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Two Different Primary Care Approaches for Caring for People With Dementia and Their Families

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Two Different Primary Care Approaches for Caring for People With Dementia and Their Families

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A B S T R A C T

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This study explored an established primary care–based dementia pathway in New Zealand (NZ) and nurse practitioner dementia diagnosis and care in 1 small United States state that has adopted a value-based delivery model. Central to the NZ model was the education of primary care providers, clear delineation of specialists' support and referral pathways, and routine and predictable family carer respite. The US respondents reported that the essential resources necessary to support the diagnosis and management of dementia were lacking. The primary care of older adults may increasingly be provided by nurse practitioners in the US, and the structured NZ pathway offers a promising approach to adopt in the US. Potential strategies for implementation are detailed.

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Concerns are growing about the rapidly growing incidence of dementia, with a 3-fold increase predicted by 2050.¹ One strategy to ease individual distress and caregiver burden is to provide an early diagnosis to enable more effective management of this chronic condition.² Unfortunately, many older adults with dementia never undergo a thorough cognitive evaluation.³ Diagnosis by specialists in the United States is a common alternative to diagnosis by a primary care provider, but this approach may not be feasible as the prevalence increases. Additionally, the US primary care workforce has limited training in best practices for dementia care.^{4,5} The shift to value and cost accountability in the US system⁶ underscores the need for individuals to be diagnosed early and managed within the most cost-effective setting. Unlike the US specialist-centric system, other nations have created a robust primary care foundation with integrated dementia care.

One such approach is a standardized care pathway to support the primary care workforce tasked with dementia diagnosis and management. Exemplar pathways mobilize primary care for early diagnosis/management and also provide guidance on developing sustainable primary care/carer partnerships. This study explored one such example, the *New Zealand Framework for Dementia Care*.⁷ The New Zealand (NZ) model is standardized, nationally implemented, and primary care led. To better understand potential transferability to US nurses in primary care, the current practices of nurse practitioners (NPs) in the rural US state of Vermont were also explored. The rationale for selecting Vermont is that it has adopted a statewide, value-based, all-payer accountable care organization and thus has some parallels to nations like NZ that deliver care in a cost-cognizant environment.

US Approaches

The first US *National Plan to Address Alzheimer's Disease* was published by the US Department of Health and Human Services in 2012,⁸ but systematic implementation efforts remain scattered. A study of dementia care policies in dual-eligible Medicare and Medicaid beneficiaries in 7 states showed little consistency.⁹ The authors identified promising practices and advocated for adoption, but none on a national level. More recently, the National Institutes of Health posted a helpful guide entitled *Dementia Resources for Health Professionals: Assessing Cognitive Impairment in Older Patients*¹⁰ that advocates for early screening by a variety of health care professionals, particularly primary care providers. Finally, 1 study used care managers in collaboration with primary care physicians supported by memory clinic specialists; the authors caution that attention to the complexities and resource constraints of health care systems is needed for such models to be broadly adopted.¹¹

The NZ Model

In response to dramatic projected increases in the proportion of New Zealanders living with dementia¹² and carers' calls for recognition of their efforts,¹³ the NZ Ministry of Health promulgated the *New Zealand Framework for Dementia Care*.⁷ This was followed by the creation and dissemination of the HealthPathways Cognitive Impairment and Dementia, an electronic document that can be accessed by any clinician or staff in NZ's primary care system.¹⁴ This electronic document was the most frequently accessed pathway in NZ's HealthPathways collection, which guides primary

Table
Participant Demographics

Title	Sex	Profession	Experience	Setting
GP 1	Male	Medicine/general practitioner ^a	High	Primary care/rest home
GP 2	Female	Medicine/general practitioner ^a	Some	Primary care/rest home
GP 3	Female	Medicine/general practitioner ^a	Some	Primary care
GP 4	Male	Medicine/general practitioner ^a	High	Primary care/rest home
GP 5	Male	Medicine/general practitioner ^a	Moderate	Primary care/rest home
NP 1	Female	Nursing/FNP	High	Primary care
NP 2	Female	Nursing/ANP	Moderate	Primary care/nursing home call
NP 3	Female	Nursing/ANP	Moderate	Primary care/nursing home call
NP 4	Male	Nursing/FNP	Some	Primary care
NP 5	Female	Nursing/FNP	Some	Primary care
NP 6	Female	Nursing/FNP	Moderate	Primary care

ANP = advanced nurse practitioner; FNP = family nurse practitioner; GP = general practitioner; NP = nurse practitioner.

