

EMPIRICAL PROJECT

**SHARED DECISION-MAKING PROCESS IN
HEALTHCARE**

A Project Presented to the course: **Advanced
Microeconomics**

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ABSTRACT

Despite the fact that many people share a desire for more information and participation in the health-care process, it is unclear if they have taken a more participatory stance by involving in health-care decisions. Research indicates that, in actual practice, individuals are differentially willing or able to be active patients. We have used dataset of 2017 Wisconsin Longitudinal Study mail survey (<https://www.ssc.wisc.edu/wlsresearch/>), that included measuring preferences for four categories of the decision making process: 1) physician awareness of patient medical history/background; 2) physician disclosure of treatment choices; 3) discussion of treatment options, and 4) treatment choice availability. Our cluster analysis was used to classify preference forms for 5,199 older adults. Published surveys indicate that most patients want to be informed about their diseases, that a proportion of patients want to participate in planning management of their illnesses, and that some patients would rather be completely passive and would avoid any information. 57% of those surveyed wished to maintain personal influence over major medical decisions ("autonomists"). 81% of autonomists wanted to explore care options with their doctor. 39% of people said they wanted their doctor to make important medical decisions for them ("delegators"). Among the delegators, 41% preferred to discuss treatment choice availability. The overwhelming majority of older adults want to be given treatment options and have their physician know everything about their medical history; however, there are substantial differences in how they want to be involved in discussing and selecting treatments.

Introduction

Models of doctor-patient relations vary between “paternalistic” and “informative.” The paternalistic model emphasizes doctors' authority; alternative models allow patients to exercise their rights to autonomy. On the one hand, it has been recommended that patients should have a mandatory function as autonomous decision makers, as they are the ones who suffer the effects of their medical treatment. On the other hand, others argue that patients should be able to participate to the extent they desire, completely delegating decisions to their physicians if they so choose .

Early work in this area identified 2 distinct components of patient participation: information exchange and decision making (Ende, Kazis, Ash, & Moskowitz, 1989; Ong, de Haes, Hoos, & Lammes, 1995; Strull, Lo, & Charles, 1984). Later work further refined the components to 3: information exchange, deliberation, and decisional control (Charles, Gafni, & Whelan, 1999). Patients almost universally wish to receive information from their physicians, but little is understood about information delivery, or patient preferences for delivering information to their physicians. Patients' preferences for deliberation (i.e., formal discussion about options) and preferences for decisional control (i.e., influence over the final selection of treatment) are known to vary greatly, but it is uncertain whether patients who prefer discussing treatment options also prefer making the final decision about treatment.

To bridge the gap, we divided an older adult population into four types based on their preferences for engaging in each of four facets of healthcare decision-making (physician knowledge of patient, physician disclosure of treatment choices, discussion of treatment choices, and selection of treatment choice). We then define the preference categories for main socio-demographic and health variables. We use data from the Wisconsin Longitudinal Study (WLS), which for 47 years has tracked more than 10,000 men and women who graduated from Wisconsin High School in 1957. Respondents have conducted comprehensive telephone and mail surveys with high sample retention and a wide range of health conditions.

Conceptual model

A few decision-making models are depicted. In the paternalistic model, doctors manage information, evaluate options, and make decisions about patient care (presumably in the best interests of patients) without taking into account patient preferences. This model expects that there are objective criteria for deciding the best course of action, that doctors pick this course of action, and that patients consent to this course with gratitude. It is also supposed that patients who choose not to make a final decision equally do not want to participate in the exchange of information or discussion of options, while in another, informed model, physicians provide their patients with all the necessary information, and only the patients themselves evaluate their choices and make a final decision. The physician in this model serves as a technical expert to provide information and facilitate decision-making by the completely autonomous patient. The overall model combines these models into one where patients and physicians participate equally at all stages of decision-making (Charles, Gafni, & Whelan, 1999). Variations of this model include the interpretive and deliberative models that differ in their treatment of patient values.

