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Research Priorities to Advance the Health and Health Care of Older Adults with Multiple Chronic Conditions

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Abstract

Objective—Substantial gaps in knowledge exist surrounding the health and healthcare of older adults with multiple chronic conditions (MCCs). We sought to prioritize research topics relevant to the care of this growing population.

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Design—Survey of experts in MCC practice, research, and/or policy. Topics were derived from white papers, funding announcements, or funded research projects relating to older adults with MCCs.

Setting—Survey conducted through the HCSRN-OAICs AGING Initiative, a joint endeavor of the Health Care Systems Research Network (HCSRN) and Claude D. Pepper Older Americans Independence Centers (OAICs).

Participants—Individuals affiliated with the HCSRN or OAICs, and national MCC experts, including individuals affiliated with funding agencies having MCC-related grant portfolios.

Measurements—We employed “top box” methodology, counting the number of respondents selecting the top response on a five-point Likert scale, then dividing by total number of responses to calculate a top box percentage for each of 37 topics.

Results—Highest ranked research topics relevant to the health and healthcare of older adults with MCCs included: health related quality of life in older adults with MCCs; development of assessment tools (e.g., to assess symptom burden, quality of life, and function, etc.); interactions between medications, disease processes, and health outcomes; disability; implementation of novel (and scalable) models of care; association of clusters of chronic conditions with clinical, financial, and social outcomes; the role of the caregiver; symptom burden; shared decision-making to enhance care planning; and tools to improve clinical decision-making.

Conclusions—Our findings serve to inform the development of a comprehensive research agenda to address the challenges relating to the care of this “high-need, high-cost” population, and the healthcare delivery systems responsible for serving them.

INTRODUCTION

One in four Americans has multiple chronic conditions (MCCs).¹ This number rises to three in four Americans aged 65 and older.² While the conventional approach to caring for patients has been to address one disease at a time,³ there has been a growing appreciation that it is counterproductive to think in terms of individual disease “silos.”^{4,5} Unfortunately, our current medical model tends to focus on individual organ systems, often ignoring the full complexity of the care needs of older patients with various combinations of diseases and conditions.⁶

MCCs increase the risk of mortality and functional decline,^{7,8} and adversely impact quality of life.⁹ Older adults with MCCs use the most health care services,¹⁰ and a direct relationship exists between the number of chronic conditions and health care costs.^{11,12,13,14} The 14% of Medicare beneficiaries with six or more chronic conditions account for 46% of total Medicare spending, and for 55% of Medicare spending on hospitalizations.¹⁵ These individuals also account for 63% of post-acute care Medicare costs, including care in skilled nursing facilities, as well as home health care.¹³

There are many important gaps in our knowledge surrounding the care of older adults with MCCs. Our paper describes an effort to prioritize research topics relevant to advancing the health and healthcare of this growing population, through a survey conducted under the auspices of the HCSRN-OAICs AGING Initiative (“Advancing Geriatrics Infrastructure and

Network Growth”), a joint endeavor of the Health Care Systems Research Network (HCSRN, www.hcsrn.org) and Claude D. Pepper Older Americans Independence Centers (OAICs, www.peppercenter.org). The HCSRN includes 1900 non-university-based investigators and staff affiliated with research centers within some of the nation’s leading health care systems. The OAICs are university-based research entities supported by the National Institute on Aging with a mission to increase scientific knowledge to allow older adults to maintain or restore independence.

METHODS

Survey Development

We conducted a search of published white papers, reports, grant announcements, and funded research projects (see Supplementary Appendices A and B) between 2010 and 2015 that included the terms “multiple chronic conditions”, “multimorbidity”, and/or “comorbidity”, and for relevance to older adults with MCCs. The search employed: PubMed, the funding and grants sections of the Agency for Healthcare Research and Quality (AHRQ), the Patient-Centered Outcomes Research Institute (PCORI), and National Institutes of Health websites; the National Academy of Medicine website; and Google Scholar. A list of research topics and a set of themes organizing these topics were developed. These were reviewed by Steering Committee of the AGING Initiative, which led to refinements of themes and the addition of topics not previously specified. The final survey included 37 topics organized under 11 themes (Table 1).

