

DEBATE - COMMENTARY

Removing the blindfold: The centrality of care in caring for patients with multiple chronic conditions

Chronic multimorbidity is one of the most important problems in contemporary health care. The average middle-aged American lives with at least one chronic condition, and nearly everyone ages with chronic multimorbidity. In this supplement on the care of patients with multiple chronic conditions, readers of *Health Service Research* will find a collection of reports that offer evidence about health services research's response to the problem of chronic multimorbidity. In this commentary, I focus on the role that primary care and health services research can play in responding to this challenge, with particular attention to the centrality of care itself.

1 | DISEASE-ORIENTED HEALTH CARE RESPONDS POORLY TO CHRONIC MULTIMORBIDITY

Disease-oriented health care for patients with multiple chronic conditions leaves gaps in knowledge. Clinical research funding and conduct, guideline formulation and quality measurement, clinical training, and health care delivery are all largely organized by specific organs or diseases. And yet, this approach creates gaps in which we find interactions between diseases and treatments that reduce the efficacy and safety of care.¹ It is the accumulation of conditions, across the organs they affect, that results in a substantial burden of illness—for example, frailty, general symptoms such as fatigue or pain, loss of function—that disease-specific surrogate markers all but miss.

Disease-oriented health care also leaves gaps in care that patients with multiple chronic conditions must work to bridge. Patients are often left to integrate and coordinate visits, tests, and treatments across siloed specialist services; to make sense of disparate information and recommendations; to complete administrative and medical errands; to figure out what to pay and who pays for what; and to take treatments and implement recommended behaviors with high fidelity.² Thus, multimorbidity and our disease-specific response can lead to substantial burden of treatment as the work of being a patient—of accessing and using care and enacting self-care—accumulates.^{3,4}

Completing health care tasks must compete against the demands of daily living for a person's limited energy, time, and attention.⁵ This is particularly problematic as patients who live under substantial socioeconomic stress, including poverty and racism, tend to accrue more chronic conditions at an earlier time in their lives and tend to have access to fewer resources to self-manage, adapt, and thrive.⁶ Rather than technical, material, and emotional support, health care

prescribes blame, education, and behavioral interventions—including remote behavioral surveillance and management.⁷ Patients with enough capacity and well connected may find emotional and practical help in family and among peer expert patients who can help form care routines more likely to be useful, usable, and desirable.⁸ Others must struggle alone. These realities, which contribute to inequities, are glossed over when we assess the performance of health care's response by either zooming out to measures of health care utilization and cost to payers or zooming in onto markers of disease control and guideline-concordant care.

2 | PRIMARY CARE FOR MULTIMORBIDITY

To respond well to multimorbidity, health care must care, that is, respond with compassion and competence to the confusing and confused situation in which each patient lives and the complicated interactions of biology (comorbidity and their interactions and frailty⁹), biography (lived experiences), psychology (beliefs, values, goals, fears, resilience, endurance, and self-efficacy), and socioeconomic (community, barriers, and resources) to which each patient must adapt and with which each patient must eventually thrive.¹⁰ This requires experts on the patient's human condition, not just on each of their medical conditions.¹¹ Many functions can contribute to excellent chronic care as follows: continuity of care; relationships within which patients can endure, recover from disappointments, and gain resilience; participatory forms of decision making; and care coordination and integration across disease specialties and community resources. These themes, along with alignment of information technology and financial models, are confirmed central to emerging models of chronic care in the excellent scoping review by Savitz and Bayliss¹² reported in this issue. These are also functions of optimal primary care.^{13,14}

Because of chronic under-investment in primary care and the expectation that primary care should do more and better with less,¹³ primary care remains far from responding well to the explosion of chronic multimorbidity. This has largely resulted in resource-poor implementations of primary care innovations, mostly aimed at lowering costs while achieving guideline concordant care for populations rather than goal-concordant care for individual patients. In this issue, Adjognon¹⁵ used qualitative methods to uncover how leadership, support, teamwork, and design promoted or hindered the arduous implementation of Geriatric Patient-Aligned Care Teams, a patient-centered medical home for older

adults within the Veterans Health Administration, across eight geographically diverse implementation sites. Given the opportunity costs of implementing ineffective models, emerging models need to be carefully evaluated.

