Needs Great, Evidence Lacking for People with Multiple Chronic Conditions

October 2012

One of the most pressing challenges facing our health care system today is how to care effectively for the significant and growing number of Americans coping with more than one chronic condition. The population affected is significant: more than one in four Americans lives with multiple chronic conditions, including one in 15 children.1 Two out of three Medicare beneficiaries, including those also covered by Medicaid, have more than one chronic condition, reducing the quality of life for seniors and driving health care costs up significantly. Almost $2 out of $3 spent on health care in the U.S. is directed toward care for the twenty-seven percent of Americans with multiple chronic conditions.2

The statistics are startling, yet, despite the high prevalence of multiple chronic conditions, their devastating health impact, and the cost implications, there is a notable lack of medical research on effectively preventing and managing multiple chronic conditions. This leaves patients, family caregivers, and health care providers with insufficient information on which to base important health care decisions. Within the evidence base and, as a result, in health care practice, there is an unfortunate disconnect between focusing on the individual patient and focusing on the individual disease.3

For health care reforms, whether being implemented or contemplated, identifying and pursuing ways to improve the health of the millions of Americans coping with multiple chronic conditions are worthy, much needed areas of focus. Given that it was created “to fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed health care decisions,” the Patient-Centered Outcomes Research Institute (PCORI) presents an important opportunity to fund research critically needed by patients facing multiple chronic conditions and their providers to enhance care for the large and growing number of people affected.

The Chronic Conditions Challenge

Chronic conditions, such as depression, arthritis, hypertension, and heart and lung diseases, affect nearly one in two Americans and consume more than 80 percent of what we spend on health care every year.4 Today, these illnesses cause seven out of ten deaths each year and are the leading cause of disability.5 Driven by the aging of the population and growth in

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2 Ibid.
obesity and other risk factors, the prevalence of chronic disease is growing: more than half the U.S. population is expected to have at least one chronic condition by 2020.6

Coping with a single chronic condition is challenging enough, but the cumulative effect of having a constellation of conditions increases the complications of treatment and health management dramatically. The importance of prevention in both avoiding additional chronic conditions and progression of existing ones becomes paramount, particularly given several common risk factors for many of the most common chronic conditions. Tobacco use, overweight and obesity, alcohol misuse, poor nutrition, and low physical activity are linked to several chronic conditions, including many cancers, diabetes, heart and lung diseases, depression, and arthritis, among others. The health care delivery system also presents challenges to prevention in the disconnect between medical care, public health, and community services; the reactive nature of a system focused on acute needs; and the interplay with socioeconomic issues that are not conducive to adopting healthy behaviors.

Within the Medicare population, the prevalence of multiple chronic conditions is particularly high. As many as 65 percent of Medicare beneficiaries have multiple chronic conditions,7 and the number of beneficiaries with five or more chronic conditions has risen dramatically, up from just over 50 percent in 2002.8 Among individuals dually eligible for Medicare and Medicaid, three out of five have multiple chronic physical conditions and two out of five have both a physical and mental disease or condition.9

That number will continue to rise significantly with the aging of the baby boomers and rising rates of multi-morbidity among adults aged 45 to 64. According to the National Center for Health Statistics, the percentage of adults aged 45 to 64 who suffer from two or more common chronic conditions rose from 16.1 percent (about 1 in 6 adults) to 21 percent (about 1 in 5) just over the past ten years.\(^{10}\)

Health disparities play a major role, particularly among middle-aged adults. Minorities, specifically black, non-Hispanic Americans, are disproportionately affected with 27.9 percent of adults age 45 to 64 and more than half (51.6 percent) of adults 65 and over suffering from two or more chronic conditions.\(^{11}\) Though Hispanic adults were found to have a lower prevalence of multiple chronic conditions in both the 45 to 64 and over 65 age groups, prevalence within both age groups increased by more than 30 percent in the ten-year period studied. Examining the data with reference to income levels revealed notable economic disparities, as well. An adult living in poverty is twice as likely to have multiple chronic conditions as an adult with income at 400 percent or more of the poverty level.\(^{12}\)

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\(^{10}\) V Fried, A Bernstein, and MA Bush, “Multiple Chronic Conditions Among Adults Aged 45 and Over: Trends Over the Past 10 Years,” NCHS Stat Brief No. 100, July 2012. The nine chronic conditions are: hypertension, heart disease, diabetes, cancer, stroke, chronic bronchitis, emphysema, current asthma, and kidney disease.

