Patient Decision-Making Modes and Causes: A Preliminary Investigation

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Abstract

A recent study of patient decision-making regarding acceptance of an implantable cardiac defibrillator (ICD), provides a substantial but non-random sample (N= 191) of telephone interviews with persons who have made an affirmative decision regarding an ICD. Using a coding scheme developed through qualitative analysis of transcribed interviews, the data can be subjected to exploratory statistical analysis. The reasons given by respondents for getting the ICD differed by both region and gender, and show some correlations with whether the device has or has not delivered any stimulation ("shocks") since implantation. Cluster analysis reveals association among certain important themes in the discussion of the decision process, particularly linking rather opposite concepts into clusters related to specific dimensions. The results suggest the importance, to patients, of maintaining the integrity of the self by asserting control and independence. The majority of the respondents (61%) have not received the primary intended benefit, of the device (stimulation). Thus the findings suggest that psychological benefits alone of having the device (such as anxiety reduction) serve to justify acceptance of a computerized device. Implications for other lines of computerized health support and for further study of these issues are discussed.

Key words: implantable cardiac defibrillator, patient decision-making; computer devices; patient communication.

1 Overview and Statement of the Problem

Computer instrumentation of living environments promises to extend the independent life span of our aging populations. This instrumentation is increasingly referred to as "computer assisted homes," "instrumented homes," and "wired homes" - a physical space employing monitors and sensors of human vital signs in real time networked to healthcare professionals. The contemporary version of this networked connectivity is the RFID tagged electronics and appliances found today within the home. This technological potential will not be realized unless people are willing to trust their lives to such support systems as a replacement for human support. Yet very little is known about how and why people make these important decisions to trust this technology and integrate it into their lives. The current report, drawing on data collected in a large project to investigate this issue, presents some key numerical findings about how and why people agree to place their life in the hands of computerized equipment that they cannot fully understand or control. Since there are not yet people living in fully realized "computer assisted homes" as we have defined them, we choose, as a surrogate population, patients with cardiac ailments who have adopted a computer-dependent life-saving device, the implantable cardiac defibrillator (ICD). The ICD is an increasingly popular option; 112,678 patients were implanted in the U.S. between January 1, 2006 and June 30, 2009 (Al-Khatib et al., 2011). Our sample is drawn from the analysis of nearly two hundred (N=191) telephone interviews with patients in three regions of the United States. Details of the full study and analysis are given in (Gal, Bullinger, & Kantor, 2011). The interviews use a progression of open-ended questions, in order to capture the process *as patients themselves see it and describe it.*

There is an enormous technical literature on making computers more usable, or more effective for their human users (for example the SIG-CHI conferences (http://tochi.acm.org/). There are interesting relations between usability and non-technical characteristics of systems such as aesthetics (Tractinsky, Katz, & Ikar, 2000) a lesson that has been well understood by Apple Inc. But, while there are important programs that address the issue of making computers more usable, there has been very little study of *how people decide to trust* computers when the computer plays a direct role in health and may have to play a life-saving role. Our research questions for this study include:

1. Which factors or combination of factors are most salient in the patient's decision-making?

2. Are there regional differences in the prevalence of the thematic codes developed by the qualitative coding activity?

3. Are differences between the thematic codes attributable to differences in demographic characteristics of respondents?

A quantitative analysis allows us to detect patterns and relationships that telephone survey data in the patient's own words and perspectives cannot provide directly. The questions above are moored within the understanding that the decision-making process is situated in the context of the patient-doctor relationship; which relationship acts as a constant mediator between a potential

implantee and ICD. Dimensions of this relationship are fleshed out via previous scholarship in section 3.

The details of our qualitative analysis are given in (Gal et al., 2011). We summarize only the relevant points in Section 2. Section 3 reviews closely related work on health-related decision-making and the doctor-patient dynamic. Section 4 summarizes the key qualitative codes developed in analysis of the interviews. Section 5 examines quantitative relationships among the codes themselves, and their relations to some demographic variables. Section 6 presents conclusions, limitations, and implications for future work and for computer-assisted living.

2 Materials and Methods/Procedures

2.1 The Study Population

The interview protocol and questionnaire were approved by the Rutgers University IRB. One participating hospital judged that, under the method sketched below, the hospital staff was not actually involved in research with human subjects, a position adopted subsequently by other medical organizations. We recruited doctors by a snowball method, both via physicians we knew and direct outreach to electrophysiologists in the Heart Rhythm Society. Four participating electrophysiologists mailed our invitation and consent packets directly to their qualifying patients[1]. The signed consent was mailed (pre-paid) to us by the patient, so that only those patients who consent to participate in the research are known to the researchers, and participating doctors do not know which of their patients responded. Trained interviewers contacted the respondents to complete a short telephone interview. Of 570 invitation packets; we received 231 returned consent forms (40.5% return rate).

The 191 respondents' interviews (27% female; 73% male; 61% received no shocks; mean implant time 5.39 years; 71% White) are in three different geographic locations: Central and Northern New Jersey, New Mexico and Tennessee, which provides the basis for some quantitative analysis by regions.

2.2 Participant Interviews

Some 32 patients who returned consent forms were not interviewed (language barrier, communication problems, deceased etc.) and an additional 8 could not be reached via telephone. The completed interviews are between 15 to 45 minutes long. Our attempt at snowball recruiting through respondents generated only 7 such referrals, yielding 5 of the 191 completed interviews. Respondents completing the full interview received $50 (gift card) compensation; payment for partial responses was prorated. All telephone interviews were digitally recorded, transcribed and coded.

Most of the 31 questions are open-ended and range over: the number of "shocks" received, documentation consulted while deciding, use of home monitoring, consultation with others regarding the decision, main concern(s) about the device, benefits/drawbacks of the device, why the decision was easy or a hard decision, negatives and positives about having the device, factors most helpful in making the decision, and demographic data such as gender, age and race/ethnicity.