In our empirical project, older persons are classified by types based on health decision-making preferences using the Charles, Gafni and Whelan structure (1997, 1999), which describes decision-making in three analytical stages: information sharing (divided into flow, direction, type and volume); discussion; control over the final decision. Although the overall model of decision-making by Charles and so on, as detailed, the explicit test model showed that in 62 consultations concerning prescription drugs, there was little evidence that both parties were involved or exchanged information, let alone general discussion or control of decision-making. Although this was not explicitly based on Charles and others, when Norwegian physicians were profiled in terms of their attitude to paternalism, patient autonomy and discussion, only 15% were pure paternalists, 19% were suited to an informed model (autonomists), and 12% could be called shared (deliberationists). The approach to classifying decision-making as purely paternalistic, informed or shared is clearly limited in its ability to accurately reflect real practice. To solve this issue, we develop a typology that allows the components of the decision-making process to vary among patients, for example, a strong preference for discussion of treatment options does not necessarily indicate a strong preference for maintaining control over the

decision. Our typology can better reflect the complex nature of patient preferences for participating in medical visits by allowing patients to vary their preferences across each of the dimensions.

There is no single validated tool for measuring the preferences for participation in all components of the decision-making process, as was conceptualized by Charles and others, although the two validated tools cover fundamental parts. The Autonomy Preference Index (API) comprises two scales for distinguishing between information search and decision-making (Ende, Kazis, Ash etc., 1989), and the Health Opinion Survey (HOS) includes two scales for distinguishing between information preferences and behavioural participation (Krantz, Baum & Wideman, 1980). Comparisons between the two tools revealed differences in the way they formulated the questions, in particular that the API focuses on what patients prefer to do to the physician, and the HOS asks what the patient usually does. Since we were interested in the preferences, not the behavior of the respondents, we preferred the decision-making controls in the API. Nevertheless, the API was limited for our purposes, as the exchange of information is measured only in the doctor-to-patient direction and there are no explicit points about deliberation. Likewise, the HOS does not measure the exchange of information from patient to physician, but the information subscale includes items that they are given a choice, which is the basis for discussing options during the deliberation. We have operated on the components of patient participation in decision-making by incorporating, whenever possible, elements from these proven tools, but we have developed our own element to assess the physician's preference for patient knowledge.

We anticipated respondents to have high preferences for treatment choices information from their physicians, but to differ in their preferences for other components of decision-making. Because of female gender (Kaplan, Gandek, Greenfield, Rogers, & Ware, 1995), higher education (Kaplan etc., 1995; Thompson, Pitts, & Schwankovsky, 1993) , and improved health (Degner & Sloan, 1992; Ende, Kazis, Ash etc., 1989) were associated with preferences for greater participation in health decision-making, and we expect to find similar relationships in the WLS population. We also await that preferences will vary depending on the interaction with specific providers or the healthcare system. There is some evidence that visiting patients with

chronic diseases is positively associated with an increase in joint decision-making. We expect that more active participation will be preferred by respondents with more prescription drugs or a higher burden of disease.

Empirical methods

Population and Sampling

The WLS Graduation Survey is a long-term cohort analysis of a 1/3 random sample of both men and women who graduated from Wisconsin high schools in 1957 (N=10,317). Data from the survey were collected in 1957, 1964, 1975, 1992, 2004 and 2017. About 2/3 of the respondents still live in Wisconsin, with the number of participants in each county roughly equal to the county's total population. The remaining 1/3 of the sample is spread throughout the U.S. and abroad. The response rate for the 2017 telephone survey was 80%, and the response rate for the mail survey was 89 percent among telephone respondents. The respondents who had complete data for all preference items (N=5,199 of 5,322 who completed both the telephone and mail surveys by March 2017) were used in our study.

Variables

The preference items measure respondent preferences for physician awareness of patients, disclosure of treatment options, discussion of treatment options, and treatment choice selection during healthcare visits. Since this was a population-based survey of older adults, participation preferences may vary depending on the context of a specific decision. The preference items were coded on a 5-point scale from 1 to 5, with 1 indicating strong agreement and 5 indicating strong disagreement, and were reversed scored when appropriate, so that all items represent preferences for more details, more deliberation options, or personal influence over the decision-making process.

