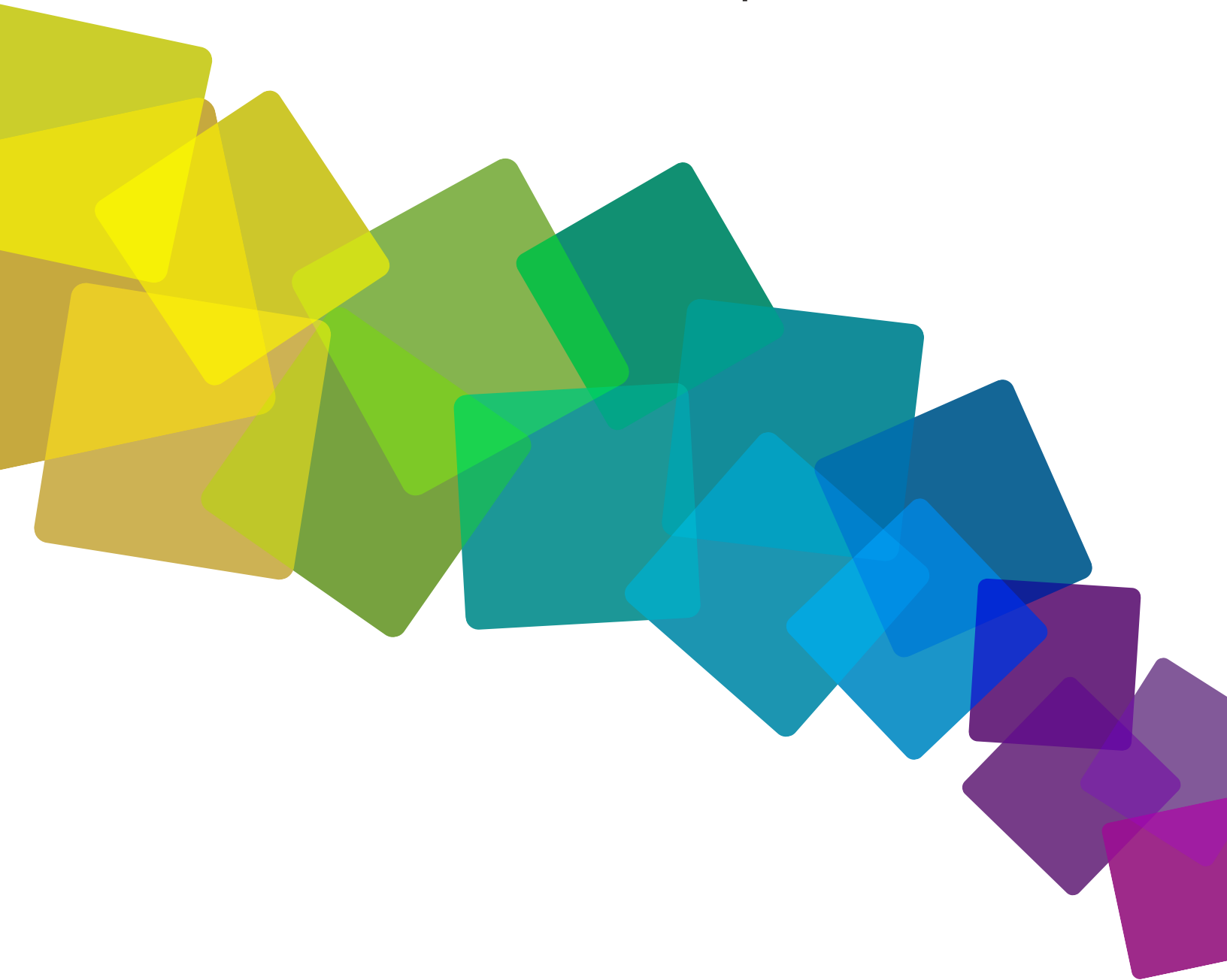


Communicating About Overuse with Vulnerable Populations



OVERVIEW

Overuse, or care that has a greater potential for harm than benefit, is widespread in American medicine, with severe effects on both quality of care and health care costs. To highlight and address this problem, the ABIM Foundation, in partnership with over 80 medical specialty societies, operates the *Choosing Wisely*[®] campaign, which promotes clinician-patient conversations about avoiding unnecessary care.

