

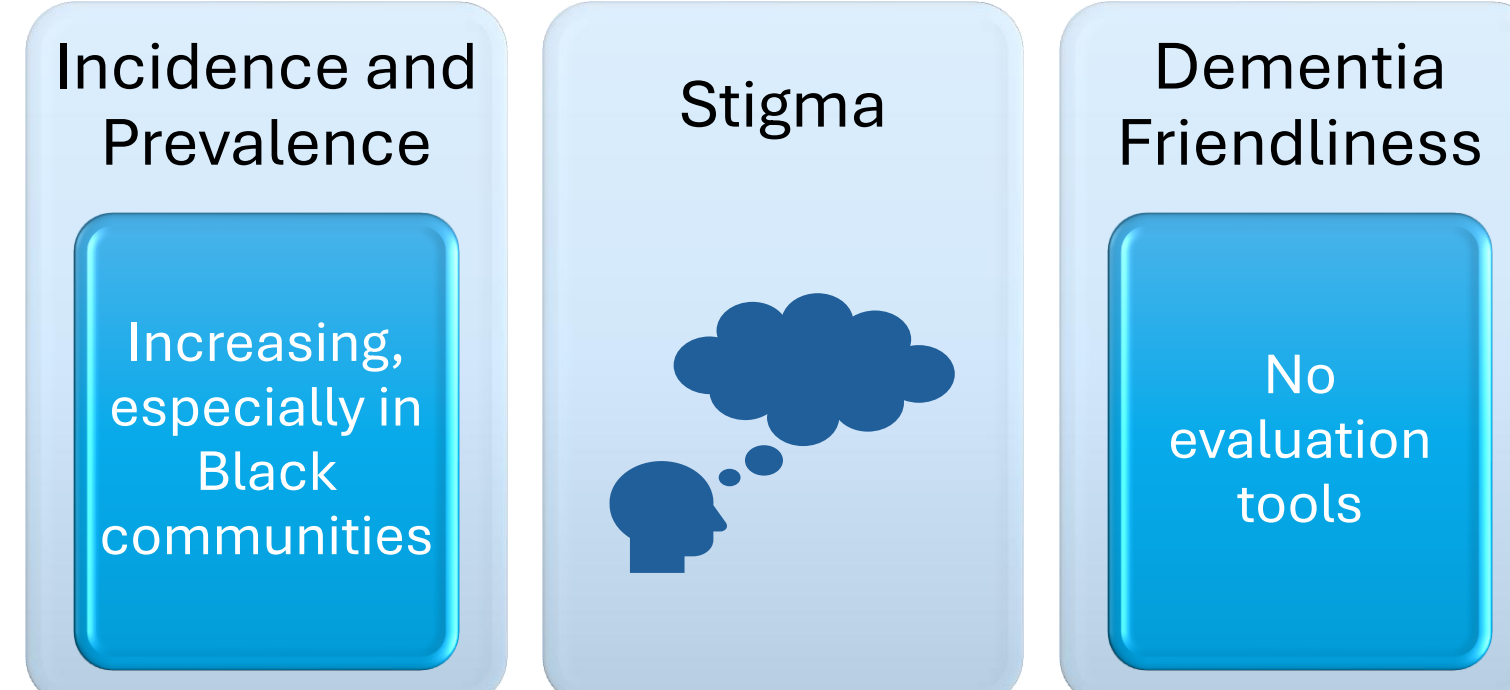
Using a Person-Centered Approach to Develop a Measure of Dementia Friendliness

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BACKGROUND

As dementia cases continue to increase, it has become critical to adapt both the physical and social environments in which people living with dementia (PLWD) engage. Among Americans affected by dementia, the rate of diagnosis and prevalence of dementia is disproportionately increasing for African Americans compared to white Americans. African American families affected by dementia are often hesitant to share a dementia diagnosis with the community due to the disease's stigmatizing nature. **African American churches play a significant role in establishing community norms and the positionality of African American churches allows heightened ability to address dementia-related stigma and increase the wellbeing for families.** Many churches do not currently have programs or the infrastructure to support and accommodate families affected by dementia.



There is growing interest in modifying social and built environments to be more dementia friendly. The term 'dementia-friendly community' is used to describe communities whose goal is to reduce dementia-related stigma, provide social interaction opportunities for people living with dementia (PLWD), and offer support resources for families. Despite growing interest in evaluating dementia-friendly community initiatives, **few comprehensive tools exist that are appropriate for small community settings, such as churches or local centers.** To address this gap, we designed a person-centered instrument, the Dementia-Friendly Community Assessment (DCAT), to measure how supportive these environments are for individuals with dementia.

