*International Psychogeriatrics* (2021), 33:7, 651–653 © International Psychogeriatric Association 2021
doi:10.1017/S104161022000335X

COMMENTARY

# Does "one size fit all" in subjective cognitive decline?

As the population ages, age-related cognitive decline is becoming a well-documented public health crisis, for which no therapeutic treatment is available. Cognitive decline exists on a continuum from slight and subjective cognitive changes, a condition referred to as subjective cognitive decline (SCD), to dementia. Although dementia is a condition that stems from several different neurodegenerative diseases, it is commonly characterized by cognitive and functional impairment, which require assistance for basic daily activities and leads to increased psychological distress and family burden.

However, even in the earliest stage of this continuum, when cognitive alterations are slight or only subjective, a certain degree of support or assistance might be needed, as individuals experience increasing difficulty with daily activities, such as medication management or appointment scheduling. Indeed, although SCD, by definition, is absent of objective cognitive impairment on the basis of clinical evaluation, no universally accepted cutoff exists to differentiate SCD from objective cognitive impairment (Jessen *et al.*, 2020). Moreover, standardized evaluations commonly used to assess the degree of cognitive impairment might not be able to capture subtle cognitive alterations in individuals with strong cognitive profiles (e.g. individuals with high cognitive reserve) – and these assessments might be culturally-specific. Finally, SCD is a heterogeneous phenotype, with different underlying pathophysiological processes linked with specific needs, which, ultimately, might be neglected by relatives and primary care physicians, due to its intrinsic nature (i.e. subjective complaints do not match with objective findings). Thus, identifying the unmet needs of individuals with SCD and the associated sociodemographic characteristics might help to mitigate the impact of developing difficulties with day-to-day activities and the associated mental and/or physical burden. Moreover, understanding unmet needs in this population might help to guide new early interventions to improve the quality of life of patients facing cognitive decline and their families.

Bouldin *et al.* (2020), in their population-based cohort study, provided a thoughtful overview of the prevalence of unmet needs in SCD individuals aged 45 years and older in the US, and the related mental, physical, and social features. The main finding was that 40% of individuals with SCD who need help are not getting it. Upon deeper examination, their findings point to larger trends and patterns. Several characteristics were effect modifiers in the relationship between SCD and having unmet needs, including economic (e.g. household income, living status), psychological (e.g. mental distress, depression), and sociodemographic (e.g. age, ethnicity) factors. Therefore, beyond the report that a vast number of SCD individuals have unmet needs, this study eloquently suggests a large amount of heterogeneity in SCD care.

Among these factors, Bouldin and colleagues reported that psychological factors, such as mental distress and depression, play a significant role in unmet needs. The result is consistent with findings suggesting that SCD often co-occurs with depression (Burmester *et al.*, 2016), which has several implications for health services and practitioners involved in the care of older people. Evaluation of mental distress might be relevant to identify those SCD individuals with unmet needs. However, it is worthwhile to highlight that depression and SCD are two independent constructs that might independently lead to neurodegenerative disorders through different neurobiological pathways (Liew, 2019). Indeed, stratifying SCD individuals by depressive symptoms, Bouldin and colleagues reported that, after adjusting for sociodemographic factors, mental distress was associated with SCD-related unmet needs only among those who had never been diagnosed with depression. This result suggests that the relationship between depression and SCD is more convoluted than might have previously been thought (Liew, 2019). Recently, in a review of magnetic resonance imaging studies, we reported a heterogeneous neurodegenerative profile in SCD, which could depend on subclinical mental distress, such as anxiety and depression (Pini and Wennberg, under review). Taken together, this evidence suggests a heterogeneous pattern in SCD where psychological factors, including depression, might underlie different trajectories and needs. All of these factors should be carefully evaluated in terms of daily support and needs in SCD individuals.

Other personality characteristics or sociodemographic factors could affect the relationship between SCD-related unmet needs and depression. As recently pointed out, the relationship between mood symptoms and SCD differs by ethnoracial group (Chapman, 2020). Meanwhile, studies have found that prevalence

https://doi.org/10.1017/S104161022000335X Published online by Cambridge University Press

and presentation of depression symptoms are different in minority groups (e.g. Hispanics) as compared to Whites (Zlatar *et al.*, 2018). In the US, depression is highest among minority groups (Xiang *et al.*, 2018; Zlatar *et al.*, 2018). This then has implications for how SCD, and its relationship with mood symptoms, may present in different ethnoracial groups, which should be considered in work identifying and intervening on SCD in different populations.