Physician awareness of patients was calculated using the statement “I believe that in order to take good care of my health, my doctor needs to know all about my medical background .” This item's wording is intended to decide how much knowledge patients want their doctors to have about them. We used strong wording (“everything about my medical history”) to establish a less

biased distribution because the literature shows that most people tend to share a lot of details with doctors.

Disclosure of treatment options was measured using the statement from the Autonomy Preference Index's information-seeking scale, "When there are more than one approach to treat an issue, I should be told about each one." The main advantage of this item is that it refers to a situation where a true choice exists ("more than one method").

Discussion of treatment choices was defined using an item "I would rather have my doctor make the decisions on what's best for my health than be offered a lot of choices" (reverse coded). This item was chosen to represent a preference for a conventional paternalistic approach or one that includes the patient in the evaluation process by providing them with a variety of choices.

Selection of treatment choice was measured using the argument "The essential medical decisions should be made by my doctor, not by me" (reverse coded). Again, this item was chosen because of its broad scope – it does not specially apply to either daily medical conditions or hospitalized patient decisions.

Statistical methods

Our objective was to see if certain types of individuals exist. We used cluster analysis to organize respondents into meaningful structures based on 4 preference items. Cluster analysis classifies individuals into different groups based on the similarity of the observed characteristics. Although the assignment methods are different, all clustering algorithms try to place individuals in groups in such a way that the characteristics of any pair of individuals within any group are more similar than any pair of individuals between two groups.

Our cluster analysis was performed using both hierarchical and non-hierarchical methods (sectionation) using a unification algorithm based on similarity measured by Euclidean distance. Within hierarchical methods, clusters were combined using 3 of the most common unification methods, which include single, complete, and average linkage. Our final typology of patient preferences was based on a hierarchical agglomerative cluster analysis using average linkage. We chose hierarchical clustering because it allows smaller clusters to be embedded in larger clusters,

reflecting the gradation of preferences. We chose average linkage because it allows clusters to be connected hierarchically, but does not depend on our preliminary knowledge that clusters resemble chains (single linkage) or are spatially compact (complete linkage).

We evaluated the reliability of cluster solutions by performing a separate analysis for each random replication of the WLS sample, which was divided into 10 random replicates for data collection to determine whether the same cluster solutions for each replication had been identified. Cluster solution patterns (preference types) were almost identical in each of the random replicates. The percentage of respondents who fell into each type of preference varied; even so, the percentage in the top 4 types combined was almost the same across all replicates. In addition, we examined various graphical representations of the data to confirm that the data were not evenly distributed across the range of possible mixtures of preferences and that our detection of individual clusters was reliable.

We used polynomial logistic regression to predict the adjusted probabilities of preference types for each socio-demographic variable, health variable, and relationship variable, with all other variables in the model held at their population averages. Using the delta method, 95 percent of the confidence intervals were calculated. We found no evidence that our result categories do not conform to the assumption of independence of irrelevant alternatives according to the generalized Hausman specification test based on the seemingly unrelated evaluation command in Stata (Weesie, 1999). The results were considered statistically significant at $p\text{-value} < 0.05$. The data were analyzed using SAS 8.2 (SAS Institute, 2002) and Stata 8.0 (StataCorp, 2003)

Results

Distribution of Responses for Each Preference Item

The vast majority of respondents want to participate in an information exchange with physicians (Table 1). More than half of the respondents strongly agreed that their doctor should know everything about their medical history in order to take good care of them, approximately 4% were neutral, and 1% disagreed or strongly disagreed. Similarly, more than half of respondents strongly agreed that their doctor should disclose all treatment options, while only 2% were

neutral and less than 1% disagreed. The two information exchange points had an interposition correlation of 0.42.

Other two points showed wider variations. More than half of respondents would like to be offered many treatment options rather than having their doctor make decisions about what is best for their health, about 20% of respondents were neutral, and almost a quarter said they did not want this discussion. Besides, more than half of the respondents wanted to maintain personal control over important medical decisions, about 20% of respondents were neutral, and almost 25% preferred the choice of doctor to important decisions. These two points had an interposition correlation of 0.56.

