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## Perceptions of dementia in faith-based organizations

Megan Elizabeth Kooker  
*University of Northern Iowa*

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# PERCEPTIONS OF DEMENTIA IN FAITH-BASED ORGANIZATIONS

A Thesis Submitted  
in Partial Fulfillment  
of the Requirements for the Designation  
University Honors with Distinction

Megan Elizabeth Kooker

University of Northern Iowa

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This Study by: Megan Kooker

Entitled: Perceptions of Dementia in Faith-Based Organizations

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Dr. Elaine Eshbaugh

\_\_\_\_\_  
Date

\_\_\_\_\_  
Honors Thesis Advisor

\_\_\_\_\_  
Date

\_\_\_\_\_  
Dr. Jessica Moon, Director, University Honors Program

### **Introduction and Purpose**

Dementia is a public health concern. The number of people who will have some form of dementia is expected to rise in the coming years (Brookmeyer, 2011). Around 50 million people have dementia worldwide. Every year, this number increases by about 10 million (World Health Organization, 2019). Because this is such a prevalent issue, each part of the community should be educated about dementia as well as how to best interact with people living with dementia (PLWD). In order to educate these individual community sectors, it is important to first research the existing perceptions about dementia among the community. Faith and religious activities are important aspects in the lives of many older adults, and these activities can still be meaningful and integral in the lives of PLWD (Plunkett & Chen, 2016).

This study focused specifically on faith-based organizations (FBOs) in Cedar Falls-Waterloo, Iowa, administering a survey to staff and volunteers in order to identify the most common existing knowledge and misconceptions among them. It also identified strengths and gaps in services provided by FBOs to PLWD. This research contributed to the development of a future training about dementia for this population. The future training will seek to teach people within FBOs how to become more dementia-friendly as well as how to best serve the PLWD within their communities. This research study seeks to answer three main questions.

1. What knowledge and misconceptions exist about dementia among FBOs?
2. What knowledge and misconceptions exist about person-centered dementia strategies among FBOs?
3. What are the strengths and gaps in services provided to PLWD within FBOs?

### **Literature Review**

Dementia refers to any changes in cognitive ability or memory severe enough to disrupt everyday functioning, both social and occupational (Shuman, Yuen & Gordon, 2017). The majority of causes behind dementia have no cure, and they are both progressive and irreversible (Potocnik, 2013). Dementia is a rising public health concern, especially in older adults. At any given time, around 5-8% of people over 60 years old have some form of dementia (World Health Organization, 2019). This prevalent issue is one that is only expected to become greater and more common with time. This rise in the number is due to the growth of the older generation as well as the growing prevalence of dementia (Annear et al., 2015). In response to this global health crisis, the World Health Organization has called for both greater awareness and education about dementia (Annear et al., 2015).

Not only are PLWD impacted by the symptoms of dementia, but the general public is, and will be, impacted as well. As the number of PLWD increases, the likelihood of a person in the community coming into contact with PLWD will also increase. It is important for members of the general public to become more aware and educated about dementia and how to interact well with PLWD (Annear et al., 2017). One response to this call for greater awareness about dementia has been the growth of dementia-friendly communities among several countries. This is a movement that involves working to create informed, safe, and respectful communities for PLWD in all sectors of the community. These communities focus on supporting PLWD through a variety of strategies including social, environmental, and physical efforts (Courtney-Pratt, Mathison, & Doherty, 2018).

Even as efforts to build dementia-friendly communities have begun, there is a great deal of progress still to be made. Unfortunately, older adults living with dementia, although common,

are still among the most devalued members of society, regardless of their previous characteristics or contributions to the community (Goldsmith, 2004). Negative attitudes and a multitude of common misconceptions exist about dementia within the general public, as well as several specific populations within the public. One study examined 34 other studies that researched the misconceptions about dementia within the general public. The three most common misconceptions appeared throughout the majority of the study: dementia is a normal part of aging, dementia is by no means preventable, and there is a cure for dementia (Cations, Radisic, Crotty, & Laver, 2018).

Other studies have focused on misconceptions within specific populations within the public. For example, one study showed that college students have misconceptions about dementia, specifically about life expectancy, risk factors, and common living arrangements for PLWD (Eshbaugh, 2014). Several other studies have confirmed that misconceptions about dementia exist among a variety of other populations within the general public including adolescent students, college students, caregivers, doctors, mental health professionals, and family members (Cations et al., 2018; Wang et al., 2018; Eshbaugh & Stratton, 2016; Isaac, Isaac, Farina, & Tabet, 2016; Jackson, Cherr, Smitherman, & Hawley, 2008). One study shows specific misconceptions that exist within the general public including knowledge deficiencies in understanding the life-limiting reality of dementia, poor symptom identification awareness, and misunderstandings of the use of pharmaceuticals as a behavioral intervention (Annear, Otani, & Li, 2016). Studies have also shown a lack of knowledge about how to interact with PLWD. One study showed that even many health professionals have a poor understanding of dementia and do not understand or use the person-centered approach when interacting with PLWD (Wang et al.,

2018). These misconceptions and lack of knowledge show the need for greater education and community awareness.