2.3 Coding and Analysis

Coding is described in detail in (Gal et al., 2011) and followed the principles of "grounded theory" as described in (Glaser & Strauss, 1967). The NVivo9 software provided a data management framework, useful for multiple coders. Initial codes were developed by one person, studying 42 transcripts. The resulting 91 specific codes were organized into 8 broad categories or "parent codes." Other coders were trained from a coding book, and then retrained after review of the intercoder reliability results for the first 6 transcripts coded. Intercoder reliability was established on 20 transcripts each analyzed by all three coders. NVivo's intercoder reliability analysis is somewhat unusual. It counts bytes of the underlying file. Thus a slight disagreement about where a particular utterance begins or ends can significantly reduce the NVivo kappa-values[2]. Generally, the three coders agreed on 37% and 45% of the bytes, with kappa values ranging from .01-.99. Most of the kappa values fell within the "moderate" to "almost perfect agreement ranges." For this analysis, codes with kappa less than 20% were eliminated. Those with $20\% < \kappa < 50\%$ were subsumed into the most appropriate broader category. Demographic information and answers to close-ended questions were merged with this coding data. The statistical analysis reported here was applied only to codes mentioned by 20 or more respondents (i.e., more than 10% of the total set of respondents).

3 Review of Related Work

This study grows out of an effort to understand patient decision-making about accepting computerized health maintenance. The long-term goal is to understand how to best move towards patient acceptance of such technologies, with anticipated patient benefits, and demonstrable social (cost) benefits. To achieve this goal, we need to first look at scholarship regarding health-related decision-making, the doctor-patient relationship, and the levels of patient involvement (active versus passive). An evolution towards shared decision-making between doctor and patient has led to many studies on shared decision-making in the context of specific treatments. Brody (1980) called for "mutual" participation. Today this notion has replaced the paternal doctor model, but the new ideal may over-simplify the division of roles (physician/facts and patients/values), leaving physicians too much under the direction of patients. Charles, Gafni, & Whelan (1997) propose a more complex model with sharing information, building consensus, and reaching agreement on treatment between doctor and patient. Not all patients may wish to be involved. (Say, Murtagh, & Thomson, 2006) explored factors that influence patients' preference for involvement, finding associations with demographics, previous illness and medical care, and health status, as well as the type of decision, attitudes towards involvement, and relationship with health professionals. The variables "level of education" and "functional health literacy" may affect how individuals conceptualize their involvement in healthcare decisions (Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). A more extensive review of the literature is given in (Gal et al., 2011).

A study on patients' perception of their involvement in routine medical care (Brody, Miller, Lerman, Smith, & Caputo, 1989) found it useful to classify patients perceptions of their involvement as active or passive, which we find useful in (Gal et al., 2011). Real life relationships between patient and doctor and decision-making scenarios most likely would include a more nuanced range with varying degrees of activity and passivity within particular patients at particular moments. For the purposes of this study, the active and passive roles as discussed in the literature act as analytical ideal types. Strikingly, in (Brody et al.) 27% of the

patients "actively" involved in their medical treatment reported improvement in their general medical condition; only 7% of the patients who were passively involved reported improvement. This spectrum of activity versus passivity is also moored within the seeking of information to inform the decision during health changes. A *model of information practices in everyday life information seeking* (McKenzie, 2003) was developed from studying Canadian women pregnant with twins and included seeking and scanning (active) and non-directed monitoring and by proxy (passive). This same model is later applied to the information practices of peri-menopausal women (Yeoman, 2010) in order to check the model's utility and fit to other health-related decisions.

Several European studies yielded additional work on patient involvement in decision-making. A study in the Netherlands has found patients' involvement in decision-making increased, especially for younger patients, after passage of the Medical Treatment Act (van den Brink-Muinen et al., 2006). A study in Germany (Schildmann, Grunke, Kalden, & Vollmann, 2008) on decision-making (for rheumatoid arthritis) found a multi-stage decision process with shifting of control and responsibility from doctor to patient. Back in the U.S., patients with heart failure (Matlock, Nowels, & Bekelman, 2010) were found to use either active (55%) or passive (45%) decision-making styles. Active participation was associated with "difficult decisions." Passivity was associated with notions such as not seeing the decision as difficult, trust in God and the physician, and the power of the physician. In Sweden (Agård, Hermerén, & Herlitz, 2004) found that cardiac patients, often, have low levels of knowledge. In a British study of patients undergoing arteriography (Burton, Blundell, Jones, Fraser, & Elwyn, 2010) only 33% of patients wanted to share decision-making with their caregiver. Fully 34% of them did not want to take any part in the decision-making. Not surprisingly, patient preference for shared decision-making decreases with increasing severity of the cardiac disease. This suggests that for adoption of computer assisted living, which should occur when the patient is not severely affected, the levels of active participation will be high.

Most strikingly, and closely related to the present work, a study in Sweden of ICD patients (Agård, Lofmark, Edvardsson, & Ekman, 2007) using open-ended questions, revealed that *none* of the Swedish patients with moderate heart failure discussed alternative drug treatment options, nor had they been informed of alternate treatment by their doctors. Generally, these patients felt the decision was too complicated for them to make, and that they had to rely upon their doctor's recommendation for their treatment options. Patients asked only whether the device would save them from fatal arrhythmias. While our study certainly included such responses, alternatively, it also contained more active patient perspectives on their role in the ICD decision-making process in the United States. This activity and passivity as mentioned in the various literatures regarding patient involvement in the decision-making process is also situated within our thematic structure (physical, psychological, social, and no decision) regarding the reasons why the patient chose implantation.

