We are a Bridge: Using Stakeholder Engagement to Bridge Gaps between Dementia Support Services and Elders on Martha's Vineyard

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Introduction

Massachusetts has consistently been a national leader in the care of elders[i] by necessity of its growing aging population. But as the baby boomers[ii] continue to live longer, they are expected to make up 25 percent of the population in less than 2 decades. Increasing life expectancies of MA elders, currently estimated at 80.7 years (sixth highest in the nation), make the 85+ population the fastest-growing cohort in MA, projected to reach ~200,000 by 2030. Researchers have labeled this exponential growth phenomenon "the silver tsunami," implying an inevitable, rapid overtaking of space and resources by the abundance of chronic disease that elders live with. In light of this impending public health crisis it has become increasingly necessary for Massachusetts communities to examine the burden of elders afflicted with dementia, the fifth leading cause of death and debilitation of people over 65 in the nation.[1]

Dementia is a syndrome characterized by a group of symptoms, including difficulties with memory, language, problem solving and cognition that impair one's ability to perform every day activities.[2] It touches the lives of those 65 and older. Based on the Aging, Demographic, and Memory Study (ADAMS), 14 percent of people aged 71 and older have dementia. Furthermore, it is predicted that 10 to 20 percent of people over 65 have Mild Cognitive Impairment, which is likely to precede a diagnosis of dementia by three to four years. In Massachusetts specifically, the 2015 Healthy Aging Data Report found that the statewide dementia rate for adults aged 65 and older is 14 percent, with the rate in some communities exceeding 20 percent. However, it is important to emphasize that prevalence rates might be even twice as high as originally predicted, because less than half of individuals who meet diagnostic criteria are actually diagnosed by a physician. In fact, less than half of those who are diagnosed are even aware that they have it.[3]

Although dementia is a syndrome, it is caused by a variety of discrete diseases. Alzheimer's Disease (AD), the most common type of dementia-causing illness, is a fatal, degenerative disease of the brain that accounts for 60 to 80 percent of incidence. Other types of dementia account for at least 1 million additional cases nationwide.[4] Other types of dementia include vascular dementia, Lewy body dementia, mixed dementia, and frontotemporal dementia. AD has been extensively studied due to its characteristic progression, pathology, and prevalence. Based on a study by Hebert et al, it is anticipated that 8.4 million Americans over 65 will have AD by 2030, and 13.8 million by 2050. Also it is predicted that by 2050, 7 million people over 85 (an increase from the current 2.1 million) will have AD, accounting for 51 percent of elders over 65 with dementia. In a study conducted by Weuve et al, Massachusetts alone is expected to have a 25 percent increase in AD prevalence from 2017 (120,000) to 2025 (150,000). Recent data show that in 2014 the mortality rate of Alzheimer's disease in Massachusetts was 25 per 100.[5]

Even before this compelling data came to light, the MA Executive Office of Elder Affairs (EOEA) was aware of the fast-approaching wave. In 2012 they developed an Aging Agenda "to attain and sustain the best possible physical, cognitive, and mental health" for MA elders. Key strategies include improving access to services for Alzheimer's and dementia issues. Additionally, the EOEA received a 2-

[i] Defined for our purposes as someone age 65 and over
[ii] Referring to those born between 1946 and 1964

year grant for the Alzheimer's Disease Supportive Services Program (ADSSP) to meet 4 goals. These goals included increasing cognitive screening in the home, decreasing caregiver burnout, improving access to diagnostics and treatment, and increasing availability and utilization of services. The MA Alzheimer's Disease and related Disorders State Plan also illustrated strategic plans for targeting populations struggling with dementia. This collaboration with the EOEA and the Alzheimer's Association suggested the formation of an Alzheimer's Early Detection Alliance that implemented quarterly home care screens using detection tools such as the Mini Cog.[6, 7, iii] And while this state-wide agenda provided well-informed recommendations, individual towns have since gotten to work on their own homegrown solutions.

Martha's Vineyard is a vibrant, rural island off the southeast coast of Massachusetts' Cape Cod that is particularly vulnerable to the surging wave of elders with dementia. The rapidly growing elderly population coupled with resource restrictions secondary to geographic isolation has called for a detailed analysis of elder demographics. In an unpublished study by the UMass Medical School Rural Scholars and the Donahue Institute in 2013, it was found that 32 percent of the year-round islanders will be over 65 by 2030 (about 6250 people), doubling from 16 percent in 2013. By applying the MA prevalence rates of dementia to this population, it can be estimated that about 1,000 islanders will be expected to be living with dementia by 2030[8]. It is noteworthy that this number could be twice as large, due to the aforementioned disparity in diagnostics. In light of this, the Vineyard has responded with an eagerness to "roll up shirt sleeves" and develop committees, non-profit organizations, and a variety of grassroots efforts supporting their elders as they navigate the treacherous waters of dementia. Organizations like Healthy Aging Martha's Vineyard (HAMV), the Martha's Vineyard Center for Living (MVC4L) and Martha's Vineyard Community Services (MVCS) have worked with the community to develop their own aging agendas that reflect the unique circumstances of elders living on the island.