### **Dementia and Faith-Based Organizations**

Although studies have researched misconceptions among several populations of the community, little research exists about existing knowledge and common misconceptions about dementia among FBOs. Ironically, scholars have identified FBOs as a community site appropriate for dementia research, education, and possible interventions (Kevern, 2009). The presence of older adults is high in FBOs. One reason for this is that religion is an important part of life for many older adults, the population that is most at risk for dementia. Sixty-five percent of Americans age 65 years and older reported religion as being very important to them, with an additional 20% considering religion to be somewhat important. When it comes to attendance at FBOs, 48% of Americans age 65 years and older attend a religious service at least once per week (Pew Research Center, 2014). In particular, FBOs are a familiar place for older adults, especially older adult women who are the population most affected by dementia, due to both having dementia and being caregivers for PLWD (Plunkett & Chen, 2016). Research has also shown the population that makes up Christian FBOs in particular are aging at a faster rate than the general public in the United States. In addition, older adults on average pray more frequently than younger adults (McFadden & McFadden, 2011). This data makes it evident: faith and attendance of FBOs is important to many older adults.

### **FBOs Offer Spiritual and Social Support**

FBOs are a major sector of the community that is impacted by dementia due to the presence of older adults who are a part of these organizations. The two main resources FBOs can offer PLWD are both spiritual support and social support. Although social support can be found

through other resources in the community, the social support provided by FBOs can be highly impactful for PLWD (Plunkett & Chen, 2016). Social integration for PLWD has been proven to be very important. Without healthy social integration, PLWD can experience isolation. Isolation is a risk factor for developing dementia, and isolation can also worsen dementia symptoms (Abbott, Sefcik, & Haitsma, 2017). Another study showed that social isolation exacerbates the cognitive challenges experienced by PLWD (Kitwood, 1997). Therefore, it is vital that PLWD experience social integration instead of isolation. Relationships are still very important and necessary for PLWD (McFadden & McFadden, 2011).

FBOs are a unique resource for social support for PLWD. FBOs have even been referred to as social networks by some scholars (Plunkett & Chen, 2016). With such a high percentage of older adults being involved in FBOs, this means they are part of the social networks created by FBOs. In particular, scholars have claimed “the Christian church is possibly one of the largest settings in which to explore social connectedness for seniors” because the majority of older adults that report a religion identify with Christianity and attend a Christian FBO (Plunkett & Chen, 2016, p. 1919). The same researchers suggest that Christian FBOs can be a powerful tool for exploring social connectedness among older adults because the church is generally accessible in a variety of geographical settings including rural, remote, suburban, and urban (Plunkett & Chen, 2016). FBOs, despite religion or denomination, are also a major asset to the community in providing human capital and volunteers, both to people inside of the congregation and outside in the greater community (McFadden & McFadden, 2011). Another way FBOs are a unique resource for social support for PLWD is that FBOs are usually a familiar place for older adults. If a person living with dementia has been attending an FBO for a majority of his or her life, this



place is likely comfortable to this person. This familiarity of the place and the people to interact with may bring comfort for a person with dementia (Plunkett & Chen, 2016).

Another main reason FBOs can serve as a unique hub for social support is due to the common factor connecting people within the community. Because FBOs are centered around faith and spirituality, the people involved in them have a common factor. The common belief system creates a strong sense of connectedness between people, even if they have not truly met before. This shared belief system leads to the potential for cross generational relationships, making the community rich and providing the ability to care for each other (McFadden & McFadden, 2011). This community-creating force leading to cross generational relationships is another reason FBOs can be a strong resource for social support for PLWD.

One of the greatest reasons behind FBOs providing social support to PLWD is the strong motivation to care for people well experienced by people within FBOs. Every major religion commands its followers to love others. For Christians in particular, the Bible provides clear guidance for the church to care for the marginalized. It speaks of serving others by clothing the naked, feeding the hungry, and visiting the sick and widowed. It is clear to Christians, as well as other congregations of major religions, that they are commanded to care for people within and outside of their congregation. This religious command provides a strong motivation for staff, as well as the congregation, within FBOs to care for and serve PLWD (MacKinlay & Trevitt, 2012). Because of religious motivations, the Christian church also seeks to view people as having inherent worth based upon the belief that all humans are made in the image of God. When dementia can threaten a person's worth in society, the Christian church seeks to view every person as important, worthy of proper care and respect. They also attempt to resist the cultural model that the responsibility for caring for a loved one is only for family members and close

friends, but try to provide support for both the person living with dementia and the caregiver (McFadden, 2012). This makes FBOs a possible place of safety for those with dementia, and it also creates a stronger social support system. Social support is a major resource FBOs have the potential to provide to PLWD.

The other major resource FBOs can offer PLWD is spiritual support. As mentioned previously, religion and spirituality are a major part of many older adults' lives. A study found that around 65% of older adults report praying daily (Pew Research Center, 2014). Spirituality is important to the majority of older adults in general, and it still plays a major role in the lives of PLWD, despite cognitive changes they experience (Kevern, 2009). If spirituality has been a part of life for someone with dementia before the diagnosis, it will still be important after they start to show signs of dementia. Unfortunately, the importance of spirituality for PLWD is often overlooked (Scott, 2016). Part of this is because dementia can cause a disruption to the familiar or normal spiritual habits of PLWD, especially for people who practice Islam. One study found that dementia impacts Muslims' ability to fulfill religious obligations such as daily prayers. Participants of this study were unaware that dementia exempts them from these religious obligations (Willis, Zaidi, Balouch, & Farina, 2018). This points to the importance of FBOs to be educated on the impact of dementia on spirituality, including practices to implement in order to continue to nurture a person's spirituality despite cognitive changes.

