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Dementia caregivers' experiences engaging supportive services while residing in under-resourced areas

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Abstract

Background: Family caregivers of people living with dementia benefit from supportive service use to address care needs associated with caregiving. Yet, research consistently demonstrates low rates of service use. Existing research has focused on barriers and facilitators to service use, with few studies examining the influence of caregivers' environmental context which often patterns social advantage and health services accessibility.

Objective: To describe the perspectives caregivers residing in socially disadvantaged areas have in regards to utilizing supportive services.

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Conflict of Interest/Disclosure Statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Methods: Ten informal caregivers residing in socially disadvantaged areas participated in in-depth interviews that were analyzed using thematic analysis.

Results: Across all interviews, caregivers spontaneously described common precedents of service use (crisis or accumulation of unmet needs) and a distinct sequence of stages (seeking, initiating and utilizing) surrounding service engagement. Major themes characterizing caregivers' experiences throughout service engagement highlight the varied influence of personal, familial, health and social system-related factors. Findings demonstrate that caregivers may have different service needs as dementia progresses and that gerontological social work practice can facilitate service use.

Conclusion: While preliminary, these findings provide important insights into new domains that can be further examined in future research and intervention efforts to improve supportive service use in socially disadvantaged and underserved communities.

Keywords

Dementia; caregiving; social support; health disparities

Introduction

In the United States, nearly 75% of the 5.8 million people living with dementia (PLWD) are supported by family or friend caregivers who function in an “informal” or unpaid capacity [1, 2]. While there has been a general increase in supportive services for family caregivers, service accessibility, quality, and utilization vary and family caregivers frequently experience a period of time of non-service use or low-service use [3–5]. Although caregivers often benefit from early use of supportive services, barriers often delay service use until advanced disease stages or crisis [6–8]. Delayed and low service use among caregivers has been attributed to poor service fit, limited service availability, physical health limitations, past experiences with illness and service use, social histories, and tensions within the caregiving network [9]. Emerging evidence suggests that social and environmental factors related to place (i.e. neighborhood) can affect dementia service use, but how these factors operate within various contexts from the first-hand perspective of dementia caregivers is not well understood [10, 11].

Some research suggests that awareness of dementia-specific services through recommendation or referral was often insufficient to facilitate service use in socially disadvantaged geographic areas in the United States, Canada, and Australia [12]. Social disadvantage, a concept of growing interest in the dementia care and services field, can be understood broadly as structural factors in a society that heighten risk and exposure to conditions that produce poorer outcomes [13]. Among PLWD, exposure to social disadvantage has been linked to accelerated cognitive decline, re-hospitalization, and poorer health outcomes, which all confer additional responsibility and burden for caregivers [14, 15]. Racial and ethnic minorities and individuals from low socioeconomic backgrounds are at significantly greater risk for residing in and having higher exposure to social disadvantage and experiencing a number of place-based structural inequities such as poverty and segregation [16]. The impact of social disadvantage is also experienced in rural areas,

with caregivers reporting lower rates of service use as a result of patterns in the geographic distribution and availability of resources [17]. For family caregivers, the context of place and exposure to social disadvantage have become salient factors influencing supportive service use to address caregiving needs.

An increasing focus on the intersections between neighborhood-level social factors and health has resulted in a greater understanding of the inter-relationships among health disparities, social determinants of health, and exposure to environmentally-linked social disadvantage [18]. However, few studies adequately capture the scope and complexity of family caregivers' experiences with dementia-specific service use within the context of social disadvantage. A majority of evidence regarding factors that contribute to service use has been generated with caregivers residing in well-resourced areas, and frequently lacks racial and socioeconomic diversity [19, 20]. This is particularly problematic as caregivers living in socially disadvantaged neighborhoods may experience higher levels of unmet needs, additional barriers to accessing supportive services, and delayed service use [21, 22]. Examining how family caregivers in socially disadvantaged neighborhoods connect to supportive services is necessary to develop strategies to mitigate barriers and delays related to service use [23].

This exploratory qualitative study examined dementia-specific service use experiences of family caregivers in socially disadvantaged contexts. The study's objectives were to describe the perspectives of caregivers with service use and identify factors that influenced caregivers' decisions to use services.