^a In New Zealand, 3 years of training in general practice after completing medical school. Experience: some, 1-10 years; moderate, 11-20 years; and high, >21 years.

care for a broad range of conditions (E. Froming, oral communication, February 28, 2019).

Purpose

This study sought to explore and describe the use of national dementia care guidelines by primary care providers in a selected region of NZ. To guide potential adoption in the US, dementia diagnosis and management experiences of primary care nurse NPs in Vermont were also explored.

Methods

After institutional review board approval (STUDY00000052), a qualitative descriptive design¹⁵ using semistructured interviews was used to explore providers' experiences of dementia care. The initial sampling strategy was typical case purposive sampling of NZ primary care providers (general practitioners [GPs]) followed by snowball sampling. Participants were interviewed for 20 to 60 minutes at their practices. The same process was used for the recruitment of 6 NPs who were located within 2 adjacent Vermont counties, 1 metropolitan statistical area and 1 non-metropolitan statistical area. Direct comparisons were not made; instead, we sought to describe the experiences of practitioners in both countries, considering the potential translation of NZ best practices to Vermont.

All interviews in both countries were audio recorded and transcribed verbatim. Data were gathered until there was data saturation. Transcriptions were assessed with qualitative content analysis, the preferred approach for analyzing studies with qualitative descriptive designs.¹⁵ Data were categorized into codes by 2 members of the research team. Next, themes were inductively developed by the full team, and then patterns were analyzed and integrated into a unified whole. Analysis was supported by HyperRESEARCH (ResearchWare, Inc., Randolph, MA) computer-assisted qualitative analysis software. Trustworthiness followed the orientation of Lincoln and Guba¹⁶ and was supported through multiple steps. Peer review and debriefing were used to further support confirmability and credibility.

Results

The Table lists the participants' demographics. The findings from NZ interviews informed the development of 3 themes: 1) national standards create a progressive pathway grounded in primary care and inclusive of early diagnosis, assessment of caregiving support, and adaptive teamwork; 2) care burden is eased, and optimal outcomes are possible with education, cultural sensitivity, and

family respite, but enhancement opportunities exist; and 3) adaptive teamwork enhances access to care at all levels and assures person-/family-centered care delivery.

NZ Participant Themes

National Standards Create a Progressive Pathway Grounded in Primary Care and Inclusive of Early Diagnosis, Assessment of Caregiving Support, and Adaptive Teamwork

Participants shared being comfortable doing routine cognitive screening in primary care settings as well as making the diagnosis and managing care. Routine testing included the Montreal Cognitive Assessment (MoCA), which was conducted by the GP or staff nurses. Participants noted the centrality of the history in tracking progression, as well as other potential physical contributors to memory impairment. Participants also described the utility of the InterRAI (resident assessment instrument) tool, which helped the teams make decisions about resource allocation for patient/family respite support.

"Then maybe ask them specific things like, have you done anything that was a bit dangerous like maybe forgetting about the stove or heaters, electrical things. Have you had any accidents, doors, keys locked out, locked in – all of those sorts of things. Try and get a handle on whether it's slightly normal forgetfulness versus what else might be going on" (GP 3).

"And also find out are there other potential causes of memory impairment – drugs, stress, depression, poor sleep – drugs and alcohol – all that kind of stuff" (GP 4).

Participants voiced confidence in the supports available for diagnosis and management, as well as timely backup specialty support from geriatricians and psychogeriatricians, as exemplified in the following statement:

"If you were very concerned about someone, you can phone up. The electronic referral seems to be for relatively routine, and you can put 'Urgent' on it if it's something that you'd like to deal with within the next week. But if things have gone to custard in anyway, then you just phone" (GP 3).

Primary care nurses play a key role and were described as the person with the greatest contact with the patient and family, including in the home. Nurses were described as follows:

". . . up to an hour appointments with our nurses to do something called 'the year of care' so they look at all the goals initially and their [patient or family] health literacy and where the

patients are at in terms of their knowledge, and the family's knowledge. . ." (GP2).

"... one of the nurses visits there [rest home] every fortnight just to really keep an eye on things and reassess" (GP 2).

One nagging area of challenge was voiced—the cognitive test at age 75 that is mandatory for driver's license renewal as exemplified by the following participant:

"And I think that is a huge – that's a big challenge, and it can often be a barrier for them to want to do [come to the clinic], to engage, because they're feeling like the doctor is going to take my license away or going to remove what independence I have. And so for them, it's really, really scary, it's very threatening" (GP 5).

Finally, participants noted that finances and access are not barriers as they can be in the US, as illustrated by the following comment:

"But more importantly, if you're old and frail, there's no arguing with the insurance company or with Medicaid/Medicare, insurance that you have – we are somewhat more fortunate" (GP 4).