While the Martha's Vineyard's community has put forth commendable efforts to assist elders struggling with dementia, the MVC4L employed a medical student to perform an environmental scan surveying the current state of dementia care. She looked to identify problems, previous services, and gaps in those services, as well as to make recommendations to bridge those gaps. The research question became: What are the current and projected gaps in needed dementia services among elders living on Martha's Vineyard?

Methods

MVC4L staff engaged 30 individuals to participate in interviews regarding the current state of dementia care. Participants were recruited via convenience sampling. Inclusion criteria were defined as any individual with a personal investment or experience with dementia care who either lived or worked on Martha's Vineyard. Exclusion criteria included individuals who did not live or work on Martha's Vineyard and did not have investment in or experience with dementia care.

The student investigator could interview participants individually or in groups in both public and private settings. Additionally, the student investigator conducted one focus group. In both environments, the student investigator contracted for confidentiality and verbal consent was obtained.

Participants were interviewed with a simple questionnaire guide to inspire conversation, but not to restrict discussion. Focus group participants were provided questions in the interview guide as discussion points. Participants were encouraged to depart from the guide. The guide contained the following questions:

[iii] The Mini Cog is a screening tool for cognitive impairment developed by Dr. Soo Borson, involving the patient performing 3-word recall and drawing a clock face depicting a certain time. Clinical trials have demonstrated its usefulness in primary care, community, and other clinical settings.

1. What is the state of dementia care on Martha's Vineyard today?
2. What are the resources available for a person living with dementia on Martha's Vineyard?
3. What are the resources that are missing on the island?
4. What are the gaps between the resources and the needs of the community in this regard?
5. How should these unmet needs be addressed?

Interviews were to be captured through audio recording and note taking by the student investigator. One of the MVC4L staff was a scribe during the focus group, capturing data in real time. All interviews were de-identified and then analyzed using a qualitative content analytic approach, defined as a "research method for subjective interpretation of the content of the text data through the systemic classification process of coding and identifying themes or patterns."[9] Due to the paucity of data and literature regarding specific observations of gaps in dementia care in rural communities, the inductive approach was used. This is theme-generating method that sorts content into themes and subthemes, developing the inductive categories from the material.[10]

Results

The student investigator obtained information from all 30 participants. Participants were organized into 13 categories, including gender. Certain participants could be placed into more than one category, illustrated in Table 1. One focus group was held at the Tisbury Council on Aging with 4 family caregivers and one private duty CNA participating.

Table 1. Categories of Participants

Category	**#**	**Category**	**#**
Nurse (RN)	9	Caregiver	5
COA Employee	2	Community Program Admin	3
Physician	4	Local Gov't Committee	2
Law Enforcement	1	Hospital Administrator	2
MVC4L Employee	2	Windemere Employee	6
VA	1	Private Duty CNA	1
Dept. of Public Health	1	Hospice	1

Female	**Male**
25	5

Interviews lasted from 14 to 80 minutes, as determined by the participants. The focus group lasted for 90 minutes. Narratives collected from interviews and the focus group were sorted into four categories: Perceived Problem, Previous Services (implemented to address problem), Gaps in these Services, and Recommendations to Bridge Gaps. The topics discussed in interviews were divided into six major themes: Medical Care Providers; Caregiver Support; Facilities and Space; Community Engagement; Elder Engagement; and Professional Programs. Each theme was broken into identified problems in dementia care on Martha's Vineyard. The problem list amounted to 25 total. These are illustrated in Table 2.

Table 2. Major Themes and Problems

Theme	Perceived Problem
Medical Care Providers	
	Hospital Readmissions have Poor Follow/Up
	Untimely Hospice Referrals/Evaluations
	No On-Island Neurologist
	Few Geriatric PCP/Hospitalists/Psychiatrists
	No On-Island In-Patient Geri Psych Unit
Caregiver Support	
	Insufficient Home Care
	Expensive Home Care
	Caregiver Burnout
	Non-Medical Assistance Lacking
	Reluctance to Seek Help/Relocate
	Insufficient Bereavement Services
Facilities and Space	
	Insufficient SNF/AL Facilities
	No Certified Dementia Unit
	Insufficient SNF Nurses
	Housing/Land Crisis
	Insufficient Elder Housing
Community Engagement	
	Lack of Laypeople Education
	Community Stigma
Elder Engagement	
	Insufficient Elder Transport
	No Community Activities with ADL/IADL Assistance (Adult Day Health)
	Elders Lose Motivation to Maintain Function
	Elders Isolated
Professional Programs	
	No Centralized Directory of Resources
	Lack of Early Intervention
	Lack of Coordination and Delineation

For each of the 25 problems, participants listed previous services that addressed that problem. Participants identified gaps in these services, as well as generated recommendations to bridge those gaps and address the corresponding problems. Recommendations generated by participants were distilled into descriptions listed in Table 3. Recommendations mentioned in regard to one problem that were applicable to multiple problems were listed in the table as such per the investigator's discretion. Most commonly mentioned recommendations are listed in bold.

