

Tracking Progress on Person-Centered Care for Older Adults: How Are We Doing?

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Executive Summary

Person-centered care is essential to a high-quality system of care, emphasizing a holistic approach oriented around individuals' goals and preferences. Analyzing the 2014 and 2016 Health and Retirement Study, we measure the extent to which older adults experience person-centered care, differences by race, income and other variables, and how receipt of person-centered care affects overall health care satisfaction and service utilization. Roughly one-third of older adults reported that their preferences were only rarely or sometimes taken into account. Results varied greatly by race. One in four Hispanics reported *never* having their preferences taken into account compared to roughly one in ten whites and one in six Blacks. When people's preferences are ignored, they are more likely to forgo medical care and report lower satisfaction with the health care system. New efforts are needed to strengthen and advance person-centered care, particularly for people of color and low-income populations.

Introduction

In the midst of the worst pandemic in more than a century, person-centered care is a core value guiding and sustaining many organizations and serving vulnerable older adults through the crisis.¹ Person-centered care is based on a holistic approach to health care that takes the whole person into account instead of a narrow perspective where the focus lies on an individual's illness or symptoms.^{2,3} Recognized as an integral part of a high-quality system of care, in 2001 the Institute of Medicine advocated for creating a more person-centered health care system that would respect and address individuals' preferences, needs and values.⁴ Nearly a decade later, the Department of Health and Human Services' National Quality Strategy included patient-centeredness as a core component of better care.⁵ More recently, The SCAN Foundation charged a team at the American Geriatrics Society in collaboration with the University of Southern California to define the essential elements of person-centered care. This work defined person-centered care to mean that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals.²

Despite the efforts to advance person-centered care, to date there has not yet been a way to ascertain its prevalence and whether and how it may be changing over time. Evaluations that have been completed tend to focus on what might be occurring with specific population sub-groups like individuals with dementia or those in nursing homes; or, they focus exclusively on the performance of specific provider-types.^{6,7} Until now, there has not been a direct way to measure and track how the health care system as a whole is performing on a key parameter of person-centeredness: whether older adults report that their goals and preferences are being taken into account when they seek care.

Study Data and Methods

DATA AND MEASURE

Using a recently available measure of person-centeredness, we provide an estimate for overall health system performance and track how this measure changes over time, across regions, and for specific population sub-groups. We rely on an important new question that was added to the 2014 Health and Retirement Study (HRS) and included again in the 2016 study.⁸ The Health and Retirement Study (HRS) is a nationally representative panel study of adults age 50 and over. It contains longitudinal data collected every two years on a variety of sociodemographic, health, economic, family/support, and lifestyle variables. In order to achieve a representative sample, the HRS has an oversampling of Non-Hispanic African Americans and Hispanics.

As part of the core survey, the HRS asked the following question: “When thinking about your experiences with the health care system over the past year, how often were your preferences for care taken into account – never, sometimes, usually or always?” This question focuses on the most fundamental component of person-centeredness – the ability of the health care system to take into account individuals’ preferences regarding how they want to experience care. In addition to this measure of person-centeredness and other measures related to satisfaction with care, the variables explored include selected socio-demographic characteristics and health and financial variables. The sample size for the HRS core survey is 17,584 individuals for 2014 and 18,920 for 2016. The overall response rates for the 2014 and 2016 surveys were 87% and 88% respectively, and 96% of respondents answered the person-centered care question.

METHOD

We conducted both simple descriptive statistics with tests of significance along with multivariate modeling, primarily logistic regression analysis. For certain longitudinal analyses, we also employed a lagged variables approach. We did this in order to determine the impact of having had one’s preferences taken into account in 2014 on subsequent health services utilization in 2016. Because initial analyses showed no statistically significant differences in responses between the 2014 and 2016 waves of the survey, we report findings from the 2016 wave to answer the following research questions:

