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A Systematic Review of Communication-Focused Dementia Interventions for Indigenous Communities

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Abstract

Dementia is a significant challenge for many Indigenous peoples who face inequities in risk factors, prevalence, progression rates, and access to quality healthcare. Culturally relevant interventions are needed across the care pathway, however, little evidence exists to guide culturally relevant communication support. This systematic review aims to understand dementia communication interventions developed for Indigenous populations and explore factors relating to their effectiveness. A systematic search of databases, repositories, and search engines was conducted. We took a comprehensive approach to communication, considering the communication skills and abilities of people with dementia, their communication partners, healthcare providers, and community-level information sharing. Studies were required to evaluate an intervention targeting communicative skills, communicative ability, or health communication and include a cultural focus on one or more Indigenous communities. Quality was appraised using an adapted Well Living House Quality Appraisal Tool. Six studies met inclusion criteria, with most studies (n = 5) conducted from 2019 onwards. No studies evaluated an intervention targeting communicative skills and abilities for people with dementia, their communication partners, or healthcare providers. All included studies evaluated a health communication intervention. Interventions utilised various resources, including storybooks, videos, flipcharts, posters, handouts, worksheets, fact sheets, and training modules, tailored towards Indigenous communities across Canada, the United States, and Australia. Content about dementia and dementia management varied across interventions. Analysis identified key

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benefits of the interventions and three factors influencing their effectiveness: (1) representation of Indigenous people, cultures, and languages in resources, (2) methods and settings for knowledge sharing, and (3) communication, connection, and collaboration. While content within resources and methods for information sharing should be tailored to local communities, common elements may support health communication developments across Indigenous contexts. Further research is needed to develop interventions specifically targeting communication skills and conduct methodologically strong evaluations.

Keywords
culture, dementia, Indigenous, intercultural, communication, health communication

Introduction

Dementia poses significant health challenges on a global level. With increases in life expectancy and an ageing population, prevalence is expected to triple by 2050 (World Health Organization [WHO], 2021). Rates of dementia seem to be increasing faster in Indigenous populations internationally (Ma'u et al., 2021; Walker et al., 2020). A higher rate of risk factors for dementia (Warren et al., 2015) and higher prevalence rates across Canada, Australia, and New Zealand have been documented compared to non-Indigenous populations (Walesby et al., 2020; Walker & Jacklin, 2019; Warren et al., 2015). Services that deliver "culturally appropriate…health and social care" (WHO, 2017, p. 23) are increasingly recognised as crucial in the treatment, care, and support of populations affected by dementia. With no current cure, interventions are needed to manage a range of symptoms and improve quality of life (Christopher, 2023). Communication interventions are a necessary component of effective dementia care (Kajander et al., 2022; Swan et al., 2018). However, greater understanding of Indigenous-specific communication interventions is needed.

The need for culturally appropriate healthcare services is paramount in Indigenous contexts (Pomerville et al., 2016). Colonisation, related historical injustices and continuing experiences of discrimination contribute to determinants of health, affecting disparities in health outcomes and restricting the quality of healthcare accessible to Indigenous populations (Griffiths et al., 2016; Health Quality & Safety Commission New, 2019). Health services in colonised countries have been described as monocultural (Greenwood et al., 2017; Health Quality & Safety Commission New, 2019), often contrasting with Indigenous approaches to health. Repeatedly, Indigenous-focused research emphasises the importance of culture and Indigenous methods in dementia care (Dudley et al., 2019; Finkelstein et al., 2012; Gubhaju et al., 2022). Recent emergence of culturally appropriate assessment tools (Bezerra et al., 2024) and cognitive interventions (Ferriera, 2024) represent the beginning stages of culturally relevant support. However, further developments are needed to address a broader range of symptoms and provide comprehensive support across the dementia care pathway.

There is a limited but growing body of evidence that offers insights into perspectives and needs relating to communication for a small number of Indigenous communities. For example, studies have explored perspectives of dementia within Indigenous communities across Canada (Jacklin & Walker, 2020), Aotearoa New Zealand (Dudley et al., 2019), and Australia (Cox et al., 2019). Findings from these studies are essential in developing appropriate services and in some cases, highlight the role that communication and connection play in promoting wellbeing for Elders living with dementia. For example, some Māori in Aotearoa New Zealand view continual performance of cultural communicative roles and listening to te reo Māori (the Māori language) as supportive of spiritual wellbeing throughout mate wareware (dementia) (Dudley et al., 2019). Moreover, Aboriginal people from rural Tasmania in Australia, have expressed the importance of supporting social and community connectedness for people with dementia (Cox et al., 2019). While these studies offer valuable insights into the value of certain communicative practices, they lack an in-depth exploration on the provision of communication support. In other conditions, such as stroke and traumatic brain injury, emerging evidence has explored experiences of acquired communication difficulties and speech and language therapy for Aboriginal Australians and Māori (Armstrong et al., 2015, 2021; Eustace et al., 2024; McLellan et al., 2014a, 2014b). These studies have highlighted the importance of therapy that is congruent with cultural identity and worldviews and offered directions for healthcare professionals in delivering appropriate services. However, considering the difference in expected progression, with gradual worsening of symptoms typical in dementia compared to expected ongoing recovery for many people with stroke and traumatic brain injury, it is critical to gain evidence that is specific to the dementia context.

Communication difficulties are one of the earliest issues to arise in people with dementia (Stanyon et al., 2016). Breakdowns can occur across all types of dementia (Alsawy et al., 2017), although each dementia type is associated with specific communication profiles due to their distinct neuropathological underpinnings (El-Wahsh et al., 2021). Language expression and comprehension difficulties across both spoken and written modalities may be present, as well as motor speech difficulties (Bayles & Tomoeda, 2020; El-Wahsh et al., 2021). Research has also emphasised the relationship between cognitive changes and speech and language difficulties due to the involvement of cognitive processes in communication (Bayles & Tomoeda, 2020). The resulting impacts can be significant for the person with dementia and their social networks, commonly resulting in social isolation, depression, and a decline in quality of life (El-Wahsh et al., 2021; Small et al., 2000). Intervention approaches, such as cognitive stimulation therapy, word retrieval intervention, script training, augmentative and alternative modes of communication, education of communication partners and adaptation of the environment, have been established (Swan et al., 2018; Wauters et al., 2023). These show improvements to language, communication, social participation, and quality of life (Desai et al., 2024; El-Wahsh et al., 2021; May et al., 2019; Perkins et al., 2021), suggesting clear benefits to implementing communication interventions for people affected by dementia.

Comprehensive support for people with dementia and their families should consider the relational, clinical, and broader societal forms of communication. Healthcare providers have a significant role to play in the facilitation of naturally occurring communication with patients and their companions. Effective skills in this area can support patient understanding, decision making, and therapeutic relationships (Street, 2013) and are particularly important in dementia contexts where supportive facilitation is often required (Dooley et al., 2015).

