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COMMENTARY

Assessing caregiver needs

> "When we are no longer able to change a situation . . . we are challenged to change ourselves." Viktor Frankl, *Man's Search for Meaning.*

The nature of caregiving, and why we need caregiver needs assessment

"Caregiving and receiving is a gift-sharing process in which we give and receive attention, affirmation, practical assistance, emotional support, moral solidarity, and abiding meaning that is complicated and incomplete. Care is the human glue that holds together families, communities, and societies" (Kleinman, 2020).

Caring for a person living with dementia changes expectations, brings deeply personal emotional, cognitive, physical, and moral challenges, uncovers unsuspected inner strengths, and prompts the growth of new ones. We now understand how unrelieved caregiving stress harms the health and well-being of the dyad, but also how accepting the responsibility of caregiving can strengthen purpose, stimulate growth, and cultivate wisdom (Roth *et al.*, 2015).

Decades of research have revealed the many ways dementia gradually diminishes autonomy, self-regulation, and agency, and transfers these functions, on behalf of the affected individual, to family, friends, neighborhoods, communities, clinicians, and healthcare systems. Today's unprecedented need for skillful, long-term dementia caregiving is a consequence of the dramatic extension of lifespan worldwide that spurred dramatic expansion of the population of older people made dependent through cognitive decline and disability (Prince *et al.*, 2012; Wimo *et al.*, 2018). Families remain the main providers of this care, in roles that have become quasi-professionalized as health care becomes more complex. We now understand the impact on caregiving of shrinking family size, geographic mobility, changes in employment – especially for women – and of the broad restructuring of social and economic life that is taking place across the world. Supplementing family-based care at pivotal points along the dementia life course is now a function carried out, with varying success, by community-based voluntary and paid service organizations, health and long-term care providers, and government-funded aging care agencies. These diverse organizations, work in a more or (often) less coordinated way to sustain the well-being of individuals living with dementia and their care partners.

Caregivers' lived experience: establishing the relevance of needs assessment

Understanding the caregiving experience is the foundation of designing services that nurture caregivers' latent strengths, and that can strengthen and repair their social safety nets. The methods of social science and mental health – ethnography, semi-structured interviews, and surveys – reveal broad commonalities in caregiving experience based on the primary effects of dementing diseases on cognition, behavior, everyday functioning, and relationships with other people and the surrounding environment. Though these processes are much the same around the world, their primary effects are moderated by many individual differences among patients and caregivers, the nature of the specific diagnosis and stage, effects of (and on) concurrent illnesses, and the relational, social, cultural, institutional, economic, and political ecosystems in which a dementia care dyad is embedded. Tools that assess a broad range of caregiver needs are the vehicle for translating this extensive body of knowledge into practical design and planning for services that will effectively sustain caregivers. DeCANT, a caregiver needs assessment tool developed by Clemmensen *et al.* (2021) and published here online in September, catalogues a range of caregiver-reported needs, supported by a scoring structure that distinguishes unmet needs, and their urgency, from those that are already met or don't apply.

Defining caregiver needs: balancing subjectivity

The primacy of caregiver perception in defining needs, though widely accepted in the field of caregiver assessment, deserves thoughtful consideration. Perceived needs cannot be the sole basis for determining what services ought to be provided and who should be eligible to receive them, with what priority, and in what "dose" or intensity. In practice,

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many factors count: whether a suitable program exists that demonstrably meets the target needs, barriers to use (supply, cost, accessibility), and expert input and judgment. In both health and social care, we need evidence that reveals what unmet needs cause harm, what services mitigate it, and who is accountable for the outcome of those services (Marosszeky *et al.*, 2006). Evidence about unmet needs that are clearly associated with poor outcomes for individuals with dementia (e.g. elder abuse, preventable hospitalizations, medication toxicity, poorly controlled comorbid conditions, psychosis with aggression) or their caregivers (e.g. impoverishment, depression, burnout, deteriorating health, premature death) offers a useful counterweight to subjective caregiver self-assessment and helps to define the operating terms for service development and deployment. Collaboration between caregivers and experienced providers of relevant care and services can help achieve the necessary balance.

Cross-sector collaboration in developing caregiver needs assessment tools

Two examples of tools developed through explicit collaboration between dementia care professionals and caregivers are DeCANT (Clemmensen *et al.*, 2021) and Managing Your Loved One's Health (MYLOH) (Sadak *et al.*, 2018). Both contain care recipient- and caregiver self-facing elements, two essential features identified by qualitative studies of caregiver needs (McCabe *et al.*, 2016). DeCANT's 25 items cover a wide range of individual perceived needs, from coping with caregivers' emotional responses, managing behavioral changes, and navigating financial and bureaucratic challenges, to engaging others as helpers, getting more sleep, finding help with housework, and maintaining a positive relationship with the care recipient. Its item content suggests that DeCANT may be most useful for assessing needs in nonmedical service settings that act to link individual caregivers to specific service providers "on the ground." With further development, DeCANT should be useful in evaluating program outcomes. Psychometric testing is planned.