\(^{11}\) Ibid.

\(^{12}\) Ibid.
Not surprisingly, as the number of chronic conditions increase, an individual's quality of life declines.\textsuperscript{13} People with three or more chronic conditions are at the highest risk of reporting fair or poor health compared with peers with no chronic conditions.\textsuperscript{14} Overall, one fifth of individuals with a chronic condition have limited ability to perform normal daily activities, such as walking, dressing and bathing without assistance.\textsuperscript{15} These limitations place an added burden on family caregivers for those with chronic conditions.

Targeting health care resources to the growing human and economic burden of caring for patients with multiple chronic diseases holds promise, but the availability of research on which to base treatment protocols and standards of practice for people with multiple chronic conditions is limited. For example, Medicare beneficiaries with four or more chronic conditions are 99 times more likely to be hospitalized for a medical need that could have been prevented with appropriate primary care compared to beneficiaries without a chronic condition.\textsuperscript{16} For primary care providers and patients, the gaps in available resources about effective management of multiple chronic conditions further challenges the development of best practices for patient-centered care.

**Research Gaps and Barriers to Patient-Centered Care**

**Limits of Clinical Practice Guidelines**

Most clinical practice guidelines focus on managing a single disease and do not envision or elaborate on effective care when facing multiple chronic conditions.\textsuperscript{17} For people coping with multiple chronic conditions, following a different clinical practice guideline for each diagnosis fails to account for the cumulative effect of the conditions occurring simultaneously, the impact different treatments can have on one another, or the feasibility and potential unintended consequences of the resulting treatment plan. Also, clinical practice guidelines may conflict with each other, making following disease-specific guidelines impossible and potentially resulting in a "near-total medicalization of the patient’s life."\textsuperscript{18}

\begin{itemize}
  \item \textsuperscript{13} H-Y Chen, DJ Baumgardner, and JP Rice, "Health-related quality of life among adults with multiple chronic conditions in the United States, behavioral risk factor surveillance system." Prev Chronic Dis 2001; 8:A09.
  \item \textsuperscript{14} Ibid.
  \item \textsuperscript{15} G Anderson, "Chronic Care: Making the Case for Ongoing Care," Robert Wood Johnson Foundation, 2010.
  \item \textsuperscript{18} R Upshur and S Tracy, "Chronicity and Complexity: Is What’s Good for the Diseases Always Good for the Patients,” Canadian Family Physician, 2008; 54: 1655-58.
\end{itemize}
Guidelines for a single disease also may fail to consider interactions among recommended therapies for treatment. In practice, using single-disease guidelines for each condition may prove impractical, against the patient’s wishes, and even potentially harmful.19

**Conflicts Arise from Single-Disease Focus**

To illustrate the potential for conflicts among treatment guidelines, researchers constructed a treatment regimen based on clinical practice guidelines for a hypothetical 79-year-old woman with 5 chronic diseases: osteoporosis, osteoarthritis, type 2 diabetes, hypertension, and chronic obstructive pulmonary disease.20 The resulting, conservative treatment regimen included the patient taking 12 separate medications as a part of a complex regimen of 19 doses per day, taken at 5 different times during a typical day. Combining all the nutritional requirements into one, the non-medication related recommendations included 14 different activities, not including recommended monitoring at various intervals or educational and rehabilitation interventions. The potential for errors, harmful interactions, and direct conflicts is clearly illustrated in the table below.