A reason spirituality is still important for PLWD is because spirituality is not only experienced cognitively, but it can also be experienced physically and emotionally (McFadden & McFadden, 2011). Therefore, PLWD can still actively take part in their faith and experience the spiritual realm. One way PLWD can still take part in spirituality is through the attendance of activities in FBOs. Although the staff at many FBOs question the importance of PLWD

attending activities, theological scholars claimed that spiritual presence can be experienced through the familiar hymns, texts and liturgy, even if cognitive loss makes it difficult to comprehend a sermon or other form of teaching. If the songs, liturgy, and text are familiar to the person living with dementia, these practices can bring great comfort to the person (McFadden & McFadden, 2014). Research has shown that PLWD as well as their caregivers can experience potential psychosocial benefits through participation in religious activities. This is because spirituality can provide relief from anxiety, reduce behavioral disturbances, and improve overall quality of life for those with dementia (Shuman et al., 2017).

Previous research has shown that practicing spirituality and religious faith can serve as more than just a source of comfort for PLWD. Faith has also been proven to be an effective emotion-focused coping mechanism. Psychologists have viewed prayer and meditation as means by which people regulate their emotions. Religious beliefs are often referred to as the most common resource for emotional coping among older adults (McFadden & McFadden, 2011). This coping mechanism provided through spirituality can be effectively used by FBOs to support PLWD, especially directly after diagnosis. Because of this, staff of religious organizations are often considered first responders to a person after diagnosis because people within FBOs frequently approach them in times of crisis (Shuman et al., 2017). FBOs can be a major source of comfort for a person in both early and later stages of dementia through the provision of spiritual support (Kevern, 2009).

### **Gaps and Misconceptions Among FBOs**

Although FBOs are strong resources providing both social and spiritual support to PLWD, misconceptions and gaps do exist within FBOs regarding both knowledge and services for PLWD. Few people within FBOs are knowledgeable about dementia, including the general

congregation as well as the staff (Goldsmith, 2004). This is partly due to the lack of seminary training and education about dementia for staff of FBOs. The majority of pastors in Christian churches have had no formal education about dementia and how to serve PLWD in their congregation. In fact, most training and education programs for staff of FBOs teach staff to focus their energy on serving younger generations (McFadden & McFadden, 2011). FBOs have been absent in speaking up about the dementia crisis because staff and volunteers feel undertrained and ill-equipped when it comes to serving and interacting with PLWD. One scholar also claimed that people within FBOs have shown a lack of effort towards serving PLWD due to the fear and unknowns that come with dementia (Mast, 2014).

FBOs have also shown an overall lack of awareness that PLWD exist in their organization. Mast (2014) claimed that the Christian church has an issue of forgetting to serve special populations, especially people who are not as involved. People who do not attend services or serve in some way are easily forgotten within FBOs. The rise in megachurches has also contributed to this lack of awareness about PLWD in FBOs. Within the last few decades, there has been a significant rise in megachurches, which can be defined as any church with a congregation of 4,000 people or more. These larger congregations have created a greater level of difficulty for volunteers and staff to know and serve each individual on a personal level. These larger congregations tend to lead people to more easily become less involved and drop in attendance without a volunteer or staff member noticing (McFadden & McFadden, 2011). This implies that as PLWD attend religious activities less often, they will likely go unnoticed.

Another negative impact that has occurred from the rise of the megachurch is that FBOs tend to be more focused on the younger generations. The staff of FBOs focus more on developing young leaders instead of the wellbeing of older adults. The sermons and services are

generally tailored toward younger people and the stage of life they are experiencing. Generations within FBOs have become increasingly separated from each other as programs specific to age groups are created. This focus on younger generations makes FBOs less aware of and less focused on the impact of dementia on their congregation. However, older adults living with dementia still exist in many FBOs. Even if no older adults are a part of the FBO, many young people within FBOs serve as caregivers or have parents or grandparents living with dementia. Although these megachurches may be leading to a younger population within FBOs, a need still exists for dementia awareness (McFadden & McFadden, 2011).

The misconceptions and lack of knowledge about dementia have led to negative consequences and gaps in services for PLWD within FBOs. One of the most evident negative consequences seen within FBOs is the drop in attendance rates for PLWD and their caregivers. Attendance of religious services declines for both PLWD and their caregivers due to physical demands and cognitive decline (Shuman et al., 2017). For example, it may be difficult for a person with dementia to physically drive to the religious activity, or the person may also feel embarrassed or uncomfortable within the service due to cognitive decline (Goldsmith, 2004). Because it can be difficult for staff and volunteers of FBOs to notice when a person is absent, the people who no longer attend due to dementia tend to be forgotten about by church leaders (Mast, 2014). Besides attendance, research has shown a decline in the amount of involvement in other ways such as attending activities or serving the FBO in some way. Several scholars point to this as being a consequence of FBOs not realizing there are still ways in which a person with dementia can serve, such as folding bulletins or other simple tasks (McFadden & McFadden, 2011).

Another negative consequence of the gap in knowledge about dementia within FBOs is reductionist language used to refer to older adults and PLWD. It is common for staff and volunteers of FBOs to use the terms “shut-ins” or “home-bounds” when referring to people who no longer attend activities. This language can be both embarrassing and belittling for older adults and PLWD (McFadden, 2012).