Survey Administration

Our sample was drawn from investigators affiliated with the HCSRN or the OAICs or those participating in quarterly webinars focused on topics relevant to older adults with MCCs. The sample also included individuals affiliated with selected funding agencies with grant portfolios relevant to MCCs in older adults, as well as thought leaders and experts identified based on authorship of white papers or participation on national panels or working groups relating to MCCs. The University of Massachusetts Medical School institutional review board reviewed this project and determined it was not human research and did not require consent.

The survey was adapted for web-based delivery (SurveyMonkey.com, Menlo Park, CA) using an embedded link within an e-mail explaining the purpose of the survey. The e-mail was sent to potential respondents up to five times over a two-week period in June 2016 and indicated that all respondents would be entered into a drawing for a \$250.00 gift card. Survey respondents were asked to rate the level of importance of each topic for advancing the science of MCCs on a five-point Likert scale with one being *not* important and five being *very* important. Respondents were also asked to suggest additional research topics and/or relevant comments.

Statistical Analyses

We employed “top box” methodology;¹⁶ top box scores display the percent of survey respondents who chose the most positive score for a given item response scale. We counted

the number of respondents selecting the fifth option (the top box) on the five-point Likert scale. We divided the top box count by the total number of responses to calculate a top box percentage for each topic.

Following completion of the survey, respondents were invited to provide comments or suggest additional research topics. These responses were loaded into NVivo qualitative analysis software,¹⁷ and the most commonly occurring terms and phrases were grouped into thematic areas.

RESULTS

Online Survey

Of 1,399 individuals invited to participate in the survey, 366 (26%) responded. Of the respondents, 37% (n=137) were investigators affiliated with the HCSRN, 25% (n=93) were affiliated with an OAIC program, 22% (n=79) were affiliated with academic health centers, 5% (n=20) were affiliated with the Veterans Affairs system, 5% (n=17) were individuals affiliated with federal agencies, 1% (n=4) were affiliated with the Patient-Centered Outcomes Research Institute (PCORI), and 4% (n=16) were affiliated with other agencies or institutes. Of the respondents, there were 109 MDs, 14 MD-PhDs, 188 PhDs, 6 PharmDs, 1 doctor of nursing science, and there were 41 without doctoral level degrees. For 7, this information was not available.

Topics

The top 15 research topics for older adults with MCCs included: health related quality of life in older adults with MCCs (62%); development of assessment tools (e.g., to assess symptom burden, quality of life, and function, etc.) (58%), interactions between medications, disease processes, and health outcomes (57%); disability (53%); implementation of novel (and scalable) models of care (51%); association of clusters of chronic conditions with clinical, financial, and social outcomes (50%); the role of the caregiver (49%); symptom burden (49%); shared decision-making to enhance care planning (48%); tools to improve clinical decision-making (47%); treatment burden (47%); self-management interventions (46%); Alzheimer's disease and other dementias (44%); intervention designs with multiple components and pragmatic trials (44%); and management of pain and/or other symptoms (43%). The complete list of topics, ranked according to the top box percentage, is provided in Table 2.

Open-Ended Responses

A total of 231 open-ended responses were provided. While in the majority of instances, the specific comments were unique to only one or two individuals, these open-ended responses, when relevant to MCCs research topics, clustered most frequently among the following five thematic areas: family and caregiver roles and dynamics (21 mentions); symptom and condition management/self-management (10 mentions); prevention strategies (10 mentions); end-of-life care (7 mentions); and coordination of care (6 mentions).

DISCUSSION

Blumenthal and colleagues have written that “improving the performance of America’s health system will require improving care for patients who use it most: people with multiple chronic conditions that are often complicated by patients’ limited ability to care for themselves independently and by their complex social needs.”¹⁸ A robust research agenda will be required to better understand the ever growing population of complex “high-need, high-cost” patients, the vast majority of whom are elderly, and to lay the groundwork for effective interventions to address the multifaceted needs of these patients. It is also well understood that the science of MCCs must transition from simply describing the extent of the problem to pursuing studies that address specific aspects of care and the resulting outcomes for these very complex patients.