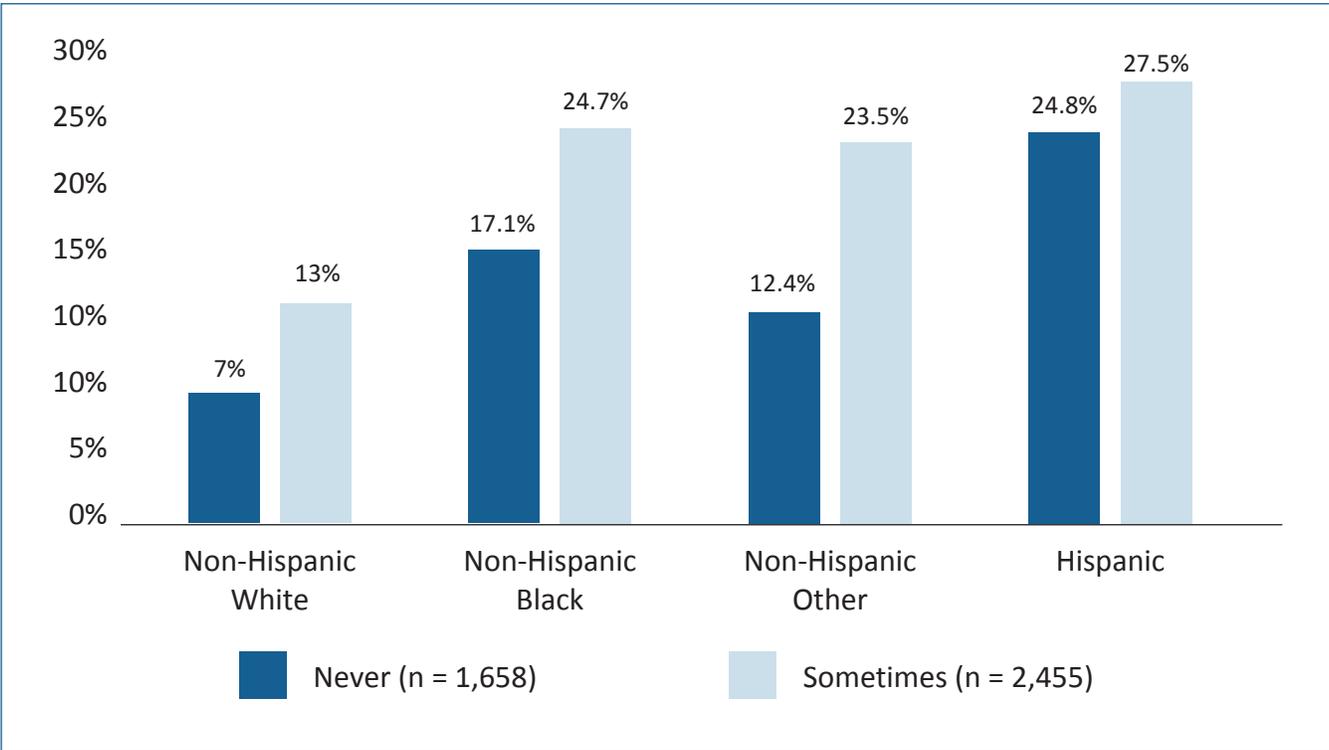
1. What percentage of individuals in 2014 and 2016 who are age 50 and over indicate that the health care system has taken into account their preferences for care?
2. What is the relationship between selected socio-demographic, health, and economic characteristics and the likelihood of an individual reporting that their preferences were taken into account?
3. What is the independent impact of having particular socio-demographic, economic and health characteristics on the probability of reporting that the health care system is taking into account one’s preferences for care?
4. How does the fact that the health care system does or does not take into account individuals’ preferences affect their subsequent use of health care services?

Study Results

In the 2016 survey wave, two-thirds of individuals over age 50 reported that, over the past year, the health care system “usually” or “always” took their preferences for care into account. One-third of respondents reported that their care preferences were “sometimes” or “never” taken into account. There was little variation across age groups, although individuals age 65 to 74 were somewhat more likely than other age groups to feel that their preferences were “always” taken into account – 50% compared to between 40% and 46%.

