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Experiences Surrounding an Early Cognitive Diagnosis in Older, Rural-Dwelling Adults

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Introduction

Misdiagnosis, lack of specialists, and patient dismissal of symptoms can contribute to delayed detection of early cognitive impairment. Compounding these issues, it can be difficult for primary care providers to identify or diagnose cognitive disorders, especially at early stages (Kotagal et al., 2015). Delayed detection of dementias may lead to increased patient and care partner burden over time and a lost opportunity to seek treatment for modifiable risk factors or conditions contributing to cognitive health.

Mild cognitive impairment (MCI) and mild Alzheimer's disease (AD) are recognized as early stage cognitive disorders, a time when many patients live independently and are able to still perform many instrumental activities of daily living (Petersen, 2004; Sperling et al., 2011). Early cognitive symptoms associated with these disorders may also go unnoticed by patients, family, friends, and even healthcare professionals for a wide range of reasons including a patient's ability to compensate for changes and the potential for the changes to be overlooked or viewed as a normal part of aging (Peacock, Hammond-Collins, & Forbes, 2014; Rajan, Wilson, Weuve, Barnes, & Evans, 2015; Teel & Carson, 2003). While associated with numerous barriers, recognizing worsening cognitive symptoms and taking initiative to seek out specialty healthcare can ultimately have a positive impact on overall health and disease management. Understanding the experiences of patients and families who overcome such barriers could provide important insights for nurses and other clinicians who may be working to promote early detection and diagnosis of cognitive disorders. Yet, there remains a gap in the literature exploring patients' and care partners' perspectives during and around the time of cognitive diagnosis, especially in underrepresented populations.

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This study focuses on older, rural-dwelling adults with early-stage cognitive impairment. Rural-dwelling adults live in less populous, non-metropolitan areas, typically defined at the zip code or census tract level (Health Resources & Services Administration, 2017; US Department of Agriculture Economic Research Service, 2013b). They may face additional, unique barriers to undergoing timely cognitive evaluations and accessing care delivery and have been shown to under-utilize both medical and social services (Bradford et al., 2009). There are also fewer rural-dwelling health care providers (Doescher, Andrilla, Skillman, Morgan, & L Kaplan, 2014; Gamm, Hutchison, Bellamy, & Dabney, 2010) and limited resources in rural areas (Gamm et al., 2010), further emphasizing the importance of early detection of cognitive changes in this population.

There is limited research on the experiences surrounding early cognitive diagnoses, and data are particularly lacking in older, rural-dwelling adults. Patient and family member descriptions of experiences and feelings during this time may ultimately inform interprofessional healthcare teams, including nurses, to provide targeted, population-specific care and services during critical times of cognitive change. Thus, the purpose of this study was to explore experiences of older, rural-dwelling adults with early cognitive changes and their family care partners (patient-care partner dyads) surrounding cognitive diagnostic evaluation. Patient and family experiences prior to, during, and after a diagnostic cognitive evaluation at a specialty research center are explored to understand and improve the recognition of cognitive symptoms, ways in which symptoms are addressed (or not addressed), and subsequent changes made following diagnosis.

Methods

Design

This study used qualitative description, as presented by Sandelowski (2000, 2010), to describe subjective experiences of older, rural-dwelling adults with early cognitive changes and their care partners at three time periods: pre-specialty research center visit (SRC), SRC visit, and post-SRC visit. The SRC is a research center that specializes in the diagnosis of AD and other dementias through outpatient evaluations with an interdisciplinary team. The three times periods examined do not reflect equal periods of time, but rather are defined as follows: 1) pre-SRC visit includes events and experiences recounted by the dyad prior to the in-person SRC visit, 2) SRC visit includes only the events and experiences recounted by the dyad to have occurred during the SRC visit that was attended by both members of the dyad, and 3) post-SRC visit includes events and experiences recounted by the dyad to have occurred after the in-person SRC visit. The methodological approach of qualitative description provided the opportunity to characterize the events and experiences across these periods of time as recalled in “the everyday terms of those events” (Sandelowski, 2000).