MYLOH was developed to assess the needs of caregivers specifically in the context of health care for people living with dementia. As indispensable members of a health care "triad" that binds them in partnership with patients and clinicians (Fortinsky, 2001), caregivers' quasi-clinical roles, though often quite demanding (Riffin *et al.*, 2019), are not well represented in established caregiver assessment tools (Family Caregiver Alliance, 2012). The initial version of the tool, Partnering for Better Health – Living with Chronic Illness (PBH-LCI) (Sadak *et al.*, 2015) was created in a multistep collaborative process with a diverse group of 16 dementia care professionals (primary care clinicians, geriatricians, geriatric psychiatrists, nurse practitioners, social workers, community-based service providers) and experienced caregivers. The process followed a systematic approach to developing participant-reported outcome measures (PROMs). Its psychometric properties were found to be superior to a number of other caregiver needs assessments in a recent systematic review (Kipfer and Pihet, 2020). PBH-LCI, and MYLOH, its slightly briefer revision renamed after further testing and cultural tailoring with African-American and Latinx caregivers (Sadak *et al.*, 2018), were conceptualized as a way to assess, and ultimately enhance, caregiver "activation" for health care of people with dementia (Sadak *et al.*, 2016). Its items identify caregivers' perceived knowledge and skills in essential domains of care grouped into seven factors, allowing for scoring elements for which the caregiver is not personally responsible. Domains encompass management of cognitive impairment, behavior, everyday functional deficits, medical conditions, and medications; recognizing and knowing how to deal with changes in the care recipient's health; communicating and working with clinicians; advocating for the care recipient and making healthcare decisions; and maintaining caregiver well-being through self-care and getting help from others. Low caregiver agreement with an item reflecting knowledge or skill indexes unmet need for coaching and/or support by a clinician or other designated provider. MYLOH is structured to frame conversations and collaboration between caregivers and clinicians on behalf of individual patients; its items and domains have been found to be relevant to caregiving across a range of chronic diseases as well as dementia (Borson *et al.*, 2018). More work remains to be done to define the optimal format for deploying MYLOH in practice and test its responsiveness to change with targeted caregiver interventions.

Harmonizing caregiver needs assessment across service settings, countries, and cultures

Differences between the two tools described here illustrate the influence of the culture in which measures are developed on what and how they ask caregivers to report. The professional disciplines of their authors, the service setting for which a tool is intended, and the national approach to the

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organization of services all affect the choice of content and method of assessment, despite the broad commonalities of caregiver needs around the world.

A unifying approach would help harmonize assessments across service sector divides, promote more effective integration of international and multidisciplinary perspectives, and simplify the coordination of care and support services across health and community care regardless of where in the world that care is needed.

One approach could be to use a two-stage assessment process similar to that used in the epidemiological study of complex conditions. For caregiver needs, it could begin with a simple screener for unmet needs. The Dementia Services Mini-Screen (Borson *et al.*, 2014) is a basic first-stage screener that can be completed in under 5 minutes: caregivers report whether they needed dementia-related medical and/or social services in the past year and whether they had used them, answer a single-item caregiver stress question, and complete a brief patient behavior problem checklist. In this initial study, empirically derived thresholds for stress and behavior problems predicted unmet needs in both health and social care sectors. The second stage to follow a positive screen would then be a more detailed assessment to identify the specific types of service most relevant to the individual dyad.

In many countries, health and social care sectors are divided by strong institutional boundaries, reinforced by different policy agendas and separate, uncoordinated funding streams. These gaps are particularly difficult to bridge in countries that, like the USA, embrace an ethos of self-reliance rather than communalism, have large, highly diverse populations distributed over enormous geographic territory, lack national health and social care systems, and vary widely in regional investment in public health. In smaller and more socially cohesive countries like Denmark, public responsibility for the social safety net for older adults is assumed. Despite their important differences, all developed countries struggle to some degree with how to reconcile social responsibility for compassionate help for the vulnerable with the common realities of budget constraints, maldistribution of needed services, and excessive family burden. The gaps are most obvious where care is viewed as mainly a private responsibility, and this may influence caregivers' expectations, what they define and identify as needs, and whether and to whom they are willing to reveal the needs they have. Moreover, when needs are assessed with measures developed in languages or cultures other than that of a given target group, simple language translation cannot be assumed to yield a comparable understanding of or responses to the items they contain. Cross-national, cross-cultural collaboration would make an international approach to universalizing assessment feasible and create possibilities for new transnational learning.

