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**Implementation of a Primary Care Toolkit to Improve Dementia Diagnosis and
Management in a Rural Setting**

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5/17/2022

Submitted in Partial Fulfillment of the Requirements of the Doctor of Nursing Practice Degree

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Abstract

BACKGROUND: There are six million people with dementia living in the United States and this number is expected to rise exponentially due to the aging population. In the United States, it is estimated that only two thirds of dementia cases are recorded during primary care visits and an estimated, one third of cases have been either missed or disregarded.

LOCAL PROBLEM: In a remote primary care clinic on Kodiak Island, off the southeastern coast of Alaska, there is a lack of dementia and related cognitive diagnoses in the primary care setting due to patients' and families lack access to the healthcare system and information related to the disease process. Primary care clinicians, healthcare entities, caregivers and patients are presented with unique challenges due to geographical location. In this setting, as with many other rural settings across the country, there are significant numbers of delayed or under detected diagnosis of dementias and cognitive concerns due to lack of resources and provider confidence in managing dementia centered care.

PURPOSE: The purpose of this project is to help community entities, patients and caregivers, and providers within this community become more familiar with early diagnosis and treatment of dementias/cognitive concerns to improve quality of life for patients and caregivers.

METHODS: The Chronic Care Model was used to guide this quality improvement project which implemented an abbreviated locally tailored KAER Model Toolkit. The Toolkit was designed to aid in the early diagnosis and management of cognitive concerns/dementias in a primary care setting. The PDSA cycle was used to guide the development, implementation, and evaluation of the project.

INTERVENTIONS: After feedback from local entities, a locally-tailored toolkit included the locally-tailored KAER Model as well as resources within the KAER Model, which was discussed with local healthcare entities, patients and caregivers to assess for cultural appropriateness and feasibility in a rural island community setting.

EVALUATION: Local healthcare entities, patients, caregivers, and providers will engage in collegial discussion group to form a coalition of key stakeholders within the community. The coalition of stakeholders will assess the KAER Toolkit and a pre-pilot survey will measure stakeholders opinions of the toolkit resources for feasibility of use. A locally tailored version of the KAER Toolkit will then be administered to each group of stakeholders for use. After six months of use in the local community setting, the locally tailored KAER Toolkit was reassessed through a post-pilot survey by the coalition of stakeholders for confidence, helpfulness, resources, feasibility, and necessity of the Toolkit.

RESULTS: The overarching aim of the proposed project, to implement a locally tailored and culturally appropriate Toolkit, to primary care providers to improve accuracy and earlier diagnosis and treatment of patients with cognitive concerns/dementias at a rural Alaska primary care practice over six months was not met. However, the project was successful in convening stakeholders, adapting the KAER Model Toolkit for the local community and evaluating the revised Toolkit. Though there was a percent change evident, there was a minimal difference between the pre and post survey results, which demonstrated that opinions of the stakeholders were not dramatically affected by the implementation phase of this project. Qualitative discussion groups were analyzed and separated by themes that supported the objectives of the project.

DISCUSSION: The stakeholders found the information within the abbreviated, locally tailored Toolkit to be useful and informative. The use of the abbreviated Toolkit improved health literacy through increasing knowledge of community resources for stakeholders. Challenges associated with this project were realized during the implementation period due to the COVID-19 pandemic. The project demonstrates that there is a need for increased health literacy in rural health communities and any quality improvement projects that educates caregivers and family members on a community level can be beneficial to breaking down barriers to improvements in quality care for healthcare entities and healthcare providers. Though this project did not completely meet the aims that were desired, the project can be seen as useful for developing health literacy in rural and remote community settings among stakeholders.

Implementation of a Primary Care Toolkit to Improve Dementia Diagnosis and Management in a Rural Setting

Introduction

Problem Description

Dementia is an umbrella term for the loss of memory, thinking skills, and cognitive abilities (Alzheimer's Association, 2021). This disease can include one or more of the following types of dementia; Alzheimer's Disease, Lewy Body Dementia, Vascular dementia, frontotemporal dementia, Huntington's Disease dementia, Parkinson's Disease dementia, or mixed dementias (Alzheimer's Association, 2021).

There are roughly 46.8 million persons with dementia worldwide (Alzheimer's Association, 2021). In the United States, more than six million Americans are living with dementia (Alzheimer's Association, 2021), with unpaid family caregivers providing the majority of dementia care to patients (Samus et al, 2018). That number is expected to triple by the year 2050 due to the rapidly aging population (Alzheimer's Association, 2021).

In 2021, the United States total cost of dementias will be 355 billion dollars (Alzheimer's Association, 2021). The average annual cost for a patient living with dementia is between \$30,554 to over \$70,000, which can vary depending on clinical setting and services (Samus et al, 2018). The National Institute on Health (NIH) reports that care of dementia is more costly than any other disease, including cancer and heart disease (2015). Concern about missed or delayed diagnosis of dementia within primary care has been expressed for over 40 years (de Vries et al., 2013). In the United States, it is estimated that only two thirds of dementia cases are recorded during primary care visits with the resulting one third of cases having been either missed or disregarded (Ford et al., 2018).

Primary care providers (PCPs) are the first point of contact for aging patients and their family members and are critical to early detection of dementia. However, when polled, the majority of PCPs reported they have very little training on dementia care and 39 percent reported they lack either confidence or knowledge in making a diagnosis of dementia (Alz.org, 2021). Primary care providers should be equipped with the tools and knowledge to manage this disease as they would any other chronic condition. Dependence on the referral resources to make a diagnosis is not always an option due to the critical shortage of dementia specialists around the country (Alz.org, 2021). Primary care providers can play a critical role in initiating conversations about brain health and cognitive status with their older patients, detecting cognitive impairments early into the disease, and conducting (or referring) diagnostic evaluation when appropriate.

Without a diagnosis, patients with dementia and their families are unlikely to receive community-based educational support and skill-building services that often lead to improved outcomes and reduction in stress, depression, feelings of isolation, and burden for family caregivers (GSA, 2020). In addition to improved quality of life, early diagnosis of dementia can lead to potential cost savings (Brooker et al., 2014). It is estimated by the Alzheimer's Association that if patients were diagnosed at the stage of mild dementia as opposed to moderate to severe dementia, there would be 7.9 trillion dollars saved in health and long-term care costs (Alz.org, 2021). Patients and families that have time and knowledge of this disease process would more likely be able to financially plan for the cost of future care.

Local Problem

In a remote primary care clinic on Kodiak Island, off the southeastern coast of Alaska, primary care providers are presented with unique challenges due to their geographical location. There are limited primary care and urgent care resources for residents and if the level of care

needs to be escalated, there is only access by ferry certain times of the year or daily plane flights to mainland Alaska. There is a diverse population of residents on Kodiak Island, it is apparent that there is a mistrust of the healthcare system and lack of diagnoses of dementia due to lack of patients and caregivers' report of symptoms as well as lack of knowledge on dementia and dementia related diseases. Providers do not "force" the topic of mild cognitive impairments, memory loss, or dementias with patients and families; therefore, there has not been a high number of cases or investigation into memory impairment symptoms among residents on Kodiak Island. In addition, the community does not have access to a neurologist or gerontologist, therefore primary care providers are responsible for managing a myriad of disease processes, including dementia and cognitive concerns. It is apparent that in this remote location, as with many other settings across the country, there are delayed or missed diagnoses of dementias and cognitive concerns due to lack of resources and the need for greater provider confidence in managing dementia-centered care. The purpose of this project is to help community entities, patients, caregivers, and providers within this community become more familiar with early diagnosis and treatment of dementias/cognitive concerns to improve quality of life for patients and caregivers.

Available Knowledge

A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guided systematic review of the literature was undertaken to identify strategies that have been shown to assist in early diagnosis and treatment of dementia in the primary care setting (Moher et al., 2009). The search yielded one qualitative study, one quantitative study, and seven non-research evidence articles (Appendix A).

Many other articles, both qualitative and quantitative were reviewed for this project but were excluded because they did not examine strategies to mitigate underdiagnosis of dementia. Through this literature search it became apparent that there is robust literature examining the barriers to early diagnosis and treatment of primary care patients with dementia as well as tools to diagnose dementia. However, there is little empirical evidence that examines systems level strategies to improve early detection of dementia. More research is needed, but in the interim current practice is guided by a variety of guidelines that have been promulgated by respected professional organizations and government bodies (Dang & Dearholt, 2018).

All non-research literature was conducted in the United States, except one article, which was conducted in Australia (Pond,2012). Six of the seven pieces of literature had a sample description of primary care providers working with patients with mild cognitive impairment or dementia in a primary care setting (Alzheimer's Association, 2020; California Alzheimer's Disease Centers, 2018; GSA, 2020; Pond, 2012; Santacruz & Swagerty, 2001; Tung et al., 2018). One piece of literature is an online curriculum dedicated to healthcare providers who are working with patients with mild cognitive impairment or dementia in the palliative care or hospice setting (CAPC, 2020).

After preparing a synthesis table four primary interventions to improve early diagnosis and treatment of dementia in a primary care setting were identified. The first intervention involved the implementation of a primary care liaison (PCL) position to assist in the management of care of mild cognitive impairment and dementia patients (de Vries et al., 2012). The main role of the PCL was to assist general practitioners in counselling, screening, education, and health promotion of patients with dementia and mild cognitive impairments as well as to address the needs of patients' families (de Vries et al., 2012).

The second intervention that was identified was the implementation of a community consultation center (Ishiwata et al., 2014). This would be an expensive intervention, and likely unaffordable without state or federal funding for most communities. However, the center was free to all community members and had dedicated staff who were trained in dementia care and were effective in diagnosing and treating mild cognitive impairments and various dementia cases in a timely manner (Ishiwata et al., 2014).

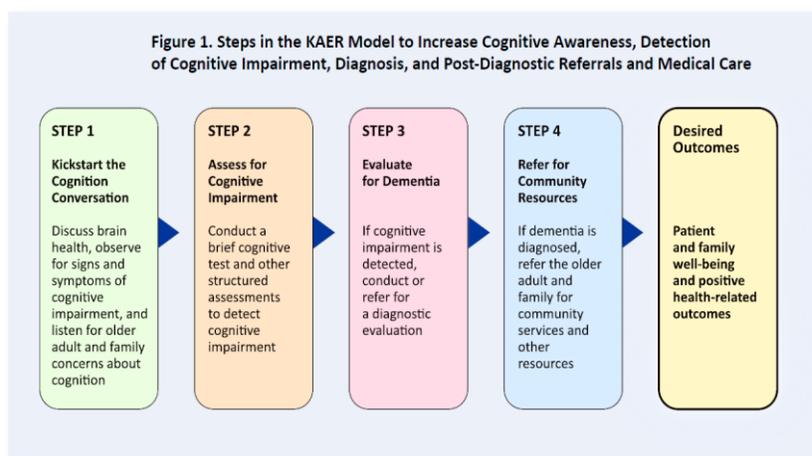
The third intervention identified was the use of algorithms, or decision aids, that are written by experts in the field of dementia care (Pond, 2012; Santacruz & Swagerty, 2001; Tung et al., 2020). The use of the algorithms and decision aids concerning differential diagnoses, for mild cognitive impairment and age-related memory changes are addressed. Access to such resources is an important resource for many primary care providers (Pond, 2012; Santacruz & Swagerty, 2001; Tung et al., 2020). The diagnostic criteria and additional algorithms for treatment options can greatly aid PCPs who lack experience and confidence in the decision-making process for geriatric patients presenting with memory changes (Pond, 2012; Santacruz & Swagerty, 2001; Tung et al., 2020).

The most promising intervention for a rural primary care setting is a bundle of diagnostic tools, or toolkit, which includes algorithms, scripts for providers, educational articles and modules, and provider resources (GSA, 2020; Alzheimer's Association, 2020; California Alzheimer's Disease Centers, 2018; CAPC, 2020). Each toolkit varies in resources that are presented. All the reviewed toolkits are intended for the use of healthcare providers who are assessing, diagnosing, or treating patients with cognitive changes, or diagnosed dementia.

