DEBATE-COMMENTARY

Transforming care for people with multiple chronic conditions: Agency for Healthcare Research and Quality's research agenda

1 | INTRODUCTION

> Care more particularly for the individual patient than for the especial features of the disease. William Osler[1]

One of the most daunting challenges confronting the health care system is how to prevent and manage multiple chronic conditions (MCC) effectively and efficiently. MCC are commonly defined as the co-occurrence of two or more chronic physical or mental health conditions. Some use the term multimorbidity as synonymous with MCC, while others define MCC as including additional factors that contribute to the burden of illness, including disease severity, functional impairments and disabilities, syndromes such as frailty, and sometimes social factors such as homelessness.[2] Regardless of definition, MCC are common, costly, and place a high burden on individuals, their caregivers, clinicians, health care teams, and health systems alike. Our fragmented, disease-focused health care system is ill-designed to meet the needs of this growing population.

Although prevalence varies with definition,[3] MCC is the most common chronic condition seen in clinical practice. One in three American adults, four in five Medicare beneficiaries, and a growing number of children have MCC. People living with MCC account for a disproportionate share of health care utilization and costs, 64% of all clinician visits, 70% of all inpatient stays, 83% of all prescriptions, 71% of all health care spending, and 93% of Medicare spending. Almost half have functional impairments. Nearly all readmissions among Medicare beneficiaries occur among those with MCC.[4] The prevalence of MCC will grow with our aging population. The need to improve the care of people living with MCC has been recognized nationally and internationally.[5,6]

There is a mismatch between the way care is delivered (disease-specific) and needs (patient-centered) resulting in care that is fragmented and of sub-optimal quality, leading to poor outcomes including avoidable adverse events, hospitalizations, and institutionalization as well as increased costs. People with MCC typically see multiple providers in multiple settings of care and have multiple care transitions. Many experience barriers in access to care or have difficulty navigating the health system to obtain needed services and therefore present with avoidable and costly late-stage diseases. Fragmented care too often leads to problems including drug–drug or drug–disease interactions, therapeutic duplication, polypharmacy, contradictory and confusing recommendations, or a therapeutic regimen that is complicated, burdensome, and challenging to follow. Transforming care for people living with MCC entails organizing health care to take care of people living with illnesses in the context of their lives, respecting their values and preferences, supported by clinical research and guidelines that provide needed evidence and guidance on managing co-existing illnesses and different constellations of diseases.

While interventions to improve MCC care have been developed and tested, results have been mixed and when effective modest at best.[7] We have learned much about components of effective interventions. However, we do not know which constellation of these components, for which populations, and in which settings of care will result in improved outcomes nor how to widely implement and scale these interventions. The Agency for Healthcare Research and Quality's (AHRQ's) vision for "a sustainable health care system that delivers high-value coordinated, integrated patient-centered care based in primary care, optimizing individual and population health by preventing and effectively managing MCC" remains elusive.

2 | CORONAVIRUS DISEASE 2019 AND MCC

The coronavirus disease 2019 (COVID-19) pandemic has underscored the need to increase attention to MCC and the challenges MCC present. People living with MCC are at higher risk for severe disease and mortality from severe acute respiratory syndrome–related coronavirus (SARS-CoV-2) infection.[8] In a study from a large integrated health system, 88% of individuals hospitalized with SARS-CoV-2 infection had

MCC.[9] A growing number of people manifest persistent, debilitating symptoms after infection, postacute sequelae of SARS-CoV-2 infection. These "long haulers" experience consequences across multiple organ systems (e.g., neurologic, cardiac, pulmonary, musculoskeletal), potentially compounded by underlying conditions, with negative impacts on health and quality of life.[10] These sequelae may coexist with behavioral and psychosocial consequences of the pandemic (e.g., depression, financial strain, substance abuse, social isolation).[11,12] Thus, the burden of MCC will grow.

3 | HEALTH EQUITY AND MCC

Racial/ethnic minorities and those who are socioeconomically disadvantaged develop MCC at earlier ages and have more conditions, greater severity of illness, and more functional limitations.[13] Women are more likely than men to have MCC across all age groups. At-risk populations are also more likely to encounter access barriers, experience care of lower quality due to well-documented disparities, have multiple social risks, and have less resources to navigate the health system. These factors in the context of MCC increase the risk of poor health outcomes. The prevalence of MCC also varies by geography—one study found MCC prevalence to range from 37.9% in the District of Columbia to 64.4% in West Virginia.[8] To be effective, interventions will need to be tailored to local context and resources.

