

Consumer Attitudes Toward Health Care Costs, Value and System Reforms: A Review of the Literature

HEALTH POLICY
LITERATURE REVIEW
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SUMMARY

Any effort to engage consumers on health care cost, quality and reform issues must start with a robust understanding of their habitual way of thinking about the topic. With an eye towards learning how to engage consumers, Consumers Union conducted a literature review to better understand consumers' prevailing attitudes and awareness of key health care topics. We find that consumers have generalized concern and awareness of health system problems but little grasp of specifics. Our review details these gaps in consumers' understanding of how the health system works, as well as areas for additional research that will help complete our picture of how consumers view health care costs, quality and delivery reforms.

Introduction

While there is much that works well, problems in our health system are well documented: high prices, wasteful harmful care, unjustified variation in health care costs across providers, a lack of cost transparency and unacceptable variation in quality.

Consumer support for effective measures to control costs and improve the quality of care is fundamental to getting policymaker and regulator action. But efforts to engage consumers on health care cost, quality and reform issues must start with a robust understanding of their existing frame of reference— that is, their prevailing, habitual way of thinking about the topic. Why? Information must be crafted with this frame of reference in mind. When consumers receive information that is *outside* this frame of reference, they may act upon it, but they may also reject the information and/or rationalize why the new information is not true. It is often the case that “values” and “perceptions” are often more important than “facts” in terms of engaging consumers.

With an eye towards learning how to engage consumers, Consumers Union conducted a literature review to better understand consumers' prevailing attitudes and awareness of six key health care topics:

- 1) cost of health care;
- 2) paying for health care;
- 3) quality of health care;
- 4) getting health care (“delivery system”);
- 5) reforming health care;
- 5) priorities (health care system improvement relative to other issues); and
- 6) taking action.

We hoped to learn whether current research was sufficiently robust to inform a consumer engagement strategy.

Costs of Health Care

Consumers generally define health care costs as what they pay at the time of service – their out-of-pocket costs, including insurance premiums, deductibles and co-pays.^{1,2} Thinking about health costs more systematically is not at the forefront of their minds.

Consumers felt the strain of rising health care costs on their pocketbooks,³ and were struck by how rapid the increase has been in their lifetimes.⁴ Participants in a Minnesota focus group identified affordability as the biggest health care challenge among ten choices.⁵ This was true across all political ideologies and identities.⁶ Respondents in another group of forums agreed that the cost issues pose the greatest threat to the American health care system.⁷

The cost of health care affects consumer use of services--almost half of those who skipped care in 2012 did so because of cost concerns.⁸ In 2013, more than one-third of U.S. adults went without recommended care, did not see a doctor when they were sick, or failed to fill prescriptions because of costs.⁹

Cost concerns are not universal, however. Some felt the rising costs were affecting their families' financial situation and others did not. Among people with a serious illness (both insured and uninsured), 20 percent considered the cost of healthcare to be a very serious problem for their families' financial situation, 23 percent somewhat serious, 10 percent not too serious, and 47 percent not a problem.¹⁰ When asked about affordability in a different way, however, only 30 percent of Americans say they are confident that they can afford the care they need without suffering economic hardship.¹¹ Additionally, almost one in five

insured consumers feels somewhat “insecure” that their insurance will shield them from cost-related impacts.¹²

When asked to identify the cause of rising health care costs, consumers were quick to talk about insurance and pharmaceutical companies, hospital costs, and fraud. Some also included doctors as a cause.^{13,14,15} Many consumers focused on reasons why people might need more medical care – poor nutrition, lack of exercise, pollution, stress¹⁶ – but relatively few consumers attribute rising costs to the increased number of Medicare beneficiaries and/or more people on Medicaid.¹⁷

Just before open enrollment for 2013 began, 51 percent of the general public and 67 percent of the uninsured said that they did not have enough information about the Affordable Care Act to know how it would impact their families’ costs.¹⁸

Paying for Health Care

Americans are uncomfortable talking about the role money plays in delivering their health care to them, and insist that dollars should not be a part of the care equation.¹⁹ In general, Americans do not want to think about how and when health care providers are paid for delivering their health care.²⁰ Linking money or payment to their health and health care makes them uncomfortable at best, very angry at worst.²¹

Consumers are generally unaware of how we pay for health care or how insurance works.²² Consumers have little to no knowledge about how the current reimbursement process works.²³ Until moderators explained the system in one study, consumers were unaware that we pay for our health care by paying for each service separately (fee-for-service).²⁴

Consumers find information on the cost of care difficult to obtain because insurance companies consider their cost information to be proprietary, and providers often do not have information on costs of procedures to share with consumers. When they do get the information, it is difficult to understand because the bill is often received in pieces and long after they have received treatment for a procedure, the costs are often without explanation, and consumers do not receive adequate assistance with understanding their bills.²⁵