Regarding the Medical Care Provider theme, a frequently identified gap was dissatisfaction with PCPs regarding hospice referral frequency, psychiatric medication management, accuracy of initial dementia diagnosis, and frequency of interval visits. Recommendations for these issues included

increased Telemedicine for training PCPs in neuropsychiatric care for patients with dementia, as well as recruitment of more PCPs, or supplementation of physician PCPs with psychiatric NPs.

Regarding the Caregiver Support theme, it was suggested often that more CNAs and volunteers are needed to offset the caregiver burden and provide respite. While on-island programs embedded within MVH have increased the recruitment and training of CNAs and volunteers, challenges remain. These included the small prospective employee pool due. Allegedly, the lack of interest is to the difficulty of CNA work with elders with dementia, as well as the insufficient compensation for that work, given the high cost of living on Martha's Vineyard. This results in the pool of private duty CNAs collectively setting the cost as $25-$35 per hour, which is prohibitive for many families needing 24-hour care. Therefore it was suggested that wider utilization of nursing cost offsetting measures was needed. One example of this was wider advertisement of income supplementation programs provided by Elder Services, including the Frail Elder Waiver and CHOICES. Frail Elder Waiver was reported infamous for its strict criteria, but participants were aware of few subsidization programs outside of this. Another suggestion was an "au pair model" for caregiving. For example, if private duty CNAs could live in the patient's home, that could subsidize their hourly rate, as well as address the housing challenges experienced by professional caregivers of lower income. In addition, it was recommended that the volunteer force be bolstered and receive more dementia specific training with mandatory clinical hours through the MVC4L to be another source of respite for caregivers.

Regarding the Facilities and Space theme, it was suggested that the housing crisis appears inextricably linked with the paucity of nursing facilities and staff available to care for elders with dementia. It was repeatedly voiced that there is a need for graduated facilities of care including a rest home, assisted living, skilled nursing, and hospice on the same campus. Others suggested that such a graduated campus would be most effective as a Green House model, defined as a branded design of long-term care focused on individual empowerment and maximization of quality of life.[11] The current model of long-term care available on-island has been limited to rest homes[iv] and skilled nursing facilities[v]. Recommendations for addressing this problem included finding available land to build a graduated care Green House. One could obtain this land by removing land from the land bank, regionalizing town facilities (libraries, police stations, fire stations) to make land more available, or buying a pre-existing building to remodel. In the meantime, to bolster the nursing workforce that would staff the Green House, it was suggested that more subsidized housing was needed. This could take the form of "tiny houses"[vi], made available especially for CNAs willing to train and work on-island. Yet ultimately, it was felt that the way to achieve fair and livable wages and ratios is to lobby and promote political activism.

In terms of Community Engagement, it was suggested that community stigma and lack of education decreased the effectiveness of integration of elders with dementia into the community. Individuals repeatedly mentioned that Martha's Vineyard had attempted to adopt the Iowa University Gatekeeper Program[12] for creating a dementia-friendly community. However, due to lack of funding and inadequate program customization to the issues specific to the Vineyard, this program was discontinued. A salient opinion of several participants was that either the reinvigoration of Gatekeepers or implementation of a similar, customized program was needed. Such a program could be Safe Seniors, a homegrown how-to guide for dementia-friendly community education. Planning for this initiative was a collaborative effort of the Councils on Aging and HAMV, and is already in the process of being implemented via a grant from the Permanent Endowment awarded to MVC4L. Other

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[iv] On-island rest homes include: Windemere Unit 2 (recently closed), Henrietta Brewer House, and Long Hill (also scheduled to close).

[v] The only on-island federally qualified skilled nursing facility is Windemere, part of MVH

[vi] A "tiny house" is less than 400 sq. feet, and part of a greater social movement in the US for simpler living.

less formal ways to bring dementia into the public eye include holding Dementia Health Fairs at a centralized location such as Martha's Vineyard Hospital (MVH), conducting dementia-themed seminars at local libraries or cafes, or even writing a weekly advice column in the MV Times answering questions about caring for elders with dementia.

