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A Proposed ‘Health Literate Care Model’ Would Constitute A Systems Approach To Improving Patients’ Engagement In Care

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Abstract

Improving health outcomes relies on patients’ full engagement in prevention, decision-making, and self-management activities. Health literacy, or people’s ability to obtain, process, communicate, and understand basic health information and services, is essential to those actions. Yet relatively few Americans are proficient in understanding and acting on available health information. We propose a Health Literate Care Model to improve patient engagement in health care. As health literacy strategies are integrated into the widely adopted Care Model, the subsequent improved evidence-based framework can help promote the delivery of safe, effective, and collaborative care to patients. Our model calls for first approaching all patients with the assumption that they are at risk of not understanding their health conditions or how to deal with them, and then subsequently confirming and ensuring patients’ understanding. For health care organizations adopting our model, health literacy would then become an organizational value infused into all aspects of planning and operations, including self-management support, delivery system design, shared decision-making support, clinical information systems to track and plan patient care, and helping patients access community resources. We also propose a measurement framework to track the impact of the new Health Literate Care Model on patient outcomes and quality of care.

Patient engagement in health care has been termed the “blockbuster drug of the century,” with the potential to transform the practice of medicine.¹ As noted in the Affordable Care Act, however, engaging patients in their own health care fundamentally relies on health literacy—that is, their ability to obtain, process, communicate, and understand basic health

information and services. Unfortunately, relatively few people are proficient in understanding and acting on available health information to fully engage in their own care.²

Incorporating health literacy themes and tools into the widely adopted Care Model can encourage engagement among health care staff and patients, as well as the families and caretakers who support patients' prevention, decision-making, and self-management activities. The Care Model, first proposed in 1996 by Edward Wagner and coauthors as the Chronic Care Model, represents an evidence-based framework that could promote the delivery of safe, effective, and collaborative care to patients.³ Over time, the Chronic Care Model was expanded to explicitly encompass high-quality care such as patient-centeredness and timeliness—as well as preventive care. As a result, it is now simply called the Care Model.^{4,5}

This article first reviews the basic principles of patient engagement in health care and the Care Model, while also addressing the urgent need for health literacy in the United States. We then propose a new Health Literate Care Model based on “health literacy universal precautions”—that is, the need for health care providers to approach all patients with the assumption that they are at risk of not understanding information relevant to maintaining and improving their health. By incorporating specific interventions from the 2010 Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit,⁶ the Health Literate Care Model offers specific ways in which to drive systems change.

The article concludes with a scenario for a health-literate approach, as well as suggestions for continuously monitoring and improving health literacy outcomes and quality based on patients' feedback. We believe that the new Health Literate Care Model can help build a future in which patients are better informed and more engaged in their own health care.

Patient Engagement And The Care Model

High-quality health care depends on successful patient engagement, defined as “actions individuals must take to obtain the greatest benefit from the health care services available to them.”⁷ To this end, the Affordable Care Act seeks to expand the use of innovative health care delivery models—including the patient-centered medical home and accountable care organizations^{8,9}—that rely on patient engagement for their success. These new models build on growing evidence that both patients and organizations benefit from supporting patients' active involvement in health care services. A systems approach to health, as exemplified by the Care Model, has the potential to maximize patient engagement in health care.

Hundreds of health care organizations have employed the Care Model since 1996 as a system to increase quality of care.¹⁰ The literature provides a wealth of evidence for the model's impact on health outcomes.^{10,11}

According to the model,¹² the entire health care organization needs to be structured to make interactions between health care teams and patients as productive as possible. High-quality care, then, results from teams that use the “necessary expertise, relevant patient information, time, and resources to act, rather than just react,”¹²(p68) with informed and activated patients who are engaged in their own care.¹³

The Care Model consists of elements that have effectively supported productive interactions at both the individual and organizational levels. Central to the model is the health care organization itself, with its leadership creating a culture and mechanisms that promote safe, high-quality care. The health care organization implements the other elements of the model, including self-management support whereby patients are empowered and prepared to manage their health and health care. Self-management support itself can include collaborative assessment, goal setting, action planning, and problem solving around patient goals. The Care Model also calls for delivery system design that ensures effective and efficient clinical care and self-management support, such as the use of group visits for primary and secondary prevention.

