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Barriers to Completion of Patient Reported Outcome Measures

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ABSTRACT

Patient Reported Outcomes Measures (PROMs) are commonly used in total joint arthroplasty (TJA) to assess surgical outcomes. However certain patient populations may be underrepresented due to lower survey completion rates. The purpose of this study is to evaluate factors that influence PROM completion rates for 1997 TJA patients between 7/1/2007 and 12/31/2010. Completion rates were lower among patients who were over 75, Hispanic or Black, had Medicare or Medicaid, TKA patients and revision TJA patients ($P < 0.05$ for all comparisons). Having multiple risk factors further reduced completion rates ($P < 0.001$). Overall participation increased significantly during the study period, after electronic data capture methods were introduced. Awareness of these factors may help physicians and researchers improve participation of all patient populations so they are well represented in TJA outcomes research.

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Clinical outcomes research is an important tool for determining the efficacy and value of various healthcare interventions [1–4]. The Patient Protection and Affordable Care Act of 2010 created the Patient-Centered Outcomes Research Institute (PCORI) which uses outcomes assessment as a key component of comparative effectiveness research to determine best practices in medicine [2]. The increasing emphasis on patient reported outcomes (PROs) makes the evaluation and improvement of our current tools and techniques especially timely. Outcomes assessment is an important and widely used tool in the field of orthopedic surgery in general, and total joint arthroplasty (TJA) in particular [5–8]. However, there may be discrepancies in participation rates among certain patient populations, which could lessen the value and generalizability of outcomes measurement.

Researchers have noted that implant survivorship and other traditional outcome parameters (e.g., range of motion, radiographic findings) often fail to adequately capture patients' perception of the impact of surgical procedures on their overall functional status and quality of life [9,10]. For instance, two years after surgery, although an implant may be well fixed and well-aligned, a patient may continue to experience pain and limitations in mobility. A number of studies have emphasized the importance of adding the patient perspective to comparative effectiveness research in order to provide a complete

assessment of treatment impact [11–15]. This perspective is usually ascertained by having patients complete surveys about factors such as pain level, degree of disability, and how their condition limits their functioning or affects their quality of life [16,17]. The increasing focus on patient experience as a measure of the effectiveness of medical interventions has led to the inclusion of patient reported outcome measures (PROMs) in TJA registries such as those in New Zealand, Sweden, and Great Britain, and those that are currently being implemented in the United States.

Despite efforts to obtain PROM information for all TJA patients, there has been little study of which patients have the highest response rates to outcomes questionnaires and what methods are most successful in obtaining a truly representative sample of the patient population. A 2011 study by Gayet-Ageron et al evaluated patient characteristics, including literacy, language and cultural differences, physical and cognitive disabilities, mental illness, and drug abuse as potential barriers to participation in a patient satisfaction survey [18]. We expanded on this research to examine patient age, gender, race, comorbidities, primary language, mental disability, type of insurance, type of surgery and number of previous surgeries as potential factors that may influence PROM participation. This study also evaluated the impact of the introduction of electronic surveys at our institution on PROM participation rates.

Our goal was to assess possible barriers and facilitators to participation in patient reported outcomes measurement for TJA patients at a large urban academic medical center. In doing so, we speculate about possible ways to overcome these barriers, as part of a larger strategy to increase reporting rates.

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Materials and Methods

All 1,997 patients from a single academic medical center (University of California, San Francisco) who underwent primary or revision TJA between July 1, 2007 and December 31, 2010 were asked to complete PROM surveys pre-operatively, 6 months after surgery, and annually from the date of surgery for as long as the implant remained in place. PROM instruments administered were: Hip dysfunction and Osteoarthritis Outcome Score (HOOS) and Harris Hip score (for total hip arthroplasty [THA] patients only); Knee injury and Osteoarthritis Outcome Score (KOOS) and Knee Society Score (for total knee arthroplasty [TKA] patients only); and Current Health Status, UCLA activity score, EQ-5D Visual Analogue Scale, and SF-12 (for both THA and TKA patients). Only English language surveys were available, however translators (typically staff or family members) were used to help non-English-speaking patients complete surveys when possible.