Subjects and Methods

Participant Selection and Recruitment

Eligible participants were unpaid family or friend caregivers who had been involved in the care of a person diagnosed with dementia, spoke English, and lived in a rural and/or 25% most disadvantaged neighborhood in Midwestern United States. A rural area was defined as an area that contained fewer than 200 people per square mile, a cut-off determined with the assistance of a geographer [24]. A validated geospatial index of neighborhood-level social disadvantage, the Area Deprivation Index, was used to identify the 25% most disadvantaged neighborhoods in the region [25]. The study was approved by the University of Wisconsin-Madison Institutional Review Board (2018-0941), and written consent was waived. The study was explained to participants during a recruitment call, participants received an information sheet describing the study, and verbal consent was obtained at the beginning of the interview. Ten participants were recruited through existing university-based research registries utilized to increase participation of dementia caregivers in research ($n=4$), flyers distributed by regional dementia-related organizations ($n=4$), and government-operated aging resource centers ($n=2$).

Procedure

In-depth interviews lasting 45–60 minutes were conducted via telephone, following a flexible, semi-structured question guide (Supplementary Table 1). Participants received a

\$25 honorarium for participating in the study. All interviews were audio-recorded and transcribed verbatim for analysis.

Data Analysis

Data were analyzed using thematic analysis procedures as outlined by Braun and Clarke (2006) [26]. Two authors (AJK, LB) established the initial coding framework by identifying relevant dimensions specific to supportive service experiences across interviews (Supplementary Table 2). The coding framework was then iteratively reviewed in conjunction with supporting interview data with other members of a multidisciplinary study team. Study team members confirmed consistency of individual codes with interview data, examined codes for overall coherence and precision, revised and finalized the coding framework [26]. The final coding framework was then applied to all interviews by four trained coders using a qualitative data management software package. Each transcript was coded independently by at least two coders, and disagreements were resolved through consultation with a third team member. Following completion of line-by-line coding, the study team reviewed codes across all interview data to identify and organize broader categories, and generate emergent themes [26]. These themes also underwent iterative revision through team meetings wherein the study team compared themes to interview data and developed thematic maps to reflect on precision and coherence of themes to inform ongoing refinement of each theme [26]. Saturation was achieved through consensus process when the team determined there were no more emergent themes [27].

Results

Participant Characteristics

Of the ten participants, six qualified through Area Deprivation Index criterion and four through the rurality criterion; there was no overlap. Caregivers were primarily female (n=9) and over the age of 65 (n=10). Three caregivers identified as African American and one as Hispanic white. Participants identified as children of PLWD (n=7), spouses (n=2), or caregivers for more than one PLWD (n=1). All participants self-identified as the primary caregiver for the PLWD, and all but two were still providing care at the time of interview. Caregivers lived in the same household as the PLWD (n=5) or lived apart from care recipient (n=5).

Thematic Findings

Caregivers described their experiences with dementia-specific supportive services as uniformly following a sequence toward service use. The sequence of seeking, initiating and utilizing services presented in this paper characterizes the dimension of time and actions associated with service use. Seeking services refers to the absence of services and the period of time when circumstances necessitate active searching. Initiating describes a brief but distinct step of entry into services. Utilizing describes long-term connection to service and referral to additional supports. The service use sequence described is not necessarily linear (i.e., a caregiver may seek or initiate new services to address an existing need that is currently being met through long-term service utilization or multiple unmet needs may

be addressed differentially and present at different stages in the service use sequence) but provides contextualization of common sequences and experiences with supportive services.

Consistent with the paper's methodological approach and the goal of prioritizing caregivers' first-hand experiences and perspectives, the co-authors did not strictly confine or define supportive services during interviews (i.e. caregivers were asked what services help with dementia care). Caregivers focused predominantly on social services when describing what helped them to manage their caregiving responsibilities, commonly citing caregiver support groups or the Alzheimer's Association helpline; however, caregivers also shared experiences with health services that were relevant to their use of and access to supportive services. Overall, service use was often prompted by a crisis event that required immediate mobilization of services, or the accumulation of unmet needs resulting in a gradual seeking of services. The sequence of service use was more specifically characterized by associated themes that shaped individual caregivers' actions, decisions, and service-use outcomes within and across these distinct stages, with Figure 1 illustrating caregiver progression through the service engagement process.

