

“That’s the Doctor’s Job”: Overcoming Patient Reluctance To Be Involved

Jennifer A. Blumenthal-Barby, PhD

Assistant Professor of Medicine and Medical Ethics and Health Policy

Baylor College of Medicine

Houston, Texas

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I will be talking about patient reluctance. I will first talk about some of the barriers to engagement and then turn to talking about some potential strategies to increase participation.

Participation in Decisionmaking

- **Barriers: Why Are Patients Reluctant To Participate in Decisionmaking?**
 - Individual barriers (education, language, culture/attitudes)
 - Contextual barriers (time/timing, medical uncertainty)
- **Ways To Increase Participation**
 - Communication (decision aids, normative messaging)
 - Time (for processing, reduce need for quick decisions)

The talk will have a negative side and then an optimistic side.

Patient Involvement in Decisionmaking

■ Areas of Engagement

- Amount of information flow, role in health decisions, role in organization/policymaking

Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*. 2013 Feb;32(2):223-31. PMID: 23381514.

■ Benefits of Involvement and Activation

- Impact patient experience and health outcomes

Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013 Feb;32(2):207-214. PMID: 23381511.

■ Patient Desire for Involvement

- Varies by individuals, number of treatment options, and treatment certainty (e.g., Arora & McHorney, 2000; Guadagnoli & Ward, 1998)

Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? *Med Care*. 2000 Mar;38(3):335-41. PMID: 10718358.

Guadagnoli E, Ward P. Patient participation in decision-making. *Soc Sci Med*. 1998 Aug;47(3):329-39. PMID: 9681902.

■ Involvement Often Lower Than Desired



In terms of what we know about patient involvement in decision making, Carman and colleagues pointed out in a really helpful article that patients can be engaged at a wide variety of levels and a wide variety of different ways. So when we talk about patient engagement, we could be talking about them wanting to be really involved in the information exchange --what their condition is, what their options are, what the risks and benefits are, or we can be talking about patients being engaged in the actual decision-making process and the final decision made, or we could be talking about this at a meta level where you might have patients engaged in policymaking or in the case of PCORI, helping us a researchers think about what outcomes matter to patients. I think it's helpful to have in the back of our mind that even though we're primarily concerned with patient engagement and decision making, there are a lot of ways that patients can be engaged -- not only the patient experience, but also health outcomes. This desire to be engaged varies by individual and may vary by conditions that are more complex with more uncertain outcomes for the choices available. But at a basic level we know that patients really do have a strong desire to be involved. However, we know that patient involvement is often lower than desired.

Patient Barriers to Engagement in Medical Decisionmaking



What are some barriers to patients being engaged? What are some of these causes of reluctance I'm going to kind of break this down into two broad conceptual categories.

Individual Barriers: Education (1 of 3)

■ Health Literacy

- Medical terminology is complex and hard to understand.
 - Even the vocabulary used in common adult screenings is hard to comprehend.

Davis TC, Dolan NC, Ferreira MR, et al. The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Invest.* 2001;19(2):193-200. PMID: 11296623.



The first conceptual category is individual barriers. What are things that might cause a patient to be reluctant to be engaged? The first major factor is the issue of education and health literacy. There's this great example of a study that was done that showed that the majority of patients in the study did not understand the terminology that was being used around colorectal cancer screening, that they didn't even know where their colons were. So if you think about something that we might view as a really basic medical decision for people who aren't trained in medicine or aren't educated in medicine like many of us, this is really complicated, jargon-y sort of information. And we also know that not only is it complicated information but it's a lot of information.

Individual Barriers: Education (2 of 3)

- **And, there is often a lot of information.**

- Consultations for maternal-fetal surgery involved ~1 hour of information delivery.

Blumenthal-Barby JS, Krieger H, Kim D, et al. Communication about fetal surgery for myelomeningocele and congenital diaphragmatic hernia: preliminary findings with implications for informed consent and shared decision-making. *J Perinat Med.* 2015 Apr 14. DOI: 10.1515/jpm-2015-0039. PMID: 25870957.



This was a study that I did with some colleagues where we observed consultations and communications between maternal fetal doctors and women who had their fetus diagnosed with an abnormality. They were potential candidates for *in utero* fetal surgery. We found that they were an hour-long and the physicians talked close to 90 percent of the time, delivering important clinical information about the prognosis, the diagnosis, what the surgery would be like, the risks and the benefits to the fetus, the mom, and short term and long term. I honestly have no idea how any of these women remembered or processed any of that information and it was al extremely important.