<table>
<thead>
<tr>
<th>Type of Disease</th>
<th>Medications With Potential Interactions</th>
<th>Medication and Other Disease</th>
<th>Medications for Different Diseases</th>
<th>Medication and Food</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>Hydrochlorothiazide, lisinopril</td>
<td>Diabetes: diuretics increase serum glucose and lipids*</td>
<td>Diabetes medications: hydrochlorothiazide may decrease effectiveness of glyburide NA</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>Glyburide, metformin, aspirin, and statin</td>
<td>NA</td>
<td>Osteoarthritis medications: NSAIDs plus aspirin increase risk of bleeding</td>
<td>Aspirin plus alcohol: increased risk of gastrointestinal tract bleeding Atorvastatin plus grapefruit juice: muscle pain, weakness Glyburide plus alcohol: low blood sugar, flushing, rapid breathing, tachycardia Metformin plus alcohol: extreme weakness and heavy breathing Metformin any type of food: medication absorption decreased</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>NSAIDs</td>
<td>Hyper tension: NSAIDs: raise blood pressure; NSAIDs plus hypertension increase risk of renal failure</td>
<td>Diabetes medications: NSAIDs in combination with aspirin increase risk of bleeding Hypertension medications: NSAIDs decrease efficacy of diuretics NA</td>
<td></td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Calcium, alendronate</td>
<td>NA</td>
<td>Diabetes medications: calcium may decrease efficacy of aspirin; aspirin plus alendronate can cause upset stomach Osteoporosis medications: calcium may lower serum alendronate level</td>
<td>Alendronate plus calcium: take on empty stomach (&gt; 2 h from last meal) Alendronate: avoid orange juice Calcium plus oxalic acid (oxalate and pyrrolidone) or phytic (bran and whole cereals); eating these foods may decrease amount of calcium absorbed (&gt; 2 h from last meal)</td>
</tr>
</tbody>
</table>

Source: C Boyd, et al., “Clinical Practice Guidelines and Quality of Care for Older Patients with Multiple Comorbid Diseases: Implications for Pay for Performance,” JAMA 294; 716-724.

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In the example above, few of the guidelines incorporated patient-centered considerations such as quality of life, burden of comprehensive treatment, or balancing short- versus long-term treatment and quality of life goals. Decision-making tools to help patients and providers weigh options, evaluate benefits and risks, and prioritize among treatment goals are essential to a patient-centric treatment plan, but are not readily available. Providers and patients need shared decision-making tools to weigh the unique challenges and opportunities the individual patient possesses. Variables in play include patient preferences and goals, health status and prognosis, risk tolerance, cognitive and emotional capacity, and the reasonableness of a treatment plan given these factors.

### Enhancing Care Quality and Measuring Outcomes

**Vulnerability to Poor Quality of Care**

Adding to the challenges, patients with multiple chronic conditions often see multiple health care providers, receive care in a variety of settings, and take several over-the-counter and prescription medications. People with multiple chronic conditions are particularly vulnerable to poor quality of care given their frequent interaction with the health care system, the need for multiple providers, and the variety of health care settings encountered. The challenges are even greater for patients with behavioral health conditions given the significant lack of integration among mental and physical health providers.

Integrated, collaborative care models that facilitate communication and incorporate treatment plan and medication reconciliation and management are critical. Through a variety of quality and performance-driven initiatives, such as patient-centered medical homes, pay-for-performance, and accountable care organizations, the health care system is heading toward greater care coordination and collaboration. An emphasis on quality of care measured by performance and outcomes is helping to drive this transition. Quality enhancement efforts can present new vulnerabilities to people with multiple chronic conditions, however, without careful consideration of how “quality” is measured and evaluated.

### Risks of Single-Disease Quality Measures

In evaluating quality of care, often the same single-disease clinical practice guidelines, which pose challenges to appropriate management and treatment for people with multiple chronic conditions, are applied. This can overlook the complexity and burden of managing multiple chronic conditions, as well as the unique needs of individuals with multiple conditions.

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**Reflection from a Patient's Perspective**

“As I approached the exam room, I looked at the clinic schedule, which noted the next patient’s reason for visiting as “DM” (medical shorthand for diabetes). Upon entering the room and speaking to Louise, I realized that the 58-year-old woman not only had diabetes, she also had high blood pressure, hypothyroidism, high cholesterol, asthma, and arthritis (not to mention a history of depression). She brought with her a plastic bag of medications – eight in all – for which she needed multiple refills. She watched her diet (though too much salt was still a problem), tried to be physically active (though her knees always ached), and made sure she took her medications on time.

Under the circumstances, Louise is in pretty good shape. But along with the 75 million other Americans who have multiple chronic conditions, she is at high risk for hospitalizations, adverse drug events, and poor quality of life, not to mention high health care costs.”


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21 Ibid.

chronic conditions, are the basis for care quality performance measures. As previously examined, using single disease clinical treatment guidelines to develop an appropriate treatment plan for a patient with more than one condition may lead to conflicts in recommendations, harmful interactions, over medicalization, and care that fails to meet the patient’s overall needs or wishes by encouraging unnecessary or potentially harmful care. Specifically, providers are evaluated, rated, and rewarded or penalized based on their performance on disease-specific outcomes.