Data Collection Prior to May 2009

Paper surveys were collected during the pre-operative patient education class (1–4 weeks before surgery). If patients did not come to class they were mailed paper surveys to their home with a self-

addressed stamped envelope (SASE), as well as notified by telephone and asked to complete the survey and return before their surgery date. One week prior to surgery patients who still had not completed or returned surveys were called again and asked to do so. Post-op questionnaires were given to patients in the office by staff members at 6 month, one year, and subsequent annual follow up appointments. SASEs were given to patients who did not complete the questionnaire during the appointment, along with oral instructions to mail the completed survey back to the office at their earliest convenience.

Data Collection After May 2009

One week before the pre-op class, patients were emailed links to their pre-operative questionnaire (if email address was available) and notified by telephone to complete the questionnaire before the pre-op class, if possible. Those who had not completed their surveys electronically before the pre-op class were requested to do so on paper during the class. One week prior to surgery patients who still had not completed or returned surveys were called again and asked to do so. Post-op questionnaires were given to patients by research staff during their 6 month, one year, and subsequent annual follow up appointments. The only difference in protocol with follow up surveys

Table 1
Percent Cases With Completed Neither Pre/Post, Either Pre/Post, Or Both Pre/Post Disease-Specific and Generic PROM Surveys.

	Cases	Neither	Pre or Post	Both	P
Total # cases	1997	506	400	1088	
Total % cases		25.5	20.0	54.5	
Mean age in years (±SD)	61.3 (±14)		60.8 (±13)	0.482	
Age					0.035
<50	391	27.9	17.4	54.7	
51–65	850	23.5	20.9	55.5	
66–75	460	23.0	20.0	57.0	
76–98	296	32.1	20.6	47.3	
Gender					0.297
M	880	25.5	20.0	54.5	
F	1117	26.9	19.9	53.3	
Race					<0.001
White	1434	24.6	19.2	56.2	
Black	176	25.6	21.6	52.8	
Hispanic	151	31.8	21.2	47.0	
Asian	84	20.2	21.4	58.3	
Other/Unkn	152	30.9	23.7	45.4	
Type of Surgery					<0.001
Primary TKA	601	30.1	23.1	46.8	
Primary THA	676	16.3	13.8	70.0	
Hip Resurfacing	117	13.7	13.7	72.7	
Revision TKA	273	41.4	25.3	33.3	
Revision THA	330	27.3	24.9	47.9	
Comorbidities					0.069
0	819	24.2	18.2	57.6	
1	852	25.6	20.9	53.5	
2	278	27.0	21.9	51.1	
3 or more	48	39.6	22.9	37.5	
Revision Surgery					<0.001
no	1394	22.0	17.8	60.2	
yes	603	33.7	25.0	41.3	
Previous Ortho Surgeries					<0.001
0	1449	24.2	18.2	57.7	
1	364	26.1	22.0	51.9	
2–3	129	30.2	32.6	37.2	
>3	55	47.3	25.5	27.3	
English Primary Language					0.068
no	144	32.6	21.5	45.8	
yes	1853	25.0	19.9	55.2	
Psychiatric Diagnosis					0.579
no	1763	25.3	19.8	54.9	
yes	234	27.4	21.4	51.3	
Drug Dependency					0.644
no	1895	25.3	20.0	54.7	
yes	102	29.4	19.6	51.0	
Altered Mental Status					0.094
no	1938	25.3	19.8	54.9	
yes	59	32.2	27.1	40.7	
Type of Insurance					0.003
Commercial	828	21.0	21.0	58.0	
Medicare	233	33.9	18.0	48.1	
Medicaid	921	27.5	19.7	52.9	
Other	15	26.7	13.3	60.0	
Number of Barriers					<0.001
0	1194	22.5	19.3	58.2	
1	519	28.9	20.8	50.3	
2 or more	284	32.0	21.5	46.5	
Electronic Collection					<0.001
no	1840	27.7	21.7	50.6	
yes	157	0.0	0.0	100.0	

after May 2009 was that patients were offered computer tablets in the office to complete their surveys electronically, and only offered paper as a backup method if the patient could not or would not complete the survey on the tablet. Like before, paper surveys and SASEs were given to patients who did not complete the questionnaire during the appointment, along with oral instructions to mail the completed survey back to the office at their earliest convenience.