Individual Barriers: Education (3 of 3)

- **Some people do more research regarding their condition and treatment options and ask more questions.**
 - Women with higher levels of education asked more questions during fetal consultations.

Blumenthal-Barby JS, Krieger H, Kim D, et al. Communication about fetal surgery for myelomeningocele and congenital diaphragmatic hernia: preliminary findings with implications for informed consent and shared decision-making. *J Perinat Med.* 2015 Apr 14. DOI: 10.1515/jpm-2015-0039. PMID: 25870957.



Another interesting thing we found in this fetal surgery study and this was that the women who had higher levels of education asked more questions and were more engaged. We did question counting and we saw that these women had more questions and there was much more of a two-way dialog in those consultations.

Individual Barriers: Language

■ Barriers between languages lead to problems.

- Reduce ability to communicate symptoms and needs

Flores G. Language barriers to health care in the United States. *N Engl J Med.* 2006 Nov;355(3):229-31. PMID: 16855260.

- Reduce understanding of the medical situation

Wilson E, Chen AH, Grumbach K, et al. Effects of limited English proficiency and physician language on health care comprehension. *J Gen Intern Med.* 2005 Sep;20(9):800-6. PMID: 16117746.

- Reduce satisfaction with care

Carrasquillo O, Orav EJ, Brennan TA, et al. Impact of language barriers on patient satisfaction in an emergency department. *J Gen Intern Med.* 1999 Feb;14(2):82-7. PMID: 10051778.



A second important individual barrier that we should be mindful of has to do with language barriers. There was an article published in 2006 in the *New England Journal of Medicine* that brought up the point that 23 million Americans have limited English-language proficiency. And we know that for people who have limited English-language proficiency, they get worse care, they are less engaged in their care. And there have been studies that showed that they are even reluctant to come back and visit the doctor again and seek care. That's a huge issue to be mindful of when we're thinking about barriers to engagement.

Individual Barriers: Culture and Values (1 of 2)

■ Health care providers are figures of authority.

Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012 May;31(5):1030-8. PMID: 22566443.

- Doctor knows best; doctors act as gods; patients fear being "difficult"
- Particularly problematic with individuals from cultures who highly value authority figures
- Even in serious, life-altering decisions

Blumenthal-Barby JS, Kostick KM, Delgado ED, et al. Assessment of patients' and caregivers' informational and decisional needs for left ventricular assist device placement: implications for informed consent and shared decision-making. *J Heart Lung Transplant*. 2015 Sep;34(9):1182-9. PMID: 26087668.



Another overarching theme at the individual level that might cause some reluctance to be engaged is the broad theme of culture and values. The predominant theme here is the fact that we seem to live in a culture that views healthcare providers as figures of authority. There was an excellent focus group study of 48 patients done by Frosh and colleagues where they found three main factors of reluctance. First was a feeling that deferring to the docs was socially appropriate. They called this “doctor knows best.” Second, there was a perception that doctors could be themselves authoritarian. And then third, a few expressed concern about being perceived as being “difficult.” Interestingly they found that this held true even for patients who were affluent or highly educated.

Recently I was studying with my colleagues decision making around end-of-life decisions, where end-stage heart failure patients are deciding whether they want a ventricular assist device or not. We interviewed a 45 people who had one of these devices or were making a decision about this device, and also their caregivers. We looked at when they described how they made this medical decision, whether they deferred to their providers. And we found that 22 out of 45 interviewees said that they made this decision by just deferring to their provider. This is serious end-of-life decision making and we’re still seeing this sort of deferential culture. An example is this quote from a patient’s spouse, she said, “They said that the LVAD,” that’s this device, “is probably the best way to go. And I trust these doctors with his life and when they said that that’s what we decided. I really didn’t ask for statistics or even really any details. I just went with what they said. They said it would work so I trusted them.” A really powerful quote.

Individual Barriers: Culture and Values (2 of 2)

- **Disparities in cultural understanding and values can lead to poor patient care (e.g., Institute of Medicine, 2001; Institute of Medicine, 2002).**

Committee on the Quality of Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.

Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press; 2002.

- **Many physicians have not been trained in cross-cultural medicine.**
Weissman JS, Betancourt J, Campbell EG, et al. Resident physicians' preparedness to provide cross-cultural care. *JAMA*. 2005 Sep;294(9):1058-67. PMID: 16145026.
- **Trust in physicians leads to better involvement in care.**
Trachtenberg F, Dugan E, Hall MA. How patients' trust relates to their involvement in medical care. *J Fam Pract*. 2005 Apr;54(4):344-52. PMID: 15833226.