Capacity of Informal Care Network—Caregivers described the role of their informal care network and its capacity – specifically, the number of people, their respective roles, and the degree of collaboration – to either delay or expedite decisions to seek services. Some caregivers reported their informal care networks could adequately meet their care needs while others expressed their informal care networks could not, which motivated them to seek services – most commonly cited for social service use. Some caregivers described informal care networks that converged or underwent major changes to provide care for their loved one: *“My brother just moved back a week ago. He relocated from [city] because I told him I just can't do it.”* Beyond immediate family, caregivers also describe the role of neighbors: *“all the neighbors pitched in, the lady down the hall puts the drops in [my mother's] eyes because she needed them three times a day, and another lady put it in in the morning.”*

Other caregivers described informal care networks which were unable to adequately meet caregiving needs due to distance, busyness or family conflict, prompting them to seek services. Another caregiver described the presence of informal help, but a lack of expertise among their informal network, which also drove them to pursue services: *“I couldn't count on my friend who's ignorant about the disease – hey, what do you think I should do? No. I needed professional help.”* While initiating services, which often required several decisions, the extent of family or informal network agreement, including the PLWD when possible, played a role in the caregivers' experience.

Other considerations concerning capacity included the number of health or behavioral care needs of the PLWD, as well as the caregiver's health status. Specifically, caregivers described factors such as experiencing major challenges with their health or feeling that their loved one's behavioral care needs became too challenging for them to address as playing a role in the caregivers' decisions to initiate the seeking phase, and to a lesser extent, as influencing continued service use: *“If [my mom's] feeling moody and I'm feeling okay, she's going to go to the program. If she's feeling moody and I'm getting [health condition] I do not battle her.”*

Familiarity with Dementia Services and Resources—Caregivers described *familiarity* with dementia and dementia-specific services or access to individuals with such familiarity as a jump-starter to seeking supportive services. Particularly when seeking supportive services, caregivers reported that personal and broader networks played an important role in shaping views toward dementia, caregiving, and supportive services. Familiarity was described as originating from prior personal experiences but more commonly arose from experiences shared through informal networks. Referrals from informal networks were often well-received, precipitating a transition from “seeking services” to “initiating services.” For example, one caregiver learned of support group services from a co-worker, which then connected the caregiver to memory care services: *“I had gotten word of a caregiver support group from a former co-worker that I would meet several gals for lunch pretty regularly.”* Caregivers also described the importance role informal networks play in “vetting” services.

Service Fit—When initiating and utilizing services, caregivers often described the degree of “fit” or “matching” between their wants and needs, the PLWD, and the type or modality of the service provided. Service fit appeared to be shaped by many factors including logistics and practicality. When the PLWD was able to express their views on care and service decisions, their personal preferences or acceptance of the plan of care were also important influences: *“They tried to have [meal service] for a couple days and [my aunt] stopped it she said she didn’t like their food, she wasn’t going to eat their crappy food.”*

Caregivers described feeling more satisfaction when there was a match between service modality and their needs and feeling more supported when services were available more frequently: *“It also met my needs when we went into the care group meeting once a month. And that wasn’t like, way over much, but it was enough to look forward to,”* and *“I would call the Alzheimer’s Association number maybe like three times a month in the beginning I remember I was on the phone with them for almost three hours.”*

Most caregivers shared holding high standards for care and the service quality, sharing stories where standards were met and unmet with both supportive and health services. For example, caregivers shared valuing regular and prompt contact: *“[The facility has] three extremely dedicated people who are there during the daytime hours... I appreciate that they share those stories with me, of what [my mother’s] daily life is like.”* However, other caregivers described specific situations that influenced service engagement such as staff lacking knowledge of dementia, professionalism, and poor communication skills.

