

## **KILLER CURE**

### **READERS' DISCUSSION GUIDE**

This discussion guide was downloaded from [www.killercure.net](http://www.killercure.net). Please feel free to visit the website for more information about *Killer Cure* and the author Elizabeth L. Bewley.

Readers in discussion groups are welcome to select questions to answer from the list below; there's no need to feel that you have to answer them all.

Of course, all readers should feel free to abstain from answering any questions which they are not comfortable addressing in a group discussion. Readers should also feel free to alter the details of any examples they give as necessary to protect the privacy of family and friends.

#### **Chapter One**

1. How does your own experience, or that of family and friends, support or contradict the picture painted about deaths and injuries caused by health care?
2. Do you think that medical errors, hospital-acquired infections, post-surgery blood clots, and adverse drug events are inevitable? (One might call this the "You can't make an omelet without breaking eggs" perspective.) Why or why not?
3. Shannon scarcely left Bob's side when he was hospitalized. Explaining why, she said, "He was just lying in a crib in a room. They wouldn't necessarily hear him cry. If he needed something, it's not like he could press the call button." Can you think of an example from your life in which a health care provider put himself or herself in the patient's shoes as Shannon put herself in Bob's shoes? Should they do that? Why or why not?
4. Bob lived because Shannon noticed obscure details -- whether the drug in the syringe appeared clear or cloudy and the volume of the drug in the barrel of the syringe -- and spoke up. How does that story compare with your expectations about the role of patients (or their parents or other advocates) when they are hospitalized?

#### **Chapter Two**

5. What do you think accounts for the fact that nearly 10 million women are tested for cancer "in an organ that they don't have"? How would doctors need to change their thinking and behavior for this situation to change? How would the women being tested need to change?
6. One critic of the tendency to prescribe drugs to large numbers of people with mild abnormalities asked, "What if you put 250 people in a room and told them they would each pay \$1,000 a year for a drug they would have to take every day, that many would get diarrhea and muscle pain, and that 249 would have no benefit? . . . How many would take that?" Would you take a drug with that profile? Why or why not?
7. Doctors often complain that *insurance companies* try to *limit* tests and treatments to foster their own financial interests rather than the patient's well-being. This chapter provides data indicating that *doctors* may *order* tests and treatments to foster their own financial interests rather than the patient's well-being. With the insurance company

saying one thing and the doctor saying another, how might you go about figuring out if a proposed test or treatment is in fact likely to foster your well-being or not?

### Chapter Three

8. This chapter points out that the role of the individual has shifted over time. A hundred years ago individuals didn't have to do anything for big health improvements to happen. Fifty years ago they simply had to show up so that Marcus Welby, M.D. could perform his miracles. Today they need to be CEOs of their own health and health care. Do you think that most people understand that they have this job? What needs to be done to help people learn about this new role? Whose responsibility is it to educate them about it?
9. Some health care policy makers don't quite agree with the "individual as CEO" idea. They believe that patients should be "co-pilots" or "co-producers" of their health, in partnership with their doctor. What are the advantages and disadvantages to you of viewing your health as a responsibility shared with your doctor? If it's a shared responsibility, are you both equally responsible for everything? Or do you have one set of responsibilities and the doctor another set? If so, what kinds of things are each of you responsible for? How does it work if you have more than one doctor?
10. What images does the label "patient" call up for you?

### Chapter Four

11. This chapter opens with a comparison between hospital ICUs and prison camps for terrorist suspects. How did you feel when you read that section? Why?
12. Do you know people who developed ICU Psychosis or were prescribed too many drugs? What impact do you think that experience had on their long-term wellbeing?
13. Have you, or family or friends, experienced situations in which you concluded that simple, inexpensive changes on the part of care providers could make a huge difference in the patient's comfort or health? What would need to happen for these changes to be made?
14. If you had a choice, how would you like to communicate with your doctor? (In person, by phone, via e-mail, through the regular mail, or some other way.) Is there a difference between how you'd prefer to communicate and what your doctor supports?

### Chapter Five

15. Have you, or friends or family, had a treatment that didn't solve the health problem or that caused side effects that outweighed the benefits of the treatment? How quickly did it become evident that there were issues with the treatment? Who noticed the problem - the patient or the doctor? What could the individual (or parent, partner, or other advocate) do differently in similar situations in the future to get a better outcome faster?
16. Research shows that when people report side effects, doctors "very often dismiss their concerns." How would you deal with the situation if that happened to you?
17. Do you feel that your job as the patient is to follow doctors' orders? Why or why not? Does your answer to that question change if the orders involve *what* treatment to have (e.g., surgery vs. physical therapy for a shoulder problem) vs. *how* to execute the

treatment (e.g., take one pill four times a day for ten days)? Does your answer change if you experience side effects?