4 Methods

We analyzed relations between the frequencies of qualitatively coded data on factors affecting the decision, regional, and demographic data. This study includes no information from medical

records. The literature suggests that such information does bear on the patient's decision-making. Frequencies of the 91 qualitative codes were exported from NVivo9 software into spreadsheets and chi-square was run on combinations of demographics, region, closed-ended telephone survey questions, and the qualitative codes. Our sample is not drawn randomly; the statistics presented here represent a convenient numerical way of summarizing some important apparent relations. The results cannot be assessed for "statistical significance" for several reasons. First, as noted, the sample is not random. Second, we have applied qualitative and exploratory methods, and have looked at the data in many ways. We report here only those findings showing the strongest association. Under the customary null hypotheses (no relation) some fraction of these would have occurred by chance, even if there were no systematic relation among the variables (the null hypothesis). As introductory context, we present in the next section the thematic codes culled from our qualitative analysis, which helps to situate our quantitative results.

5 Findings

5.1 Key Themes

The detailed qualitative analysis (Gal et al., 2011) reveals that reasons for deciding to be implanted fall[3] into two general categories. We conceptualize these as (1) **contributing factors** and (2) the patient's **relation to the doctor.** The high level branches of the resulting taxonomy are shown in Exhibit 1. Within each category, sub-themes emerged as patients detailed their reasons. These themes are not exclusive, and most respondents report combinations of sub-themes. However, in many cases, some dominant theme seemed to emerge from the full interview, appearing in several answers. Table 1 summarizes the number of patients who mention each major theme. The dominant themes are the ones we have labeled as "manage a problem (prevent) recurrence" and "want to live – save my life."[4] Echoing the finding of Matlock et al., we group these themes as representing an active relationship to the decision. In Table 1 we see that both of these active themes occur more frequently than two themes that seem to us to represent a passive stance: the doctor as an authority figure, and "health event prompted me." The two modalities, active and passive, continue to be interwoven as we move down the list of leading themes. Some are clearly passive (e.g., "just agreed", mentioned by 24% of respondents) and of course these themes appear in many combinations in the individual narratives.

1. **Contributing Factors**
    a. *Physical Reasons* (**Manage Health Problem**, *Health Event Prompted Me*)
    b. *Psychological Reasons* (**Peace of Mind-Safety Net, Want to Live-Save My Life,** *Afraid to Die*)
    c. *Social Reasons/Family Involvement in Decision* (Family Members a Factor in Decision, Confirm with Others/Help with Decision)
    d. *No Decision/Event Forced Me* (*Just Agreed, No Choice, Need It*) These appear in narratives where the impact of the event seemed (to the patient) to minimize or nullify and chance of agency.
2. **Doctor's Role**
    a. *Status/Expert* (*Authority Figure*)
    b. *Quality of the Relationship* (**Confident in Doctor**)
    c. *Evaluation and Explication of Evidence* (**Detailed Explanation-Test Results**)

Exhibit 1. Principal considerations affecting patient decision-making. In this outline, **bold font** represents considerations that we regard as "active" while *italic font* represents those that we consider to be more passive.

5.2 Prevalence of Thematic Responses

Table 1. Major decision-making themes for respondents with an ICD (telephone survey, N=191 respondents). The specifics of each code are detailed in (Gal et al., 2011).

Theme	Number of Respondents (1)	Percent (%)
Recurrence-Manage problem	111	58
Want to Live-Save my life	110	58
Authority Figure	83	43
Health Event Prompted Me	73	38
Detailed Explanation-Test results	64	34
Confident in Doctor	60	31
Need it	58	30
Family a factor in decision	56	29
Peace of Mind-Safety Net	55	29
Just Agreed	45	24
Others helped with Decision	45	24
No Choice	44	23
Confirm Decision with Others	44	23
Afraid to Die	40	21
(1) Most patients mentioned several themes in the course of the interview.		

5.3 Regional Variations in the Prevalence of Themes

We have noted several studies in other countries, and would not be surprised to find differences among countries, in attitudes and practices regarding medical decisions. The United States is a large country, with strong homogenizing cultural influences (television, cinema, the Internet); however, there are notable differences among, for example, regional dialects. With this is mind, we extended the analysis summarized in Table 1, to look for interactions of this distribution, with the demographic data.

Since patients were, in all cases, local to their treating physicians, we used the anonymizing code representing the physician to represent the corresponding geographic regions (Northeast, the South, and the Southwest). We culled patient interviews from four physicians within these three regions; two from the Northeast, one from the South, and one from the Southwest.

Chi-squared tests were used to screen many possible relations among these variables. Since scores of relationships were examined, we cannot assign statistical significance to the specific values of chi-squared, and the *p-value* is reported here only to indicate the relative strength of the

various relationships we find. For true confidence one would need a random sample and a preset hypothesis to be tested.

5.3.1 **Regional Differences**

There are substantial differences among regions for the contributing factors. These included physical reasons (a health event prompted the decision [passive]) and psychological reasons (peace of mind and safety net [both active]) (see Table 2b). Table 2a summarizes complex data. We detail the meaning for one case.

Each χ^2 analysis references a two-variable cross tabulation, such as is shown in Table 2a.