Regarding Elder Engagement, several individuals mentioned that current models of engagement, such as the COAs or MVC4L, only exist in communal settings. This results in elders who prefer solitude, have extensive medical needs, or lack the IADLs necessary for easy travel, becoming isolated from vital services. As a result, it was suggested that programs responsible for elder outreach develop mechanisms for home visits. For example, the COAs, which hold group exercise programs, could bring chair exercises to an individual's home on a weekly basis. Alternatively, MVC4L staff could visit an elder's home for controlled socialization and enrichment by bringing activities that normally occur during the day program. Another suggested solution to this problem was broadening the capacity of the day program to support those with increased medical needs by adopting a medical model. Barriers to this include adoption of extensive regulations, as well as fiscal complexity with regard to third party payers. To bypass this it was recommended that licensed clinicians be integrated, to mitigate a broader range of functioning among elders. Another frequently mentioned challenge was transport, implying that the current mechanisms in place for transporting elders to programs outside of their home were insufficient. It was suggested that caregivers should be further educated on a Consumer Directed Care stipend through Elder services that can allow a caregiver to hire a driver to transport individuals to their activities.

Finally, regarding the Professional Programs theme, a gap frequently mentioned was a perceived lack of coordination and delineation among preexisting programs. It was identified that Martha's Vineyard, a community that contains well-educated people passionate about public health, has a tendency to create numerous initiatives committed to addressing multiple facets of dementia care and healthy aging at large. Although the differences in these facets are apparent to those on the inside, the perception of caregivers and loved ones trying to navigate the system is uncoordinated services and interference, resulting in feelings of frustration, animosity, and helplessness. The Councils on Aging were enacted via enabling state legislation, but have to coexist with Healthy Aging Martha's Vineyard enacted by the Dukes County Health Council. These organizations exist in a parallel governmental structure but share territory regarding dementia care, resulting in overlapping and occasionally conflicting initiatives. Participants frequently complained about the inconsistency of referrals from different agencies, particularly difficulty navigating the maze of phone numbers leading to dead ends at answering machines and waitlists. While almost every subject had at least one positive experience, universally participants expressed frustration with almost every on-island organization with a mission to ameliorate dementia care burdens. Overall, participants urged that these diverse organizations put forth efforts to better communicate, delineate, or combine their missions as appropriate, and streamline and unify the referral processes, as well as clean up user interfaces.

These suggestions dovetail an additional problem: the short life cycle of programs and their subsequent resurrections. An example of this includes First Stop and the Caregiver Manual, each created about a decade apart from each other to meet the need for a centralized resource directory. Safe Seniors, similarly, is the second iteration of Gatekeepers, programs focused toward building dementia-friendly communities. It was proposed that the cause of this cyclical pattern is that these programs are grant-funded for a limited amount of time, and when the grant period ends the program dissolves. Then, after several years had passed, the community would re-identify the same problem, and a renewed initiative would implement a solution similar to the old, beginning the process of applying for grant funding again. This results in the recycling of similar programs, which impedes the ability to achieve a long-term, sustained goal. It was suggested that task forces, committees, and subcommittees with similar missions should collaborate in terms of funding, without competing with each other, and thus be able to sustain their missions with long-term financial support.

The complete table of subject-generated themes, perceived problems, previous services, gaps in services, and recommendations can be found in Table 3 below. Of particular note is that 12 recommendations identified by participants addressed gaps within several themes. These recommendations were considered to be higher impact due to their cross-sectional relevance and are listed in Table 4.

Table 3. Perceived Problems, Solutions, Gaps, Recommendations

Theme	Perceived Problem	Previous Services	Gaps in Previous Services	Recommendation to Bridge Gap
Medical Care Providers				
	Hospital Readmissions have Poor Follow-Up	Horizons GCM[7], Discharge Planners, Public Health Nurse	Private pay care management challenging, too few discharge planners/public health nurses to follow-up frequently, lack of dementia ED[8] protocol, legal limits of Elder Protective Services to remove/relocate elders	Increase HR recruitment of Elder Services for VNA[9]/CM[10]/SW[11] for follow-up, Dementia Training (Safe Seniors) for MVH[12] ED to develop protocol, **re-utilize public health nurses**
	Untimely Hospice Referrals/Evaluations	Hospice MV, Hope Hospice	PCPs[13] have difficulty determining <6 mos prognosis of patients with dementia in absence of concurrent medical problem	Increase hospice referrals via education of diagnosticians about Medicare Hospice Benefit, increase force of hospice nurses relieving patient burden in SNFs[14]
	No On-Island Neurologist	Referrals to off-island neurologists (Cape Cod Hospital), on-island psychiatrists voluntarily bolster neuropsychiatry knowledge base	Traveling off-island challenging/expensive, need more on-island neuropsych specialists to manage individuals with concurrent dementia + behavioral symptoms	Volunteer Neurology Clinic for follow-up after initial off-island evaluation, increase **neurology Telemedicine** for psychiatrists and PCPs.
	Few Geriatric PCPs/Hospitalists/ Psychiatrists	On-Island Geriatricians (<5), VA[15] Primary Care, Windemere Nurses (dementia trained), Medicare-accepting Psychiatrist	PCPs not well-compensated by Medicare therefore few, PCP/VA/Psychiatrist waitlists long, dementia challenging to diagnose and treat with infrequent outpatient visits, VA no longer doing home visits, hospitalists have difficulty communicating with dementia patients	Increase MVH recruitment of **psychiatric NPs/MDs** for psych prevention and med management, increase **home visits by NP/RNs** for dementia/safety screening, increase **neurology Telemedicine** for PCPs, Gerontology training for hospitalists, create **Dementia Wellness CAM[16] Clinic** for multimodal treatment at specific time/location

