Beyond Infrastructure: Understanding Why Patients Decline Surgery in the Developing World
An Observational Study in Cameroon

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Objective: The aim of this study was to quantify and describe a population of patients in rural Cameroon who present with a surgically treatable illness but ultimately decline surgery, and to understand the patient decision-making process and identify key socioeconomic factors that result in barriers to care.

Methods: Standardized interviews were conducted of a random sample of adult patients with treatable surgical conditions over a 7-week period in a tertiary referral hospital in rural Cameroon. Main outcome measures included participant’s decision to accept or decline surgery, source of funding, and the relative importance of various factors in the decision-making process.

Results: Thirty-four of 175 participants (19.4%) declined surgery recommended by their physician. Twenty-six of 34 participants declining surgery (76.4%) cited procedure cost, which on average equaled 6.4 months’ income, as their primary decision factor. Multivariate analysis revealed female gender (odds ratio [OR] 3.35, 95% confidence interval [95% CI] 2.14–5.25), monthly earnings (OR 0.83, 95% CI, 0.77–0.89), supporting children in school (OR 1.22, 95% CI 1.13–1.31), and inability to borrow funds from family or the community (OR 6.49, 95% CI 4.10–10.28) as factors associated with declining surgery.

Conclusion: Nearly one-fifth of patients presenting to a surgical clinic with a treatable condition did not ultimately receive needed surgery. Both financial and sociocultural factors contribute to the decision to decline care.

Keywords: barriers to care, general surgery, global health, global surgery

In the past decade, a growing body of literature has emerged to support the role of surgical intervention as a critical, cost-effective component of health care in the developing world. However, despite the substantial prevalence of surgical disease in low- and middle-income countries (LMICs), this aspect of primary health care is often neglected in both research and practice. Over one-tenth of the global burden of disease requires surgical treatment, and up to 90% of trauma-related deaths occur in LMICs. A recent report of the Surgeons OverSeas Assessment of Surgical Need estimated that nearly one quarter of all preventable deaths in Sierra Leone occurred from conditions that may have benefited from surgery.

A variety of factors contribute to the disparity between prevalence of surgical disease and actual treatment provided. Thus far, much of the research in global surgery has focused on the dire need to improve surgical infrastructure. In certain regions of eastern Africa, the availability of surgical beds can be as low as 1 per 5000 people. Many public district hospitals lack trained anesthetists, and some rely on the equivalent of nurse-practitioners to perform major surgical procedures.

However, providing physical access to a surgeon does not guarantee access to surgical care. Factors such as financial limitations, fear of surgical risk, and community decision-making dynamics can influence patients (both voluntarily and nonvoluntarily) to either neglect to seek care or refuse physician-recommended surgery. Both outcomes lead to failure to receive needed treatment. These presence of these factors as barriers to care in LMICs has been previously described in the pre-hospital setting, but their relationship with patient decision-making in the context of the surgical clinic has not yet been examined.

Although patient decision-making in surgical care has been studied extensively in the United States, observations from the insurance-based health care economies of the developed world cannot reliably be extrapolated to the out-of-pocket, market-driven health care systems that are the reality on the ground in the majority of LMICs. The Lancet Commission on Global Surgery recently estimated that every year over 81 million people in LMICs face catastrophic costs from accessing surgical services. It is in these regions that patients most strongly feel the financial burden of life-altering and life-saving surgical care, and it is in these communities that research on barriers to care is most desperately needed.

Mbingo Baptist Hospital (MBH) is a rural, high volume surgical referral center in the Anglophone North-West region of Cameroon. The general surgery clinic sees hundreds of patients each week, and when elective surgery is recommended, the patient is required to pay the estimated surgical fee in full before being scheduled for the procedure. This structure, in which patients pay a predetermined fee out of pocket before receiving care, provides an ideal setting to examine the intersection of economics and culture in the decision-making process. Furthermore, because the hospital is run by a faith-based organization, prices are set at significantly lower levels than in government-run or private hospitals. Thus, we may reasonably expect that any financial barriers to patients that we observe here would be heightened, not diminished, in other health care settings throughout the region.

In this study, we aim to both quantify and describe the population of patients with surgically treatable illness who present...
to the surgical clinic, but ultimately refuse surgery. By administering a comprehensive survey to a randomly selected cohort of new patients over a 2-month period, we are able to both estimate the incidence of patients refusing care and evaluate the relationship between financial and cultural factors and the decision-making process. Others have previously identified barriers to surgical care using quantitative methods. However, none have utilized interviews in the clinic setting to determine the degree to which each of these barriers is associated with the actual uptake of surgical care. We hypothesize that both absolute cost of care and family decision-making dynamics and priorities will factor significantly in determining patient’s acceptance of a procedure.

