knowledge and attitudes about AD compared with an online module and no dementia-specific intervention.	Need to provide simple facts and experiential learning
Kontos et al. (2018) Canada	Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society	Evaluate the impact of a research-based drama performance on dementia-related stigma	Cracked: A New Light on Dementia; play follows how two families experience stigma associated with dementia	Not provided, but 602 submitted surveys	602 completed post-play surveys, using Likert scale questions, from audience from 16 different theatre performances	Play was effective in reducing stigma by decreasing prejudice and fostering critical reflection and a commitment to address stigma	Research-based drama to shift perceptions and challenge stereotypes of dementia-related stigma
Lokon, Li, & Kunkel (2018) USA	Allophilia: Increasing college students' "liking" of older adults with dementia through	Evaluate whether an arts-based intergenerational program improves	Intergenerational weekly service-learning program offered for a semester where students paired	216 students	Quantitative, pre- and post-tests of the Allophilia Scale were used to compare 216 students	After one semester, participation was positively associated with students'	Emphasis necessary to improve positive

(Continued)

Table 1. Continued

Authors	Title	Aim	Intervention	Sample	Research Design	Findings	Key Components
	arts-based intergenerational experiences	dementia-related attitudes of students	with elders who have dementia		who participated and 499 students who did not	affection, comfort, kinship, engagement, and enthusiasm towards seniors with dementia	attitudes rather than focus on negativity
Lokon, Li, & Parajuli (2017) USA	Using art in an intergenerational program to improve students' attitudes towards people with dementia	Improve college students' attitudes towards people with dementia	OMA - intergenerational weekly service-learning program offered for a semester in which students paired with elders who have dementia to support the elders' creation of visual art projects	156 students	Quantitative, Dementia Attitude Scale administered at beginning and end of semester to measure changes in attitudes	Study found significant improvement in students' comfort with and attitude towards dementia	Regular interactions with the same partner and having a shared goal (artwork)
Mitchell, Dupuis, & Jonas-Simpson (2011) Canada	Countering stigma with understanding: The role of theatre in social change and transformation	Share lessons about a play challenging dementia stigma	I'm Still Here, a research-based drama, a play on dementia	48 family members of people with dementia, 50 health professionals, and 8 nursing students	Qualitative, 15 pre- and post-play focus groups conducted in 4 different cities in Ontario	Theatre provided ways of educating, telling, and showing the harm of stigma in ways not possible with text alone	Theatre shows that there is more to dementia than memory loss
Mitchell et al. (2011) Canada	Engaging with research-based drama: Evaluation and explication of synergy and transformation; Qualitative Inquiry	Understand audience transformation from a play about dementia realities	I'm Still Here, a research-based drama, a play on dementia	48 family members of people with dementia, 50 health professionals, and 8 nursing students	Qualitative, 15 pre- and post-play focus groups conducted in 4 different cities in Ontario	Key themes identified: seeing anew, placing and relating self, meaningful learning, and expanding perspectives	Power of the arts to show dementia more than memory loss. Theatre enhances learning and insight to reduce stigma.
O'Conner, Mann, & Wiersma (2018) Canada	Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship	Understand what people with dementia need to live well and strategies to challenge stigma	No intervention, rather to develop an intervention of a curriculum of a proposed self-management program	Eight people with dementia	Qualitative, 16 monthly group meetings	Participants described importance of disclosing their diagnosis to others as a key strategy for stigma resistance	Recognize the value/expertise of persons with dementia to educate and challenge stigma
Parveen, Farina, Shafiq, Hughes, & Griffiths (2018) UK	What do adolescents perceive to be key features of an effective dementia education and awareness initiative	Identify education needs and dissemination strategies for reducing stigma	No intervention, rather aimed to inform educational interventions to reduce dementia stigma among adolescents	42 adolescents	Qualitative, 8 focus groups in schools and colleges	Key themes included: dementia awareness, preferred learning methods, inclusion of people with dementia, and the use of social media	Dementia awareness initiatives need to be tailored towards specific groups (adolescents)
Phillipson et al. (2018) Australia	Involvement of people with dementia in raising awareness and changing attitudes in a	Reduce fear and stigma of living with dementia.	Dementia Friendly Kiama pilot- used dementia education events which included presentations,	2016 - 174 participants 2014 - 131 participants	Quantitative, to assess project reach and changes in attitudes of community members,	Respondents reported less negative dementia views than people who did not attend	Involve people with dementia as educators, spokespersons,

(Continued)