A second point under this theme of culture and values is that sometimes differences in culture between providers and patients can cause failure in communication or feelings on the part of the patient that their voice isn't welcome, understood, or heard. The Institute of Medicine has stressed the importance of cross-cultural training for this reason. Despite this, one recent study demonstrated that 41 percent of family medicine residents and eighty-three percent of surgery and OB/GYN residents reported receiving little or no evaluation or training in cross cultural communication and care. Another study found that trust in one's physician caused patients to be more deferential their decision making, but it also caused them to be more engaged in their healthcare, generally. So when we think about trust and whether that's a good thing or a bad thing in terms of patient engagement, we might want to separate out the different things we mean by engagement because we could find different answers and that might be an interesting point for discussion.

Contextual Barriers: Time

■ Insufficient time with health care providers

Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012 May;31(5):1030-8. PMID: 22566443.

■ Results in less detailed explanations and lower patient satisfaction

□ Leaves unanswered questions

Ogden J, Bavalia K, Bull M, et al. "I want more time with my doctor": a quantitative study of time and the consultation. *Fam Pract*. 2004 Oct;21(5):479-83. PMID: 15367468.



Moving on to contextual barriers, one of the major factors is the issue of time; that is patients having insufficient time with their healthcare providers. Going back to the Frosh study with the 48 focus group participants, these participants frequently described how insufficient time with their physicians impinged on their opportunity and ability to ask questions, voice concerns, or seek guidance as they deliberated with their physicians. One patient said, "I don't know if the reason why I was so poorly informed was because I didn't ask enough questions or because they didn't give me enough information. It seems to me everybody is in a hurry and I began to feel guilty about taking up their time. And after it's all over I think to myself why didn't I ask them more questions?" Similarly another participant in this study reflected on how the lack of time had inhibited their interaction, saying, "I think the thing that inhibits people -- you do feel a little self-conscious about the amount of time that you start taking when you're in there because I really need to talk about this and try to figure out all of the different nuances of it. And then you get in there and you start talking and there's a little bit of an internal clock that starts to run. And I know for the doctor there's going to be an internal clock too." So patients are really conscious of the power of time, how limited it is and that clearly makes them reluctant to engage in any meaningful sort of way. We know from the study done by Ogden and colleagues that this desire for more time actually results in them being less satisfied and having lower intentions to comply. So it's pretty significant at any number of different levels.

Contextual Barriers: Uncertainty

- **Timeline of diagnostic testing leads to uncertainty.**
 - Inability to provide answers to patients because of incomplete testing
 - Giving patients information on treatment options that may not be viable to them

Han PK, Klein WM, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Med Dec Making.* 2011 Nov-Dec;31(6):828-38. PMID: 22067431.



The final barrier I'll talk about before turning to some potential ways to overcome reluctance, is the barrier of uncertainty. I don't mean medical uncertainty because medical uncertainty is always going to be there. I mean the uncertainty that comes with the timeline – the clinical diagnostic testing and how patients experience that timeline. Going back to the study that we did with the end-stage heart failure patients who were being evaluated for this ventricular assist device, one of the surprising things that we found was that a good number of these patients were being evaluated for both the assist device and transplant. Then some of them were told later, after the fact, "Oh you're not actually eligible for transplant. You're just making a decision about this device or no device." Then some of them were told they weren't even eligible for this device. So they're being evaluated for these options and starting to engage in decision making about these options and then certain options are taken off the table. We found the same thing in the fetal center study with these hour-long consultations, when the clinicians would say, "Well, hypothetically we might offer you this or you might have these risks or these benefits but it's contingent on how these imaging tests or these lab tests turn out. So we still have to have you go through that before we know these pieces of information." It is really difficult for patients to engage in meaningful way if it's not clearly exactly what they're making a decision about and what the risks and the benefits are. I'll talk about this more in the next part of this talk.

Ways To Increase Participation



What can we do, some ideas from the evidence about how to increase participation.

Communication Techniques: Start on the Same Page (1 of 3)

- Gauge patient desire for a role.



It is very important to start on the same page by gauging from the start, the patient's desire for how much of a role they want to play.

Communication Techniques: Start on the Same Page (2 of 3)

- Gauge patient desire for a role.



- What role do you prefer to play in your visits to the physician?
 - You make all of the final decisions.
 - The physician and you make the final decisions together.
 - The physician considers some of your ideas but still makes most, if not all, of the final decisions.
 - The physician takes the initiative and decides what is best for you.

Brody DS, Miller SM, Lerman CE, et al. Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. *J Gen Intern Med.* 1989 Nov-Dec;4(6):506-11. PMID: 2585158.