[7] Geriatric Care Management
[8] Emergency Department
[9] Visiting Nurses Association
[10] Case Managers
[11] Social Workers

	No On-Island In-Patient Geri Psych Unit	Windemere manages behaviors until referral needs to be made off-island to BIDMC[17]/St. Anne's in-patient geripsych	Windemere lacks 1-on-1, cannot keep patients with behaviors separate from other patients, not enough psychiatrists who take MA Health for prevention, PCPs overwhelmed by behavioral meds	Increase MVH recruitment of **psychiatric NPs/MDs** for psych prevention and med management, off-island van to transport pt + families to in-patient geripsych, build **dementia group home** on-island for crisis management (see Insufficient SNF/AL[18] Facilities)
Caregiver Support				
	Insufficient Home Care	CNA[19] training programs at local high school/Fitchburg State/Coastal Career Academy, acute care hospice nurses more available, Caregiver Homes stipend, previous Supportive Home Care Aid Program, MVC4L[20]	Not enough manpower from Home Care Agencies, Windemere cannot meet student:teacher ratio, expensive to have off-island students travel, CNAs salary similar to minimum wage (see Insufficient SNF Nurses)	Increase HR recruitment of CNAs for On-Island CNA/HHA[21] Certification program, reinvigorate Supportive Homecare Aid, investigate Seven Hills/United CP model of care recruitment, build **dementia group home** to offset nursing cost, **subsidized CNA housing/"au pair" model**
	Expensive Home Care	Elder Services Subsidies (Frail Elder Waiver/CHOICES Program/Income Based), Home Care Agencies, MVC4L	Elders "not frail enough" for Waiver eligibility, private duty too expensive, hospice donations cannot cover private duty cost	Increase MA Health Eligibility counseling, **subsidized CNA housing/"au pair" model,** wider advertisement of Elder Services Subsidies
	Caregiver Burnout	Caregiver Support Group/Hospice Support Group, Memory Café, MVC4L Day Program,	Lack of professional caregiver support (HHAs), VNA burnout due to documentation	Volunteer Respite Group + Caregiver Retreat, Overnight Respite, **Dementia Volunteer Training** with clinical requirement at MVC4L, Caregiver Education Workshop for combatting burnout, Professional Caregiver Support Group
	Non-Medical Assistance Lacking	Vineyard Village, Hospice volunteers, MVC4L	Volunteers apprehensive with managing difficult behaviors, MVC4L lacks 1-on-1 care for elders with behavioral issues (FTD).	**Dementia Volunteer Training** with clinical requirement at MVC4L, Supportive Homecare Aid Certification at MVC4L
	Reluctance to Seek Help/Relocate	Windemere, Elder Protection Hotline, intervention by adult children of elders	Misconceptions of Windemere regarding readmission/wait list/future plans, elder cognitive decline associated with relocation, legal protection of elders living in squalor if they so choose	Windemere Caregiver Education about Misconceptions and increased transparency (see Community Stigma), **Dementia Health Fair** at MVH with seminars
	Insufficient Bereavement Services	Hospice MV Center for Grief and Loss, Hope Hospice of the Cape and Islands	Program too robust to continue being supported by hospice resources	Dementia-Specific Bereavement Group at MVC4L

[17] Beth Israel Deaconess Medical Center
[18] Assisted Living
[19] Certified Nursing Assistant
[20] Martha's Vineyard Center for Living Supportive Day Program
[21] Home Health Aide