All survey input was stored in our clinical outcomes database. For the purposes of this study, a patient was considered to have “participated” in outcomes reporting if he or she completed in its entirety and received an overall score for at least one disease-specific (Harris Hip/Knee Society and/or HOOS/KOOS) and one generic (SF-12, UCLA Activity and/or EQ-5D VAS) health instrument at both pre-operative (up to 6 months prior to surgery) and at least one post-operative (5–18 months after surgery) time interval. These data were linked to administrative claims data including diagnosis, procedural codes and insurance status, which were used to define the total number of cases in the denominator for the analysis.

Patient characteristics, such as age, gender, race, type of surgery, comorbidities, number of previous orthopedic surgeries, primary language, mental health status, and type of insurance were evaluated for their effect on PROM participation rates. The impact of the introduction of web-based survey modes at our institution in May 2009 (after which time both paper and electronic input methods were available) was also evaluated for its impact on PROM participation rates. This study was approved by our institution's internal review board.

Chi-square test was used to calculate significance of the tabulations in Table 1, and Student's T-Test was used to assess differences in mean ages of the population groups. Logistic regression was used to determine odds ratios to define factors associated with non-participation in Table 3. Stata/SE version 12 (College Station, TX) was used for statistical analyses. The ICD-9 diagnosis codes to define variables were derived from Elixhauser codes on the AHRQ website [19].

Results

Of the 1,997 primary and revision total joint arthroplasty procedures performed at our institution between July 1, 2007 and December 31, 2010, 906 (45.5%) were determined to be “non-participants” and 1088 (54.5%) were determined to be “participants” (i.e. both pre-operative and post-operative surveys completed) in PROM reporting. PROM survey completion was significantly lower for patients over age 75 ($P < 0.05$), Hispanic and Black patients ($P < 0.001$), TKA versus THA patients ($P < 0.001$), revision versus primary TJA patients ($P < 0.001$), and patients with Medicare or Medicaid insurance ($P < 0.005$). PROM rates were also lower in patients who had undergone previous orthopaedic surgeries ($P < 0.001$). The presence of more than one of these factors further reduced participation ($P < 0.001$). In contrast, gender of the patient as well as psychiatric diagnoses, substance abuse, and altered mental status (when analyzed separately) did not affect survey completion rates. The presence of one or more major comorbidities, such as heart disease, diabetes mellitus, or cancer, did decrease the likelihood of

Table 2
Yearly PROM Participation and Electronic Survey Utilization.

Year	# Cases	% PROM Participation	% Electronic Capture
2007	240	30.8	0.0
2008	553	30.6	0.0
2009	589	57.1	6.1
2010	615	82.8	19.7
2011			43.1
Total	1997	50.4	

Table 3
Independent Predictors of PROM Non-Participation.

	Odds Ratio	95% Confidence Interval	P Value
Age >75	0.67	0.48–0.92	0.015
Revision TJA	0.43	0.34–0.55	<0.001
Knee Surgery	0.34	0.27–0.42	<0.001
3–4 Prior Orthopaedic Surgeries	0.51	0.32–0.81	0.004
>4 Prior Orthopaedic Surgeries	0.20	0.1–0.41	<0.001

reporting, although the difference was not significant ($P = 0.069$). Similarly, the lower participation rate for patients with a primary language other than English was nearly significant ($P = 0.068$). There was no difference in the mean ages of the participating and non-participating groups.