Nine semi-structured interviews with participant-care partner dyads were conducted in participant’s homes. Details of the parent study have been described previously (Mattos, Burke, Baernholdt, Hu & Lingler, 2017). Briefly, a 14-question interview guide guided interviews, and there was one question that asked members of the dyad about their last SRC visit, with follow-up probes that encouraged participants to describe feelings and events during the visit. Although not the primary purpose of the interview, pre-SRC and post-SRC

visit experiences were described, often spontaneously, throughout interviews. All interviews were audio recorded and later transcribed verbatim. XXX Institutional Review Board approved all procedures prior to study recruitment.

Sample

The sample was recruited from an SRC in XXX that enrolls study participants in various ways, including referral from clinicians, self-referral by participants or concerned family members, active recruitment through community organizations, and volunteers who wish to contribute to research. Data are collected at the initial visit and each annual follow-up visit by nurses, physician assistants, social workers, neuropsychologists, and other SRC research personnel over the course of 2–4 hours, with at least 17 standardized tests administered at each visit. Participants are required to come with a care partner for SRC visits, as care partners provide information about the participant's clinical symptoms; thus, care partners were concurrently recruited and invited to consent to the study provide a thicker description of experiences and events. Care partners contributions to interviews have been found to help convey participants' stories (Holstein & Gubrium, 1995) and aid in reducing recall bias. During one interview, an additional care partner asked to participate in the interview, and data from both care partners were included in analysis. After the multidisciplinary evaluation and consensus conference with clinicians, a standardized diagnostic feedback session is conducted by a neurologist and social worker with the dyad to discuss findings from the evaluation (Lingler et al., 2006).

Participants were drawn from a longitudinally-followed cohort at an XXX. Inclusion criteria were: >30 years of age, English speaker, >7 years of education, adequate visual and auditory acuity to complete neuropsychological testing, and a reliable care partner capable of providing information about the participant's clinical symptoms. Additional inclusion criteria for the current study were 1) 65 years of age, 2) current diagnosis of either a) MCI based on Petersen et al. (2001) and Lopez et al. (2003) or b) Probable Alzheimer's disease (AD) diagnosis based on McKhann et al. (1984) and a Mini Mental Status Exam score 18 (Folstein, Folstein, & McHugh, 1975); and 4) rural-dwelling. United States Department of Agriculture Rural-Urban Commuting Areas Codes (RUCAs) were used to classify rural and urban residence by ZIP code, where rural included primary RUCA codes 4–10 (US Department of Agriculture Economic Research Service, 2013a). RUCA codes "classify US census tracts using measures of population density, urbanization, and daily commuting," where urban-dwelling is defined as metropolitan (1–3) and rural as micropolitan, small town, and rural areas ("USDA Economic Research Service - Rural-Urban Continuum Codes," 2013). Purposive sampling, specifically sampling for participant characteristics (e.g., sex, degree of rurality, and relative degree of cognitive impairment) was used during recruitment to maximize diversity and promote heterogeneity within the sample (Glaser & Strauss, 1967). The purpose of using this approach was to minimize the possibility that participants may have advanced cognitive symptoms that possibly hindered their ability to share their insights.

The SRC coordinator identified individuals meeting study inclusion criteria and called eligible participants to ask if they would be interested in study participation. If the

participant agreed, the study PI called to present the study in greater detail. Family care partners were invited to participate in the study at that time. Previous participation by dyads in SRC activities allowed for previously-consented contact by the SRC coordinator for other study participation and helped promote trust in this sample. Capacity to consent was assessed using the University of California, San Diego Brief Assessment of Capacity to Consent (Jeste et al., 2007), and no indications of a lack of decisional capacity were noted during the consent process. XXX Institutional Review Board approved all procedures.

Measures

In addition to interview data, we computed distance from participant home to SRC to understand the dyad's commute and possible access issues arising from travelling from a rural area to an urban-located SRC. Home-SRC distance was calculated between participant home address and SRC address using Google Maps (Google Maps, 2016)¹ and measured in miles, rounded to the nearest whole number. A review of research data from the SRC participant charts was also performed to confirm current medication list and also obtain comprehensive descriptive characteristics of the sample, both already collected by the SRC.

Analysis

Transcribed data were entered into Atlas.ti[®] (version 4.2, Scientific Software Development, Berlin). Qualitative content analyses were performed by three independent investigators beginning with line-by-line coding. Findings were organized by time period and categories of shared or similar experience. Category similarities, differences, and counter examples were then discussed among investigators until findings were verified by consensus and convergence. These analytic methods were selected because they: 1) permit large amounts of data to be condensed, clustered, sorted, and linked over time and 2) facilitate examination of components and relationships revealed in the data (Miles & Huberman, 1994).