Table 2a. A single χ^2 analysis

	Northeast	South	Southwest
"Peace of Mind/Safety Net"	41	5	8
Did **not** mention this theme	62	27	43
Sums	103	32	51
Odds for SafetyNet	41:62=0.66	5:27=0.19	8:43=0.19

These data provide several useful statistical indicators. The $[\chi^2 = 18.1; p = .0012]$ value is an overall indication that the observed differences among the columns is very unlikely to have occurred by chance. The corresponding probability is: $p = 2 \times 10^{-6}$ which is reported by the statistical package (SPSS) as 0.000. More informative is the information on odds ratio, which can be derived from this table. We can contrast those patients from one specific region with each of the other two. Since there are only three possible comparisons among the three regions, we summarize them by giving three odds ratios (of which two are independent). For Northeast compared to South the odds ratio is 0.66/0.19, which is 3.57. The exact calculation for Northeast:West odds ratio is not quite exactly the same, and is 3.54. Finally, the odds ratio for South:West 1.00; if the chi-squared value were quite small (indicating no statistically significant differences among the regions) then the odds for each of the three regions would be very similar. Expressing differences in terms of the ratio of the odds is very convenient for comparing regions with different numbers of respondents. We summarize these results by saying that patients in the Northeast sample are 3.57 (or "approximately three and one half") times more likely as those in the other regions to mention "peace of mind" as a benefit of having the ICD device.

We do not repeat this detailed analysis for each regional finding, but rather summarize the observed *positive* number of cases in each region, and the ratios of the odds in each region. It is not quite possible to reconstruct the underlying data from these summaries, and the details are available on request.

Northeast patients are 2.6 times more likely than those in the South to report that a health event prompted them to get the ICD device. Patients in the South are 1.3 times more likely than those

in the Southwest to report that they got the ICD due to a health event. The third odds ratio contains no new information, since it is, logically, the product of the first two numbers.

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Table 2b. Association of geographical region and some specific themes

Categorical Variables	U.S. Regions			Odds Ratio		
	Northeast	South	Southwest	Northeast / South	South / Southwest	Northeast / Southwest
Peace of Mind-Safety net $[\chi^2 = 18.1; p = .0012]$	41	5	8	3.6	1	3.6
Health Event Prompted Me $\chi^2 = 26.3;\ p = 2\times10^{-6}$	52	9	12	2.6	1.3	3.3

The Nature of Conversation with Others

As one would expect, there are some interesting details available on the respondents who reported social reasons or family involvement in the decision as a contributing factor; specifically the sub-themes of *confirm their decision* [active] with others or *have others help them* [passive] make the decision. Discussion of the decision with others (besides their physician) is analyzed with respect to four reasons or sub-codes: to confirm their decision [active], to help them decide [passive], to inform the others of already made decision [active], and that others made the decision for them [passive]. We acknowledge our assumption that the patient initiates these conversations; which may not be true in all instances. This assumption is rooted in a scenario beginning with a routine consultation between doctor and patient or emergency situation between patient and emergency room personnel. However, in both scenarios, significant others and assorted family members may be included within the initial dialogue, especially in cases of elderly patients or split-second emergency room decisions when the patient is unable to provide consent.

We see "confirm with others" as an active relation to the decision, although "not confirming with others" could be viewed as an "even more active" role in the decision. Not surprisingly, those who spoke with others in order to "confirm" and those who spoke to "help them decide" were coded at almost identical frequencies, with "informed them of decision" slightly lower. Typically on each code the odds ranged from 2.5 to 3.4 that the conversation was used to confirm, help decide, or to inform them of decision. Only about one person out of twenty-five is coded as having "others made the decision for me" (see Table 3).

Table 3. Reasons for discussing the decision with others (N=154 who discussed the decision with others).

Confirm with Others	Not Confirmed		Ratio
43	111	Yes	2.58
Help Me Decide	Did Not Help		Odds
44	110	Yes	2.50
Informed Them of Decision	Did Not Inform		Odds
35	119	Yes	3.40

Others Made Decision for Me 6	I Made Decision 148	Yes	Odds 24.67

5.3.2 **Talking with Others and the Active-Passive Distinction**

Obviously, discussion of the decision with others has significant interrelation with a number of related sub-themes such as "family members were a factor in the decision,"[5] and that confirming with others" [active] helped in the decision within the contributing factor of social reasons (Table 4). Somewhat more surprisingly, discussion of the decision with others (social reason) is also correlated with both the contributing factor of "health event forced me/no choice" and the doctor's status as "expert." The specific sub-themes that corresponded include the respondents' tendency to say that they "need(ed) it [the ICD]" (p-value = 0.01) [passive], "health event prompted me" (p-value = 0.02) [passive], "no choice" (p-value = 0.03) [passive], and doctor as authority figure (p-value = 0.04) [passive] (see Table 4). Patients who do report that "talking with someone helped them decide" are 7.8 times as likely to report that "family members were a factor in their medical decision-making;" they are 8.2 times as likely to have "confirm(ed) their decision with others;" more than twice (2.6 times) as likely to report that "they needed the ICD," and are 2.3 times as likely to report that a "health event prompted them" to get the ICD. In addition, those patients are 2.5 times more likely to report that they had no other choice but to get the ICD as a treatment for their cardiac problem.

Finally, the patients who reported that "talking with someone helped them," are twice as likely to report that they "view the doctor as an authority figure" in their medical decision-making.

Table 4. Themes associated with discussing the decision with others.

Categorical Variables	Did Talking with Someone Help You to Decide?		Odds Ratio
	Yes	No	
Family Members a Factor in Decision $[\chi^2 = 19.9; p = .000]$	51	5	7.8
Confirm with Others/Help with Decision $[\chi^2 = 6.5; p = .0107]$	70	9	8.2
Need It $[\chi^2 = 6.2; p = .0125]$	47	11	2.6
Health Event Prompted Me $[\chi^2 = 5.3; p = .0215]$	57	16	2.3
No Choice $[\chi^2 = 4.7; p = .0302]$	36	8	2.5
Authority Figure $[\chi^2 = 3.9; p = .0470]$	63	20	2.0

5.3.3 **Gender Differences**

We found five concepts or codes that were distributed quite differently with regard to gender (see Table 5). Our sample total (191 interviews) breaks down across gender as follows: there were 140 men and 51 women. Four of the variables were contributing factors including psychological (afraid to die) and social reasons (confirm with others/help with decision), as well as believing there was no decision or that the health event forced the patient into the decision (no choice and need it). One theme under doctor's role (detailed explanation-test results) is also associated with gender. Specifically, women are 2.9 times more likely than men to state that they are "afraid to die" [passive] (p-value = 0.003), and this is one of the main reasons to get an ICD. Women are also 2.4 times more likely than men to report that they had "no choice" [passive] (p-value = 0.01), but to get an ICD. Oddly, they are 2.2 times *less* likely than men to report that they "needed the ICD" [passive] (p-value =0.02). Both men and women "confirmed their decision with others" [active] and let "others help them decide" [passive] about their medical treatment. However, women are 2.7 times more likely than men to confirm their decision with others [active] (p-value = 0.02). Women are also twice as likely to report that their doctor gave them an explanation using test results and other data to help them understand their current heart condition and what medical options they had [active] (p-value = 0.04).