4 | PREVENTING MCC

Multiple factors, compounded by the COVID-19 pandemic, including rising inequality, social deprivation and isolation, food insecurity, smoking, substance abuse, sedentary lifestyles, and diet, have contributed to the current syndemic of MCC. One single factor alone (e.g., smoking, insufficient physical activity, poverty) can increase the risk of developing multiple conditions such as cardiovascular disease, diabetes, dementia, and depression. While attention has been paid to the sickest individuals with MCC, those with high cost and high needs, limited attention has been paid earlier in the disease continuum. There is opportunity for both primary and secondary prevention among those with multiple risk factors and among those with rising risk who have multiple conditions before they have complex needs, disability, or frailty. Prevention of MCC could be fostered through clinical, public health, and policy interventions.

5 | MCC: A WICKED PROBLEM

The challenge of MCC is a *wicked problem*, one that is "complex, unpredictable, open ended, or intractable,"[14] as it entails people with complex medical, social, and psychological needs interacting with health systems that are also complex. Wicked problems require innovative solutions that address their complexity. Transforming

care for people with MCC is essential for health system sustainability, especially for federal programs including Medicare and Medicaid, that provide care to a disproportionate share of the MCC population. Improving MCC prevention and management is fundamental to supporting the move to value-based payment. A number of concurrent factors provide the foundation for addressing MCC, including a growing body of evidence on the delivery of patient-centered care, advances in implementation science, and increasing recognition of the need for investment in primary care and primary care research.[15] Lessons from the disruption and innovation in the way care is delivered generated by the COVID-19 pandemic (e.g., the rapid adoption of telehealth) are providing evidence that can be applied to improve MCC care. These trends along with the growing capability of data and analytics to generate evidence within learning health system make it the opportune time to invest in MCC care.

6 | CARING AND LEARNING

AHRQ developed the Care and Learn Model to bring together two streams of research where there have been considerable advancements over the last decade—patient-centered care delivery and the approaches that support the cycle of evidence synthesis, generation, and implementation within learning health systems.[15] Recognizing that the primary function of the health system is to care for people, their families, and caregivers in the context of the communities that they live in and aligned with their goals, values, and preferences, the Care and Learn Model provided a framework for developing this research agenda. We present a research agenda for transforming care for MCC, that builds on AHRQ's portfolio of research in this area, ongoing stakeholder engagement, and informed by an MCC Research Summit held in November 2020.[16]

7 | DEVELOPING A RESEARCH AGENDA TO TRANSFORM CARE FOR PEOPLE LIVING WITH MCC

Beginning in early 2019, AHRQ launched a series of stakeholder engagement activities along with dialogs with federal partners to develop a research agenda to guide future investments in improving MCC care. This included key informant interviews, open forums, and panel discussions at professional society meetings. Our goal was to elicit comprehensive and diverse perspectives from clinicians, patients, health system leaders, academia, and philanthropies to identify the most pressing challenges in improving MCC care and research needed to address these challenges. Important areas being addressed by others including biomedical research on clinical management or measurement of MCC[17] were acknowledged and considered out of scope.[17,18] Three priority areas were identified through this process as follows: patient and family engagement, models of high-value care,

and health information technology applications solutions to support people living with MCC and to their improve care. Evidence reviews on each of these issues were commissioned to assess the state of the evidence in the specified domains and to identify knowledge gaps.[7,19,20]

In 2020, we used a systematic process for identifying and prioritizing a research agenda. This process began with an invitation to 40 subject matter experts to review and provide feedback to the evidence review authors, as well as identify key topics, issues, or themes not covered by the evidence reviews. This informed the Virtual Research Summit on Transforming Care for People with Multiple Chronic Conditions, which AHRQ convened in November 2020 and was attended by over 100 researchers, clinicians, patients and caregivers, health IT professionals, health care system and policy experts, and other potential funders of MCC research. Upon registration, participants were asked to provide responses to open-ended questions about care delivery and research gaps and opportunities. Plenary speakers provided high-level overviews of the challenges facing patients and providers and innovative research methods for developing and testing strategies for addressing them. Finally, in a series of sequential and facilitated working sessions, participants identified, consolidated, integrated, and prioritized a group-generated list of key research questions. The research agenda below was developed through this process. Details can be found in the meeting proceedings.[16]