Decision support, which promotes clinical care consistent with scientific evidence and patients' preferences, represents another element of the Care Model. Clinical information systems can help organize data at the patient and population levels to facilitate the delivery of timely, outcomes-oriented care. Finally, the Care Model calls for health care organizations to forge partnerships within its community to provide resources that can help meet patients' needs. For example, proactively referring patients with transportation or housing needs to effective community resources can help patients' daily lives.

Although the Care Model has brought much-needed attention to informed patient engagement and high-quality care, it has not yet explicitly incorporated health literacy strategies. Doing so can offer a path for achieving quality and patient engagement goals.

The Need To Improve Health Literacy

In too many clinical encounters, patients fundamentally do not understand the medical information presented to them¹⁴ and therefore cannot act in an informed fashion. In fact, the only national health literacy survey conducted to date shows that just 12 percent of Americans are proficient in completing tasks considered essential to successfully navigating the health system and acting on health information.²

Many patients demonstrate insufficient knowledge of their medical conditions and difficulty completing basic forms, as well as other barriers.^{15–17} Compared to informed patients, the uninformed are less likely to use preventive services¹⁸ and manage their conditions,^{7,19,20} while being more likely to have unnecessary hospital admissions or visits to the emergency department.²¹

Health care organizations often assume that their patients understand their own health conditions and can act appropriately. But in reality, many demands routinely overwhelm patients' capabilities. For example, parents may be unable to determine the correct dose of a pediatric medicine based on the instructions on the label, a seemingly simple task that can be made complex by confusing directions. Similarly, elderly people may suffer from multiple conditions that become too complex for both the patient and the family caretakers to manage effectively.

Recognizing these challenges, the Institute of Medicine identified the combination of self-management and health literacy as a crosscutting priority area for national action.²² In that

regard, over the past decade a national consensus has emerged that health literacy represents a systems issue, not just a problem at the individual level.^{23–26}

For example, a 2009 Institute of Medicine roundtable portrayed health literacy as determined both by individuals' skills and abilities and by the demands and complexity of the health care system.²⁷ Recently, an Institute of Medicine discussion paper coined the term *health-literate organizations*—that is, organizations that support people as they navigate, understand, and use information and services to take care of their health.²⁸

Realizing the potential of a health-literate organization to deliver better care requires teamwork, committed leadership, and outcomes monitoring.²⁸ Health-literate organizations can begin by reaffirming the fact that patients want to know but are not offered all of their health care options.²⁹ Such organizations can commit to being fundamentally concerned with, and adaptive to, patients' needs and perspectives.³⁰ A range of accreditation, quality, and health professional organizations has begun to recommend system-level changes to make organizations health literate.²⁸

Health literacy experts have begun to advocate health literacy universal precautions.²⁴ Initially, the concept of universal precautions applied to across-the-board preparations instituted by health care organizations to prevent the transmission of blood-borne diseases among patients.

Adopting health literacy universal precautions acknowledges that the complexity of the health care system challenges virtually everyone. The new term calls for standard procedures for confirming patients' understanding of their medication regimens, as one example. It also recognizes that health literacy can vary by situation. For example, a patient's normally adequate health literacy skills may be diminished by the stress of a new serious illness. And it recognizes that all patients benefit from clear, actionable information²⁴ and simple patient education materials.³¹

AHRQ released the Health Literacy Universal Precautions Toolkit in 2010.⁶ Developed in response to providers' increased awareness of health literacy issues and their inexperience in addressing them, the toolkit consists of twenty brief interventions that provide step-by-step implementation guidance and resources for integrating health literacy into practice.

The limited evidence available shows the possibility of improving quality outcomes by reducing the health literacy demands placed on patients.²⁵ For example, research demonstrates the following points: Using pictograms can reduce medication errors;³² provider communications training and feedback on patients' cancer screening rates can enhance these rates;³³ a heart failure self-management program using picture-based materials and other health literacy strategies can help reduce rates of death and readmissions to the hospital;³⁴ and confirming patients' understanding of new concepts (such as health information, advice, and change in self-management) can increase glycemic control in patients with diabetes.³⁵

For other health literacy interventions, however, more research is needed.²¹ For example, studies of the effect of alternative media—such as videos, online material, or slide shows—

on patients' understanding of treatment or advance-directive options have had mixed results. The best methods for exploiting the potential of alternative media have not yet been determined.