### **Chapter Six**

18. What does one health care expert mean when he says, "Healthcare systems have always transferred uncertainty and risk to the patient?" In what ways is that view consistent or inconsistent with your experience?
19. The author describes a two-month process to get a diagnosis when endometrial cancer was a possibility. Have you or a friend or family member had an experience in which it took what seemed like a long time to be diagnosed? How would your feelings be similar to or different from the author's in such a situation? What would you do differently in dealing with the doctors?

### **Chapter Seven**

20. How do you feel about the idea of having access to all of your own medical records? Under what circumstances would you be interested in actually reading them? Have you ever needed old medical records and been unable to get them?
21. Do you make a point of finding out if your test results are normal or not? How easy is it for you to find out? How long does it typically take to get the results? How long do you think it should take?

### **Chapter Eight**

22. Have you, or family or friends, felt that your voice simply wasn't being heard when there was a medical problem that didn't seem to fit the doctor's expectations? What would you do if you faced a situation like this in the future?
23. How would you feel if you were prescribed a drug that caused significant weight gain? What would you do?
24. Care providers in a hospital assumed that involving families would be a drain on their time. Instead, patients got better faster and nursing turnover dropped. What do you think the role of families should be when someone is hospitalized?
25. Knowing how being discounted or belittled impacts people, what can you do if you find yourself in that situation with a health care provider?

### **Chapter Nine**

26. How would you respond if you were in the emergency room and the staff reacted to you as they did to Stephen when he was being treated for food poisoning?
27. How would you respond if you were in the hospital and realized that the doctor was about to embark on the wrong procedure?
28. This chapter includes the quotation: "Many physicians are trained 'to think of [them]selves as little gods' and resist patients who question their authority." Faced with that reality, as well as the impact of Stockholm syndrome (which tends to shut people down to avoid angering those with power over them), what can you do to deal with the power disparity you face in dealing with the health care system?

29. Should doctors and nurses pay attention to patients' feelings when dealing with their physical disorders? Is it their job to do so, or is it up to patients to control their emotions so that the professionals can get their work done? What leads you to your conclusions?

### Chapter Ten

30. What are your expectations about the role doctors play in relation to you? Do you secretly want them to be gods -- all-powerful and having all the answers? What are the benefits and risks of wanting doctors to be gods?
31. Have you ever been tempted to lie to a doctor? What emotions led you to consider lying as an option? (Embarrassment? Fear? Some other feeling?) If you were giving other people advice, what would you advise about lying?
32. What examples of unintended consequences can you identify in your experiences with health care?

### Chapter Eleven

33. Of the possible process gaps on your side of the equation that you might experience in relation to a visit to the doctor's office, which have you experienced? (Examples include: not making effective choices about whether to seek medical care; masking or worsening symptoms through care at home; failing to explain the problem adequately; forgetting what the doctor said; not understanding what you were told; not following the instructions even though you agreed that they made sense; being unclear about how to translate the instructions into everyday life; and not understanding why it matters whether you follow the instructions or not.) How did these process gaps affect the outcome you got?
34. Have you or friends or family experienced other process gaps in health care delivery? Why do you think these arose?
35. Identify one situation in which you might use FMEA (Failure Modes and Effects Analysis) to solve a process problem.

### Chapter Twelve

36. What two questions are essential to ask before starting to fix a broken process? Why do these questions matter?
37. The author concludes that the purpose of health care today is to deliver acute interventions. Based on your experience, what do *you* think the purpose of the health care system is?
38. The author goes on to propose that the purpose of health care should be *to enable people to lead the lives they want*. What do you think it should be?
39. Dr. Don Berwick is quoted as saying "I have come to believe that we -- patients, families, clinicians, and the health care system as a whole -- would be far better off if we professionals recalibrated our work such that we behaved with patients and families not as hosts in the care system, but as guests in their lives." What does he mean by that? Do you agree with him?
40. Of the fourteen steps in the process of health care listed, which one or two seem to you to have the biggest or most troublesome gaps? (These include: wellness, risk assessment, prevention, early intervention, triggers, triage, diagnosis, interpretation of

the meaning and impact of the diagnosis, selection of treatment, preparation for treatment, delivery of treatment, post-treatment management, feedback loop, and integration of episode of care into life.) If it were up to you, what would you do to close those gaps?