People living in poverty have long faced limited access to care and poorer morbidity and mortality. While some attribute poor outcomes directly to underuse, a growing body of research shows that overuse is prevalent in Medicaid and uninsured patients and in people of color of all income levels. Several studies have supported that low-value care is common among patients without insurance or with Medicaid and that physicians practice similar rates of low-value and high-value care regardless of their patients' insurance status. A recent study of Medicare beneficiaries by William Schpero et al. suggests there is "a possible double jeopardy for minority patients: long understood to be at risk of receiving less effective care, they appear often to be at risk of receiving more ineffective care." Additionally, because the high cost of care is one of the greatest barriers to access, low-income health care consumers are at increased vulnerability from financial harm from tests and treatments that have little to no benefit.

With support from the Robert Wood Johnson Foundation, the ABIM Foundation has begun to learn more about reducing overuse in vulnerable populations. As the first step in this project, we sponsored a series of four focus groups to explore perceptions and beliefs about overuse in a historically marginalized group.

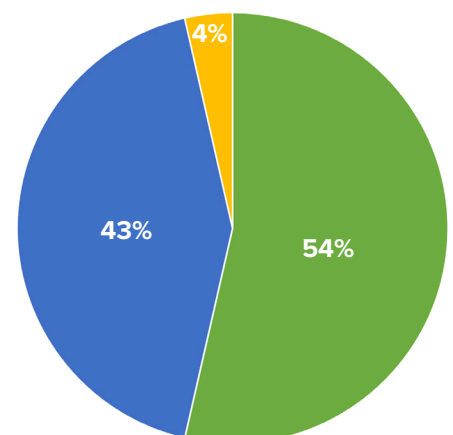
METHODOLOGY

The ABIM Foundation hired McCabe Message Partners to conduct four focus groups: two in November 2018 in Philadelphia and two in December 2018 in Hartford, Connecticut. Each group consisted of eight participants. Overall, participants identified as 48% men and 52% women and 39% black, 24% white and 36% Hispanic. All participants were "low income," which we defined as less than 250% of the federal poverty level. Because we wanted our participants to have opinions and comments on the topic, we chose people who are frequent healthcare consumers and said they interacted with a health care provider at least four times per year. Nineteen self-identified as caregivers as well as patients. Participants had mixed insurance coverage, with the majority on Medicaid (15 participants); five participants were uninsured.

Because of our small sample size, we solicited vigorous community partner participation. Our partners included the Camden Coalition of Healthcare Providers, the Hispanic Health Council (CT) and the University of Connecticut Health Diversity Institute. These partners helped design the focus group guide, observed the focus groups and helped guide conversation through directed notes to the focus group leaders. After the focus groups concluded, they shared insights and contributed to written focus group findings. Representatives from the Donaghue Medical Research Foundation, Network 4 Health Ministries and Qualidigm also observed the focus groups and shared their impressions. Additionally, the *Choosing Wisely* Patient Engagement Advisory Committee has reviewed and added input to this white paper.

Our hope is that this iterative process has added community context and nuance to our findings.

Participants sought medical care from:



- Primary Care Doctors
- Urgent Care
- Emergency Room

THE FINDINGS

1. Participants are comfortable challenging their doctors about care decisions.

Ten years ago, many low-income people like those in the focus groups would not have been insured. In 2018 – several years into the implementation of the Affordable Care Act – the great majority of the focus group participants were insured through a job or Medicaid. According to the Henry J. Kaiser Family Foundation, the number of uninsured nonelderly Americans decreased from over 44 million in 2013 to approximately 27.5 million in 2017.

Focus group participants described a health care system where they actively took charge of their care, knew about treatments, and relied on a primary care provider to manage their care. Nearly all participants said they felt comfortable questioning their clinicians and routinely questioned doctors about care decisions. Whether privately or publicly insured – or uninsured – the majority of participants depicted themselves as activated advocates for their own health during clinical encounters. To ABIM Foundation staff, the focus group moderators, and invited partners/observers, this felt like a noticeable shift from a decade ago, when patients were hesitant to speak up to their physicians.