The New Health Literate Care Model

The proposed Health Literate Care Model incorporates health literacy principles into the Care Model. For each of the Care Model's elements, an updated "health-literate" version includes relevant tools from the Health Literacy Universal Precautions Toolkit and maximizes the potential for system change.

Although some providers may initially object that becoming a health-literate organization would be too time-consuming, implementing the Care Model with integrated health literacy approaches could ultimately serve to reduce duplication and inefficiency while improving patients' understanding of and engagement in health care. Exhibit 1 shows how the tools pertain to each element of the Care Model. (A more extensive version of this exhibit can be found in online Appendix A.)³⁶ Together, the elements of the new Health Literate Care Model can potentially create a more integrated organizational environment that nurtures and fosters informed patient engagement.

THE HEALTH CARE ORGANIZATION

In health care organizations, health literacy can become a cultural value, modeled by leadership and integrated into all aspects of planning and operations.²⁸ The Care Model calls for effective improvement strategies that promote comprehensive system change, encourage transparency of quality problems, and provide incentives for delivering high-quality care. The leadership of an updated, health-literate health system would explicitly address health literacy as part of continuous quality improvement.

The first three tools in the Health Literacy Universal Precautions Toolkit provide guidance for creating such a new health-literate organizational culture. Tool 1 explains the rationale for assembling a health literacy team, headed by a leader who will champion universal precautions. The team and leader should be accountable for implementing health literacy strategies, setting targets, and monitoring results.

The team uses the assessment tool (tool 2) to gauge how well the patients' health literacy needs are being met and could raise awareness (tool 3) to educate all staff throughout the health system. Also, an organization with a health-literate culture values patients' feedback (tool 17)—solicited through patient surveys and other means—on basic issues such as ease of understanding the organization's signage, other written materials, medical terminology, and complex care processes.

SELF-MANAGEMENT SUPPORT

Many health literacy strategies can improve patients' self-management. When asked whether they understand information, too many confused patients will simply—and inaccurately—answer "yes." The teach-back method (tool 5) represents a mainstay of health-literate self-management support (Exhibit 1). In this method, providers ask patients to explain back to

them what they have learned, their understanding of their own condition, the options available to them, and their intentions to act on the information provided. Based on this information, providers can then assess the match between their expectations and patients' understanding.³⁵

An additional promising self-management practice involves helping patients develop a personal action plan that breaks tasks down into manageable chunks.³⁷

DELIVERY SYSTEM DESIGN

When implementing the Care Model, a health system typically develops team-based care, redesigns roles and workflow, and conducts routine proactive follow-up. In a Health Literate Care Model, staff members take on new roles, such as scheduling interpreter services in advance, facilitating patient education during group visits, and calling patients to confirm their understanding of laboratory results or complex medication regimens.

One high-impact redesign would incorporate “brown bag” medication reviews at each patient visit to detect and correct medication errors and improve patients' adherence to medication. Tool 8 (Exhibit 1) describes how to conduct such reviews, including encouraging patients to bring in all of their medicines and dietary supplements and reviewing what all the medicines are for and how to take them properly. In keeping with the Care Model's emphasis on team-based care, brown bag medication reviews can be conducted by a nurse or medical assistant before or after the patient meets with the primary care clinician.

DECISION SUPPORT

The Health Literate Care Model emphasizes sharing evidence-based guidelines with patients and encourages their participation in decision making about options in care. Preliminary evidence finds that shared decision making has the potential to influence health outcomes.¹⁸

Although decision aids can help patients choose from among an array of screening and treatment options, a recent Cochrane review noted that the effects on patients with relatively low literacy need further evaluation.³⁸ The Affordable Care Act specifically calls for decision aids to reflect the needs of consumers with diverse levels of health literacy.³⁹

Encouraging patients' participation in decision making through simple interventions can potentially make patients more engaged and more informed. The Health Literacy Universal Precautions Toolkit can improve the decision support element of the Care Model. For example, tools 11 and 12 (Exhibit 1) provide guidance for designing easy-to-read written materials and reviewing materials with patients, as well as suggesting the use of nonprint alternatives such as pictures or other visual aids.