Service fit and quality often influenced the degree of trust in a service, which played a role in fostering long-term utilization of a service. Many experiences around trust centered on care and safety for the PLWD, home, and belongings when in the care of others, and often related to home or respite care. When caregivers trusted services and staff, caregivers expressed feeling relief along the domains of safety: *“That’s one of the things that makes life much easier for me. If I had to be worrying about, you know, are they being careful with [my mom] that she’s gonna fall or, you know, that would be a whole lot more stressful but I trust them.”* However, several caregivers described an absence of trust in services and staff,

“you know, someone who would be able to be here [respite] whom I could trust, that’s the biggest gap.”

Sense of Ownership and Resilience—When initiating and utilizing services, several caregivers emphasized a strong preference for a sense of ownership over the situation, often intertwined with a sense of familial obligation or “duty” to the PLWD. In demonstrating a sense of ownership, caregivers frequently described their own role or responsibility in finding solutions and making services work, for example, by seeking information and education. Caregivers described their sense of duty as an aspect of their relationship with the PLWD that allowed them to accomplish the necessary caregiving work.

All participants described encountering multiple challenges when navigating health, social and government systems, and all described attitudes, outlooks and strategies – for example, a commitment to overcome these challenges. In this paper, resilience refers to caregivers’ maintenance of a positive outlook beyond situational conditions that present challenges and increase caregiving stress [28]. Stories of overcoming barriers and maintaining a positive outlook were frequent, arising across descriptions of seeking, initiating and utilizing service: *“Once it got hard, it was like, what do I do? It got hard, let me try this number. And lo and behold, it worked,”* and *“You will have your ups and downs with every system but every system isn’t perfect. So just stick with the kinks.”*

Social Positioning—Social positioning was consistently identified through caregivers’ narratives regarding barriers and decision-making. The features of the caregiver’s or PLWD’s position in society exerted influence across all stages of their service engagement process. Overall, language, education, income, immigration experiences or concerns, and geographic constraints played large and universal roles in caregivers’ experiences with service engagement. For example, a caregiver described the challenge posed by limited income, wherein choosing a lower cost service option might compromise the quality of services: *“I would need someone to be with my mom to help her [with care] if necessary, and those people, you know, who you don’t have to pay \$20 an hour or something are, they, that’s a big gap.”* Another caregiver described the role of rurality in service availability to accessibility: *“...and then step two is probably even harder to find someone... just out in the country, you know.”*

Similarly, socially congruent identities – a more personal or familial aspect – played a role particularly when initiating and utilizing services. Some caregivers described a strong preference for staff with social and cultural backgrounds, congruent to their own and/or the PLWD. When social identities were congruent, caregivers expressed a heightened interest in engaging with services and service staff. *“When I met [Alzheimer’s Association educator], a Latina, who understood this disease, I fell in love with this woman.”*

Delayed or Unhelpful Experiences with Diagnosis—Caregivers expressed disappointment, frustration and dissatisfaction with timeliness of diagnoses, identifying this as a major impediment to receiving dementia-specific care and services when they were needed. Not only did a delayed diagnosis cause set-backs in the delivery of care, but it also created frustration by prolonging time in the seeking phase, *“The difficulty in those years*

before diagnosis, were just baffling.” In general, the lack of a medical diagnosis contributed to a lack of clarity on the condition of dementia, services to seek, and ineligibility for services without a diagnosis.

Navigating Fragmented, Inaccessible System—Health and social system-factors were also described as shaping service engagement across all phases. During a transition to service initiation, caregivers described three common system resources facilitating entry into service systems: social workers, primary care providers, and government-operated county or area program. Nearly all participants described successful introduction or access to needed services following integration with social services, with some specifically citing the importance of social workers: “[A social worker] gave me the numbers to the [local county], to the aging department, she gave me a whole bunch of numbers.” Similar to challenges with diagnosis in primary care, many caregivers expressed perceiving primary care as an unsupportive setting and not viewing its roles as connecting patients to services.

During initiation of services, caregivers highlighted aspects of navigating a complicated, bureaucratic system, with several participants commenting on lengthy registration and insurance steps. Caregivers also highlighted issues of cost and transportation. Later, when utilizing services, caregivers expressed an appreciation for integration and ease of access across social work, primary and memory care systems. Again, caregivers highlighted the need for transportation to facilitate continued use of services: “I have [a small car] and getting in there with [my mom’s] mobility issues ... It was just a total ordeal getting her to doctor appointments.”

