



# Utilizing Research & Policy Development to Address the Needs of Alzheimer's Patients & Their Families

Kelly Krumwiede PhD, RN

Kristen Abbott-Anderson, PhD, RN

# Objective

Describe an innovative community-academic partnership and service learning experience that provides an opportunity for students to be involved in research and policy development.



# Purpose

The purpose of this community-academic partnership was for nursing students to assist in data analysis and advocate for system level changes to address the needs identified by individuals with Alzheimer's and their families.



# Purpose

The purpose of this research study was to explore undergraduate students' perceptions of participating in data analysis of archival data from the ACT on Alzheimer's community health needs assessment as well as in writing policy briefs and presenting them to key stakeholders in the community or to a Minnesota legislative representative.

# Service Learning

Service learning in nursing education provides opportunities for students to apply skills and knowledge to address real-world issues to meet individual, family, and societal needs (Shannon, 2016).



# Background

- Worldwide, ~44 million people have Alzheimer's disease or another type of dementia.
  - Globally, the cost of Alzheimer's disease and dementia is ~\$605 billion.
  - An estimated 5.5 million people have Alzheimer's Disease in the US
    - 5.3 million of those diagnosed are age 65 or older
    - 200,000 of those diagnosed have early onset disease
    - 6<sup>th</sup> leading cause of death in the United States
    - Among people aged 70, 61% diagnosed with Alzheimer's will die before age 80 compared with 30% of those not diagnosed with Alzheimer's Disease
- (Alzheimer's Association, 2017)
- When hospitalized, patients with dementia have higher risks “of delirium, falls, agitation, new incontinence, untreated pain, and other adverse events” (Maslow & Mezey, 2008, p. 42).

# Method

- Qualitative study
- Step One – Research Class & Data Analysis
  - Junior nursing students analyzed archival data from the ACT on Alzheimer’s community health needs assessment.
  - Students completed surveys after working in groups to analyze the data & present their findings to their peers.
- Step Two – Community Health Class & Advocacy
  - Senior nursing students wrote and presented policy briefs to community key stakeholders and legislative representatives. One group presented policy brief to rural critical access hospital.
  - Students completed surveys after working in groups to write and present the policy briefs.



# ACT on Alzheimer's Dementia-Friendly Communities

[www.ACTonALZ.org](http://www.ACTonALZ.org)

# Dementia-Friendly Community



A dementia-friendly view →



Early diagnosis and quality care; patient and caregiver support

Specialized memory loss supports and services

Dementia-aware and responsive client services

Welcoming and supportive spiritual environments

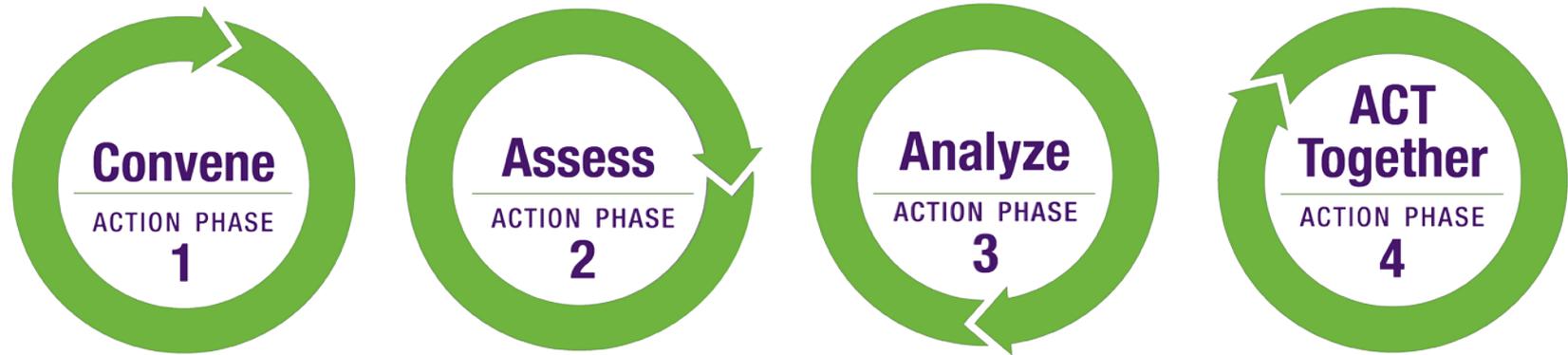
Dementia-friendly businesses; customer and employee support

Accessible, user-friendly transportation and environments

Emergency preparedness and response

Independent living and meaningful engagement

# Four-Phase Toolkit Process



1. **Convene** key community leaders and members to form an Action Team.
2. **Assess** current strengths and gaps within the community.
3. **Analyze** findings to understand your community's needs and develop a plan to take action.
4. **ACT Together** to pursue priority goals that will assist your community in becoming dementia-friendly.

# Nursing Students



# Student Perceptions - Data Analysis

## Research Class - First Session (N=26)

Theme	Student Comments
Feeling of Being Overwhelmed	It was interesting but a little overwhelming. I felt overwhelmed as I wasn't sure how to exactly understand the data.
Confusion	I was confused a majority of the time which made me kind of angry. I felt as if I was looking at foreign material but as I read into it more it made more sense.