A Typology of Preferences for Participation in Decision Making

The four largest cluster solutions were presented by 96% of respondents (Figure 1). As expected, most respondents want doctors to disclose all possible treatment options, and most also want doctors to know everything about them. Therefore, the hallmark of these four most common cluster solutions is the variability of preferences in discussing and choosing treatment options that represent four possible high-and-low combinations on these two counts. We called the types who wanted them to be offered many options as “deliberative”. Instead, the types that did not want much choice, we called “non-deliberative”. We called the types that characterize patients who wanted to make important decisions for themselves “autonomists”. Contrariwise, we have called the types who prefer the doctor to make important decisions “delegators”.

The four most common types of preferences were non-deliberative delegates (23%), deliberative delegates (16%), non-deliberative autonomists (11%), and deliberative autonomists (46%) (Table 2). Each of these four types had high averages for information exchange points (Figure 2). Non-deliberative delegates preferred a low degree of deliberation and the doctor's control over decisions, although deliberative delegates preferred a high degree of deliberation and the doctor's control. Non-deliberative autonomists preferred a low degree of deliberation and personal control over decisions, although deliberative autonomists preferred a high degree of deliberation and personal control. The three smaller types included the remaining 4% of respondents (Table 2). Whilst these types had a small number, we included them as they

represent the full range of patient preferences to participate in. Groups that we have called “suspicious deliberative autonomists” and “uninformed deliberative autonomists” are almost identical to deliberative autonomists, except that they scored low on the doctors desire to know everything about them and get information from the doctors, respectively. Less than half of the 1% of respondents could not describe any of these types.

Descriptive Characteristics for Preference Types

In general, WLS respondents are generally married, insured, in very good or excellent health with few medical conditions or prescription drugs, and have a relatively long relationship with their doctor or treatment location (Table 3). However, the characteristics of the respondents for the 4 most common types of preferences differed significantly (Table 4). Men, respondents with less education, lower self-esteem of health, fewer OARS conditions, or longer relationships in the usual place of care, were significantly more likely to be non-deliberative delegates. Respondents with less education or more prescription drugs were significantly more likely to be deliberative delegates. Women, respondents with more education, better self-reported health, more OARS conditions, fewer prescription medications, or shorter relationships in a regular care setting, were significantly more likely to be deliberative autonomists. There were no significant differences between socio-demographic factors or health factors for non-deliberative autonomists. Marital status, insurance status and the duration of a relationship with an ordinary doctor did not predict the type of preference (data are not shown).

Discussion

The four most popular patient types desire a high degree of knowledge sharing, but their preferences for discussing and choosing treatment options vary. Non-deliberative autonomists favored decisional control without deliberation, while deliberative autonomists preferred deliberation and decisional control. Deliberative delegators preferred discussion, with their physician retaining control over decision making, however non-deliberative delegators preferred neither discussion nor control over important decisions. Gender, educational level, and self-reported health have traditionally been used to explain differences in preference, and this study confirms previous findings suggesting that women, better educated patients, and better

health patients preferred the most active decision-making role (deliberative autonomists), while as men, less educated patients and patients with poorer health prefer the least active roles (delegates without discussion). Sociodemographic, health, and physician-patient relationship variables, on the other hand, were less effective in explaining variance among the remaining two prevalent patient preference groups (non-deliberative autonomists and deliberative delegators).

Our findings are in line with recent studies showing that patients prefer a high degree of knowledge sharing with doctors. Contrary to our expectations, the vast majority of respondents did not differentiate between groups in their preferences for the two information exchange objects. Moreover, a strong preference for discussing treatment options does not necessarily indicate a strong preference for the latter. There is a clear need for strategies to facilitate the sharing of knowledge and to differentiate between the priorities for addressing and choosing treatment alternatives, and it is also important for physicians to have both partnership building and mutual decision-making skills.

