


# Quality of Life and Needs of Deaf Informal Caregivers of Loved Ones with Alzheimer's and Related Dementia

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## Abstract

No studies have included the experiences and needs of informal caregivers who are deaf, use American Sign Language (ASL), and care for a loved one with Alzheimer's disease or related dementias (ADRD). The CDC's BRFSS Caregiver Module and PROMIS-Deaf Profile measures were administered via an online bilingual English/ASL platform between October 2019 and March 2020. Out of 194 deaf adult signers who completed an online survey, 42 respondents (mean age = 66; SD = 12; 74% White) endorsed informally caring for someone with a medical condition. In this survey subsample of informal caregivers, more years of education was significantly associated with higher generic quality of life and higher deaf-specific quality of life. A smaller subset of informal deaf informal caregivers who were currently taking care of loved ones with ADRD were then invited to participate in a semi-structured interview. Among the 22 informal caregivers who were interviewed, there was a strong agreement among the participants who felt that their quality of life as informal caregivers was worse than hearing informal caregivers who took care of loved ones with ADRD. Findings highlight the importance of a call to action to address the needs of deaf informal ADRD caregivers.

## Keywords

Disability, caregiving and management, alzheimer's/dementia, quality of life, needs

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## Background

According to the World Health Organization's definition, quality of life (QoL) is achieved when an individual's value systems are in harmony with one's cultural background, which can be defined through language, ethnicity, race or lifestyle. Key points from a conceptual model of deaf-specific QoL study include being accepted as a deaf individual by others, having access to deaf peers who share the same language and cultural values, and being able to access information in a primarily speaking society (Kushalnagar et al., 2014). The intersecting social determinants of health intrinsic (e.g., low education) and extrinsic (e.g., barrier to healthcare services) to the deaf person creates a mutually constituted vulnerability for greater health disparities and poorer quality of life outcomes if the deaf person is not provided equitable access to health information and resources (Kushalnagar & Miller, 2019; Lesch et al., 2019; Smith & Chin, 2012). Deaf informal caregivers of loved ones with Alzheimer's and related dementia

(ADRDs) are also affected. Given the longstanding history of inequitable access to language and education, many deaf people who fall in the role of informal ADRD caregiving may not be aware of ADRD-related resources or do not have access to caregiving classes or support groups due to the lack of interpreting services. As a result of these systematic barriers, deaf informal ADRD caregivers may not be prepared for their caregiving role and associated stress.

Due to multiple and often demanding tasks associated with caregiving responsibilities over an extended

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period of time, an extensive body of research has found that individuals who informally care for or assist in the care of community-dwelling older adults often experience physical stress as well as psychosocial impacts including caregiver-burden and restrictions on social participation (Lim et al., 2020; Lim & Zebrack, 2004; Schulz & Sherwood, 2008; Sullivan & Miller, 2015). The adverse effects of informal caregiving on a person's health outcomes were found to be moderated by the caregiver's education level (Schulz & Sherwood, 2008). Less years of education was significantly associated with greater caregiving challenges and poorer overall wellbeing (Pandya, 2019).

Although the aforementioned studies did not include informal caregivers who are deaf and use ASL, it would be reasonable to expect that psychosocial, physical, and accessibility issues impacting perceived quality of life also emerge in this overlooked group. Within this subgroup, it is expected that a deaf person with a college degree may experience relatively better access to caregiving resources compared to a deaf person who has a high school degree. The current study reports quantitative results from CDC's BRFSS Caregiving Module survey, supplemented by qualitative, narrative data from semi-structured interviews with deaf informal caregivers of loved ones with ADRD. This paper concludes with a discussion about the importance of a call to action to address the quality of life and needs of deaf informal caregivers who use ASL.

## Methods

The CDC's Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module items were translated to ASL and back translated to the original language prior to survey administration. The PROMIS Deaf Profile with Global Health and Communication Health domains is available in ASL and English (Kushalnagar et al., 2020). Following approval from the institution's human subjects review board, online data collection for these survey measures was gathered between October 2019 and March 2020. Participants were recruited through snowball sampling and community networks. We reviewed the informed consent letter with those who are eligible and interested; and enrolled those who provided their signed consent. All participants completed the BRFSS Caregiver Module via an online bilingual English/ASL platform.