Quality of Health Care

Consumers find it hard to believe that a provider, and certainly not their provider, could deliver truly substandard care.²⁶ Most consumers believe that more care, newer care, and more costly care is better care.^{27,28}

Many consumers believe that high-quality care is necessarily expensive and that low-cost care means needed care is being withheld, or is being provided by less competent professionals.^{29,30} In the absence of other usable signals of quality, consumers will rely on cost as a proxy.³¹ One survey, however, found some consumers do not believe that the cost and quality of care are positively associated.³²

In a series of experiments, one set of researchers found that it was possible to get consumers to choose high-value health care by using a well-designed report that combined costs and quality.³³ The researchers found that making the quality information easy-to-interpret and highlighting high-value options improved the likelihood that consumers would choose those options.

Getting Health Care (“Delivery System”)

While consumer views on the general performance of the health care system are mixed, consumers have a great deal of respect for the system’s clinical capabilities.³⁴ Most Americans say they are satisfied with their health services (71 percent in national polls).³⁵ However, when they are dissatisfied, insured and uninsured people alike cite high costs, poor service delivery, bad customer service, and access/availability as their main complaints.^{36,37}

Just over 60 percent of Americans have considerable trust in their own doctors, and doctors in general are among the mostly highly trusted professionals.³⁸ Consumers rely heavily on their doctors for information, interpretation, and guidance on treatment options, and may be reluctant to question or challenge what a doctor advises.³⁹

Despite having considerable trust in their doctors, many participants in one study talked about quitting many doctors, perhaps before finding a practitioner they trusted.⁴⁰ Additionally, though most consumers are highly satisfied with their own primary care doctors,⁴¹ they believe uneven quality exists elsewhere in the health system. This sometimes manifests itself as believing that specialists and renowned hospitals provide better care than primary care physicians or public hospitals.⁴²

A common complaint among consumers is the desire to spend more time with their physicians, and to have better coordinated care among their various providers.⁴³ Of American adults surveyed in one study, 47 percent had experienced failures of coordination, such as doctors not sharing information with other medical professionals or not informing patients about their test results.⁴⁴ Many participants in another study described the services they received from health-care providers as impersonal and inefficient, particularly for uninsured patients.⁴⁵

Data from the Deloitte *2009 Survey of Health Care Consumers* show that only 27 percent of consumers report that they understand how the health system works,

with 16 percent reporting that they have no understanding or very slight understanding.⁴⁶

Reforming Health Care

Most consumers believe that the American health care system is in need of reform, with seven out of ten adults saying the system needs fundamental change or complete rebuilding.⁴⁷ In another study, 75 percent of U.S. adults said their health system needs to undergo fundamental changes or be rebuilt entirely.⁴⁸ Though specific reasons for change were not addressed, American consumers in the same study felt that the cost of care is prohibitive and that they spend too much time dealing with insurance paperwork and disputes.⁴⁹

Consumers are interested in what communities and individuals can do to promote better health, but do not think that prevention efforts alone can solve the health care spending problem.⁵⁰

Another idea, the use of electronic communication when clinically appropriate, has both perceived advantages and disadvantages.⁵¹ Perceived advantages include convenience, patient satisfaction, efficiency, and safe, high-quality care, and a perceived disadvantage was more work for providers. Overall, there appears to be little demand by providers or patients for using electronic communication.⁵²

Consumers have varying ideas about the creation of a better payment system for health care. A flat fee payment system was perceived with skepticism, with some consumers feeling this system would give the patient a sense of control, prevent doctors from over-testing and over-treating, and allow doctors to focus more on taking care of patients rather than dealing with insurance companies. However, these positives were balanced by fears that charging flat fees may lead doctors to skimp on care and that flat fees would have to reflect regional variations in the cost of living.⁵³

A performance-based pay system sparked ambivalence.⁵⁴ Some felt this system would make doctors work harder, but most felt that it wouldn't work because doctors are well paid and perhaps greedy and would game the system or turn away sicker patients who were unlikely to earn them sufficient performance-based pay.⁵⁵ In general, consumers do not want to think or talk about how, when or why their health care providers are paid.⁵⁶

Many health care experts are eager to advocate for evidence-based health care and the use of comparative effectiveness research, but consumers do not fully understand these concepts.⁵⁷ Consumers perceive the use of these strategies for decision-making as limiting their choice of providers, inappropriately interfering with physicians' recommendations for treatment, or appearing to ration care based on cost.⁵⁸

While consumers do not want to discuss payment and reform, they do want changes in care delivery – and these changes open the door to the conversation. Patients want to spend more time with their physicians, and they want the care they receive from different doctors to be better coordinated among them. While they are not keen to think about the role of money in their own personal health care, they are open to hearing about new methods of structuring the system if it would result in more of what they want without more cost to them.⁵⁹