Caregiver Recommendations for Supportive Services—Caregivers shared suggestions for improving service delivery systems and processes. Several comments focused on the provider’s approach when delivering a new dementia diagnosis, with one caregiver recommending the use of visual tools. Caregivers described the importance of the tone and delivery of information, along with the level and type of detail provided. Caregivers also cited the important role providers can play in simplifying and clarifying otherwise ambiguous next steps and coordinating care across fragmented systems, particularly during crises: “I wish they could kind of lay out the path for you, you know when you first start working with them,” and “then the problem is finding who... who deals with Alzheimer’s, who’s covered by insurance, et cetera et cetera...” Finally, caregivers suggested strategies for educating families about dementia. Caregivers appreciated information and classes that covered a range of dementia-related topics across its progression, from its diagnosis to activation of guardianship, with an emphasis on knowledge of diverse populations and dementia.

Discussion

This paper reports on supportive service use experiences of family caregivers living in socially disadvantaged areas in Midwestern areas in the United States. Caregivers described personal, familial, institutional (health and social systems) and social factors shaping their experiences and decisions seeking, initiating and utilizing dementia services.

Family caregivers cited challenges throughout their engagement with service use (i.e. fragmented services, complex systems, and inadequate resources) but demonstrated resilience. Challenges were often overcome through increasing caregiver responsibilities and strategic management of caregiving work. Research suggests that some historically excluded populations appraise the responsibilities and burdens of caregiving differently – demonstrating more adaptive coping mechanisms and normalizing caregiving as a familial responsibility [29]. The present findings suggest that caregivers who are exposed to high levels of social disadvantage may develop or hold similarly distinct coping and appraisal processes by virtue of cumulative resilience navigating a daily life in resource-limited areas.

Caregivers in this study delineated an important but more limited role for primary care providers that focused on sharing information on health conditions and setting the stage for different aspects of care. Social workers and other professionals with service coordination responsibilities were noted by caregivers as being particularly effective at the kind of information-sharing that leads to service engagement [30]. However, delayed diagnosis and dissatisfaction with diagnosis experiences impacted awareness of and access to applicable services. These experiences reported by caregivers may reflect broader barriers in access to care and services, limited awareness about early disease symptoms, or limited availability of specialty diagnostic resources. While preliminary, these findings suggest that efforts to improve service use absent efforts to accelerate earlier diagnosis in socially disadvantaged areas may be unsuccessful and points to a strong need for additional research focused on understanding the informational needs of this population.

Present findings are consistent with prior work that has found that high functional needs of either the caregiver or the care recipient, availability of other caregivers, prior satisfaction with the health system, contact with a social worker and challenging behavioral symptoms are predictive of service use [31–33]. Participants in the present study routinely described social workers as influential in entering service use and navigating a challenging system. In general, participants described more positive experiences with providers filling a social service role than with health system providers, suggesting that further integration of social workers into health systems where people with dementia and their caregivers commonly present may be helpful in improving connections to supportive services.

This paper's findings have broader implications for gerontological social work research and practice. Research methodologies that examine structural and environmental features of place on service use among dementia caregivers are needed and highlight the ongoing need for the person and environment perspective that is unique to the discipline of social work. Contextualizing the impact of social disadvantage on dementia care offers a new lens for intervention development that take into account the dimensionality of family caregivers' experiences that address both individual and structural dynamics. Traditional roles for social workers related to service use focuses on building capacity for self-care, resource identification, assisting caregivers complete paper work, client advocacy, assistance with communication between service providers and the caregiving team, counseling, and information sharing [34]. Efforts utilizing biomedical approaches originating in health care under the direction of a physician are insufficient and must continue to be coupled with innovations that address structural factors observed in socially disadvantaged

environments. The current paper's discussion on social positioning reinforces the need for gerontological social work practice to target organizational, community-system and environmental conditions that may place constraints on dementia care and management. Opportunities for increased involvement of social work includes health and social care systems-integration, policy advocacy for resource allocation and policies impacting service use, communication to address stigma and normalize dementia, workforce development, and to address the information and services needs of dementia family caregivers at the structural level.

