

Dodson01
Patient Preferences
Version1
Patient Preferences

Participant ID code

COVER

Interview Date

Interviewer ID #

- Interview Outcome** 1 - **COMPLETED**
..... 2 - **Partial (refusal)**
..... 3 - **Partial (other)**
..... 5 - **Partial (Medical Condition/Illness)**
..... 6 - **Partial (Other)**
..... 7 - **Not Done: Other**

Specify

Introduction and Consent

Hi, my name is [name of interviewer] and I am calling from Yale School of Medicine as a follow-up to the letter we sent you in the mail last week. We are conducting a study of patients who have received an implantable cardioverter-defibrillator, also known as an ICD, at Yale in the past. We are trying to get a sense of patients understanding about their devices, and whether there were situations where they would want the shocking function of their device deactivated if they were very ill. The interview should last about 30 minutes, and you will be compensated 25 dollars for your time. Are you willing to speak with me, and if so is now a good time?

1. Is this a good time to talk? 1 - Yes
2 - No

Chronic Conditions

Do you have, or have you had in the past, any of the following medical problems?

	Yes	No
1. Heart Attack	1	2
2. Congestive heart failure	1	2
3. Peripheral vascular disease	1	2
4. Stroke	1	2
5. Dementia	1	2
6. Chronic lung disease	1	2
7. Connective tissue disease	1	2
8. Ulcer disease	1	2
9. Liver disease	1	2
10. Diabetes	1	2
11. Hemi-paralysis	1	2
12. Kidney disease	1	2
13. Cancer	1	2
14. Liver disease	1	2
15. Dizziness	1	2
16. Chronic pain	1	2
17. Frequent falls	1	2
18. Hearing loss	1	2
19. Vision loss	1	2
20. Incontinence	1	2
21. Arthritis	1	2

Depression

Over the last 2 weeks, how often have you been bothered by any of the following problems?

1. **Little interest or pleasure in doing things**
- 1 - **Not at all**
 - 2 - **Several days**
 - 3 - **More than half the days**
 - 4 - **Nearly every day**
2. **Feeling down, depressed, or hopeless**
- 1 - **Not at all**
 - 2 - **Several days**
 - 3 - **More than half the days**
 - 4 - **Nearly every day**

Activities of Daily Living

Do you have any problems with doing any of the following by yourself?

	Yes	No
1. Feeding	1	2
2. Bathing	1	2
3. Dressing	1	2
4. Using the toilet	1	2
5. Transferring from bed to chair	1	2
6. Shopping	1	2
7. Preparing meals	1	2
8. Housekeeping	1	2
9. Laundry	1	2
10. Transportation	1	2
11. Taking medications	1	2
12. Handling finances	1	2

ICD

1. What do you feel are the potential benefits of your ICD?
(Responses will be open-ended; general themes may include "to deliver a shock if heart stops", "to pace heart", "to prevent heart attack", etc.)

2. What do you feel are the potential harms of your ICD?
(Responses will be open-ended; general themes may include "giving an inappropriate shock", "getting infected", "needing the battery replaced", etc.)

3. How many years ago did you receive your ICD? (if you don't know exactly, you can give approximate number of years)

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4. Have you ever received a shock from your ICD?

- 1 - Yes
- 2 - No

5. Are you aware that the shocking function of your ICD can be deactivated by your cardiologist?

- 1 - Yes
- 2 - No

ICD Follow-up

As you may know, the purpose of your ICD is to deliver an electrical shock to your heart if it goes into a life-threatening abnormal rhythm. Most of the time the device is just listening to the heartbeat, and as long as the heartbeat is normal, it doesn't do anything. If your heart does develop a rhythm which otherwise might be lethal, it will give the heart a shock. As your doctors have probably explained to you, if you haven't received one previously, a shock is like a kick in the chest. The device is not the same as a pacemaker, which provides a continuous electrical input that paces the heart. All ICDs do have a pacemaker function, but the shocking and pacemaker functions work separately.

Approximately 25% of ICDs deliver a life-saving shock during the lifetime of patients who have received them.

A physician may deactivate an ICD if a patient does not wish to receive any more electrical shocks, without affecting the pacemaker. Sometimes patients are at a point in their lives when the ICD may seem like more of a burden than a benefit and they choose to ask their doctor to deactivate it, to avoid painful shocks from the device when the end of their life may be approaching. Everyone feels differently about this. For the purposes of this questionnaire we are only going to be talking about the shocking function of the device.

Before survey part 2, if subject's answer to questions ICD 1 2 imply they don't know function of their ICD

- | | |
|---|----------------|
| 1. Did patient responses imply they don't know function of their ICD | 1 - Yes |
| | 2 - No |

Survey Part 2

The next set of questions refers to the ICD function of your device, and not the pacemaker function. I am going to give you five hypothetical scenarios, and I would like you to answer on a scale of 1 to 5 for each question. 1 means 'definitely no', 2 means 'possibly no', 3 means 'uncertain', 4 means 'possibly yes', and 5 means 'definitely yes'. Since this is a research study, your answers are confidential and will have absolutely no effect on your usual care. They will not be shared with your cardiologist

1. Do you think you would want the ICD turned off if you were permanently unable to get out of bed by yourself, and needed other people to help you get up?

SCALE: 1 (Definitely No) to 5 (Definitely Yes)

2. Do you think you would want the ICD turned off if you had permanent memory problems, so that you could no longer recognize your friends or family members?

SCALE: 1 (Definitely No) to 5 (Definitely Yes)

3. Do you think you would want the ICD turned off if you were ill for a long time and caring for you was a significant burden to your family members?

SCALE: 1 (Definitely No) to 5 (Definitely Yes)

4. Do you think you would want the ICD turned off if you were ill in the hospital on an artificial breathing machine for longer than one month?

SCALE: 1 (Definitely No) to 5 (Definitely Yes)

5. Do you think you would want the ICD turned off if you had an advanced disease that was incurable, such as metastatic cancer?

SCALE: 1 (Definitely No) to 5 (Definitely Yes)

6. Are there any other situations that you have thought about or discussed with your cardiologist where you would want your ICD deactivated? (responses will be open-ended and recorded by the interviewer).

Patient Preferences when ill

The following set of questions refers to other preferences that people may have when they are very ill. Again, your answers will not affect your health care at all, and everything is completely confidential. I would like you to answer on the same scale as above: 1 means 'definitely no', 2 means 'possibly no', 3 means 'uncertain', 4 means 'possibly yes', and 5 means 'definitely yes'

1. **Do you think you would want to be kept alive by artificial feeding (such as a feeding tube) if you were unable to take food by mouth?**
SCALE: 1 (Definitely No) to 5 (Definitely Yes)
2. **Do you think you would want to receive dialysis if your kidneys failed?**
SCALE: 1 (Definitely No) to 5 (Definitely Yes)
3. **Do you think you would want to be on a mechanical ventilator for a prolonged period of time (greater than one month), if you were unable to breathe on your own?**
SCALE: 1 (Definitely No) to 5 (Definitely Yes)

Questions

AFTER PATIENT PREFERENCES QUESTIONS:

Just as a reminder here at the end of the interview, this discussion is just for research purposes, and will not impact your clinical care in any way. Your answers here will not be shared with your physician, and you should discuss your wishes with your doctor should the occasion arise.

Thank you very much for your time. Thank you again

4. Do you have any questions before we conclude?
- 1 - Yes
 - 2 - No