Figure 1 shows how responses vary by race and ethnicity. Non-Hispanic whites were only .53 times as likely as are Non-Hispanic Blacks and .45 times as likely as are Hispanics to report that the health care system *only sometimes* or *never* takes their preferences into account. Put another way, nearly one in four Hispanics (22.7%) report *never* having their preferences taken into account compared to roughly one in ten Non-Hispanic whites (8%) and one in six Non-Hispanic Blacks (16.3%). Moreover, between 2014 and 2016 only Non-Hispanic whites and Other Non-Hispanic groups showed modest improvement in their ratings (data not shown).

FIGURE 1: HOW OFTEN PREFERENCES FOR CARE WERE NEVER OR ONLY SOMETIMES TAKEN INTO ACCOUNT, BY RACE/ETHNICITY (2018)



*T-test difference among race/ethnic groups significant at $p < 0.05$

Table 1 summarizes the relationship between various financial and health characteristics and the extent to which people feel that the health care system has taken into account their preferences for care.

TABLE 1: Relationship between Financial and Health Characteristics and Extent to which Preferences for Care were taken into Account (2018)

FINANCIAL AND HEALTH CHARACTERISTICS	HOW OFTEN PREFERENCES WERE TAKEN INTO ACCOUNT			
	NEVER (N=1658)	SOMETIMES (N=2455)	USUALLY (N=3175)	ALWAYS (N=5565)
Total Population	12.9%*	19.1%	24.7%	43.3%*
Financial Characteristics				
Household Income (Mean)	\$47,374*	\$64,362*	\$83,920*	\$82,574*
Net Wealth (Mean)	\$251,250*	\$335,811*	\$512,050*	\$529,648*
Below FPL	22.4%*	19.1%*	9.4%*	10.1%*
Receives Government Assistance Benefits	16.6%	17.4%	14.2%	15.3%
Insurance Status				
Has Medicare	59.4%	61.0%	62.9%	64.9%*
Has Medicaid	10.3%*	12.0%*	4.9%	6.1%
Is Dually Eligible for Medicare and Medicaid	8.5%*	9.3%*	6.0%*	7.3%*
Health Characteristics				
Self-Rated Health Scale (Mean) (1 to 5; 1=poor And 5=excellent)	3.0	2.8*	3.0	3.2
Poor/Fair Health	34.8%*	42.5%*	29.8%*	26.1%*
Health Improved	7.9%*	8.2%*	9.3%*	10.2%*
Health Worsened	16.3%*	22.1%*	23.5%*	19.1%*
Depression	25.2%*	30.7%*	21.6%*	16.3%*
Chronic Conditions (Mean)	2.0	2.4	2.3	2.2
Impaired Cognition	1.5%	1.2%	1.1%	1.6%
Current Smoker	20.2%*	17.5%*	12.8%*	12.2%*
Exercise Moderate/Vigorous > once/week	66.6%	64.5%	69.2%	70.0%
Health care Utilization				
Had a Hospital Stay (last 2yrs)	18.2%*	26.9%*	27.6%*	25.4%*
Had a Nursing Home Stay (last 2yrs)	2.1%	4.3%	4.7%	3.7%
Number of Doctor Visits (last 2yrs) (Mean)	5.7*	10.3*	11.8*	10.4*
Utilized Home Health care (last 2yrs)	4.6%*	10.2%*	9.4%*	9.3%*
Utilized Specialized Health Facility (last 2yrs)	7.0%*	17.1%*	20.6%*	18.0%*
Had Outpatient Surgery (last 2yrs)	10.8%*	17.3%*	22.3%*	21.0%*
Currently Taking Regular Prescription Drugs	69.5%*	80.0%*	84.9%*	83.3%*
Has Usual Source of Care	68.1%*	81.7%*	90.5%*	90.7%*
Census Region				
Northeast	16.3%	16.0%	16.0%	15.6%
Midwest	18.2%	21.6%	24.1%	24.0%
South	41.7%	37.8%	33.1%*	37.0%
West	20.8%	22.8%	23.1%	22.1%
Health care Satisfaction Rating (0 to 4; 0=very dissatisfied and 4=very satisfied)	2.2	2.7	3.1	3.5

* T-test between groups significant at $p < 0.05$.