Results

Participants with cognitive impairment (n=9) were 73.7 ± 6.0 years of age with 14.2 ± 3.1 years of education; 44.4% were female, 100% white, 88.9% married, and 100% lived with someone. Five of the nine participants (55.6%) had a diagnosis of mild cognitive impairment, four a diagnosis of early-stage AD. Care partners (n=10) were 70.9 ± 7.4 years of age with 15.6 ± 2.3 years of education; 70% were female, 100% white, 80% married, and 90% lived with someone, specifically their care partner. In-home interviews took place across four states.

Participant and care partner experiences were explored across three time periods: 1) pre-SRC visit, 2) SRC visit, and 3) post-SRC. Most pre-SRC visit dyad experiences were similar overall, while SRC visit and post-SRC visit experiences varied. Details about the SRC visit typically emerged when specifically asked about the visit; however, the events and experiences before and after the SRC visit emerged spontaneously during the interview process.

Pre-SRC Visit

There were four categories identified: 1) Description of cognitive symptoms, 2) Health care provider (HCP) visits before SRC visit, related to cognitive symptoms, 3) Reasons for making an SRC appointment, and 4) Reactive to cognitive changes.

Description of cognitive symptoms.—Both participants and care partners offered rich characterizations of symptoms and specific examples of the cognitive changes exhibited by participants prior to the SRC visit. Most descriptions (5/9 dyads) pointed to cognitive changes occurring over a period of time; however, there were four care partners who described a sudden onset of participant symptoms. For those participants with cognitive changes occurring over time, there were a number of reported symptoms including: difficulty balancing the checkbook, getting lost while driving, “forgetting things,” repeatedly asking questions, intermittent confusion, difficulty conjuring specific words, “losing words,” difficulty concentrating, and discontinuing activities that previously made participants happy (e.g., journaling or reading). One 71-year-old female care partner said her husband repeatedly asked her the same questions, but thought “he was just not paying attention to me.” It was not until a close work colleague told her “there was a definite problem,” that she realized she was not the only one noticing her husband’s memory changes. Two care partners noticed a sudden onset of cognitive symptom(s) or decline in cognitive abilities, and there were two dyads where the participant noted sudden changes and the care partner shared both specific event(s) and long-term cognitive changes. Both sudden and insidious cognitive symptoms were described by dyads.

HCP visits before SRC visit.—Seven of the nine participants mentioned seeing another HCP for cognitive concerns before attending a SRC cognitive evaluation, while one participant did not see a HCP for such concerns, and the last participant did not share this information during the interview. Of the seven who saw another HCP prior to SRC visit, five were seen by their primary care provider (PCP) and two sought out specialty care. Two participants were prescribed cognitive medications after seeing the HCP and the immediate initiation of a cognitive medication with limited diagnostics was concerning to both dyads (one saw his PCP and the other a specialist). The 67-year-old care partner quoted the PCP as saying, “We’ll start you on Aricept™ because it couldn’t hurt.” The other dyad’s 65-year-old female care partner said that following her husband’s visit to the specialist, her husband told her that he was prescribed a cognitive enhancing medication, and when she asked what tests the specialist ran, her husband answered, “Well he didn’t.”

At three of the seven visits, HCPs shared with participants that they did not have Alzheimer’s disease, one 73-year-old male with MCI saying, “In fact I talked to my one doctor about [my cognitive symptoms], and he told me I didn’t have Alzheimer’s, I had CRS [Can’t Remember Sh*t].” The majority of participants saw another HCP prior to their SRC-visit and current diagnosis, and there were inconsistencies in evaluation and treatment of cognitive concerns across interviews.

Reasons for making SRC appointment.—For most dyads, participation and evaluation at a specialty research center was related to, or in response to, previous diagnostic

uncertainty, seeking additional information, and concern related to a family history of AD. One care partner (62-year-old female) said that before their SRC visit, “we were just trying to get some answers to have some sort of understanding of what was going on...” Those participants with a family history of AD spoke to wanting to know their current status, including diagnosis and any other available descriptive testing. A family history of AD was also included as a reason for SRC participation and evaluation.