Yet another negative consequence in FBOs due to the misconceptions and lack of knowledge about dementia is a lack of theological understanding about dementia. Research has shown that the diagnosis of dementia can be extremely devastating, and it can leave people, Christians specifically, with a multitude of questions regarding theology of how the diagnosis impacts their view of God (Kevern, 2011). Pastoral care of those who have dementia is a growing challenge. This is an issue that needs to be addressed because pastors are often sought after to provide care and answers to theological questions (Kevern, 2009). Some people within FBOs believe that dementia is punishment from God, and several other misconceptions exist regarding the theological implications of dementia (Goldsmith, 2004).

The final negative consequence due to the lack of knowledge about dementia is a dearth of programs and services offered for PLWD. For example, many FBOs have a visitation program for older adults who are no longer able to attend services. However, PLWD are often considered ineligible to be a part of this program. Most FBOs do not see dementia as a condition that requires a visit like cancer or heart disease. They simply do not understand the benefits of visiting someone with dementia because they assume the person will not remember the visit; therefore, the FBO considers the visit to have no value (McFadden & McFadden, 2011).

Many FBOs have a misconception about person-centered strategies for PLWD. Research suggested that FBOs should extend and improve visitation programs to PLWD. Previous

research also suggested that volunteers who are deployed for these visits should be trained in person-centered strategies in order to best interact with a person with dementia. There is a major gap in knowledge in FBOs when it comes to using person-centered strategies with PLWD (Plunkett & Chen, 2016).

Previous research has suggested several ideas to make FBOs more dementia-friendly when it comes to the provision of services provided to those with dementia. Enhancing home visit programs by providing the service for PLWD as well is a vital suggestion made by many scholars for FBOs to implement. This would also include training and education for volunteers who are visiting PLWD (Plunkett & Chen, 2016; McFadden & McFadden, 2014; Goldsmith, 2004). Previous research has shown that training on dementia is positively correlated with knowledge of dementia (Annear, 2018). Another suggestion made by scholars to improve services for PLWD in FBOs is to modify religious services (Goldsmith, 2004). These modifications could include implementing common prayers, music, and liturgy within religious services. If these suggestions are not appropriate for a particular FBO, they may choose to provide an additional and separate service for PLWD. It could also include the creation of a system to ensure PLWD have another person to sit by to guide them through the service. This would also help ensure that PLWD are continually able to attend (Goldsmith, 2004). These suggestions, if implemented, all contribute to making FBOs a more dementia friendly environment.

The physical space of the worship service can also be modified to best serve PLWD by including a clear space with no trip hazards and a space with minimal noise distraction. Another helpful way to serve PLWD would be to provide the song lyrics and readings. Congregants can also help PLWD feel more comfortable by wearing name tags (Goldsmith, 2004). Another

suggestion is to provide means by which PLWD can still serve the church. Even if the task is smaller or less important than before, PLWD still have a desire to contribute to the community and the FBO as a whole (McFadden & McFadden, 2011).

Finally, scholars suggest that FBOs should seek to serve the caregiver of a person with dementia. Dementia not only makes it difficult for the person directly impacted to continue to attend services, but it also impacts the caregivers. FBOs could improve services for caregivers by providing the following: respite care, practical housekeeping needs, covering financial burdens, and transportation services (Mast, 2014). It is important for FBOs to remember the caregiver in the creation and provision of services for people impacted by dementia.

FBOs are a major resource for social and spiritual support for PLWD as well as their caregivers. FBOs have potential to be an appropriate setting and tool for both education and intervention for PLWD. Overall, there is little research about existing knowledge and misconceptions about dementia within FBOs. Little research exists about perceptions of dementia within FBOs of religions other than Christianity. There is more research regarding suggestions for FBOs to improve on gaps in services. Regardless, there is an evident need for improvement regarding knowledge of dementia and services provided for PLWD within FBOs.

## **Methods**

### **Design and Sample**

The data were collected through a one-time online questionnaire distributed to staff and volunteers of FBOs. Participants were recruited via email to staff email addresses listed on the public websites of FBOs of all religious affiliations located in Cedar Falls and Waterloo, Iowa. The list of emails found on public websites included seventy-four different FBOs representing six different religions (Unitarian Universalism, Protestant Christianity, Catholic Christianity,



Judaism, Islam, and Mennonite). The total number of email addresses used to send the recruitment email was 259. The recruitment email included a link to a survey through the Qualtrics Survey Software. The recruitment email invited the staff member to forward the survey on to volunteers and other staff members within the organization. The participants gave consent for the study before they began the online survey. The survey took about seven to ten minutes to complete. There was no compensation offered for the survey. Data collection lasted for one month. A total of 101 participants responded to the survey, a response rate of 39%. However, only eighty-eight participants met the criteria for inclusion (see criteria for exclusion in analytic strategy section). Refer to “Table 1: Sample Demographics” for demographics in detail.