Indeed, another significant finding reported in the study of Bouldin and colleagues was the association between ethnicity and having unmet needs among individuals with SCD. As the population ages, it is also becoming more racially and ethnically diverse (Colby and Ortman, 2015), and differences in reporting, progression, and care of SCD are coming to light. The SCD Initiative (SCD-I) highlighted the importance of identifying how SCD might impact and manifest differently in ethnoracial groups (Jessen *et al.*, 2014). Needs and care look different by ethnoracial group. Still, half a decade after the SCD-I report, a deep understanding of these differences is lacking, as stated by a report from the International Society to Advance Alzheimer's treatment: "SCD prevalence, incidence and final outcomes in ethnoracial groups are areas that have received little attention" (Babulal *et al.*, 2019). Evidence of SCD prevalence among ethnoracial groups is mixed, with some studies reporting no differences and others showing higher prevalence among minority groups (Molinuevo *et al.*, 2017). Additionally, lower income, lower education, reporting poorer physical health, and being a dual-eligible beneficiary (i.e. those enrolled in both medicare and medicaid) or not having health insurance are all associated with higher odds of SCD (Babulal *et al.*, 2019; Bouldin *et al.*, 2020; Molinuevo *et al.*, 2017). In the US, non-Whites are more likely to experience these demographic factors (Sohn, 2017) and are more likely to experience more negative life events (Zlatar *et al.*, 2018). Hispanics are twice as likely to report mental health problems, but they also report problems with access to care (Xiang *et al.*, 2018; Zlatar *et al.*, 2018). Cumulative Disadvantage Theory (Crystal *et al.*, 2017) may help explain health inequalities in older age because of adverse consequences in health, education, and economic areas that accumulate over a lifetime. Because disadvantaged groups are more likely to experience illness and injury and subsequent health, disability, and well-being disparities (World Health Organization, 2010), it would follow that minority groups have more need for assistance than Whites.

Unmet needs are associated with several poor health-related outcomes that can lead to further reduced quality of life and disability and are associated with preventable hospitalizations (Allen *et al.*, 2014). Older adults with unmet needs are more likely to need hospitalization and enter long-term care facilities, as compared to those without unmet needs (Berridge and Mor, 2018). Blacks, as compared to Whites, are twice as likely to report an unmet need, are more likely to receive no help with their unmet need, and are more likely to have adverse consequences because of these unmet needs (Berridge and Mor, 2018). Though adjusting for medical need, health and functioning, insurance status, education, and living arrangement mitigates this association (Berridge and Mor, 2018). However, even when these factors are similar, non-Whites have lower health service use (Manuel, 2018), suggesting that structural racism and factors related to culture, language, and discrimination are at play. Moreover, different ethnoracial groups have different available resources to pay for care and different family structures equipped to provide care, which might further explain differences in unmet needs among ethnoracial groups.

We are now beginning to recognize the varying levels and facets of SCD-related unmet needs, but we need to both better understand them and begin addressing them through more effectual care models. Findings are beginning to shape our understanding that several factors, including mood symptoms and ethnoracial identity, affect SCD presentation and risk, both independently and interrelatedly. The observed differences in prevalence, presentation, and trajectories have implications for outreach in these individuals and communities. The number of and support given by family caregivers has been declining, which may, in part, be attributable to the increase in dual-income households and delayed childbearing (Freedman and Spillman, 2014). Patient-centered medical home care has become more common, including care that is compassionate, comprehensive, patient-focused, and with enhanced access. However, the large majority of older adults experiencing SCD are not receiving long-term care in-line with these principles, and access to this care is lower among non-Whites (Tarraf *et al.*, 2017). Though as clearly shown by Bouldin and colleagues, many SCD individuals have unmet needs. This suggests that care models need to be restructured and access to care, especially among groups that have traditionally been siloed, needs to change.

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https://doi.org/10.1017/S104161022000335X Published online by Cambridge University Press

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