Table 5. Gender differences and associated themes (N=191; 140 men and 51 women).

Categorical Variables	Gender		Odds Ratio
	Men	Women	
Afraid to Die [$\chi^2 = 8.7; p = .0033$]	22	18	2.9
No Choice [$\chi^2 = 5.9; p = .0152$]	26	18	2.4
Need It [$\chi^2 = 5.4; p = .0205$]	36	22	1/2.2
Confirm with Others/Help with Decision [$\chi^2 = 5.3; p = .0211$]	56	33	2.7
Detailed Explanation-Test Results [$\chi^2 = 4.2; p = .0405$]	41	23	2.0

5.3.4 **The Device as a Life-saver**

The most fundamental reason for implanting an ICD is to be able to automatically provide defibrillation in the event of ventricular fibrillation. The defibrillating signal is referred to informally as a "shock," since it is, in fact, and electrical shock. A substantial number of the persons we interviewed are not aware of ever having received a shock (N=191; 117 had no shock, 70 did have a shock, and 4 were not sure). It is plausible that there may be some relation between their experience of defibrillation and their description of the device in terms that code to "saved my life."

We did, indeed, find a correlation between the number of shocks received and the code "saved my life" (when respondents said "save my life" [active] was a benefit of having the ICD (p-value = 0.004), see Table 6 and Figure 1). To save my life was a contributing factor for the decision-making and falls under psychological reasons for agreeing to implantation.

Table 6. Responses coded "saved my life" by number of shocks				
Number of Shocks	N	"Saved my life"	NotSaved	Odds
0	122	24	98	0.24
1	25	9	16	0.56
2-4	17	5	12	0.42
5-10	18	5	13	0.38
>= 11	9	6	3	2.00

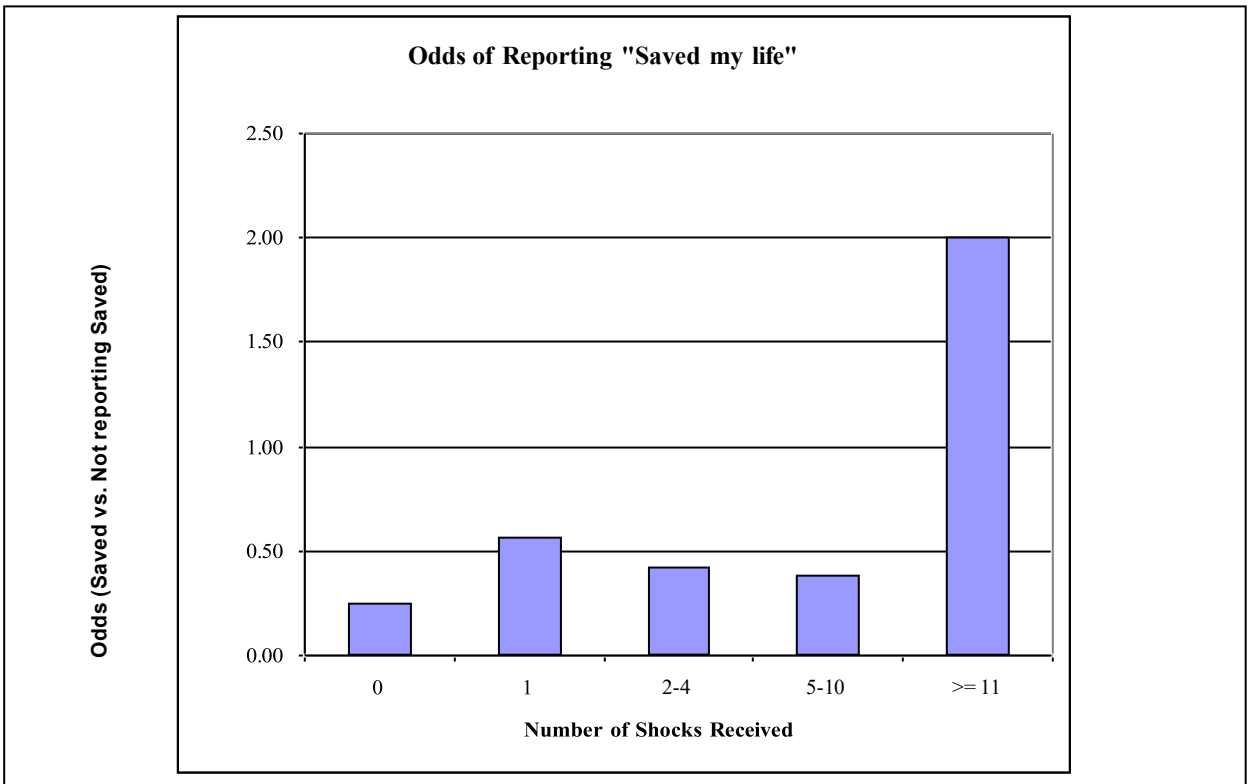

Figure 1. The odds that a patient will respond with the code "saved my life" are lowest (about 1 to 4 against) for the large group (122 respondents) who are not aware of having received any shock. In the group who have received more than 10 shocks, the odds are 2 to 1 in favor of reporting this code. While one expects a steady growth, the statistics on the intermediate blocks are low enough that the apparent drop could easily be due to random variation. (The actual numbers responding "saved" are 9, 5 and 5, in those three blocks.)