Table 1. Continued

Authors	Title	Aim	Intervention	Sample	Research Design	Findings	Key Components
Reynolds, Innes, Poyner, & Hambidge (2017) UK	dementia-friendly community pilot project "The stigma attached isn't true of real life": Challenging public perception of dementia through a participatory approach involving people with dementia (Innovative Practice)	Challenge the stigma and negative perceptions of dementia.	videos, speakers, and panels co-designed/presented with people affected by dementia BUDI Orchestra- public viewing of orchestra performance comprising people with dementia, family, student volunteers, and symphony members	Audience members (109)	two cross-sectional surveys conducted with adults Qualitative, open-ended self-completion questionnaires from audience at three performances	Before orchestra, 53% of audience had low or no expectations; following performance all respondents but one (108) reported the orchestra met or exceeded expectations	and champions to reduce stigma Showcase the achievements of people with dementia to challenge negative perceptions
Zheng, Chung, & Woo (2016) USA	Exploring the impact of a Culturally Tailored Short Film in Modifying Dementia Stigma Among Chinese Americans: A Pilot Study	Address the impact of media through a culturally tailored film to modify dementia-related stigma	Caring for Dementia Patients, a 7 minute film in Cantonese to depict a common life struggle of a family with loved ones with dementia	150 Chinese Americans completed dementia stigma questionnaire, and of these participants, 90 asked to provide feedback	Quantitative pre-film questionnaire in Chinese about dementia attitudes. Post-film - 90 randomly selected to provide feedback on whether the film changed their dementia misconceptions	Film was a useful way to modify misconceptions about dementia. Participants with shorter duration in the USA found to have higher baseline of stigma and found film less useful	Dementia education needs to be culturally sensitive and tailored to the group

Note. AD = Alzheimer's disease

Table 2. Study design and location

Study type	Number of Studies	Australia	Canada	United Kingdom	United States
Qualitative	11	—	5	3	3
Quantitative	8	1	1	—	6
Mixed methods	2	—	—	1	1

Table 3. Summary of key components of stigma reduction interventions reviewed

Type of Intervention	Key Components
Education interventions	Provide facts to replace myths about dementia
	Keep information brief and accessible
	Use multiple media to share knowledge (e.g. theatre, social media)
	Emphasize that dementia is more than losing one's memory
	Develop culturally informed education tailored to specific groups
Contact and mixed interventions	Showcase the achievements of those living with dementia
	Engage in experiential/service-based learning
	Focus on the positive rather than the negative
	Integrate relationship building with social interaction time
	Incorporate purposeful learning with shared objective or common goal
	Show that it is possible to lead an active life with dementia
	Engage people with dementia as research partners, participants, educators, spokespersons, and champions to reduce stigma of dementia
Work as a team and treat everyone as equals	

2012; Kontos et al., 2018; Mitchell, Dupuis, & Jonas-Simpson, 2011; Mitchell et al., 2011) and a film (Zheng, Chung, & Woo, 2016). These articles focused on research-informed plays about people living with dementia. Using pre and post-tests, the articles all reported improved knowledge and attitudes towards persons with dementia. Key components of these studies emphasized the usage of theatrical plays to share dementia education, knowledge, and awareness.

One study used a film in Cantonese as an educational intervention to show common life struggles of dementia and care giving (Zheng et al., 2016). One hundred and fifty Chinese Americans completed a dementia stigma questionnaire prior to the film, and of these only 90 were asked to provide feedback after the film. The study reported that 89 per cent (n = 80) of respondents found the film useful for improving knowledge and addressing misconceptions of dementia (Zheng et al., 2016). Key components of this

research included cultural sensitivity and tailoring dementia education towards specific groups.

### Curriculum-based interventions

Three studies focused on the development of educational curricula to reduce stigma and improve knowledge of dementia-related stigma (Herrmann *et al.*, 2018a; O'Conner, Mann, & Wiersma, 2018; Parveen, Farina, Shafiq, Hughes, & Griffiths, 2018). Herrmann *et al.* (2018a) developed and tested a stigma awareness and education curriculum for the 21 member staff of an Alzheimer's Association Chapter. The curriculum covered a range of topics, from the effects of stigma to challenging real-life scenarios of stigma. Using pre and post-surveys, the researchers found that staff had an improved ability to identify and address issues of stigma. A key component of this study focused on the need for dementia education to be brief and accessible for participants (Herrmann *et al.*, 2018a).

Two studies did not include interventions but aimed to inform educational interventions to support dementia education and challenge stigma. A study by Parveen *et al.* (2018) conducted focus groups with 42 students (ages 12–18) to establish the dementia education needs of adolescents. The findings highlighted the need for more dementia awareness and preferred methods of education (e.g., videos and social media) for adolescents. A key component from this study was the importance of targeted interventions tailored towards specific age groups.

