

**Perceptions of Stigma:
People Living with Dementia**

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**Perceptions of Stigma:
People Living with Dementia**

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Abstract

Dementia is an umbrella term that covers a number of diagnoses that affect the cognitive and behavioral functioning of an individual. This diagnosis carries with it a surrounding stigma that impacts a person with dementia's life negatively leading to social isolation, low self-esteem, a delay in care-seeking, and poorer health outcomes. This research seeks to address the perceptions and experiences of this stigma from the point of view of people living with dementia. There has been little research done about the stigma surrounding dementia and none from the perspective of those diagnosed with dementia. If more was known about this stigma and the role it plays in this population's lives, we could begin to bring awareness to the matter to bring about change. This qualitative descriptive study gathered data using transcribed first-person interviews and identified themes using qualitative analysis. The findings revealed that there is a stigma from the general public toward people with dementia that leads to dehumanization, self-stigma, increased reliance on the caregiver, and stigma within the healthcare system. The results also showed a call for more education about dementia in the healthcare setting from people with dementia. The presence and impact of the stigma surrounding dementia that was seen in the data shows a need for more education and awareness both for the public and especially for the healthcare setting in order to mitigate the negative impact stigma has on people with dementia.

Introduction

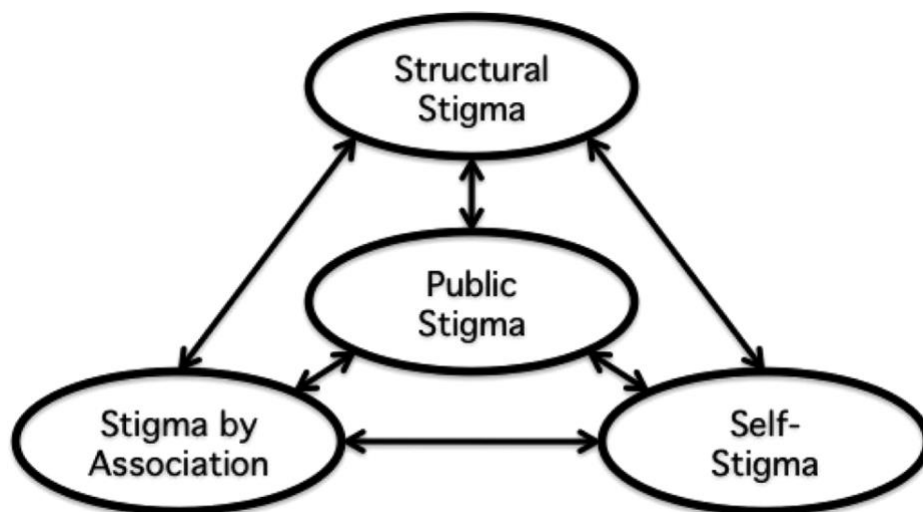
A diagnosis with dementia impacts not only a person's physical health but their social and emotional well-being. The stigma surrounding dementia negatively impacts people with dementia socially, mentally, and emotionally. Unfortunately, this stigma also manifests itself in the lives of care partners of people with dementia and within the healthcare system. This study was a part of a multiple case study that identified and explored people with dementia and their caregivers' experiences with this stigma specifically within the healthcare system to uncover areas where society can begin to reduce this stigma and improve the population's experiences. The purpose of this case study was to understand how people with dementia describe stigma surrounding dementia and to explore their experiences.

Theoretical Framework

The semi-structured interview guide was designed using concept elements from the Pryor and Reeder (2011) conceptual model. Stigmatization occurs on societal, interpersonal, and individual levels. Concepts from the Pryor and Reeder model guided the interview questions. Bos et al. (2013) suggest a framework for describing how stigma affects different facets of one's life. At the center, the authors describe public stigma: how others perceive the individual being stigmatized (Bos et al., 2013). Public stigma is the root of the other forms of stigma including self-stigma, structural stigma, and stigma by association (Figure 1). Self-stigma, in this study, represents the experience of those who are living with dementia. Structural stigma describes the experiences within the healthcare system of caregivers and people with dementia. Stigma by association then is the caregiver's perceived stigma surrounding their counterpart's diagnosis.