Another way of looking at this information is to compare those people who did report that the device "saved my life" to those who did not, breaking them into the group that received no shocks, and those who have received one or more shocks. Here, odds ratio analysis reveals that patients who have received shocks from the ICD are 2.15 times as likely to report that it "saved their life" compared to the patients who did not receive any shocks.

Table 7. Shocks and benefit of saved my life

Categorical Variables	Have You Received Any Shocks?		Odds Ratio
	Yes	No	
Saved My Life [$\chi^2 = 3.86; p = .0493$]	25	24	2.15

5.3.5 **Time Since Implantation**

We also find an association between the number of years that the patient has had the implant and the contributing factor and psychological reason "afraid to die" [passive]. Those respondents who have had the device between 5 to 10.5 years were most likely to say they got the device because they were "afraid to die." There is an apparent monotone trend in the odds ratio (increasing with the number of years implanted, see Table 8 and Figure 2), except for the apparent dip from the first group to the second. We cannot assert that this indeed is a dip, as the first group has a very small number of positive cases, and reasonable variation in that number would restore monotonicity in Figure 2. Overall, the dependence of the odds on the number of years implanted is statistically significant (p-value = 0.01; see Table 9).

Table 8. Responses coded "afraid to die" by number of years implanted

Number of Years Implanted	N	"Afraid to Die"	Not Afraid	Odds
Less than 1 year	16	3	13	0.23
1 to 4.75 years	84	10	74	0.13
5 to 10.5 years	73	19	54	0.35
from 12 years and over	18	8	10	0.80

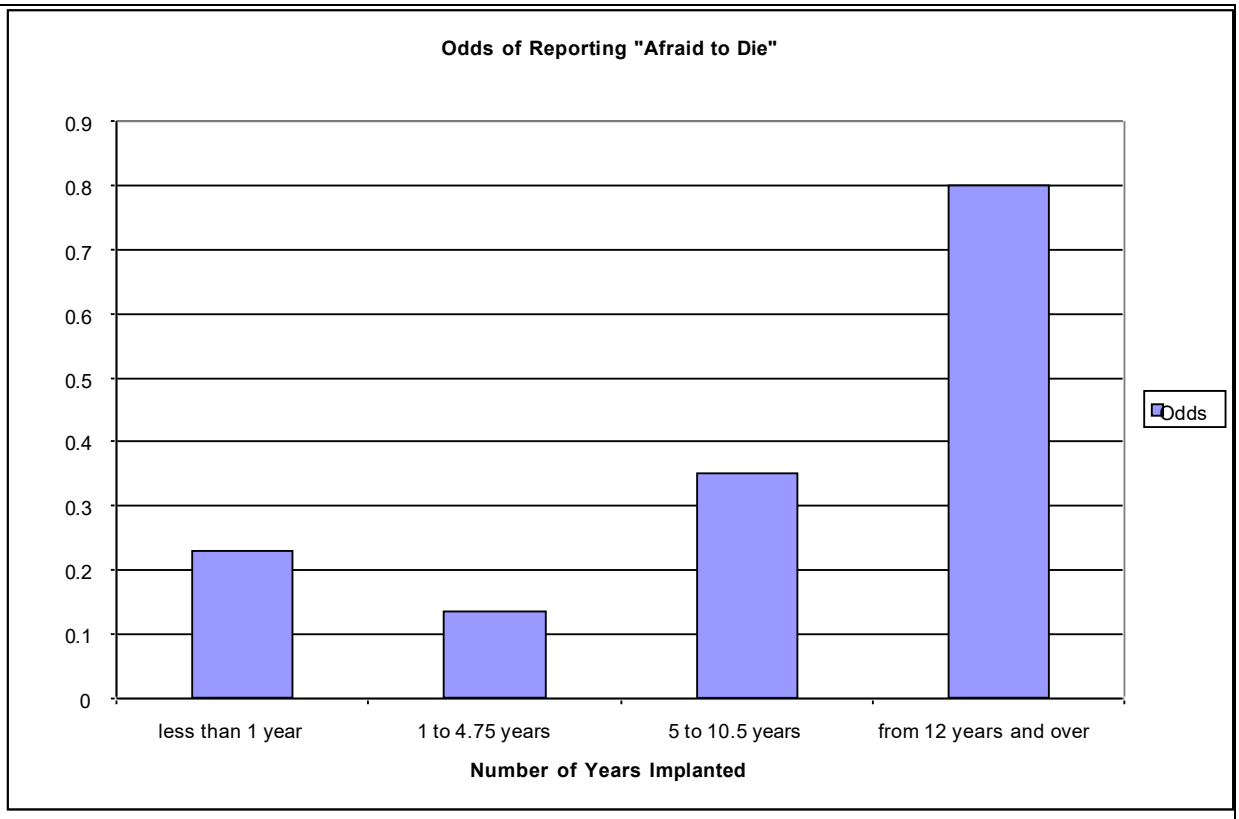

Figure 2. Odds of reporting "Afraid to Die" by Number of Years Implanted

Table 9. Length of time implanted by "afraid to die"			
			Categorical Variable
Chi-sqd	*df*	**p-value**	**Length of Time Patient has had Implant (YEARS)**
11.3	3	0.0100	*Afraid to Die*

5.3.6 **Peace of Mind and Afraid to Die**

Finally, we find a significant relation among the occurrences of three themes. Patients who reported having received "benefits" from the implant also mention three contributing factors and psychological reasons – two active and one passive - for why they made the decision to be implanted. Patients who report "benefits" from the implant state the reason "peace of mind" [active] more often especially since the ICD would act as a "safety net" [active] (p-value = 0.02), and they are also more likely to mention the reason that they were "afraid to die" [passive] (p-value = 0.02) (see Table 10). The corresponding odds ratios is 2.0 for "peace of mind," while those who report "benefits" are 2.2 times ***less*** likely to state that they got the implant because they are "afraid to die." These results suggest those who report receiving benefits are more likely to report psychological reasons based around concepts of security and less likely to report psychological reasons based around the emotion of fear.