<b>Table 1: Sample Demographics (n=88)</b>	
Measure	Results
Gender Identity	<ul style="list-style-type: none"> <li>● Female- 67% (n=59)</li> <li>● Male- 31.8% (n=28)</li> </ul>
Age	<ul style="list-style-type: none"> <li>● 18-25 years old- 9.1% (n=8)</li> <li>● 25-34 years old- 10.2% (n=9)</li> <li>● 35-44 years old- 11.4% (n=10)</li> <li>● 45-54 years old- 14.8% (n=13)</li> <li>● 55-64 years old- 28.4% (n=25)</li> <li>● 65-74 years old- 19.3% (n=17)</li> <li>● 75-84 years old- 4.5% (n=4)</li> <li>● 84+ years old- 2.3% (n=2)</li> </ul>
Highest Level of Education	<ul style="list-style-type: none"> <li>● High School or GED- 1.1% (n=1)</li> <li>● Some College- 13.6% (n=12)</li> <li>● Bachelor’s Degree- 35.2% (n=31)</li> <li>● Graduate or Professional Degree-50% (n=44)</li> </ul>
Ethnicity	<ul style="list-style-type: none"> <li>● White- 94.3% (n=83)</li> <li>● Asian- 1.1% (n=1)</li> <li>● Black/African American- 1.1% (n=1)</li> </ul>

	<ul style="list-style-type: none"> <li>● Other- 3.4% (n=3)</li> </ul>
Marital Status	<ul style="list-style-type: none"> <li>● Married- 78.4% (n=69)</li> <li>● Divorced- 5.7% (n=5)</li> <li>● Single or Never Married- 12.5% (n=11)</li> </ul>
Role within FBO	<ul style="list-style-type: none"> <li>● Staff Other Than Pastor- 50% (n=44)</li> <li>● Volunteer- 27.3% (n=24)</li> <li>● Pastor or Associate Pastor- 19.3% (n=17)</li> <li>● Intern- 2.3% (n=2)</li> </ul>
Religious Affiliation of FBO	<ul style="list-style-type: none"> <li>● Protestant Christian-79.5% (n=70)</li> <li>● Catholic Christian- 6.8% (n=6)</li> <li>● Unitarian Universalist- 5.7% (n=5)</li> <li>● Jewish- 2.3% (n=2)</li> <li>● Islam- 1.1% (n=1)</li> <li>● Other- 1.1% (n=1)</li> </ul>

## Measures

**Experience with Dementia:** Participants were asked to indicate their experiences with dementia including if they had ever attended a dementia training. Participants indicated if they have had a close friend or family member with dementia or have been a caregiver (professional or personal) for someone with dementia. Lastly, participants indicated if they know someone within their FBO who has dementia. These questions were answered on a Likert Scale of 1-10 labeled strongly disagree (1) and strongly agree (10),

**DKAS:** This section included the Dementia Knowledge Assessment Scale (DKAS), a 27-item true/false questionnaire designed to identify existing knowledge and misconceptions about dementia (Annear et al., 2015). In previous research, the internal consistency reliability for the scale was .89 (Annear et al., 2016). Specific components of the scale include causes and characteristics, communication and engagement, care needs, and risks and health promotion (Annear et al., 2015). In this study, the scale and scoring method were slightly modified. On the

original scale, participants are able to choose “true, false, probably false, probably true, or I don’t know.” For the sake of clarity, the survey in this study allowed for true or false as the only answer choices. In original uses of this scale, scoring is based off of all five answers, but this study scores assessments based on incorrect answers valued at zero points and correct answers valued at one point.

**Perceptions of Services:** Participants identified perceptions of services within FBOs. These questions were created by the researcher to identify participants’ perceptions of services offered by their FBO to PLWD. This section of the survey began with a basic definition of dementia to provide a baseline understanding to answer the following questions. The questions involved knowledge about the effects of dementia on a person’s faith and involvement in their FBOs. Participants indicated the level to which they believe that their FBO is dementia-friendly. Finally, participants self-reported their level of comfort in regards to interacting with and answering questions for a person with dementia or their caregiver. Most of these questions asked the participant to answer on a Likert Scale of one to ten. A few of the questions were true/false.

### **Analytic Strategy**

A total of 101 participants responded to the survey. However, the sample size was filtered based on a criteria for exclusion. Responses were excluded if the participant did not indicate he or she was a staff member or volunteer. The respondent was also removed if he or she did not complete the full DKAS portion of the questionnaire. The final sample size used was 88 participants. All analyses were conducted using SPSS Version 24. Descriptive statistics were run on the experience with dementia, DKAS, and perceptions of services. Correlations and partial correlations were performed using experiences with dementia, DKAS, perceptions of dementia, role type, age, gender, and level of education.

## Results

### Experience with Dementia: (Table 2)

Of the 88 participants, 35.2% had attended some form of dementia training. Participants responded with a mean of 7.19 (SD=2.82) on a scale of one to ten, one being “Strongly disagree” and ten being “Strongly agree,” in response to the statement “I know someone in my faith-based organization who has dementia.” Participants also indicated their experience in caregiving for someone with dementia.

<b>Table 2: Experience with Dementia Results (N=88)</b>		
Question	Mean (Likert Scale, 1-10)	Standard Deviation
I have had a close friend or family member with dementia.	6.39	3.99
I have been a caregiver for a friend or a family member with dementia.	2.72	3.63
I have been a professional caregiver for someone with dementia.	1.69	3.41
I know someone in my faith-based organization who has dementia.	7.19	3.82

### DKAS Results: (Table 3)

The mean of the DKAS was 21.93 (SD=2.46; min=16, max=27) out of 27 (81.1% answers correct). The mean for women on the DKAS was 22.47 (SD=2.63), where the mean for

men on the DKAS was 20.89 (SD=2.63). Gender was positively correlated with DKAS scores with a statistical significance of  $p<.004$ .