One toolkit was developed by the Alzheimer’s Association in 2001, for the development of the Medicare Annual Wellness Visit (AWV) (Alzheimer’s Association, 2020). This bundle of tools is up to date and undergoes frequent best practice revisions related to how to administer the AWV. The toolkit contains algorithms, validated cognitive assessment tools, validated informant assessment tools, and an assessment of patient tools for providers (Alzheimer’s Association, 2020).

Figure 1

KAER Model Toolkit



Note. Image from Gerontological Society of America. (2020). *The GSA KAER Toolkit for Primary Care Teams; Supporting conversations about brain health, timely detection of cognitive impairment, and accurate diagnosis of dementia.* Retrieved from: alz.org

care practice (California Alzheimer’s Disease Centers, 2018).

The most inclusive toolkit that was found was the Gerontological Society of America’s toolkit for diagnosis and treatment of dementia in the primary care setting (GSA, 2020). The KAER Model, as seen in Figure 1, follows a four-step model which stands for; Kickstart, Assess, Evaluate, and Refer (GSA, 2020).

The KAER Model Toolkit includes screening tools, situational scripts, and various further information and referral resources for primary care providers (GSA, 2020). Because the

The California Alzheimer’s Disease Center (2018) has also developed a toolkit. This toolkit is much shorter in length and focuses on detailed scripts for providers, referral resources, and guidance on billing within a primary

KAER Model Toolkit was developed with all elderly individuals in mind, as opposed to those who will be assessed during the Medicare AWW, this toolkit is the most cost effective and realistic intervention to implement in a rural community health setting that services a diverse socioeconomic primary care population.

All the above-mentioned toolkits, including the KAER Model Toolkit, are compendiums of expert opinions and evidence-based practice to guide and optimize primary care practice until more empirical evidence becomes available.

The inclusion criteria for the National Guideline Clearinghouse (NGC) to assess the strength of the toolkits was met by the following organizations: Alzheimer's Association, California Alzheimer's Disease Centers, and Center to Advance Palliative Care (NGC, 2013). Below is the list of inclusion criteria:

- Contains systemically developed statements, including recommendations to optimize patient care and assist physicians and other healthcare providers to make decisions
- Have been produced by a medical specialty association, relevant professional society, government agency, or healthcare organization
- Based on systematic review of the evidence
- Contain an assessment of benefits and harms recommended care and alternative care options
- Have the full text guideline available in English for the public
- Is the most recent version published and have been developed, reviewed, or revised within the past five years (Dang & Dearholt, 2018).

In addition, the qualities of the KAER Model Toolkit (Figure 1) include the following elements: (a) addressed appropriate stakeholders involved in the development of

recommendations, (b) clearly discussed who the recommendations applied to, (c) potential biases have been addressed, (d) had clear recommendations and a clear subject matter.

The literature is relevant and up to date with helpful analysis of the conclusions across the articles included in the review. Most importantly, recommendations are made for future practice (Dang & Dearholt, 2018). This toolkit contains clear aims and objectives and demonstrates consistent results across multiple settings. The toolkit was designed using formal quality improvement, and has definitive conclusions, consistent recommendation, and comprehensive references with research-based evidence (Dang & Dearholt, 2018). Given the numerous strengths of the toolkit and the fact that the resources align well with the needs of Kodiak's community entities, patients, caregivers, and primary care providers, the KAER Model Toolkit is the choice for use in this project.

Rationale

The Chronic Care Model (CCM) (Figure 2) guides the implementation of this quality improvement project (Turner, 2018). The CCM is an appropriate theory to guide interventions related to chronic care because it requires an informed, activated patient as well as a prepared, proactive patient team (Turner, 2018). The CCM assumes a team-based approach to delivering evidenced-based care that focuses on patient safety, cultural sensitivity of delivery system designs, care coordination, and community-based resources and policies (Turner, 2018). The use of a toolkit model for providers supports the assumptions of the CCM for improving the mechanisms that promote safe, high-quality care to patients (Turner, 2018).

The organizing approach of the CCM for improving treatment of chronic illness is well aligned with the motivating factors of this quality improvement project. The assumption of the CCM that connecting patients and caregivers with local and national resources that are low cost or free of charge to the needs of the patients is a key goal for the implementation of this quality improvement project (Turner, 2018). The CCM proposition of forming improved partnerships with community and national resources that will be potentially beneficial to the setting is also a goal that aligns well with this proposed project (Turner, 2018).

More specifically, the CCM consists of six components of the health system. They are: community, the health system, self-management support, delivery system design, decision support, and clinical information systems. On Kodiak Island, the health system consisted of community health entities, including one primary and urgent care office, dl, which supported the project and the quality improvement initiative. Another community health

entity is Senior Citizens of Kodiak, Inc., which is the adult day health center as well as the council on aging for this community. This health entity is critical in providing seniors with information and services such as meals and assistance with activities of daily living and can be considered self-management support for stakeholders during implementation of this project.

Figure 2

The Chronic Care Model



Developed by The MacColl Institute
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Note. Image from *The chronic care model*.
<http://www.improvingchroniccare.org>

The delivery system design and decision support, assures the delivery of efficient clinical care and brings evidenced based guidelines into clinical practice through the use of the KAER Model Toolkit packet and additional resources provided by the project administrator.

An assumption of the Chronic Care Model is that through the use of these components, stakeholders will be informed as well as motivated for participation, which will produce productive interactions between patients/caregivers and the prepared and proactive primary care team members

Specific Aims

The purpose of the proposed project is to help community entities, patients, caregivers, and providers within the Kodiak community to become more familiar with early diagnosis and treatment of dementias/cognitive concerns to improve quality of life for patients and caregivers. The overarching aim of the proposed project is to implement a locally tailored and culturally appropriate toolkit to key stakeholders in the community in order to achieve the objective of improving accuracy and earlier diagnosis and treatment of patients with cognitive concerns/dementias over six months.

Objectives:

- Engage stakeholders to review toolkit, discuss how toolkit could be refined to meet the needs of the community including:
 - PCPs and clinic leadership
 - Community healthcare entities
 - Patients, caregivers, families

- Implement a locally tailored and culturally appropriate KAER Toolkit to improve accuracy and earlier diagnosis and treatment of patients with cognitive concerns/dementias in a rural Alaskan community over six months
- Stakeholders in the community utilize the locally tailored KAER Toolkit when working with or caring for those with cognitive concerns/dementias

Methods

Context

The proposed improvement project was implemented in a rural community on an isolated island setting in Southeastern Alaska. According to the 2019 census data there were 12,998 people living on Kodiak Island at the time of the project (*U.S. Census Bureau QuickFacts: Kodiak Island Borough* 2019). Although the data was provided by the United States Census Bureau, a large number of Native Alaskans as well as others lived off the road system and were not able to fill out census information. There was a large United States Coast Guard Base that had 3,500 active-duty members and their dependents residing in Kodiak. The 2019 U.S. Census reported that 11.4% of the population was age 65 and older. However, this number was likely an inaccurate representation of the geriatric population that resided on the island based on discussion with town officials (*U.S. Census Bureau QuickFacts: Kodiak Island Borough* 2019).

There were several community healthcare entities, including Kodiak Elder Care House, Senior Citizens of Kodiak, Inc., and Kodiak Counsel on Aging, which were solicited for feedback on the implementation of toolkit within the community. The primary care clinic, Kodiak Island Ambulatory Care Clinic, was made up of two physicians and two part time nurse practitioners. The average number of patients seen per day, between two providers was 65 to 70 patients. There was a large amount of support staff at this clinic including front desk staff,

nursing assistants, and administrative personnel. The specialty of the clinic was primary care services as well as urgent care services for new and established patients.

The primary care clinic could order computerized tomography (CT) scans, magnetic resonance imaging (MRI), and radiographic scans (Xrays) on the island at the community hospital. If there was a need for further evaluation or any additional services including advanced imaging, advanced laboratory testing, neurology, and specialty care referrals off-island care was required. There was access to two on-island pharmacies, but there was no compounding pharmacy services and laboratory tests were flown off island for analysis, which could delay results by up to four days depending on weather conditions.

The community health entities and providers were expected to face challenges including lack of knowledge of the disease process, and lack of confidence in diagnosis and management of dementia, communication issues, and for some providers, therapeutic nihilism, which is defined as a disbelief in the efficacy or value of a therapy from patients and caregivers. The practice factors that could lead to underdiagnosis of dementia include time constraints, availability of visits and resources, and access issues. At a patient level, lack of awareness, isolation, inability to self-report symptoms, and mistrust and lack of education about the healthcare system are factors that could contribute to delayed diagnosis and treatment of dementia. A Force Field Analysis (Appendix D) was done for this quality improvement project and demonstrate the following driving and restraining forces.

The driving forces of this primary healthcare setting was strong leadership of clinical practice and desire for improvements in education and training. Potential driving forces for this setting were long-term financial incentives of dementia screening, improved patient outcomes, and decreased caregiver burden and overall improved patient satisfaction. Current restraining

forces included time constraints due to high patient volume, which could be mitigated using an abbreviated version of a toolkit for diagnostic guidance. Potential restraining force include time constraints of using a new toolkit in an already brief visit time and provider discomfort with the toolkit.

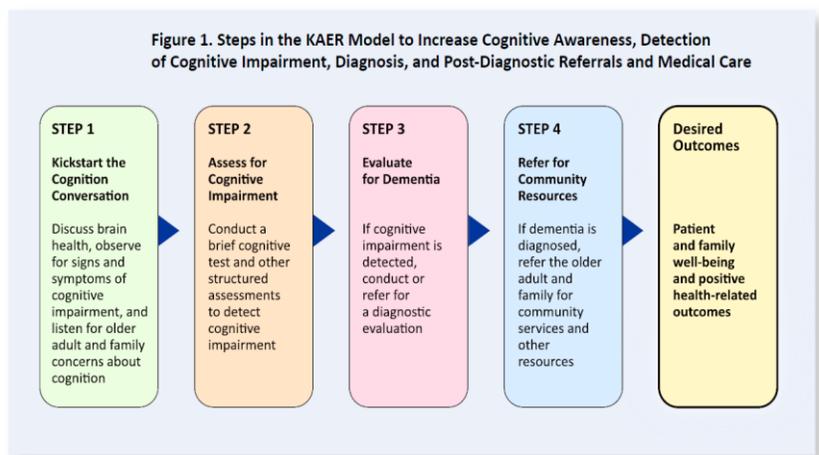
Other constraining factors associated with the limitations of this rural island setting included the following: socioeconomic constraints (low incomes and high cost of living), isolation of and lack of support for elders in certain population groups, problems associated with no insurance or limited insurance coverage, established patterns of crisis-driven healthcare versus seeking healthcare for preventative or early intervention care among several population groups. There were several other driving and restraining factors that can be found in the Force Field Analysis (Appendix D).

Intervention

The proposed intervention was based on the premise that cognitive changes and/or dementias were not being recognized and managed in a timely or evidence-based manner in the rural community setting.

Step 1 of the intervention was to engage separate groups of stakeholders; providers, patients and caregivers, and community healthcare partners who worked with residents with cognitive concerns and dementias. All of these groups were shown the KAER Toolkit and asked their opinion on the efficacy of the toolkit contents for use within the community setting. The stakeholders were surveyed on their opinion of the KAER Toolkit in a pre-pilot survey and through a qualitative discussion group between the stakeholder and the project administrator. Based on the feedback after discussion groups with each group of stakeholders, the project administrator was able to tailor the information of the KAER Toolkit to an abbreviated locally

tailored KAER Toolkit specific to each group of stakeholders. The intervention was continued with Step 2, when the modified and abbreviated KAER Toolkit was presented to each group of stakeholders based on their feedback from Step 1. At this point, the project administrator encouraged the stakeholders to utilize the abbreviated Toolkits over a six-month period of time. The final step, Step 3, included the project administrator checking back with each group after six months to see if stakeholders: implemented the locally tailored KAER Toolkit, if stakeholders felt the toolkit helped early diagnosis and treatment in patients with cognitive concerns/dementias, or helped identify issues with memory or cognitive decline in family members, if stakeholders benefited from the use of the toolkit, and at what frequency they utilized it. This was measured through a post pilot survey. A qualitative discussion group occurred with each stakeholder at the time of the post pilot survey.