41. What experience can you recall in which your health, or that of family or friends, suffered as a result of the fact that it was very difficult for the patient to interpret the meaning and impact of a diagnosis and figure out how to move forward? If you were advising others, what would you tell them about this step?
42. How could implementing feedback loops improve health care? What can you do in your own health care to address this gap?

### **Chapter Thirteen**

43. Pick one of the commonly discussed approaches to addressing the health care crisis. (These include: Universal Coverage, Single Payer, Regulation, Cost Controls, HIT, Comparative Effectiveness, Transparency, CDHP, P4P, Focused Care, Accountable Care Organizations, and Medical Home.) If the purpose of health care changes to be more individual-centric, are the benefits of the approach you picked more likely or less likely to occur? Why?

### **Chapter Fourteen**

44. Implicit in the book is the suggestion that the problem with health care isn't primarily financial; it's primarily about who has power -- who gets to set the priorities and call the shots. Do you agree? Said another way, if there were suddenly enough money to pay for health care for everybody without any limitations, would that fix the problems identified in *Killer Cure*?
45. Why does the author use the term "revolution?" Why does she compare efforts to change how patients are viewed to efforts that freed the slaves or granted women the right to vote?
46. The author attributes bad outcomes in health care partly to choices that professionals in the health care system make. Do you agree? Do you think that people are generally victims of circumstances, or do you believe that they can choose to act differently?
47. What two problems, according to the author, result from ceding so much power and control to the health care system? Do you agree?
48. Why does the book start to shift its focus from how the health care system behaves to how people served by the health care system behave?
49. What does the story *The Fisherman and His Wife* have to do with health care? Do you know people who have unrealistic expectations about what health care can do for them? Do you think that any of *your* expectations about what health care can do for you might be unrealistic?
50. What examples in your own life or those of family or friends can you think of that illustrate the impact of stress on health?
51. What one or two steps can you imagine taking to reduce or manage the stress in your life?

52. How can your health care be managed as a process if care is fragmented across many doctors, hospitals, labs, etc?

### **Chapter Fifteen**

53. What point is the author making by drawing an analogy between computer processing thirty or forty years ago and health care today?
54. If you were going to pick one step to start with, which of the CEO responsibilities seems most appealing to you? (These include: ask questions, keep a Personal Health Record, and learn how the health care system works.)
55. Can you think of an experience you or a family member or friend has had that illustrates a problem with one of the danger spots? (These include: diagnosis, treatment options, care delivery, and post-treatment management.) What resources might you draw on in the future to help prevent a similar problem?
56. Of the many resources listed, which one or two sound the most useful to you? How do you think they might help you?

### **Chapter Sixteen**

57. What experiences have you had of financial incentives related to your health and health care? (For example, these might include reduced insurance premiums for taking certain actions, lower co-pays for some drugs and higher co-pays for others, or other adjustments to your cost of care intended to change your decisions or behavior.) In what ways have these encouraged you to take better care of yourself? In what ways have they seemed counterproductive?
58. Have you had any experience with any of the new models of care described? (These include: retail clinics, medical tourism, telemedicine, group visits, concierge medicine, and e-mail consultations.) If so, what did you like about the experience? What did you dislike? If you haven't tried any of these, which one seems most appealing? Why?
59. What health-related games have you or family members or friends played? How did the experience affect your health or your thinking about your health and health care?

### **Chapter Seventeen**

60. What health improvement changes have you made that you've been able to stick with for a while? What do you feel has contributed to your success?
61. One source notes that people with multiple health problems are treated "as collections of malfunctioning body parts rather than as whole human beings. . . . And treating one disease in isolation . . . can make another disease worse." In other words, treating each body part separately can make diseases involving other body parts worse. Have you, or family or friends, experienced this problem?
62. What experiences have you had of doctors, nurses, or other health care professionals saying something to you that engaged and energized you?
63. What examples can you think of in which you, or family or friends, had a voice in deciding what test or treatment to have and decided to do something different from the doctor's initial suggestion? What led to the decision? Are you (or family or friends) glad

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- that you made that choice? If you have not had this experience, how would you go about getting a voice in the next decision you face about a major test or treatment?
64. How have you used -- or how might you use -- social networking sites to help improve your health?
65. What other changes do you think will happen in health care when you are treated with more respect and when its purpose becomes *to enable people to lead the lives they want*?

**Conclusion**

66. The book's title, *Killer Cure*, could have more than one meaning. What does it mean to you?
67. How will you change the way you deal with your health and health care, and how you talk with others about health care, as a result of reading *Killer Cure*?

*Please note that sources for all quotations are identified in the related chapters in Killer Cure.*