The mean for people who reported attending a previous training on dementia for the DKAS was 22.97 (SD=2.18), and the mean for people who have not attended a previous training on dementia was 21.37 (SD=2.43). Previous training was positively correlated with DKAS scores with a statistical significance of  $p<.003$ . Participants who have had a close friend or family member with dementia were also more likely to score higher on the DKAS with a statistical significance of  $p<.012$ . No other variable showed a correlation with statistical significance with DKAS scores including age, highest level of education completed, religion, role grouping, or previous caregiving.

Any item on the DKAS that less than 65% of participants answered correctly was considered a misconception. Six items in the DKAS were considered misconceptions. Of these misconceptions, four of the six fall into the theme of “Causes and Characteristics.” Two of the six misconceptions are in the “Risks & Health Promotion” theme. Six items on the DKAS were considered existing knowledge when 95% or more participants indicated correctly. Of these six items indicating existing knowledge, two are within the theme “Causes and Characteristics,” three are part of the “Care Needs” theme, and one is part of both the “Communication & Engagement” and “Risks & Health Promotion” themes. Refer to “Table 3: DKAS Results” for item scores in detail. Items which indicate misconceptions are noted with pink highlighting, and items that indicate existing knowledge are noted with green highlighting.

<b>Table 3: DKAS Results (N=88)</b>		
Item	Theme	Number Responding Correctly (%)
Most forms of dementia do not generally shorten a person's life [False]	Causes & Characteristics	38 (43.2%)
Blood vessel disease (vascular dementia) is the most common form of dementia [False]	Causes & Characteristics	47 (53.4%)
People can recover from the most common forms of dementia [False]	Causes & Characteristics	80 (90.9%)
Dementia is a normal part of the aging process [False]	Causes & Characteristics	77 (87.5%)
Most forms of dementia reduce the length of a person's life [True]	Causes & Characteristics	52 (59.1%)
Dementia does not result from physical changes in the brain [False]	Causes & Characteristics	85 (96.6%)
Planning for end of life care is generally not necessary following a diagnosis of dementia [False]	Causes & Characteristics	80 (90.9%)
People experiencing dementia do not generally have problems making decisions [False]	Causes & Characteristics	85 (96.6%)
Alzheimer's disease is the most common form of dementia [True]	Causes & Characteristics / Care Needs	56 (63.6%)
It is impossible to communicate with a person who has advanced dementia [False]	Communication & Engagement	80 (90.9%)
A person experiencing advanced dementia will not generally respond to changes in their physical environment [False]	Communication & Engagement	77 (87.5%)
It is important to correct a person with dementia when they are confused [False]	Communication & Engagement	78 (88.6%)
People experiencing advanced dementia often communicate through body language [True]	Communication & Engagement / Care Needs	86 (97.7%)

Uncharacteristic behaviors in a person experiencing dementia are generally a response to unmet needs [True]	Communication & Engagement / Care Needs	69 (78.4%)
People with dementia are unlikely to experience depression [False]	Communication & Engagement	79 (89.8%)
Medications are the most effective way of treating behavioral symptoms of dementia [False]	Communication & Engagement	62 (70.5%)
Movement is generally affected in the later stages of dementia [True]	Care Needs	74 (84.1%)
Difficulty eating and drinking generally occurs in the later stages of dementia [True]	Care Needs	81 (92.0%)
People with advanced dementia may have difficulty speaking [True]	Care Needs	86 (97.7%)
People experiencing dementia often have difficulty learning new skills [True]	Care Needs	77 (87.5%)
Daily care for a person with advanced dementia is effective when it focuses on providing comfort [True]	Care Needs	84 (95.5%)
Having high blood pressure increases a person's risk of developing dementia [True]	Risks & Health Promotion	54 (61.4%)
Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia [False]	Risks & Health Promotion	66 (75.0%)
Symptoms of depression can be mistaken for symptoms of dementia [True]	Risks & Health Promotion	80 (90.9%)
The sudden onset of cognitive problems is characteristic of common forms of dementia [False]	Risks & Health Promotion	35 (39.8%)
Exercise is generally beneficial for people experiencing dementia [True]	Communication & Engagement / Risks & Health Promotion	85 (96.6%)
Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition [False]	Risks & Health Promotion	77 (87.5%)

**Perceptions of Services Offered (Table 4 & 5):**

Greater than 85% of participants indicated that in general “Attendance of faith-based activities tend to drop when someone has dementia” and “People living with dementia often feel more embarrassed, uneasy, or awkward in a worship setting with a lot of people than they did before.” Refer to “Table 4: Perceptions of Services Offered (T/F).” Any item with a mean of seven or below was considered a potential gap in services provided. The remainder of the statements in this section allowed for responses on a scale of one to ten with one being “Strongly disagree” and ten being “Strongly agree.” Refer to “Table 5: Perceptions of Services Offered (Likert).” Any item with a mean of nine or above was considered a potential strength in services provided. Items which indicate gaps are noted with pink highlighting, and items that indicate existing knowledge are noted with green highlighting.