A smaller subset of informal deaf caregivers who were currently taking care of loved ones with ADRD were invited to participate in a 1-hr interview via a protected Zoom platform. The informal deaf caregivers provided signed consent prior to the interview conducted by a trained deaf person who had previously cared for a loved one with ADRD. All interviews were recorded and then transcribed by a deaf interviewer with bilingual proficiency in ASL and English. About 30% of these interview transcripts were reviewed for quality assurance by the project lead. All videos were destroyed after this step was completed. The findings were

presented in the form of categories (i.e., informal deaf caregiver participants' quotations) that linked the qualitative evidence to the quantitative findings. All participants were compensated for their time.

## Results

### Sample Characteristics

Out of 194 early-deafened (born deaf or became deaf early) adult signers who responded to the survey that included the CDC BRFSS Caregiver Module items, 42 respondents (mean age=66; SD=12; 74% White) said yes to an item that asked about caring for someone with a medical condition and completed subsequent items about their caregiving experiences. More than half of the BRFSS informal caregiver sample had an Associate degree or higher, while 71% were unemployed, retired, or disabled (Table 1). When asked about the relationship of the person being cared for and the person's medical condition, the majority of those being cared for were parents or had dementia or other cognitive impairments (Table 2). For the semi-structured qualitative interview portion of the study, a total of 22 deaf informal caregivers ranging from 36 to 87 years old (mean age=67; 64% White) who were taking care of their loved ones with ADRD completed the interview. All informal caregivers were deaf, and the loved ones with ADRD being cared for were a mix of deaf and hearing people.

### Quality of Life and Access to Information/Resources

In a bivariate correlation analysis, more years of education was significantly associated with higher generic quality of life ( $r = .32$ ;  $p < .04$ ) and higher deaf-specific quality of life ( $r = .37$ ;  $p < .02$ ). However, more years of caregiving were associated with worse quality of life specific to being deaf ( $r = -.35$ ;  $p < .03$ ), and this was more prevalent among the participants who were not able to obtain assistance with or access resources for informal caregivers. There was a strong agreement among the participants who felt that their quality of life was worse than hearing informal caregivers.

*"I think hearing people have access to all services while deaf people do not. Here in this city, I have to search until I find a support group that I can join – but this requires an interpreter. This is just an example. Hearing people have easier access to services than us deaf people."* (Female caregiver, college educated)

*"I would say mine [quality of life] is much worse [than hearing people] . . ."* (Male caregiver, college educated)

When asked about sources of ADRD information during the early phase of informal caregiving, most identified websites and family/friends as the go-to sources for ADRD and caregiving. Yet, none of the participants used the toll free national caregiving resource number to

**Table 1.** Sociodemographic Characteristics of Deaf Informal Caregivers (N=42).

Characteristics	Mean (SD)	n (%)
Age	66 (12)	
Gender		
Male		9 (21.4)
Female		33 (78.6)
Race		
White		31 (73.8)
Non-White		11 (26.2)
Occupation		
Employed		11 (26.2)
Unemployed/Retired/Disabled		30 (71.4)
Education		
HS degree		18 (42.8)
College degree		24 (57.1)
Income		
Lower		12 (28.6)
Middle		23 (54.8)
Upper		6 (14.3)
Preferred language		
Sign language		29 (69.0)
Both sign language and spoken language		13 (31.0)

access ADRD information because they were not aware that this service was available. There is also a clear disparity in the perceived access to ADRD resources among deaf people who use ASL compared to hearing people who speak English.