All participants attended SRC evaluations on their own accord, however the person who scheduled the appointment was not always the participant. Of the nine participants, only three participants scheduled their own SRC evaluations, five care partners scheduled the evaluation, and one participant’s sister scheduled the evaluation. Motivations or reasons for the decision as to who made the appointment were not captured in interviews.

Reactive to cognitive changes.—Overall, dyads spoke about being reactive and seeking out medical care and information for participants or self with cognitive changes (9/9 dyads). Four participants clearly stated they sought out medical attention for cognitive concerns; the other five dyads discussed both personal and care partner concerns about cognitive changes. Dyads wanting to “get answers” was offered as a reason for making the SRC appointment, but it also showed the initiative and motivation of the dyads to seek out care. Dyads shared that at the time of cognitive symptom recognition, they also sought out information to describe or explain changes via internet websites (e.g. Mayo Clinic), primary care providers, specialists, or in two cases, they directly contacted the SRC for an appointment.

There were no questions asked during the interview regarding family history of dementia or Alzheimer’s disease; however, four participants spontaneously mentioned family history of dementia/AD, and this was also presented by participants as a precipitous for seeking information in response to their cognitive changes. For example, a 75-year-old male with AD stated “there’s some pressure behind me [to look into cognitive changes]” due to his family history of AD. There was variation in how dyads were reactive in that some used internet health resources, others health care services, and others directly sought out an SRC as a resource. However, all dyads spoke to being proactive or demonstrated proactive behaviors at the time of cognitive symptom recognition.

SRC Visit

There were three categories that emerged from interviews describing the SRC visit: 1) SRC evaluation, 2) information presented was helpful, and 3) distance traveled to SRC.

SRC evaluation.—Overall, dyads stated that the SRC evaluation was thorough, “helpful and informative.” The majority of dyads mentioned spontaneously that staff was “friendly”, “kind” or helpful. There were two participants who did not remember the last evaluation with much or any detail and another participant that seemed confused as to the purpose of the visit. As the sample was cognitively impaired, these findings are not surprising, but it is important to note that not all participants were able to recount the events of or their feelings regarding their SRC visit.

Information presented was helpful.—Participants or care partners said the information provided by the SRC staff was helpful, and two participants spoke to the amount of information provided. One participant, a 66-year-old male with MCI said the evaluation was “extremely comprehensive,” and a 65-year-old female care partner reflected that SRC staff provided “a lot of good information.” A 73-year-old female care partner spoke about how SRC staff provided “suggestions that are... helpful, and...we follow through on them... when we think we should.” This highlights the idea that although there is “a lot of information” provided by SRC staff, the dyads’ ultimately chose what they hear and act upon.

There was limited discussion of events, such as specific testing, that occurred during the evaluation, but two participants spoke about the experience as being stressful. One 70-year-old participant with MCI focused on “how tough it is to go through that [testing].. I was just wiped out. It was the worst thing I have ever done going through that.” Although this sentiment was not shared by most participants, it is important to acknowledge the commitment these individuals undertook to participate in SRC-related activities, sometimes lasting as long as four hours a visit.

Distance traveled to SRC.—Overall, eight of the nine dyads did not believe the distance to the SRC was a concern or they did not discuss the distance or commute. To help describe possible burden of an SRC evaluation, the average distance traveled from participant home to SRC was calculated. On average, dyads traveled about 100 miles to reach the SRC (99 ± 52 miles, Range: 40–182). This is around a two-hour commute each way, depending on traffic and road conditions. There was mention of the process of scheduling and traveling to the SRC by one 73-year-old female with MCI who said that the “tough[est] thing is getting there.” This quote was not surprising as the sample was rural-dwelling and the SRC was located in a busy, large urban area, however this was an isolated counter example, and the majority of dyads did not indicate that the commute was a concern.

Post-SRC Visit

There were two categories describing the post-SRC visit experience for participants with cognitive impairment and their care partners: 1) emotional and psychological reaction to diagnosis, and 2) changes following SRC diagnosis.

Emotional and psychological reaction to diagnosis.—Reactions to cognitive diagnoses were generally positive and dyads stated feelings of relief after learning the diagnosis. For example, 73-year-old female with MCI said, “Just psychologically, I feel so much better [since I’ve learned my diagnosis].” Another care partner said that a follow-up brain scan showed improvement, and he “burst into tears.” Dyad’s emotional responses to the SRC diagnoses and psychological effect on everyday life demonstrated the dyadic impact of learning of a cognitive impairment diagnosis.