<b>Table 4: Perceptions of Services Offered (T/F) (N=87)</b>	
<b>Question</b>	<b>Results</b>
In general, attendance of faith-based activities tend to drop when someone has dementia.	True- 78 (87.9%) False- 9 (10.2%)
In general, people living with dementia often feel more embarrassed, uneasy, or awkward in a worship setting with a lot of people than they did before.	True- 79 (89.8%) False- 8 (9.1%)



<b>Table 5: Perceptions of Services Offered (Likert Scale, 1-10) (N=87)</b>			
<b>Question</b>	<b>Mean (out of 10)</b>	<b>Standard Deviation</b>	<b>Min./Max.</b>
It is still important for people living with dementia to remain spiritually active and receive spiritual care.	9.66	.819	min=6 max=10
The physical environment of my faith-based organization is suitable for someone with dementia.	6.84	2.29	min=1 max=10
My faith-based organization actively involves people living with dementia (i.e. opportunities to serve, home visits, respite care for caregivers, etc).	5.74	3.04	min=0 max=10
My faith-based organization could improve on how well it serves people living with dementia.	7.85	1.98	min=3 max=10
I feel personally equipped to interact well with a person living with dementia.	5.48	2.90	min=0 max=10
I feel personally equipped to answer questions regarding the impact of dementia on a person's spirituality.	4.08	2.87	min=0 max=10
I feel personally compelled, based on my religious beliefs, to give people with dementia both dignity and respect.	9.63	.878	min=6 max=10

### **Discussion**

This study sought to identify knowledge and misconceptions among volunteers and staff members of FBOs about dementia and person-centered dementia strategies. The misconceptions regarding dementia shown in this study through the DKAS were congruent to misconceptions of dementia in other populations. Participants in this study showed a lack of knowledge in the specific themes of “Risk & Health Promotion” and “Causes and Characteristics.” Specifically,

this study showed that staff members and volunteers of FBOs are less knowledgeable about the different forms and causes of dementia. This population is also less knowledgeable about the life-limiting nature of dementia as well as the risk factors for developing dementia than other dementia-related topics. In another study which used the DKAS, the population studied showed a misunderstanding about the lifespan reducing outcome of dementia (Annear, Otani, & Li, 2016). In another study which sought to identify gaps in knowledge of Alzheimer's Disease in college students, the common misconceptions also related to life expectancy and risk factors (Eshbaugh, 2014).

In contrast, staff members and volunteers of FBOs had a strong sense of existing knowledge in the specific themes of "Care Needs" and "Communication & Engagement." Specifically, our study showed that staff members and volunteers of FBOs showed an existing knowledge regarding care needs including the importance of communication through body language, the need for care with a focus on comfort, and the benefit of exercise for people living with dementia. This sample also showed a strong sense of understanding about the possibility of a person with dementia having a difficult time speaking and making decisions. The existing knowledge about care needs as well as communication and engagement for staff and volunteers of FBOs is a major strength considering FBOs are often a source of comfort and social support for people living with dementia (McFadden & McFadden, 2011).

Previous research suggested education on dementia was positively correlated with higher scores on the DKAS (Annear, 2018). Our study also showed a positive correlation between previous training on dementia and score. Those who self-reported attendance of any form of dementia training (35%) tended to score higher on the DKAS. The data found in this study will

be used to create a training for staff and volunteers of FBOs to eradicate misconceptions about dementia within this population.

Previous research suggested the physical space of worship services can be improved to best serve PLWD such as clear spaces, limited noise distraction, song and reading sheets, and name tags (Goldsmith, 2004). Our study did not show a strong gap or strength in the physical environments of FBOs. Participants were asked if the physical environment of their FBO was suitable for PLWD. The reason this mean was neither high nor low could be because of the lack of education about physical space and dementia. It also could be because the physical environment is such a case by case factor within FBOs based upon their services and building.

Studies have suggested every major religion commands its followers to love and serve others. This religious command provides a strong motivation for staff within FBOs to care for and serve PLWD (MacKinlay & Trevitt, 2012). Because of these strong religious motivations, when dementia can threaten a person's worth in society, the Christian church in particular seeks to view every person as important, worthy of proper care and respect (McFadden, 2012). Our study confirmed this claim. Our results showed a strong sense of responsibility within staff and volunteers of FBOs to give PLWD both dignity and respect. This population also strongly believes it is still important for people living with dementia to both remain spiritually active and receive spiritual care. This showed that FBOs are a possible place of safety for those with dementia, and they also have the potential to provide a strong social support system. This is a potential strength in services provided by FBOs. However, when it comes to actually providing the services, our research indicated a gap may exist.

This study also sought to identify strengths and gaps in services provided to PLWD in FBOs. According to our research, a strong majority of participants indicated that PLWD often

feel more uncomfortable in worship settings than before, and that attendance of faith-based activities tend to drop after diagnosis. This is congruent with previous research which showed a decline in attendance of religious services for PLWD (Shuman et al., 2017). In addition to this, our study showed a gap in the active involvement of PLWD within FBOs due to a lack of provision of services for PLWD. Previous research supported this finding, claiming that staff of FBOs often forget about PLWD or are not confident in creating or finding ways PLWD can still serve within the organization (McFadden & McFadden, 2011). Our research showed that although staff and volunteers have a strong sense of responsibility to PLWD, the lack of services provided and active involvement of PLWD showed a major gap.

