

KANSAS ALZHEIMER'S STATE PLAN:
THE KU ALZHEIMER'S DISEASE CENTER CONTRIBUTIONS TO EDUCATION, EXPANDING
DEMENTIA CAPABILITY AND SUPPORT SERVICES

Testimony: Kansas Senior Care Task Force
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The KU Alzheimer's Disease Center has been working tirelessly to improve and expand statewide dementia capability through targeted initiatives. Many of those initiatives align with recommendations cited in the 2020 Alzheimer's State Plan. Our initiatives have been developed to address gaps in both education and services, provide a diverse menu of access and support options and to move dementia capability in the direction of an empowerment-based model. These efforts work alongside advancing research efforts which Dr. Jeff Burns addresses in his testimony.

Primary focus has included advancement of early detection through education and an embedded interdisciplinary post diagnosis support structure, building dementia capacity in community professionals, expansion of virtual education and increasing access to dementia specialized counsel and support to those in rural Kansas and underrepresented minorities. The following provides an update of the Center's efforts in State Plan recommended areas of focus.

RURAL KANSAS/ACCESS TO CARE/FAMILY CAREGIVER/PERSON LIVING WITH A DEMENTIA

The Cognitive Care Network

The Cognitive Care Network (CCN) began in 2019 and has continued to grow. The CCN is a partnership with primary care providers to:

1. Provide a collaborative system to extend dementia specific resources in primary care.
2. Move the current crisis driven model of dementia care to an empowerment model of support.
3. Extend function, prevent neuropsychiatric crisis, reduce caregiver burden and decrease avoidable health care costs.

Providers receive education in early detection, dementia evaluation, diagnosis disclosure and disease management and are provided with a practice-based dementia specialized navigator to follow with their patients and families at point of diagnosis. This initiative not only provides needed education and support to those primary care providers who are on the front line in advancing early detection, but also to bridge patients and families to education and support at this key juncture. This practice based support increases service usage typically dismissed in these mild stages. There are currently 62 providers in the CCN. In addition to practices in the Kansas City area, the CCN also supports practices in Barton county, Wilson county and Harvey county. Through a new partnership with the University of Kansas Health System's Care Collaborative, Smith county will be added in the coming weeks, with eight additional rural practices within the next four months.

Figure A and B show the results of survey data both to families served as well as providers in the Cognitive Care Network.

Figure A: Survey results from individuals and families who has received navigator support

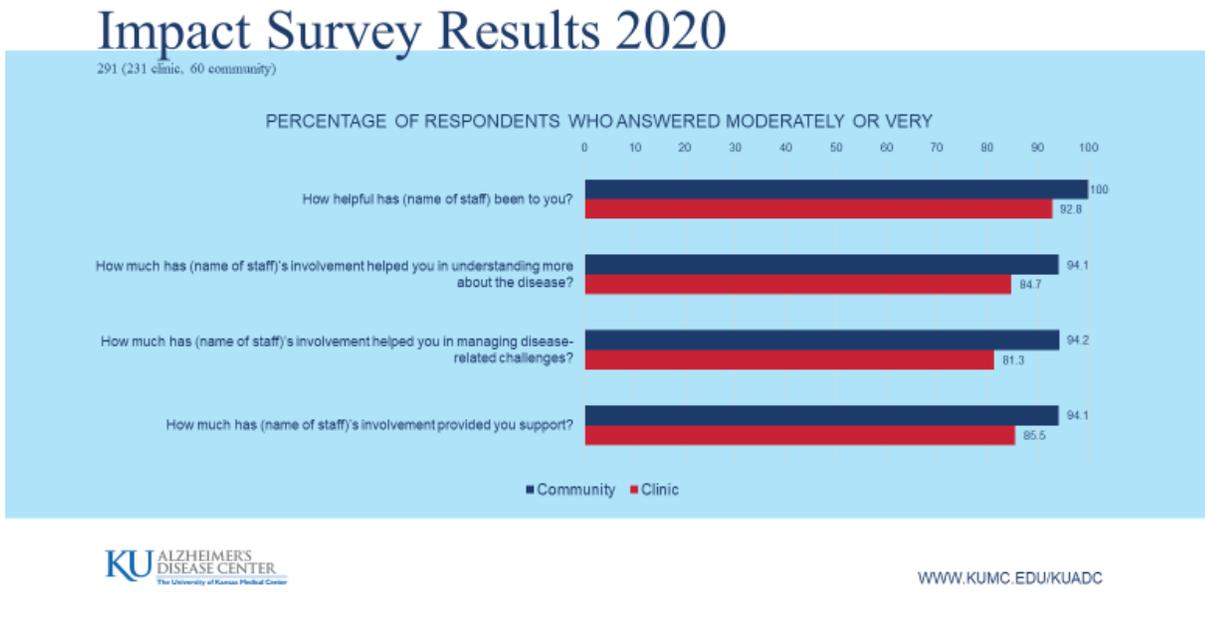


Figure B: Survey results from Providers participating in the CCN.



Kansas Care EcoSystem Initiative

The Kansas Care EcoSystem Initiative is an Administration of Community Living funded effort that links community facilitators with dementia specialized social workers. This project is a partnership with OCCK, Inc of Salina, Futures of Winfield, Garden City Community College and Prairie Faith Shared Health Ministries which serves six congregations located in Wakeeney, Ellis and Ogallah.