Self-stigma can result from an awareness of public stigma, as people with stigmatized conditions are keenly aware of the social devaluation connected with their condition.

Figure 1. Four types of stigma.



Note. This model was used to guide the interview questions.

Literature Review

CINAHL Complete, Medline, and Academic Search Ultimate were searched using the following terms: “dementia”, “caregiver”, “stigma”, “quality of life”, and “shame”. Searches were limited to the last five years and in English.

Dementia is an umbrella term used to describe a family of diseases that affects an individual’s cognitive and behavioral functioning. Today, there are about 50 million people with dementia, and 10 million more are diagnosed each year (World Health Organization, 2020). A diagnosis of dementia places a strain on both the patient and their loved ones who have now stepped into the caregiver role. Unfortunately, one of those strains is the stigma associated with dementia diseases. Caregivers, healthcare providers, and people with dementia themselves, will experience some manifestation of stigma throughout the course of the disease that will negatively affect the patient or the caregiver. There is a need to further study stigma and its effects on the population. Understanding the impact of stigma will help caregivers and healthcare

providers recognize its influence on individuals with dementia and may prompt more public awareness. Both results would improve care and quality of life for everyone who feels its impact.

Stigma functions as a method of domination, norm enforcement, and disease avoidance (Bos et al., 2013). Stigma in people living with dementia can be devastating to a person's quality of life, care-seeking, and overall health. People with dementia tend to report a loss of self-worth and identity after their diagnosis (Harper et al., 2019). Stigma is also associated with higher levels of depression, anxiety, and behavioral symptoms of dementia (Harper et al., 2019). The authors reported internalized shame and feeling like a child as their disease progressed (Harper et al., 2019). This debilitating stigma exists not only in public life but within healthcare professionals which directly impacts a patient's health (Nguyen & Li, 2020). Discrimination, another experience that people with dementia face related to stigma, from healthcare professionals affects the help-seeking behaviors, service access, and a timely diagnosis of people with dementia who may be experiencing symptoms (Nguyen & Li, 2020). There is also an internalized stigma that has been identified in people with dementia towards themselves. Self-stigma instills fear, anger, grief, loss of confidence, and depression in people with dementia (Nguyen & Li, 2020). This self-stigma causes people to further withdraw from society and activities previously enjoyed before their diagnosis which has been shown to trigger the progression of the disease.

Stigma also tends to impact the caregivers of people living with dementia negatively. Most caregivers will report a sense of shame surrounding the diagnosis which manifests itself in silencing or ignoring the diagnosis, concealing the diagnosis, and feeling shunned by others because of the diagnosis (Lopez et al., 2020). Shame that comes from providing care for or being associated with someone with dementia prevents people from seeking care, which is detrimental

to early treatment that could slow the progression of their loved one's disease. Caregiver stigma also impacts expressed emotion and quality of life (de Mamani et al., 2018). Higher levels of expressed emotion, including criticism and hostility, were related to stigma while the poorer quality of life is related to higher expressed emotion (de Mamani et al., 2018). Higher expressed emotion towards people with dementia can also negatively affect their self-esteem and confidence, which have already been shown to be lower due to their stigma. In short, stigma in caregivers indirectly impacts them and their loved one's quality of life. If caregivers cannot take care of themselves, how are they expected to care for their loved ones properly?