Two studies in this supplement illustrate the significance of evaluating care models. Swietek¹⁶ reports on an observational study of new enrollees into patient-centered medical homes in North Carolina; they found that longer duration of enrollment was associated with more guideline-concordant care. Chang¹⁷ reports on the results of a randomized trial in the Veterans Health Administration estimating the value of intensive care management within a patient-centered medical home and alongside a smorgasbord of programs targeting the same patients but classified by age or disease. They found no sizable effect on cost of care or hospitalization rates. These results could reflect true lack of incremental value (given the available programs), diluted effect of a valuable program (since almost half of the patients allocated to the intervention never enrolled to receive it), or the selection of policy-pertinent but insensitive outcome measures. These articles draw attention to the importance of building evaluation into the implementation of new models in practice, a feature of learning health care systems and a responsibility for health services researchers embedded within those systems. Furthermore, since some care delivery initiatives—that is, medical homes, intensive primary care—often reach some of the population in ways that are helpful to a selected few, it is not uncommon, as seen here, to find positive results among early adopters and negative results in more rigorous and pragmatic experimental designs that account for selection bias.

Emerging care models may have also undermined trust in primary care physicians. In another important study in this issue, Tuzzio¹⁸ conducted a series of interviews with a diverse group of patients facing different forms of complexity. Among other findings, researchers noted that patients have developed low expectations about how patient-centered their physicians' response can be. They see their doctors as more interested than other clinical team members in advancing health care goals than in forming individualized care plans with and for them. Ultimately, the focus on delivering services while reducing costs—rather than investing in primary care as a public good¹³—has limited the potential of primary care redesign efforts to respond well to the challenge of caring for people living with multiple chronic conditions.

3 | PROBLEMATIC ALTERNATIVES TO INVESTING IN PRIMARY CARE

Instead of investing in primary care teams, in care relationships, and in time to care well, health care systems may choose to rely on carved-out and outsourcing models that promise improvements in surrogate measures of care (e.g., HbA1c levels) and prevention of unplanned care (e.g., emergency department visits, hospitalizations) at lower cost. These services often place increasingly complex patients under the direct care of individuals with limited clinical training. These care coordinators and coaches, often well-meaning and culturally aligned, may

otherwise be strangers to the patients seeking to educate them and to modify their behavior.

Health information technologies can support their work by capturing and processing behavioral and physiological surveillance data to trigger disease-specific recommendations. The scoping review by Samal,¹⁹ however, found scarce evidence of their effectiveness. Furthermore, these systems are not usually well attuned to the patient's view or can account for the wicked biological and socioeconomic complexities of each patient's situation.²⁰ Nonetheless, the promise of health information technologies speeds ahead of the evidence of its effectiveness. This promise fuels the surge of venture-funded primary care companies that have found ways to profit from technology-enabled, coaching-based, and large-scale population management.

Is it quaint and unreasonable to wonder if there are features of primary care that these models seem to leave behind, but which may be essential in the care of patients living with multiple chronic conditions? I do not believe so, and this leads me to make two proposals as follows: we must invest in primary care relationships and we must invest in more health services research focused on studying patient care itself.

4 | INVESTING IN PRIMARY CARE RELATIONSHIPS

To care for patients with chronic multimorbidity and to learn while doing it, health care systems must shift some of their attention from responding to regulation and market conditions toward working together with patients and families. Participation—not just of patients and families but also of frontline and back-office professionals—is the engine that connects the caring and learning functions of health care systems.²¹ At the point of care, collaborations are fundamental.

Consider, for example, continuous and long relationships of care between patients and their clinicians, that is, any professional with the privilege of participating in the care of the patient. Not only are these relationships a source of rewarding clinician and patient experiences that may protect against burnout and the basis for their joint resilience, but also a hub for practical support.²² Patients with multiple chronic conditions spend a minute fraction of their time in the health care setting. These patients themselves, their informal caregivers, and other direct care workers do most of the work of health care most of the time.^{23,24} Outcomes are therefore mostly in their hands. It is in the collaborative space of the ongoing conversation between the patient and familiar members of the primary care team at the point of care that useful, usable, and desirable plans of care emerge that are then implemented at the point of life.²⁵ These plans must reflect patient priorities, fit within the complexities of their lives, and take into account personal, family, and community demands and resources.²⁶

In this issue, Vick²⁷ conducted a scoping review about patient and family engagement in the care of patients with multiple chronic conditions. They found very limited evidence about point-of-care interventions to promote patient engagement and even less evidence

about systemic interventions to promote patient and family engagement. A key limitation, in my view, is that patient participation is seen as the delegation of work and responsibility necessary to achieve health care's goals at lower cost. There is a richer alternative in focusing on patient-centered purposes and consequences of engagement, such as co-developing goals of care and co-creating goal-concordant,²⁸ evidence-based, and minimally disruptive care.²⁹

A deeper understanding of the evolving goals and needs of each patient, arising from unhurried ongoing conversations,^{30,31} should shape the care of patients with chronic conditions. Yet, these conversations are difficult to scale up. Should primary care evolve toward highly scalable carved-out models based on tech-enabled, low-skill interchangeable workers—or eventually AI-enabled bots? Even if these models produce good outcomes and lower costs, could they possibly care well? I believe in inventing and investing in primary care models focused not just on achieving optimal outcomes but also on caring well for all patients. This mission will demand an expanded investment in health services research focused on patient care itself.