The teach-back method, described above, can also facilitate shared decision-making conversations to ensure that patients' decisions are informed in a linguistically and culturally appropriate way.

CLINICAL INFORMATION SYSTEMS

Clinical information systems provide real-time reminders about needed services during patient visits, help track care delivered to different populations, and assist with planning future care. To be health literate, clinical information systems also should include automatic reminders for health literacy–related tasks, such as brown bag medication reviews, use of the teach-back method, and proactive and frequent follow-up. Additionally, electronic health records can facilitate personalized online patient education, care coordination, and referrals, easing the burden currently carried by many patients.

In addition to serving providers, clinical information systems can include a user-friendly interface to enable patients to view their health-related information through a personal health record. Examples include a patient portal to an electronic health record or a stand-alone personal health record system that is established in a way that protects patients' privacy and security. The record can be designed according to health literacy principles for ease of access and navigation as well as presentation of understandable content.

This online and printable record could also become an essential patient engagement tool.⁴⁰ And simple interactive self-management and decision support could link patients to relevant community resources and services.²⁴

COMMUNITY PARTNERS

Whereas the Care Model encourages patients to connect with resources in their communities—such as disease prevention and management professionals—health-literate community partnerships can broaden these resources to address the social determinants of health (tools 18, 19, and 20 in Exhibit 1). For example, patients can suffer from a number of cultural and social vulnerabilities, such as poor housing, inadequate access to nutritious food, limited transportation, and low levels of formal education. Establishing relationships with nonmedical and literacy organizations can help patients begin to manage these vulnerabilities.

Part of providing patient-friendly support includes using a simple referral form to community resources, such as adult basic education, food assistance, and discount prescription programs. Another aspect of patient-friendly support for accessing community resources includes ensuring that referrals have been completed and helping patients with financial difficulties obtain medicines. Establishing partnerships with community organizations also makes it possible to share the Health Literacy Universal Precautions approach with them.

The elements of the Care Model, as widely implemented, include many features that are necessary, but not sufficient, to achieve informed patient engagement. Exhibit 2 shows how prioritizing health literacy can improve each element to achieve a Health Literate Care Model. (A more extensive version of this exhibit can be found in Appendix B.)³⁶

Patients' Potential Experience Under The New Model

At present there are few, if any, examples in the US health care system of the Health Literate Care Model in action. The following scenario sketches the potential of implementing the model.

Ms. Wright, sixty-two years old, has heart failure and diabetes and recently moved to a new town to be near her daughter. She calls a local doctor's office to make an appointment. The scheduler reminds her to bring in all of her medicines and supplements. At the first visit, the receptionist asks her whether she would like help in filling out forms. Ms. Wright notes that the forms are simple and understandable and is able to proceed without help.

Next, a medical assistant reviews all of the medicines Ms. Wright brought and enters relevant information into an electronic health record. Then the doctor reviews with Ms. Wright the medical history forms she has completed and asks her what she understands about her conditions. After discussing her current symptoms, the doctor explains the treatment options, and together they create a care plan. The doctor asks Ms. Wright to explain in her own words how she will take her medicines and the complications she might anticipate. The doctor clarifies any confusion and then asks her again to share her understanding.

When the doctor leaves, a nurse enters the room, asks Ms. Wright about any remaining questions, and reviews with her a one-page handout on key points about medicines and the treatment plan.

Next, the nurse or another health educator gives Ms. Wright a copy of her medicine schedule to keep on her refrigerator and guides her through an easy-to-use personal health record. This includes her personal health information in plain language and simple interactive tutorials. The nurse also refers Ms. Wright to a diabetes education program.

Before Ms. Wright leaves, a scheduling assistant makes an appointment for her to return in three months. The following week, a member of the patient support team calls Ms. Wright to confirm the referral and appointment, to ensure that she is taking her medicines properly, and to verify that she was able to use her personal health record.

Between visits, Ms. Wright takes her medicine regularly, takes advantage of the personal health record's interactive learning activities related to nutrition and physical activity, and participates in a diabetes peer support group offered by her neighborhood YMCA. When Ms. Wright returns for her annual wellness visit, she is confident about her ability to manage her condition and ready to further engage with providers to improve her health.