The idea of integrated health care delivery systems is somewhat popular with 52 percent of consumers saying that these systems have great potential to reduce overall costs and spending, 49 percent saying it would provide greater value to consumers, and 46 percent saying it would deliver better quality of care than a system of independent practitioners and hospitals.⁶⁰ Nearly half the participants in a Minnesota focus group said that coordinated care is an essential strategy to reducing health care costs.⁶¹

A single-payer system elicited a divide among consumers, with polling from 2009 showing that 40 percent of respondents favored a single-payer system and 56 percent opposed it.⁶²

A popular idea among academics and some policymakers gives consumers the ability to shop around for health care. However, this idea seems challenging to most consumers, who feel that comparing prices would be difficult because patients don't necessarily know in advance what combinations of tests and treatments they will need.⁶³

Data from the Deloitte *2012 Survey of U.S. Health Care Consumers* found that many consumers say they would like more transparency from both doctors and hospitals regarding the quality of care and prices.⁶⁴ Three quarters of respondents in one survey believed that providers should publish quality information online while two thirds said price should also be published online.⁶⁵

Consumers can understand the idea of value if it is presented in a way that is relatable to other choices that they make outside of health care. Data presented needs to be clear and easy to understand, because while many agreed that they would use this information in making health care decisions most would only be willing to look at the information for a few minutes.⁶⁶

When consumers are presented with value data that includes both cost and quality, they often draw on their experiences using similar information when purchasing other products and services, such as using customer reviews, product quality ratings like *Consumer Reports*, and price comparisons, and envision using a similar process to help them choose health care providers or a health plan.⁶⁷

One study found that consumers did not expect or even want their doctors to have price information, rather they wanted doctors to focus on their care and not

prices, feeling that appointments are short and they want to spend time talking through their medical concerns in the few minutes they have to see their doctor.⁶⁸ However other studies found that consumers repeatedly said they wanted to see a resource, or the ability to ask their doctor, to better understand what a particular test or procedure would cost before they agreed to it, and wanted to comparison shop among providers when possible.⁶⁹

There is tension about how and how much the federal government should be involved in health care. Most favor limiting annual increases in insurance premiums, getting generic drugs to market more quickly, and restricting pharmaceutical companies' marketing to physicians. But more conservative individuals did not like the idea of government price setting.⁷⁰

This tension reflects consumer beliefs regarding health care as a right vs a commodity in American society. In a Minnesota focus group, participants agreed that citizens had the right to expect affordable health care.⁷¹ Another study found that a large number of consumers saw health care as a public good, and that everyone deserves at least minimal care.⁷²

Priorities (Health System Improvement Relative to Other Issues)

Consumers believe that the U.S. spends more money than other countries on health care- but do not know if that is a good or bad thing.⁷³ When asked if health care costs are a problem for the country, 65 percent believed it was a very serious problem, and among the sick 73 percent believed it was a very serious problem. Furthermore, 65 percent believed the problem had gotten worse in the last five years and 70 percent of the sick believed it had gotten worse.⁷⁴

In one study, before being informed by moderators about aggregate health care spending as a national problem, consumers had not necessarily considered it a national problem. However, they were eager to learn. Only one third of consumers who filled out pre-discussion surveys in the study agreed that the country is spending more on health care than it can afford.⁷⁵

In 2102, consumers in one study identified the economy (35 percent) as the most pressing issue in America, with unemployment (17 percent), health care (16 percent), the federal budget deficit (13 percent), and education (12 percent) as the next most frequently selected pressing issues.⁷⁶

Taking Action

In general, consumers feel disempowered to change the complicated and troubled health care system, though many believe that further deliberation among consumers could raise public awareness and would constitute an important step towards constructive change.⁷⁷

Consumers are not motivated to address high costs because it's 'what's good for the country' or 'what helps the economy' or even 'what can increase jobs across the nation' – they are motivated because they believe it is what can save them money.⁷⁸

When working to activate consumers on issues of health care costs, reform is not a popular word to use –the term “improvements/changes to the payment and reimbursement system” is better liked among consumers.⁷⁹ Consumers also do not like to discuss efficiency and value, which makes people feel that their care will be cheapened, time with their physician will be lessened, or – worst of all – that their care will be curtailed.⁸⁰ Instead, frame the conversation as “spending dollars more wisely” – not cutting costs from the system.⁸¹

Consumers are ambivalent towards messages about changing the way health care is reimbursed to help physicians overcome barriers to practicing medicine in a more consumer-friendly manner. While they like their own doctors, they have little sympathy for the complaints of physicians. These feelings were especially strong when discussing incentivizing doctors for doing things they do not currently get paid for, or “rewarding” them for providing high-quality care.⁸²