5 | INVESTING IN MORE HEALTH SERVICES RESEARCH FOCUSED ON PATIENT CARE

For health care to contribute to improving the lives of people with multiple chronic conditions, it is not sufficient to study policies, programs, and their impact on outcomes and costs. We must study carefully what happens between policy and outcomes: we must study patient care. Health services researchers rarely study how patient care is affected by health care redesign. When research demonstrates that outcomes and costs do not meet policy expectations, what often follows is new policy recommendations along with evaluation of their impact on outcomes, without developing sufficient understanding of how policies affect care and how care affects outcomes. We hit the piñata blindfolded until candy comes out. Because care takes place between inputs (policies, people, technology, and dollars) and outputs (access, health care utilization, practice variation, deviation, patient outcomes, and costs), it remains assumed and invisible to many health services researchers and, in consequence, to evidence-based policy makers.

Most health services research has been largely blind to these consequences as it has studied health care financing, organization, and performance at the macro levels. This is why so little is understood about the contribution of patient-centered care innovations (e.g., priorities-based care,²⁸ shared decision making³²) short of the time and resources they take (input) and the variation in care (sometimes guideline discordant) and outcomes they produce (outputs). The result of this blindness at level of patient care is a long list of unintended consequences of extant policies that threaten the sustainability of health care, including clinician burnout, the processing of categories of patients rather than of each one, the delegation of medical errands to overwhelmed caregivers and patients, the corruption and bloating of patient records, and the cruel dismantling of the patient-clinician relationship.³³ It is difficult to overcome this blindness relying exclusively on administrative data. Work on patient

experience and variations in documented care can offer some indirect views—to the extent these are proximal consequences of care—but cannot stand fully for what could be learned by directly observing care. Care, the fundamental purpose of health care, remains, for the most part, outside of the scope of health services research.

Direct observations can reveal how care happens: how clinicians and patients co-develop an appreciation of the problematic human situation of the patient and co-create a competent and compassionate response to it. It is in these care conversations that many policy priorities translate into health care's value to society at the macro level and into plans of care that make intellectual (evidence-based response to the problems as they are), practical (a feasible plan given the conditions and resources available), and emotional (attends to the complicated emotional components of the patient's situation) sense.³⁴ A health services research agenda focused on care would follow Donabedian in capturing contributions to quality using appropriate measures of process (e.g., timely, empathic, unhurried conversations, with attention to the problematic situation and co-creation of sensible care plans), structure (e.g., accessible and well-integrated care teams, continuity of care), and outcomes (e.g., patient enablement, quality of life, disease control, burden of treatment).³⁵

In my view, the central hypothesis to be tested in future work is that these most complex of patients require (a) careful and kind care that notices and responds to each person's evolving circumstances and values, within (b) strong personal, continuous, and trusting relationships, supported by (c) material, emotional, and data resources, by (d) highly collaborative interactions with specialists, community services, and informal caregivers, (e) caring and learning together in high-value and equitable learning health care systems. To test this central hypothesis, health services research must combine well-honed far-away observations of the health care system—of assessing policies through the lens of utilization, outcomes, and costs—with experimental and observational dive-ins into the intimate space of patient care.

Over time, a health services research focused on patient care must help policy makers and a broad array of health care stakeholders understand what methods help achieve a compassionate and competent response, and how extant policies promote or hinder the selection and use of these methods and their relative effectiveness. A focus on care must recognize that the social, economic, corporate, and political determinants of health that fuel the expansion of chronic psychological and physical health problems and contribute to care deficits.³⁶ This recognition must translate into prioritized investments in primary care, supporting the clinicians and teams working to care for, about, and with people living with multiple chronic conditions. In this issue, Bierman³⁷ offer a research agenda for health services research focused on the care of patients with multiple chronic conditions that should help stakeholders in formulating—at home, in the community, within health care, and as a nation—an effective response to the challenge of caring for people with chronic multimorbidity.

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