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Social networks, decision aids, and patient decisions regarding knee-replacement surgery

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Abstract

Objective

Examine how information from social networks is associated with patient decisions in the presence of information from multiple professional sources including decision aids.

Methods

We conducted a stated-choice experiment in which respondents made recommendations for hypothetical patients about whether full knee-replacement surgery should be performed to treat knee osteoarthritis. In addition, we administered a background questionnaire in which we explicitly asked respondents about the experience of people in their social network with knee osteoarthritis and possible treatment options. We examined the manner in which respondents' recommendations for vignette persons were associated with the experiences of members of their own social networks.

Results

Controlling for the information obtained from professional sources, satisfaction with full knee-replacement surgery within the respondents' social networks was strongly associated with respondent decisions.

Conclusion

Information from the social network may complement or compete with information from professional sources as patients make decisions.

Practice Implications

Professionals should offer to assist patients in making sound use information they obtain from their social networks.

1. Introduction

Contemporary emphasis on the responsibility of patients to participate actively in making the medical decisions that affect them invites questions about the basis on which patients make their choices. Because of a concern that when acting independently patients may make poor choices, health professionals have invested heavily in the development of decision aids to improve the quality of choices made by patients. According to International Patient Decision Aid Standards (IPDAS) over 500 decision aids are available or being developed world wide (IPDAS, 2012). Decision aids often include testimonies of patient experiences. Designers of decision aids include testimonies because they can have a powerful impact on patients. At the same time, designers have concern if patients are heavily influenced by a few atypical testimonials (Winterbottom, Bekker, Conner, & Mooney, 2008).

However, aside from professional and professionally developed sources of information, patients have access to another large source of information, their social networks. Through communication with members of their social networks, patients are able to obtain additional testimonials about their social network's experience with treatment strategies. The quality of information obtained from this source may, however, differ greatly from that obtained from professional sources such as health care providers and decision aids. Furthermore, the information that patients obtain in this way may compete with or complement the information obtained from professional sources. In any case, information from the social network of a patient adds a random element to the decision-making process whose potential to play a role in patient behavior was recognized long ago (Birkel & Reppucci, 1983). Up to now, influences of social networks on health behavior have been established in various areas (Cohen, 2004), and the importance of social networks in patient decision making has been confirmed (Valente, 2010).

This paper expands this strand of literature by examining the association of information from social networks with patient decisions regarding full knee-replacement surgery to treat knee osteoarthritis in the presence of information from professional sources. Because knee osteoarthritis is a

common condition among middle aged and older people and knee surgery is a common discretionary intervention, the condition and the intervention lend themselves well to examination of the role of social networks in decision making. In this study, we examine whether having members in the social network with experience with knee-replacement surgery can be associated with respondents' decisions and examine in depth which kind of social network experience plays a role.

Understanding how information from social networks (friends, relatives, neighbors, and co-workers) is associated with patient decision making is important because the quality of information patients obtain through their social networks may differ greatly from that obtained from professional sources and may have a great impact. Consider, for example, the information provided in decision aids. Decision aids are designed to provide an understanding of the condition and a balanced, objective perspective on the relative strengths of various treatment options. Decision aids often include both testimonials from patients on their experiences in considering treatment options and outcome probabilities based on results of outcome studies based on large samples of patients.

In contrast to evidence from outcome research, what patients learn from the experiences of their social networks is informal and probably based on a relatively small number of experiences. Further, in contrast to the carefully balanced perspectives offered in testimonials in decision aids, the views that patients obtain through their social networks are uncontrolled. The members of a patient's social network who share information about their treatment experiences are under no obligation to provide balanced or objective information.

Controversy about the impact of patient testimonials included in decision aids or available on the web provides additional reason for examination of the impact of testimonials patients receive through their social networks. On the basis of a systematic review of the influence of testimonials in decision aids, Winterbottom et al. (2008) call attention to the possibility that testimonials may have strong impacts on patients relative to statistically-based information and may introduce bias because

they encourage heuristic rather than systematic thinking. Information that patients obtain through their social networks may be even more powerful than testimonials in a decision aid when the information is delivered through face-to-face interaction from a source whose credibility has been established through previous personal interaction.