Pre-Implementation

Planning

The approach for assessing the impact of the intervention started with review of current practices at the community level for

patients who were seen with cognitive concerns/dementia. There needed to be a formed coalition of stakeholders, which included, advanced practice nurses, medical doctors, community resources, patients, and caregivers living/working in the local community setting. This coalition had the ability to help create and manage the locally tailored KAER Toolkit. To educate

stakeholders on the content and use of the toolkit, the project administrator hosted discussion group with primary care medical providers, caregivers, patients, and community entities to discuss the toolkit and what is needed to make it successful in a local primary care setting. The second step of the discussion group provided education on the contents of the full KAER Toolkit as well as locally tailored KAER Toolkit.

Evaluation of the Intervention

The Plan, Do, Study, Act (PDSA) Model was used to implement and evaluate this project (Deming, 2021). The PDSA Model is an ongoing four stage problem solving model that is used for process improvement in a variety of settings (Deming, 2021). The planning stage involves identifying the problem and developing a concrete aim statement while accurately describing the problem. The doing stage involves implementation of the action plan developed in the planning stage and data gathering. The study stage involves analysis of the data to determine if the plan resulted in improvements. The final stage would be to act, which involves reflecting on the project and the outcomes. If another plan is necessary then return to the planning stage is warranted (Deming, 2021).

To evaluate if this toolkit was useful in this practice setting, the project administrator hosted discussion groups with stakeholders and conducted a pre-pilot and post pilot surveys.

Stakeholders were surveyed for their opinions on feasibility of the toolkit in the local community and discussion groups during and after the implementation of the toolkit, which was to ascertain stakeholders' opinions, beliefs, and attitudes about dementia/cognitive concern in the community and primary care setting. After the conclusion of the pilot project, the stakeholders were surveyed about their confidence and knowledge and discussion groups were hosted to

assess the toolkit’s ability to aid in early diagnosis and treatment of those with dementias/cognitive concerns.

Measures

A Measurement and Analytic Strategy Table (Appendix F) and a Measures Table (Figure 4) were used to demonstrate how specific aims of the intervention will be measured.

The first objective was to engage stakeholders, to review KAER Model Toolkit, and discuss

Figure 4

Measures Table

Aim or Objective	How Operationalize/ Measure
- Engage stakeholders to review KAER Toolkit, discuss how this toolkit can be refined to meet the needs of the community including: -PCPs and clinic leadership -Community healthcare entities -Patients and care partners	- Pre Pilot Survey report proportion of people who agree or strongly agree with statements (do you feel comfortable using this toolkit when discussing cognitive changes with patients and their families, do you feel the use of this toolkit is feasible for use of dementia and cognitive impairment cases in the primary care setting in this community, do you believe additional tools to help manage dementia diagnosis and management would be helpful in this community, do you feel sufficient care is provided to dementia and cognitive impairment patients in this community?) Qualitative Discussion with Stakeholders
- To implement a locally tailored and culturally appropriate KAER Toolkit in order to improve accuracy and earlier diagnosis and treatment of patients with cognitive concerns/dementias in a rural Alaska community over six months	-Participation in qualitative discussion group with stakeholders post implementation. Qualitative content analysis.
- Stakeholders in the community utilize the locally tailored KAER Toolkit when working with or caring for those with cognitive concerns/dementias	Post Pilot Survey- reported proportion of people who agree or strongly agree with statements (do you feel comfortable using this toolkit when discussing cognitive changes with patients and their families, do you feel the use of this toolkit is feasible for use of dementia and cognitive impairment cases in the primary care setting in this community, do you believe additional tools to help manage dementia diagnosis and management would be helpful in this community, do you feel sufficient care is provided to dementia and cognitive impairment patients in this community?) Qualitative Discussion Group

problems and demographics and need of the local community. The outcome was a formed coalition of stakeholders that came together for a collegial discussion. This outcome was measured through a pre-pilot survey and qualitative content analysis of discussion groups with stakeholders.

The second objective was to implement a locally tailored and culturally appropriate KAER Toolkit to improve accuracy and early diagnosis and treatment of patients with cognitive concerns/dementias in this rural Alaskan community over a six-month period. The objective was measured through collegial discussion groups with stakeholders and qualitative content analysis.

The third objective was to assess if stakeholders utilized the locally tailored, culturally appropriate KAER Toolkit when working with and caring for those with cognitive concerns/dementias over the six-month implementation period. This outcome was measured through use of a post pilot survey and qualitative discussion groups with stakeholders.

Analysis

For Objective 1, Engage stakeholders, to review KAER Model Toolkit, discuss problems and refine the Toolkit, qualitative content analysis was conducted as well as pre-pilot survey using a Likert scale on a 0-5 scale, which contained nine questions that linked back to the objectives of the project. Qualitative discussion groups were conducted to get feedback from stakeholders on which components of the Toolkit they found helpful. Based on the feedback received, the project administrator made locally tailored, culturally appropriate abbreviated Toolkits, one for providers and one for caregivers. Once the Toolkit was adapted, it was delivered to caregivers, family members, healthcare entity administrators, and providers within the local community for use when working with those with cognitive concerns/dementias.

For Objective 2, pre-implementation and post implementation collegial discussion groups were conducted. The topics of discussion were local concerns about dementia and need for reformed dementia care throughout the community. The discussion groups were reviewed through qualitative content analysis. The information gathered through the discussion group was

used to further adapt an abbreviated, locally tailored Toolkit for providers to ease use in a primary care setting.

For Objective 3, stakeholders in the community utilize the locally tailored KAER Model Toolkit when working with or caring for those with cognitive concerns/dementias was measured through a post-pilot survey. The post-pilot survey used a Likert scale, which contained nine questions that linked back to the objectives of the project. A percent change was calculated based off the pre and post survey results from stakeholders. Additionally, qualitative content analysis was conducted from the post implementation discussion groups to determine frequency of utilization and barriers to utilization of the locally tailored Toolkit.

A Percent Change Table (Figure 6) was used to draw inferences from the data collected in the pre and post survey as well as through general discussion with key stakeholders, which included family members, caregivers, administrators of healthcare entities, and providers. Each stakeholder was interviewed separately at the time of their pre and post survey, the interview was recorded by the project administrator. To assess the variation in data, pre survey results were compared with post survey results. The sample was too small to do a meaningful quantitative analysis of any kind but did allow for identification of repetitive themes that existed among the stakeholders. After the conclusion of the post implementation discussion groups, theme tables were created to support each objective of the project.

Ethical Considerations

As outlined in the University of Massachusetts Boston Clinical Quality Improvement Checklist (Appendix H), the proposed project meets the criteria for quality improvement and does not involve human subjects. The clinical practice unit at the project clinic has agreed that this a QI project that was implemented to improve the process and delivery of care.

The project met the criteria for quality improvement at the University of Massachusetts Boston, which was the academic partner. The project proposed was quality improvement and did not meet the definition of human subjects research because it was not designed to generate generalizable findings but rather to provide immediate and continuous improvement feedback in the local setting in which the project was carried out. The University of Massachusetts Boston IRB determined that quality improvement projects do not need to be reviewed by the IRB.

Results

The stakeholders that were participants in this project were represented on the Demographics Table (Figure 5). There were six total participants: two nurse practitioners, one health clinic administrator, two caregivers, and one family member. Two of the participants were male, four were females. There were no participants under the age of 25, and no participants over the age of 65. Majority of the participants were between the ages of 35 and 45. The participants had a college degree or higher level of education.

Figure 5
Demographics Table

Participant Demographics	Participants (N=6)	Percent
Gender		
Male	2	33%
Female	4	67%
Age		
26-35	2	33%
36-45	3	50%
46-55	1	17%
Highest Level of Education		
College Degree	2	33%
Master's Degree	3	50%
Post Master's Degree	1	17%
Role		
Family Member/Caregiver	3	50%
Healthcare Provider	2	33%

Healthcare Administrator	1	17%
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The overarching aim of the proposed project, to implement a locally tailored and culturally appropriate Toolkit, to primary care providers to improve accuracy and earlier diagnosis and treatment of patients with cognitive concerns/dementias at a rural Alaska primary care practice over six months was not met. However, the project was successful in convening stakeholders, adapting the KAER Model Toolkit for the local community, and evaluating the revised Toolkit.

The six participants, key stakeholders, were asked to take a pre-implementation survey as well as a post-implementation survey. The survey was a nine question, Likert scale design. The survey questions were separated into five categories: resources, necessity, helpfulness, feasibility, and confidence. After the pre- and post-survey, percent change was calculated, a positive percent change indicated that there was an increase in the stakeholder's perception of the project, and a negative percent change demonstrated a decrease in the stakeholder's perception of the project. The results were demonstrated in the Percent Change Table (Figure 6). Though there was a percent change evident, there was a minimal difference between the pre and post survey results, which demonstrated that opinions of the stakeholders were not dramatically affected by the implementation phase of this project.

Question one and two, addressed the resources within the Toolkit, the percent change for question two was notable at negative 11%, which indicated that stakeholders did not feel that additional resources within the community throughout implementation of this project were helpful; because majority of the recommended resources were closed or had limited operation due to COVID-19 this was an expected outcome. There was no change in stakeholders' opinion of adequate resources within the Kodiak community after implementation of the Toolkit.

Majority of stakeholders did not believe there were adequate resources before and after implementation of the project.

Question three and four addressed the necessity of this project and the need to address gaps in care for patients with cognitive concerns and dementias within the Kodiak community setting. The stakeholders had no change of opinion, or percent change, when answering if they believed that this project was necessary in the Kodiak community, therefore this project had no impact on their perception of necessity. The pre-implementation survey reported that all stakeholders believed that this project was necessary in the Kodiak community setting.

Stakeholders had a negative eleven percent change when answering whether they believed that there were gaps in care for patients with dementias and cognitive concerns, which demonstrated that after the Toolkit highlighted resources within the community, a small number of stakeholders believed that dementia care was addressed through Kodiak healthcare.

Figure 6

Percent Change Table

Domain/Category	SURVEY QUESTIONS	Pre Mean	Post Mean	Percent Change
Resources	I currently have adequate resources within the Kodiak community to help a patient/person with cognitive impairments or dementia	2.17	2.17	0%
Resources	I believe that additional tools and resources would be helpful in my healthcare/community setting when working with patients with cognitive impairments or dementia	1.50	1.67	-11%
Necessity	I believe this project is necessary in the Kodiak healthcare/community setting	1.33	1.33	0%
Necessity	I believe there are gaps in care for patients with dementia and/or cognitive impairments in the Kodiak community	1.50	1.67	-11%

Helpful	I believe this toolkit provides helpful resources for providers, families, and patients dealing with cognitive concerns/dementias	1.50	1.33	11%
Helpful	After reviewing the KAER Toolkit, I believe that resources from this toolkit will be helpful in my healthcare setting	1.50	1.17	22%
Feasibility	I am likely to use or implement at least one recommendation or resource from the KAER Toolkit in my healthcare setting	1.83	1.50	18%
Confidence	I am going to use the recommendations from this toolkit while working with patients, families, or persons with dementia/cognitive impairments in the Kodiak community	1.83	1.50	18%
Confidence	I am going to use the resources from this toolkit while working with patients, families, or person with dementia/cognitive impairments in the Kodiak community	1.33	1.00	25%

Question five and six addressed the helpfulness of the Toolkit. After reviewing the Toolkit pre and post implementation, the stakeholders reported a percent change of 11% and 22%, which demonstrated that though several resources were closed throughout the implementation period, the abbreviated, locally tailored KAER Toolkit resources were perceived as helpful to all stakeholders.