Facilities and Space				
	Insufficient SNF/AL Facilities	Windemere, Unit 2 Rest Home, Henrietta Brewer/Long Hill	No Assisted Living on-island, just rest homes and SNFs, Unit 2 Closing, male beds hard to come by due to rooming policy	Obtain more land: **regionalize town facilities**, take from **land bank**, build Greenhouse with graduated care
	No Certified Dementia Unit	Windemere Unit 4: dementia-training, HB/LH	Windemere not designed like Dementia Unit due to architectural expense, HB/Windemere not locked.	Investigate regulations of Dementia Unit, add features to Unit 4
	Insufficient SNF Nurses	Traveling Nurses, CAN/HHA Courses, CNA Add-On Bonuses, MVH Health Insurance Incentive for CNAs	Travelers decrease care continuity, CNA salary comparable to minimum wage, cannot fill CNA/HHA class with on-island/off-island recruits, patient:nursing ratios exhausting compared to acute care nursing	Political Activism: lobby for adjustment of patient:nursing ratios, lobby to increase CNA wage, increase MVH CNA Incentives: childcare, dental insurance, job mobility, etc.
	Housing/Land Crisis	Traveling Nurses	Travelers decrease care continuity, local nurses cannot get year-long leases due to summer rentals	**Subsidized CNA housing/"au pair model",** take from **land bank, regionalize town facilities**
	Insufficient Elder Housing	Island Elderly Housing, Island Co-Housing	Long waitlist, specific income eligibility	Take land from **land bank**, **regionalize town facilities** to build more Elderly Housing/Co-Housing
Community Engagement				
	Lack of Laypeople Education	Law Enforcement Education Program regarding Elders, Gatekeepers (Iowa University)	Law Enforcement Education Programs not personalized to MV issues, Gatekeepers discontinued	**Safe Seniors**- similar to Gatekeepers, home grown and personalized for MV, **Annual Dementia Health Fair** at MVH with seminars, **Dementia Volunteer Training**
	Community Stigma	Community Havens for elders with dementia: Museum, Featherstone, Yard, MVC4L, American Legion Memory Café, COAs	First Responders unsure how to respond to distressed elders with dementia, Windemere stigmatized, elders afraid to lose autonomy	Increase public visibility and normalization of dementia (book clubs, theater/art, newspaper advice column, integration of children), **Safe Seniors**, **Annual Dementia Health Fair** at MVH with seminars, **Dementia Volunteer Training**
Elder Engagement				
	Insufficient Elder Transport	Vineyard Village, MVTA Shuttle, Caregivers, Elder Services Consumer Directed Care	MVTA Shuttle expensive, Frail Elder employees cannot transport, Vineyard Village understaffed	Better advertise Consumer Directed Care, MVC4L van, increase Vineyard Village Recruitment
	No Community Activities with ADL/IADL Assistance (Adult Day Health)	MVC4L, Memory Café	MVC4L not a Medical Model, high staff attrition, not enough volunteers for excursions	MVC4L Adult Day Health/Medical Model, **MVC4L/COA Home Outreach**
	Elders Lose Motivation to Maintain Function	PT referrals at Windemere Rehab,	Not enough PT referrals for strength maintenance	**Volunteer** Home Health Coach Program, **MVC4L/COA Home Outreach**

		COA/MVC4L Group Exercises		
	Elders Isolated	GCM, COAs, Elder Services, Public Health Nurse, VNA	GCM limited by cost, stigma interferes with outreach to COAs, low COA/MVC4L appeal to elders preferring solitude, Elder Services lacks CMs for community outreach, Public Health nurse has infrequent follow-up and redundant assignments	**Safe Seniors**, **MVC4L/COA Home Outreach**, Family Assessment Tool for Elder Safety**,** increase **home visits by NPs** for dementia/safety screening, **re-utilization of Public Health Nurse**, increase advertisement base (billboard?)
Professional Programs				
	No Centralized Directory of Resources	First Stop, COA Outreach Workers, Caregiver Manual Booklet	First Stop not updated since 2016 due to insufficient funding, COA Outreach inconsistent, online resources replaced paper	Revisit paper resource, **reinvigoration of First Stop**, emailed bulletin from MVC4L spotlighting resources, Newspaper Advice Column, COA Outreach re-training, **Dementia Health Fair** at MVH with seminars
	Lack of Early Intervention	COAs, PCPs, Mental Health NP Home Screening for those at risk, Elder Services Referral	No Dementia- Wellness Clinic (do have Parkinson's and HTN), infrequent PCP visits decreases early detection and intervention	Seminars for families regarding early detection, **Dementia Wellness CAM Clinic,** increase **home visits by NPs** for dementia/safety screening
	Lack of Coordination and Delineation	Parallel Governmental Structure: Local Gov't- DCHC empowering HAMV; State Gov't- COA creating through enabling Legislation.	Multiple agencies invested in elder care with impeded inter-communication gives appearance of redundancy, Public Health nurses given unclear directives, COAs across six towns have coordination difficulties	Collaborative applications for funding, **reutilization of Public Health Nurse**, **Annual Dementia Health Fair** at MVH with seminars, quarterly coordination meeting of initiatives, Program Leadership Retreat, **reinvigoration of First Stop**