The Burden of Care Is Eased by Education, Cultural Sensitivity, and Financial Support of Respite, but Enhancement Opportunities Exist

Participants noted the available decision supports, yet also voiced appreciation of additional education and updates via websites and workshops. This enabled the confident provision of dementia care from a primary care base. Nevertheless, family culture and ongoing challenges fighting disease stigma were described. Participants noted that the NZ culture emphasizes self-sufficiency, and much work had been done to help people understand that needing and accepting help is not a failure. This challenge differentially impacts Pasifika families and the Māori, who hold a strong sense of duty to care for family.

"... Pasifika families, Māori families are under a lot of pressure and suffer because they have this strong sense of duty. I think we need to educate them to understand that actually it's an honorable thing, it's a good thing for them to release mom or dad to the care of professionals, to go into a home care setting when it's appropriate and right for them without causing them strain, but without them feeling guilty about that as well. Because I think there's that sense of guilt – I'm giving up too soon, mom has looked after me all these years and I feel I want to give back. And so yeah, education support, helping them through that process to understand" (GP 5).

Although underscored in Pasifika and Māori families, this sentiment was widespread. Respondents noted a "sense of defeat" as a reason NZ spouses might resist help. Team-based care, inclusive of respite for families, was thus a key approach named by the GPs.

"... the team will be the assistors to respite care, which is available for the carers, like 21 days a year respite care with local rest homes . . . and/or these day care things, and/or help in the home" (GP 1).

Such support was viewed as central to assuring care in the setting of choice—the home. Teams were described as flexible and able to adapt to whatever demands emerged rather than being tightly role bound, forming the third and final theme.

Adaptive Teamwork Enhances Access to Care at All Levels and Ensures Person

The family was clearly viewed as the hub of care but within a supportive, integrated team. Licensed roles included GPs, registered nurses, NPs, social workers, occupational and physical therapists, geriatricians, and psychogeriatricians. Primary care extended to cover the homebound and those in rest homes. Other levels of care included dementia care units, which are reserved for those who can no longer be managed at home or in a rest home.

"... because I'm a practitioner who is also going to a rest home, I have a relationship with the rest home [staff] and sometimes it works out well that they [patients] can even go to that rest home and I continue to be their GP" (GP 1).

The [Figure](#) illustrates the NZ pathway for dementia care as informed by these interviews. It depicts the support of the "whānua" (extended NZ family) by an interprofessional, primary care–led team guided by the NZ Ministry of Health pathway guidelines. The model starts with governmental intention and financial support (including essentials of education and cultural sensitivity), encourages early diagnosis, provides respite support for families, and fosters continued disease management and planning for appropriate care settings including end-of-life and palliative care.

US Participant Themes

The tone of US participants and the content of their responses dramatically differed from those of NZ participants. The themes were as follows: 1) a reactive rather than a proactive approach leads to a difficult and painful diagnosis for the individual, family, and provider; 2) paradoxical perceptions of specialty care are present; and 3) an evolving appreciation of interprofessional teams is impeded by time and limited resources.

A Reactive Approach Rather Than a Proactive Approach Leads to a Difficult and Painful Diagnosis for the Individual, Family, and Providers

Some participants voiced hesitancy with initiating the screening and making the diagnosis.

"I'm actually hesitant to start doing MoCA tests because they tend to scare people. And everyone knows immediately you're looking for dementia. But then the question that really becomes blatantly obvious is negatively impacting functioning, to say okay, I think there's a problem here, what do we do about it?" (NP 5).

"Sometimes a patient might come in for a Medicare Wellness, and you screen them, and there's all these positive screens that need to be dealt with" (NP 3).

"If I have a suspicion that something's going on, I'll start with the Mini-Mental Status exam in the office" (NP 2).

"When I'm pretty sure somebody has memory impairment, then I will do a panel of labs and cranial imaging and then I meet with them after that, depending on what the individual wants to do" (NP 6).

"It's a very painful process for patients and families, and they really want a definitive diagnosis. They want somebody to say without a doubt, this is what this is, and this is where it's going" (NP 4).