There are validated instruments that you can use to measure how active a role a patient wants to play. Then clinicians can sort of hold themselves and the patient to that expectation; things may change and that should be part of an open dialog. But if you know going in that this patient wants to play really active role that should shape the way you move forward with that patient.

Communication Techniques: Start on the Same Page (3 of 3)

- Ask what patients already know and understand about their condition.
 - Knowing what information patients already have saves unnecessary repetition and can identify misconceptions.



Under the heading of starting on the same page, another important technique that might help is to start by asking the patients what they know and understand. Often we do this to check their level of understanding and that's really important but I think there's a second way in which this helps as well. If you have a patient who has already had a bunch of consults with other providers, your colleagues, or has done a lot of research and reading and they come in with the sort of spiel that they know that you're about to give them then you can focus more on questions that the patient might actually have that matter to them because we know from research that the things that a physician thinks a patient needs to make an informed decision and what a patient actually wants to know, don't always line up. So if you can create more time by bypassing the usual "spiel" and get to more substantive information, that could be helpful.

Communication Techniques: Explaining Everything (1 of 2)

■ Frame information in multiple ways.

□ Positively and negatively (e.g., survival/benefit and mortality/risk)

Armstrong K, Schwartz JS, Fitzgerald G, et al. Effect of framing as gain versus loss on understanding and hypothetical treatment choices: survival and mortality curves. *Med Decis Making*. 2002 Jan-Feb;22(1):76-83. PMID: 11833668.

Banks SM, Salovey P, Greener S, et al. The effects of message framing on mammography utilization. *Health Psychol*. 1995 Mar;14(2):178-84. PMID: 7789354.

□ In percentages and frequencies

Slot KB, Berge E. Thrombolytic treatment for stroke: patient preferences for treatment, information, and involvement. *J Stroke Cerebrovasc Dis*. 2009 Jan;18(1):17-22. PMID: 19110139.

Smith DM, Sherriff RL, Damschroder L, et al. Misremembering colostomies? Former patients give lower utility ratings than do current patients. *Health Psychol*. 2006 Nov;25(6):688-95. PMID: 17100497.

Positive:

- Chance of **remission** if treated:
60%
- **6 in 10** people will be in **remission** following treatment.

Negative:

- Chance of **recurrence** if treated:
40%
- **4 in 10** people will experience **recurrence** following treatment.



This has been stressed earlier today but the importance of explaining things by framing information in multiple ways. This is, I think, a big message that's coming out of the literature from the communication and behavioral sciences -- to frame things both in terms of the survival and the benefit. Give patients things in terms of percentages and frequencies.

Communication Techniques: Explaining Everything (2 of 2)

■ Frame information in multiple ways.

□ In tables, words, and graphs

Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: overcoming low numeracy. *Health Psychol.* 2009 Mar;28(2):210-6. PMID: 19290713.

70% of patients experience
a full recovery.



30% of patients
partially recover.

	Full Recovery	Partial Recovery
Of 20 patients	14	6
Of 50 patients	35	15

And, give them the information in multiple modalities – words, graphs, pictures -- so that depending on what works best for the individual patient, they will have a better chance of understanding what they need to understand.

Communication Techniques: Facilitate a Two-Way Street (1 of 2)

- **Assess patient understanding of the diagnostic, prognostic, and treatment information you have provided.**
 - Teach back
 - Not Good: “Do you understand?”
 - Good: “Tell me in your own words what you understand about your condition.”

National Center for Ethics in Health Care. “Teach Back”: A Tool for Improving Provider-Patient Communication. April 2006. http://www.ethics.va.gov/docs/infocus/InFocus_20060401_Teach_Back.pdf. Accessed August 11, 2015.



In an earlier presentation we heard about the importance of teach-back. How many times has our doctor asked us if we understand what they told us or if it was clear? Of course, we all just nod our heads yes, because no one really wants to speak up and say no, that we didn't understand. That approach doesn't encourage a two-way exchange. Teach-back is a much more effective approach.

Communication Techniques: Facilitate a Two-Way Street (2 of 2)

- **Use translators trained in medical terminology or remote-simultaneous interpreters to improve understanding (e.g., Flores, 2006; Hornberger et al., 1996)**
Flores G. Language barriers to health care in the United States. *N Engl J Med.* 2006 Jul;355(3):229-31. PMID: 16855260.
Hornberger JC, Gibson CD Jr, Wood W, et al. Eliminating language barriers for non-English-speaking patients. *Med Care.* 1996 Aug;34(8):845-56. PMID: 8709665.
- **Ask patients about their values and questions regarding treatment—“normative messaging” that this is encouraged.**



We also need to use trained interpreters when appropriate. Most hospitals have them as a ready resource and they're underutilized. And then another idea -- if we could somehow make it a social norm that doctors ask patients about what's important to them, or what questions they have, and that patients feel like that's a normal thing, like they're not being a difficult patient when they bring up those concerns or questions in the clinical encounter. That could really help patients be more engaged.