The seventh question addressed the feasibility of use of the Toolkit's recommendations in clinical practice. This question had a positive percent change of 18%. This demonstrated that after the implementation period, primary care providers felt that the Toolkit was feasible for use within the primary care setting.

Question eight and nine addressed the confidence that stakeholders had in recommending and/or using the resources and recommendations of the abbreviated Toolkit. Question eight, would stakeholders recommend the Toolkit in the future, had a positive percent change of 18%. The largest percent change was a positive percent change of 25% in question nine, if stakeholders would recommend resources from the Toolkit. The positive percent change in “confidence” questions could be interpreted that stakeholders planned to use recommendations and resources from the Toolkit in the future.

Percent change was calculated for this project, but statistical significance was not calculated due to the low number of participants. Therefore, though there were both positive and negative percent change reflected in the Percent Change Table, we were unable to determine if this represents a significant change of opinion among stakeholders. Because of the low number of participants, the majority of information was gathered through qualitative discussion groups that included the project administrator and each stakeholder represented in the project.

During qualitative discussion groups, the conversation between stakeholders and the project administrator were recorded. After review of the recordings, themes were identified relating to the three objectives of the project.

Objective 1: Engage stakeholders to review KAER Model Toolkit, discuss how this Toolkit can be *refined* to mee the needs to the community. The key stakeholders will include PCPs, Clinic Leadership, Community Health Entities, and Care Partners.

A theme table was developed for Objective 1 (Figure 7). The first theme identified through Objective 1 was “Communication.” The project administrator organized pre-implementation meetings with community stakeholders to discuss the KAER Model Toolkit and project goals before the implementation period. Each stakeholder met separately with the project administrator and reviewed the full KAER Model Toolkit and reported what they found useful

and what they did not find useful throughout the Toolkit’s contents. The project administrator highlighted different sections and topics within the full KAER Model Toolkit for the stakeholders during the discussion group. The stakeholders were engaged and interested in the KAER Model Toolkit and how it would benefit the Kodiak community.

At the same discussion group meeting, the project administrator asked for the stakeholders’ opinions on the Toolkit and how it could be refined to better serve those with cognitive concerns/dementias within the community. In addition, a pre implementation survey was administered to stakeholders during the discussion group. During the discussion groups, one theme that was identified was the KAER Model Toolkit had “Too Much Information.” The stakeholders reported that the Toolkit was overwhelming and abbreviation to condense the information into “key concepts” and “key information” would best serve the stakeholders and community. The project administrator created an Abbreviated Toolkit for Care Providers (Appendix I) that contained a Provider Algorithm, which would decrease the amount of time needed to implement the Toolkit during a primary care visit. An Abbreviated Caregiver Pamphlet (Appendix J) was also created to increase feasibility of use of the Toolkit during implementation for caregivers and family members.

Figure 7

Objective 1 Qualitative Response Table

Theme	Exemplar	Action
“Communication”	<p>“[Caregiver]It is nice to get together to discuss this. I haven’t done this before”</p> <p>“[Administrator] What is the project about again?”</p> <p>“[Family Member] There isn’t enough known about dementia for the family members. It isn’t really talked about, so I don’t</p>	Pre-implementation meeting with community stakeholders to discuss the KAER Model Toolkit and project goals pre-implementation.

	<p>know how to help or what to do.”</p> <p>“[Provider] I think this project is necessary, we could do more for the elderly patients.”</p>	
“Too Much Information”	<p>“{Family Member} This is a lot of information.”</p> <p>“{Administrator} There is a lot of information here, is there any way to streamline this into an easier to navigate format?”</p> <p>“{Provider} Right, I obviously wouldn’t be able to go through this whole Toolkit during the visit, I think I would maybe look at it as a reference before or after a visit if I had a question.”</p>	<p>Revised KAER Model Toolkit to an</p> <p>(1) Abbreviated Caregiver Pamphlet</p> <p>(2) Abbreviated Provider Toolkit</p> <p>for specific stakeholders to include clear, concise information.</p> <p>Created (1) Provider Algorithm and resource list for “quick” use during primary care visits.</p>
“Lack of Local Resources”	<p>{Caregiver} I definitely think there is a need for more resources for dementia in the community.”</p> <p>“{Provider} I don’t feel that I know of any resources for dementia in the community, but I also haven’t really looked.”</p> <p>“{Administrator} I definitely think there is a need for more resources for dementia in the community from my experience.”</p>	<p>Researched local community resources</p> <p>Contacted local resources for information about their services for those with cognitive concerns/dementias.</p> <p>Designed pamphlets and abbreviated Toolkits that highlighted local resources and their services.</p> <p>Included remote resources from original KAER Model Toolkit in Abbreviated Toolkit designed for stakeholders.</p>

The third theme that was identified for Objective 1 was that all stakeholders reported that they believed the community had a “Lack of Local Resources” for community residents with cognitive impairments/dementias. The project administrator searched the KAER Model Toolkit

for remote resources that would be beneficial to the Kodiak community during the COVID-19 pandemic. In addition, the project administrator researched and contacted local resources for information about their services for cognitive concerns/dementia residents. With the information that was gathered during this process, the project administrator designed both a Caregiver Pamphlet and Abbreviated Provider Resource with community and remote resources lists that were operational and could be used to aid residents with cognitive concerns/dementias.

Objective 2: To *implement* a locally tailored and culturally appropriate KAER Toolkit to improve the accuracy and early diagnosis and treatment of patients with cognitive concerns/dementias in a rural Alaskan community over six months

A theme table was developed for Objective 2 (Figure 8). The first theme that was identified for the second objective was “Lack of Visits” due to the reported minimal amount of cognitive concerns/dementia visits that took place over the pre-implementation and implementation period. The project administrator continued discussions during the pre-implementation and implementation period to stress the importance of signs and symptoms of cognitive concerns/dementias and the need for continued evaluation during well-visits, annual visits, and sick visits. As for caregivers and family members, the project administrator highlighted and provided a copy of the full KAER Model Toolkit that clearly outlines signs, symptoms, and scripted discussions to have with anyone who may have cognitive concerns/dementias.

The second theme identified for Objective 2 was “Competing Priorities.” A continuous barrier to implementation was the strain of the COVID-19 pandemic and limitations that the pandemic presented in healthcare settings as well as the community setting. The pandemic overshadowed the importance of the project during the implementation period; providers and healthcare administrators reported that their concern for COVID-19 protocols,

resources, and staffing took time and resources away from all other healthcare concerns. There was a dramatic increase in sick visits, which required covid testing and treatments, if necessary, which decreased the number well visits and annual visits. The workload of providers increased during the pandemic due to increased numbers of sick visits. Providers also reported that well visits decreased in number, which can be attributed to patients not wanting to visit an office during the pandemic. The change in visit type was a reported reason for decreased use of the Toolkit among primary care providers; memory testing was not performed as frequently during the pandemic. Providers who worked within the community reported that an influx of COVID-19 patients took precedence over the project in the clinic setting. Due to limitations of the pandemic and two different quarantine cycles during the implementation period, the project administrator conducted emails, phone calls, and socially distanced in-person follow ups with stakeholders during the implementation period to remind stakeholders about the projects' goals.

Figure 8

Objective 2 Qualitative Response Table

Theme	Exemplar	Action
"Lack of Visits"	<p>"[Provider] I didn't see any memory loss visits recently. I didn't see well visits either, majority sick visits."</p> <p>"[Health Administrator] We rarely get a memory loss concern visit here."</p>	<p>Provided Abbreviated Algorithm for PCPs to use at all well visits.</p> <p>Continued discussions about mild cognitive impairments, memory concerns, and dementias and preventative health with key stakeholders.</p> <p>Gave all stakeholders a copy of the full KAER Model Toolkit as reference to review.</p>
"Competing Priorities"	<p>"{Administrator} I have made mention of the pamphlet a few times to family members, but I haven't handed any out, we have been short staffed as well, so dealing with that pressing issue</p>	<p>Continuous Qualitative discussion groups with stakeholders during project implementation to discuss ongoing issues/barriers to implementation with</p>

	<p>of limited staff members has been hard.”</p> <p>“{Administrator} COVID is sucking up a lot of time and resources. I haven’t had anyone ask about dementia or memory care services recently, it could be because of the impacts of COVID on the community. No one is referring to group activities and stuff like that right now.”</p> <p>“{Provider} Yeah COVID is definitely our focus right now. We have had a lot to deal with.”</p> <p>“{Provider} We have had such a busy time with COVID visits, testing, treatments, follow-ups that it has been a whirlwind.”</p> <p>“{Provider} There was not a lot of well visits during the pandemic. No one wanted to come in if they didn’t have to.”</p>	<p>stakeholders and the effects of COVID-19 pandemic through the Kodiak community.</p> <p>Continued meeting with stakeholders during implementation period via in person meetings, phone contact, and email to encourage stakeholders to use the abbreviated Toolkits during implementation phase of project.</p>
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Objective 3: Stakeholders in the community *utilize* the locally tailored KAER Toolkit when working with or caring for those with cognitive concerns/dementias.

A theme table was developed for Objective 3 (Figure 9). The first theme that was identified was “Time Constraints” of all stakeholders. The “Time Constraints” that were identified, were directly related to the COVID-19 pandemic. Caregivers and family members reported that over the implementation period, local resources were functioning with reduced hours or completely closed, therefore they could not use resources as planned. Caregivers reported that they used the Toolkit as provided to get in touch with local resources, while providers reported they did not have time to use the resource at all. Time constraints within the

primary care office were apparent due to the testing and ordering requirements of sick visits, which did not allow providers enough time to use the abbreviated Toolkit. Also, limited staff to perform exams and administer the information within the Toolkit was a reported issue as well. The project administrator continued to communicate with local resources during the pandemic to find out the operating hours of community resources. This information was passed to stakeholders throughout the implementation period. The local Department of Public Health was called on numerous occasions by the project administrator to receive updates about reopening plans and the number of active COVID cases across the community. The project administrator continued to discuss and communicate with stakeholders about limitations and strain that COVID-19 was putting on the community regarding the project.

Figure 9

Objective 3 Qualitative Response Table

Theme	Exemplar	Action
Time Constraints	“{Caregiver} Unfortunately, most of the local referral sources weren’t available over the last six months, they are opening back up now though, we plan to attend Island Health for a tour at some point. Yes, I called and they said to come in at certain times for a tour.”	Communicated with local resources and the Department of Public Health about post COVID reopening protocols and planning. Communicated the re-opening plans to stakeholders through phone, email, or in person discussion.
	“{Caregiver} The only thing that has recently started operating again is meal service out of the Island Adult Day Health location, I called to ask.”	Relayed information to key stakeholders about local resources plans to reopen and resuming of local services.
	“{Provider} I don’t really know about feasibility, I thought I would get to it but after primary care testing and ordering the visit time was almost complete.”	Discussed how general primary care visits could be combined with dementia assessment during provider stakeholder discussions.
	“{Provider} At one point, all our staff was out, and we only had	Continued to discuss with providers barriers to

	<p>three providers working and had to lock the doors. We have just been trying to manage things.”</p> <p>“{Administrator} I have made mention of the pamphlet a few times to family members, but I haven’t handed any out, we have been short staffed as well.”</p>	<p>implementation in the primary care setting.</p>
<p>Post Implementation Planning for Future Use</p>	<p>“{Caregiver} I will definitely be using this (Toolkit) for social resources.”</p> <p>“{Administrator} I am going to recommend this (Toolkit) for providers to give out.”</p> <p>“{Family Member} After all the information that you gave, I am going to make an appointment for Adult Day Health now that I know when they are reopening.”</p> <p>“{Provider} I will be using this Tool(kit) in the future when I need it for sure.”</p>	<p>After the implementation period concluded, discussion groups were assembled and ease of use, overall usefulness, convenience, and feasibility of the Toolkits were discussed with stakeholders.</p>

An important theme that was identified during the project was “Post Implementation Planning for Future Use.” This theme was identified due to the numerous times that stakeholders reported they planned to use the Toolkits in a post pandemic setting. The project administrator conducted post implementation discussion groups with stakeholders to assess limitations to the project as well as ease of use, overall usefulness, convenience, and feasibility of the Toolkit.