On a broader scale, health communication, often an element of dementia health promotion or awareness initiatives, communicates health risk and information, provides details on service access, and spreads large-scale public health messages (Ishikawa & Kiuchi, 2010). Such interventions have shown promising results as people with dementia and their care partners describe increased knowledge and acceptance of dementia, enhanced communication and social participation, and a willingness to change health behaviours (Kajander et al., 2022). The importance of tailoring health and healthcare communication to Indigenous cultures and contexts has been identified across health settings including broadly within health districts, hospitals, and regional health service settings (Kerrigan et al., 2024; Lovell & Clark, 2022).

Increasingly, speech and language therapy-led interventions take a more holistic approach to supporting people with dementia-related communication changes. In the past decade, multiple intervention programmes have been developed and evaluated, particularly for people with primary progressive aphasia, which include a combination of supportive communication approaches (Watanabe et al., 2024). These programmes may involve enhancing the communication abilities and social engagement of people with dementia, providing communication strategies and communication partner training, as well as delivering broader education about dementia (Watanabe et al., 2024). These elements target varying aspects of communication. For example, the use of language activities aims to enhance specific language skills, while health communication seeks to promote knowledge of disease (Watanabe et al., 2024). However, there appear to be benefits to specific language skills, use of communication strategies, and wellbeing through intervention programmes that include a combination of approaches (Watanabe et al., 2024). The current review aims to reflect this holistic approach, considering interventions that support communicative abilities of people with dementia and their communication partners, communication skills of healthcare providers, or health communication. We refer to each aspect separately throughout this article considering that different aspects of communication are targeted and that varying skills are required to facilitate each.

Despite clear benefits of communication interventions and recent Indigenous-focused developments in dementia care, in Aotearoa New Zealand, the location of the authors, no Indigenous dementia communication research exists to inform evidence-based speech-language pathology practice with the Indigenous Māori population (Meechan & Brewer, 2022). There is also limited Māori-focused research on dementia health or healthcare communication (Dudley et al., 2023). Considering the paucity of research, the authors sought guidance from Indigenous communities across the globe and conducted a systematic exploration of dementia communication interventions designed to support Indigenous people.

While relevant insights were anticipated considering similarities in Indigenous understandings of dementia (Dudley et al., 2019; Gubhaju et al., 2022; Jacklin & Walker, 2020) and shared needs to overcome colonial domination of health and healthcare, it cannot be assumed that identified approaches can be applied universally across Indigenous people considering the vast diversity of Indigeneity. Rather, we aimed to detail transformative approaches, offer insights into methods in greater alignment with common features of Indigenous worldviews, and support further development of localised Indigenous interventions. The systematic search strategy focused on interventions targeting communicative ability of people with dementia or their communication partners, communication skills of healthcare providers, and health communication. We aimed to address three questions pertaining to these intervention types: (1) How many interventions have been implemented focusing on Indigenous peoples? (2) What are the characteristics of the interventions described in these studies? (3) What major findings have been reported relating to the effectiveness of the interventions?

Methods

Indigenous Engagement

This study was led by Author 1 (ME), who is a woman of Māori and European ancestry, located in Aotearoa New Zealand. As described previously (Eustace et al., 2024), her analytical lens is rooted in a Kaupapa Māori research approach and her broader research aims to support the inclusion of Māori knowledge and approaches in communication interventions. The second author (CLH) identifies as Pākehā (European), with primarily Western European ancestry. His neurological practice is framed by a Western model of medicine although he is motivated to support accessible and appropriate health services for Māori. The third author (JK) is also Pākehā. She holds well established relationships with knowledge holders across multiple iwi (tribes) and has been learning and teaching te reo Māori (the Māori language) for more than 45 years. The fourth author (KM) grew up as an urban Māori and is now on a reclamation journey. She is committed to supporting others on their own journey, including students completing Kaupapa Māori research, and engages with local Māori communities, facilitating connection. The fifth author (CT) is Pākehā, originating from Belgium where she completed her clinical speech and language therapy and research training. The fifth author was immersed in different languages from a young age and began learning about Māori language and culture when relocating to Aotearoa New Zealand over a decade ago.

Prior to conducting this research, the first, fourth, and fifth authors engaged in a consultation project with three local Māori communities in Ōtautahi (Christchurch, Aotearoa New Zealand) to exchange knowledge about dementia and learn about communities' needs for communication support. Through consultation, the value of global Indigenous knowledge became clear in the endeavour to revitalise and promote Indigenous dementia knowledge and Indigenous innovations in dementia care. The current project developed as part of the first author's doctoral research which underwent consultation with the University of Canterbury Ngāi Tahu Consultation and Engagement Group and with kaiārahi (cultural guides) at the University of Canterbury.

This systematic review was completed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Page et al., 2021). The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) was also followed due to the strong qualitative design of the identified studies (Page et al., 2021; Tong et al., 2012). A Population, Intervention, Outcome (PIO) framework was developed to guide inclusion of records. Population included one or more Indigenous communities. We refrained from restrictive definitions of Indigeneity in alignment with the United Nations' (2007) right to self-identification. Intervention included three dementia-related approaches: (1) interventions aiming to enhance communicative ability of people with dementia or their communication partners, (2) interventions aiming to improve the communication skills of healthcare providers, and (3) health communication interventions. Interventions were required to include a focus on cultural aspects relevant to one or more Indigenous communities. Outcome data had to be reported relating to communicative ability, environmental barriers or facilitators to communicative success, personal factors relating to communicative success (such as knowledge of communication strategies), quality of life, caregiver burden or stress, knowledge of dementia, or participants' perspectives relating to the intervention. We selected broad outcomes to allow responsiveness to unexpected findings. Records were excluded if they were written in languages other than English or were not original research.

A subject librarian was consulted to develop a search strategy. Search terms included keywords within the following topics: Indigenous, dementia, communication, and intervention. The full list of search terms and complete search strategy are presented in supplemental material 1. We conducted a pre-planned search in the Embase (OvidSP), MEDLINE (OvidSP), Scopus, PsycINFO (EBSCOhost), The Cochrane Library, and CINAHL (EBSCOhost) databases on 26 September 2023. A search of grey literature has been suggested when conducting systematic reviews on dementia in Indigenous contexts as it has only recently gained research momentum (Jacklin & Walker, 2020). Google Scholar was additionally searched on 15 August 2023. The first 100 hits were selected due to the likelihood of relevant results while also being feasible to screen. The Bielefeld Academic Search Engine (BASE) and ProQuest Dissertations and Theses A&I were searched on 16 August 2023 and Trove, NZresearch.org,nz, and Theses Canada Portal on 26 September 2023. The search of published academic literature was updated on 7 September 2024 and the grey literature search was updated on 9 September 2024. Duplicates were removed manually and in EndNote20 and records were imported into Covidence.

Authors 1 (ME) and 5 (CT) independently screened titles and abstracts of the identified records in Covidence. Disagreements were discussed and consensus reached. Then, each researcher independently screened the full texts of included studies. Theses, book chapters, and reports were manually searched for relevant chapters or sections which were read. Additionally, researchers used the search function for the following terms if they were not identified during the manual search: Indigen, Aborigin, Māori, American Indian, Alaska Native, First Nation, Inuit, Métis, dementia, and communicat. Again, disagreements were resolved by reaching consensus through discussion. In cases where there were multiple reasons for exclusion of a report, researchers followed a hierarchy of exclusion reasons related to (a) population, (b) intervention, and (c) outcomes.

