

October 21, 2022

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Division of Behavioral and Social Research

RE: NOT-AG-22-028 Request for Information: Invitation for Input on the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and their Caregivers/Care Partners

Dear Dr. Keller, Summit Leaders, and NIA Colleagues:

On behalf of The Gerontological Society of America (GSA), thank you for the opportunity to provide input on the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and their Caregivers/Care Partners. As you know GSA members and staff have been active in the previous summits as well as the upcoming summit. With the assistance of GSA Visiting Scholar, Katie Maslow and input from the GSA Alzheimer's Disease and Related Dementias and the Family Caregiving Interest Groups, GSA has prepared the following recommendations.

Measuring outcomes that matter to PLWD

GSA appreciates and strongly encourages NIA's ongoing support for research to identify outcomes that matter to people living with MCI and dementia and their care partners and its support for the development and testing of measures that can be used in research on ways to achieve those outcomes.

Many existing measures for research on dementia care and services focus on negative outcomes, but a substantial number of valid and reliable measures of positive, person-centered outcomes have been identified (see, e.g., Mast et al, 2021). Additional measures of positive outcomes still need testing for validity and reliability in samples of people living with MCI and dementia and dementia care partners. Examples of such measures include resilience and feelings of acceptance and belonging in social and other settings. We also need to learn more about what constitutes "coordinated care" from the perspective of people living with MCI and dementia and their care partners and how to measure this concept in research.

A summit session on measuring outcomes that matter to people living with MCI and dementia and dementia care partners could focus on existing positive measures, and thereby increase awareness of these already validated measures among researchers and others. The session could also encourage identification, development, and testing of positive research measures of additional outcomes that matter to people living with MCI and dementia and their care partners.

Lastly, GSA researchers are familiar with existing measures of financial strain but believe that additional conceptual work is needed to identify positive outcomes in this area. In addition, while financial strain measures have been used in research with dementia care partners, some and perhaps many people living with MCI and dementia also experience financial strain. Thus, new measures should be developed and validated for people living with these conditions as well as dementia care partners.

The impact of detection and diagnosis on individuals and care partners, as well as social, economic, and structural barriers to, and facilitators of, detection and diagnosis and ethics and equity issues.

Improved detection and diagnosis of cognitive impairment and dementia are critical for better treatment, care, and services for people living with MCI and dementia and their care partners. GSA and many government and other non-government organizations are working on approaches to address this difficult issue.

One aspect of the issue that has received little attention to our knowledge is the effect on people living with MCI and dementia of the increasing use of biomarkers and data from electronic health records to identify individuals to be recruited for all types of dementia-related research. The benefits of using these methods are clear from the perspective of researchers. Little is known, however, about how use of these methods affects people with possible MCI and dementia and their care partners, particularly with respect to their understanding about the person's current cognitive abilities and deficits. We need to learn more about what people living with MCI and dementia and their care partners think when they learn that possible dementia has been detected by these methods. How are these relatively new processes being explained to them now, and what are their reactions, assumptions, and conclusions. Are there better ways to explain these relatively new detection processes and increase understanding of their results among people living with MCI and dementia and their care partners?

Disparities and inequities in healthcare access, utilization, and equality for PLWD.

GSA applauds the increased attention at NIA and NIH more broadly to disparities and inequities in healthcare access, utilization, quality of care, and in research processes generally. GSA members are concerned about and focused on these problems and excited about new research opportunities to study and help to resolve them. We have a long way to go to fully understand and address these problems. Funding for research and importantly, funding for training and engagement of researchers from populations that have experienced disparities and inequities in health care are clearly essential. GSA suggests that disparities and inequities should be a cross-cutting theme for the 2023 summit as it has been for other summits.

Approaches to participatory research and recruitment and retention of stakeholders and research participants from heterogeneous backgrounds.

With support from NIA and other funders, people living with MCI and dementia and their care partners are increasingly being engaged as advisors and partners in research projects and as members of community-based participatory research initiatives on dementia care, services, and supports. It is clear that these individuals can contribute to the selection of important research topics. In some projects, they are also being asked for advice about outcomes to be measured. In at least a few research projects and community-based participatory research initiatives, they have been able to suggest research practices that will help with recruitment and/or retention of people living with MCI or dementia and dementia care partners who could be engaged as research subjects. Lastly, a few organizations are engaging people living with MCI and dementia and dementia care partners in the review of some portions of research proposals, for example, asking them to comment on the relevance and importance of the proposal to people like them.

Engagement of people living with MCI and dementia and dementia care partners as research advisors and partners is growing. The field would benefit from careful classification and comparisons among different approaches that are being tried. Questions about equity and inclusion in the processes that determine which people living with MCI and dementia and care partners are engaged as research advisors and partners should be studied. Research is also needed on the kinds of supports that will allow them to be successful research advisors and partners.

A summit session focused on the progress that has been made in engagement of people living with MCI and dementia and dementia care partners as advisors and research partners could encourage more research teams to try this approach. Such a session could also encourage attention to important questions about equity, inclusion, and needed supports for people living with MCI and dementia and dementia care partners who are engaged in these roles.