Our typology adds to our understanding of patient needs by identifying four distinct categories of patients when it comes to discussing and choosing treatment options. This has important implications for how shared decision making should be promoted in healthcare visits. Some individuals believe that doctors should never make choices about their patients. Others also argued that patients should not be pressured to participate in medical decisions if they do not want to. We agree that patient-centered treatment should aim to meet the needs and interests of particular patients wherever possible. However, as our typology demonstrates, only a small percentage of patients choose to be involved in neither deliberation nor major decisions. We advocate direct evaluation of patient preferences for all components of the decision-making process, perhaps eliciting preferences on intake or patient history types, since sociodemographic and health variables do a poor job of predicting patient preference type.

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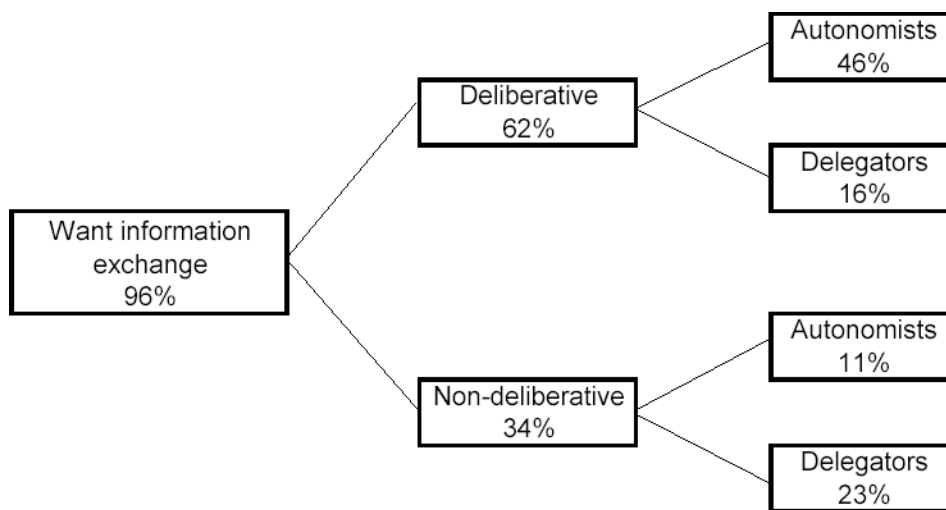


Figure 1.
Percent who desire each component of the decision making process for the four most prevalent preference types.