We designed a data extraction spreadsheet in Excel which the first author used to extract data from the included studies. Author 1 (ME) entered data into the spreadsheet, double checking for accuracy. When study information was unclear, we contacted authors of reports to provide further details, however, three were not contactable. We sought all data compatible with the outcomes included in our PIO criteria. No restrictions were placed on the number of outcome measurement points. We additionally collected data on the author and year; country; targeted Indigenous community; Indigenous community involvement; study design; guiding methodologies and frameworks; intervention characteristics including resource type, development method, mode of delivery, core intervention topics, and language; participant characteristics and sample size of evaluations; evaluation methods and tools; and reported outcomes. Summary data are reported in Table 1. Data extraction and reporting were guided by and adapted from Hardy et al. (2023).

Studies were synthesised using textual narrative synthesis to identify factors relating to the effectiveness of the interventions. We also explored the characteristics of the interventions and the involvement of Indigenous people and how these factors may have contributed to intervention effectiveness. The narrative approach has strengths in clearly identifying context related to each study and presenting heterogeneity in a transparent manner (Barnett-Page & Thomas, 2009), an important consideration for reviews including multiple Indigenous communities. We followed a process outlined by Popay et al. (2006), including theory development, preliminary synthesis, exploring relationships in data, and assessing the robustness of the synthesis.

The theoretical starting point of this review developed from the growing body of literature indicating the importance of culturally and contextually relevant approaches to dementia management for Indigenous peoples (Dudley et al., 2019; Finkelstein et al., 2012; Gubhaju et al., 2022). This knowledge suggests that communication interventions delivered in appropriate ways, considerate of Indigenous perspectives and needs, may further enhance knowledge of dementia and supportive communication strategies, improve accessibility of communication support, and lead to positive effects on quality of life for members of Indigenous communities. Given our theoretical underpinnings, we focused our search on studies which specifically included Indigenous culture in the evaluation of dementia communication interventions.

After extracting the characteristics of included studies, the first author documented intervention characteristics and Indigenous involvement for each study using written descriptions and tabulation. Thematic analysis was then used to inductively develop a preliminary synthesis of study findings. This method was chosen given the strong qualitative nature of the data and the ability to identify the main ideas of each study's findings (Popay et al., 2006). Results of each included study were read and findings relevant to the effectiveness of interventions were labelled with codes, that is, text labels which described the main ideas of each section of data. Variable labels from surveys were integrated with their corresponding survey question topic and extracted as codes. Codes were then combined to form broader themes and subthemes within each included study. Results of each individual study were then reread to ensure all relevant findings were identified.

Once an initial synthesis was complete, the first author compared relationships within and between studies (Popay et al., 2006). Themes and subthemes were further developed based on similarities and divergences between data. During this stage, context was essential to understanding heterogeneity within and across studies. Characteristics of the study designs, populations, interventions, and settings, as well as Indigenous involvement in the study were reviewed to deepen understandings of relationships between data and themes and contribute to explanations of how and why interventions worked. As a key aim of this review was to detail factors that influenced the effectiveness of interventions, identified factors were arranged into a conceptual diagram (see Figure 2).

To assess quality of the included studies in alignment with an Indigenous framework, the first author used an adapted version of the Well Living House Quality Appraisal Tool (WLHQAT) (Hardy et al., 2023). This tool was designed for heterogeneous Indigenous studies including both qualitative and quantitative components and has strengths in its focus on community relevance, Indigenous knowledge systems, and Indigenous values (Morton Ninomiya et al., 2017). Studies were assessed according to three appraisal categories: (1) community relevance, (2) internal validity and rigour of the methodology, and (3) strength of the evidence (Hardy et al., 2023). A maximum score of 12 was possible. Author 5 (CT) was consulted for verification in cases of uncertainty. We did not exclude studies if they received a low score on the WLHQAT as the current review focuses on identifying and examining all emerging evidence. Results of the quality appraisal are presented transparently and inform interpretations of intervention effectiveness.

Results

Study Selection

Figure 1, adapted from Covidence software, shows the PRISMA flow diagram for inclusion of reports. We identified 251 records from published literature databases, 259 records from the grey literature search, and 530 records from the updated search conducted between 7-9 September 2024. Following de-duplication manually and using EndNote20, 421 records were imported into Covidence for title and abstract screening. We reviewed the full texts of 91 reports. Finally, we included seven reports. Two articles (Lindeman et al., 2012; Taylor et al., 2012) report different findings from the same study and hence are grouped together in our analysis.

Study Characteristics

Of the six studies included in this review, publication dates ranged from 2012 to 2023. Five were reported in journal articles (Bourassa et al., 2021; Browne et al., 2022; Lindeman et al., 2012; Mateo-Arriero et al., 2023; Taylor et al., 2012; Webkamigad et al., 2020) and one in a book chapter (Hulko et al., 2019). Indigenous communities were the sole focus of all studies and included Indigenous peoples in Canada (Bourassa et al., 2021; Webkamigad et al., 2020), Secwépemc people (Hulko et al., 2019), Aboriginal and Torres Strait Islander people in Australia (Mateo-Arriero et al., 2023), Aboriginal Australians in the Northern Territory (Lindeman et al., 2012; Taylor et al., 2012), and Native Hawaiians (Browne et al., 2022).

Evaluation sample sizes ranged from 9 to 31 and participant characteristics varied across studies. Studies included Indigenous people with cognitive impairment but not dementia (Mateo-Arriero et al., 2023), Indigenous caregivers of people with dementia (Bourassa et al., 2021; Webkamigad et al., 2020), and Indigenous older adults (Webkamigad et al., 2020). Two studies combined community members with other participant groups including Indigenous aged care workers and aged care service users (Lindeman et al., 2012; Taylor et al., 2012) or teachers and Indigenous Elders (Hulko et al., 2019). Browne et al. (2022) did not report participant demographic information for the evaluation phase of their research.

Community-based research approaches were utilised in four of six studies (Bourassa et al., 2021; Browne et al., 2022; Hulko et al., 2019; Webkamigad et al., 2020) and three were guided by Indigenous research methodologies or tribal and decolonising frameworks (Bourassa et al., 2021; Mateo-Arriero et al., 2023; Webkamigad et al., 2020). Intervention evaluations were predominantly qualitative, although three studies used a mixed methods design (Browne et al., 2022; Hulko et al., 2019; Mateo-Arriero et al., 2023). A combination of focus groups, individual interviews and post-intervention surveys, including both Likert-type and open-ended questions were used across the six studies. Two were pilot studies (Hulko et al., 2019; Mateo-Arriero et al., 2023).

Quality Appraisal

Quality appraisal was conducted using an adapted version of the WLHQAT (Hardy et al., 2023; see Table 2). Overall, studies were of mixed methodological quality, with scores ranging from six to twelve out of twelve. Studies scored highly on questions pertaining to community relevance, indicating relatively strong alignment with the values and needs of the Indigenous communities involved. Rigour and strength of evidence scores were most commonly lowered by weak evaluation design, particularly due to lack of depth in data collection, limited reporting of evaluative questions, high risk of nonresponse bias, and low rates of member checking.