The findings of our survey provide only a starting point for pursuing a comprehensive research agenda relevant to the care of older adults with MCCs. In many respects, the research topics that the survey respondents were asked to rate might be considered simplistic and overly general. However, a case can be made that the topics reflect the “state of the science.” For example, there is still a lack of consensus on how best to define and measure the burden of MCCs in older adults, something which is fundamental to being able to characterize and fully understand this population.¹⁹ Clinical trials relevant to the treatment and prevention of chronic disease in older adults continue to exclude the participation of individuals with MCCs,²⁰ and fail to measure important outcomes including health related quality of life, symptom burden, and disability free survival.²¹ There is a need for better approaches to measurement that can allow information on “universal health outcomes”²² to be efficiently and validly assessed in the context of routine clinical care and incorporated in electronic health records.²³ The presence of such information in electronic health records may provide a way to address the need for large, heterogeneous populations to examine treatment effects and “the outcomes that really matter” to older patients with MCCs, an essential tool in conducting impactful applied health research through observational studies and pragmatic trials.²⁴ Most important, the lack of evidence regarding benefits and risks of available treatment approaches severely compromises efforts at shared decision-making in caring for older patients with MCCs. All of these issues intersect with the research topic areas receiving the highest rankings in the survey.

Our work complements prior efforts to develop a research agenda addressing the healthcare needs of older adults with MCCs sponsored jointly by the Agency for Healthcare Research and Quality, the Society of General Internal Medicine, and the John A. Hartford Foundation.²⁵ Research priorities emanating from that effort included: (1) to develop and evaluate more effective models of health care; (2) to develop and evaluate management practices and organizational structures that lead to improved long-term care; (3) to develop and implement relevant and effective preventive health strategies; (4) to determine the most effective interventions in patients who have concurrent cognitive and emotional impairments; and (5) to determine how interventions during and after hospitalization affect outcomes of hospitalized patients. In addition, a strategic framework for improving health outcomes and quality of life in Americans with MCCs, developed by the U.S. Department of Health and Human Services (HHS), articulated four primary objectives in relation to an

overarching goal to facilitate research to fill knowledge gaps about, and interventions and systems to benefit, individuals with MCCs.²⁶ These included: (1) increasing the external validity of clinical trials relevant to individuals with MCCs; (2) improving understanding of the epidemiology of MCCs including identifying population subgroups of individuals with MCCs who are at high risk for poor health outcomes; (3) increasing community and patient-centered health research with an emphasis on improving measurement of patient-centered outcomes; and (4) addressing disparities in populations of patients with MCCs.

Our efforts to rank research topics relevant to MCCs in the geriatric population have a number of limitations. Importantly, our approach allowed us to characterize the “popularity” of individual topics, but it did not assess how respondents ranked the topics relative to each other. Although there was representation among the respondents to the survey of individuals affiliated with other entities including the VA and various funders, we did not seek to identify all individuals from those entities with expertise or interest in MCCs in older adults. It is also apparent that our sample of survey respondents, by virtue of the nature of the AGING Initiative, was not inclusive of researchers focused on geroscience and its intersection with chronic disease and multimorbidity, potentially discounting many emerging research priorities relevant to advancing the science of MCCs.²⁷ Our “one-shot” Survey Monkey approach also limited what we could accomplish through our efforts, which were not iterative and did not involve in-person meetings and discussions in contrast to the efforts of others described above.^{25,26} Most notably, patients, caregivers, and family members were not included in the sample of surveyed individuals. These groups and other important stakeholders, including hospitals, nursing homes, health plans, social service organizations, and advocacy groups, could provide important perspectives that have not been captured through our efforts to date.