There are a number of important findings. First, lower levels of household income and wealth are associated with a higher chance that the health care system **does not** take into account one's preferences for care. In addition, a much higher proportion of individuals who reported that the system never accounts for their preferences had incomes below the Federal Poverty Line (FPL) compared to those reporting that the system always takes account of their preferences (22.4% versus 10.1%) respectively. Higher proportions of individuals reported that the system only *sometimes* or *never* meets their needs were receiving Medicaid compared to those reported that needs are at least usually met. The opposite trend is found for Medicare, with higher proportions of those who reported the system "always" taking their preferences into account receiving Medicare, compared to those who experienced the system as never addressing their preferences.

The pattern for beneficiaries with both Medicare and Medicaid coverage (dually eligible beneficiaries) is more similar to that of Medicaid beneficiaries: among individuals who indicated that the health care system "never" or only "sometimes" takes account of their preferences, a slightly higher percentage were dually eligible for Medicare and Medicaid than was the case for individuals experiencing the system as taking their preferences into account.

Second, higher proportions of people that only sometimes or never have their preferences taken into account reported their health as fair or poor, had a greater likelihood of reporting depression, were more likely to be smokers, and were less likely to indicate that their health has improved over the past two years. Third, in terms of health care utilization, individuals reporting that the system never or only sometimes takes account of their preferences were less likely to have used hospital care over the preceding two years, and they reported far fewer doctor visits, home care use, specialty visits and outpatient surgeries. They were also less likely to be taking prescription medications. Fourth, individuals who reported that the system usually or always takes into account care preferences were far more likely to have a usual source of care – 91% compared to only 68% of those who reported that their care preferences are never taken into account.

Finally, there is a very strong correlation between people's overall satisfaction with health care and the extent to which their preferences are taken into account. Respondents were asked, "Thinking about the quality, cost and convenience of your health care, how satisfied are you overall? Very satisfied, somewhat satisfied, neutral, somewhat dissatisfied, or very dissatisfied." We constructed a scale ranging from 0 (very dissatisfied) to 4 (very satisfied). As shown, individuals who reported that the health care system never takes into account their preferences for care had an average score of 2.2 – skewing to the "dissatisfied" end of the scale – compared to 3.5 for those who reported that the system always takes into account their preferences.

There are few significant differences across geographic regions, although there have been some notable changes in ratings between 2014 and 2016, particularly in the West and Midwest census regions (not shown in the table). The percentage of individuals who indicated that the health system only sometimes or never took into account their preferences for care declined from 2014 to 2016 by 13% in the Midwest and 17% in the West; in addition, the proportion of individuals who indicated that the system always takes account of their preferences increased by 14% in the Midwest and 11% in the West over the same two-year period.

To evaluate the independent impact of having a specific trait on the probability of having one's preferences for care taken into account, while holding other variables constant, we employed logistic regression analysis. We examined the factors associated with reporting that one's care preferences

were **never** taken into account. Table 2 shows the odds ratio as well as significance level for individual variables. An odds ratio that is significant and less than 1 means that having a particular trait **reduces** the odds of reporting that the health care system **never** took into account care preferences; this would be a positive result. An odds ratio greater than 1 indicates that having a particular trait **increases** the odds of reporting that the system **never** took into account care preferences, which would be a negative result. The reference groups in the analysis for categorical variables include Non-Hispanic white, Non-Married (Divorced/Separated, Widowed, Never Married), and the Northeast Region.