Indigenous Involvement

Overall, there was moderate to high involvement of Indigenous people, although this differed across studies and across study phases (see Table 3). Author positionality was mentioned in four studies, however, was largely limited to statements of authors' ethnicity (Bourassa et al., 2021; Browne et al., 2022; Mateo-Arriero et al., 2023; Webkamigad et al., 2020). All studies included Indigenous guidance through community partnerships or advisory groups. However, only two explicitly evolved from a research need identified by Indigenous community members (Bourassa et al., 2021; Hulko et al., 2019).

The perspectives of Indigenous communities are essential in evaluating healthcare approaches that intend to support them (Hardy et al., 2023). Most studies (n = 5/6) involved Indigenous consultation or collaboration in the development of the intervention, with Indigenous Elders (Browne et al., 2022; Hulko et al., 2019; Mateo-Arriero et al., 2023; Webkamigad et al., 2020), members of the target populations (Bourassa et al., 2021; Browne et al., 2022), or Indigenous healthcare staff (Browne et al., 2022; Mateo-Arriero et al., 2023). Indigenous participation in the delivery of interventions was explicitly described in three studies which involved an Indigenous Elder (Bourassa et al., 2021), an Indigenous member of the research team (Webkamigad et al., 2020), or Indigenous health practitioners (Mateo-Arriero et al., 2023). Most studies (n = 5/6) clearly involved Indigenous people in evaluation (Bourassa et al., 2021; Hulko et al., 2019; Lindeman et al., 2012; Mateo-Arriero et al., 2023; Taylor et al., 2012; Webkamigad et al., 2020). All five of these studies evaluated the intervention with Indigenous participants, while three additionally included the Indigenous advisory group (Bourassa et al., 2021; Webkamigad et al., 2020) or an Indigenous researcher (Mateo-Arriero et al., 2023) in data analysis or discussion of themes.

Table 1. Summary of Study Characteristics

Author (year)	Country, target community	Intervention type	Intervention topics	Intervention delivery	Evaluation data collection methods	Participants involved in evaluation	Reported outcome(s)
Bourassa et al. (2021)	Canada, Indigenous peoples in Canada	Toolkit consisting of training modules	Dementia information; medication management; preparing for a medical visit; de-escalating crises; creating a power of attorney; Indigenous teachings; resources for caregivers	3 × 2 hours workshops	Pre-survey and post-survey; research circles (following each of 3 workshops)	First Nations and Métis caregivers of family members with dementia (n = 11)	Useful resource to start the learning journey and learn how to deal with dementia. Online delivery both a limitation and facilitator.
Browne et al. (2022)	United States, Native Hawaiians	Storybook modelled on fotonovela	Alzheimer's disease facts; dementia symptoms; recommendations for supporting someone with dementia; links to further resources	Printed copies provided to organisations and shared at conferences	Post-survey	No demographic information (*n* = 16)	Very useful resource to understand dementia (n = 15 [94%]). Reported enhanced understanding of dementia symptoms and ability to differentiate between dementia and normal ageing. Normalised dementia and reaching out for support.

(continued)

Table 1. (continued)

Author (year)	Country, target community	Intervention type	Intervention topics	Intervention delivery	Evaluation data collection methods	Participants involved in evaluation	Reported outcome(s)
Hulko et al. (2019)	Canada, Secwépemc Nation	24 page storybook (for children); 22 min video (for youth)	Secwépemc views on ageing; memory loss	Physical DVD; printed book; online	Post-survey; 3x consultation sessions	Teachers from 3 Secwépemc schools; Secwépemc Elders and other community members (n = 29); 86% of participants involved in the evaluation were First Nations	High ratings of utility, novelty (new material from a Secwépemc perspective), practicality, and applicability from community members (average scores ranged from 4.57 to 4.79 out of 5 across these domains). Moderate-high ratings of utility, novelty (new material from a Secwépemc perspective), practicality, and applicability from teachers (average scores ranged from 3.17 to 4.83 out of 5 across these domains). Reported benefits included the portrayal of cultural ideas, knowledge, and values; supportiveness of intergenerational knowledge exchange; increased understanding of dementia and potential to increase understandings of dementia for youth and kids.
Lindeman et al. (2012); Taylor et al. (2012)	Australia, Aboriginal people in the Northern Territory	16 min DVD in English, Warlpiri, Kriol, and Djambarrpuyngu languages; flipchart; poster	Not reported	Implementation by external dementia educators during typical work role	5x focus groups (up to 1 month post-intervention); 5x individual interviews; observation	Indigenous aged care workers, aged care service users, and community members (n = 26); healthcare professionals and service coordinators (n = 5)	Themes developed: 1) the target audience, 2) intercommunity and intersectoral relationships, 3) elements of good intercultural communication, 4) implications for health literacy: Developing a shared vocabulary, 5) 'I know what's dementia now': The difference that good communication can make to a single issue, 6) connections with culture, 7) awareness, and 8) impact.

(continued)

Table 1. (continued)

Author (year)	Country, target community	Intervention type	Intervention topics	Intervention delivery	Evaluation data collection methods	Participants involved in evaluation	Reported outcome(s)
Mateo-Arriero et al. (2023)	Australia, Aboriginal and Torres Strait Islander people	Dementia Prevention and Risk Management Program for Aboriginal Australians (DAMPAA)	Introduction to DAMPAA; nutrition; exercise and brain health; medication management; diabetes prevention and management; falls prevention	Education session handouts, resources and worksheets; home exercise handouts (pictures and text descriptions of exercises and a monthly exercise calendar)	9x individual phone interviews	Aboriginal people with cognitive impairment not dementia (*n* = 10); 1 participant withdrew at week 1	Social interaction reported as an enabler to programme attendance. Suitable environment and logistical aspects, such as motivation, and scheduling around family commitments identified as enablers or barriers.
Webkamigad et al. (2020)	Canada, Indigenous peoples in Canada	2x dementia fact sheets	Indigenous perspectives and cultural understandings of dementia; an Indigenous guide to signs and symptoms of dementia	Presented by members of the research team	2x focus groups; 5x individual interviews	Indigenous caregivers of a person with dementia (n = 7); Indigenous older adults (*n* = 5)	Major themes developed: 1) the need for shared understandings of Indigenous and Western cultures in health care, 2) improving cross-cultural communication within health-related encounters, 3) grounding health promotion materials in culture, and 4) Indigenous health literacy strategies for dementia awareness.

DAMPAA = Dementia Prevention and Risk Management Program for Aboriginal Australians.