Despite their comfort in asking questions – and perhaps a reason to do so – participants expressed some concern that a doctor’s recommendations could be influenced by factors other than optimal use of tests and treatments for their individual care, such as incentives from pharmaceutical companies or reimbursement levels from insurers. The growing prevalence of consumer driven plans and marketplaces has increased some patients’ awareness of potential conflicts of interest in the health care system, and increased access has given greater voice to marginalized populations and communities of color who have historic distrust of a health care system that has in the past deliberately harmed them. Patients are more sophisticated about health care now, but that cuts both ways. They are more ready to engage but also more suspicious, and feel the need to guard against clinicians’ potential conflicts of interest.

2. Focus group participants expressed relatively low levels of trust in their providers.

About half of participants expressed mistrust of their doctors and/or cynicism about their doctors’ care decisions. Several said they thought their doctors might be influenced by perks from pharmaceutical companies, or reimbursement levels from insurers. Skepticism of doctors’ perceived financial motivations for recommending various types of care was greater among men, but some women participants also expressed concerns. Most participants said they frequently question their doctors’ recommendations. Only a small minority said they never questioned their clinicians and always followed their direction. To the moderators and focus group observers, this felt like a noticeable shift from a decade ago when patients demonstrated implicit trust in their doctors.

While participants expressed a desire for trusting, long-term relationships with clinicians, they also expressed a heightened awareness of how financial factors affect the health care system. These factors make patients more skeptical of the care they are receiving and require clinicians to invest more in establishing relationships built on trust and shared decision making.

Many of the participants reported using urgent care or having a poor relationship with their primary care physician. Those who felt they had a rapport with their doctor also expressed a higher level of trust. Participants characterized a good relationship as one in which they do not feel rushed, the clinician engages in conversation, has an understanding of their previous health history, social factors and mental health factors, and is open to questions.

“If the doctor says, ‘Do X, Y and Z,’ and you’re not sure about that, what do you do? I will question it first. If you give me a good enough reason, I say, ‘Yes, let’s do it.’ If not, then I’ll say, ‘No. I won’t do that.’”

- Philadelphia Participant

“A couple visits that I’ve had, at the doctor or the ER specifically, where I go in there with a problem, and they’re not addressing it...they were completely looking past everything I was saying, and they were just pushing me out the door.”

– Hartford Participant

3. Participants said they conducted fairly extensive research about treatment options and trusted their own judgment about what's best for them.

The majority of participants described the detailed research they conducted before a medical appointment. They were very knowledgeable about medical conditions and potential diagnoses and treatments. One participant who had been homeless – and until very recently was incarcerated – said he consulted *The Pill Book* before taking any medications. Virtually all felt informed and empowered to decide what care or treatment would be best for them. They talked about how they believed the care they want is almost always the care they need. In fact, most initially said they would go to another doctor if their doctor did not provide the specific treatment they desired and acquiesce to their wishes as patients. In reality, patient surveys show that opportunity costs, such as the additional time off and inconvenience, and financial costs, such as extra co-pays and transportation costs, may make this “doctor shopping” difficult. However, the sentiment is an important indication of the growing role of the patient as a consumer, which was the intent of the ACA.

“Before I go, I try to do as much research as I possibly could so that I’m educating myself a little bit as to what the diagnosis might be, or what the options might be, so that she doesn’t try to sell me on something that I don’t know anything about.”

– Hartford Participant

In addition, while patients said they were willing and capable of researching their health care decisions, many participants were still swayed by misinformation, such as misleading accounts about the dangers of vaccines and the inherent safety of “natural” remedies.

An improvement to the health system setting would be a culture, with supporting activities, that encourages clinicians to collaborate with and support patients who are researching their health, including helping them understand complex topics that are subject to misinformation or misinterpretation. As one of our community experts said, “Being ill-informed but activated could be a disaster.”

Another insight is that sometimes participants questioned tests and treatments that may have been appropriate and necessary, but they did so because no clinician effectively communicated the rationale.

4. More than anything, low-income focus group participants wanted to be heard by the health care system.

Nearly every participant said being ‘heard’ by physicians was the most important aspect of the clinical encounter. Many said they value their clinician listening to them more than anything else. Virtually all said that the quality of the relationship mattered as much as the quality of care – and they judged that relationship by whether they felt listened to and respected. The desire to be heard was so strong that most even expressed sincere appreciation to the focus group moderators for asking them their opinions about these issues. This was most pronounced among African American men, who repeatedly thanked moderators for inviting them to the focus groups and listening to them.