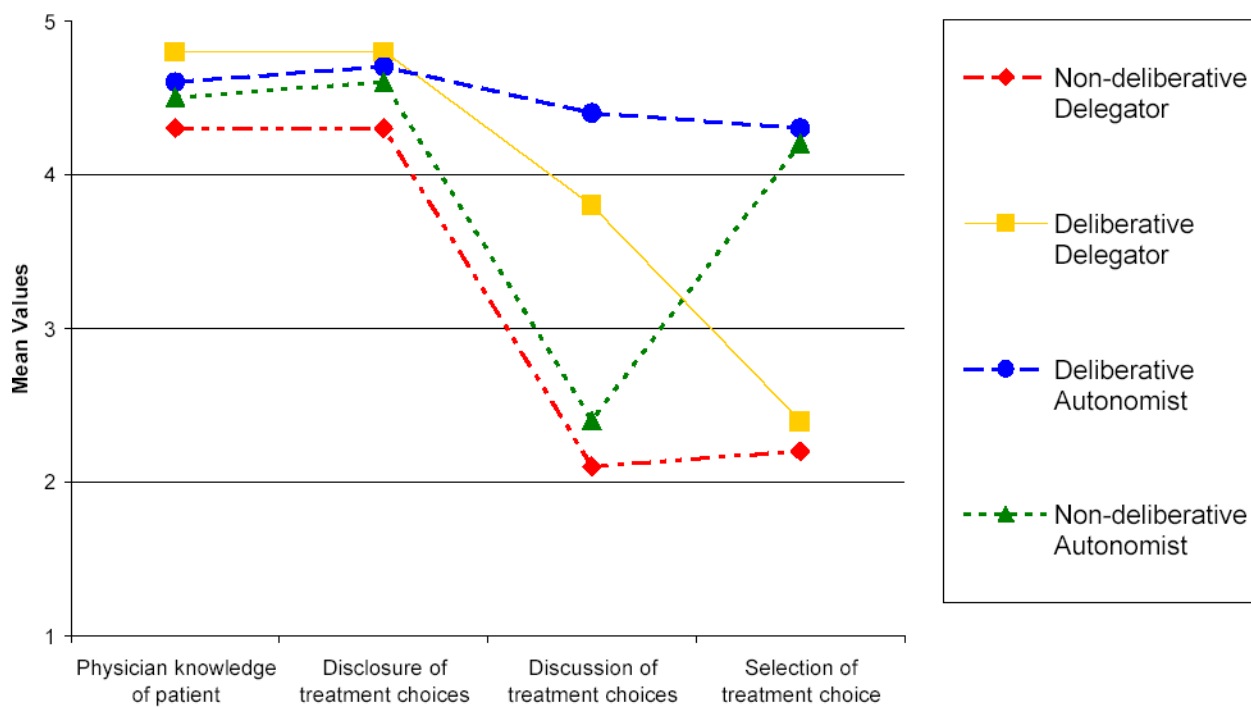


Figure 2.
Mean values of preference items for the four most prevalent preference types.

Table 1

Distribution of responses to items describing preferences for decision-making with usual providers. N=5,199

Percent (%) of respondents in each category

Items	Agree Strongly	Agree	Neutral	Disagree	Disagree Strongly
When there is more than one method to treat a problem, I should be told about each one	59.7	37.8	2.2	0.3	0.0
I believe that my doctor needs to know everything about my medical history to take good care of me	53.9	40.7	4.4	0.9	0.1
I would rather have my doctor make decisions about what's best for my health than to be given a whole lot of choices*	4.9	17.2	19.5	35.9	22.5
The important medical decisions should be made by my doctor, not by me*	5.7	17.9	20.3	36.1	20.0

*
Reverse scored for analysis

Table 2

Typology of patient preferences for participation in decision making, including number (N) and percent (%) of respondents in each type and the mean values (standard deviations) for each item used to construct the typology. N=5,199

Mean value* (standard deviation) for each item used to construct typology						
Types	N	%	Physician knowledge of patient	Disclosure of treatment choices	Discussion of treatment choices	Selection of treatment choice
Non-deliberative Delegator	1226	23	4.3(0.62)	4.3(0.60)	2.1(0.66)	2.2(0.71)
Deliberative Delegator	844	16	4.8(0.39)	4.8(0.43)	3.8(0.75)	2.4(0.66)
Non-deliberative Autonomist	559	11	4.5(0.60)	4.6(0.52)	2.4(0.68)	4.2(0.41)
Deliberative Autonomist	2390	46	4.6(0.50)	4.7(0.48)	4.4(0.51)	4.3(0.59)
Suspicious Deliberative Autonomist	133	3	2.7(0.46)	4.4(0.50)	4.2(0.49)	4.0(0.90)
Uninformed Deliberative Autonomist	29	1	4.1(0.77)	2.8(0.38)	3.8(0.47)	3.9(0.41)
Other	18	0	--	--	--	--

*Higher mean values indicate preference for more information, discussion, or personal choice.

Table 3

Unadjusted sociodemographic and health characteristics of WLS respondents. N=5,199

Variable	Percent	Variable	Percent
Gender		Self-rated health	
Male	45	Excellent	25
Female	55	Very good	39
		Good	27
Marital status		Fair	7
Married	80	Poor	2
Not married	20		
Education		# of OARS conditions	
High School	56	0–1	20
Some college	15	2–3	39
College degree	14	4+	41
Postgraduate degree	15	# of prescription medications	
		0	20
		1–2	35
		3+	45
		Relationship length at usual place	
		0–4 years	25
		5–14 years	29
		15+ years	46
		Relationship length with usual provider	
		0–4 years	38
		5–14 years	35
		15+ years	27