There have been few qualitative studies on stigma in self-stigma in people with dementia including Lopez et al. (2019) and de Mamani et al. (2018). Further, there have been no qualitative studies to this researcher's knowledge focusing on the impact that dementia's stigma has on people with dementia's experiences in the healthcare system. There is also a lack of research that gathers data directly from people with dementia using first-person interviews. Studying stigma and its impact on people with dementia, especially in their treatment seeking, could return important information about how the healthcare industry needs to alter its perspective on dementia diagnoses. Research is necessary on the topic of stigma in persons with dementia and disseminated publicly so that educational campaigns can be implemented to reduce the stigma around dementia and thus, improve the quality of life and care in people with dementia and their caregivers.

Methods

Design

This was one case of a multiple case study exploring the stigma surrounding dementia. The other two cases focused on caregivers and nursing students. This descriptive qualitative

design used online personal interviews to better understand how people with dementia describe stigma and explore and their experiences.

Sample & Setting

A purposive sample of people living with dementia ($N = 6$) recruited individuals with the ability to provide rich, in-depth descriptions of their experiences surrounding stigma. The inclusion criteria included a self-report of diagnosis of dementia, able to consent to study, and English speaking. All were participants in support groups aimed specifically at those in the early stages of dementia. Exclusion criteria included non-English speaking because this was beyond the scope of this study. The interviews were conducted online using Zoom. Potential participants were notified via email and co-investigators attended online support groups to explain the study and answer questions.

Data Collection

Participants participated in a one-time online interview. Open-ended questions were used to explore their experiences of stigma that surround dementia. Interviews lasted from 18 minutes to 50 minutes. Interviews were audio recorded for professional transcription purposes. The questions explored their thoughts and experiences surrounding living with dementia (Appendix A).

Ethical Considerations

The Institutional Review Board was approved by the university. No personal identifiers were collected or identified in transcripts to preserve anonymity and confidentiality. The study was explained during video- conference meetings with the person with dementia and caregiver. All participants provided signed online informed consent without any assistance.

Data Analysis

Interviews were transcribed verbatim and verified. Researchers simultaneously listened to audio recordings of the interviews and read transcripts correcting any errors made during transcription. Demographic information was collected, and recruitment continued until no more themes emerged. Qualitative analysis was performed simultaneously with data collection so that earlier findings informed later interviews; no revisions to interview guides were necessary. With the Pryor and Reeder (2011) model and propositions as a backdrop, each co-investigator coded the raw data and identified categories.

Yin (2018) suggests methods to promote construct, internal and external validity, and reliability. Construct validity was achieved via multiple sources of evidence, the three cases, multiple researchers coding and discussing data, and member checking. Internal validity was ensured via pattern matching across cases and explanation building. A theory-based study promotes external validity and a study protocol and interview guides ensured reliability. Researchers avoided and challenged one another regarding inferences or assumptions.

Trustworthiness of the qualitative was attained by thematic saturation and member checking, a process of returning to persons living with dementia to get their feedback on categories and subcategories, which further ensured the trustworthiness of the qualitative data and analysis (Korstjens & Moser, 2018). Participants felt that the experience was accurately represented, and no revisions were required.

Findings

Demographics

A total of 6 community-dwelling people living with dementia participated in the interviews. Persons living with dementia included 2 females and 4 males with mean age 68.3 years (range 60–72 years) all living at home with their spouse.

Qualitative Themes

From the data collected through interviews, four major themes emerged. These included self-stigma, public stigma, structural stigma, and recommendations to healthcare workers and the public. Sub-themes from the data included caregivers as protectors, dehumanization, and the thought of people with dementia as a baby or a child.

Public Stigma

Public stigma is defined as the cognitive, affective, and behavioral reactions of those who perceive the stigmatized (Bos et al., 2013). When asked about public perception, five out of six participants explained that strangers would not know whether they had dementia just by looking at them. One participant stated that “they would not necessarily know that I have a form of dementia unless they talked to me for a longer period of time.” Another said, “other than just maybe just an extra glance, I can't make out that people perceive me any different than before.” Several participants focused on a desire to appear intelligent to others in public with one expressing, “I would say is that the person with dementia is still a person and they still have intelligence, and they still have feelings.” When asked about the reactions of others to their diagnosis, one participant reported friends distancing themselves after learning of their diagnosis, saying “one friend I thought would be a really-- she couldn't even finish a two-minute phone call before she hung up.”