METHODS

Study Design and Population

We conducted a cross-sectional study at MBH, a 300-bed referral hospital located in rural Northwest Cameroon. Every clinic day during the 7-week period from June 19 to August 9, 2015, a survey was randomly administered to an average of 5 new patients presenting for surgical consultation at the general surgery clinic. All patients selected who fulfilled the inclusion criteria were consented to participate.

Inclusion Criteria

All new patients over the age of 21 with conditions requiring surgical treatment were eligible for inclusion in the study. New patients were defined as those presenting to the surgical clinic for the first time during the course of their current condition. Patients who did not speak Pidgin English were excluded (~10% otherwise eligible patients). All patients included on the basis of language spoke French, the official language in all but 2 regions of Cameroon. Age ≥21 years was used as an inclusion criterion because 21 is the age at which the Cameroon Baptist Convention Health Board institutional review board (IRB) considers participants to be adults capable of autonomously consenting to participation in medical research. Patients fulfilling these criteria were recruited, and oral informed consent was obtained (no recruitment materials were used). When the indicated primary health care decision-maker was not self, consent was still obtained from the patient to participate in the study. Ethical approval for this study was granted by the Stanford University IRB and Cameroon Baptist Convention Heath Board IRB.

Survey Instrument

Participants were interviewed with a 2-part survey developed in collaboration with Cameroonians, piloted to assess comprehensiveness and cultural appropriateness, and revised before being administered to patients and caregivers. The survey questions were administered orally in Pidgin English through a translator and answers were recorded. The same translator (JC) and researcher (BL) administered all surveys.

All consenting participants were interviewed twice during their visit to the surgical clinic. Participants were first interviewed before their consultation with a physician. During this time, information was collected regarding patient demographics, the history of the current condition (including previous care received), the identity of the patient’s primary healthcare decision-maker, and how the patient intended to pay for his or her care. Three metrics were used to gain a holistic view of participants’ finances and ability to pay: average monthly income, number of children supported in the home, and number of children supported in school.

Participants were interviewed for a second time immediately after their consultation with one of the surgical residents (3) and attending surgeons (3). At this time, all patients for whom surgery was not recommended were removed from the study. The patients who remained were asked what surgery was recommended, what deposit was required, and whether they would elect or decline to undergo the procedure.

At MBH, the surgical clinic nurse uses the physician’s note in the patient’s chart to estimate the eventual cost of surgery based on an institutional fee schedule, and the patient pays that amount in the form of a deposit. This deposit is required before the patient is eligible to schedule his or her surgery, and on average ends up covering approximately 90% of the overall cost of his or her hospital stay. In the event, the nurse overestimates the deposit, and the patient is refunded the balance when discharged from the hospital. Because this deposit amount is the figure presented to the patient at the time he or she is deciding whether to undergo the procedure, we elected to record this rather than the eventual hospital bill as the relevant cost of care.

The final component of the survey was modeled after the DECISIONS tool, which assesses patient priorities in health care decision-making. Patients were asked to rate a multitude of factors in the clinic setting to determine the degree to which each of these barriers is associated with the actual uptake of surgical care. We hypothesize that both absolute cost of care and family decision-making dynamics and priorities will factor significantly in determining patient’s acceptance of a procedure.

Analysis

Data were analyzed using R. Descriptive statistics, the $x^2$ test, Student $t$ test, and logistic multivariate regression were used to examine factors associated with refusal of surgery. $P$ values <0.05 were used to establish statistical significance.

RESULTS

Population Characteristics

One hundred seventy-five participants with a treatable surgical condition were interviewed. One hundred forty-one selected to proceed with surgery (80.6%) and 34 declined (19.4%) (Table 1). A wide variety of surgical procedures were offered to our participants for both benign and malignant conditions. Procedures included but were not limited to hernia repair, prostatectomy, cholecystectomy, mastectomy, colectomy, hysterectomy, lower limb amputation, gastrectomy, nephrectomy, wound debridement, and superficial mass removal (all of which had at least 1 participant “accept” and “decline” the procedure). The majority of patients with suspected or proven cancer accepted surgery (78.4% accepted, 21.6% declined); near identical numbers were seen for acceptance of procedures that are typically classified as ambulatory (78.6% accepted, 21.3% declined).

Overall, patients presenting to the clinic were disproportionately male (57.4%) and minimally educated (70.3% primary school education or less). Nearly one quarter (24.6%) traveled more than 5 hours to reach the clinic and one-tenth (10.9%) more than 10 hours. Over half of participants (63%) had previously sought care with a physician for their current condition, spending an average of 44,713 CFA ($75.72) before presenting to our clinic. Participants earned, on average, 30,584 CFAs ($51.79) per month and supported just over 4 children in the home and 2 children in school.