Our participants’ belief that their clinicians did not listen to them stresses the need not only to support patients in asking questions but also to encourage a more equal power dynamic between clinician and patient. As Goodyear-Smith and Buetow assert in their article published in *Health Care Analysis* on “Power Issues in the Patient Doctor Relationship,” “Lack of concordance between doctors and patients can encourage paternalism but may be best resolved through negotiated care.” Additionally, a 2017 study by Oliver Wyman found that low-income people of color are three times more likely than the population as a whole to feel disrespected by clinicians. This insight also underscores an important theme heard throughout the focus groups: participants’ need for respect and the positive role of humility from providers in these conversations.

Framing Conversations



5. When having conversations about potential overuse and what care is right for the patient, the patients want a clear rationale for recommendations – including explaining potential harm – and recognition that there was a comprehensive plan in place.

Because the participants felt strongly that they already knew what care was best for them, they initially were quite concerned and upset that a doctor might not prescribe a drug or order a test at the patient's request. But after the focus group discussions, all participants said they recognized the issue and felt inspired to have a conversation with their doctors about whether a given test, procedure and/or medication was really appropriate for them.

Nearly all agreed that their concerns about potentially not getting the treatment they wanted would be lessened if (i) their doctor listened closely to them – ensuring them that they had been heard as emphasized in point 4 – and then (ii) provided a clear rationale, whether or not they agreed, including explaining if harm could result. If the doctor recommended a different path, the participant wanted (iii) to know what would come next, in case the doctor's care plan didn't achieve favorable outcomes.

This insight taps most closely into the fears patients have from historical marginalization. Patients want to understand that their request is not being denied but that the clinician is trying to guide them to a better, safer option and that, if appropriate, their request might be fulfilled in the future.

When asked for comments at the conclusion of the focus groups, a majority of participants said they were most struck by hearing statistics about the frequency of inappropriate/ineffective care, and felt willing to discuss what care was right for them at their next medical appointment.

6. Some participants believed their clinicians displayed bias when ordering tests or treatments for them.

While a minority of participants felt they were victims of physician bias, very few felt this bias was related to their race. Most believed the bias was based on socioeconomic status. Notably, however, one African American man described being repeatedly questioned about risky sex and drug use, even though he engaged in neither and his symptoms were unrelated to these behaviors. Several participants said bias occurred because of insurance status, with uninsured people being given limited options for tests, treatments or procedures, and generally “not respected.”

The strong voices expressing bias based on insurance status and the underlying issues of lack of respect in care implies that clinicians would benefit from more training in this area, and indicates a need for a systematic look at how bias may be structural rather than merely part of the Point of Care conversation. For example, many clinicians will not know the insurance status of a patient unless the scheduling is set to group Medicaid or uninsured patients on a specific day for specific times or if Medicaid or uninsured patients are sent to a specific location.

“I think this – it's like finding a good doctor that you trust – I think it's the key. Bouncing ideas off of each other, [the doctor] knows what you're looking for, and he knows your health goals, and of course, he should have goals for you as well, and they should be geared towards you, not towards a group of patients; geared towards you. And I think that's a special thing to have.”

– Hartford Participant

“When I told them I didn't have insurance, they basically opened up the door and dumped me on the street. It was crazy. I never felt like—They basically were like, ‘Get out of my hospital.’”

– Philadelphia Participant

7. While about half of the participants initially thought “more care is better,” a simple statistic about overuse made them question their beliefs.

While some participants believed receiving more care was probably better than less, they questioned this after hearing a statistic used by *Choosing Wisely*: “20–25 percent of the tests, treatments or procedures that doctors order for their patients have no benefit – they don’t help the patient get better, or may not even be recommended for their condition.”

Virtually all participants felt the statistic was shocking yet believable, and very persuasive.

While this idea resonated with participants, the concept was brought up about midway through the focus group discussion and may not have resonated without that context. In many ways, the focus groups created awareness and inspired conversation and analysis from peoples’ lived experience. This indicates the value for patients to have safe group conversations that can help educate them on topics important for their own health-related decision making.

8. Participants said “procedures” can cause the most unintended harm.

The majority of participants firmly believed that the most harm could result from unnecessary procedures, followed by unnecessary prescription drugs. Few initially saw harm in unnecessary tests. But after a couple minutes of dialogue (typically led by one member of the group who raised concerns about radiation exposure), the group quickly saw potential dangers in unnecessary or duplicative tests.