It has been established in previous research that social networks consisting of family, friends, neighbors, and work colleagues can influence health behavior in various ways (Cohen, 2004). Examples of this influence on health behavior include matters such as tolerance to obesity (Mora & Gil, 2013, Christakis & Fowler, 2007), use of health services in general (Schafer, 2013; Deri, 2005), and use of specific services such as mental health care and adoption of preventive health behavior (Pescosolido , Write, Alegria, & Vera., 1998; Drukker, Driessen, Krabbendam, & Van Os., 2004; Southwell et al., 2010; Suarez et al., 2000). Additionally, previous research has shown that patients rely heavily on the opinions and experiences of peers (social network sources) when making treatment choices (Berry et al., 2003; Katz et al., 2011).

This study examines the association of information from social networks with decisions of middle-aged and older patients in a context in which the influence of other forces on patient decisions was also considered. The study was specifically concerned with knee surgery for the treatment of knee osteoarthritis. Beyond its importance in its own right as a serious chronic condition, knee osteoarthritis is useful for research on patient decision making for several reasons. First, various treatment options exist for knee osteoarthritis with varying chances for success, costs, and risks. Therefore, the decision to accept or reject full knee-replacement surgery is highly discretionary and is characterized by a strong patient role in decision making. This strong role speaks for a need for patients to seek information from many sources, including the social network. Second, because osteoarthritis of the knee is a widespread chronic condition among middle-aged and older people, patients are likely to have persons in their social networks with the condition, including some who have had knee-replacement surgery who can

serve as informal information networks. Third, there seems to be relatively little stigma associated with the condition. Thus, those with a history of treatment for knee osteoarthritis are likely to be more willing to talk about their experiences than patients with more stigmatized conditions (Link & Phelan, 2006; Goffman, 1963). Finally, since it is a chronic condition, patients have time to consider various treatment options. Therefore, information from the social network can be easily obtained in this case.

2. Methods

We conducted a stated-choice experiment in which respondents were asked to make treatment recommendations for hypothetical vignette persons who were considering knee-replacement surgery. In addition, we asked respondents about the actual experiences of members of their social networks with knee osteoarthritis and knee-replacement surgery. We provide an overview of the experiment to set the stage for our examination. The methodology of the experiment and the main findings are reported in detail elsewhere (blinded for review).

2.1 Procedure. We administered a random fractional factorial survey (Rossi & Anderson, 1982) to a representative sample of middle-aged and older adults. Respondents were asked to make treatment recommendations for vignette persons who were considering knee-replacement surgery to treat their knee osteoarthritis.

After receiving background information about treatment of knee osteoarthritis, respondents were asked to review the situation of multiple vignette persons who were considering knee-replacement surgery to treat knee osteoarthritis. These scenarios were constructed to include some aspects of the patient's situation (pain, opportunity cost, and employment status), a physician's recommendation, a second opinion, a patient-specific outcome forecast, and patient testimonials. Respondents were presented with vignette descriptions containing randomly chosen levels of these substantive dimensions.

Six middle-aged actors (male and female) performed as vignette persons. After each vignette person, respondents were asked to recommend whether or not the vignette person should have knee-replacement surgery. When this experiment was completed, we administered a background questionnaire in which we explicitly asked respondents about their own experiences with chronic knee pain and knee osteoarthritis as well as the experience of their social networks (close relatives and friends) with the disease and possible treatment options.

2.2 Measures. The recommendations for or against surgery for the vignette persons are used to generate the binary variable *surgery recommendation*, which takes the value 1 if surgery was recommended by a respondent for this specific vignette person and 0 if not.