METHODS

The assessment tool integrates both new and previously validated measures to evaluate dementia-friendliness within churches participating in a dementia-friendly congregation program, Alter, in African American communities. We used a multi-phase, community engaged participatory research approach starting with sharing early draft of the survey with key stakeholder groups including church leaders, care partners, PLWD, and members of the Alter advisory board, to solicit input on the tool's domains, clarity, and overall suitability. The instrument was iteratively revised and tested with additional stakeholders (church leaders, care partners, PLWD, and congregants) before pilot testing with 1,162 members of 15 churches. Final steps included item reduction and factor analysis to determine a score of dementia friendliness.

PROCESS



Community Feedback Phases



Testing Phases

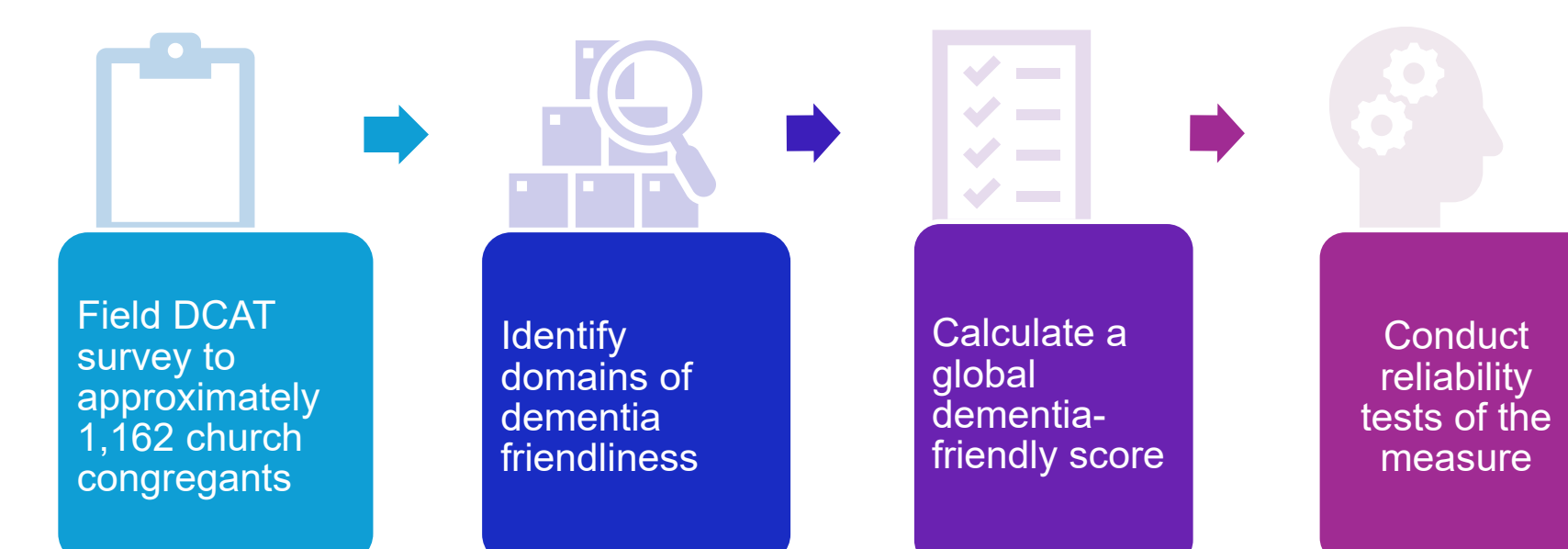


Table 1. Example Feedback

Feedback	Focus Group	Interviews
Respondents expressed need and desire for a new tool	<i>The tools that you're using right now to reach out to us, to reach out to other people and everything is just making it better for caregivers. It's making it better for family members who's going through this... It's heartening. Just having another person there that's aware of what's going on, it's helpful.</i> - Care partner	<i>One of the things that I see that it's a great need, and there's a lot of areas where the church or faith community can improve to address the needs of individuals dealing with memory loss or dementia. Like everything else it's a ministry, and all our ministry is just meeting a need... The [survey] will help us improve.</i> - Church leader
The tool was appropriate for target population	<i>Overall, I think this is a good way for the church to get information that they probably would never get because no one is gonna stand up in front of their congregation and say, I have dementia or even that I'm a caregiver... Then once it's gotten that that church can use it to help their entire congregation be whole in a sense.</i> - Alter advisory board member	<i>I think that they're ready to try to do something and that people in the congregation have been very receptive to it. I think [the survey] would be appropriate.</i> - Care partner

RESULTS

Table 2: Demographic Characteristics (N=1,162)

