Workers covered through their employer pay 97 percent more for their family insurance premiums than they did in 2002, while their wages increased just 33 percent over the same period.1 New focus group research shows that families are well aware of the rising cost of health care, and some participants say they are changing their behaviors to avoid illness as they struggle to pay insurance premiums and out-of-pocket medical costs.

To gain a better understanding of what consumers think about the rising cost of health care, the Robert Wood Johnson Foundation (RWJF) recently convened a series of eight focus groups with consumers in four U.S. cities: Philadelphia; Charlotte, N.C.; Chicago; and Denver. The participants had diverse backgrounds. Half of the groups were comprised of people with employer-sponsored insurance with deductibles of $500 or more. Two groups were comprised of people who purchased their insurance on the private market, and also had deductibles of $500 or more. One group was made up of Medicare beneficiaries, and one group was uninsured. This brief contains key insights from the focus group discussions.

Participants defined health care costs as what they paid for care and insurance.

Participants identified the phrase “health care costs” as what they paid “out-of-pocket”—insurance premiums, deductibles and/or co-pays that came out of their pocket or paycheck. They were more likely to associate health care costs with the increasing costs of health insurance rather than the rising costs of health care. The notion of rising health care costs in broader terms—to the system, society, U.S. economy or government—was scarcely mentioned.

Few participants seemed to really understand how insurance works and/or how doctors are paid, though there was considerable commentary about doctors no longer making the salary that they once did. The issue of massive Medicare costs hardly came up, unless it was in reference to Medicare deductibles or one falling into the so-called ‘donut-hole’ of non-covered prescription costs.

Participants were aware of rising costs of care, but didn’t understand why it’s happening.

Universally, participants were extremely aware of the effects the rising cost of care had on their pocketbooks and the accelerating speed at which costs have risen in recent years. That said, they didn’t know why costs are going up or how to decipher them.

Nearly all of the participants said they experienced increased out-of-pocket costs in recent years, primarily due to rising premiums and deductibles. Since what comes out of participants’ pockets or paychecks has been increasing, they were highly attuned to it. For those with employer-sponsored insurance, one or two credited their employer with paying more in recent years to help share the increasing cost burden. Others reported employers changing health plans multiple times in recent years in an effort to cut costs, but most participants seemed to view the insurance cost increases as largely being absorbed by employees themselves.

Participants were asked what they paid for monthly premiums, co-pays for doctor visits, or prescriptions and deductibles. Almost every person in every group could explain exactly—practically to the penny—what he/she spent on premiums, deductibles and co-pays each month. This level of specificity is not something observed in previous focus groups conducted on behalf of RWJF.

Participants said rising costs were affecting their daily lives and purchasing behaviors.

Across demographics, participants said they were cutting back in other areas of their lives in order to absorb rising health insurance premiums, co-pays, etc. Many cited taking fewer vacations or holding off on major purchases like a new automobile. Others volunteered that they have postponed starting families. Numerous participants indicated that they were now looking at seemingly nominal expenses and beginning to cut corners.

This issue is personal, and focus group participants expressed that they are getting angry.

Asking to list the first feelings that came to mind when hearing the phrase “rising health care costs” the participants said that they felt anger, fear, frustration, anxiety, helplessness and confusion.

They were very clear in saying that they were 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 were motivated because they believe it is what can save them money. They said that they needed more money in their household budgets and felt helpless in the face of the large health care costs.

Across the board, there was a sense that participants were nearing the breaking point. They said that costs were likely to continue to increase faster than their salary increased. Many expressed concern that they were falling behind—not saving money, or dipping into their savings to help cover health care costs.

Some participants said they increasingly questioned their doctors’ recommendations.

In a new twist, some participants said that they now questioned the necessity or timing of care that their doctors recommended, and cost was a major reason. Not only did they say they could not afford the care, but several mentioned that their physician may have had a profit-motive in recommending certain care. There was still significant respect for most physicians—particularly those with whom they’ve had relationships for a long time and have grown to strongly trust—but questioning doctors’ recommendations has not been heard to this degree in previous focus groups conducted for RWJF in recent years.