Dementia care models, coordination of care, and transitions across a care continuum

NIA and other organizations have supported research on many different dementia care models, most of which are intended to increase coordination of care. Coordination of care from the perspective of some health care plans and providers often focuses primarily on coordination within health care systems and/or among parts of a health care system, rather than coordination of health care and non-medical home and community-based care. As noted earlier, we need to learn more about what constitutes "coordinated care" from the perspectives of people living with MCI and dementia and their care partners, but it is likely that they hope for care that is coordinated across health care and non-medical home and community-based systems and providers. Research that uses clearly defined, tested, and validated measures of coordination of care that include the perspectives people living with MCI and dementia and their care

partners as well as the perspectives of health care and home and community-based care providers could result in findings about how to create meaningful coordination of care that meets the needs of people living with MCI and dementia and their care partners.

Interventions to support dementia care partners and caregivers, including interventions tailored to address differences in caregiving needs, supports, and sources of resilience that may exist across various cultures.

Many research articles and commentaries have highlighted the vast heterogeneity of dementia care partners and caregivers. Some researchers and developers have attempted to develop interventions that address this heterogeneity directly, often by employing assessment procedures to connect individuals to care and services that are likely to meet their needs. Other researchers and program developers have tried to more clearly specify the characteristics of the care partners and caregivers that are expected to benefit from a particular intervention. Costs and other limitations on sample size and problems in enrolling care partners and caregivers with specific characteristics increase the difficulty researchers and program developers face in developing and testing new interventions intended to support these people.

NIA and the Summit Steering Committee might choose to address the difficult issue of heterogeneity in research on dementia care and services in a summit session. Alternatively, NIA might decide to convene researchers, program developers, and others in another meeting focused entirely on how to develop and evaluate interventions for the extremely heterogeneous population of dementia care partners and caregivers.

The paid dementia care workforce, including the nursing home and community-based care

The pandemic has increased attention to the many workforce-related problems in nursing home, assisted living, and home-based and other community-based care organizations that provide care and services for people living with MCI and dementia and dementia care partners. These problems often boil down to the generally low payment levels for care workers in these settings and will, therefore, ultimately require policy-related solutions. Excellent training programs are available to increase dementia-capability among these workers. A summit session that highlighted these training programs and reviewed the low payment levels in relevant settings could help to inform and motivate researchers, advocates and others to seek ways to increase the use of existing training programs and to address the needed policy-related solutions to workforce issues.

The financial costs of dementia care to PLWD, care partners, families, health systems, payers, and others

Numerous reports by researchers, policy analysts, advocates, and others have documented the high costs of care and services for people living with MCI and dementia, care partners, families, health systems, payers, and others. A comprehensive analysis of findings from these reports that compares their methods and conclusions could help in evaluating the validity of each report's findings.

One problem has been that most people living with MCI and dementia also have serious co-existing medical conditions, and the combination of conditions requires care that should not be attributed completely to their MCI or dementia. It is difficult but important to try to separate costs of care and services that should be attributed to MCI and dementia vs. other serious, co-existing medical conditions. Greater attention to this issue could clarify estimates of financial costs. Greater attention might also increase research and clinical efforts to manage co-existing medical conditions in people with dementia and conversely, to manage dementia in people with other serious medical conditions.

The economic impact of innovations in care and treatment

Recent experiences with Aduhelm and its projected monthly cost of \$28,000 for infusions have raised concern about the economic impact of innovations in treatment for MCI and dementia. Although hopes for Aduhelm and concerns about its potential economic impact have decreased, recent press releases have announced other new drugs, at least one of which will apparently require at least 2 monthly drug infusion and other costly tests.

GSA shares the general excitement about the possibility of effective treatments for MCI and dementia, we also recognize that people living with MCI and dementia, their care partners, and extended families and social networks will need help to understand the likely benefits and associated risks of new drugs as well as the cost implications of using the drugs. Raising this issue at the 2023 Summit could result in collaborations among government and non-government organizations to develop information that will help them and to make this information widely available.

Two Additional Topics for Possible Inclusion in the Summit

Numerous research articles and reports have documented the frequent failure of health care systems and providers to include dementia care partners sufficiently in health care discussions and decisions about the care of the person with MCI or dementia for whom they are providing care. It would be valuable if NIA and the Summit Steering Committee could find a place in the 2023 Summit to review this problem and discuss recent publications and ongoing research on approaches to resolve the problem.

Growing attention to what has been referred to as Living Well with Dementia and Positive Dementia, as well as the impressive increase in the number of Dementia-Friendly Communities and states, are interesting and potentially very valuable to people living with MCI and dementia, care partners, and the field as a whole. Although research is still limited, it would again be valuable if NIA and the Summit Steering Committee could find a place in the summit to discuss these relatively new and exciting care concepts and approaches.

Thank you for considering our recommendations and we look forward to working with you. Please do not hesitate to contact GSA Vice President of Policy and Professional Affairs, Trish D'Antonio at pdantonio@geron.org or 202-587-5880 if we can provide further assistance.

Sincerely,



James C. Appleby, BSPharm, MPH, ScD (Hon)
Chief Executive Officer

Reference:

Mast, B.T., Molony, S.L., Nicholson, N., Keefe, C.K., and DiGasbarro, D. ((2021) Person-centered assessment of people living with dementia: Review of existing measures. *Translational Research & Clinical Interventions. Alzheimer's and Dementia* 7:e12138.