TABLE 2: Logistic Regression for Odds that Health Care System Never Took into Account Care Preferences over the Preceding Year (2016) (n=17,478)

ODDS THAT HEALTH SYSTEM NEVER TOOK ACCOUNT OF CARE PREFERENCES IN PRECEDING YEAR		
	ODDS RATIO	SIGNIFICANCE LEVEL
Satisfaction with Health Care (0=Very Dissatisfied; 4=Very Satisfied)	0.80	0.00
Age	1.03	0.00
Female	0.79	0.00
Non-Hispanic Black	1.95	0.00
Non-Hispanic Other	1.87	0.00
Hispanic	2.38	0.00
Education Years	0.97	0.00
Married/Partnered	0.95	0.32
Household Income <\$30K	1.58	0.00
Household Income \$30k to \$74.9K	1.48	0.00
Below FPL	1.20	0.00
Self-Rated Health (0=poor and 4=excellent)	0.94	0.06
Number of Chronic Conditions	0.94	0.03
Depression	1.18	0.01
Current Smoker	1.38	0.00
Had a Hospital Stay (last 2yrs)	0.93	0.34
Had a Nursing Home Stay (last 2yrs)	0.81	0.37
Number of Doctor Visits (last 2yrs) (Mean)	0.98	0.00
Utilized Home Health care (last 2yrs)	0.69	0.00
Utilized Specialized Health Facility (last 2yrs)	0.53	0.00
Had Outpatient Surgery (last 2yrs)	0.73	0.00
Currently Taking Regular Prescription Drugs	0.78	0.00
Had Usual Source of Care	0.49	0.00
Medicare Beneficiary	0.97	0.13
Medicaid Beneficiary	0.94	0.59
Dual Eligible	0.93	0.03
Midwest Region	0.98	0.82
South Region	1.10	0.14
West Region	0.86	0.15

Source/Notes:

Note: Lagged variable regression analysis with socio-demographic, health, insurance status, and census region as covariates. Coefficient/odds ratios are statistically significant at $p < 0.05$.

All other variables held constant, people who are more satisfied with their health care are 1.25 times more likely to have had their preferences taken into account at least sometimes, showing that satisfaction with health care is very much related to whether care preferences are taken into account. As one ages, the odds of having care preferences taken into account decline by roughly 3% per year. When focusing on race/ethnicity, we find that compared to Non-Hispanic whites, minorities are roughly 1.9 to 2.4 times more likely to report that their care preferences were never taken into account. Compared to all other variables, race has the single largest impact on the odds of reporting that the health system never takes preferences into account. In addition, compared to those with incomes above \$75,000, those with lower incomes are 1.5 (for incomes between \$30,000 and \$74,999) and 1.6 (for incomes less than \$30,000) times more likely to have experienced the system as never accounting for their health care preferences. The same is true of individuals living below the federal poverty level (FPL): being below the FPL makes one 1.2 times more likely to report that care preferences were never accounted for.

In most cases, variables associated with poorer health status (i.e., self-rated health as fair or poor, having depression, and being a current smoker) were associated with a lower likelihood of care preferences being taken into account. The exception is having chronic conditions. Here we found that individuals with more chronic conditions were somewhat less likely to report that their care preferences are never taken into account.

The relationship between utilization of health care services and care preferences being taken into account is mixed. Individuals who had a hospital or nursing home stay in the preceding two years were no more or less likely to have reported that their care preferences were never taken into account. In contrast, those who had outpatient surgeries, had to visit a specialized health facility, or used home health care services over the preceding two years had between 27% and 47% lower odds of reporting that the system never took their preferences for care into account. As the number of doctor visits increased, there was a slight lowering of the odds that someone would report that the health system never took their care preferences into account. Higher prescription drug use is associated with 32% lower odds of reporting that the system never took into account care preferences. Finally, having a usual source of care is associated with 51% lower odds of reporting that the system never took preferences into account.