Despite these limitations, we feel that our findings are of value in the context of the current nascent state of the science of MCCs, a field that begs for increased sophistication before research findings can be translated into meaningful practice change and improvements in the care of this growing high-need, high-cost, and highly vulnerable population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. http://www.hhs.gov/sites/default/files/ash/initiatives/mcc/mcc_framework.pdf
2. <http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/prevention-chronic-care/decision/mcc/mccchartbook.pdf>
3. US Burden of Disease Collaborators. The state of US health, 1990–2010: burden of diseases, injuries, and risk factors. JAMA. 2013; 310:591–608. [PubMed: 23842577]

4. Parekh AK, Barton MB. The challenge of multiple comorbidity for the US healthcare system. *J Am Med Assoc.* 2010; 303:1303–1304.
5. Tinetti ME, Fried TR, Boyd CM. Designing healthcare for the most common chronic condition – multimorbidity. *JAMA.* 2012; 307:2493–2494. [PubMed: 22797447]
6. Applegate WB, Ip E. The evolving taxonomy of health in older persons. *JAMA.* 2016; 316:2487–2488. [PubMed: 27997661]
7. Newman AB, Boudreau RM, Naydeck BL, et al. A physiological index of comorbidity: relationship to mortality and disability. *J Gerontol A Biol Sci Med Sci.* 2008; 63A:603–609.
8. Marengoni A, Von Strauss E, Rizzuto D, et al. The impact of chronic multimorbidity and disability on functional decline and survival in elderly persons. A community-based, longitudinal study. *J Int Med.* 2008; 265:288–295.
9. Bayliss EA, Ellis JL, Steiner JF. Subjective assessments of comorbidity correlate with quality of life health outcomes: initial validation of a comorbidity assessment instrument. *Health Qual Life Outcomes.* 2005; 3:51. [PubMed: 16137329]
10. Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Arch Intern Med.* 2002; 162:2269–2276. [PubMed: 12418941]
11. Vogeli C, Shields AE, Lee TA, et al. Multiple chronic conditions: prevalence, health consequences, and implications for quality, care management, and costs. *J Gen Intern Med.* 2007; 22(Suppl 3): 391–395. [PubMed: 18026807]
12. Paez KA, Zhao L, Hwang W. Rising out-of-pocket spending for chronic conditions: a ten-year trend. *Health Aff.* 2009; 28(1):15–25.
13. Lehnert T, Heider D, Leicht H, et al. Health care utilization and costs of elderly persons with multiple medical conditions. *Med Care Res Rev.* 2011; 68:387–420. [PubMed: 21813576]
14. Madden JM, Graves AJ, Zhang F, et al. Cost-related medication nonadherence and spending on basic needs following implementation of Medicare Part D. *J Am Med Assoc.* 2008; 299:1922–1928.
15. <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Downloads/2012Chartbook.pdf>
16. Compare Survey Data. Agency for Healthcare Research and Quality; Rockville, MD: Content last reviewed March 2016 <http://www.ahrq.gov/cahps/surveys-guidance/cg/compare/index.html>
17. NVivo qualitative data analysis Software. QSR International Pty Ltd; Version 10, 2012
18. Blumenthal D, Chernof B, Fulmer T, et al. Caring for high-need, high-cost patients – an urgent priority. *N Engl J Med.* 2016; 375:909–911. [PubMed: 27602661]
19. Goodman RA, Posner SF, Huang ES, et al. Defining and measuring chronic conditions; imperatives for research, policy, program, and practice. *Prev Chronic Dis.* 2013; 10:E66. [PubMed: 23618546]
20. Jadad AR, To MJ, Emara M, Jones J. Consideration of multiple chronic diseases in randomized controlled trials. *JAMA.* 2011; 306:2670–2672.
21. Gurwitz JH, Go AS, Fortmann SP. Statins for primary prevention in older adults: uncertainty and the need for more evidence. *JAMA.* 2016; 316:1971–1972. [PubMed: 27838724]
22. Working Group on Health Outcomes for Older Persons with Multiple Chronic Conditions. Universal health outcome measures for older persons with multiple chronic conditions. *J Am Geriatr Soc.* 2012; 60:2333–2341. [PubMed: 23194184]
23. Bayliss EA, McQuillan DB, Ellis JL, et al. Using electronic health record data to measure care quality for individuals with multiple chronic conditions. *J Am Geriatr Soc.* 2016; 64:1839–1844. [PubMed: 27385077]
24. Lieu TA, Platt R. Applied research and development in health care – time for a frameshift. *N Engl J Med.* 2017; 376:710–713. [PubMed: 28225671]
25. Norris SL, High K, Gill TM, et al. Health care for older Americans with multiple chronic conditions: a research agenda. *J Am Geriatr Soc.* 2008; 56(1):149–59. [PubMed: 18047493]
26. Parekh AK, Goodman RA, Gordon C, et al. Managing multiple chronic conditions: a strategic framework for improving health outcomes and quality of life. *Public Health Rep.* 2011; 126(4): 460–471. [PubMed: 21800741]