PROM participation increased significantly during the time period studied, from 30.8% in 2007 to 82.8% in 2010 ($P < 0.001$) (Table 2). 100% of the patients who filled out the survey using electronic methods completed both a pre-operative and post-operative questionnaire (versus 50% overall participation rate for non-electronic methods) (Table 1). Overall, the most significant predictors of non-participation in the outcomes program were age over 75 years, revision TJA, TKA surgery, and 3 or more prior orthopaedic surgeries. (Table 3)

Discussion

Our research shows certain patient characteristics seem to hinder successful PROM completion. Non-participants were more likely than participants to be older than age 75, Hispanic or Black, have Medicaid or Medicare insurance, and have had previous surgeries. Patients with comorbidities or a primary language other than English showed a trend towards lower completion rates, but this was not significant with the numbers of patients available in our study. In contrast, the gender of the patient, cognitive limitations, psychiatric diagnoses or drug and/or alcohol dependency issues did not account for a statistically significant difference in completion rates. This study also shows a significant increase in PROM completion rates with the introduction of electronic methods ($P < 0.001$). Although this study reveals association rather than causation, it allows us to speculate about some of the barriers to completion of PROM survey forms, which may help in developing strategies for improvement.

We found that patients older than 75 years had lower reporting rates than those in younger cohorts. Elderly patients may have more difficulty understanding questions and completing questionnaires, or they may be more difficult to reach by email. A report by The Pew Research Center in June 2012 found that internet and broadband use among adults over age 75 is much less prevalent than other age groups [20].

Patients with Medicaid and Medicare insurance also had significantly lower participation rates than those with commercial insurance or those who paid out-of-pocket. One major reason for lower participation rates among Medicare patients is likely the large number of adults over age 75 in this group. Medicaid insurance includes low-income families (earning less than \$22,050 for a family of 4 in 2009–10) and other highly vulnerable populations, including persons with disabilities and children in foster care. People in this category tend to have less access to healthcare and poorer health outcomes, as well as lower education levels and more difficulty with transportation to appointments [21,22]. People who earn less than \$40 K annually are much less likely to use the internet or email, and to have a computer and internet access in their home [23]. It is especially important to ensure that this group is well represented in outcomes research because of the limitations that often come with very low-income status. For instance, some patients in transitional housing may be less able to comply with proper post-operative care

regimens, or come to the doctor's office as frequently as necessary for proper follow-up care.

Another factor that was found to affect participation rates was whether the surgery was a primary (first time) or revision surgery. Patients who had revision TJA procedures had lower participation rates than patients who had primary TJA procedures. We hypothesize two likely reasons for this discrepancy. First, the majority of primary TJA patients attend a pre-operative patient education class where they can be encouraged to complete a survey, whereas most revision patients do not attend the class. Second, patients having revision surgery may be frustrated at having to undergo surgery again and may not perceive any personal benefit from previous outcomes reporting. This study also found that THA patients were much more likely to complete PROMs than TKA patients, for both primary and revision surgery. This may be a good area for future investigation.

Another risk factor that was nearly significant was language, i.e. patients with a primary language other than English. Other studies have looked at the impact of language differences in questionnaire completion [12,17,24]. Our research confirmed that not having English as a primary language can be a barrier to completing PROM surveys, although not to a statistically significant level ($P = 0.068$). Our surveys were available only in English, so patients who do not speak English at all were typically unable to complete questionnaires except in the rare occasions where a staff or family member was available to translate for the patient during their appointment. Having questionnaires available in multiple languages may be one effective and relatively low-cost way of decreasing the reporting gap between English and non-English speakers. Several of the survey instruments in use for orthopaedics are available and have been validated in multiple languages.

We suggest a number of ways to improve reporting rates for specific groups and for the general population. One tactic for increasing PROM participation at our institution was the implementation in 2009 of a web-based PROM data capture tool. This electronic research system was intended to increase the options available to patients in terms of PROM completion, including mode of entry as well as time and location of PROM completion. Beginning in 2009, all arthroplasty patients were offered the option of completing outcome surveys electronically, either on their home computer or on a tablet when they came to the doctor's office. Patients were emailed a link to the online survey before their appointment (if email was available) and notified by phone to complete the survey. If the survey was not completed before their appointment, they were offered the tablet to complete it electronically upon arrival. If they could not or would not complete the surveys electronically, paper forms were offered. Support staff was available to answer questions and help complete surveys by phone, email or in person similarly for all modes of administration.