Table 10. Benefits from the ICD and associated themes.

Categorical Variables	Have You Had Benefits from the Implant?		Odds Ratio
	Yes	No	
Peace of Mind-Safety Net $[\chi^2 = 7.8; p = .0200]$	86	5	2.0
Afraid to Die $[\chi^2 = 7.4; p = .0246]$	34	5	1:2.2

5.3.7 **Cluster Analysis of Variables**

Since codes occur in the responses of each individual, we presume that pairs of *codes* that appear together in more transcripts are "more closely related in patients' thinking" than are those that appear together less frequently.

We built a binary matrix of *codes-by-transcripts:* "1" means that the code was assigned one or more times to that transcript, and "0" means that it was not assigned. We reduced the matrix by eliminating any codes that did not appear in at least 20 of the 191 transcripts. The remainder was clustered using Ward's algorithm, which joins clusters based on maintaining tight merged clusters, as measured by a Euclidean metric on the vectors representing the variables[6]. The clusters are formed "bottom up" by Ward's algorithm, so that concepts are paired with those with which they co-occur most often. These relations - which are based on the responses of individuals - reveal conceptual structures different from those in our coding hierarchy (Gal et al., 2011). In the coding taxonomy, positive and negative aspects of the device form separate major categories. But cluster analysis reveals that the same people that mention positive aspects tend to mention *related* negative aspects in the same interview.

The largest, and first level cluster (N=445 mentions) is represented by its leading code: "Patient status" (N=64 mentions) and it has associated concepts such as "major health event" (63) and

"aesthetic concerns" (50). We summarize this numerically by describing the group as {**Patient Status**} (64 of 445). In this notation, the term in braces is the most prevalent code in the cluster; the first number in brackets is the incidence of that specific code; the second number is the total number of incidences of codes in the cluster as a whole. The other first level grouping revealed by the cluster analysis is: {**Multiple Devices**} (61 of 435).

Clusters appearing for the first time at the second level are: {**afraid to die**} (34 of 64) and {**gives detailed information**} (49 of 329). Appearing first at the third level are: {**not sure it helps/can't tell if it works**} (33 of 68); {**knows someone with it**} (51 of 142); {**get it as soon as possible**} (37 of 97); and {**higher quality of life**} (47 of 188). Finally, there are three clusters appearing only at the fourth level of aggregation: {**no choice**} (31 of 125); {**no worries**} (42 of 131); and {**authority figure**} (10 of 46). This last cluster contains many codes that were applied only very rarely in our qualitative analysis, and this "remnant cluster" is perhaps not meaningful at all.

Overall, the fact that a relatively small number of clusters covers the great majority of the coding, suggests that these clusters may become a useful smaller set of dimensions along which to explore the patient's decision-making process.

6 Discussion

Regionally, respondents in the Northeast were more likely to report feelings of "no agency" in the decision and gave more psychological reasons for making the decision. We may speculate that the severity of the cardiac disease was high in these cases (Burton et al., 2010) or the level of education or "functional health literacy" (S. K. Smith et al., 2009) played a role. Whether such regional differences reflect differences in thinking, or in patterns of communication, cannot be resolved in this study. We note, in passing, that our patients in the Northeast reported *more reasons* than did those in other regions. Hence some part of the odds ratios that we report is simply due to those regional differences in responding to the interview. That ratio is 1.6, and can be applied as a correction factor, if the reader wishes. The research design cannot determine whether this is a difference in regional patterns of conversation. It could conceivably be an artifact tracing to the fact that our interviewers were calling from the Northeast, and either their introductory remarks, or their regional accents, or both, might have created a more comfortable "conversational environment" for the respondents. However, the prescription for communicating effectively in both regions would remain the same: expression in terms of peace of mind is more likely to resonate with patients in the Northeast than in the South. Extensive examination of the relations between regions and both gender and ethnicity revealed *no strong associations,* so we infer that any variations we find, across regions, are due to regional culture, rather than, specifically to gender or ethnicity.

The differences associated with gender included that women were more likely than men to report "no agency" and "emotional reasons" as contributing factors in the decision-making; and women were more likely to present the doctor as detailed "fact giver" rather than "authority figure." These differences seem to support the findings regarding demographics and relationship with health professionals reported by Say, Murtagh, & Thomson (2006), though we must be careful not to imply to reinforce stereotypes of women as "helpless and emotional," especially since many women also reported reasons for implantation which included both survival and to

maintain an active role as matriarch for their immediate and extended families. In contrast, men were more likely to cite "need it" as an explanation for the decision. This passive reason ("need it") supports Matlock, Nowels, & Bekelman's (2010) findings on passivity as related to decision not perceived as difficult. These men perceived the solution as "obvious" thus it was not difficult to say yes.

While the first two of our findings in Table 4, results ("family member" and "confirm") are somewhat tautological, the remainder are not obvious. In particular, it is not clear why patients who do *not* report talking with someone else are *less* likely to view the doctor as an authority figure. One possibility is that those respondents interpreted the phrase "someone else" to mean "another doctor," or they immediately decided to get the ICD and saw discussion with others, whether further discussions with doctors, family members or others, as irrelevant. In this scenario the patient views the medical situation as "obvious" or in their own words "a no brainer" and this reality superseded authority as represented by either physician (doctor's role) or social reasons (contributing factors).