Another study used a peer support model to develop an intervention of a proposed educational curriculum to help people with dementia live well and challenge dementia stigma (O'Conner *et al.*, 2018). The participants included eight people with dementia (ages 57–82) who met regularly for 16 monthly group meetings. A key component of this study included recognizing the expertise of people with dementia to educate and challenge dementia-related stigma.

### Contact interventions

A variety of contact interventions were identified including: intergenerational storytelling; performing arts such as an intergenerational choir, ballet, and orchestra; and visual arts programs.

#### *Intergenerational storytelling*

In a mixed-methods study, Di Bona, Kennedy, & Mountain (2017) used the Adopt a Care Home program to educate children (ages 9–10) about dementia by visiting people with dementia. A Lifestory booklet was used to encourage conversation and reinforce the children's literacy skills. Using pre and post-intervention dementia awareness questionnaires, observations, interviews, and focus groups, the study found that the program increased children's knowledge of dementia (Di Bona *et al.*, 2017). Key components of this study highlighted the importance of intergenerational contact and social interaction for improving dementia knowledge among young children.

Another study (George, Stuckey, Dillon & Whitehead, 2011) used TimeSlips, a group-based storytelling program held over the course of a month, with persons with dementia and 15 medical students. At the end of the term, course evaluations found more positive attitudes towards people with dementia. Key components of this study included relationship building and social interaction between medical students and people with dementia outside of the medical setting.

#### *Performing arts*

Four articles examined performing arts interventions including a choir, ballet, and orchestra performance. Two of the articles focused on an intergenerational choir as a contact intervention between college students and people with AD (Harris & Caporella, 2014, 2018). This research involved interviews on attitudes and knowledge of AD, collected at different points throughout the study. Over time, students exhibited less stigma and more positive attitudes towards people with AD. Similarly, another intervention used a weekly ballet class with seven children and care home residents with dementia (Canning, Gaetz, & Blakeborough, 2018). Using semi-structured interviews over 6-month intervals, the study found that over time, the children described the residents more positively, highlighting their abilities and strengths. Key components from these studies included designated social interaction time, relationship building, and purposeful learning with a shared goal (e.g., choir and ballet).

Another study focused on the general public's viewing of the BUDI Orchestra, a group of people with dementia, family members, students, and professional symphony members (Reynolds, Innes, Poyner, & Hambidge, 2017). Qualitative, open-ended, voluntary, self-completion questionnaires from the audience ( $n = 109$ ) at three public performances were used for evaluation. Before viewing the performances, 53 per cent of respondents had low or no expectations of the orchestra formed of people with dementia. Following the performances, all respondents (108) except one reported that the orchestra either met or exceeded their expectations. A key component of this study was challenging stereotypes by showcasing the achievements of people with dementia in the orchestra.

#### *Visual arts*

Two articles focused on a visual arts intervention with college students and people with dementia (Lokon, Li, & Kunkel, 2018; Lokon, Li, & Parajuli, 2017). The *Opening Mind through Arts* was a service-learning program offered for a semester in which students were paired with elders with dementia to support the elders' creation of visual art projects. Using pre- and post-surveys, the study found improvements in the students' attitudes and comfort levels towards people with dementia. Key components of this study included focusing on the positive, allocated social interaction time, and a shared goal of artwork.

#### *Mixed interventions*

Two studies combined education and contact interventions (Kimzey, Mastel-Smith, & Alfred, 2016; Phillipson *et al.*, 2018). The Dementia Friendly Kiama (Phillipson *et al.*, 2018) pilot consisted of two events involving people with dementia as educators and spokespersons in panel discussions. Two surveys were conducted with adults using validated scales to assess the study's impact. The study found that intervention attendees had fewer negative views about dementia diagnosis, compared with people who did not attend an event. Key components of this study included collaboration with people with dementia as educators, spokespersons, and champions to reduce stigma of dementia.

Kimzey *et al.*'s (2016) study examined the impact of education interventions (e.g., on-line modules), contact interventions (e.g., clinical rotations with people with AD) and no interventions on 94 nursing students' knowledge and attitudes of people with AD. Using mixed methods, the study found that clinical placements increased knowledge and improved attitudes compared with



an online module and no AD-specific intervention. Key components of this study included the importance of hands-on experiential learning and designated social interaction time between students and people with AD.

## Discussion

The stigma of dementia is a well-documented issue that reduces the quality of life for people living with dementia (Alzheimer's Disease International, 2019). Despite this knowledge, there are no known attempts to examine the current state of the literature on interventions to address dementia-related stigma. However, reducing dementia-related stigma is necessary to support the uptake of early dementia diagnosis, facilitate cognitive health promotion, and optimize health care services to support people with dementia. Moreover, an early diagnosis enables people with dementia to acquire relevant information and support services, plan for the future, and access pharmaceutical treatments that may improve their quality of life (Public Health Agency of Canada, 2019). Accordingly, the aim of this scoping review was to synthesize the existing literature and identify key components of interventions to reduce the stigma of dementia.