8 | AHRQ's RESEARCH AGENDA FOR OPTIMIZING THE CARE OF PEOPLE LIVING WITH MCC

There is ample opportunity to conduct research to provide the needed evidence to improve the quality and outcomes of care for MCC and the experiences of people living with MCC, their families and caregivers, and the clinicians who provide their care. Evidence reviews revealed a nascent literature in all three priority areas with large gaps that need to be filled to make progress in tackling this wicked problem. Patient-level, practice-level, community-level, and health system–level interventions all have potential, as do multilevel interventions that align these efforts. Progress will require culture change in practice and training for widespread adoption of the paradigms needed to widely implement whole-person care, including the integration of behavioral health and primary care. Current payment models often present a barrier to innovation to redesign care, and evidence is also needed for the effectiveness of different payment models and incentives to support these efforts. Partnerships and policy are needed to address social determinants of health (SDoH) and to assure that these efforts address pervasive health inequities. We not only need to deliver care differently; we need to do research differently to address identified gaps. The research domains below are not mutually exclusive, and effective interventions are likely to be multicomponent and draw from multiple domains. Key questions that emerged from the MCC summit are shown in Table 1.

8.1 | Person-centeredness

By expanding the "whole-person" approach to embrace medical, behavioral, social, spiritual, and economic dimensions, we need to redesign care for people *living* with diseases rather than focusing on specific diseases in isolation. This "precision" care needs to be provided in the context of their lives and aligned with their priorities, preferences, and goals.[21] This entails not only partnership in patient-centered care planning but also co-design of practices and health systems and co-production of evidence. Strategies are needed to effectively engage people living with MCC and their caregivers and self-management support to help individuals achieve their goals. Clinical practice guidelines and clinical decision support that can inform decision making and minimize harms in managing heterogeneous constellations of conditions are also needed.

8.2 | Renovating the medical home

The recent transformation of primary care toward team-based care in the form of medical homes has been an important structural change, but the potential for this care delivery model has been unrealized and needs renovation. Patients living with MCC would benefit from continuing relationships with a primary care team to help plan and coordinate care. Currently, not all primary care practices have the systems or expertise do this well. Better management of processes of care to address MCC will be required, using collaborative care and disease management models, adapted to the complexities of chronic disease interaction. This will require case identification, goals of care planning, shared decision making, case management, and continuous driving toward achieving optimal patient-centered multidimensional goals. Higher performance of medical homes has been shown to improve preventive services and provider work–life satisfaction,[22] and so measurement of medical home performance, will be required to ensure primary care teams have the capacity to deliver the required complex care.

8.3 | Breaking down the clinic walls

While the patient–provider relationship will still require the human need for one-on-one relationship building to engender the trust necessary to potentiate care, the paradigm of care solely within fixed facilities is over. Telehealth and virtual care will remain a significant part of how primary care is delivered, but how to do this optimally and safely without overburdening primary care providers will require rigorous research. IT solutions to support care outside of the office can be designed to specifically address the unique challenges in improving MCC care from patient, caregiver, and clinician perspectives. These technologies will play a crucial role in improving access to care (both primary and specialty), but appropriate boundaries will be required to balance immediacy of care needs with burnout among

TABLE 1 Sample of key research questions for multiple chronic conditions research, by domain area, as identified by stakeholders using a systematic approach