Measuring And Improving The New Model

Complex adaptive health care systems⁴¹ can establish goals and measures to monitor progress and continually improve strategies for health literacy and patient engagement.²⁸ These actions can help health-literate organizations—and their quality improvement teams—track the implementation of changes, while monitoring their ability to meet patients' health

literacy needs. Hence, incorporating health literacy into overall quality measurement activities entails conducting periodic organizational assessments.

A robust quality measurement framework and measures to track both the implementation of the Health Literate Care Model and patient outcomes can include patients' feedback about their experiences of care. Health care organizations can gauge their progress in decreasing health literacy demands by using health literacy self-assessment tools (such as tool 2 in Exhibit 1) at regular intervals. Also critical is the collection of measures of patients' experiences of care to facilitate adaptations that improve quality. Exhibit 3 lists several measures of patient experience from validated instruments that capture patients' accounts of how well their health literacy challenges are being met.

Examples of these instruments are the Consumer Assessment of Healthcare Providers and Systems⁴² and the Patient Assessment of Chronic Illness Care^{43,44} surveys. Some of these measures are already being tracked as part of Healthy People 2020⁴⁵—a set of national ten-year objectives for improving the health of all Americans—and have been endorsed by the National Quality Forum.⁴⁶

Exhibit 3 offers a way to align such measures with each element of the Health Literate Care Model. Each measure arises by incorporating the corresponding question into the organization's surveys that track patients' experiences of care, monitor their satisfaction, or obtain their feedback for quality improvement purposes (tool 17 in Exhibit 1).

Tracking the outcomes of a Health Literate Care Model allows health care organizations to assess trends over time and learn whether actions succeed in making patients more engaged and informed. In addition, the health communication and health information technology objectives of Healthy People 2020⁴⁵ include national targets for improving interactions between providers and patients, increasing the use of personalized health information, and increasing shared decision making during the decade.⁴⁶ The use of these measures, validated by the National Center for Health Statistics and the Healthy People 2020 Federal Interagency Workgroup, can help assess progress toward these national goals.

Conclusion

Substantial evidence shows that the Care Model can lead to improved health outcomes.^{10,11} Research has also shown that the ability to understand and use health information affects people's use of the health care system and their health. In addition, limited but growing evidence notes that health literacy interventions can improve health care quality and outcomes.²¹

In recognition of these themes, the Health Literate Care Model represents a practical systems framework for organizations that aspire to adapt to all patients' health literacy challenges comprehensively, synergistically, and proactively. It offers the potential for patients to better understand their options; benefit from community services that improve wellness, prevention, and chronic care management; view their relationships with provider teams positively; and make informed decisions.

Further research can explore basic questions, such as the impact of the Health Literate Care Model, the most effective ways to train health care providers to implement it, and how best to improve and incorporate these strategies in a time of limited resources. Failure to answer these and other related questions may well have cost implications, because people's inability to successfully engage in their health care and health maintenance can increase the burden of illness and lead to avoidable health expenditures.²⁰

But answering these questions and identifying evidence-based approaches to implementing the new model could lead to effective systems change. Doing so could help increase the future blockbuster potential of patient engagement, while producing the high-quality health care that all patients need and deserve.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Biographies



Howard K. Koh is the assistant secretary for health at the Department of Health and Human Services.

In this month's *Health Affairs*, Howard Koh, the assistant secretary for health at the Department of Health and Human Services (HHS), and coauthors describe a proposed Health Literate Care Model to improve patient engagement in health care. The model would incorporate strategies to boost patients' health literacy into the widely adopted Care Model and would be predicated on the assumption that every patient is at risk of not understanding his or her health conditions or how to deal with them. The authors describe how the model would work and propose a measurement framework to track its impact on patient outcomes and quality of care.