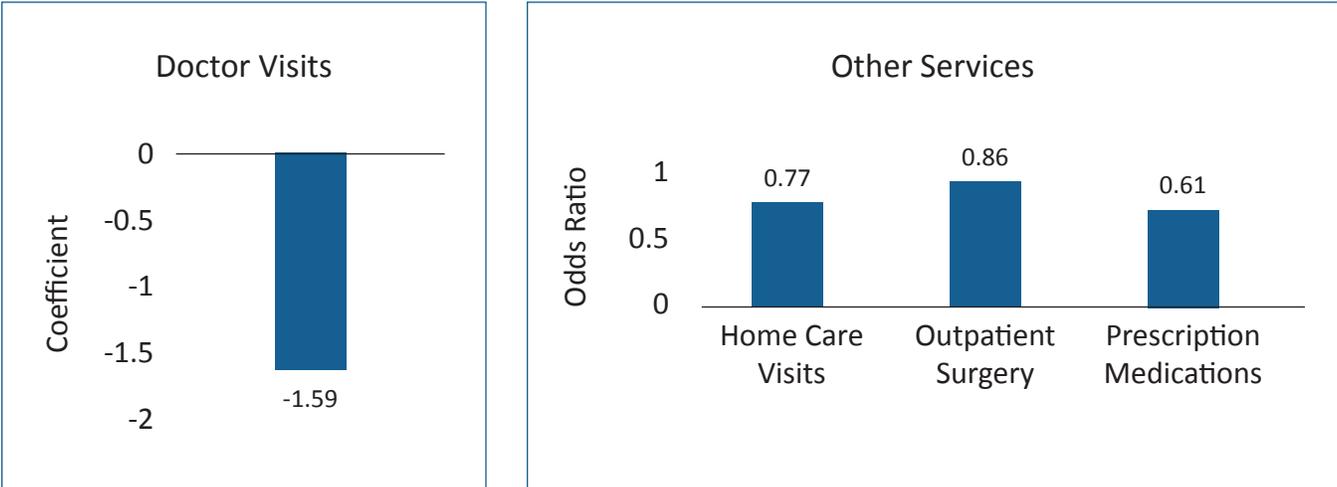
Health insurance matters, but only for individuals dually eligible for Medicare and Medicaid. Being a dual eligible beneficiary is associated with 7% lower odds of reporting that your preferences are not taken into account. Having Medicare or Medicaid coverage alone has no significant impact. Finally, when controlling for all these other variables, living in a particular region is not related to the likelihood of having preferences taken into account.

In order to further test these relationships, we also used a lagged variables approach where the values of independent variables in 2014 were used to predict whether someone rated the health care system as never taking into account their preferences in 2016. The approach yielded similar findings to what was found in the logistic regression; that is, the same set of variables with relatively similar odds ratio values were found to be statistically significant in both analyses.

Sub-Group Analysis: Effect Of Inclusion Of Care Preferences On Subsequent Service Use

We employed a lagged variables approach to understand whether having one’s preferences for care taken into account influences subsequent health care utilization. In this approach, independent variables in 2014, including whether care preferences were taken into account, were used to predict service use in 2016 of four types of services: (1) doctors’ visits; (2) home care; (3) outpatient surgery; and (4) prescription medications. Results presented in Figure 2 show the coefficients for doctor visits and the odds ratios for home care use, outpatient surgery, and prescription medication use for each of the independent variables tested along with their significance levels.

FIGURE 2: IMPACT OF 2014 “PREFERENCE RATING” ON USE OF HEALTH SERVICES IN 2016



**Note: Lagged variable regression analysis with socio-demographic, health, insurance status, and census region as covariates. Coefficient/odds ratios are statistically significant at $p < 0.05$.*

Across all service settings, individuals who felt that the health system never took account of their care preferences in 2014 were less likely to access services in 2016. For example, even when accounting for health and financial variables, they visited a doctor fewer times and were less likely to use home care and outpatient surgery services. The largest impact was on use of prescription medications: they were 39% less likely to use prescription medications. Second, although not shown in the figure, people who reported having chronic conditions, depression or poor health status in 2014 were more likely to use health services in 2016. As well, dually eligible individuals, Medicare beneficiaries and Medicaid beneficiaries, were more likely to use health care services (doctors’ visits and home care), compared to individuals who either had no insurance or were privately insured in 2014. Finally, having a usual source of care is positively associated with health care use. Individuals who reported having a usual source of care in 2014 were 1.3 times more likely to report home care use and outpatient surgeries in 2016. They are also more likely to have more visits to the doctor.