Additionally, we used the following variables generated from the background questionnaire: *Respondent with chronic knee pain* (indicator variable, =1 if respondent reported to have chronic knee pain, =0 otherwise), *respondent with knee osteoarthritis* (indicator variable, =1 if respondent reported to be diagnosed with knee osteoarthritis, =0 otherwise), *social network with knee osteoarthritis* (indicator variable, =1 if respondent reported to have members in the social network that were diagnosed with knee osteoarthritis, =0 otherwise) and *social network with full knee-replacement surgery* (indicator variable, =1 if respondent reported to have members in the social network that have had the surgery, =0 otherwise). To gain a better understanding of the nature of the social network experiences, we also generated variables for which alternative strategies have been tried by the members of the social network that are affected by knee osteoarthritis: *social network tried exercising* (indicator variable, =1 if respondent reported that affected members in the social network tried exercising as a coping strategy, =0 otherwise), *social network tried weight loss* (indicator variable, =1 if respondent reported that affected members in the social network tried weight loss as a coping strategy, =0 otherwise), *social network tried medication* (indicator variable, =1 if respondent reported that affected members in the social network tried medication as a coping strategy, =0 otherwise); *social network tried none of these*

approaches (indicator variable, =1 if respondent reported that affected members in the social network tried none of these coping strategies, =0 otherwise). Additionally, we used the respondents' assessments of their affected social networks' experiences with these coping strategies and full knee-replacement surgery to generate the following satisfaction measures: *social network's satisfaction with alternative treatments* (ranging from 1= very dissatisfied to 4= very satisfied) and *social network's satisfaction with surgery* (ranging from 1=dissatisfied to 3=satisfied). These variables are used to examine how especially the experiences of the social network can be associated with respondent's surgery recommendations. The wording of items in the background questionnaire can be found in the Appendix.

2.3 Study sample. Study participants were members of the **RAND** American Life Panel (ALP) who were aged 50 and older at the time of the survey. Members of the ALP are drawn from the general population and are surveyed periodically in an internet format. The ALP seeks to be representative of the adult population of the United States.

Our survey generated a response rate of 70.6% (2296 survey invitations, 1622 completed interviews). Background characteristics were incomplete for six respondents, who were subsequently dropped from the analysis. This resulted in a total respondent sample size of 1616.

We had access to standard demographic data about respondents obtained previously based on their participation in the panel. Background characteristics of the final sample are summarized in Table 1. Respondents were fairly evenly represented by men and women and reflected a broad age range: between age 50 to 93. Respondents were well educated and relatively well-off financially. (Compared to data from the Current population Survey [2011] for the population 60 and over, our sample is more highly educated and underrepresents racial and ethnic minority populations. However, data from the ALP sample that we used is much more generalizable than studies based on student or patient samples.)

Table 1

2.4 Data analysis. The unit of analysis in this study is the recommendation made on individual vignettes. Our final sample consists of two vignette observations obtained from each of the 1616 survey respondents. With one instance of item-nonresponse in these decision tasks, our vignette sample consists of a total of 3231 vignette observations.

We use ordinary least squares models with the dependent variable *surgery recommendation* to identify the association between respondents own experiences and their social networks' experiences with the decision for or against surgery. Since our dependent variable is binary, these models are linear probability models, and the estimated coefficients are changes in the probability of surgery recommendation in percentage points. We controlled for the specific characteristics of the vignette persons who were presented to the respondents in our experiment. We also controlled for the recommendations of physicians and information provided on the probability of successful surgery. For a detailed analysis and description of how the substantive dimensions of the vignettes affected the surgery recommendations, see [blinded for review]. We also control for the following respondent characteristics: gender, age, marital status, education, respondent's labor force status, ethnicity, and yearly household income.

3. Results

3.1. Descriptive statistics. Table 2 provides summary statistics for the variables generated from the background questionnaire. Respondents reported extensive experience with the disease; 42 % reported having chronic knee pain, and 21% reported that they were diagnosed with knee osteoarthritis. Most importantly, a clear majority of respondents (66%) has members in their social network that have been diagnosed with knee osteoarthritis, and 53% have members in their social network who have had full knee-replacement surgery. These persons have almost entirely tried one or multiple alternative strategies to cope with knee osteoarthritis. Almost 90% have taken medications,

roughly 75% tried exercising, and roughly 60% tried to lose weight to deal with the disease. The overall satisfaction of the social networks with these alternate strategies is mixed. On the one hand, only a small fraction of respondents reported that overall the affected members of their social networks were very satisfied or very dissatisfied, whereas almost 50% reported that these members were satisfied, and 30% reported that these members were dissatisfied. The experience regarding the overall satisfaction of the affected social network members with full knee-replacement surgery on the other hand is mainly reported to be positive. Most respondents (61%) reported that overall, the affected members of their social networks were satisfied, 31% reported mixed satisfaction, and only 11% reported that these members were overall dissatisfied with the surgery. Therefore, respondents' perceptions of the surgery based on the experiences of members of their social networks are generally positive.