Ultimately, harmonizing caregiver needs assessment starts with a focus on the basic aims of care and support for people with dementia and their caregivers. The recent release of a major international workgroup report on the current state of dementia prevention and care (Livingston *et al.*, 2020) acknowledges that well-being – emotional, physical, and social, for both people living with dementia and their caregivers – is the goal of much of care today, and that both health and social care attentive to the needs of the dyad are fundamental to achieving that goal. Asking caregivers what they need lays the necessary foundation (Bangerter *et al.*, 2019), but it is not sufficient. To become dementia-capable, societies must choose to invest more creatively in policies and practices that address those needs (Fazio *et al.*, 2018), despite the constraints inherent in their political, economic, philosophical, and care delivery systems, and invite caregivers to help evaluate how successful we are. Perhaps we can look forward to a time when fewer caregivers are overwhelmed, depressed, exhausted, isolated, lonely, and conflicted, feel they can trust what we have to offer, and don't wait too long before getting help: when what caregivers can expect to receive is what they need to foster mastery, sustain a sense of purpose, and nurture the wisdom that grows from doing well the thing you fear you cannot do.

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References

Bangerter, L. R., Griffin, J. M., Zarit, S. H. and Havyer, R. (2019). Measuring the needs of family caregivers of people with dementia: an assessment of current methodological strategies and key recommendations. *Journal of Applied Gerontology*, 38, 1304–1318. https://doi.org/10.1177/0733464817705959

Borson, S., Mobley, P., Fernstrom, K., Bingham, P., Sadak, T. and Britt, H. R. (2018). Measuring caregiver activation to identify coaching and support needs: extending MYLOH to advanced chronic illness. *PLoS One*, 13, e0205153. https://doi.org/10.1371/journal.pone.0205153

Borson, S., Scanlan, J. M., Sadak, T., Lessig, M. and Vitaliano, P. (2014). Dementia Services Mini-Screen: a simple method to identify patients and caregivers in need of enhanced dementia care services. *American Journal*

https://doi.org/10.1017/S1041610220003877 Published online by Cambridge University Press

of Geriatric Psychiatry, 22, 746–755. https://doi.org/10.1016/j.jagp.2013.11.001

Clemmensen, T. H., Kristensen, H. K., Andersen-Ranberg, K. and Lauridsen, H. H. (2021). Development and field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT). *International Psychogeriatrics*, 33, 405–417. https://doi.org/10.1017/S1041610220001714

Family Caregiver Alliance (2012). Selected caregiver assessment measures: a resource inventory for practitioners. Available at: https://www.caregiver.org/selected-caregiver-assessment-measures-resource-inventory-practitioners-2012; last accessed 10 December 2020.

Fazio, S., Pace, D., Maslow, K., Zimmerman, S. and Kallmyer, B. (2018). Alzheimer's association dementia care practice recommendations. *Gerontologist*, 58, S1–S9. https://doi.org/10.1093/geront/gnx182

Fortinsky, R. H. (2001). Health care triads and dementia care: integrative framework and future directions. *Aging and Mental Health*, 5, S35–S48. https://doi.org/10.1080/713649999

Kipfer, S. and Pihet, S. (2020). Reliability, validity and relevance of needs assessment instruments for informal dementia caregivers: a psychometric systematic review. *JBI Evidence Synthesis*, 18, 704–742. https://doi.org/10.11124/JBISRIR-2017-003976

Kleinman, A. (2020). *The Soul of Care: The Moral Education of a Husband and a Doctor*. United States: Penguin.

Livingston, G. *et al.* (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, 396, 413–46. https://doi.org/10.1016/S0140-6736(20)30367-6

Marosszeky, N., Rix, M. and Owen, A. (2006). Knowing what you need to know about needs assessment. Available at: https://ro.uow.edu.au/gsbpapers/86; last accessed 30 September 2020.

McCabe, M., You, E. and Tatangelo, G. (2016). Hearing their voice: a systematic review of dementia family caregivers' needs. *Gerontologist*, 56, e70–e88. https://doi.org/10.1093/geront/gnw078

Prince, M. *et al.* (2012). Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. *International Journal of Geriatric Psychiatry*, 27, 670–682. https://doi.org/10.1002/gps.2727

Riffin, C., Van Ness, P. H., Wolff, J. L. and Fried, T. (2019). Multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers. *Journal of the American Geriatrics Society*, 67, 277–283. https://doi.org/10.1111/jgs.15664

Roth, D. L., Fredman, L. and Haley, W. E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist*, 55, 309–319. https://doi.org/10.1093/geront/gnu177

Sadak, T., Korpak, A. and Borson, S. (2015). Measuring caregiver activation for health care: validation of PBH-LCI:D. *Geriatric Nursing*, 36, 284–292. https://doi.org/10.1016/j.gerinurse.2015.03.003

Sadak, T., Souza, A. and Borson, S. (2016). Toward assessment of dementia caregiver activation for health care: an integrative review of related constructs and measures. *Research in Gerontological Nursing*, 9, 145–155. https://doi.org/10.3928/19404921-20151019-02

Sadak, T., Wright, J. and Borson, S. (2018). Managing your loved one's health: development of a new care management measure for dementia family caregivers. *Journal of Applied Gerontology*, 37, 620–643. https://doi.org/10.1177/0733464816657472

Wimo, A., Gauthier, S. and Prince, M. (2018). Global estimates of informal care. Available at London: https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf; last accessed 18 September 2020.

https://doi.org/10.1017/S1041610220003877 Published online by Cambridge University Press