Dehumanization. A subtheme that emerged from public stigma was the dehumanization of those living with dementia. Two of the participants used the term “demented” when referring to themselves or other people with dementia. One stated “the demented person is not going to be wanting to show it off.” One participant associated having dementia with being a baby or a child, saying “it's just a lot about this I don't like but I've been trying to be a big boy.”

Self-stigma

Self-stigma emerged from the data as a theme, which is defined as the negative beliefs and feeling surrounding possessing a stigmatized condition (Bos et al., 2013). When asked about how people have reacted to their diagnosis, many participants reported being selective about those they have told, if any at all. One stated, “I've been selective about who I told I had a problem at all.” When asked “what does having dementia mean to you?” one participant described the title as “outdated,” “old fashioned,” and having a “heavy negative connotation.” Another elected to not answer the question at all. One participant denied their diagnosis entirely, stating “I've never seen myself with dementia.... I just don't see myself as a demented person.” Some participants reported feeling demeaned by the effects of their dementia on daily life. They reported relying on their caregiver more or taking more time to answer a question. One participant expressed that it is “a little demeaning to have to take a little longer to answer a question or not be able to get the word you're looking for.” When asked about how being diagnosed with dementia has changed their life, participants described being limited on how much they leave their house, saying “I mean, there are days that I probably shouldn't go out in public because I'm just terrible.” One focused especially on their heavy dependence on their caregiver, stating “I'm kind of a dependent partner.”

Structural Stigma

Structural stigma is the reinforcement of the stigmatized status of a condition by institutions and societal systems (Bos et al., 2013). When asked about experiences in the healthcare system, people with dementia described feeling treated differently. One stated that “my doctors and nurses usually treat me as a person that they have to pay special attention to or

something.” Three out of six participants explained they felt as though their providers tended to ignore or make assumptions about their diagnosis. One stated that “most don't bring it up.”

Caregiver as Protector

Another theme that emerged from the data was the reliance on the participant's caregiver as their protector because of the barriers their diagnosis creates for them in society. One participant described their caregiver as being there to facilitate daily life for the person with dementia. They explained that people would often look to the caregiver first before the people with dementia themselves, with one describing having trouble answering a question, stating “she would make sure to step in and answer it for me.” When asked about experiences in the healthcare system, one participant described their caregiver as being the one to tell them about the person with dementia's diagnosis, stating “my wife told them that I have dementia and so they put the bed alarm on.” When asked about how their lives had been changed by dementia, one participant described their caregiver as making changes to their own life, expressing that “he's been so sweet and careful, and changed his life, not mine.”

Recommendations

Several recommendations were made by people with dementia. When asked what they would like nursing students to know, one participant focused on maintaining the humanity of people living with dementia explaining that “they're real people with real histories, and just the fact they have dementia doesn't make them count for less.” Another participant emphasized the need for more education on the topic, saying “if they knew more about dementia, I think it might make them be able to feel comfortable around someone who has it.”

Discussion

The purpose of this study was to identify and explore the impact that societal stigma has on people with dementia through case interviews. Results were similar to Harper et al. (2019) revealing that the overall impact on people with dementia is negative. Almost all participants described their disease process as being mostly undetectable to the public eye. As well, many described their reluctance to share their diagnosis with family, friends, and strangers. This was likely due to the fear of being dehumanized for their diagnosis—an experience that has affected many of the participants and has led to much frustration. This fear can even prevent or delay the seeking of treatment by these patients and negatively impact their health.

Another contributor to people with dementia's frustration was their increasing reliance on their caregiver. Societal demands do not accommodate for the needs of those diagnosed with dementia. This caused people with dementia to turn to their caregiver for assistance rather than take the time to explain their needs or ask someone to repeat a question.