Anecdotally, based on surveys of systems trying to implement *Choosing Wisely* recommendations, tests are often harder to reduce than procedures. While there are multiple factors that could lead to this, including defensive medicine, habit and hospital regulations, a relatively unexplored factor is the psychological concept of cognitive dread for both patients and clinicians. Dr. Leon Seltzer suggests, “A primary motivating force in human nature is to avoid anxiety—unquestionably one of our most distressing emotions. So, when given the opportunity, we’d rather go ahead and process it than be paralyzed by it.” This additional complexity to the decision making process may require a more multi-modal approach to interventions and a more behavioral approach to patient education.

9. Focus group participants feel empowered by the Choosing Wisely mission and want a health system that recognizes the individual needs of patients.

All participants understood that *Choosing Wisely* aims to increase awareness of overuse and empower patients and physicians to have a discussion – where patients feel genuinely heard – about what care is right for their condition. Several participants said that personalizing these discussions based on patients’ race and/or gender would make them even more effective.

The participants were clear that *Choosing Wisely’s* messaging is effective, but that they need help getting to the place where these conversations can happen. While the ideal is clinicians who have sophisticated, sensitive communication skills, the inference is that many don’t have them –it is a goal rather than their lived reality. Furthermore, the health care system bears responsibility for creating a culture in which questions are welcomed, clinicians have support in having these conversations, and patients are supported in their education about specific diagnoses, tests and treatments relevant to their health.

“If it’s not quality care, you can get all the care you want. If it’s not quality, I’m not getting better, you’re not figuring out what’s wrong with me. As long as the care is quality, then quantity doesn’t really matter.”

– Philadelphia Participant

“When it comes down to surgeries and procedures and stuff like that...I’ve become more skeptical. I definitely, when it comes to procedures, I’ve definitely become more questionable.”

– Philadelphia Participant

“Having a conversation, to me, it lets you know, ‘We’re going to go back and forth about this.’ It’s not like an argument. Dialogue between you and your doctor. You guys are finding out what’s the best way to treat your illness. They’re not just talking at you. They’re talking with you and they’re listening and you’re listening and you’re working together rather than just, ‘This is what you’ve got. Here you go. Here are some pills,’ and telling you what to do.”

– Philadelphia Participant

LIMITATIONS

As with any focus group, the opinions of these participants do not necessarily represent all of the opinions of a large and diverse population. We have tried to add context with historical comparison and known research. Additionally, our sample size was relatively small.

The focus groups were not structured to explore the role of structural racism. The facilitator guide was structured to gain a better understanding of effective overuse messaging to low-income patients with a particular emphasis for engaging African American and Latinx patients. Participants frequently acknowledged the need for culturally and linguistically appropriate communication, leading the Foundation team to believe that themes such as equity and social racism in the context of overuse should be explored in other studies. Unfortunately, this study wasn't designed to allow space to further explore this topic. Studies should be inclusive of other races and ethnicities who experience vulnerability. The focus groups were conducted in English; additional issues might have been raised if we included participants who face a language barrier to holding a care conversation.

Participants expressed nuanced views that were not always concordant. For example, they would express a desire to have a relationship with their clinician and then list all of the reasons they don't trust doctors. In many ways, these juxtapositions are helpful information points. As patients are pushed into more activated roles and gain a greater understanding of outside factors that affect our health care system, their role and their relationships with their clinicians and the health care system as a whole are changing. This speaks to the need for sources of trustworthy help and information as patients assume a larger role navigating their own care.

DISCUSSION AND NEXT STEPS

As noted above, these focus groups were the first step in the Foundation's larger exploration of vulnerable populations and overuse. In addition to this white paper, the ABIM Foundation is creating a technical assistance package for *Choosing Wisely* implementation in safety net settings and convening an affinity group of safety net care providers working on overuse. The focus groups yielded interesting glimpses into areas that could be more fully explored, including patient trust, misinformation and the role of structural racism.

The results of these focus groups have also informed our approach to the implementation of *Choosing Wisely*. For example, we are considering incorporating balancing measures into *Choosing Wisely* projects so both overuse and underuse are measured; adapting measures to look more closely at utilization based on determinants of vulnerability such as race or ethnicity; and incorporating cultural humility into communication trainings.

We hope that the findings from these discussions are helpful to the field. We are very grateful for the grant support of the Robert Wood Johnson Foundation for this work.

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