People do not initially believe that doctors should be paid more to coordinate care, but certainly want coordination between their different doctors' offices to be improved. Therefore, phrases like “improving care by having doctors and nurses and other medical professionals work together more” elicit positive reactions.⁸³ Consumers react poorly to messages of getting the wrong tests or medication but respond more positively when the issue is framed as, “[making] sure you get the right medications and tests.”⁸⁴ Additionally, people want to hear about actions being taken, not ideas being discussed – instead of “our doctors and hospitals are *talking about*” say “our doctors and hospitals are *working with*”.⁸⁵ Finally, consumers do not prefer the term “high-value care”; instead, terms like “high-quality care at a reasonable price” or “high-quality care at an affordable cost” are preferred.⁸⁶

Consumers' interest in applying cost information to decision-making is high when they have a high level of exposure to out-of-pocket costs, a non-severe or non-urgent condition, or few or no preconceptions about the quality of providers.⁸⁷ Consumers are more likely to use information on cost when they have the time and energy to consider treatment options, so present costs for procedures that allow consumers this time, such as joint replacement or maternity instead of a heart attack.⁸⁸ Additionally, because the same cost can mean something different to different people, clear labels and definitions that explain who a cost applies to, what is included in the cost, and the certainty of the cost may help consumers interpret the information correctly.⁸⁹

Consumers trust only a few sources for information about health care costs. As noted above, 61 percent of Americans have considerable trust in their own

doctors, and doctors in general are among the mostly highly trusted professionals.⁹⁰ Medical associations and societies are highly trusted by 51 percent of consumers, followed by academic medical centers and teaching hospitals at 50 percent.⁹¹ Independent companies, organizations or associations, employers, and government agencies are other trusted sources of information by at least a quarter of consumers (numbers vary depending on the survey).⁹² Consumers are more likely to trust cost information from organizations that are reputable and do not have a financial motive in presenting the information.⁹³ Insurance companies are not highly trusted.⁹⁴

When explaining measures, quality, and guidelines, consumer concerns can be defused by emphasizing that national medical experts/organizations created the guidelines, and that they are based on scientific evidence and are not binding for anyone.⁹⁵

While both men and women expressed deep commitment to their doctor-patient relationship, men were far more ready to consider quantifying the relationship in terms of care-provided-for-dollars-earned. Women, in contrast, almost always spoke of the relationship in much more personal terms, and repeatedly expressed concerns that data alone do not provide information on the patient's personal experience with the doctor. Communications research has shown that women are typically a family's gatekeeper to the health care system and choose doctors for family members.⁹⁶

Conclusion

If we are to engage regular consumers in a national debate to stem rising health care costs, and to measure and improve quality, we need to meet consumers where they are. We need to understand their values and perceptions in order to harness their energy and political.

With respect to consumer attitudes towards the affordability of health care, this review shows that survey data do not paint an entirely uniform picture. Although consumers widely recognize that health care is very expensive in the U.S., they do not answer health care affordability questions in a consistent manner. For example, about 45% of the seriously ill considered health care costs to be a very serious or somewhat serious problem.⁹⁷ However, when an affordability question was asked in a different way, only 30% said they were confident that they could afford the care they needed without suffering economic hardship.

Our review also found important gaps in consumers' understanding of how the health system worked, as well as gaps in the evidence that may delay our ability to engage consumers on these topic. According to the literature we reviewed, consumers have generalized concern and awareness of health system problems but little grasp of specifics. In part, this is because their understanding of the "health care system" is based almost exclusively on their personal experiences.⁹⁸

Specific gaps in consumers' understanding appear to include:

- reasons why health care costs are so high;
- how providers are paid by insurers;
- role of comparative effectiveness research and evidence-based guidelines; and
- reforms that might improve care coordination and/or provide better value.

The literature we reviewed also did not contain very robust information on the following consumer topics:

- Patient Safety -- very little is known about consumers' attitudes towards patient safety. There is a perception, though not well documented, that health system variation in provider treatment styles and treatment intensity is not widely recognized among consumers.⁹⁹
- High health costs as a proxy for quality – there is mixed information about whether consumers believe high health costs signal high quality.
- Affordability – as mentioned above, there is conflicting information on how worried consumers are about costs and not being able to afford care. Consumers' views may be very sensitive to how the question is framed.
- Taking action – more information is needed on how to frame the issues of high cost and medical delivery reform in a way that will harness consumer outrage and dissatisfaction to push policymakers to take action.

Sarah Melecki, CU policy intern, is the primary author of this report. Victoria Burack, policy analyst and Lynn Quincy, Associate Director, provided significant review of the draft. The review was originally conducted in February of 2014 but not publicly released until October. Hence, it does not incorporate new research that may have been released since February of 2014.

TABLE 1 — LITERATURE CONSULTED

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ENDNOTES

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