We found that Corrigan and Penn's (1999) stigma reduction framework provided a useful approach for classifying the various interventions and their key components. For example, this review found that key components of education interventions included: providing facts to replace myths, using multiple mediums to improve dementia knowledge, and developing culturally informed strategies for specific audiences. Key components of contact and mixed interventions included: showcasing the achievements of people with dementia, highlighting the different stages of dementia, relationship building, and engaging in purposeful learning. No studies examined protest interventions (i.e., drawing public attention to stigma behaviours). In the broader mental health and stigma literature, few studies evaluate protest interventions, possibly because of concerns about creating a rebound of stigma or entrenching stigma-related attitudes (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012). However, protest interventions may repress overt stigma-related behaviours, suggesting that there is some value to this approach (Corrigan et al., 2012). This review, which focused on education and contact interventions, makes an important contribution to the literature, as it provides a comprehensive understanding of existing interventions to reduce dementia-related stigma to inform future health care policies, programs, and services for people with dementia.

Few studies addressed the importance of culture or geographic context (e.g., urban, rural or remote) in developing interventions to reduce the stigma of dementia (Kontos et al., 2018; Zheng et al., 2016). However, local culture and context play an important role in addressing stigmatizing beliefs surrounding dementia. For example, in rural South Africa, dementia is often viewed as witchcraft rather than as a disease (Mkhonto & Hanssen, 2018). Consequently, cultural beliefs and geographical context may affect whether dementia is identified, whether there is early diagnosis, and whether it is openly accepted within the community (Australian Government, 2009). Accordingly, more research is needed to develop culturally and geographically informed interventions to address the stigma of dementia.

Consistent with existing literature (Herrmann et al., 2018b), our scoping review found that studies often did not provide clear

conceptualizations or operationalizations of dementia-related stigma. However, it is important for a study to clearly define stigma and to identify the specific measures and outcomes used to assess the impact of the intervention on dementia-related stigma. This would enhance the replicability of the study and enable researchers to evaluate and compare study findings.

This scoping review also identified the need for more rigorous methods in future research on dementia-related stigma. More specifically, many of the studies suffered from methodological limitations including: poorly defined samples (e.g., lack of consistency in reporting demographic information of the participants such as age and/or gender), informal evaluation methods, and self-report evaluation methods that are subject to positive impression management. These limitations make it difficult to draw firm conclusions regarding the effectiveness of the specific intervention or intervention type on reducing dementia-related stigma. Accordingly, these are important considerations for future research.

## Limitations

This review aimed to summarize the existing literature and identify key components of interventions to reduce the stigma of dementia. Subsequently, the findings from this review are relevant for health professionals, community leaders, and policy makers working to improve the quality of life for people living with dementia. However, our review is not without limitations including the exclusion of non-English manuscripts, and of manuscripts published before January 2008. Consequently, it is possible that relevant research was excluded from this review.

Another limitation of this work is the lack of a quality assessment to evaluate the methods used in each of the 21 studies. The aim of this review was to synthesize the scope of the existing literature, and it refrained from assessing the quality of the studies. Accordingly, future research would benefit from an instrument to formally assess the quality of the work, including the specific measures used to evaluate the interventions to reduce the stigma of dementia. Additionally, further research is needed to evaluate the long-term impact of the different interventions in reducing stigma over time.

## Conclusion

Dementia-related stigma can detrimentally impact interactions with health care providers, experiences in acute care settings, and access to specialist services (e.g., geriatricians and neurologists), and can lead to misdiagnosis, social isolation, depression, and suicide (Public Health Agency of Canada, 2019). Dementia-related stigma pervades society and even health care institutions such as primary care, hospitals, and long-term care settings (Alzheimer's Disease International, 2019; Public Health Agency of Canada, 2019). Research on interventions to reduce the stigma of dementia is critical for improving the quality of life of people living with dementia and their care partners. This scoping review synthesized the existing literature and key components of interventions to reduce the stigma of dementia. Our review makes an important contribution to the literature as it identifies a variety of interventions to address dementia-related stigma ranging from a culturally tailored educational film (Zheng et al., 2016) to an intergenerational choir consisting of college students and people living with dementia (Harris & Caporella, 2018). In moving forward, more rigorous methods are necessary to develop stronger evidence-

informed interventions to reduce the stigma of dementia. In addition, future studies need to clearly define stigma and articulate the specific measures used to assess dementia-related stigma in order to enhance the replicability and utility of the study findings. The findings from our study are relevant to health care providers, researchers, and policy makers working to inform the development of stigma reduction interventions to improve the quality of life for people living with dementia.

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