

UNCOVER THE MEANING OF DEMENTIA FRIENDLY

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BACKGROUND

- WHO urges governments worldwide to set dementia as public health priority and promote building a dementia-friendly society globally.
- No agreed-upon definition for *dementia-friendly*
- Scant research conducted on concept of dementia-friendly or building dementia-friendly communities in U.S.

STUDY PURPOSE

- Understand meaning of “dementia-friendly” from perspectives of persons with dementia (PWDs) and family caregivers (FCs)
- Elicit recommendations for promoting dementia-friendliness in communities.

METHODS

- Data collection: focus group (N=7), dyadic interview (N=2), 1:1 interview (N=6)
- Qualitative content analysis

PARTICIPANTS (N=37)

- 12 PWDs (8F/4M; 60-85 years old); 25 CGs (16F/9M, 58-92 years old)
- 33 Caucasian, 3 Hispanic, 1 African American
- Private home (N=22); Independent living (N=15)

Self Acceptance. *“I guess the only way that I could think of it is that from an insider’s perspective I have accepted the fact that I have dementia. I’m comfortable with it. I attached no stigma to it, and I am not reluctant to tell people that I have dementia.”* (PWD)

Living a Normal Life with Dementia. *“It’s a disease and people get all kinds of diseases. You can still live a normal life, somewhat of a normal life and do things just like other people do. To me that’s being friendly.”* (FC)

Knowing How to Interact with PWD. *“I sort of think of how I respond as either friendly or not for my father-in-law. There are certain ways to respond to him so that he feels like he’s being listened to and not told what to do. Trying to tell him what to do isn’t interpreted by him as very friendly.”* (FC)

An Environment that Supports PWD *“I would say that it’s an environment, values, and then treatment that supports and respects people with dementia and Alzheimer’s.”* (FC)

Caring for PWD. *“When you have dementia, it makes you aware of how important caring means. You may care a lot about your family and not be able to express that. It would be important for a family to express caring for that person with dementia so that they feel safe and taken care of.”* (PWD)

A Place for Both PWD and FC. *“It’s probably more for the caregiver than it is for the person with dementia, even though the dementia person is getting stimulation like we were talking about — whether you’re singing or painting, but there’s got to be something for that caregiver as well.”* (FC)

Recognizing What Dementia Is. *“As well as having the friendly, which is an obvious thing, but it’s also a recognition that you’re speaking with someone who had a diminished level of capacity.”* (PWD)



Going into Their World *“It’s whatever is going on at that point. If she’s 12 years old again, you don’t have to work so hard to bring her back to the fact that she’s 78. Let her be 12 and play in a way that is, you know, what do you want to do today?”* (FC)

SETTINGS NEED TO BE MORE DEMENTIA FRIENDLY

- Retail establishments & stores
- Hospitals
- Organizations & facilities
- Fire department & law enforcement
- Neighborhood
- Media
- Entertainment Industry
- Programs & services



RECOMMENDATIONS FOR THE COMMUNITY

- Educate the public
- Prepare the next generation
- Social inclusion (into larger disability culture, “having places to go”)
- Become spokespersons, self-advocacy
- Provide protection and sense of security
- Create caring atmosphere/“lift them up”
- Dementia training for healthcare providers, businesses, etc.
- Proper reaction towards persons with dementia
- Be friends with someone with dementia
- Affordable dementia-friendly programs
- Improvements in transportation system
- Accessible social and health insurance programs
- Access to accurate dementia-related information
- Old-fashioned village concept (feelings of community and helping each other)
- Keep PWDs motivated/engaged/active
- Remove of fear & stigma
- More publicity (TV, radio, newspapers, etc.)
- Accommodations in physical environments (simple/clean designs, visual cues, familiar music, etc.)



CONCLUSIONS & IMPLICATIONS

- PWDs and FCs would like communities to adopt the recommendations above.
- **Implications for healthcare providers:** Receive training in dementia; provide timely dementia-specific resources at diagnosis.
- **Implications for future research:** Consider including people with mild cognitive impairment when designing future dementia-friendly studies.