Characteristic	N (%)
Age Group	
18 to 29	77 (7)
30 to 39	104 (9)
40 to 49	170 (15)
50 to 59	233 (20)
60 to 69	294 (25)
70 or older	274 (24)
Female Gender	862 (74)
Black/African American Race	1,130 (97)
Not Hispanic or Latino Ethnicity	1,133 (98)
Education	
Less than high school	18 (2)
High school diploma/GED	172 (15)
Some college	289 (25)
Associate's Degree	108 (9)
Bachelor's Degree	291 (25)
Professional degree	272 (23)
Knows Someone with Memory Loss	184 (16)
Role*	
Living with memory loss	108 (9)
Caregiver	694 (60)
Faith leader	113 (10)
Faith Community	376 (32)
Education/Healthcare	306 (26)

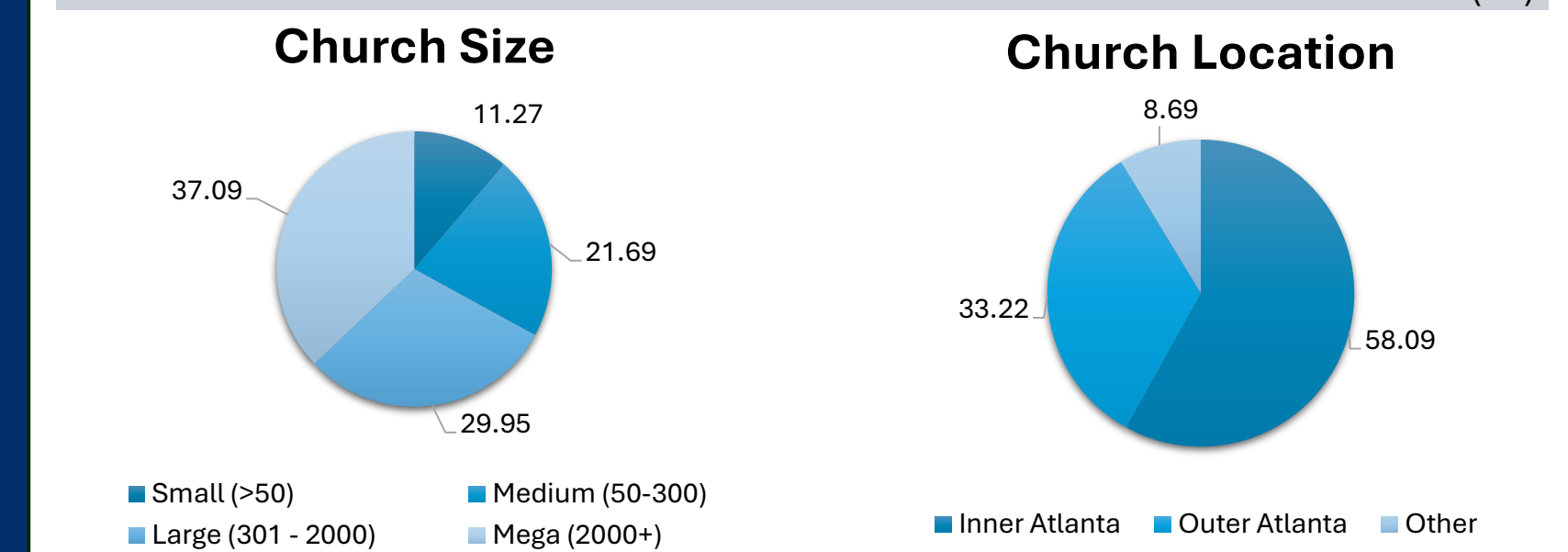


Table 3. Correlations of Overall Score, Stigma, Dementia Knowledge, and Skills

	Self-Stigma (n=192)	General Stigma (n=733)	Caregiver (Affiliate) Stigma (n=222)	Knowledge of Warning Signs (N=1162)	Skill Assessment (N=1162)
Overall Score	-.203**	-.080*	-.132*	.066*	.164**
Self-Stigma				-0.093	-.193**
General Stigma				-0.005	-0.069
Caregiver (Affiliate) Stigma				-0.131	-.224**
Knowledge of Warning signs					.375**

**Correlation is significant at the 0.01 level (2-tailed).
*Correlation is significant at the 0.05 level (2-tailed).

Participants responded favorably to the tool, with most indicating that its generated scores would be valuable for their communities. The final scoring resulted in an overall score and five sub scores. **The overall scale showed excellent reliability ($\alpha = 0.88$).** Higher total scores were significantly associated with greater dementia-related knowledge and skills, and with lower levels of stigma across all measured domains.

CONCLUSION

Our research validates a tool that other programs can tailor to measure the impact of their programs on the dementia friendliness of their community. Engagement with the tool and subsequent measurement testing suggest it has potential to facilitate conversations and identify areas for improvement that may help reduce stigma.

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