Discussion

Summary

The key findings of this project suggests that though the Toolkit was not implemented or utilized as frequently as anticipated, the stakeholders found the information within the abbreviated, locally tailored Toolkit to be useful and informative. The first specific aim, to engage stakeholders to review and modify the KAER Model Toolkit was achieved through frequent discussion groups with stakeholders and participation by all stakeholders in a pre-implementation survey. The second specific aim, to implement the abbreviated, locally tailored Toolkit in order to diagnose and treat dementia was not met due to lack of cognitive concern/dementia visits and competing priorities associated with the COVID-19 pandemic. Though the Toolkit was reviewed by primary care providers, it was not used to diagnose and treat any new or pre-existing cases of dementia or cognitive concern in a primary care setting during the implementation period.

The third aim, to utilize the locally tailored, abbreviated Toolkit, was partially met. Stakeholders reported that they had referenced and referred to several resources that were outlined within the Toolkit, though the resources were not currently operating due to the pandemic. The positive percent change from questions eight and nine of the survey could imply that the stakeholders plan to use the information and resources within the Toolkit going forward when seeing cognitive concern/dementia patients. Therefore, it can be said that though the Toolkit was only partially utilized during the implementation period, it could be used by stakeholders for in the future. The results of the survey also demonstrated that the stakeholders found the Toolkit helpful and feasible and had confidence in the future use of the Toolkit.

Though all objectives were not met, there were several strengths of the project, including finding and learning about local resources that are available in the Kodiak community setting that were not being utilized by the stakeholders that participated in this project. Another

strength of the project was improved community networking between nonmilitary resident services and military resident services through information sharing. The continuous discussion groups allowed for improved information sharing between providers, caregivers, family members, and health entities that would have not occurred without the implementation of this project.

Interpretation

The association between the objectives and the outcomes can be highlighted through a positive percent change in the pre and post implementation level of confidence that stakeholders had in the resources and recommendations contained within the abbreviated Toolkit. This project was perceived as feasible and helpful for stakeholders within the Kodiak community. Though the community appeared to need more resources for dementia care, the stakeholders' survey results and discussions did not reflect that there was a "pressing" need for more resources for residents with cognitive concerns or dementias. One of the challenges of the Kodiak setting was the limited concern for dementia care among community health entities and stakeholders.

There is limited comparable data for implementing projects in rural and remote communities. The lack of data from rural or remote communities suggests that there is a need for further projects in rural and/or remote settings. The initial project was designed for providers to use in a primary care setting, but it became apparent that in a rural, remote community there are barriers for primary care providers to diagnose and treat dementia and cognitive concerns. Those barriers were not addressed in this project, though it was observed that less resistance was met when caregivers, family members, and healthcare administrators were asked to implement abbreviated Toolkits to improve quality of life for their clients and loved ones.

A strength of this project was the community members that participated in the project were eager to help, learn and integrate the Toolkit within their healthcare settings. The project administrator felt that this project did have an impact on the way the community views dementia care, and the Toolkit brought attention to specific resources that can be utilized locally and remotely in the future. As a healthcare system, this project was not as effective in eliciting change at a primary care level as anticipated, but it did elicit change of the perception of dementia care at a community level.

The Chronic Care Model (CCM) was used to guide the implementation of this quality improvement project. The CCM was the appropriate change theory for this project because the project was successful in developing informed and activated care team members, specifically caregivers and family members. By the end of the six-month implementation period, family members, caregivers, health administrators, and providers had improved access to local resources and expressed interest in improved partnerships with local health resources catering to geriatric care. The use of the abbreviated Toolkits improved health literacy through increasing knowledge of community resources for stakeholders. Educating providers, family members, and caregivers about what resources are available on a local level will improve health literacy, which can eventually lead to education about resources that are available on a remote level. The utilization of remote resources is extremely important, but often overlooked in a rural/remote setting. The improvement of health literacy in a primary care setting is a large part of the CCM and developing an activated, informed healthcare team is essential for those with a chronic care disease, such as dementia.

Rural healthcare provides specific challenges to integration of this project. It was anticipated that there would be some resistance to a “need” for this project and a level of

suspicion from community members, primarily because the project administrator was not known to the local community. The participants in this project were accommodating and honest with their feedback, but initial recruitment of participants in the first stage of the project was challenging. Previous literature has discussed the issues of stigma and perception of confidentiality of healthcare information in rural community (Douthit et. al, 2015). There were many community members who were unwilling to accommodate a doctoral project and did not return calls, emails, or text messages from the project administrator. This could be due to the lack of a community partnership with the project administrator, which could have influenced stakeholders to refrain from participating. Lack of anonymity, an observed issue with rural healthcare, was an expressed concern among stakeholders. Though the project administrator educated stakeholders on the content of the project, there was some concern about anonymity surrounding family and healthcare information, which could have led to lack of participation. Another reason for limited participation could have been wariness of health interventions for persons with mental health concerns or complaints, which is a known barrier to seeking health care services in rural populations (Douthit et. al, 2015).

Additional challenges associated with this project were realized during the implementation period due to the COVID-19 pandemic. Area resources, healthcare agencies, caregivers/family members, and providers were difficult to reach initially due to the restrictions of COVID-19. The pandemic caused two “shut-down” periods of two weeks during the implementation period. The focus of the healthcare entities were on management of COVID cases and maintaining the safety and health of the community. Another COVID-19 issue that was not anticipated during the implementation phase were workforce shortages that lingered post “shut-down,” which kept health partner participants lower than anticipated. Lack of staff also

kept local resources, that were recommended in the abbreviated Toolkits, closed for longer than anticipated. To remedy this issue, the project administrator continued to point out the ease of use of these online and remote resources in the abbreviated Toolkits, but they were not utilized during the six-month period by stakeholders. The lack of utilization of remote health resources could be related to issues with health literacy among some stakeholders, which is a common issue in the rural health setting that should be considered.

What can be learned from this project is that there are several challenges to implementation of a quality improvement project in a rural/remote community. This project demonstrates that there is a need for increased health literacy in rural health communities and any quality improvement projects that educate at the community level can be beneficial to breaking down barriers to improvements in quality care for healthcare entities as well as healthcare providers.

Limitations

Limitations that were identified throughout the project, but not included in the qualitative discussion groups, were the number of participants, age of participants, as well as the lack of diversity of the participants. There were no participants greater than age 65, therefore there was no firsthand experience of memory loss or cognitive concern evaluated for the project in the Kodiak community. The majority of Kodiak Island is made up of community members of Asian descent, yet there was only one Asian stakeholder represented in this project.

Another limitation of the project is the generalizability. This project was conducted in a rural, remote island setting in Southeastern Alaska, therefore the locally tailored tools that were developed for this project would not be applicable in other settings. The premise of the project, implementation of a Toolkit that implements local and culturally appropriate resources can be

replicated in any setting. The COVID-19 pandemic may have affected the internal validity of this study. The recruitment process for participants was affected by limited response, workforce shortages, social distancing protocols and busy work schedules that were all associated with the COVID-19 pandemic in this setting.

To minimize the effects of COVID-19 and encourage participation, remote surveys were offered through Survey Monkey, and socially distance discussion groups with only one participant at a time were conducted. Participants were asked their comfort level with meeting in person, phone interviews were offered and encouraged if desired to mitigate risk of noncompliance among stakeholders during the pandemic.

Conclusion

Though this project did not completely meet the desired outcomes, the project can be seen as useful for developing health literacy in rural and remote community settings among stakeholders. This project is sustainable for the next six months in this community; as the number of active COVID-19 cases decreases in Kodiak, Alaska, more healthcare entities have expressed interest in this project's Toolkit for their caregivers, healthcare providers, and families as a resource. In the primary care setting, the abbreviated Toolkit for providers has not been implemented, which demonstrates that it will not be sustainable in the future.

This project has demonstrated that improvements in community health literacy can mobilize activated, informed caregivers and families and their effects on the healthcare system in improving outcomes for loved ones, which warrants further study and investigation. It would be beneficial if future scholarship took this project in a more productive direction, which would

include improving health literacy among patients, families, and caregivers and then monitoring if improved health literacy improves the quality of care provided in a primary care setting.

The suggested next step for this project is to increase the number of health entities, patients, caregivers, families, and providers reached in a post COVID-19 community. The implementation phase would be more effective and less time consuming with the use of a local champion, a person with connections throughout the community unrelated to healthcare, that could assist the project administrator in a wider recruitment of stakeholders with more diverse backgrounds. Another suggestion is to implement the structure of this project in an alternate setting, specifically an urban community health center, to compare to the results with a rural, remote setting.

Though the overarching aim of implementation of the KAER Toolkit to increase early diagnosis and treatment of dementia and cognitive concerns in a rural and remote community were not met, improved health literacy was achieved in this rural community because of the implementation of this project.

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Appendix A

Evidence Summary Table & PRISMA Diagram

Clinical question/topic being systematically reviewed (generic PICO format): What strategies have been shown to have been shown to help aid in early diagnosis and treatment of dementia in primary care patients?
Inclusion/Exclusion criteria: Full text, last ten years, English language
Keywords/search terms: Diagnosis delay, early diagnosis, early intervention, primary health care
Databases Searched: ProQuest, CINAHL, PubMed

Qualitative Studies

Author(s) /year	Objective or purpose of the study (Identify the independent variable and the dependent variable)	Conceptual Framework AND Research Design used	Level of Evidence and Quality of Study (use John Hopkins Tool)	How was sample recruited/ Setting	Instruments used to collect data; briefly describe the instruments	Description of sample; Sample size	Most important significant findings <u>that answer your PICO question</u>
de Vries et al, 2013	To improve the response of primary care in terms of identifying people with undiagnosed dementia through the use of Primary Care Liaison position.	Explanatory mixed methods	III, B	Relevant stakeholders (GPs, organizations, multidisciplinary teams, nurses, psychologists, community matrons, health service commissioners, service users, caregivers, etc) were identified across West Midlands region of England. Widespread circulation of documents as the project proceeded to allow stakeholders to	An initial questionnaire was given to identified professional stakeholders to assess level of skill and knowledge. Focus groups were assembled and audio recorded. Consultation with people (n=70) with dementia and caregivers was made through chat groups, discussion with contacts, phone calls, and support groups.	Though no specific demographics are given about the sampled population, the West Midland has within it both urban and rural communities and a “mix” of socio-demographic groups.	The implementation of a Primary Care Liaison position to deal with mild cognitive impairment (MCI) and dementia patients would be beneficial in a primary care setting. Three main roles were identified for the PCL to assist GPs, counselling, screening, and education and health promotion. This position would be an integrated part of the Primary care team. Professional development and up to date competencies are needed among primary care providers to increasing their dementia-specific knowledge base. Education and a

				respond electronically, telephone conversations and meetings were set up with interested parties.	Researchers collected “stories” about experiences from these participants.		development program should be developed for GPs.
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Quantitative Studies

Author(s)/year	Objective or purpose of the study	Conceptual Framework AND Type of quantitative research design used	Description of how sample was recruited; Setting	Instruments used to collect data; briefly describe the instruments	Description of sample; Sample size	Most important significant findings <u>that answer your PICO question</u>
Ishiwata et al, 2014	This study reports community consultation center’s activity and outcomes and does this center make a significant difference in early diagnosis and treatment of MCI and dementia in Japan. The goal of this study and the Center was to identify early stage dementia.	Cohort study design	Free to public clinic that coordinates with PCPs. Recruited to this free standing clinic through word of mouth (495), casual visiting (260), mass median All patients that visited this clinic from November 20047 to January 012 was 2802. Center is an independent medical institute with one neurologist, one psychiatrist, three clinical psychologists, three receptionists. Consultation appointments are free of charge.	Consent upon arrival, interview is conducted and TPST is used to assess memory loss (listen to audio and answer questions). Staff interviews patient, caregiver, or family members on variety of questions. If patient is hearing impaired MMSE is performed by psychologist instead of TPST.	1565 registered patients. 519 men, average age 74 years old. 1046 women, average age 72 years old. 561 patients consulted with center once or more.	81% of dementia cases in this study are Alzheimer’s disease, 18% cerebrovascular dementia. Lewy body and frontotemporal dementia were less prevalent than previously reported. About half of all users at the center were suspected of dementia, both MCI and dementia (n=244) were diagnosed by medical institutes and consisted of 60% of final diagnoses (n=409). When interviews by trained staff and self screening (TPST) indicated dementia, coordination with PCP and community medical institutes makes rapid diagnosis and treatment of dementia possible. Did they answer the question?