Domain	Key research questions
Patient-centeredness	• What is the best process for eliciting/understanding people's needs and preferences? • How do we develop and ensure use of clear and common language to support meaningful goal setting? • How can we integrate social, behavioral, and economic factors into the person-centered care plan? • How do we identify meaningful outcomes, measure them, and use them in care? • To what extent do current measures of the patients' experience capture their life experience and function? • How can health IT support shared decision making to prioritize care that meets patient goals?
Renovating the patient-centered medical home	• What functions and aspects of team care lead to improved outcomes? • How can we provide individuals with complex needs effective care management? • How can we optimally coordinate care for people living with multiple chronic conditions? • How can we develop, test, and implement risk stratification and decision support tools to improve care?
Breaking down the clinic walls	• How can we co-design IT solutions to facilitate activation, engagement, and co-production of health? • How might we leverage mHealth and remote patient monitoring in providing self-management support and implementing cost-effective and patient-centered care? • How can we develop and evaluate interoperable shared electronic care plans that integrate other patient-generated health data to promote communication and improve health outcomes? • How can home- and community-based services best contribute to improved health outcomes?
Integrating the medical neighborhood	• How can specialty care services best integrate with primary care including using stepped care and collaborative care models? • How can we improve and coordinate the delivery of clinical, community, and home services to improve health outcomes? • How do we increase awareness of and access to community resources and ensure that people understand and can benefit from the services available to them? • How can we integrate social and medical care such that people can seamlessly access the care they need and want, when they need it? How can health information technology facilitate such integration? • What are the most effective approaches for addressing the social determinants of health?
Advancing health equity	• How can we increase access to primary care in order to reduce and ultimately eliminate inequities of receipt of recommended services? • How can quality improvement activities routinely be implemented so that they reduce and ultimately eliminate inequities in quality and outcomes of care? • How can we develop and evaluate tailored multilevel interventions to reduce health inequities? • How can we partner with individuals and communities served to co-design interventions to achieve these goals?
Healthy people and populations	• How can we integrate social and community services within clinical care to address the social determinants of health and improve population health outcomes? • How can we better prevent and manage multiple chronic conditions by integrating clinical care and public health?
Reducing burden on patients, caregivers, and clinicians	• How do we measure, minimize, and monitor the burdens of care on people living with multiple chronic conditions, their families, and caregivers? • How do we assess the preferences, needs, priorities, and goals of people living with multiple chronic conditions, their families, and caregivers to minimize burden while improving outcomes? • How do we redesign care to reduce and ultimately eliminate provider and caregiver burnout? • How do we develop evidence to inform value-based decision making to maximize high-value care and minimize low-value care?
Research methods for transformation	• What are the best study designs for answering critical questions in order to generate needed evidence in a timely manner? • What are the optimal approaches to implementing these methods? • How can we best engage individuals, caregivers, and communities in co-designing interventions and co-producing evidence?

providers. mHealth applications can allow the collection patient-reported outcomes and provide self-management support. Interoperable shared electronic care plans can not only allow coordination across providers but also enable better communication with the care team and capture preferences, values, goals, and progress toward attaining them along with other patient-generated health data to support care management. We need evidence for the best mix of in-person and virtual care as well as evidence for the effectiveness and safety of IT solutions.

8.4 | Integrating the medical neighborhood

A redesigned and better supported medical home is necessary but not sufficient. Improved coordination of primary care and specialty care, seamless transition across settings including acute and postacute care, and access to and coordination with community services are all needed to improve MCC care. There is a need to develop, implement, and evaluate models of care that deliver patient-centered coordinated care to people living with MCC. Health information technology will also be instrumental in allowing the broader health systems to function more seamlessly, allowing for higher quality and safer care transitions, from referral processes to hospital admissions and discharges. Better flow of information would support collaborative and stepped care models to occur in a more integrated manner. Across systems, this will require advances in interoperability and health information exchange capacity.

8.5 | Advancing health equity

Systemic societal influences that lead to inequitable care will require systemic solutions and the research necessary to optimally program equity into systems of care. Recognition of universal access to primary care as a common good will provide the equal playing ground for the necessary quality improvement processes to raise the health of all, including the most vulnerable and those with the highest illness burden. Without such equal access to care, quality improvement efforts will exacerbate current inequities of care. Additionally, quality improvement activities can narrow, maintain, or widen inequities in quality and outcomes depending on their relative effectiveness and the degree to which they meet the needs of diverse populations. Evidence is needed for interventions tailored specifically to the needs of people living with MCC so that new models of care aimed at improving MCC care do not widen pervasive inequities in this population.