Table 2

3.2. Multivariate analysis. In this subsection, we establish an association between basic respondent experiences and those of their social networks with the decision to recommend surgery. All estimation results are reported in Table 3.

Table 3

Model 1 is estimated using the full study sample. In this model we include four variables that were obtained from our background questionnaire: *Respondent with chronic knee pain, respondent with knee osteoarthritis, social network with knee osteoarthritis* and *social network with full knee-replacement surgery*. The estimation results of Model 1 reveal that both one's own as well as the social network's experiences are associated with the probability of recommending surgery. Respondents who have chronic knee pain are 5 percentage points less likely to recommend surgery than respondents without chronic knee pain, but respondents with members in their social networks who have had full knee-replacement surgery are 9 percentage points more likely to recommend surgery than respondents without this peer experience. Models 2 and 3 then split up the study sample in two mutually exclusive

subsamples of respondents that reported not to have members in their social networks with full knee-replacement surgery (Model 2) and respondents who reported having members in their social networks with full knee-replacement surgery (Model 3). Both models have the same specification, and both include the two variables that capture whether the respondent has chronic knee pain and whether the respondent has been diagnosed with knee osteoarthritis. Looking at the estimated coefficients in the subsample that does not have members in their social network with surgery, we see a strong association between surgery recommendation and whether a respondent has chronic knee pain or not. In this subsample, respondents with chronic knee pain are 7 percentage points less likely to recommend surgery than respondents without chronic knee pain. However, in the subsample that has members in their social networks with full knee-replacement surgery, we cannot establish a significant association between the respondents' personal experiences and the probability of recommending surgery. Neither the estimated coefficient of having chronic knee pain nor of being diagnosed with knee osteoarthritis is significantly different from zero. Thus, the effect of personal experience with the disease on the decision for or against surgery depends on the presence of experience within one's social network. If these social network experiences exist, one's own experiences play less of a role. Model 4 then again uses the subsample of respondents who reported having members in their social networks with full knee-replacement surgery. With this model, we explore in depth which aspects of social network experiences are associated with the probability of surgery recommendation in our study. Therefore, this model includes the two variables that capture respondents' own experiences as well as additional variables relating to their social networks' experiences. These are: three of the indicator variables that capture which alternative strategies of dealing with knee osteoarthritis have been tried by a respondent's social network (*social network tried exercising, social network tried weight loss, social network tried medication*; reference category: *social network tried none of these approaches*), the measure for the satisfaction of the social network with these alternative approaches (*social network's satisfaction with*

alternative treatments), and the measure of the satisfaction of the social network with full knee-replacement surgery (*social network's satisfaction with surgery*). In this model, two aspects of the social network experience are associated with respondent's probability of recommending surgery. First, if members in their social networks tried exercises as an alternative coping strategy, respondents are more likely to recommend surgery. Second, the social network's satisfaction with full knee-replacement surgery is associated with respondent's surgery recommendations. The more positive the satisfaction of members of the social network with surgery, the more likely that a respondent recommended surgery.

4 Discussion, Conclusion, and Practice Implications

4.1 Discussion

4.1.1. Summary of findings. In a vignette experiment, we found that experiences of a respondent's social network are associated with the recommendations regarding knee surgery that respondents made for vignette persons. Even controlling for respondents' own experiences with knee osteoarthritis and knee surgery, satisfaction with surgery among the respondents' social networks is strongly associated with the surgery recommendations in the presence of information from multiple professional sources. Additionally, we found that for respondents with social network experiences, their own medical backgrounds play less of a role than for respondents who do not have experiences in their social networks.