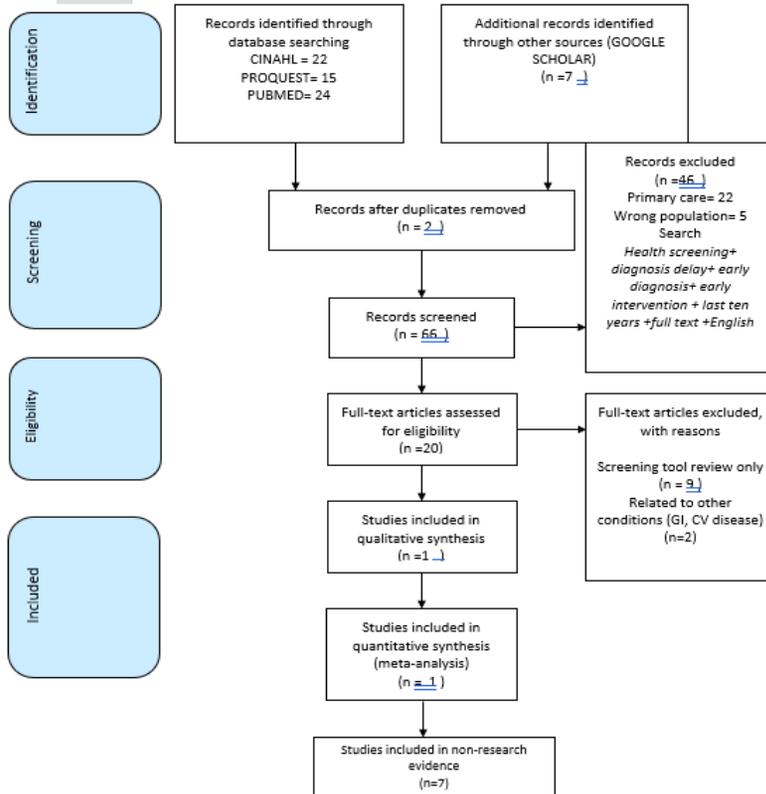
Non-Research Evidence

Authors(s)/year	Type	Setting	Findings that help answer the EBP question	Limitations	Evidence level and quality
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Pond, D (2012)	Algorithm	Primary care dementia patients in Australia.	General practitioners are provided with education and measures to investigate, diagnose, and treat a patient with memory changes and dementia. Lab testing and appropriate course of action was outlined for general practitioners.	Socioeconomic and cultural variation was not discussed.	V / B
Santacruz & Swagerty (2001)	Algorithm	Dementia in primary care patients, management and treatment.	Algorithms and differential diagnoses such as MCI and age related memory changes are addressed in this expert opinion piece. Diagnostic criteria and algorithms for treatment options and decision making were provided for confidence and education to primary care providers.	Outdated, some treatment options have changed since the time of this article.	V/B
Tung et al (2018)	Opinion of respected authorities	Diagnosis guidelines in dementia syndrome in primary care	Mayo Clinic conducted research, proposed a systematic, evidence-based approach to managing the patient with new cognitive symptoms in primary care setting.	Diversity of patients and some major systems barriers to diagnosis were not discussed	IV/ B
GSA (2020)	Toolkit	Patients with cognitive impairment in primary care setting	Toolkit helps primary care healthcare providers use the KAER Model to diagnosis and treat dementia and/or cognitive impairment. Provides step by step algorithm and educational tools for primary care providers to have confidence in diagnosing and treating dementia.	Limitations of access to care were not discussed.	V/A
Alzheimer's Association (2020)	Toolkit	Patients presenting for Medicare Annual Wellness Visit at primary care.	Bundle of tools including algorithms, three validated cognitive assessment tools, three validated informant assessment tools, assessment of patient tools, includes article on how to conduct assessment of Medicare Annual Wellness Visit.	Limited patient population (Medicare patients).	V/A
California Alzheimer's Disease Centers (2018)	Toolkit	Patients with cognitive impairment in primary care setting	Bundle of tools including scripts for providers, referral resources, and guidance on billing directed towards primary healthcare providers.	Toolkit could be more inclusive for diverse populations and educational resources.	V/A
Center to Advance Palliative Care (2020)	Online Toolkit	Patient with MCI and/or dementia in palliative care, hospice care setting	Online bundle of tools and curriculum for healthcare providers. Included is curriculum of cognitive assessment tools, patient symptom tools, caregiver strain tools, advanced planning tools, and anxiety and depression tools. Educational modules concerning dementia care, communication skills, pain management, symptom management, managing care gaps, and prevention of crisis.	Cultural implications of patients and caregivers were not discussed in this curriculum.	V/A



PRISMA Flow Diagram

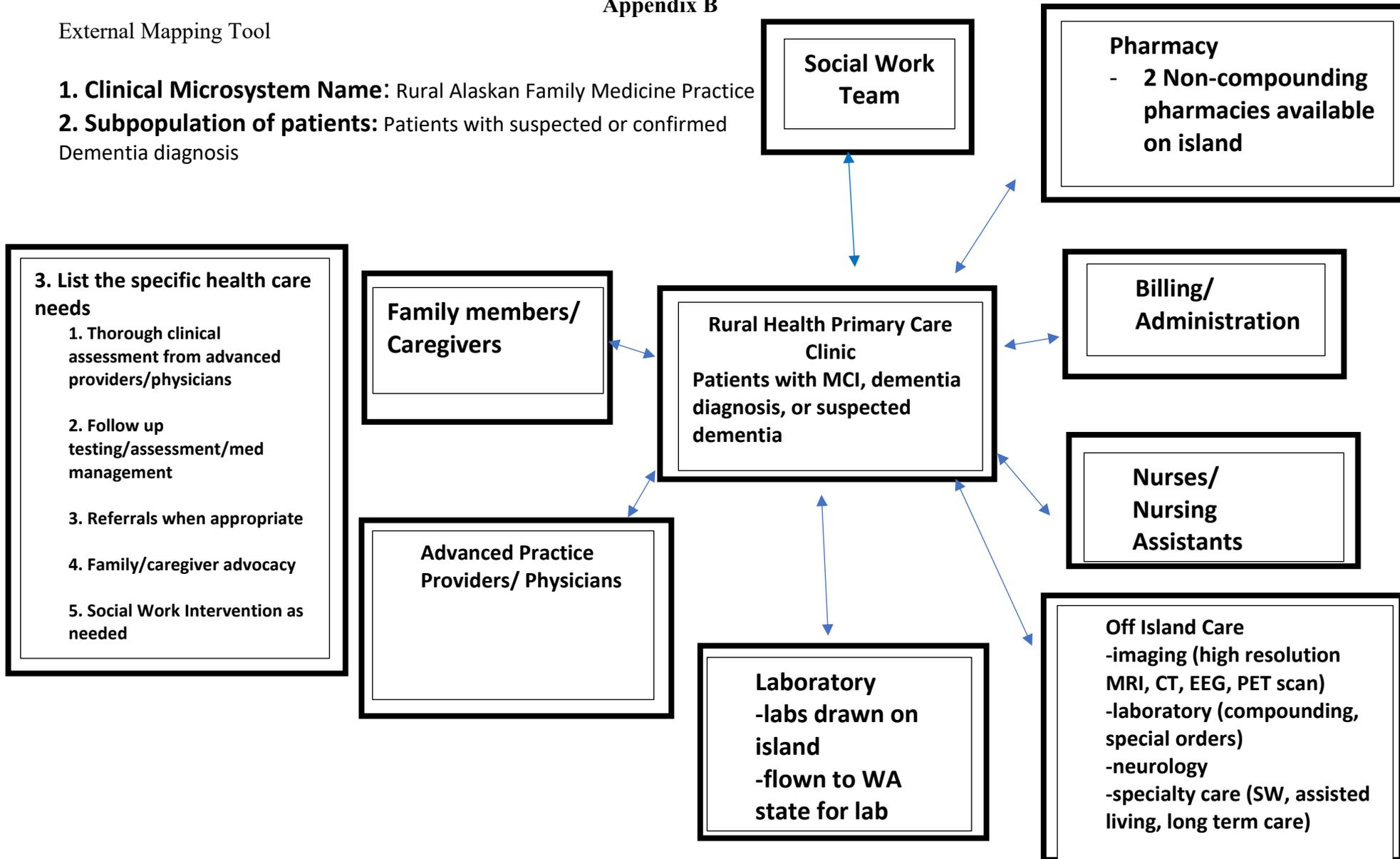


From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *CMAJ* Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Appendix B

External Mapping Tool

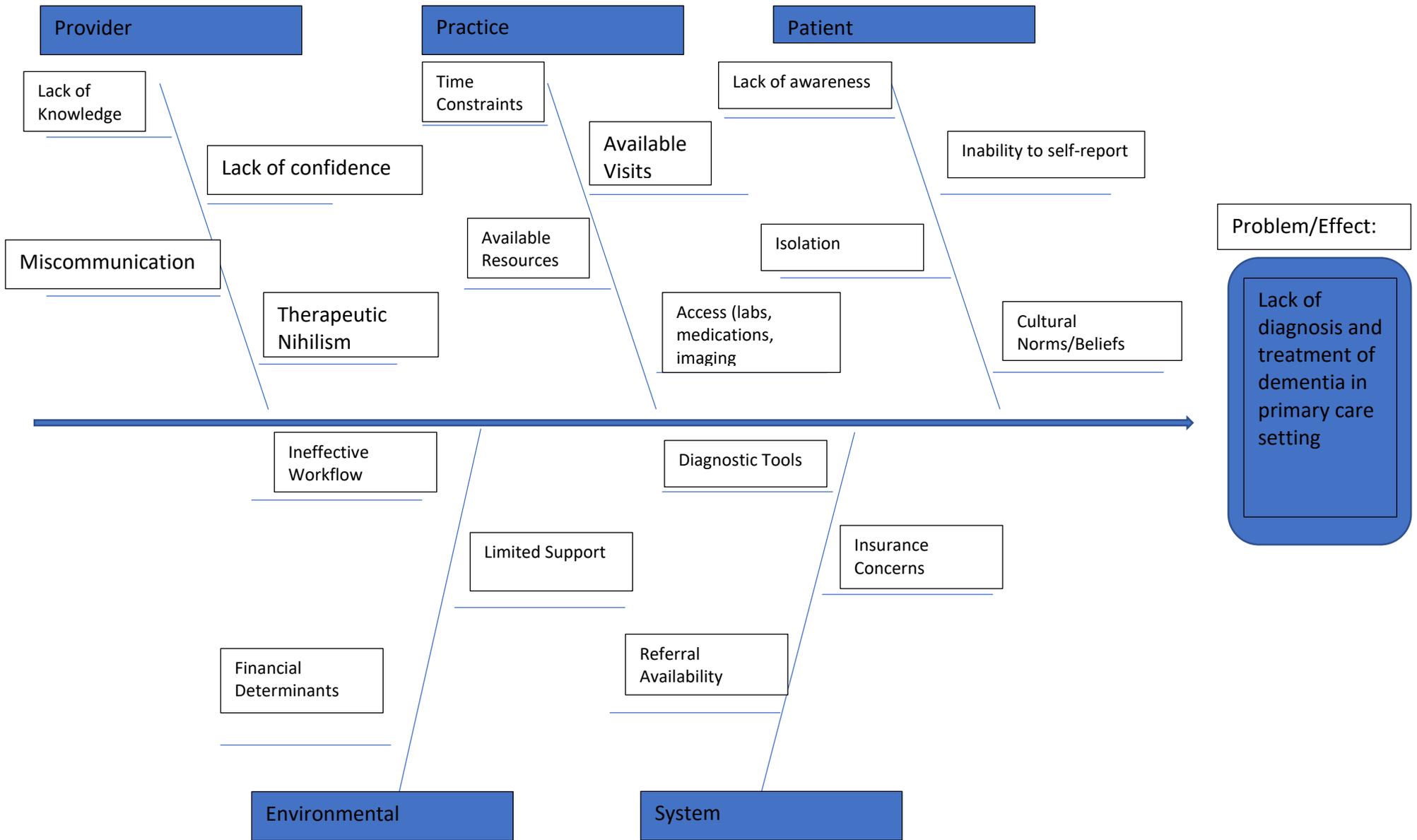
- 1. **Clinical Microsystem Name:** Rural Alaskan Family Medicine Practice
- 2. **Subpopulation of patients:** Patients with suspected or confirmed Dementia diagnosis



Improvement Ideas: Feedback from NA and Nursing Staff. Thorough assessment from Advanced Practice Providers/Physicians for dementia and memory loss using a guided toolkit that includes dementia screening tests (2), caregiver screening, and guided algorithms of lab and imaging testing that should be ordered.