Community facilitators serve as a bridge between individuals and families and dementia specialized support provided both in person and virtually, through the creation of “Zoom Rooms”.

The Memory Clinic

The Memory Clinic at KU ADC is the diagnostic and dementia management center for the region. Since 2019, patients have come from 59 Kansas counties, including 21 counties from the western half of the state.

Education

Education is important to the KU ADC. Efforts to ensure that educational opportunities are available to those who live in rural areas have been significant and discussed further below.

TRAINING AND WORKFORCE/ACCESS TO CARE

Effective early detection and dementia capable education, management and support require a continuum of prepared community workers and professionals. KU ADC, therefore, provides customized training based on point of contact and potential role in continuum.

Pocket Talks

The pocket talks address the needs of busy providers and other health care professionals while providing a forum for ongoing education. The monthly pocket talks occur over the lunch hour and last for ½ an hour. CME is provided. A flyer indicating the topics this year is attached to this testimony. 247 providers have attended the pocket talks.

Managing Dementia

This training is for providers and practice based nurses, primarily geared to those who have agreed to partner with the CCN or interested in adopting CCN protocols. 76 providers have attended this year.

SPARK

SPARK is a program created by the Lewy Body Disease Association in partnership with the Mayo Clinic. It focuses on the diagnosis and management of Lewy Body Disease. 144 providers attended the April event and are expecting over 100 for an October program.

The Dementia Intensive

The Dementia Intensive is a partnership of eight social work programs. It is a day long event looking at social work practice with individuals with a dementia and their families. While primarily directed at social work students, those social workers who are new to working with individuals who are at risk for or have a dementia are also welcome. In 2019, 91 students attended. Pre/post testing demonstrated significant impact in the area of stigma. The Journal of Social Work Education has accepted a subsequent article. A virtual dementia intensive was held in 2021, with 36 students attending.

MentorD

Directed at practicing social workers who have a fundamental knowledge of dementia, this program is a small group mentorship program. Registrants participate in 12 monthly sessions which provide both content and time for case discussion and application. The pilot year ran from July 2020 to June 2021. Over half of the participants were from rural areas.

Community Health Worker Training

Funded through a grant from the National Institutes of Health, the KU ADC formed a community advisory committee with representation from diverse populations to create a curriculum for community health workers. This curriculum addresses basic knowledge about cognitive changes and guidance on when/where and how to connect with appropriate resources.

The Experience League

This program is driven by individuals who have been diagnosed with Mild Cognitive Impairment or other early-stage dementia. Panelists share information about when they recognized cognitive concerns, journey in obtaining diagnosis, how they cope and what is useful from professionals. This is shared virtually to academic classrooms across the state. In the last academic year, they presented to approximately 120 students ranging from occupational therapy, social work, nursing and certified nurse's aide training programs.

PAIRS

PAIRS is a program that connects first year medical students with individuals diagnosed with MCI or in early stages of Alzheimer's or related dementia to expand the medical student's knowledge and understanding of the subtleties of early diagnosis as well as the impact on life.

This is the 8th year of PAIRS, with 103 medical student alumni of the program.

Other

In addition to the above programs, KU ADC provides opportunities for interns and fellows to expose and encourage pursuit of neurology and dementia related specialization.

PUBLIC AWARENESS/FAMILY CAREGIVER/PERSON LIVING WITH A DEMENTIA

MyAlliance Program

MyAlliance is a web-based support program. People join through the KU ADC website and are provided customized weekly information ranging from brain health tips, caregiver advice and support, advice and tips for individuals living with a dementia, weekly webinars and research opportunities. Currently, there are more than 1200 people who take part in MyAlliance.

Aging with Grace

Aging with Grace is an education program provided through faith communities culturally tailored to the African American Community. Aging with Grace has been presented dozens of times over the last 3 years.

Envejecimiento Digno

This is an education program about dementia geared to individuals who are primarily Spanish speakers. In addition to this education program, a text based support program for caregivers who are primarily Spanish speakers has recently started.

Community talks

KU ADC faculty and staff are also invited to speak to various community groups and oblige those requests as much as possible.

LEAP

The Lifestyle Empowerment for Alzheimer's Prevention Program. Dr. Burns addresses this program in his testimony.

Virtual and live support groups

The ADC now hosts 10 support groups, ranging from general caregiver groups, to specific disease-specific caregiver groups and early-stage support groups.

Despite all the work being done and new programs being planned, there continues to be significant needs among those who have a dementia and their families. The consequences of the pandemic were devastating to these individuals. Further work is needed to not only fully understand impact, but also integrate new responses as part of an emergency preparedness plan. Many families also continue to be lost between insufficient resources to secure needed respite care help, but outside of current criteria for aide. Early stage activity programs continue to be rare. Finally, stigma and lack of information continue to pose challenges to early recognition and education.

Our efforts continue. We ask given the significant role of the KU Alzheimer's Disease Center in research, education and support that faculty of the ADC be considered for participation in any future Alzheimer's task force and related advisory committee.

Thank all of you for efforts in moving the approach towards Alzheimer's disease and other dementias in a stronger direction.