# Student Perceptions - Data Analysis

## Research Class – Second Session (N=25)

Theme	Student Comments
Feeling of Being Useful	I felt useful & like I was actually participating in the work for this action team. I felt like I was learning to do something that seems so simple but actually is more complicated than I thought (transcribing).
Teamwork	I felt our group worked well together and accomplished everything quickly and promptly. Sense of teamwork.

# Student Perceptions - Data Analysis

## Research Class – Third Session (N=35)

Theme	Student Comments
Eye Opening	It was eye-opening to see how communities are struggling and the barriers around us every day. It was more clarifying. It finally made sense of what we have been doing the past few weeks.
Challenge of Data Analysis	A little more difficult interpreting data. Exhaustive data & took time to sort through the data.

# Student Perceptions - Data Analysis

## Research Class – Final Session (N=32)

Theme	Student Comments
Learning about Needs of a Population	<p>Learning that more awareness &amp; teaching is needed about the Dementia/Alzheimer's Disease population.</p> <p>We got to see other aspects of the data. More knowledge of our community.</p>
Appreciation for Research	<p>I appreciate the research process, the work of collecting data.</p> <p>Developing conclusions from the data so that we may play to our patient's strengths and weaknesses.</p>

# Student Perceptions - Data Analysis

## Contributions to Learning & Nursing Practice

Taught me teamwork, leadership, delegation and more about how to interpret data.

It helped me realize how perspectives change from city to city.

This activity helped me to understand problems in our community and how we as nurses could help improve these problems.

It gave me a better understanding of research.

# Step Two – Community Health

- Senior nursing students wrote and presented policy briefs to community key stakeholders and legislative representatives during a Student Nurses Day on the Hill event.
- One group of students presented a policy brief to a rural hospital to encourage the implementation of the Purple Angel Project to improve hospitalization experiences of those with Alzheimer's disease and their family members.

# Advocacy Through Policies

- What is the issue?
- Data to support the need for change.
- What would you like the decision makers to do to address the issue?
- Impact statement.

## *Improving Care for Dementia Patients: The Purple Angel Project*

Dementia is an umbrella term that describes a wide range of symptoms associated with debility in memory or other thinking skills that impact a person's capability to perform activities of daily living. At least two of the following mental functions must be significantly impaired to be considered dementia: memory, communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception (Alzheimer's Association, 2015a). We are senior nursing students at Minnesota State University, Mankato, who have encountered patients with dementia in different care settings. Our clinical experience has made it evident that patients with dementia receive less than deserved care, where health care providers have little training to safely handle a patient with dementia.



The purple angel wristband project aims to increase health care provider awareness of dementia patients through the use of purple angel logo on ID bracelets, a purple angel sign on every door of patients who have dementia, staff training on dementia, sitters to relieve family caregivers, and dementia screening at the time of admission. Implementing this program at Mayo Clinic Health System in Mankato would benefit healthcare providers as well as patients with dementia. If staff members are aware of the underlying diagnosis of dementia, misunderstandings between patient and healthcare providers will be greatly reduced. Precautions can be taken to minimize falls and wandering, and address signs of aggression, confusion, and sun-downing before the issue escalates (The Purple Angel, 2015).

# Students' Perceptions - Advocacy

## Community Health Class – First Session (N=31)

Theme	Student Comments
Advocacy	Today's activities helped me realize the amount of impact I could potentially have on policy reform. It felt empowering to learn how to make a difference. This helped us learn how to better advocate for patients through policies.
Inspiration	I was able to look at policies that other students wrote and felt inspired. Makes me want to advocate for this population [those with Alzheimer's disease].

# Students' Perceptions - Advocacy

## Community Health Class – Day on the Hill (N=31)

Theme	Student Comments
Students have a Voice	<p>I felt like the legislators wanted to hear what we were saying and genuinely cared.</p> <p>I felt like my voice was heard by the different legislators.</p> <p>Had a great response from our representatives about our policy brief.</p>
Stressed & Rushed	<p>I felt overwhelmed and rushed to get from one area to another.</p> <p>I felt rushed similar to what the legislators feel on a day to day basis. I was happy all the representatives were so willing to listen.</p>

# Student Perceptions - Advocacy

## Contributions to Learning & Nursing Practice

Already a political advocate. This experience just reinforces the need to research concerns and present valid, evidence-based arguments and ideas for change. I will be able to center my research around issues see going on.

Becoming more involved with policy making & advocacy for patients.

Inspired me to be involved.

Builds my confidence in political advocacy.

# Conclusion

Through community-academic partnerships students engage in research and service learning projects that focus on families in communities. Service learning strengthens a student's understanding of their social and political responsibility in their future practice. These students are empowered to make a difference in their communities and advocate for people with Alzheimer's disease and dementia and their families. This particular partnership is on-going and continues to benefit not only the students but also the community.

# References

- Alzheimer's Association. (2016) Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia, 13*, 325-373.
- Mezey, M., & Maslow, K. (2008). How to try this: Recognition of dementia in hospitalized older adults. *The American Journal of Nursing, 108*(1), 40-50.
- Shannon, C. (2016). The power of one: Using service learning to promote community engagement. *International Journal of Health, Wellness, & Society, 6*(1), 23-33.

# Contact Information

- Kelly Krumwiede, PhD, RN  
kelly.krumwiede@mnsu.edu
- Kristen Abbott-Anderson, PhD, RN  
kristen.anderson@mnsu.edu