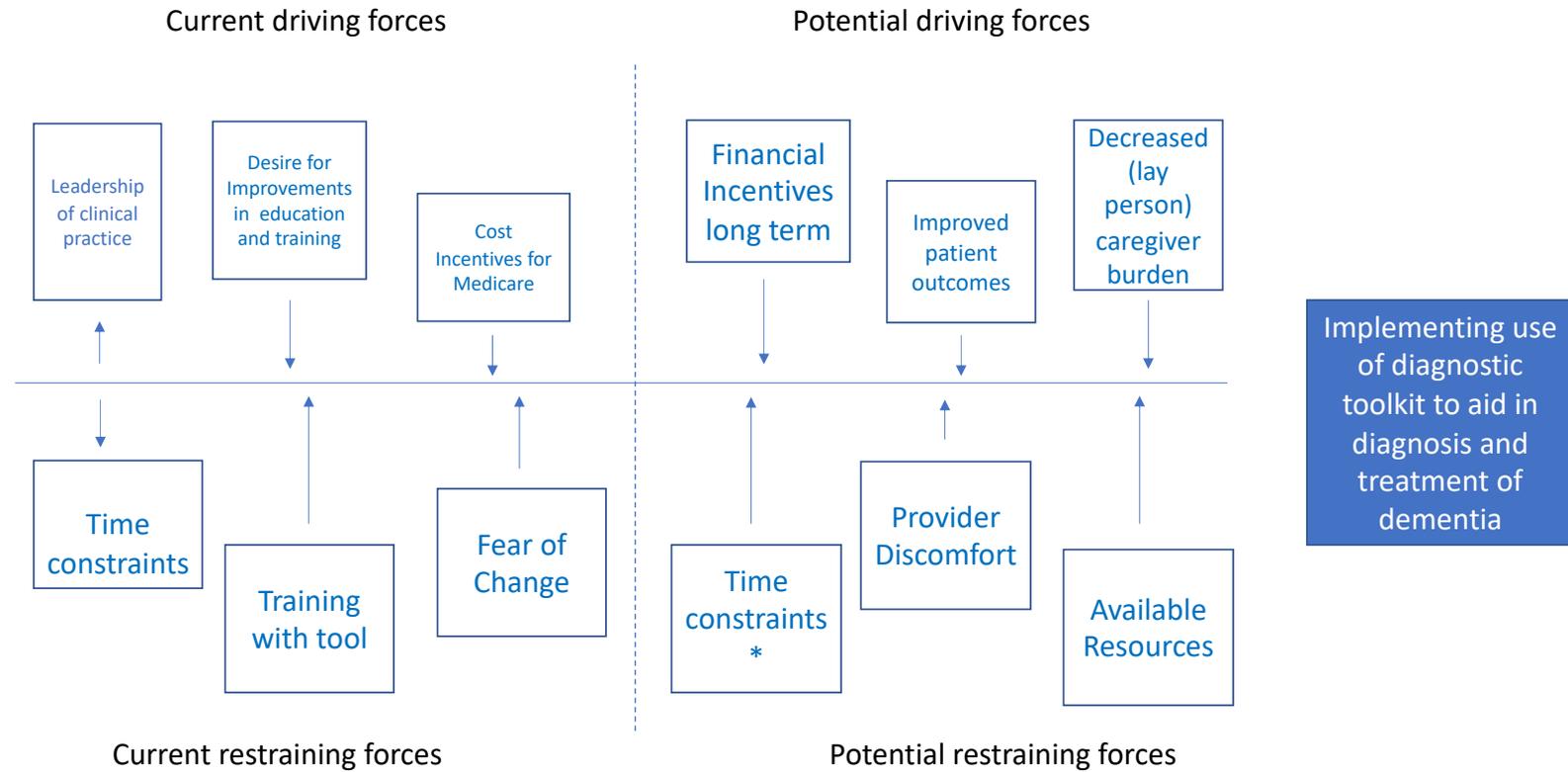
Appendix C

Cause and Effect Diagram



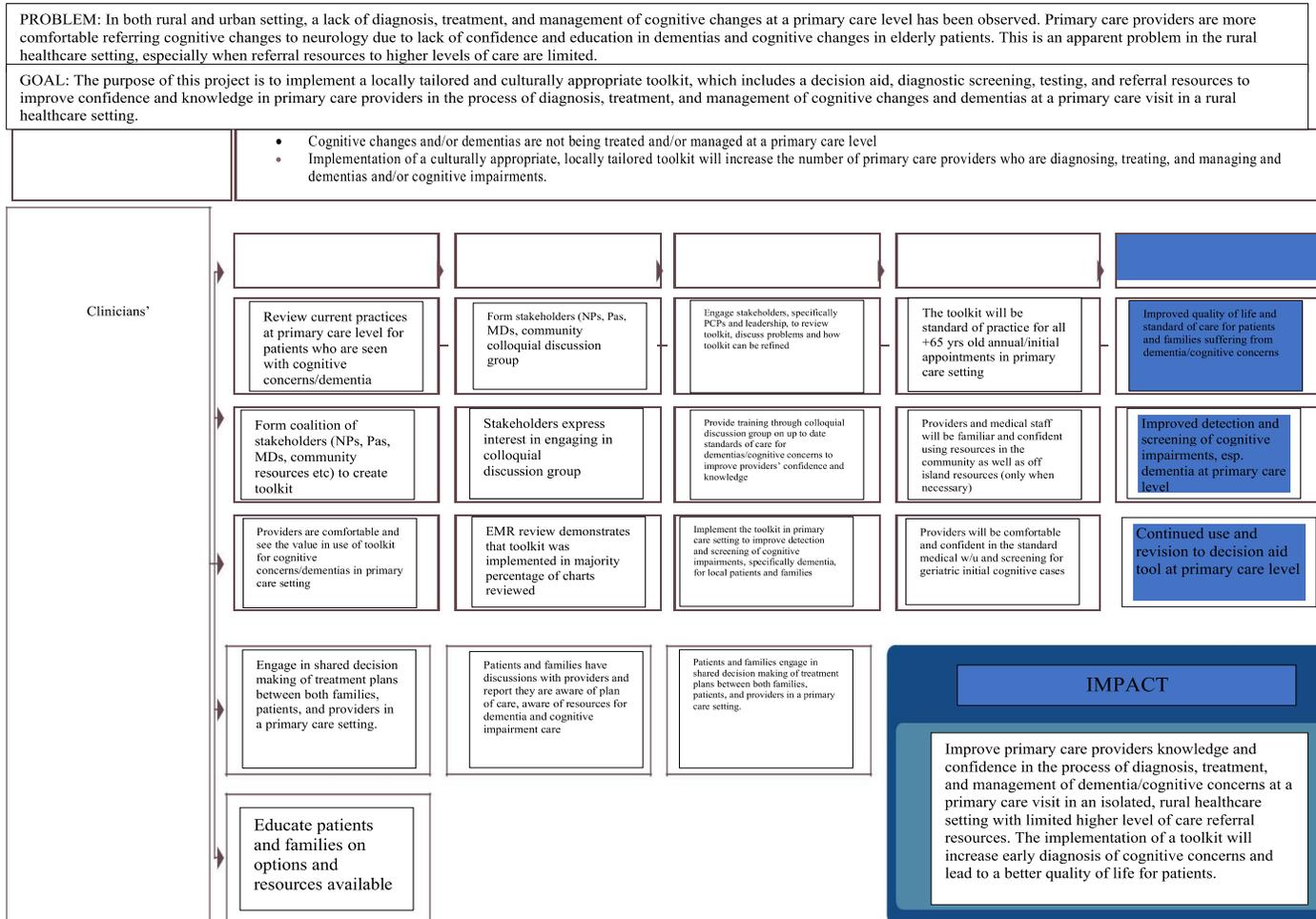
Appendix D

Force Field Analysis



Appendix E

Logic Model



Appendix F

Measurement and Analytic Strategy Table

Measures					Analysis
Aim or Objectives	Outcomes/ outputs	How operationalize/ measure	Where will you get the information	Will you have a comparison	Analysis
Engage stakeholders, specifically PCPs and leadership, to review toolkit, discuss problems and how toolkit can be refined	Form coalition of stakeholders (NPs, Pas, MDs, community resources etc) that come together to form collegial discussion group	Participation in collegial discussion group	Minutes taken from discussion group meeting	No	Anecdotal Evidence
Provide training through collegial discussion group on up to date standards of care for dementias/cognitive concerns to improve providers' confidence and knowledge	Provide education on developed toolkit; including diagnostic screening tests, medical workup, and referral resources to key stakeholders	Participation in collegial discussion group	Minutes taken from discussion group meeting	No	Anecdotal Evidence
Implement the toolkit in primary care setting to improve detection and screening of cognitive impairments, specifically dementia, for local patients and families	The toolkit will be standard of practice for all +65 yrs old annual/initial appointments in primary care setting	Greater than 95% of the 10 charts of patients, greater than 65 years old, reviewed on monthly basis (denominator) had results for one/or more (numerators): <ul style="list-style-type: none"> - Screening test - Lab testing - Referrals - Discussions with patients/families (# of elements/10)	EMR Review	No	Frequency, proportions
Providers are comfortable and see the value in use of toolkit for cognitive concerns/dementias in primary care setting	Providers will be comfortable and confident in the standard medical w/u and screening for cognitive cases	Post Pilot Survey- reported proportion of people who agree or strongly agree with statements (do you feel confident discussing cognitive changes with patients and their families, do you feel confident in the tools provided in primary care for making decisions regarding dementia diagnosis, do you feel comfortable managing dementia as the disease progresses, do you believe additional tools to help manage dementia diagnosis and management would be helpful to your practice, do you feel confident prescribing dementia medications at this time?)	Survey constructed for providers' opinion	No	Frequency, proportions
Engage in shared decision making of treatment plans between both families, patients, and providers in a primary care setting.	Family members, patients, and community members will be aware of plan of care, aware of resources for dementia and cognitive impairment care	Post Visit Survey- reported proportion of people who agree or strongly agree with statements (did patients/families feel listened to, do you understand the information that the provider was sharing with them about both disease progression, diagnosis, and treatment planning; did you feel involve/engaged in the decision-making process, did you feel involved in the treatment decisions at the time of the visit?)	Survey constructed for patient/caregivers/families	No	Frequency, proportions

Appendix G

Survey Domains Table

: For Stakeholders Coalition (NPs, PAs, MDs)