Somewhat ironically, stigma's effects can be felt in the healthcare setting as well. As observed in Nguyen and Li (2020), where one would think that this population would be most understood, participants reported providers making assumptions about them based on their diagnosis. They also reported that their providers possessed a lack of knowledge about their dementia and that they would often simply ignore that information altogether.

Similar to findings from Patel et al. (2021) and based on these results and recommendations offered by the participants, there is a need for more widespread education about dementia and the reality behind it. Our results support the framework offered by Bos et al. (2013) that explains the source of all stigmas felt by people with dementia is public stigma. By educating the public on the realities of dementia, its progression, and its signs and symptoms, the self, structural, and associated stigmas can be mitigated. In addition, participants made

recommendations for nursing students specifically. Offering education dedicated to this fast-growing patient population in the healthcare profession would allow for better-informed care to patients and will restore humanity and reduce systemic stigma toward people with dementia in the clinical setting. The need for general and healthcare-specific education about dementia is imperative as the population ages and dementia is increasingly diagnosed. Dementia is now the seventh leading cause of death worldwide, and few people have a clear understanding of what the diagnosis means (Kim et al., 2022).

Strengths, limitations, and clinical implications:

This study was strengthened by thematic saturation from the data and the use of primary sources through first-person interviews. However, this study had several limitations. The participants may not represent the perspectives of all those living with dementia, especially those who are not involved with community resources. Due to the COVID isolation precautions that were in place at the time of the interviews, some answers about socializing and public life may be skewed.

The clinical implications revealed by the results include the need for more education and training for healthcare workers in providing care for people with dementia. They also identified a need for increased awareness and education for the public which may serve to decrease the stigma.

Conclusion

The stigma surrounding dementia is present and is constantly affecting the lives and well-being of people with dementia. It causes frustration, barriers to quality patient care, and a sense of low self-esteem and dehumanization. Research is necessary on the topic of stigma in persons with dementia and disseminated publicly so that educational campaigns can be implemented to

reduce the stigma around dementia, and thus, improve the quality of life and care in people with dementia.

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Appendix A

Interview Guide Person with Dementia

1. How do you think people, who do not know you, perceive you when out in public? (public stigma; cognitive)
 - a. Probe: Can you give an example?
 - b. Probe: How does this affect you? (self-stigma)
2. How do people, who do not know you, respond or behave when they meet you? (public stigma; behavioral)
 - a. Probe: Can you give an example?
 - b. Probe: How does this affect you? (self-stigma)
3. Do you behave differently around people you don't know?
 - a. If yes, probe: Can you give an example?
 - b. Probe: When you behave differently around other people, how does that affect you? (self-stigma)
4. How do you feel in a public setting? (public stigma)
5. What does it mean to have dementia? (self-stigma)
6. What have been healthcare providers' (doctors, nurses, nurse practitioners, etc.) responses to your dementia? (structural stigma)
7. Describe an experience you have had with the healthcare system that had an impact on you.
 - a. Probe (if answer was positive, probe negative experience and vice versa)
8. Have dementia symptoms affected your relationship with other people? (public / self-stigma)
 - a. Probe
9. How has dementia affected your social life? (public / structural / self-stigma)
 - a. Probe
10. Has your life or interactions changed? (public / structural / self-stigma)
 - a. Probe
11. Describe what daily life was like before you had dementia and describe what it is like now? (public / structural / self-stigma)
12. Please share any examples that people with dementia's post to social media - for example, Facebook, webpages, or blogs - about society's perceptions of them. (structural stigma)
13. Has COVID-19 affected your experiences related to how others view dementia?
14. Have you found anything positive about having dementia?
15. What do you want nursing students to know about a diagnosis with dementia? 16. Is there anything else you would like to share?

*Probes...tell me more, can you elaborate, can you give an example, please be specific, I am not sure I follow you...