8.6 | Healthy people and populations

Preventing and managing MCC to optimize health outcomes require an increased emphasis on health, functioning, and wellness. It is well known that living and working conditions or the SDoH are the primary drivers of health status among both individuals and populations, and

the people for whom this is most acutely the case are those living with MCC. The SDoH both increase the risk of developing MCC, may impede access to care, and provide barriers to optimal management. Optimizing health requires alignment and coordination of health promoting interventions and policies outside of the health system. Evidence is lacking on how social and community services that address SDoH can best be integrated with clinical care. Community-oriented primary care, despite multiple barriers to implementation, integrates the individual focus of clinical care delivery with a population health focus. This involves partnering with communities served and "combining epidemiologic study and social intervention with the care of individuals" to improve both individual and population health outcomes.[23] Community health workers may help people living with MCC obtain needed services both inside and outside the health system. There is emerging evidence that alignment and coordination between public health and primary care can improve outcomes and reduce inequities.[24] Collaboration across sectors that contribute to health (e.g., education, housing) is also needed. Evidence is needed for models of care that can align and integrate community and human services, public health, and nonhealth sectors to advance MCC care.

8.7 | Reducing burden on people, caregivers, and clinicians

The complexity of care for MCC imposes an burden on people living with MCC and their caregivers who must navigate the health system, share information, attend multiple appointments for physician visits and diagnostic testing, are asked to adhere to complex treatment regimens, and make lifestyle changes frequently against the backdrop of challenging social situations. Unconsidered application of multiple disease-specific guidelines that fail to address multimorbidity contributes to overly complex treatment regimens. Measures of treatment burden have been developed to support evaluations of interventions aimed at reducing burden. Approaches to care delivery have been developed to help minimize treatment burden, including minimally disruptive medicine[25] and patient-priorities care.[26] Evidence is needed to inform decision making, priority setting, and goal identification and attainment to support care planning to optimize outcomes and minimize burden.

The burdens clinicians experience in delivering care to people with MCC are exacerbated by fragmented care, insufficient coordination across multiple providers and care settings, practice organization, scheduling and workflows ill-designed to support MCC care, and inadequate electronic health record systems increasing the risk of burnout. Future efforts to reduce patient, caregiver, and clinician burden are likely to require organizational changes and process redesign.

8.8 | Research methods for transformation

Generating the evidence needed to transform care for individuals living with MCCs will require new research methods for developing, testing,

and implementing complex interventions that address complex patient needs in a range of care settings. Including people living with MCC, caregivers, communities, and health care teams to co-produce intervention designs and evaluations holds promise in accelerating learning.[27] Traditional randomized control trials fail to account for the complexity inherent in implementing interventions to redesign care delivery. Prespecified protocols do not allow adaptation of the intervention to increase effectiveness based on new evidence that emerges during the implementation process nor the ability to tailor the intervention to local context including population needs and available resources. Fortunately, there is a growing armamentarium of research methods that can be employed to build the evidence base to improve MCC care. Hybrid trial designs can provide evidence for implementation strategies. Sequential Multiple Assignment Randomized Trials (SMART),[28] agile implementation methods,[29] rapid cycle evaluations,[30] and complex adaptive trials drawing on complexity science[31] maintain rigor while allowing adaptations to the protocol based on intermediate outcomes. Mixed methods studies provide insights into why and how the intervention succeeded or failed and in which contexts. Ideally, interventions would result in sustainable changes and would address health inequities as an integral component of studied interventions.

8.9 | Training as a cross-cutting theme

The complexity of care for MCC will need to be matched by the health care workforce's competencies for managing and addressing complex care, to include expertise in diagnostic reasoning, awareness of the dimensions of biopsychosocial interconnectedness, high-level communication skills, team-based collaboration, and patient-centered approaches. This has enormous education and training implications for health professions workforce development. This will require innovative ways to link education research with clinical research in ways we have not done before. Coinciding with these endeavors will be the necessary cultivation of attitudes that embrace the value of diversity in care teams, and advocacy for the development of a diverse workforce that more closely resembles the population they serve.

9 | CONCLUSION

The problem of MCC is a ticking time bomb that threatens health system sustainability, the future of Medicare and Medicaid, and the health and well-being of the American people. Transformation, while exceedingly difficult, is urgently needed. Nevertheless, we can design and support research to generate the evidence to make progress and continuously learn as we implement change. By developing, implementing, evaluating, scaling, and spreading innovative models of care to effectively prevent and manage MCC in partnership with people living with MCC, their families, and caregivers, communities, and clinicians, we can avert the impending threat. We can produce the evidence needed for policy to promote health and well-being and advance health equity. The health system changes required to

improve MCC care will also lead to more effective and person-centered care for all. The AHRQ research agenda presented provides a roadmap for future research investment to advance the field.

DISCLAIMER

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