*“I had to become a caregiver for my husband because there were no caregiving resources specifically for deaf people with dementia.”* (Female caregiver, college educated)

### Informal Caregiver Needs: Medical/Nursing Care Training

A quarter (11 out of 42 BRFSS respondents) took care of their loved ones for more than 20 hr per week. Within this subsample who spent more time on informal caregiving, many (62%) needed but did not receive medical/nursing care training. Chi-square analysis revealed significantly higher unmet medical/nursing care training needs among deaf informal caregivers who had a college degree compared to those who did only a high school degree. In-depth qualitative interviews suggest that being educated about ADRD resources or having awareness about the person’s condition is necessary to be able to recognize the need for medical/nursing care training.

*“. . . Deaf people who now take care of deaf patients really do not have skills just like hearing caregivers do. I think hearing caregivers are able to provide better treatment because they have the knowledge and skills. They get paid more because they can communicate directly [without an interpreter]. I always have difficulty communicating with the facility manager. We exchange probably two lines before our conversation is over. I can see the hearing*

*workers at the facility talking with hearing residents. They [hearing workers] do not do that with deaf people.”* (Male caregiver, college educated)

### Informal Caregiver Needs: Respite Care and Counseling

Among informal caregivers who spent more time caring for the person with AD/ADRD, some (45%) needed but did not receive respite care, and many more caregivers (60%) needed but did not get counseling to help cope with their wide range of caregiving responsibilities.

*“You mentioned setting up a support group for deaf caregivers. Here in my community, there is not much. You told me that there are deaf caregivers all over the country. Here in my town, I know that there is only one deaf caregiver and that is me. . . oh yes, there is another deaf person who is a caregiver. . . there are only two of us here. It would be nice to have more for a support group. Maybe Facebook could be used to start a support group for deaf caregivers in America? Someone could volunteer to lead. We would be able to talk about our experiences and frustrations.”* (Female caregiver, college educated)

*Informal Caregiver Needs: home aide or facility that can sign; culturally humble care and awareness of working with deaf patients who are placed in care facilities*

A recurrent issue that came up across interviews is the lack of home health care aides or staff that can sign or have awareness about deaf people’s needs. Of the interview participants taking care of loved ones with ADRD, 73% (11 out of 15 interviewees) reported taking care of them at home in part due to inaccessible services.

**Table 2.** Prevalence of BRFSS Caregiver Module Questions (N=42 deaf informal caregivers).

Question	n	%
What is his or her relationship to you?		
Parent	19	47.5
Child/Grandchild	4	10.0
Spouse	8	20.0
Relative/Sibling	2	5.0
Non-Relative/Friend	7	17.5
For how long have you provided care for that person?		
Less than 30 days	6	14.3
1 month to 2 years	3	7.1
2 years to 5 years	5	11.9
More than 5 years	9	21.4
In an average week, how many hours do you provide care or assistance?		
19 hr or less per week	26	47.5
20 hr or more per week	14	23.4
What is the main health problem, long-term illness, or disability that the person you care for has?		
Dementia/Cognitive Impairments	21	50.0
Chronic diseases	5	12.5
Mental illnesses	4	10.0
Others	9	22.5
In the past 30 days, did you provide care for this person by . . . Managing personal care such as giving medications, feeding, dressing, or bathing?		
Yes	23	54.8
No	17	40.5
In the past 30 days, did you provide care for this person by . . . Managing household tasks such as cleaning, managing money, or preparing meals?		
Yes	30	71.4
No	10	23.8
As a caregiver, have you ever needed and/or received training on how to perform medical/nursing tasks (for example, giving medicine, changing bandages, managing side effects or symptoms)?		
Did not need or already received	11	26.2
Needed and not received	26	61.9
As a caregiver, have you ever needed and/or received help in getting access to services such as nurses, home care aides, Meals on Wheels or other community services?		
Did not need or already received	15	35.7
Needed and not received	22	52.4
As a caregiver, have you ever needed and/or received short-term or long-term breaks for caregivers (respite care)?		
Did not need or already received	18	42.9
Needed and not received	19	45.2
As a caregiver, have you ever needed and/or received support groups for caregivers?		
Did not need or already received	21	50.0
Needed and not received	16	38.1
As a caregiver, have you ever needed and/or received Individual counseling to help cope with giving care?		
Did not need or already received	12	28.6
Needed and not received	25	59.5

*“Yes, I did [provided care] by myself. The long-term care insurance can cover payment for in home aides but none [home aides] are able to sign. If I put her husband in a non-signing facility, he will decline rapidly. He is better off staying here at home.”* (Female caregiver, college educated)

One deaf female caregiver stated that due to a lack of interpreter access, the deaf loved one with ADRD was misdiagnosed as needing to go to the psychiatric ward when a urinary tract infection was the culprit.