4.1.2. Implications. Our findings invite questions about how information from a patient's social network influences the quality of medical decision making. Information from social network sources can have either a positive or negative effect on the quality of patient decisions. The impact of information from network sources is likely to be affected by the amount of information obtained from other sources. While it is clear that testimonials from strangers in decision aids or on bulletin boards can have an extensive unwarranted impact on decision making, especially if they are extremely positive or negative, the case is less clear for social network experiences. In contrast to testimonials of strangers, information

obtained from members of the social network may not stand alone. In this case, patients may have more information about the health history of the person giving the testimonial. This may enable patients to interpret these testimonials more effectively than they do when the receive testimony from strangers. Patients also may be selective in seeking input by approaching those in their social networks whose advice they particularly trust. Seeking out information from a person's social network may make a constructive contribution if it softens the impact of potentially biasing testimonials of strangers. In our study, the presence of social network experiences appears to reduce the role of own experiences. This could be a first indication that respondents feared their own experiences were subjective and biased and therefore they increasingly relied on information from their social networks that is likely to be based on a larger sample and thus perceived to be more objective than a single experience of their own. Thus, information from a patient's social network may have less potential to weaken the quality of patient decisions than testimonials from strangers. On the other hand, this information is likely to be more subjective than, for example, outcome probabilities often included in decision aids. While these outcome probabilities are derived from large samples of patients, the social network information about outcomes is derived from a much smaller sample and may thus have potential for unwarranted effects on the quality of decision making, especially considering that the social network of a person hardly evolves randomly.

From a professional perspective, the lessons that patients derive from the experiences of others in their social networks add a random element to the medical decision-making process. Health professionals may be uneasy about the contributions of the stories heard informally by patients. The effects of these stories may, in fact, depend on the accuracy of information, the size and composition of the social network that shares these stories, and the relevance of the obtained information in terms of the specific medical decision. On the other hand, the possibility of speaking with others and hearing

their stories may increase patients' confidence in decision making. Further, it may help patients clarify their aims and weigh their assessments of risks and benefits.

4.1.3 Limitations. In this study, social network influences were examined in the context of a stated-choice experiment. In spite of the uncertainties about the potential for generalizing from stated-preference studies, these designs make it possible to examine the effects of options that could not be studied in research on actual patients because of ethical concerns.

Future studies should also examine the contributions of information from multiple sources for actual patients as they make their medical decisions.

In this study, respondents were asked only a few general questions about the experiences of their social networks (close relatives and friends) with treatment for knee osteoarthritis. Further research should seek out more thorough information about communication with members of the social networks. It might address the number of others from whom patients obtain information, the extent to which patients are proactive in seeking information through their social networks, the extent to which patients receive divergent accounts of treatment experiences, and the circumstances in which patients are more or less impressed by these accounts. Also of interest is the extent to which information from social networks is similar to that received from professional sources. In instances in which messages from social network sources diverge from the messages coming from health care providers, researchers might examine the extent to which patients seek interpretation from their health care providers.

4.2 Conclusion.

Implicitly, shared medical decision making invites patients to base their decisions on multiple sources. When patients have a common condition, they may be influenced not only by their own doctor, second medical opinions, and decision aids, but also by accounts of members of their social networks who received the treatment they are considering. Additional research is needed to understand how the testimonials patients receive through their social networks contribute to the quality of their decisions

and how this relates to the contributions of other sources of information, such as patient testimonials or outcome probabilities.

4.3 Practice Implications.

Professionals have reason to recognize the likelihood that patients will communicate with others in their social networks during their consultations and provide patients with advice on how to deal with information obtained from members of the social networks. This advice may range from encouraging patients to talk with more rather than fewer people and to seek information about the circumstances surrounding the social networks' experiences to providing a topical outline that could be used by patients when talking to others about their information and to discuss with patients what they have learned informally. Such procedures could possibly reduce the potential of small sample biases and enable patients to obtain a rich case study with complete and accurate information on the background of other patients, their treatment experiences, and their medical outcomes.