Changes following SRC diagnosis.—Both participant and care partners shared examples of how things have changed since receiving the SRC diagnosis, both by individual participants and by dyad. For example, three participants shared how they changed or made

accommodations to certain activities in response to SRC staff recommendations following diagnosis, such as stopping driving voluntarily.

Dyads also spoke to how they made changes in their lifestyle after diagnosis, ranging from improved eating/exercising habits to withdrawing from community involvement. Speaking to improving health behaviors, one 73-year-old female with MCI said that after her SRC visit and diagnosis, “All of the sudden I don’t know why I decided to get healthy.” Another participant, a 70-year-old male with AD, begun exercising six times a week, doing crossword puzzles and online brain stimulation games, and drinking green tea in response to the diagnosis. However, not all dyads spoke to perceived positive changes in response the SRC visit and diagnosis. For example, a 73-year-old male with MCI said, “I know there’s a lot of things that I don’t get into [anymore]. I used to, but I just kind of just pull back a little bit right now because I have a hard enough time trying [to] not make myself look silly without actually extending myself.” Overall, there were many reactions to SRC diagnoses and subsequent changes, both positive and negative, made by participants and care partners during the post-SRC visit period.

Discussion

Rural-dwelling participants with cognitive impairment and their care partners’ experiences varied across the three time periods explored. Although dyads presented similar experiences prior to the specialty research center (SRC) visit, experiences within categories varied, and SRC visit and post-SRC visit time period experiences further highlight differences in dyad reactions and subsequent life changes following SRC visit. Overall, dyads presented their experiences leading up to the SRC visit and reactions to cognitive changes in greatest detail and quantity. As participant diagnoses ranged from MCI to early-stage AD, there was variation in cognitive symptoms described; however, dyads consistently reported seeking to learn more about cognitive symptoms, and they all spontaneously described the impact of cognitive changes on everyday life throughout the three time periods.

Rural-dwelling individuals’ diagnostic uncertainty combined with participant’s reactive approach to investigate cognitive changes mirror subthemes presented in a recent metasynthesis of qualitative research on adults with MCI by Gomersall et al. (2015). Participants and care partners present narratives about how they make sense of the cognitive diagnosis across a continuum in both our study and the studies presented in Gomersall et al. (2015). Similar to our selected time periods, Gomersall et al. (2015), presents cognitive changes across three time periods: past, present, and future. However, the “nostalgia for past relationships, roles and experiences” seen in the past period, which was found throughout the literature included in the metasynthesis, did not emerge in our interviews, but rather the reactive, or proactive, efforts undertaken by dyad’s at the time of symptom recognition. Our study also captured care partner experiences describing the uncertainty in their loved one’s diagnosis and how they tried to make sense of the diagnosis over time.

Our findings support and build on the work of Johansson, Marcusson, & Wressle (2015), that explored participants with cognitive impairment and care partners’ experiences with

cognitive impairment and its consequences in everyday life. Categories emerged in our work mirroring similar categories found in their interviews: recognition and burden of cognitive symptoms, uncertainty about the future, and changes patients made to their activity patterns. Johansson, Marcusson, & Wressle (2015) also found substantial variation in both participants and care partners experiences in their sample comprised of both MCI and mild dementia participants and care partners. The variation in experiences, especially at and after SRC visit, may be related to this cognitively diverse sample (Grundman et al., 2004; R. Petersen et al., 2014).

Our findings demonstrate that dyads made conscious, pointed efforts to seek out information and care in response to cognitive changes prior to SRC diagnosis. This is in contrast to previous work where rural HCPs identified a lack of awareness of cognitive changes and less use of resources early in the disease process for rural-dwelling patients (Morgan, Semchuk, Stewart, & D'Arcy, 2002). Based on our study findings, dyads did not seem to lack awareness, but rather they shared that they lacked clarity and consistency in the health care services and diagnoses provided locally. We also found that few participants with early-stage cognitive impairment scheduled their own SRC evaluation. The interviewer did not probe into reasons why so few participants scheduled their evaluations, but some reasons may include that participant's cognitive deficits may have prevented them from scheduling or that they preferred care partners to make appointments.