*“. . .when my mother got UTI, she became disoriented and incoherent. The nurses could not understand what was happening. I was not there. . .she became belligerent and combative- hurting a nurse’s hand.”* (Female caregiver, college educated)

This deaf caregiver had the additional responsibility of serving as an advocate during the subsequent psychiatric evaluation and it was a long process to get the facility to cover interpreting services and implement sign language classes for staff.

## Discussion

Our findings show that deaf informal caregivers' quality of life, both generic and deaf-specific, are impacted by barriers to caregiving-related support and resources. Deaf informal caregivers were in agreement about the need to create a workforce of paid caregivers who are able to communicate fluently with deaf ADRD patients who use ASL. Also, the majority of the deaf informal caregivers experienced dwindling availability of their support networks, and desired increased awareness of ADRDs among members of the Deaf community. The need for awareness and support becomes even more important for the health-related quality of life of people who had to retire and become full-time caregivers for their loved ones with ADRD (Majoni & Oremus, 2017). Some deaf informal caregivers in our study have expressed frustration in locating a suitable facility that supports accessible communication and full inclusion. Because of this constraint, the deaf caregivers had no choice but to keep their loved ones at home with almost no external resources provided to them. The following recommendations were shared by the informal caregivers who participated in the interview study.

Facilities that provide care to deaf people with ADRD need to be accessible and inclusive of deaf patients. The sense of isolation experienced by deaf patients could be alleviated by establishing a facility with both deaf and hearing patients and caregivers, all of whom can sign. A brightly lit, deaf-friendly facility, with open spaces would optimize deaf people's ability to communicate and connect with others, improving quality of life. Transparency on facility practices and sharing consistent updates on the patient's condition or status—in regard to their health and wellbeing—with their family was an expressed desire among some participants.

The majority of interviewees taking care of a deaf person with ADRD had to advocate for accessible communication with doctors, nurses, and facility staff. Interviewees reported increased stress associated with needing to advocate or educate them about interacting with deaf people. The time spent on educating others could instead be used to take care of their own health. Therefore, clinics and facilities need to furnish accessible technology (videophones, strobe fire and carbon monoxide detectors, and captioned televisions) and provide interpreters to support full inclusion in planned activities.

There is a strong desire for support groups for deaf informal caregivers who needed to cope with caring for a loved one with ADRD. Informal caregivers of people with ADRD may provide care for a long time and their quality of life may be impacted. As such, it is critical for the deaf informal caregivers to receive accommodations needed for inclusion in mainstream support groups for caregivers, membership in ADRD or older adult-serving

organizations or access to related social service programs. Deaf informal caregivers need to also access practical feedback and guidance on managing care for people with ADRD.

Alzheimer's Association and other major older adult-serving service providers, organizations and non-profits providing resources for the public need to be made accessible, including via American Sign Language (ASL) as well as captioning. In addition, it is essential that specific services including assisted living, primary care, in-home aides, geriatricians, occupational & physical therapists and other specialists follow ADA accessibility guidelines in order to ensure that informal caregivers can effectively support the care of their loved ones with ADRD. Accessible medical and nursing care training and support for deaf informal caregivers needs to be developed so that deaf informal caregivers can maintain high perceived quality of life outcomes in order to provide the best care possible to loved ones with ADRD.

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## Ethics approval and consent to participate

The institutional review board at Gallaudet University approved the study (#PJID2777). All human subjects provided signed consent to participate in the study.

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