In the first year that the electronic mode was offered, 6% of patients utilized this mode, increasing to 43% in 2011 (Table 2). Those who used electronic methods had much higher likelihood of completing the surveys in full and at both pre-operative and post-operative time periods (100% participation) than those who used paper forms (50.6% participation) ($P < 0.001$). In other words, a patient who utilized electronic methods for his or her pre-operative survey had 100% chance of completing both generic and joint-specific surveys, and of completing the post-operative surveys in full as well. The difference may be partially due to a feature of electronic surveys that requires each question be answered in sequence before one can proceed to the next question, in contrast to paper forms where one or more questions may be skipped or left blank, preventing the calculation of a cumulative score.

Web-based questionnaires also make it easier for patients who require more time to complete them, and can be filled out in the comfort of their own home rather than in the pressured environment of the doctor's office. This technology may allow patients who require

more time than could reasonably be allotted in the clinic to join the reporting population. Offering online PROM entry may be an especially effective strategy for certain groups that are less likely to go to the doctor's office, such as patients who live far away and those who are extremely disabled. It could also be a useful approach for institutions that do not have specific appointment times for pre-operative patients where surveys can be administered. It would be helpful to determine whether the introduction of this web-based reporting option has improved access and increased PROM reporting rates specifically for patients in the lower-reporting groups.

There are clear benefits of electronic PROM systems, such as increased access for patients, data availability in real time, and the possibility of incorporating data into clinical care during the appointment. Nevertheless, the traditional paper and pencil format is still much more prevalent in academic and clinical settings, possibly due to cost barriers and other difficulties in implementing electronic data collection methods [25]. Furthermore, the use of electronic technologies still represents a challenge for a portion of the population, especially older adults, who may have less familiarity with or access to computers [20]. For that reason, especially with older populations such as those in an arthroplasty practice, it is important to have paper questionnaires as a backup method of entry [26]. Furthermore, there are still disparities in internet usage according to age, race/ethnicity and income levels [25]. Other research suggests that low participation rates may be due to lack of motivation and forgetfulness [27]. To address the latter concern, clinician feedback and follow-up reminders could be beneficial. Research staff at our institution provide automated (email) and personal (email and telephone) reminders for patients who do not complete surveys on their own. Our personal experience indicates that offering follow-up reminders does increase PROM participation rates, although there is a trade-off in personnel time and costs.

This study has several strengths. We are not aware of other studies evaluating the role of language, insurance status, comorbidities, type of surgery or previous surgeries in PROM survey completion, so it contributes new information to the field. Also, the methodology included all patients within a certain time frame in the analysis rather than just a sample, which provides more accurate information than extrapolating the results of a small sample to the larger population. In addition to examining potential barriers to survey completion, this study offers possible solutions.

This study also has limitations and a number of questions remain unanswered. Most significantly, the retrospective study design can only establish association and not causation. We can only speculate as to the reasons for non-participation or decreased participation rates among certain subgroups. Further, due to the large population size we relied heavily on medical center administrative data, which are not always entirely accurate, rather than using chart reviews to pull direct information.

This study should be supplemented by future prospective research to evaluate both barriers and enablers to PROM survey completion. We suggest that this work test whether encouragement by the clinician increases reporting rates and reporting satisfaction. For instance, do patients perceive increased benefit to reporting if doctors emphasize the value of PROM participation, or distribute written materials to that effect, during the appointment? This simple change may increase the desire of patients to participate, as they perceive a greater value in their time investment. Also, it may be helpful to learn more about the preferences of the patient groups found to have lower participation in this study as well as reasons for non-participation. It would also be valuable to determine whether the design and format of the survey impacted PROM completion (and patient satisfaction) for both paper and electronic surveys.

In conclusion, we identified several barriers to PROM survey completion and suggested ways to increase participation. Further study is needed to expand on this research and find more solutions to

the problem of non-participation. With the increasing use of patient reported outcome measures in healthcare, it is important to reduce the reporting gap among different patient groups so that all populations are appropriately represented in outcomes research.

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