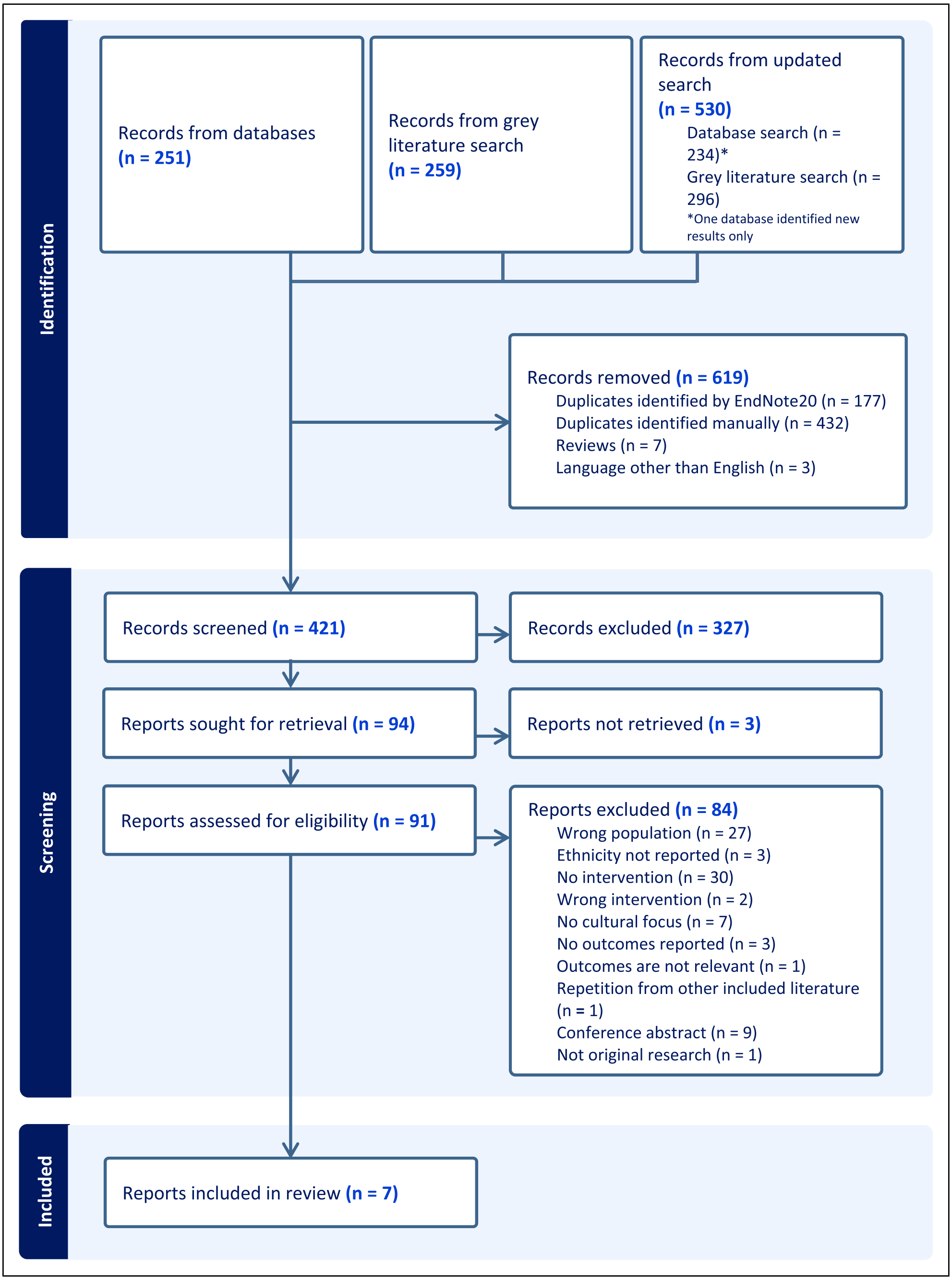

Figure 1. PRISMA Flow Diagram of Report Selection
Note. Six studies were identified across the seven included reports.

Table 2. Quality Appraisal Using the Well Living House Quality Appraisal Tool (WLHQAT)

	WLHQAT category[b]			Total score	
Author (year)	Local community relevance (score /4)	Rigour and internal validity (score /4)	Strength of the evidence (score /4)	(Score/12)	Summary comments
Bourassa et al. (2021)	4	3	2	9	Strengths: There was strong Indigenous community involvement throughout the research process from identification of the research need to analysis of the intervention evaluation data. Indigenous research methodologies were incorporated. There was coherence between research approach and methods. Weaknesses: Evaluation questions or prompts were not reported, however, conversations were largely participant led. There was no description of member checking. Additional data was needed to strengthen some interpretations.
Browne et al. (2022)	3	3	1	7	Strengths: The study was initiated and carried out by an Indigenous-led research centre. The inclusion of an advisory council and community engagement at each stage centred community needs. Native Hawaiian communication styles were considered in data collection methods. Weaknesses: The risk of nonresponse bias was high. Limited evaluation data was collected and participant characteristics of the evaluation were not reported. Questions could have allowed for a broader range of responses and additional data were needed to substantiate some qualitative findings.

(continued)

Table 2. (continued)

Author (year)	WLHQAT category[b] Local community relevance (score /4)	Rigour and internal validity (score /4)	Strength of the evidence (score /4)	Total score (Score/12)	Summary comments
Hulko et al. (2019)	3	2	1	6	Strengths: The research was initiated from Secwépemc community-identified need. Thorough collaboration took place with Secwépemc Elders and artists to design the intervention and there was explicit incorporation of Secwépemc values. Weaknesses: There was a high risk of nonresponse bias and response rate appeared low. The survey had not been pre-tested or validated previously. Some evaluation questions were not reported.
Lindeman et al. (2012); Taylor et al. (2012) [a]	3	2	3	8	Strengths: Indigenous input was described with an Indigenous researcher throughout and an Indigenous advisory group. There was alignment between the research approach and methods. Triangulation was used in data collection and analysis. Weaknesses: It was unclear to what degree and at which stages the Indigenous advisory group was involved. There was no mention of data reaching saturation or member checking. Interpretations of data would have been enhanced with the use of a clear analytic lens.

(continued)

Table 2. (continued)

	WLHQAT category[b]			Total score	
Author (year)	Local community relevance (score /4)	Rigour and internal validity (score /4)	Strength of the evidence (score /4)	(Score/12)	Summary comments
Mateo-Arriero et al. (2023)	3	2	1	6	Strengths: The use of Indigenous research methodologies and community consultation supported the involvement of Indigenous people in intervention design and evaluation. The qualitative data analysis method was appropriate to the methodologies and data interpretation was cross-checked by an Aboriginal researcher. Weaknesses: There was limited description of analytic methods for quantitative data and quantitative results were not reported. Additional qualitative data would have strengthened interpretations. There was no report of member checking.
Webkamigad et al. (2020)	4	4	4	12	Strengths: Indigenous community involvement was evident and guided all stages of the research. The research was grounded in tribal epistemology relevant to the Indigenous researcher. Data were collected until saturation was met. Data underwent member checking and themes were discussed with the Indigenous advisory group. Weaknesses: Themes were not checked with participants.

[a] Lindeman et al. (2012) and Taylor et al. (2012) are grouped together as findings stem from the same study.

[b] Well Living House Quality Appraisal Tool (WLHQAT) categories include the following scoring options and questions.
Local community relevance of method and measures (yes = 2, partial = 1, no = 0) (total score /4 across two questions).
Did the measures of success reflect local Indigenous community understandings of success?
Had methods and tools been validated previously in a similar Indigenous context and reviewed for relevance by appropriate community members?
Rigour and internal validity of the evaluation method (excellent = 4, fair = 3, barely acceptable = 2, poor = 1).
Do the quantitative or qualitative methods meet relevant rigour and internal validity?
Strength of the evidence (excellent = 4, fair = 3, barely acceptable = 2, poor = 1).
Is the evidence strong?