Findings from the present study should be interpreted in light of the following limitations: 1) although saturation was achieved across major themes, the lack of emphasis in exploring variation in experiences such as supportive service use across disease state tempers transferability of this study; 2) because interviews focused on caregivers' experiences, data regarding appraisal of services and service use are not triangulated with other data sources so the study did not report on service use patterns for participants; 3) positive aspects of caregiving and service use and its relationship to resiliency were not explicitly pursued in this study but warrant future consideration especially in socially disadvantaged context, and; 4) the study concentrated on caregivers' experiences, the perspectives and characteristics of PLWD were not equally explored in this study, though caregivers offered both prompted and spontaneous accounts of care recipients' wants and needs. However, further examination of the role and influence of the PLWD on these processes is an important area for future inquiry.

In summary, findings from this exploratory study contribute to the fields understanding of how dementia caregivers from socially disadvantaged areas experience the complex and dynamic process of engaging in the use of supportive services. Collectively, findings demonstrate that study participants residing in socially disadvantaged areas identify distinct experiences with obtaining supportive services that are not adequately represented in the current narratives and evidence base for facilitating service use, highlighting the importance of engaging more racially and socioeconomically diverse populations in caregiving research. Contextualizing the experiences of caregivers from historically excluded backgrounds and under-resourced environments is imperative and warrants deeper consideration of diverse understandings about aging and dementia, prior experience accessing health services, and preferences regarding specific services.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

- [1]. Schulz R, Martire LM (2004) Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*, 12(3), 240–9. [PubMed: 15126224]
- [2]. Alzheimer's Association (2020) Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 16(3), 391–460.
- [3]. Macleod A, Tatangelo G, McCabe M, You E (2017) "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study. *Int Psychogeriatr*, 29(5), 765–776. [PubMed: 28351450]
- [4]. Morrisby C, Joosten A, Ciccarelli M (2018) Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature. *Int Psychogeriatr*, 30(1), 5–14. [PubMed: 28784193]
- [5]. Mukadam N, Cooper C, Livingston G (2013) Improving access to dementia services for people from minority ethnic groups. *Curr Opin Psychiatry*, 26(4), 409–14. [PubMed: 23454888]
- [6]. Lauritzen J, Pedersen PU, Sørensen EE, Bjerrum MB (2015) The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JB I Database System Rev Implement Rep*, 13(6), 373–433.
- [7]. Leon J, Neumann PJ, Hermann RC, Hsu M, Cummings JL, Doraiswamy PM, Marin D (2000) Health-related quality-of-life and service utilization in Alzheimer's disease: A cross-sectional study. *American Journal of Alzheimer's Disease*, 15(2), 94–108.
- [8]. Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Verdonck C, Annemans L (2016) Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. *Int J Geriatr Psychiatry*, 31(12), 1277–1288. [PubMed: 27245986]
- [9]. Carpentier N, Ducharme F, Kergoat M-J, Bergman H (2008) Social representations of barriers to care early in the careers of caregivers of persons with Alzheimer's disease. *Research on Aging*, 30(3), 334–357.
- [10]. Ward R, Clark A, Campbell S, Graham B, Kulberg A, Manji K, Rummery K, Keady J (2018) The lived neighborhood: understanding how people with dementia engage with their local environment. *Int Psychogeriatr*, 30(6) 867–880. [PubMed: 28462764]
- [11]. Yen IH, Michael YL, Perdue L (2009) Neighborhood environment in studies of health of older adults: a systematic review. *Am J Prev Med*, 37(5), 455–63. [PubMed: 19840702]
- [12]. Phillipson L, Jones SC, Magee C (2014) A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health Soc Care Community*, 22(1), 1–12. [PubMed: 23530738]
- [13]. German D, Latkin CA (2012) Social stability and health: exploring multidimensional social disadvantage. *J Urban Health*, 89(1) 19–35. [PubMed: 22131164]
- [14]. Clarke PJ, Weuve J, Barnes L, Evans DA, Mendes de Leon CF (2015) Cognitive decline and the neighborhood environment. *Ann Epidemiol*, 25(11), 849–54. [PubMed: 26253697]
- [15]. Jang JB, Hicken MT, Clarke PJ, Sol K, Melendez R, Kim MH, Mullins M, Judd S (2019) Racial residential segregation and cognitive decline among older adults. *Innov Aging*, 3(Suppl 1), S26–7.
- [16]. Lichter DT, Parisi D, Taquino MC (2012) The geography of exclusion: race, segregation, and concentrated poverty. *Social Problems*, 59(3) 364–388.
- [17]. Gibson A, Holmes SD, Fields NL, Richardson VE (2019) Providing care for persons with dementia in rural communities: informal caregivers' perceptions of supports and services. *J Gerontol Soc Work*, 62(6), 630–648. [PubMed: 31250733]
- [18]. Holden TR, Keller S, Kim A, Gehring M, Schmitz E, Hermann C, Gilmore-Bykovskyi A, Kind AJH (2018) Procedural framework to facilitate hospital-based informed consent for dementia research. *J Am Geriatr Soc*, 66(12), 2243–2248. [PubMed: 30246863]

