

The Role of Patients and Families in Avoiding Avoidable Care

Jessie Gruman

[Center for Advancing Health](#)

The speakers and discussants at this Avoiding Avoidable Care Meeting have not attributed to patients and families a significant role in curbing unnecessary care and overtreatment. Thank goodness.

Indeed, we have heard little about “consumers” and “empowered patients,” the benign, egalitarian words that are so often used to disguise shifts onto patients risks and responsibilities that rightfully belong to clinicians and institutions. While some of us will be able to shoulder those new responsibilities, many of us will not. We are sick, we lack the time and resources, the cognitive skills or the confidence to take them on. This means we will be an unreliable force in challenging the status quo in which avoidable care is so common.

Avoiding avoidable care presents particular problems for the public. Focus groups and surveys repeatedly show that we believe that [more care is good and that more expensive is better](#); that [cancer screening](#) will save our [lives](#) and that we don’t have to die.

The pharmaceutical industry is often credited as the source of such beliefs, and the size and nature of its investments in direct-to-consumer advertisement suggest culpability. But those messages are reinforced by trusted, authoritative medical sources – the health voluntaries, hospitals and individual physicians. For example, despite highly visible professional dismissal of the value of widespread PSA screening, *The Daily News* in New York City will, in collaboration with dozens of local hospitals, [reprise](#) its highly successful free PSA screenings on Father’s Day this year. The [comprehensive cancer centers](#) in New York City compete for patients in print and on the airwaves with [misleading pictures and stories](#) of people who have “beaten” cancer. And doctors – like the one palliative care physician Diane Meier described during the meeting – continue to offer terminally ill patients yet one more aggressive, painful and futile intervention, thereby supporting our own desperate belief that maybe we don’t have to die – at least not now.

Who, really, can blame us for believing these messages? The alternative is that in order to benefit from our care, we have to learn about complicated diseases and treatments, challenge familiar, trusted experts and admit the impact of medical intervention is uncertain, all of which are daunting when we are health and can be terrifying when we are ill.

Avoiding avoidable care will be a heavy lift for most of us. Further, we cannot fix this problem. It is the responsibility of the research and clinical professions to agree about what constitutes good care, to tailor that care to our needs, to recommend it to us and to invite our informed participated in decisions about it preferences about it.

In the meantime, however, each of us is at risk for receiving – and being injured by avoidable care; we should know about this and act on this knowledge as part of our effort to get the most we can from the care available to us.

What will it take for significant numbers of us to do this?

Efforts to reduce avoidable care, like patient safety and public reporting on health care quality, are located in different parts of hospital systems and clinics. Those responsible have different expectations for how patients and families will behave in response to messages about choosing good care, protecting against medical errors or avoiding unnecessary care.

We patients, however, are unaware of this jagged organizational geography and can't see relevance of these different pieces to solving the problems posed by our newly diagnosed diabetes, our mom's congestive heart disease or our kid's bike accident.

Each of these organizational initiatives point to our need to pay attention to what's going on, to learn about what's wrong with us and how it might be fixed, to ask questions when we don't understand and to weigh the pros and cons of various testing and treatment decisions with our clinicians. These actions [constitute a radical change](#) in attitudes and behaviors for most of us: most of us are not particularly engaged in our care right now.

But we will not transform ourselves into involved, vigilant patients unless we get a clear message from our clinicians – and other trusted sources such as Consumers' Union and AARP – that it is *important* for us to do so: we probably won't get the most out of our care unless we do.

We will not make these changes unless we know that it is *possible* to take on what is now required of us; we need to know how to care for ourselves when we leave the office or clinic or hospital.

And we will not engage in our care until we are confident that it is *safe* for us to do so, that we will not be punished with less or poor care for asking questions or expressing preferences, and that we won't be asked to take on responsibilities that we can't handle, given our age, resources and cognitive or health status.

We patients and our families as a group will never exert sufficient demand on our clinicians and hospitals to drive general solutions to the problem of avoidable care. However, we have a significant stake in it being solved. We are all affected by the growing price of health care. And we, our siblings, neighbors, friends and kids are the ones who experience personally the effects of over-diagnosis, misdiagnosis and injury associated with unnecessary testing and treatment.