Table 3. Summary of Indigenous Involvement in the Research Process

Author, year	Positionality	Community partnerships/advisory group	Research need	Study design	Intervention development	Intervention delivery	Intervention evaluation
Bourassa et al. (2021)	Partial	Yes	Yes	Yes	Yes	Yes	Yes
Browne et al. (2022)	Partial	Yes	None reported	Partial	Yes	None reported	None reported
Hulko et al. (2019)	None reported	Yes	Yes	None reported	Yes	None reported	Partial
Lindeman et al. (2012); Taylor et al. (2012)	None reported	Yes	None reported	Partial	None reported	None reported	Partial
Mateo-Arriero et al. (2023)	Partial	Yes	None reported	None reported	Yes	Yes	Partial
Webkamigad et al. (2020)	Partial	Yes	None reported	Yes	Yes	Yes	Yes

Intervention Characteristics

Health communication was the only identified dementia communication intervention targeted towards Indigenous peoples in the studies published so far. We found no studies that focused intervention on enhancing the communicative abilities of people with dementia or their communication partners. Of the studies included, most focused on dementia (Bourassa et al., 2021; Lindeman et al., 2012; Mateo-Arriero et al., 2023; Taylor et al., 2012; Webkamigad et al., 2020), although one was specific to Alzheimer's disease (Browne et al., 2022). Most interventions ($n = 4/6$) were newly developed and evaluated in the studies (Bourassa et al., 2021; Browne et al., 2022; Hulko et al., 2019; Mateo-Arriero et al., 2023). Interviews, discussion meetings, roundtables, yarning, and a focus group session with key community members were used to inform intervention development (Browne et al., 2022; Hulko et al., 2019; Mateo-Arriero et al., 2023) as well as a curriculum review (Browne et al., 2022) and collaboration with First Nations artists (Hulko et al., 2019). A range of materials were used, including dementia fact sheets (Webkamigad et al., 2020); handouts, resources, and worksheets (Mateo-Arriero et al., 2023); storybooks (Browne et al., 2022; Hulko et al., 2019); a video (Hulko et al., 2019); a DVD accompanied by a flipchart and poster (Lindeman et al., 2012; Taylor et al., 2012); and a toolkit consisting of training modules (Bourassa et al., 2021).

Overall, there was variability in content reported across interventions. Only three explicitly incorporated Indigenous views or knowledge relating to dementia (Bourassa et al., 2021; Webkamigad et al., 2020) or ageing (Hulko et al., 2019). While three interventions covered dementia symptoms (Browne et al., 2022; Hulko et al., 2019; Webkamigad et al., 2020), memory loss was the primary focus of one study (Hulko et al., 2019). Resources to support caregivers were included in two interventions (Bourassa et al., 2021; Browne et al., 2022). Although most studies focused on the concept of dementia, symptoms, and management, one was specific to dementia risk and prevention (Mateo-Arriero et al., 2023) and one to respite care (Bourassa et al., 2021). One study did not report the content of the intervention (Lindeman et al., 2012; Taylor et al., 2012). Resources were predominantly in English, however, two studies incorporated Indigenous languages throughout (Browne et al., 2022; Hulko et al., 2019) and one provided resources in three Aboriginal languages in addition to English (Lindeman et al., 2012; Taylor et al., 2012). Two studies did not report languages used in interventions (Bourassa et al., 2021; Mateo-Arriero et al., 2023).

Factors Related to the Effectiveness of Interventions

Perceived Benefits. We first synthesised factors relating to the effectiveness of interventions. Overall, the included studies reported positive impacts resulting from the dementia health communication interventions targeted towards Indigenous communities. Findings may have been biased towards benefits due to the nature of questions asked in the studies. Limitations tended to be reported indirectly as potential facilitators for effective implementation of health communication. Benefits were reported quantitatively, with high ratings of usefulness (Browne et al., 2022; Hulko et al., 2019), practicality, and applicability (Hulko et al., 2019) (see Table 1), as well as qualitatively.

A key benefit described across five of six studies was the usefulness of interventions in increasing understandings of dementia and dementia management (Bourassa et al., 2021; Browne et al., 2022; Hulko et al., 2019; Lindeman et al., 2012; Taylor et al., 2012; Webkamigad et al., 2020). Specifically, studies reported enhanced understandings of risk factors (Taylor et al., 2012), symptoms (Webkamigad et al., 2020), behaviour changes (Lindeman et al., 2012; Taylor et al., 2012), and differences between dementia and normal ageing (Browne et al., 2022) or other neurological conditions (Taylor et al., 2012). The benefits in portraying Indigenous dementia knowledge were identified with participants believing “this knowledge will help to keep our culture alive” (educator at Switsemalph Indian Reserve 6; Hulko et al., 2019, p. 223).

Interventions were also thought to facilitate improved dementia support, through enhanced caregiver and family understandings of dementia or encouragement to access health services. Interventions that took a family-centred approach were seen as beneficial. They raised awareness of need and held potential to educate younger community members (Hulko et al., 2019; Taylor et al., 2012), as well as increasing awareness of the need to include the whole family in the dementia care plan (Browne et al., 2022). The potential of one intervention to enhance family and community understandings of dementia was also seen to address issues such as tension, fighting, abuse, and neglect (Lindeman et al., 2012; Taylor et al., 2012). Furthermore, interventions were described as enabling connection to health services (Browne et al., 2022; Taylor et al., 2012; Webkamigad et al., 2020). The information normalised dementia (Browne et al., 2022) or aided understandings of symptoms, encouraging participants to seek support: “Yeah, again to when it comes to my own health, ensuring that I should make an appointment with my doctor very soon to address some of these symptoms that are outlined in your handout here” (caregiver; Webkamigad et al., 2020, p. 243).

Factors Perceived as Influencing Effectiveness. Next, we synthesised and arranged factors influencing the effectiveness of interventions into a conceptual model, shown in Figure 2. The model captures key aspects of the educational resource, appropriate methods for knowledge sharing, and accompanying communication skills and collaboration. The outer layer reflects the importance of Indigenous community involvement throughout intervention design and development, delivery, and evaluation, an important element of the methods of the included studies.

Indigenous People, Cultures, and Languages in Resources. Participants expressed a preference to include Indigeneity in educational dementia materials (Hulko et al., 2019; Taylor et al., 2012; Webkamigad et al., 2020). The value in Indigenous philosophies and health models, such as the medicine wheel was reported (Hulko et al., 2019; Webkamigad et al., 2020). Similarly, inclusion of Indigenous cultures, including cultural ideas, values, and examples was considered important (Hulko et al., 2019; Webkamigad et al., 2020). Indigenous adults and caregivers preferred to learn from experienced Indigenous Elders, health care providers, teachers, and carers (Webkamigad et al., 2020). Studies reported mixed perspectives on the use of Indigenous languages in educational materials. Overall, the inclusion of Indigenous languages was appreciated as it validated historically undervalued languages, portrayed Indigenous knowledge through culturally grounded words, and facilitated understanding of information (Taylor et al., 2012; Webkamigad et al., 2020). However, resources in the English language were considered acceptable or useful in some contexts dependent on the languages spoken within the community (Webkamigad et al., 2020) and opportunities for subsequent discussion in Indigenous languages (Taylor et al., 2012). The need for comprehensive information in resources (Taylor et al., 2012), particularly in alignment with Indigenous values and concepts of holism, was also considered important (Webkamigad et al., 2020).