Table 4.) 12 Recommendations to Bridge Gaps across Several Themes and Problems

Recommendations to Bridge Gaps	Themes Addressed	Problems Addressed
Reutilization of Public Health Nurse	Medical Care Providers, Elder Engagement, Professional Programs	Hospital Readmissions Have Poor Follow Up, Elders Isolated, Redundant Programs Not Communicating
Telemedicine	Medical Care Providers	No On-Island Neurologist, Few Geriatric PCPs/Hospitalists, Psychiatrists
More Psych NPs/RNs for Home Visits/Screening	Medical Care Providers, Elder Engagement	Few Geriatric PCPs/Hospitalists, Psychiatrists, No On-Island Inpatient Geripsych, Elders Isolated, Lack of Early Intervention
Dementia Wellness CAM Clinic	Medical Care Providers, Professional Programs	Few Geriatric PCPs/Hospitalists, Psychiatrists Lack of Early Intervention
Dementia Group Home	Medical Care Providers, Caregiver Support	No On-Island In-Patient Geri Psych Unit, Insufficient Home Care,
Subsidized CNA Housing/"Au pair" model	Caregiver Support	Insufficient Home Care, Expensive Home Care
Volunteer Training	Caregiver Support, Community Engagement, Elder Engagement	Caregiver Burnout, Non-medical Assistance, Lack of Laypeople Education, Community Stigma, Elders Lose Motivation to Maintain Function
Land Bank/Regionalize Town Facilities	Facilities and Space	Insufficient SNF/AL Facilities, Housing Crisis, Insufficient Elder Housing
Annual Dementia Health Fair	Community Engagement, Professional Programs,	Reluctance to Seek Help/Relocate, Lack of Lay People Education, Community Stigma, No Centralized Directory of Resources, Redundant Programs Not Communicating
Safe Seniors	Medical Care Providers, Elder Engagement, Community Engagement	Hospital Readmissions have Poor Follow-up, Lack of Lay People Education, Community Stigma, Elders Isolated
MV4CL/COA Home Outreach	Elder Engagement	No Community Activities with ADL/IADL Assistance (Adult Day Health), Elders Lose Motivation to Maintain Function, Elders Isolated
Reinvigoration of First Stop	Professional Programs	Centralized Directory of Resources, Redundant Programs Not Communicating

Discussion and Recommendations

After identifying 12 recommendations that exhibited high impact in addressing gaps in services, we chose 6 recommendations that were considered most efficient to implement as the next focus for strategic planning. These included:

1. Reutilization of the Public Health Nurse
2. More Psychiatric NP/RNs for Home Visits/Screening
3. Volunteer Training
4. MV4CL/COA Home Outreach
5. Safe Seniors
6. Annual Dementia Health Fair

Interview results highlighted the contentious topic, the public health nurses' role. It appeared that expectations of the public health nurses included following up on patients admitted to the emergency department, frequent home visits, and detecting elders who are isolated and have not yet received services. The current design of the public health nurse's position is to receive referrals from the COAs and the Department of Health. Within the first 8 months of her employment, the public health nurse has received very few referrals specifically for elders with dementia, and those patients ironically appeared to be sufficiently connected with services already. For example, one patient even asked the public health nurse to no longer visit her, because she was already receiving attention from Caregiver Homes. In addition, the public health nurse is only expected to follow up on patients every 3 to 4 months if they are receiving 24-hour care, simply to determine if the care is continuing. If someone has declining memory and is not receiving this level of care, she is expected to follow up every 2 to 3 months. In light of this, the reality appears to be much different from the public perception of the nurse's role. Therefore, we recommend that meetings be held with the COAs in the Department of Public Health to discuss restructuring her role in dementia care.

In addition to public health nurses, psychiatric NPs and RNs are equally valuable personnel to provide safety and cognitive screening during home visits. In light of the paucity of PCPs and psychiatrists on the island, increased use of psychiatric NP/RN home visit screening would be beneficial for tracking elders at risk, as well as initiating early intervention. Tools that could be administered include MoCAs[13], the Folstein Mental Status Exam, Fall Risk Assessment Tools[14], and Housing Enabler Rating Tools[15]. In addition to risk stratification, NP/RN home visits would help mitigate long waitlist with on-island psychiatrists, as well as provide medication management to prevent behavioral health crises that would lead to off-island psychiatric hospitalization. Additionally, because home visits can be taxing on the provider in terms of transportation and time, an NP-run Screening Clinic could be held weekly at a centralized location such as the COAs or the MVC4L. A next step of the strategic planning would be determining which party would fund such a program.