Who is the intended recipient of your questionnaire?	The intended recipient of these questions are for MDs , PAs, or NPs who are working in the primary care/ urgent care clinical setting that will be using a new toolkit to help <u>diagnose and treat dementia/cognitive impairments.</u>
When will you administer the questionnaire? (e.g. pre, post, both, monthly, etc)	These questions will be discussed as baseline data collecting about providers' opinions about dementia, resources, and quality improvement projects. It will be evaluated by <u>collecting minutes from the group discussion and evaluating anecdotal evidence.</u>
What outcome are you measuring? (refer to your logic model)	Providers' opinion and attitudes about dementia/cognitive concerns in primary care visits.
What concepts/domains/attributes are you measuring? (Examples: Knowledge, beliefs, attitudes, perceptions, opinions, confidence, self-efficacy, behavior, attributes, feasibility, value added, etc.)	The questions will measure providers' opinions, beliefs, attitudes and perceptions about the following: do you feel this quality improvement project is necessary in the rural primary care setting, do you face challenges when diagnosing patients with cognitive changes/dementia in the rural healthcare setting, do you face challenges when treating patients with cognitive changes/dementias in the rural healthcare setting, do you believe you have adequate resources available in this community to manage a patient's dementia prognosis and care, is dementia a priority problem?
What is your change theory?	Lewin's Change Theory
What dimensions from your change model are relevant to be included in your questionnaire?	Change because it is critical for the behaviors, attitudes, and perceptions of providers to be able and willing to change for this quality improvement project

Table G.2 Post Pilot Survey: For Coalition (NPs, PAs, MDs)

Who is the intended recipient of your questionnaire?	The intended recipient of this survey are MDs , PAs, or NPs who are working in the primary care setting that will be using a new toolkit to help diagnose and treat <u>dementia/cognitive impairments.</u>
When will you administer the questionnaire? (e.g. pre, post, both, monthly, etc)	This survey will be administered after the pilot of the "toolkit" has been implemented for three months. It will be evaluated using a Likert Scale
What outcome are you measuring? (refer to your logic model)	Providers' confidence and knowledge and effectiveness of the toolkit during primary care visits for appropriate patients.
What concepts/domains/attributes are you measuring? (Examples: Knowledge, beliefs, attitudes, perceptions, opinions, confidence, self-efficacy, behavior, attributes, feasibility, value added, etc.)	This survey will measure providers' confidence and knowledge as well as their opinions. There will be questions that pertain to the treatment of dementia and cognitive concerns to measure provider's self-confidence including do you feel confident discussing cognitive changes with patients and their families, do you feel confident in the tools provided in primary care for making decisions regarding dementia diagnosis, do you feel comfortable managing dementia as the disease progresses, do you believe additional tools to help manage dementia diagnosis and management would be helpful to your practice, do you feel confident prescribing dementia medications at this time?
What is your change theory?	Lewin's Change Theory
What dimensions from your change model are relevant to be included in your questionnaire?	Change and Refreezing- goal is for long term use of this toolkit to improve quality care and outcomes to patients suffering from cognitive impairments in a rural primary care setting.

Table G.3 Post Visit Survey: For Patients, Families, or Caregivers

Who is the intended recipient of your questionnaire?	Patients, caregivers, or family members will fill out a survey about their experience after the visit is completed.
When will you administer the questionnaire? (e.g. pre, post, both, monthly, etc)	A survey will be conducted any time after the completed visit of a patient visit that a toolkit was used to determine cognitive impairment/ dementia. The toolkit does not have to be completed or successfully used by the provider during the visit. The family members/caregivers who were present at the visit can also be responsible for this survey in addition to the patient.
What outcome are you measuring? (refer to your logic model)	Caregivers/ patients confidence in plan of care, resources for their loved one, referrals to on island or off island resources for dementia and/or cognitive impairment care. It will be evaluated using a Likert Scale.
What concepts/domains/attributes are you measuring?	Measuring perceptions and attitudes of family members about primary care visit for their loved one, including their opinions about shared decision making and improved

Appendix H

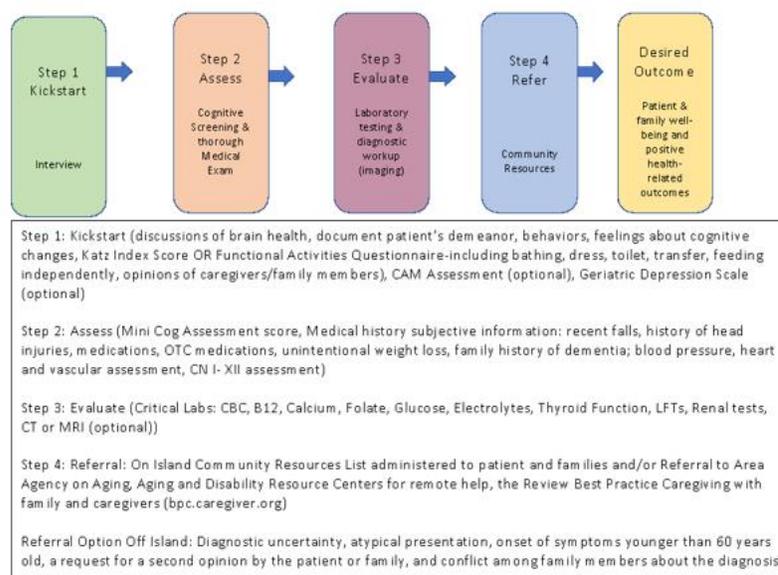
Clinical Quality Improvement Checklist

CLINICAL QUALITY IMPROVEMENT CHECKLIST		
Date: 04/01/21	Project Leader: Meredith George	
Project Title: Improvement of Diagnosis and Treatment Outcomes for Dementia Patients in Primary Care		
Institution where the project will be conducted: Kodiak Island Ambulatory Care Clinic		
Instructions: Answer YES or NO to each of the following statements about QI projects.	YES	NO
The specific aim is to improve the process or deliver of care with established/ accepted practice standards, or to implement change according to mandates of the health facilities' Quality Improvement programs. There is no intention of using the data for research purposes.	X	
The project is NOT designed to answer a research question or test a hypothesis and is NOT intended to develop or contribute to generalizable knowledge.	X	
The project does NOT follow a research design (e.g. hypothesis testing or group comparison [randomization, control groups, prospective comparison groups, cross-sectional, case control]). The project does NOT follow a protocol that over-rides clinical decision-making.	X	
The project involves implementation of established and tested practice standards (evidence based practice) and/or systematic monitoring, assessment or evaluation of the organization to ensure that existing quality standards are being met. The project does NOT develop paradigms or untested methods or new untested standards.	X	
The project involves implementation or care practices and interventions that are consensus-based or evidence-based. The project does NOT seek to test an intervention that is beyond current science and experience.	X	
The project has been discussed with the QA/QI department where the project will be conducted and involves staff who are working at, or patients/clients/individuals who are seen at the facility where the project will be carried out.	X	
The project has NO funding from federal agencies or research-focused organizations, and is not receiving funding for implementation research.	X	
The clinical practice unit (hospital, clinic, division, or care group) agrees that this is a QI project that will be implemented to improve the process or delivery of care.	X	
The project leader/DNP student has discussed and reviewed the checklist with the project Course Faculty. The project leader/DNP student will NOT refer to the project as research in any written or oral presentations or publications.	X	
ANSWER KEY: If the answer to ALL of these questions is YES, the activity can be considered a Clinical Quality Improvement activity that does not meet the definition of human research. UMB IRB review is not required. Keep a dated copy of the checklist in your files. If the answer to ANY of these questions is NO, the project must be submitted to the IRB for review.		

Appendix I

Abbreviated Toolkit for Healthcare Providers

Locally- Tailored KAER Model Toolkit Resource



Appendix J

Abbreviated Toolkit for Caregiver/Family Member Pamphlet

LOCAL HOUSING

Senior Housing Options:

Independent Living: Bay View Terrace, Heritage Heights, Emerald Heights

Assisted Living: Sunrise Assisted Living (907) 539-8827

Skilled Nursing: Chiniak Bay Elder House (907)486-7800

STAY SAFE

Lifeline: Managed by Senior Citizens of Kodiak, Inc. Lifeline provides an emergency button, on either a necklace or bracelet, that is connected to a response center allowing the security to live independently, while still having help close at hand in an emergency. Phone: (907)486-6181

ON ISLAND SUPPORT

Family Caregiver Support Program (FCSP)
Provides caregivers of persons over 60 with information and support, whether the senior lives on Kodiak Island or in the lower 48. FCSP can identify and assess caregiver needs and provide respite services, information & referral, caregiver training, and the "Caring Islander" newsletter. We schedule two family caregiver trainings per year and have monthly support groups. Address & Phone: 302 Erskine Ave. Kodiak, AK 99615 (907)486-6181

Island Cove Adult Day Program A program of Senior Citizens of Kodiak, Inc., Island Cove provides persons with dementia, those needing socialization or just a safe active environment during the day, with exercise, activities, coordination of appointments and transportation. Breakfast, lunch, and snacks are provided. Care coordination and medicine management are available. Open M-F 8-5 and 9:30-3:00 on weekends. Address & Phone: 302 Erskine Ave. (Lower Level) Kodiak, AK 99615 (907)486-2203

FOR CAREGIVERS AND FAMILY MEMBERS

CARING FOR A LOVED ONE ON KODIAK ISLAND

This pamphlet is designed for family members and caregivers with loved ones suffering from cognitive impairments and/or dementia while living in Kodiak, Alaska.



LOCAL HEALTHCARE

Providence Kodiak Island Medical Center
(PKIMC) Phone: (907)486-3281

Kodiak Community Health Care Clinic
(KCHC) KCHC is proud to offer discounts to those individuals with or without insurance coverage. Phone: (907)481-2484

Kodiak Island Ambulatory Care Clinic
(KIACC) A family practice clinic that provides urgent care and takes walk-in appointments. Phone: (907)486-6188

Hospice and Palliative Care of Kodiak, Inc.
Phone: (907) 512-0600

Kodiak Area Native Association (KANA)
KANA provides medical & dental services to beneficiaries on Kodiak Island. KANA also provides information and outreach to help elders find needed services. KANA provides congregate and home delivered meals in the villages. Phone: (907)486-9800



AIDS FOR INDEPENDENT LIVING

Equipment Loan Program Senior Citizens of Kodiak, Inc. has wheelchairs, walkers, canes, bedside commodes, hospital beds, shower chairs and other medical equipment for loan to anyone in the community. There are no rental fees for this service. Phone: (907)486-6181

Alaska Center for Independent Living ILC is an Aging and Disability Resource Center (ADRC) offering options counseling and person-centered intakes for elders and those with disabilities seeking long term services and supports, including nursing home transitions and a Veterans-directed program that enables Veterans to receive what they need in a self-directed manner. Phone: (907) 486-0493

“There are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.”

- Rosalyn Carter -



COMMUNITY HELP

Senior Citizens of Kodiak (SCOK): SCOK provides a variety of support services for those persons over 60. Congregate Meals are served Monday – Friday, noon to 1:00, at the Kodiak Senior Center. Home Delivered Meals are available for 7 days a week. Helps with information and outreach, link-up to needed services, housing, state and federal benefits, insurance, completion of forms and care coordination. Senior In-Home Service Program, providing care coordination and chore service for non-Medicaid CHOICE Waiver eligible seniors. Phone: (907)486-6181

Need a Lift?

 Kodiak Area Transit System (KATS) KATS is a coordinated transportation service operated by Senior Citizens of Kodiak, Inc. Rides are scheduled 24-hours in advance. The fare is \$2.00 per ride, and the hours of operation are: 6:30 am to 6:30 pm Monday—Friday and 10 am to 3 pm Saturday and Sunday. Phone: (907)486-8308

• REMOTE RESOURCES:

Kodiak Senior Center:
kodiakseniorcenter.org

Best Practice Caregiving Courses:
bpc.caregiver.org

National Alzheimer's Call Center:
 1(800) 272-3900

National Alzheimer's and Dementia Resource Center (NADRC):
Nadrc.acl.gov

Silver Sneakers Workouts:
Tools.silversneakers.com