Participants said they were denying needed care for themselves and their family members due to cost.

Participants said they were adapting to increased out-of-pocket costs by increasingly going without needed medical care. There were several tales of fractured bones that had not been set, severe pain that had been ignored and knee replacement surgeries that were postponed. Participants repeatedly said they were avoiding or putting off doctor visits for themselves and their children, even young children.

Participants said they wanted to act more like consumers with their health care.

Participants repeatedly said they wanted to see a resource, or 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. They said that they also wanted the ability to know what a treatment should cost before they agreed to it, and needed more transparent information on price in order to do this. The participants said they were very interested in efforts to share information on price and quality.

Many participants did not think prices were tied to quality.

Perhaps surprisingly, many focus group participants did not assume that higher prices were tied to higher quality. They did, however, say that price was generally tied to the location of the medical office or hospital. There was a lot of discussion about prices being what the market will bear—a general belief that private practices located in higher-income neighborhoods, or hospitals located in more affluent areas charge more for the same procedures and services.

As part of the focus group, various prices for common procedures/surgeries (i.e., appendix removal, colonoscopy, knee replacement) were shared with participants. While they assumed that different doctors and hospitals charged different prices, they were not sure why, nor did they seem to realize the magnitude, in some instances, of those price differences. Overall, they were extremely surprised about the variation in price.
Participants didn’t know why costs were rising, but were quick to suggest possibilities.

When asked why health care costs are rising and which entity—consumers, employers, providers, government—is best positioned to help control them, there were nearly as many answers as there were participants.

Generally, however, there were three or four reasons participants consistently offered for increasing costs. These included (a) increasing insurance company profits; (b) a significant hospital building boom and rising hospital profits; and (c) development of expensive pharmaceuticals and/or medical technologies.

Relatively few participants attributed rising costs to the increased number of Medicare beneficiaries and/or more people on Medicaid.

Participants were largely uncertain who can best address rising costs.

Asked to identify the groups that should play a role, participants suggested a list of mixed responses, including individuals, insurance companies, pharmaceutical companies, hospitals, government, employers and “everyone.” Most of the participants said that the federal government has the most power to reduce health care costs, but felt skeptical about whether government could or would do so.

Participants said they had no idea what they could do to lower the cost of care, aside from avoiding getting sick.

When asked to identify actions or behaviors that they themselves could undertake to reduce health care costs, the responses were mixed. Many identified living “healthier lifestyles”—such as eating better, exercising, quitting smoking, etc., which they said they were already doing to try to stay healthy and avoid health care expenses. Many also identified requesting generic drugs as a way to lower spending, which many said they already did.

Conclusion

Consumers participating in recent focus groups sponsored by RWJF were well aware that their health care costs have risen, and said it was taking a serious toll on their household budgets. Most said they that their insurance premiums, deductibles and co-pays have increased several times in recent years, along with rising out-of-pocket costs. While they didn’t comprehend the reasons for these escalating costs, they felt an increasing sense of anger about them, and about their helplessness in reversing the trends.

This increased awareness—and even the increased anger—provides openings to effectively engage people who pay high premiums, deductibles and/or co-pays in consumer-oriented efforts to control spending and reduce waste in the health care system. Focus group participants said they wanted reliable, transparent information on the cost and quality of the care delivered by their local providers. Some said they have already used this type of comparative information—or word of mouth—and based care decisions on the information that they found. Many said they were avoiding needed care until they could better afford it. In a few instances, focus group participants even questioned providers’ own financial motives in recommending tests or procedures.

The focus group participants said taking action to improve their own wellness could help them save money on health care, and cited quitting smoking, eating healthier and exercising as examples, in addition to opting to purchase generic medications rather than name-brand competitors.

Focus group participants recognized that rising health care costs have a negative effect on the U.S. economy and job market. That concerned them, but their primary concern was their own family’s finances. They said that they needed to reduce health care costs because—after paying their premiums, co-pays and other out-of-pocket costs—there was not enough money left in their household budget for other things. For those who pay high out-of-pocket costs for their health care, the anger and frustration they expressed about the rising cost of care makes them ripe for mobilization.