Volunteer utilization is a low hanging fruit for bolstering a community response to dementia care. According to our findings, volunteer training addresses 6 individual problems spanning 3 themes. Volunteers can be utilized as nonmedical companions at home, in community venues such as COAs or MVC4L, or at skilled nursing facilities. Additionally, they can be used for social transport, in-home health coaching, and to increase the capacity for MVC4L off-site field trips. In light of the on-island caregiver deficit secondary to the housing crisis and high cost of living, volunteers can bridge the gap between elders and the rest of the community while also providing much-needed respite for caregivers. One can incentivize a strong volunteer base through community education about dementia and its prevalence, equipping potential volunteers with tools that can assist their own parents and friends if they should develop dementia in the future. In addition, volunteers can be gathered from local high schools with students looking to pursue careers in healthcare, and possibly receive some type of "extra credit" or commendation for providing this service. Volunteer training programs can

involve mandatory clinical hours at the COAs, MVC4L, or Windemere, thus mitigating challenging patient-staff ratios.

In a similar vein, volunteers and COA/MVC4L staff members alike should be further utilized for home outreach. This is an easy way for elders to receive socialization and enrichment in the comfort of their own home, providing respite for caregivers, while simultaneously gaining insight into the home and safety situation. Home outreach specifically assists elders who are not interested in community activities with other elders of similar function. Services that could be brought directly to the home include chair exercises, memory games, meditation and yoga, creative writing and illustration, etc. In addition, home outreach is an excellent opportunity for staff members to connect with caregivers and answer any questions as well as provide resources regarding dementia progression. Additionally, with a medical caregiver simultaneously present during the home outreach session, the elder could participate in activities that they normally would not be able to join at the COA or MVC4L because these venues are not medically equipped. The challenge in this, which has already been undertaken by HAMV and the COAs, is identifying which elders are homebound. Considering that it was previously established in HAMV surveys that fewer than 50 percent of on-island elders call the COAs to connect to services, Safe Seniors would arm community members to be vigilant for elders who are cloistered.

Safe Seniors is an effort undertaken by the COAs and HAMV to create a dementia-friendly community. This involves community education tailored to specific interfaces of interaction with elders, including storeowners, restaurant staff, bankers, law enforcement, first responders (police officers, firefighters, EMTs and paramedics) through customized PowerPoint and video vignettes depicting common interactions with an elder who is disoriented or combative. Through this training, community members can learn appropriate recourse for enabling the "safety net" of services available. This program is reminiscent of the Gatekeeper program created by Iowa University in 1986, and uses similar techniques for community engagement. Safe Seniors could be customized to situations frequently encountered on Martha's Vineyard. Because Gatekeepers has been proven to be successful in other settings[16], we would recommend trial implementation of Safe Seniors education materials as soon as they are available. It is also recommended that Safe Seniors education material continue to be edited and improved upon, and that focus groups of target audiences be held to ensure specific questions are answered.

In a manner similar to the multitude of craft fairs and farmers' markets thriving on Martha's Vineyard, an annual Dementia Health Fair would be a simple way to bring the community together and share knowledge and resources about this impending public health challenge. With each dementia-related organization providing its own table, education materials, and personal accounts, information could be disseminated to caregivers and laypeople as well as among program administrators. In this way, both community members and professionals could collectively learn more about the resources available, as well as appraise the aforementioned redundancy of programs. Through the transparency of seeing all of the relevant programs together in one place, partnerships and alliances can be made that will encourage joint application for grant funds. Dementia-related organizations could also give seminars to caregivers and family members during these fairs, while also receiving seminars about leadership and the dynamic landscape of dementia care in the rest of the state. Dementia care is truly an undertaking that warrants a multidisciplinary approach, and providing an opportunity for medical, social, and financial parties to come together and learn from each other will undoubtedly be beneficial.

Of note, recommendations regarding affordable housing for on-island caregivers were not chosen as the 6 to be implemented, although they are certainly high impact. The interviews have unanimously shown that the "housing crisis" is inextricably linked with the prevalence of CNAs and HHAs, and that an extremely effective way to bolster the trainings pools is to provide subsidized housing. This would be a monumental effort requiring purchase of land/buildings by MVH, an upswing in families hosting live-in caregivers, and possibly reconstruction and consolidation of public facilities. These initiatives would require time, money, and numerous meetings with the parties involved, and

would be appropriate to address when more resources became available and after these other gap filling service ideas have been developed and implemented.

Conclusion

In conclusion, through carefully conducted interviews and focus groups with 30 participants, we have characterized 25 distinct challenges/gaps and 6 themes regarding dementia care needs on Martha's Vineyard. We have identified previous services established to address each of these 25 problems, as well as gaps in their efficacy. Using ideas and insights from our participants as well as background information about the history of dementia care on Martha's Vineyard, we have crafted recommendations to bridge the gaps in these services. We have identified 12 recommendations that span more than one problem and/or theme, and subsequently selected 6 recommendations that are the least complex to implement while providing greatest cross-sectional impact. We will take these 6 recommendations and incorporate them into our strategic planning as the next phase of the MVC4L's public health intervention for solidifying the network of resources used to support our growing population of elders that will need dementia care services over the next decade.

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