Table 4

Mean predicted probability (95% confidence intervals) of preference type, overall and by key socio demographic and health variables. N=5,199

Variable	Non-deliberative Delegator (N=1,226)	Deliberative Delegator (N=844)	Deliberative Autonomist (N=2,390)	Non-deliberative Autonomist (N=559)
Overall	0.24 (0.237, 0.243)	0.17 (0.165, 0.167)	0.48 (0.479, 0.486)	0.11 (0.111, 0.112)
Gender				
Male	0.29 (0.27, 0.31)	0.17 (0.16, 0.19)	0.42 (0.4, 0.44)	0.12 (0.1, 0.13)
Female	0.18 (0.17, 0.2)	0.17 (0.15, 0.18)	0.54 (0.52, 0.56)	0.11 (0.1, 0.12)
Education				
High school	0.30 (0.28, 0.32)	0.18 (0.17, 0.2)	0.40 (0.38, 0.42)	0.12 (0.109, 0.13)
Some college	0.21 (0.18, 0.23)	0.17 (0.14, 0.2)	0.51 (0.47, 0.55)	0.12 (0.09, 0.14)
College degree	0.13 (0.11, 0.16)	0.15 (0.12, 0.18)	0.61 (0.58, 0.65)	0.10 (0.08, 0.12)
Postgraduate degree	0.12 (0.09, 0.14)	0.13 (0.1, 0.15)	0.66 (0.63, 0.7)	0.09 (0.07, 0.113)
Self-rated health				
Excellent	0.17 (0.15, 0.19)	0.19 (0.16, 0.21)	0.53 (0.5, 0.57)	0.11 (0.09, 0.13)
Very good	0.22 (0.2, 0.24)	0.17 (0.16, 0.19)	0.48 (0.46, 0.51)	0.12 (0.1, 0.13)
Good	0.27 (0.25, 0.3)	0.16 (0.14, 0.18)	0.45 (0.43, 0.48)	0.12 (0.1, 0.14)
Fair	0.30 (0.25, 0.36)	0.15 (0.11, 0.19)	0.41 (0.35, 0.47)	0.13 (0.09, 0.17)
Poor	0.33 (0.23, 0.42)	0.15 (0.08, 0.22)	0.47 (0.36, 0.57)	0.05 (0.01, 0.1)
# of OARS conditions				
0–1	0.28 (0.255, 0.32)	0.17 (0.14, 0.19)	0.44 (0.4, 0.47)	0.11 (0.09, 0.13)
2–3	0.24 (0.22, 0.25)	0.17 (0.16, 0.18)	0.48 (0.46, 0.493)	0.11 (0.1, 0.12)
4+	0.19 (0.18, 0.21)	0.17 (0.15, 0.19)	0.52 (0.491, 0.54)	0.12 (0.1, 0.13)
# of prescription medications				
0	0.21 (0.19, 0.24)	0.13 (0.11, 0.1512)	0.54 (0.5, 0.57)	0.12 (0.1, 0.14)
1–2	0.22 (0.21, 0.24)	0.16 (0.1506, 0.17)	0.50 (0.48, 0.51)	0.12 (0.11, 0.13)
3+	0.23 (0.21, 0.25)	0.20 (0.18, 0.22)	0.45 (0.43, 0.48)	0.11 (0.1, 0.13)
Relationship length at usual place				
0–4 years	0.19 (0.17, 0.22)	0.16 (0.14, 0.18)	0.54 (0.505, 0.57)	0.11 (0.09, 0.13)
5–14 years	0.22 (0.21, 0.23)	0.17 (0.16, 0.18)	0.50 (0.479, 0.511)	0.11 (0.1, 0.12)
15+ years	0.25 (0.23, 0.27)	0.18 (0.16, 0.19)	0.45 (0.43, 0.476)	0.12 (0.1, 0.14)

^a Adjusted for all other variables in the table as well as marital status, health insurance status, and relationship length with usual provider. No significant differences were found for marital status, health insurance status, and relationship length with usual provider.