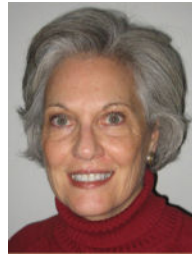
Koh oversees fourteen public health offices, including the Office of the Surgeon General, the Public Health Service Commissioned Corps, ten regional health offices across the country,

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Relationship Between The Care Model And The Health Literacy Universal Precautions Toolkit

Exhibit 1

Tool ^a	Elements of Care Model					
	Health care organization	Self-management support	Delivery system design	Decision support	Clinical information systems	Community partners
1: Form a team	●					
2: Assess your practice	●					
3: Raise awareness	●					
4: Tips for communicating clearly		●		●		
5: The teach-back method		●		●	●	
6: Follow-up with patients		●	●			
7: Telephone considerations		●	●			
8: Brown bag medication review		●	●	●	●	
9: How to address language differences		●	●	●		
10: Culture and other considerations		●	●	●		
11: Design easy-to-read material		●		●		
12: Use health education material effectively		●		●		
13: Welcome patients: helpful attitudes, signs			●			
14: Encourage questions		●	●	●		
15: Make action plans		●		●	●	
16: Improve medication adherence and accuracy		●		●	●	
17: Get patient feedback	●	●	●	●		
18: Link patients to nonmedical support		●	●		●	●
19: Medication resources		●			●	●

Elements of Care Model							
Tool ^a	Health care organization	Self-management support	Delivery system support	Delivery system design	Decision support	Clinical information systems	Community partners
20: Use health and literacy resources in the community	●				●	●	●

SOURCE Department of Health and Human Services, Office of Disease Prevention and Health Promotion.

^aSee Health Literacy Universal Precautions Toolkit (Note 6 in text).

Exhibit 2**Examples Of The Use Of Care Model Elements In A Health Literate Care Model**

Care Model element	Care Model examples	Health Literate Care Model examples
Health care organization	Leadership gives health care teams adequate time to implement quality improvements Everyone reports errors and engages in quality improvement	Performance goals for addressing health literacy are set based on assessments and patient feedback Systemwide training of the workforce occurs in communication and health literacy skills
Self-management support	Members of the team are trained in motivational interviewing Patients are referred to self-management support	Teach-back method is used in every patient interaction All self-management support resources follow principles of plain language and health literacy
Delivery system design	Team members proactively schedule appointments and send patients reminders about them Team members actively recruit patients for group visits and participate as educators and facilitators in the visits	Brown bag medication review is incorporated into the team's workflow Team members follow up to verify patients' comprehension of care plans
Decision support	Patient encounters include computerized prompts Care is delegated using protocols, such as standing orders	The team provides self-paced, interactive patient decision aids Providers engage in shared decision-making conversations with patients
Clinical information systems	Providers receive clinical reminders during patient encounters Disease registries are used to manage patient populations and generate reports on gaps in care	Teams receive reminders for health literacy-related tasks, such as conducting brown bag medication reviews Personal health records include patients' care plans, health-literate decision aids, self-management tools, and links to community resources
Community partners	The team refers patients to peer-based support groups The team partners with community organizations to develop and support interventions that fill gaps in needed services	The team develops referral relationships with providers of adult education and other nonmedical support, such as GED classes and housing The team collaborates with community partners around health literacy universal precautions and cultural-competence principles

SOURCE Department of Health and Human Services, Office of Disease Prevention and Health Promotion.

Exhibit 3

Examples Of Measures Of Patients' Experience Of Care In The Care Model

Care Model element	Measure
Self-management support	Survey question: "My provider always asks me to describe how I will follow instructions about what to do to take care of an illness or health condition" ^{a,b}
Delivery system design	Survey questions: "In the last twelve months, I talked with someone in my provider's office at each visit about all the prescription medicines I was taking" ^a "In the last twelve months, I got reminders from my provider's office (e.g., about tests, treatments, or appointments) between visits" ^a
Decision support	Survey question: "My provider always involves me in decisions as much as I want" ^b
Clinical information systems	Survey question: "I have online access to my personal health information (care received, test results, and upcoming appointments)" ^b
Community partners	Survey question: "Over the past six months when I received care for my chronic condition, I was encouraged to attend programs in the community that could help me" ^c

SOURCE Department of Health and Human Services, Office of Disease Prevention and Health Promotion.

^a Consumer Assessment of Healthcare Providers and Systems survey (see Note 42 in text).

^b Healthy People 2020 measure (see Note 45 in text).

^c Patient Assessment of Chronic Illness Care measure (see Note 43 in text).