As discussed above, for patients with multiple chronic conditions, the priorities may need to be different based on individual considerations. Similarly, health care providers following patient-centered treatment plans for their patients with multiple chronic conditions may face financial penalties for not meeting disease-specific performance targets though, in its totality, the care provided meets the needs of the patient. Accounting for variables including risk adjustments in reimbursement, performance measures, and careful consideration of comparison populations and benchmarks are essential to avoid unintended consequences including penalizing providers by not accounting for patient needs or complexity of conditions or discouraging providers from caring for patients with complex needs. Criteria are needed to encourage and reward approaches known to improve health outcomes, functional status, and quality of life. Additional research on effective treatment for people with multiple chronic conditions is critically needed to develop clinical guidelines that not only enhance the quality of care, but also guide the measurement of it.

**Prevention Opportunities**

Medical models alone are not sufficient to stem the growth in multiple chronic conditions; population-based approaches to prevent and manage chronic conditions are needed. There are significant opportunities for improvement through better integration of traditional medical care with public health and community resources that promote healthy behaviors, assist with daily living activities, and enhance self-management skills. Even within the medical system, preventive services, including screenings for chronic conditions, immunizations, and wellness are often managed opportunistically -- as an add-on to a medical visit about an acute issue. Research to support delivery system changes that integrate public health and community resources with medical care and position prevention and wellness care proactively hold tremendous potential for reversing the growth in prevalence of multiple chronic conditions. These efforts could also optimize improvements in access to preventive services and prevention investments made as part of the Affordable Care Act.


24 Ibid.

Policy Implications and Conclusion

Quality Framework for MCC

An early, significant step forward in improving the quality of care for people with multiple chronic conditions came this May. The National Quality Forum published a measurement framework to guide developing, evaluating, and establishing performance measures that specifically address multiple chronic conditions. The framework provides the foundation on which to build measures, but critical gaps remain in the evidence base upon which to set standards and, most importantly, to improve the quality of care and quality of life for people with multiple chronic conditions.

The work, funded by the US Department of Health and Human Services (HHS), aligns with HHS’s Multiple Chronic Conditions Strategic Framework. The Framework is a national-level roadmap for assisting HHS programs and public and private stakeholders to improve the health of people coping with multiple chronic conditions. The Framework includes many laudable goals that should enhance the quality of care for people with multiple chronic conditions and, as importantly, boost prevention efforts to reduce the prevalence of multiple morbidities. The level of funding for the initiative is not clear. Also, unclear yet important is how the HHS Framework interacts with research and funding efforts at the Medicare and Medicaid Center for Innovation or PCORI, two important funding sources for filling critical research gaps.

Essential Opportunities for Patient-Centered Outcomes Research Institute

Current gaps in the evidence base present significant obstacles to providing high quality, patient-centered care that are acutely felt by people coping with multiple chronic conditions. In developing its National Research Agenda and Research Priorities, PCORI noted the importance of research on multiple chronic conditions. Specifically, in response to comments from hundreds of stakeholders, PCORI included the following references to multiple chronic conditions and gaps in research in its National Research Agenda draft:

- “Especially needed are studies to improve care and outcomes for patients faced with multiple conditions.”
- "Research that compares alternative approaches to models of care delivery or coordination of care across health care services or settings, including for patients with complex, chronic, and/or multiple conditions.”

The list of beneficial research topics under these broad considerations is substantial, but PCORI’s specific recognition of these needs is both encouraging and promising. It is difficult to envision a patient-centered research agenda that does not focus on improving health care’s quality and effectiveness for its greatest consumers. For the 75 million Americans

coping with more than one chronic condition and making health care decisions with notably limited information that work cannot start soon enough.

Ideally, the stakeholder process PCORI has initiated this fall will add the clarity and details needed to drive positive change. Because of the challenges people with multiple chronic conditions and their family caregivers face within their daily lives, however, personally making their case for additional research at public forums will likely prove difficult. Though the value of the message is high, its volume is also limited by the absence of specific patient or other advocacy groups for people with multiple chronic conditions.

To bring much needed attention to the multiple chronic condition challenge and opportunities for PCORI research to address them, the Partnership to Fight Chronic Disease is convening a group of health care stakeholders and leading experts to discuss and identify the critical questions PCORI research could begin to answer. With greater attention to the challenges people with multiple chronic conditions face and recommendations on critical areas of focus for research, we can make a significant and sustainable difference.