Just over half of patients served as their own health care decision-maker (50.3%). Seven patients deferred all medical decisions to their spouses (4.0%) and the remainder deferred to family members (in all cases parents, siblings, or children). On average, participants presenting to the clinic had suffered from their current condition for 39.4 months, with just over 10% (19 participants) presenting after more than 10 years. When queried before the consultation, 27.7% of all participants did not expect to have surgery, and 31.2% did not want to have surgery.
Effects of Characteristics on Decision to Accept or Decline Surgery

Univariate analysis revealed multiple factors associated with the decision to accept or decline surgery (Table 2). Gender was associated with differences in decision-making, with females more likely to decline surgery than males (odds ratio (OR) 2.23, confidence interval (CI) 1.04–4.79). Patients for whom family members played a significant role in the decision-making process showed a reduced likelihood of declining surgery (OR 0.44, CI 0.20–0.98). Earnings and financial commitments (estimated by the number of children supported in school) were associated with an increased odds of declining surgery. Those who earned higher pay were less likely to decline surgery (OR 0.83, CI 0.78–0.89), and those supporting more children in school were more likely to decline (OR 1.16, CI 1.09–1.24). Furthermore, inability to secure contributions to the cost of care from external sources (crowd-source), such as family-members or the community, was associated with an increased odds of declining recommended surgery (OR 5.0, CI 2.17–11.5).

Input of selected variables into a multivariate regression model confirmed that gender, ability to crowd-source funds for care, number of children supported in school, and earnings all independently associate with the decision to accept or decline recommended surgery (Table 3). Of these, variables payment source (OR 6.49, CI 4.10–10.28) and gender (OR 3.35, CI 2.14–5.25) had the highest impact. Basic elements of the medical history such as length of presenting problem, previous hospitalization, or previous surgery were not associated with an increased likelihood of accepting or declining surgery.

Priorities in Decision-making

Participants accepting and declining surgery were asked to rate 11 different factors on a Likert Scale they considered in their decision of how to proceed with their care. These ratings differed between those who accepted and those who declined surgery (Fig. 1). Participants who accepted surgery reported improving health (3.44 vs 2.58, P < 0.001), alleviating pain (3.75 vs 3.02, P = 0.002), and the potential of being able to do things they cannot currently do (3.08 vs 2.55, P = 0.045) as more important to their decision than those who declined. Participants who declined surgery placed increased importance on the cost of care (4.5 vs 2.77, P < 0.001) and fear of risks of the procedure (2.32 vs 1.35, P < 0.001), and reported less trust in physicians (3.05 vs 4.05, P < 0.001) than those who accepted. Regression analysis confirmed that level of education did not act as a confounder to these relationships (data not shown). All factors were rated as "quite important" or higher by at least 1 participant in each group (accept vs decline).

The top reason to accept surgery was to alleviate pain (most important reason in 36.9% of cases), and the top reason to decline surgery was the cost of care (most important in 76.5% of cases) (Table 4).

DISCUSSION

LMICs suffer a substantial disparity between burden of surgical disease and access to proper surgical care. Although research...
TABLE 2. Crude (Unadjusted) Odds Ratio of Selected Factors Influencing Patient Decision-making

<table>
<thead>
<tr>
<th></th>
<th>Declines Surgery</th>
<th>Accepts Surgery</th>
<th>Odds Ratio† (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (reference)</td>
<td>14</td>
<td>86</td>
<td>2.23 (1.04–4.79)*</td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
<td>55</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not complete primary school (reference)</td>
<td>11</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Completed primary school</td>
<td>17</td>
<td>51</td>
<td>1.30 (0.55–3.08)</td>
</tr>
<tr>
<td>Completed secondary school</td>
<td>4</td>
<td>34</td>
<td>0.46 (0.13–1.57)</td>
</tr>
<tr>
<td>Completed post-secondary</td>
<td>1</td>
<td>13</td>
<td>0.30 (0.04–2.55)</td>
</tr>
<tr>
<td>Decision maker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient (reference)</td>
<td>22</td>
<td>66</td>
<td></td>
</tr>
<tr>
<td>Family member</td>
<td>11</td>
<td>75</td>
<td>0.44 (0.20–0.98)*</td>
</tr>
<tr>
<td>Source of payment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Borrow from Family/Community (reference)</td>
<td>9</td>
<td>90</td>
<td></td>
</tr>
<tr>
<td>Out of pocket</td>
<td>25</td>
<td>50</td>
<td>5.0 (2.17–11.5)*</td>
</tr>
</tbody>
</table>

† P < 0.05.