Appropriate Methods and Settings for Knowledge Sharing. Methods of sharing information about dementia need to be relevant to members of the targeted community. The use of Indigenous-grounded communication methods may facilitate understanding. For example, Indigenous people in Canada perceived value in oral teachings that took place through visiting in person, storytelling, sharing circles, and visual information (Webkamigad et al., 2020). Community-focused approaches

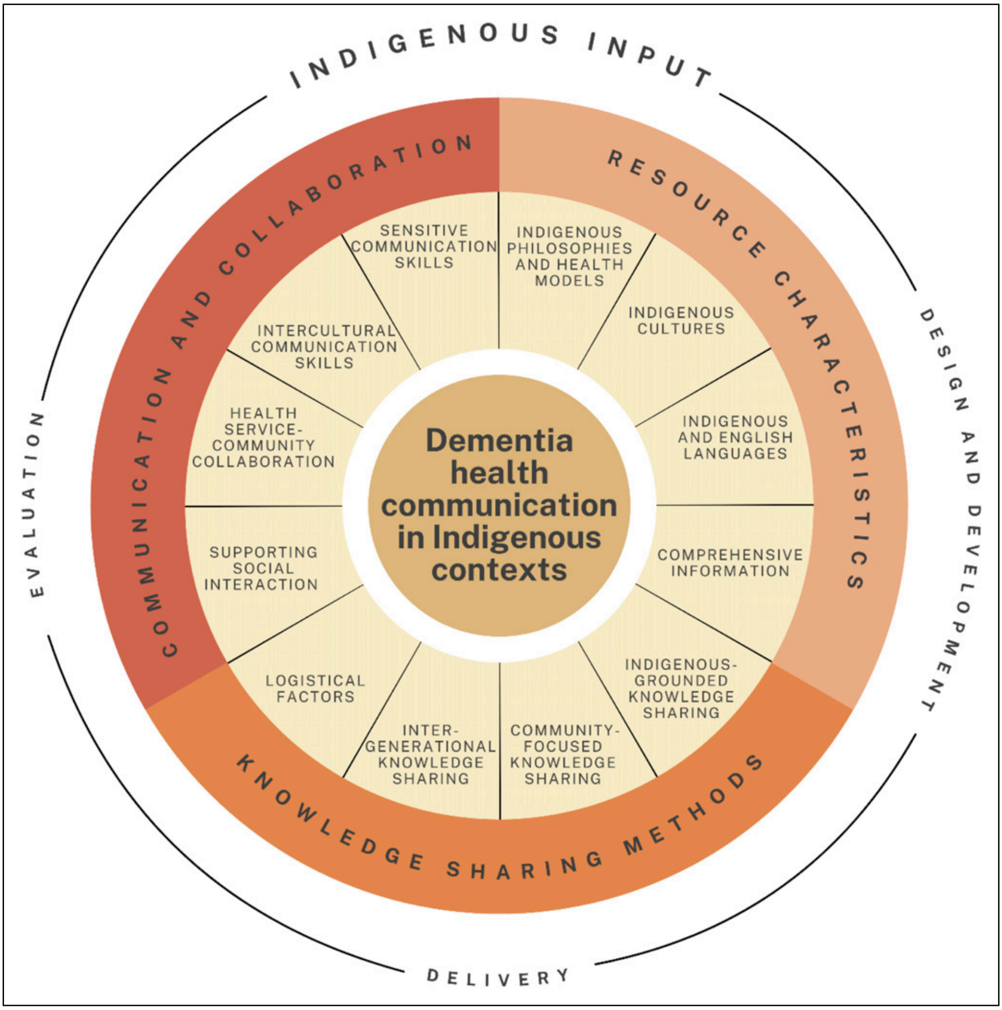

Figure 2. Facilitators of Dementia Health Communication in Indigenous Contexts as Identified in This Review

may also support the successful delivery of dementia information (Lindeman et al., 2012; Webkamigad et al., 2020). Knowledge dissemination across age groups in the community was advocated for (Lindeman et al., 2012) as well as workshops and training for community members and dissemination through organisations and modalities accessible to Indigenous people (Webkamigad et al., 2020). Lastly, successful methods for knowledge sharing should consider logistical aspects relating to the person and intervention setting. Specifically, healthcare providers should take into account motivation, transport, and family commitments (Mateo-Arriero et al., 2023), as well as a suitable environment for intervention delivery (Bourassa et al., 2021; Mateo-Arriero et al., 2023). Many First Nations and Métis caregivers perceived online settings, due to COVID-19, as a limitation, however, some recognised that online delivery could facilitate attendance for caregivers who are unable to travel (Bourassa et al., 2021).

Communication, Connection, and Collaboration. Effective communication and relationships accompanying educational dementia resources were deemed important by Indigenous communities. Social interaction between community members was a facilitator for Aboriginal and Torres Strait Islander people, aiding attendance at education sessions and increasing motivation through social accountability (Mateo-Arriero et al., 2023). Stronger relationships between health services and communities were also viewed as necessary to improve dissemination and implementation of educational resources (Lindeman et al., 2012). Furthermore, studies demonstrated the importance of knowledge sharers' communication skills, with emphasis on awareness of the needs of Indigenous and older people. This primarily involved effective intercultural communication (Taylor et al., 2012; Webkamigad et al., 2020), particularly, understanding Indigenous history, Indigenous and Western cultural values and beliefs, and different perspectives on communication across Western and Indigenous cultures (Webkamigad et al., 2020). In addition, the use of relevant cross-cultural communication strategies was suggested, such as humour, nonverbal language, listening, and some use of Indigenous languages (Webkamigad et al., 2020). Lastly, one study raised the importance of sensitive communication skills. In a group of Aboriginal elderly women, the intervention brought about anxiety that they might get dementia (Taylor et al., 2012). Skilled facilitation and discussion before and after showing educational materials may play an important role in how the content is interpreted.

Discussion

The aim of this systematic review was to identify dementia communication interventions for Indigenous populations, describe their characteristics, and detail factors influencing their effectiveness. We found limited evidence overall, with no evaluations of interventions targeting communicative ability for Indigenous people with dementia or their communication partners or targeting the communication skills of healthcare providers working in Indigenous dementia contexts. Although not captured by the inclusion criteria for the current review, our search identified a number of additional studies that described Indigenous perspectives on the importance of relation and connection in the dementia context (Allick & Bogic, 2024), changes to communication within the family (Bensemann, 2023), communication strategies used by family members (Cox et al., 2019), and culturally relevant modes of communication for Indigenous people with dementia (Hämäläinen et al., 2021; Hanssen, 2011; Henderson & Henderson, 2002). Additionally, studies have discussed Indigenous perspectives on needs for effective communication from healthcare providers (Alcock, 2019; Blix & Munkejord, 2022; Townsend, 2011) and preferred sources of information about Alzheimer's disease, such as health professionals, brochures, or the internet (Boyd et al., 2022). These studies included American Indian and Alaska Native people, Aotearoa New Zealand Māori, Aboriginal Australians, Anishinaabe and Métis people in Canada, and Sámi in Norway. In addition to findings from the current study, intervention developments should consider perspectives on factors explored across a broad range of studies, relevant to Indigenous community members in local contexts. However, to our knowledge, interventions have not yet been developed to support the implementation of previous findings in practice. Evidence-based dementia care which accounts for culture forms a key principle of the global action plan on the public health response to dementia (WHO, 2017), highlighting a strong need for culturally relevant intervention studies.

