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Struggling for access to suitable dementia care for individuals with dementia and unpaid carers

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Commentary on “A systematic review on inequalities in accessing and using community-based social care in dementia” by Giebel *et al.*

Accessing appropriate healthcare is essential for both individuals with dementia and their unpaid carers. Social care and social support services – such as paid home carers, respite care, day care centers, social worker-delivered psychosocial therapies, meals services and peer-support groups – are equally important. They play vital roles in enhancing the well-being of individuals with dementia and alleviating caregiving responsibilities. Social care services enable individuals with dementia and their carers to lead fulfilling lives by providing assistance with activities of daily living, opportunities for respite for carers, and in many ways contributing to a better mental well-being and quality of life for both people with dementia and carers (Giebel *et al.*, 2021). Their contribution to dementia care is illustrated by estimates of the cost of dementia: across all countries, ‘direct social sector costs’ accounted for 34% of the global cost, and unpaid care for another 50% (Wimo *et al.*, 2023).

In this Special issue of *International Psychogeriatrics*, Clarissa Giebel *et al.* (2023) report a comprehensive mixed-methods systematic review aiming to assess and synthesize existing evidence on the barriers and facilitators to accessing and utilizing community-based social care. Their review includes studies focusing on individuals living with dementia and/or unpaid carers (sometimes called caregivers). The screening process involved two reviewers examining titles

and abstracts from seven databases, including both English and German studies, conducted in March 2022. Two reviewers later screened the full texts. Out of 3,904 initially screened records, 39 papers were ultimately included in the review. Findings encompassed studies from 23 different countries, with a majority employing qualitative methods. Giebel et al. (2023) classified the identified barriers and facilitators into five main themes: situational, psychological, interpersonal, structural, and cultural. Notably, the review highlighted how barriers outweighed facilitators and emphasized the need for a multifaceted approach to address both systemic and individual-level concerns.

Inequalities in accessing and using community-based social care services for individuals living with dementia have long been of concern. Along with colleagues, we are currently reviewing evidence on inequalities as part of the STRiDE England project (<https://stride-dementia.org/country-page/england/>). We are finding wide disparities in many domains, including access to and quality of health and social care, with inequalities evident by reference to many personal characteristics (including ethnicity, sex/gender, disability, sexuality and age), as well as to socioeconomic and geographical factors. With the rising prevalence of dementia globally (GBD 2019 Dementia Forecasting Collaborators, 2022), understanding and addressing these disparities is crucial to ensuring equitable access to essential support services.

The often pivotal roles of social care were highlighted during the COVID-19 pandemic. Sudden service closures left many individuals with dementia and their carers without crucial support, resulting in heightened vulnerability and poorer mental well-being (Giebel et al., 2021). Su et al. (2022) emphasize that older adults not only faced the risk of more severe COVID-19 symptoms but also were more vulnerable to psychological issues, underscoring the critical importance of mitigating loneliness and social isolation among this population. Social care and support services help to maintain or improve overall health and well-being, particularly during challenging times such as a global pandemic.

Non-medical factors influence how well individuals and their unpaid carers access support services and the impacts of those services. The World Health Organization defines social determinants of health as non-medical factors that influence health outcomes and disparities.

These factors encompass various conditions, including birth circumstances, growth environment, occupational settings, living conditions, and aging experiences, as well as broader systems and influences shaping daily life conditions (World Health Organization, 2010, 2021). Jeste (2022) introduced a special issue of *International Psychogeriatrics* in which a number of authors explored how these social determinants affect older people, with strong interconnected effects: for example, the health and well-being of unpaid carers can greatly affect health outcomes for older individuals with dementia. This emphasizes the need for accessible, high-quality social care and support services for unpaid carers, both for their own benefit and to optimize the lives of individuals who have dementia (Sadavoy et al., 2022; Clare et al., 2022).

As inequalities to accessing social care and social support services are multifaceted, the paper by Clarissa Giebel and colleagues (2023) is helpful in offering a clear and comprehensive examination of the obstacles faced by individuals with dementia and their carers in accessing such services following a diagnosis. By highlighting the situational, psychological, interpersonal, structural, and cultural factors that contribute to these barriers, their review provides valuable insights into the global landscape of equitable access to social care. Moreover, these findings could serve as a foundation for future research endeavors aimed at identifying interventions that can effectively reduce barriers and enhance enablers in practice.

The findings of this review have implications, not only for social care, but for public health and clinical practice. By identifying numerous intersecting barriers and limited enablers faced by individuals with dementia in accessing social care, the review sheds light on the complexity of many care systems – a complexity that can prove so challenging for individuals to navigate. As the first comprehensive exploration of the evidence base on barriers and facilitators of accessing and utilizing community-based social care and support services for dementia, this paper acknowledges that overcoming most of the structural barriers will not be simple. Because the revealed inequalities are multifaceted, the response must be multifaceted approaches to address barriers to access and good quality care. Specifically, Giebel and co-authors (2023) call for wider system changes – including learning from experiences in other countries – to address socio-economic barriers. Recognition of these challenges calls for a comprehensive and holistic

approach in designing interventions and policies to improve access to what are often vital social care services for individuals living with dementia.

In conclusion, this new systematic review on inequalities in accessing and utilizing community-based social care in dementia underscores a pressing need for action to address these disparities. Policymakers in health and social care systems need to be aware of the barriers and enablers in accessing social care services and commit to finding ways to ensure greater fairness. This commitment should include development of policies that target the social determinants of health, which have greater impacts on health and longevity than traditionally considered medical risk factors (Jeste & Pender, 2022). By actively addressing these disparities, we can strive towards establishing care systems that are equitable and inclusive, ensuring that individuals with dementia and their unpaid carers receive the support and services they need to lead better lives within their communities.

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