Limitations

While the findings are compelling, the study does have several limitations. First, our methods allow us to identify associations between different variables, but not causality. Second, data is self-reported and may be subject to recall and response bias (even though subjective experience is one driver of future behavior and choices). Third, our data reflects population-level estimates and does not allow us to detect differences based on specific health systems or providers. Even in the context of these limitations, we are able to draw important conclusions and implications.

Discussion

The current pandemic has illustrated many shortcomings in our health care system, one of the most important being the vast racial and ethnic disparities in health outcomes and quality.^{9,10,11,12} This analysis clearly demonstrates a deep and disturbing divide in how aging adults experience their care preferences being taken into account – a key tenant of person-centered care – by race and ethnicity, insurance status, and by wealth and income. At the same time, this analysis has reinforced the importance of person-centered care, given our finding that individuals who report that the health system doesn't take their preferences into account are more likely to forgo medical care and have lower patient satisfaction with the system.

Renewed focus on advancing person-centered care, particularly for people of color and low-income populations is critically important and should be part of an overall strategy to address the structural inequities that underlie disparities in health, health care and economic security.¹³ While the primary focus of policymakers and researchers has been on reducing disparities in health care access and outcomes, we have identified an important dimension of disparity affecting these metrics; namely, in the way that health care providers listen to and take account of the preferences of individuals as they seek care.¹⁴ This raises important questions about how doctors and other care providers elicit the care preferences of patients and how systems as a whole learn about, organize and operate to address the care preferences and desires of patients.

Training is one important component for advancing person-centered care, and can help draw attention to the importance of communication and culture change toward a system oriented toward “engaging the consumer” rather than “treating the patient.”¹⁵ The concept of “co-production,” in which health care is viewed as a service, not a good, and thus necessarily co-produced by service professionals and service users, is also a helpful framework for advancing person-centered care, as are strategies to advance interpersonal medicine.^{16,17}

But training alone is not enough. If providers aren't able to spend enough time with patients, if the complexity of insurance coverage and access make it difficult for patients to connect with and maintain a relationship with a consistent provider, and if performance measurement promotes one-size-fits-all interventions, even the best-intentioned clinicians cannot overcome these barriers to deliver person-centered care.

The good news is that there are promising opportunities to change the health care system to better deliver person-centered care. Measurement focused on goal-directed care and person-driven outcomes

can be further scaled and spread. Strengthening public-facing quality reporting tools, such as the STAR rating system utilized by the Medicare program, could help boost person-centered care delivery, particularly if paired with financial incentives.^{18,19,20} The Age Friendly Health Systems initiative, which emphasizes what matters most to older adults, is an ambitious effort to transform care across all health care settings.²¹ Integrated care initiatives, such as those for individuals dually-eligible for Medicare and Medicaid, as well as delivery system reform efforts can be platforms for driving person-centered care.²² And given the finding that having a usual source of care is associated with greater likelihood that care preferences are being taken into account, strengthening primary care is another important strategy for achieving person-centered care.

A complementary approach is to build a stronger voice for consumers in clinical settings and in shaping policies and programs.²³ This can include patient tools, shared decision-making, skills-building to empower consumers to actively participate in care decisions that affect them and structures such as advisory councils that build patient and family input into the design of clinical programs.^{24,25}

All of these initiatives take on additional urgency in light of the COVID-19 pandemic. The pandemic has fundamentally disrupted the health care system. As we grapple with what comes next, it is clear that we have an opportunity to build a better, stronger system that tackles some of these fundamental challenges, including stronger primary care, a more rational approach to quality measurement, transformed payment that no longer relies on fee-for-service, and an emphasis on patient and family input. Given the findings about the impact of income and insurance coverage, public policies that address gaps in health insurance coverage and support the economic security of older adults are also implicated in this analysis of the factors influencing person-centered care. And these policies must be considered in the context of systemic racism and bias, in which economic and health inequities are deeply intertwined. Our findings suggest that unpacking and addressing these issues head-on in the organization and delivery of health care is a critical charge for all who seek to advance a person-centered health care system.

Endnotes

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