Communication Techniques: Help Patients Remember

- **Provide Information in Writing or in a Recording**
 - Patients can take home and review
 - Helps patients remember what was discussed

Blumenthal-Barby JS, Krieger H, Kim D, et al. Communication about fetal surgery for myelomeningocele and congenital diaphragmatic hernia: preliminary findings with implications for informed consent and shared decision-making. *J Perinat Med.* 2015 Apr 14. DOI: 10.1515/jpm-2015-0039. PMID: 25870957.

Going back to the fetal surgery study and the hour-long information delivery session, give patients things in writing but also how helpful would it be if patients also received a recording of those sessions that they could take home and listen to and process the information a little bit at a time, at their own speed.

Communication Techniques: Help Patients Remember

Decision aids had a positive impact on:

- Patients
 - Involvement, understanding, and preparedness
 - Decisional conflict and satisfaction
- Consultation
 - Physician-patient communication

Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2014 Jan 28;1:CD001431. PMID: 24470076.



You know, decision aids have had a positive impact on both patients' understanding of information, their preparedness and their involvement as well and their level of shared decision-making with the provider. Also, when thinking critically about this issue of time and timing, I think we really need to try to reduce the need for quick decisions whenever possible. These contexts, where the information is not there or it's not clear what's being offered to you and then all of a sudden it's there and you're asked to make this quick decision -- that's not really productive; it won't allow for patients to be engaged. We have to figure out how to streamline things in a way that makes a little bit more sense.

Timeline Recommendations: The Turtle Beat the Hare

- **Give patients the opportunity to reflect on the information given to them and create questions.**

- Reduce the need for quick decisions when possible.
- Get all information to patients in a timely fashion.
- Telehealth option—find additional safe spaces to engage.

Cosgrove DM, Fisher M, Gabow P, et al. Ten strategies to lower costs, improve quality, and engage patients: the view from leading health system CEOs. *Health Aff (Millwood)*. 2013 Feb;32(2):321-7. PMID: 23381525.

- Solicit social/family support and involvement.

Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012 May;31(5):1030-8. PMID: 22566443.



Options like telehealth or electronic resources such as MyChart are great opportunities for us to think about increasing patient engagement because they are safe spaces where a patient can go when they had a chance to think of more questions that maybe they didn't think of during the clinical encounter or maybe they didn't have time to ask. They can go into these modalities and ask questions that maybe they didn't have time to have in the actual face to face encounter.

The final recommendation is the importance of social and family support and involvement. We didn't specifically actually write about this finding in any of our studies but I think anyone involved in the research team would say one of the things we noticed is that in all of these cases, when patients had a spouse, family member or caregiver to take on the role of being engaged and activated a two-way street was facilitated even if the patient themselves sort of didn't feel up to it or was overwhelmed. So a support system is really useful recommendation in terms of increasing engagement.

Identification of Research Gaps

- **How do interventions at different levels (information exchange, individual decisionmaking, policy/organizational) affect engagement efforts and outcomes at the other levels?**

Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*. 2013 Feb;32(2):223-31. PMID: 23381514.

- **A systematic and efficient approach in encouraging patients to play a more active role is needed.**

Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013 Feb;32(2):207-14. PMID: 23381511.

- **In identifying patients whose preference for low involvement is authentic, it is important to know when to “nudge” those patients toward more involvement.**



I would like to 'll just talk about potential research gaps. Going back to one of the first slides talking the different ways in which patients can be engaged, it would be interesting to think about whether being engaged at one level makes it more likely that a patient might be engaged at another level. For example, as we're engaging patients more in research like PCORI, does that carry over and make them more comfortable in being engaged in their own healthcare decision-making.

Second, I think it's really important that we establish a systematic and efficient approach to encouraging patients to play a more active role in their health care. I've thrown up a toolbox of potential strategies that might work. But I think for busy clinicians if we can give them a list or streamlined list of exactly what you should do" that would be really important addition.

Finally, when we talk about identifying patients whose preference for involvement is authentic we need to think about asking them upfront what kind of role they want to play. If somebody says, "Well, I don't really want to play an active role," we want to be able to know that that is their authentic choice and when for those patients, we should nudge them into playing a more active role because it is important to their health outcomes.