Dyads traveled about two hours to seek out the specialty health care services in an urban SRC, and by the time of SRC evaluation, over half the dyads had already sought out local specialty health care services. The long distance traveled and additional specialty care services at an SRC demonstrate both dyad's information and answer-seeking approach to cognitive symptom identification as well as possible lack of resources or specialist care in rural areas.

There was a range in participant's cognitive functioning and SRC diagnoses as well as rurality of dyad residence, both of which may have impacted the shared experiences across all three time periods. The ranges of rural classifications and state residence of participants may be considered both a strength and possible weakness. Findings reflect the perceptions and experiences of an information-seeking and highly-motivated sample willing to undergo hours of testing and a substantial drive, which may not be typical of rural-dwelling adults. The older, rural-dwelling participants in our study likely represents a sample across a continuum of those receiving cognitive diagnoses. It is important to explore experiences of individuals who did not actively seek answers to cognitive symptoms in order to better describe rural-dwelling adults across a continuum of care-seeking behaviors. Another limitation is the lack of diversity within the sample, particularly that the sample was entirely Caucasian and found to be information-seeking and proactive in response to their cognitive changes. Within the SRC coverage area, rural-dwelling minorities comprise less than 5% of the population (RHIhub, 2010), and future studies focused on rural-dwelling minority recruitment are warranted. Noting these considerations, the primary objective was to examine older, rural-dwelling adult's experiences surrounding a diagnostic evaluation, and this study is the first to begin to explore unique experiences in this underserved and underrepresented population.

A strength of the study was the standardized feedback sessions held for the preliminary cognitive impairment diagnosis for dyads with both a neurologist and social worker present. This approach to disclosing diagnosis and reviewing evaluation results is ideal for both members of the dyad as it provides the opportunity to learn about the testing performed and ask questions about the diagnosis or resources. This team approach to disclosure may be especially useful in rural settings, where there is limited access to health care services and resources and having a multidisciplinary team may help consolidate resources.

Nurses are integral members of SRC evaluation teams and ideal team leaders in rural settings, where many nurses already provide care coordination and present social services to patients. In rural and remote areas that lack HCPs and attendance at an SRC may not be possible, nurses can serve as the point of contact for team-based approaches to diagnostic evaluations, follow-ups, and treatment. In underserved areas such as rural America, nurses can provide clinical expertise and coordination of services, as well as serve as a direct contact to a multidisciplinary team. Team collaboration and dyad participation prior to, at time of, and following a cognitive diagnosis can promote management of cognitive health and, ultimately, the overall health of rural-dwelling adults.

Another strength of this study is that the rural care partner's perspective and experiences were captured at the same time as the rural participants. Previous work in rural areas has shown that care partners/caregivers tend to express needs (e.g., information about the disease, prognosis, and treatment) more than the participant care recipient with cognitive concerns (Edelman, Kuhn, Fulton, & Kyrouac, 2006), and thus provides rich data from two perspectives to better understand context and social support. It is important to note that the SRC evaluation was the only time point in which interviews probed dyads' experience, as this directed by the interview guide. Although probed, different SRC evaluation experiences were presented by participants, and additional, explicit probing into typical SRC events may have provided richer accounts of the visit itself. Future qualitative work should continue to use narratives from both members of the dyad to explore the time periods presented in this work in real-time so that participants are not reporting their feelings and experiences retrospectively, but rather reporting them as they are experiencing them. Thus, interviews can capture experiences and feelings during the time period of interest and avoid participant recall bias.

Conclusion

There was variation in dyad descriptions of living with cognitive changes across interviews for all three time periods explored. However dyad experiences reinforced previous work that captured differences in dyad descriptions of cognitive changes, reactions to cognitive changes and diagnosis, and life changes following diagnosis. Our rural-dwelling sample illustrated a range of reactive and information-seeking individuals learning to live with their own or loved one's cognitive diagnosis. Nurses play significant roles in the diagnosis and post-diagnosis periods for patients with early-stage cognitive impairment through their clinical diagnostic expertise and appropriate direction of resources. Older, rural-dwelling adults are an underserved and underrepresented population, and their narratives can help

provide information and preferences to help nurses better direct resources and early interventions to promote cognitive health.

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