- [19]. Bartlett R, Milne R, Croucher R (2019) Strategies to improve recruitment of people with dementia to research studies. *Dementia*, 18(7–8), 2494–2504. [PubMed: 29327604]
- [20]. Greenwood N, Habibi R, Smith R, Manthorpe J (2015) Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health Soc Care Community*, 23(1), 64–78. [PubMed: 25135207]
- [21]. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM (2013) Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc*, 61(12), 2087–2095. [PubMed: 24479141]
- [22]. Innes A, Morgan D, Kosteniuk J (2011) Dementia care in rural and remote settings: a systematic review of informal/family caregiving. *Maturitas*, 68(1), 34–46. [PubMed: 21093996]
- [23]. Chertkow H (2018) An action plan to face the challenge of dementia: international statement on dementia from IAP for health. *J Prev Alzheimers Dis*, 5(3), 207–212. [PubMed: 29972215]
- [24]. Ratcliffe M, Burd C, Holder K, Fields A (2016) Defining rural at the US Census Bureau. *American Community Survey And Geography Brief*, 1(8).
- [25]. Hu J, Kind AJH, Nerenz D (2018) Area Deprivation Index predicts readmission risk at an urban teaching hospital. *Am J Med Qual*, 33(5), 493–501. [PubMed: 29357679]
- [26]. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psychol*, 3(2), 77–101.
- [27]. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C (2018) Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 52(4), 1893–1907. [PubMed: 29937585]
- [28]. Wilks SE, Little KG, Gough HR, Spurlock WJ (2011) Alzheimer's Aggression: Influences on Caregiver Coping and Resilience. *J Gerontol Soc Work*, 54(3) 260–275. [PubMed: 21462058]
- [29]. Roth DL, Dilworth-Anderson P, Huang J, Gross AL, Gitlin LN (2015) Positive aspects of family caregiving for dementia: differential item functioning by race. *J Gerontol B Psychol Sci Soc Sci*, 70(6), 813–9. [PubMed: 26033356]
- [30]. Peterson K, Hahn H, Lee AJ, Madison CA, Atri A (2016) In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatr*, 16(1), 164. [PubMed: 27662829]
- [31]. Kosloski K, Montgomery RJV, Youngbauer JG (2001) Utilization of respite services: a comparison of users, seekers, and nonseekers. *J Appl Gerontol*, 20(1), 111–132.
- [32]. Robinson KM, Buckwalter KC, Reed D (2005) Predictors of use of services among dementia caregivers. *West J Nurs Res*, 27(2), 126–40. [PubMed: 15695566]
- [33]. Toseland RW, McCallion P, Gerber T, Banks S (2002) Predictors of health and human services use by persons with dementia and their family caregivers. *Soc Sci Med*, 55(7) 1255–66. [PubMed: 12365535]
- [34]. Kaplan DB, Andersen TC (2013) The transformative potential of social work's evolving practice in dementia care. *J Gerontol Soc Work*, 56(2) 164–176. [PubMed: 23350569]

Figure 1. Major Themes Influencing Caregiver's Experiences Engaging Services.