27. Kennedy BK, Berger SL, Brunet A, et al. Aging; a common driver of chronic diseases and a target for novel interventions. *Cell*. 2014; 159:709–713. [PubMed: 25417146]

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Table 1

Research Themes

Themes	
1	Screening and Assessment Tools for Older Adults with MCCs
2	Outcomes in Older Adults with MCCs
3	Interventions in Older Adults with MCCs
4	Care Processes and Models of Care in Older Adults with MCCs
5	Health Services Research in Older Adults with MCCs
6	Clinical Decision Making and Care Planning in Older Adults with MCCs
7	Clinical Management of Older Adults with MCCs
8	Behavioral Health, Mental Health, and Cognitive Issues in Older Adults with MCCs
9	Health Care Disparities in Older Adults with MCCs
10	Genetic and Epigenetic Risk Factors in Older Adults with MCCs
11	Analytic Approaches to Studying Older Adults with MCCs

Table 2

Ranking of Research Topics by Top-Box Score

Rank	Theme*	Research Priorities	Top Box %
1	2	Health related quality of life	62%
2	1	Assessment tools (e.g. to assess symptom burden, quality of life, function)	58%
3	7	Interactions between medications, disease processes, and health outcomes	57%
4	2	Disability	53%
5	4	Implementation of novel (and scalable) care models	51%
6	2	Association of clusters of chronic conditions with clinical, financial, and social outcomes	50%
7	4	The role of the caregiver	49%
8	2	Symptom burden	49%
9	6	Shared decision-making to enhance care planning	48%
10	6	Tools to improve clinical decision making	47%
11	7	Treatment burden	47%
12	3	Self-Management interventions	46%
13	8	Alzheimer's disease and other dementias	44%
14	11	Intervention designs with multiple components and pragmatic trials	44%
15	7	Management of pain and/or other symptoms	43%
16	5	Impact of health plan benefit design on access and quality of care	40%
17	2	Risk stratification	40%
18	8	Mental illness	40%
19	2	Resilience	38%
20	11	Data harmonization across health care systems	38%
21	8	Health behaviors	37%
22	9	Health care disparities	37%
23	4	Chronic care models	37%
24	5	Health services utilization	37%
25	7	Effectiveness of pharmacologic treatments on specific dyads and triads of MCCs	36%
26	7	Treatment algorithms and guidelines	35%
27	3	Remote patient monitoring and mobile health tools to improve care	33%
28	2	Prognosis	33%
29	11	Epidemiologic methods addressing longitudinal data, missing data, and information censoring	31%
30	11	Causal methods using observational data for comparative effectiveness studies	30%
31	1	Screening algorithms related to clinical preventive services (e.g. colonoscopy, mammogram, etc.)	28%
32	11	Qualitative approaches to research patients with MCCs and their caregivers	28%
33	3	Interventions relating the built environment (refers to those surroundings created for humans to be used for human activity)	25%
34	10	Pharmacogenetics and pharmacodynamics	25%
35	11	Administrative and registry data methods, including unplanned samples at uneven intervals	22%
36	3	Mindfulness and other alternative approaches	19%

Rank	Theme*	Research Priorities	Top Box %
37	10	Epigenetic (changes in gene expression that do not involve changes in the underlying DNA sequence) parameters as risk factors	12%

* For an explanation of the Theme, please refer to Table 1.