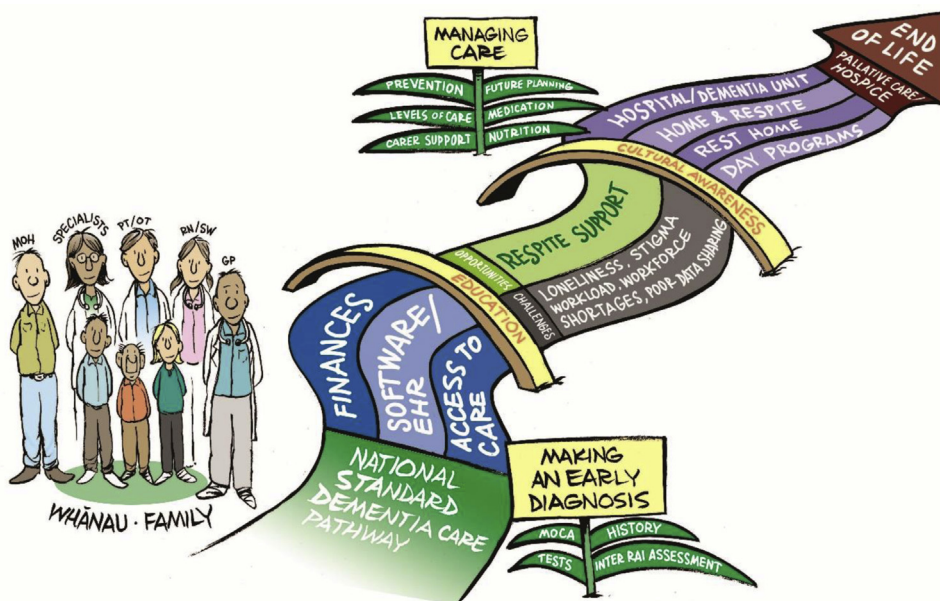


Figure. An illustration of the New Zealand Pathway for Dementia Care. MOH = Ministry of Health (NZ); OT = occupational therapist; PT = physical therapist; RAI = resident assessment instrument; RN = registered nurse; SW = social worker. Specialists include geriatrician, psychogeriatrician, and neurologist. Whānau is the Māori word for extended family in NZ.

Yet, despite this desire, there was reluctance to receive a diagnosis by some individuals/families, and there was a lack of access to the specialty clinicians who make diagnoses. Access barriers include time to appointment, geography, and family ambivalence, which together comprise the next theme.

Paradoxical Perceptions of Specialty Care Are Present

Referral to a specialty clinic to confirm a diagnosis was offered; however, barriers and ambivalence by family and NP were voiced.

“Some people clearly decide not to, and others are ready to go” (NP 6).

“The wait to get in there could be pretty long, sometimes 4 or 5, 6 months” (NP2).

“It’s going to be a 100-, 130-mile round trip to go to The Memory Care Center, and for some of these people, that’s almost impossible if they have family members who are assisting that are also working full-time” (NP 4).

“They want somebody to say without a doubt, this is what this is, and this is where it’s going. And so the Memory Care Center from that standpoint becomes pretty vital for patients and families” (NP 4).

An Evolving Appreciation of Interprofessional Teams Is Impeded by Limited Time and Resources

The NPs acknowledged valuable, even indispensable, support from a broad array of providers and organizations including designated mental health agencies, pharmacists, psychiatrists, physical therapy, social workers, community aging organizations, office staff, and care coordinators. Still, the system’s fragility was clearly acknowledged.

“We don’t have enough government-sponsored help in the area for respite care for families. I think of like a spider web of some support but it’s relatively tenuous and you can’t always get it when you need it, when someone needs it” (NP4).

Finally, the time and resources burden was consistently voiced.

“It’s a relatively small population, but it consumes and needs a lot of time, more so than the rest of the patients. It’s one of those 5% take 95% of the effort and coordination” (NP5).

Discussion

The financing and accountability model of NZ’s health care differs dramatically from that in the US. One aim of this work was to address potential transferability to US NP-led care. GP physicians and NPs were interviewed in NZ and the US, respectively, but direct comparisons between the nations were not intended or even possible. Nevertheless, over 70% of long-term care is publicly funded in the US,¹⁷ and coronavirus disease 2019 is predicted to accelerate the transition to value-based care, given the dramatic failures revealed during the pandemic.¹⁸ Thus, contrasts between the 2 groups suggest that the US can learn many lessons from a nation with a systematic, comprehensive pathway for dementia care grounded in primary care regardless of differences in overall financing methods. Providers in VT are now adopting elements of this approach aided by the use of electronic *smartphrase* prompts for comprehensive diagnosis and initial treatment supports (Box). The *smartphrase* approach may be useful for other primary care providers grappling with dementia care.