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Appendix

1. Have you experienced chronic pain in one or both of your knees?
    a. ____ Yes
    b. ____ No
2. Have you been diagnosed with osteoarthritis in one or both of your knees?
    a. ____ Yes
    b. ____ No
3. Do you have close relatives or friends who have been diagnosed with osteoarthritis of the knee?
    a. ___ Yes
    b. ___ No (End of questionnaire for respondents who do not have friends/relatives that were diagnosed with knee osteoarthritis)
4. Considering all these people together, which of the following strategies have they tried in coping with knee osteoarthritis? (Check all that apply)
    a. ___Exercise
    b. ___ Weight loss
    c. ___ Pain medication
    d. ___None of the above (SKIP to 6)
5. Considering all of them together, how satisfied are they with these strategies in coping with the problem?
    a. ___Very satisfied
    b. ___ Somewhat satisfied
    c. ___ Somewhat dissatisfied
    d. ___ Very dissatisfied
6. Do you have close relatives or friends who have had full knee-replacement surgery?
    a. ____ Yes
    b. ____ No (End of questionnaire for respondents who do not have friends/relatives who have had full knee-replacement surgery)

7. Overall, were your relatives and friends satisfied or dissatisfied with the surgery?

    a. ___ Satisfied

    b. ___Some satisfied; others dissatisfied

    c. ___Dissatisfied

    d. ___Don't know

Questions 1 and 3 were asked to all respondents, the remaining questions were posed to the relevant groups of respondents. For all respondents who reported not having chronic knee pain, it is assumed that they were also not diagnosed with knee osteoarthritis. Also, for all respondents that reported not having peers with knee osteoarthritis, it is assumed that they also do not have close peers who have had full knee-replacement surgery.

Table 1 Descriptive statistics of the study sample (n=1616)

Variables	%
Gender	
Male	43.4
Age (median=59 years)	
50-59	50.1
60-69	33.7
70 or older	16.3
Income	
<$ 25,000	23.4
≥$ 25,000 and < $50,000	27.3
≥$ 50,000 and < $75,000	16.1
≥ $75,000	33.2
Living Status	
Married or living with a partner	58.2
Employment Status	
Retired	34.3
Working	45.2
Unemployed, disabled and other	20.4
Education	
High school or less	23.9
At most Bachelor's Degree	59.2
Post graduate	16.9
Ethnicity	
Non-Hispanic white	82.7

Table 2 Summary statistics for health variables

Variable	Frequency	N
Full sample (N=1616)		
Respondent with chronic knee pain	42.08	680
Respondent with knee osteoartritis	21.23	343
Social network with knee osteoarthritis	65.84	1064
Social network with full knee replacement surgery	52.54	849
Sample: Respondents with social networks with full knee replacement surgery (N=849)		
Social network tried exercising	74.53	632
Social network tried weight loss	62.38	529
Social network tried medication	88.21	748
Social network tried none of these coping strategies	5.07	43
Social network's satisfaction with alternative treatments		
Very satisfied	9.53	77
Somewhat satisfied	49.13	397
Somewhat dissatisfied	30.69	248
Very dissatisfied	10.64	86
Social network's satisfaction with surgery		
Satisfied	61.08	518
Some satisfied, others dissatisfied	31.37	266
Dissatisfied	6.37	54
Don't know	1.18	10

Table 3 Regression results, controlling for specific vignette shown and other personal characteristics

Model	1		2		3		4	
Sample	Full		Social network w/o surgery		Social network with surgery		Social network with surgery	
	Coefficient	P-value	Coefficient	P-value	Coefficient	P-value	Coefficient	P-value
Explanatory variable:								
Respondent with chronic knee pain	-0.0514	0.009	-0.0727	0.012	-0.0239	0.387	-0.0200	0.468
Respondent with knee osteoarthritis	0.0261	0.284	0.0222	0.546	0.0200	0.554	0.0234	0.473
Social network with knee osteoarthritis	-0.0401	0.100						
Social network with full knee replacement surgery	0.0919	0.000						
Social network tried exercising							0.0667	0.022
Social network tried weight loss							-0.0278	0.280
Social network tried medication							0.0126	0.738
Social network's satisfaction with alternative treatments							0.0006	0.962
Social network's satisfaction with surgery							0.1121	0.000
N	3231		1533		1698		1676	
R^2	0.621		0.603		0.643		0.653	