*Calculated using univariate logistic regression model with the binary outcome “Decline Surgery” = 1; “Accept Surgery” = 0.
†Calculated in units of 10,000 CFA/month.
CFA indicates Central African Franc (1 US Dollar = 590 CFA as of May 29, 2016).

endavors such as Surgeons OverSeas and the WHO Global Initiative for Emergency and Essential Surgical Care have made significant progress in identifying and addressing the lack of adequate surgical infrastructure (hospitals, trained providers) in LMICs, little is known regarding the health care decisions made by underserved populations once adequate physical access to a surgeon is established.1,23

Here, we present, to our knowledge, the first quantitative analysis linking economic and sociocultural barriers to surgical care with the patient’s decision to accept or decline recommended surgery. In our study population, a full 19% of participants seeking consultation with a MBH surgeon for a surgically treatable problem did not end up receiving the surgery recommended by their treating physician. Despite adequate physical access to the hospital, availability of trained surgeons, and the health literacy necessary to recognize the need for medical treatment, nearly one-fifth of patients failed to receive necessary care. These patients had already invested in the costs of transportation and a consultation fee in having their problem evaluated. There is likely a lack of resources both the patients and motivation to seek a solution to their complaint.

If anything, this proportion likely underestimates the true prevalence of the problem, as our study site (MBH) provides patients multiple resources not available at typical public hospitals (social workers, comparatively low prices). A deeper understanding of the sociocultural and economic factors at play here is paramount to expanding access to care beyond building more hospitals and training more surgeons.

Unsurprisingly, considerations of cost ranked among the highest concerns of those who refused recommended surgery. The patient’s fee for an elective unilateral inguinal hernia, for example, is 60,000 to 80,000 CFA. If the patient has to bear 100% of the financial burden, this equates to a fee that is 2 to 2.6 times the mean monthly gross salary of our cohort—a catastrophic medical expense (>10% of gross monthly income). Thus, it is often critical that the responsibility of financing care extend beyond the individual patient and be shared among the family or community. Interviews revealed the substantial role the community plays in decision-making and financing of care. Just under half of all participants surveyed made health care decisions as a family (45.7%), and a just over half borrowed funds for their care (56.9%). It is these individuals, those who both navigated the health care system and financed their care with the help of their families and communities, who were most likely to receive needed surgery. On the contrary, our study corroborates previous work highlighting those without access to community resources as the patients most vulnerable and most unlikely to receive care.25

Beyond financial considerations, a number of sociocultural factors influenced patient decision-making. Of significant importance is our observation that simply being a woman independently associates with a reduced likelihood of receiving recommended surgery. As the women in our sample differed from the men in neither level of education nor income, some cultural force must be impeding women from receiving care. It is possible that some aspect of the shared health care decision-making process undervalues women compared with men. Perhaps family members are less willing to financially support a female relative’s care than a male’s. This matter clearly warrants further investigation.

Those who accepted and declined surgery prioritized different values when making their decisions. Although cost of care and fear of the risks of surgery dissuaded those who ultimately declined care, patients who received surgery were motivated significantly by trust in their physician and desire to alleviate pain. Surprisingly, trust in the physician outranked both faith in God and opinions of family members in influencing patients to undergo surgery.

Although every effort was made to minimize bias and maximize external validity in this study, there are inherent limitations to our data. By interviewing participants at the surgical clinic, we fail to capture those who have a surgically treatable condition and

TABLE 3. Logistic Regression of Selected Factors Influencing Patient Decision-making

<table>
<thead>
<tr>
<th></th>
<th>Odds Ratio (95% CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children in school</td>
<td>1.22 (1.13–1.31)</td>
<td>0.012</td>
</tr>
<tr>
<td>Earnings (CFA/month)</td>
<td>0.83 (0.77–0.89)</td>
<td>0.012</td>
</tr>
<tr>
<td>Gender†</td>
<td>3.35 (2.14–5.25)</td>
<td>0.001</td>
</tr>
<tr>
<td>Source of payment‡</td>
<td>6.49 (4.10–10.25)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

*Calculated using univariate logistic regression model with the binary outcome “Decline Surgery” = 1; “Accept Surgery” = 0.
†Calculated in units of 10,000 CFA/month.
‡Borrow from family or community (reference) vs pay out of pocket.
CFA indicates Central African Franc (1 US Dollar = 590 CFA as of May 29, 2016).
Therefore, when nearly one-fifth of these patients leave.

**Beyond Infrastructure**

In another model, Nara

**World J Surg**


19. James Brown, MD (Chief of Surgery, Mbingo Baptist Hospital), personal communication with the author, 2015.