Our extended qualitative interviews, reported elsewhere, reveal four key themes or contributing factors (physical, psychological, social, and no decision) that seem to organize patients' responses. Most relevant for the long-term goal of increasing the role of computers in patient support is the patients' drive to maintain independence and control. These are reflected in distinctions between answers such as "the doctor told me to," and answers such as "I wanted to have it done." Interestingly (this fact is known to physicians) most of the respondents have never received a shock. This makes the ICD rather similar to the anticipated role of instrumented homes which might never deliver an active intervention in the patient's daily life. The cluster analysis reveals that the orderly taxonomy of reasons that we developed in order to code the responses is "remixed" by the patients themselves, in their responses. This poses some interesting theoretical questions about the possible role of cluster analysis in grounded theory.

7 Conclusion

We began by asking which factors or combinations of factors were salient in a patient's decision-making. We found the nature of the conversation with others, the activity or passivity of talking over the decision with others, correlations between number of shocks and reason "to save my life," an association between time since implantation and psychological reason "afraid to die," and potential relationships revealed within cluster analysis were all such factors. We also inquired whether there would be regional differences between our thematic codes and found differences among physical and psychological reasons as contributing factors. In addition, we asked whether thematic differences existing in our sample could be attributable to demographics similar to Say, Murtagh, & Thomson's (2006) findings. The most salient differences could be attributable to gender. This suggests that in developing plans for communicating about computer-based medical devices, it may be advantageous to consider such gender-based or regional differences to find the language, and the themes, that best draw the patient into the decision-making process, to the benefit of the patient.

Limitations of this quantitative paper stem from the mostly nominal data collected through a qualitative telephone survey. This level of data only allowed for the collection of frequencies at

best. Additionally, our sample was not random since we reached out to particular physicians to provide mailings to patient lists, and only then could patients choose to participate or decline. Also, our study is on the decision-making process to accept ICD implantation, yet our study provides no data from those who have declined implantation. However, this quantitative analysis does help to round-out our understanding of the topic by filling in connections between themes (physical, psychological, social, no decision) and the principals involved in the decision-making process (patient, doctor, families, ailment itself) that we developed within our qualitative study.

Future research in the use of computer monitoring technology will challenge us to identify the role that human experts will play, within the relational dynamic between the technology user (or patient) and a highly automated medical device. It is quite likely that acceptance of such intrusive monitoring may become a condition for continuing independent living into old age, for the "baby boomer" population. With decreasing birth rates, and increasing immigration barriers, there may simply not be enough health care workers to provide human support. It is not hard to imagine that some important kinds of health monitoring software will, during the next decade, become implantable[7]. One might imagine sensors that detect a failure to rise in the morning when the alarm goes off; or that signals of a sudden fall. In addition to this "event related" monitoring, there will soon be continuous monitoring of such vital signs as blood oxygen levels, glucose levels, pulse and blood pressure. To those of us who thrilled to the exploits of Steve Austin as the Six Million Dollar Man[8], there is something oddly puzzling about the realization that the first "bionic man" may actually be considerably older and in failing health.

Today it is possible to gather responses from a very large, non-random sample, using web survey methods. Many patients seek out sites relevant to their health problems, and spend time on the Web. This easy access has its limitations. In a web-based survey, we have few of the auditory cues that help a skilled telephone interviewer to sense whether a question has been misunderstood, or interpreted in an unexpected way. The present analysis, and a companion study (Gal et al., 2011) may help to provide salient examples of "patient language" enabling researchers to build a web-based survey that communicates effectively with the patients.

8 Acknowledgements

We thank Doctors Lou-Anne Beauregard at CentraState Hospital in Freehold NJ, Archana Patel at UMDNJ, Kathleen Blake at NMHI and Walter Clair at Vanderbilt Heart and Vascular Institute for their invaluable help with this project. We also thank Nora Cosgrove at UMDNJ, Jo Pressler at the New Mexico Heart Institute, Kathryn Pontzer and Jay Vegso at the Heart Rhythm Society, and Janet Wright at the American College of Cardiology for managing contacts. Undergraduate NSF REU fellows helped with many research tasks: Justine Grosso, Elaine Tang, and Kawsar Khan, and, finally, the many ICD patients who participated in this study and shared their experiences with us. This project originated in a brief discussion with Dr. Sylvia Spengler, of the National Science Foundation.

This project is supported by the National Science Foundation (#NSF EAGER IIS-0945192 1/1, NSF IIS-0945192 1/1-REU 1, and NSF IIS-0945192 2/2-REU 2).

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[1] We requested that they include only those who were mentally competent to be interviewed and sufficiently fluent in English to be interviewed in that language, by telephone.

[2] Kappa is defined by $\kappa = \frac{Observed\_agreement - Expected\_Agreement}{1 - Expected\_Agreement}$, so that perfect agreement (bytewise) yields $\kappa = 100\%$, while agreement no better than chance yields $\kappa = 0$.

[3] Or can be pushed

[4] See (Gal et al., 2011) for detailed examples of the kinds of utterances that are associated with each of the themes.

[5] In order to discuss results clearly we place the assigned code in quotation marks. This does not mean that each such respondent used exactly the words appearing in quotes. Rather, it means that they said something which has been mapped into that code.

[6] An alternative approach would be to compute based on the *number of times* each code appeared in each document. That was not explored here.

[7] http://www.nytimes.com/2011/09/04/technology/wireless-medical-monitoring-might-untether-patients.html

[8] An overview is given in the unsigned article at http://en.wikipedia.org/wiki/The_Six_Million_Dollar_Man The original inspiration for the series is attributed to Caidin, Martin. Cyborg. Arbor House.