This study suggests that NZ’s care delivery redesign has created an environment in which primary care providers feel comfortable leading the early diagnosis of dementia. Moreover, participants’ recognition of the support of interprofessional teams and easy access to specialists suggest that these providers do not feel isolated when dealing with this challenging diagnosis. The contribution of primary care nurses was also evident because they work to the full scope of their license, conduct cognitive testing, and direct care management. The role of family carers in NZ was clearly the “hub” of care for a person with dementia. This confirmed previous findings on the criticality of educating and supporting carers to facilitate loved ones’ ability to age in place, preferably at home.¹⁹ NZ

Box**Use of a “Smartphrase” to Assist Documenting Dementia Diagnoses**

A dementia workup should be initiated by a nurse practitioner following a failed cognitive screen during the Medicare Annual Wellness Visit or complaints of memory loss from patient or family. An example of the contents of a “smartphrase” that can be used to guide dementia diagnosis note in an electronic medical record can be found at <http://go.uvm.edu/dementiasmartphraseInstructions> for its use can be found at <https://streaming.uvm.edu/media/private/videos/IS8Qgaf/>

providers also were monitoring or connected to the “rest home,” suggesting a level of comfort across the care continuum not evident among the US participants. Bundled payments, accountable care organizations, and a global budget model would benefit from NPs who can deploy this unique skill set.

Cultural awareness and respect were identified as necessary underpinnings of dementia care in NZ. Some NZ participants voiced challenges providing early intervention and ongoing support because of cultural expectations of self-care, particularly among Māori and Pasifika populations who deem outside help as a failure. The value of ongoing relationships with a health care team to destigmatize the acceptance of help was suggested as a valuable corrective strategy. Ongoing work is needed to address disparities and monitor racism as a health determinant.²⁰

Conversely, these US NPs reported hesitancy providing a dementia diagnosis, disconnection from the specialist, uncertainty in management, and inconsistent resources. They reported that the diagnosis is often known, albeit provided in a reactive rather than a proactive manner. Referral to specialty care, even when the diagnosis was known, was a common intervention, yet challenges such as travel times, waitlists for appointments, and individual/family willingness to go complicate an already difficult situation. The use of interprofessional teams including social workers, case managers, physical therapists, pharmacists, office staff, and specialists such as psychiatrics and neurologists were acknowledged as helpful in dementia care, but respondents acknowledged that these were pieced together rather than routinely and systematically available. Finally, participants noted that organizations that specialize in caring for older adults were relied on. Nevertheless, frustration with the fragile “spiderweb” of support was voiced, with services deemed insufficient or inconsistent.

Implications for Practice and Conclusions

The Alzheimer’s Association study of US primary care physicians noted similar findings.⁵ Half of the physicians in that study indicated that the medical profession is not prepared to meet the expected increase in demands in dementia diagnosis and care management. The study also found that 82% of primary care physicians reported not being confident in their care for people with Alzheimer disease and other dementias. The numbers of primary care physicians continue to shrink in the study setting, yet, at the same time, NPs in primary care have grown,²¹ a circumstance that is occurring across the US.²² Readily available “pathways” for dementia care as shown in the **Box** could be helpful in guiding diagnosis, managing care, and proactively connecting families to services that are important for persons with dementia and their carers.

In the NZ study setting, education of the primary care workforce was prioritized. The fact that the HealthPathway for Cognitive

Impairment and Dementia¹³ is more used than all other HealthPathways available to providers is a strong example of adoption and was confirmed by the knowledge of this resource in our GP sample. Unlike in the US, NZ GPs are required to evaluate people over 75 years of age to assess their ability to drive. Although likely to be unpopular in the US, evaluation of the need on a state-by-state basis may be valuable, given that the number of older drivers with dementia will continue to increase. Finally, the response to coronavirus disease 2019 at both state and federal levels dissolved long-standing, unnecessary barriers to telehealth and virtual care, and these tools can enhance the implementation of this model in the US by promoting communication among NPs, specialists, carers, and carer community-based support groups.

This qualitative descriptive study was limited in scope because it was set in only 2 areas of NZ and 1 US state. The 2 systems have differing funding mechanisms, cultures, provider types, and existing community services and supports. Furthermore, systematic evaluation of the *New Zealand Framework for Dementia Care* is necessary to determine short- and long-term cost-effectiveness, value, and impact on the quality of life for people and their families who live with dementia. However, transferable lessons abound, and a national, state-by-state, or organizational strategy of dementia care rooted in primary care and led by NPs offers an attractive avenue for the US, especially given the shrinking pool of primary care providers and the suitability of nurses for this care. As 1 NZ GP respondent noted, “Dementia care is nursing care.” US NPs are well suited to lead a transformation in dementia care. The new system should focus on the holistic needs of patient and family and be complemented by medical diagnosis, care management, and interventions within a tapestry of community connection and support. Education, proactivity, technology, and cultural awareness can enable NPs to lead interprofessional teams and provide access to quality care for individuals with dementia and their families.

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