Our search also identified recently developed resources which have not yet undergone evaluation and therefore did not meet inclusion criteria. These include communication cards for Aboriginal and Torres Strait Islander people living with dementia (Dementia Support, 2022), a mate wareware (dementia) app developed within a Māori worldview (Dudley et al., 2023), and the storybook developed by Browne et al. (2022) which has now been published in Hawaiian language (Hā Kūpuna, 2023). The development of these resources is promising, particularly with evidence of early collaboration with Indigenous community members (Dudley et al., 2023). However, the stage of development highlights a need for funding and resources to support evaluation and continual development.

Six intervention studies were identified in the current review, all of which evaluated dementia health communication. Findings suggest that this is an emerging area of research. Five studies were published from 2019 onwards and most involved a newly developed intervention. Interventions were tailored towards Indigenous peoples located in Canada, the United States, and Australia. Given the importance of dementia care interventions that are culturally and contextually sensitive (Browne et al., 2017), there is need for research that develops, implements, and evaluates tailored health communication interventions with various Indigenous communities. Evaluations in the included studies commonly lacked strength, with half interrupted by COVID-19 (Bourassa et al., 2021; Browne et al., 2022; Mateo-Arriero et al., 2023), making it difficult to reach definitive conclusions about the effectiveness of the interventions. Moreover, interventions were at varying stages of adaptation and targeted different aspects of dementia and thus were difficult to directly compare. Inclusion of Indigenous people in evaluations, however, was promising and is a necessary component of Indigenous community health promotion evaluations (Mikhailovich et al., 2007). Further research is needed to conduct high-quality evaluations with Indigenous community members and determine the effectiveness of tailored health communication interventions.

The need for ongoing work is clear, with preliminary evaluations describing perceived benefits of the resources and programmes as well as factors that were seen to influence their effectiveness. Culturally relevant dementia awareness initiatives play a central role in promoting health and quality of life for people with dementia, carers, and communities (WHO, 2017). Our findings support this, describing increased understanding of dementia and access to support from carers, community, and health services. To develop culturally relevant interventions, researchers utilised methods relevant to the local communities they collaborated with and underwent considerable community consultation. Prior research has found that community engagement with Indigenous peoples in dementia research increases contextual relevance (Kjerland et al., 2024). The depth of community consultation likely contributed to the general acceptability and perceived benefit of the interventions included in this review.

An important element of dementia health communication across cultural contexts is appropriateness to the environments and people it is intended for (Siette et al., 2023). Type of educational materials, Indigenous language use, and content varied across intervention studies. We found no single resource that clearly resulted in better outcomes or was more acceptable to community members. Common factors were perceived as contributing to the effectiveness of interventions for Indigenous peoples across Canada, the United States, and Australia. Firstly, the importance of resources and knowledge sharing methods appropriate and accessible to Indigenous communities was highlighted. Inclusion of Indigeneity in educational materials was strongly valued. The need for knowledge sharing to incorporate Indigenous beliefs, values, and languages has been previously reported by First Nations healthcare practitioners supporting community members with dementia (Forbes et al., 2013). It is also consistent with Indigenous health communication campaigns in other contexts, such as those designed to provide information about cancer in Canada and the United States (Boyd et al., 2021). Appropriate knowledge sharing also involves consideration of Indigenous beliefs about education and passing on information, including the value placed on family and intergenerational connectedness (Ullrich, 2019). In addition, information should be practically accessible, taking into account factors such as geographical location, environment (Mateo-Arriero et al., 2023;

Webkamigad et al., 2020), and motivation, with opportunities for social connection (Mateo-Arriero et al., 2023; Nash & Arora, 2021).

Furthermore, appropriate educational resources may be supported by collaboration and facilitation skills that enhance communication and connection. The development of relationships between healthcare practitioners and community members was described as a need and has been reported previously in descriptive research on knowledge sharing in First Nations dementia contexts (Forbes et al., 2013). In addition, studies suggest that healthcare practitioners should be equipped with intercultural and sensitive communication skills to accompany the delivery of educational materials. “Good talk” (Jennings et al., 2018, p. 109) has been described by Australian Aboriginal or Torres Strait Islander people as powerful and essential to Indigenous experiences of healthcare, playing a central role in developing relationships, trust, and engagement. Findings indicate that strong communication skills of healthcare providers may contribute to raising dementia awareness while Indigenous-specific dementia health communication interventions continue to be developed and evaluated.

Limitations

Due to the vast number of Indigenous populations across the world, we selected key search terms relating to populations where Indigenous dementia research has largely been conducted. An assumption was made that the term Indigen* would capture other Indigenous groups, however, this may have limited the potential to capture all Indigenous-focused studies. Additionally, we only reviewed records published in English. Studies on dementia communication interventions in Indigenous languages may not have been identified. Furthermore, our search terms did not directly target specific speech and language therapy interventions, such as script training. It is possible that specific approaches may not have been identified in our search. However, our use of broader search terms within abstracts, such as communicat*, speech, language, interven*, therap*, and program* would likely have captured most reports relating describing speech and language therapy intervention approaches.

Conclusion

Dementia communication interventions for Indigenous peoples is an emerging area of research requiring further development. Future studies are needed to support dementia awareness and enhance communication between people with dementia, their communication partners, and healthcare providers, with an absence of intervention research in the latter areas. Interventions have thus far targeted health communication and utilised a variety of educational materials including storybooks, videos, posters, flipcharts, fact sheets and handouts, and workshops. Methodological quality was promising with strong community relevance and room for improving intervention evaluations. Most interventions reported benefits to Indigenous communities. Common features may support future development of dementia health communication interventions including the incorporation of Indigenous people, languages, and worldviews in resources; Indigenous and community-centred knowledge sharing methods; intercultural and sensitive communication skills from knowledge sharers; and connection between community members and with health services. Indigenous people are vastly diverse across and within communities. Factors such as language use; concepts of dementia, health, and wellbeing; and ways of communicating information should be tailored to local community contexts. It is suggested that future research engages with Indigenous community members throughout all aspects of design, implementation, and evaluation to promote self-determination, respect for Indigenous cultures, and relevance of the interventions to community members.

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Supplemental Material

Supplemental material for this article is available online.

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Jeanette King is a Professor in Aotahi | School of Māori and Indigenous Studies at the University of Canterbury. She has substantial research experience in Māori language and languages spoken by Māori, particularly relating to linguistic change in the phrasal lexicon and language revitalisation. Jeanette's current work focuses on the protolexicon of Māori gained by adults in Aotearoa New Zealand through language exposure and the ways in which this may support language learning.

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