Surprisingly, as much as the data showed that staff and volunteers of FBOs feel compelled to treat PLWD with respect and have a desire to continue social and spiritual support, their confidence in doing this as well as actually providing the services is fairly low. Participants self-reported a lack of feeling equipped to interact well with PLWD, including a lack of confidence in answering questions regarding the impact of dementia on a person's spirituality. This showed a gap in education and understanding of dementia which is congruent with previous research that claimed staff and volunteers feel undertrained and ill-equipped when it comes to serving and interacting with PLWD (Mast, 2014) Previous research also showed most educational training for staff of FBOs does not include anything about dementia (McFadden & McFadden, 2011). Our research suggested the lack of education and training within FBOs about dementia is a major gap.

Several weaknesses in the study exist and should be noted. Additional questions in both the "Experience with Dementia" and "Perceptions of Services" sections may have been useful for data collection and analysis. For example, it would have been useful to ask whether or not the

participant has dementia themselves. This would have allowed for participants to self-identify if part of their past experience with dementia has been their own diagnosis. It also would have been useful to ask specifically what services the FBO offers for PLWD instead of combining all of the services into one question. This would have allowed the researcher to obtain results about what services are offered, indicating strengths, and what specific services are not offered, indicating gaps in services provided.

Another limitation was the lack of previous use of the DKAS. As a fairly new scale, this measure has had little previous usage, therefore, few studies to compare the results with. In addition, although the scale has been proven to be valid and reliable, there are two versions of the scale, a 27-item older version and a 25-item updated version. Our study used the 27-item scale. Although using a new scale proved to be a limitation in ways, our study has contributed to understanding the DKAS and to the usage of the scale.

Finally, the sample had limited cultural, religious, and ethnic diversity. Although the sample was somewhat representative of the population of our geographical area, the data would be more useful if it represented more than primarily white Christians. It also should be noted that our population had a fairly high education level with 50% of participants with a graduate or professional degree. The majority of our sample was also female (67%). However, our study had a diverse range of ages and roles within FBOs.

This study is valuable for several reasons. Overall, the research contributes to the Dementia Friendly America movement. This study helps to identify perceptions of dementia in a population that has had little previous research. Several studies have examined the knowledge of dementia within college students, healthcare providers, or caregivers, but little to no studies have been conducted to identify perceptions of dementia in staff and volunteers of FBOs. This study

also contributes to the validity of the DKAS, a scale that has had little previous usage. This study could be replicated in geographical areas that would allow for more religious, cultural, and ethnic variability to compare to the results of this study. However, perhaps the most valuable outcome of this research is the information it provides in the development of a dementia training for staff and volunteers of FBOs.

In terms of information that is valuable in the creation of a training, this study identifies several items of existing knowledge about dementia within staff and volunteers of FBOs. When developing a training, the items of existing knowledge within this population could be left out of the training or discussed briefly in order to utilize time more effectively to focus on gaps in knowledge. As our study identified, staff and volunteers of FBOs already have a strong grasp on the care needs and communication skills of PLWD. Specifically, this sample showed an existing knowledge in the following areas which should be maximized in the development of a training on dementia for FBOs:

- Dementia is caused by physical changes in the brain
- Exercise is important for PLWD
- PLWD may have difficulty speaking, yet they communicate through body language in later stages
- PLWD may have problems making decisions
- Care for PLWD should focus on comfort

In addition to these items of existing knowledge, staff and volunteers of FBOs showed a strong desire to treat PLWD with both dignity and respect. In addition to this, they know that it is important for PLWD to remain spiritually active. These are strengths that could be noted and

praised in a dementia training for this population. This existing knowledge provides a solid foundation to build the training.

The gaps in knowledge and services identified in this research are valuable in the development of a dementia training. These gaps will be important items to include in the training in order to educate this population to become more dementia friendly. This research helps to identify priorities of items to include in a dementia training. Specifically, the sample showed gaps in knowledge in the following areas which should be included in a training about dementia for FBOs:

- Risk factors for dementia, including high blood pressure
- Causes and forms of dementia
- Onset and progression of symptoms of dementia
- Characteristics of dementia, including the life-limiting nature of dementia
- Modifications of physical space within FBOs to best serve PLWD (including name tags, lyric sheets, calm environments, etc.)
- Ideas for outreach and opportunities to allow PLWD to serve in FBOs
- Strategies to maintain attendance for PLWD and provide higher levels of comfort when attending FBOs
- Strategies for interacting with a PLWD using person-centered strategies
- Discussion strategies regarding how dementia impacts a person's spirituality

### **Conclusion**

Dementia is a rising and prevalent public health concern, especially in older adults today. Because of the scope of this issue, each part of the community should be educated about

dementia as well as how to best interact with PLWD. To educate these individual community sectors, existing perceptions about dementia among the community must first be identified. Both spiritual and social support from FBOs are important aspects in the lives of many older adults, and their involvement within these organizations can still be meaningful in the lives of PLWD. This research provides one of the first studies of perceptions of dementia within FBOs. The evidence strongly suggests FBOs are a potential place for social and spiritual support for PLWD because of the existing knowledge regarding care needs as well as communication and engagement. It also shows staff and volunteers of FBOs feel compelled to provide dignity, respect, and spiritual support for PLWD. However, we conclude proper dementia training and education is necessary to ensure misconceptions do not continue to exist including the life-limiting nature of dementia, risk factors for developing dementia, person-centered interaction strategies for PLWD, and the impact of dementia on spirituality. The results provide data to develop and improve training for staff and volunteers of FBOs in order to build a more dementia friendly community. This future training will empower FBOs to provide quality care, services, and both social and spiritual support to PLWD.



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