

Levels of Surgical Disease and Predictors of Barriers to Care in Rural India

by

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Christopher Woods

Thesis submitted in partial fulfillment of
the requirements for the degree of Master of Science in the
Duke Global Health Institute in the Graduate School
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ABSTRACT

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Abstract

An estimated 234.2 million major surgical procedures are performed annually worldwide, yet the wealthiest third of the world's population receives 73.6% while the world's poorest third receives only 3.5%. Approximately one-third of the global population has no access to basic surgical care. Knowing that large unmet surgical need in a community can lead to high morbidity and mortality in the population, the purpose of this novel study was to assess the level of surgical conditions in rural Gadchiroli, India as well as to conduct a quantitative assessment of the barriers to surgical care. In this retrospective, cross-sectional needs assessment, a study-specific survey was administered in a clinic-based setting. Of the 500 participants, 141 (28.2%) reported surgical conditions, for a total of 175 surgical cases, in the preceding two years. The conditions with the highest prevalence were hydrocele, anorectal processes, dysfunctional uterine bleeding, cataracts, appendicitis, and spondylosis with neurologic claudication. Assessment of the conditions by a healthcare provider occurred in 133 (76.6%) of the cases of which only 32 (24.1%) reported having undergone surgery during the two year period. Overall, in this population, the burden of surgical disease is higher than previously expected and while willingness to undergo surgery is high, the completion rate is quite low. Certain factors appear to predict difficulty in seeking or receiving surgical care, including lost wages ($p=0.027$), the amount of time that family

members need to stay in the hospital to help (p=0.038), and time away from work (p=0.045). Targeting these factors is a first step towards addressing the unmet surgical needs in this rural community.

Dedication

To my husband Ben Hudson: for everything. Without your loving support of my career, dreams, ambitions, and well-being, this project would have been neither conceivable nor completed.

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1. Introduction

1.1 *The realities of surgical care globally*

An epidemiological transition is being seen in many parts of the world and the burden of disease is beginning to shift from acute diseases of pestilence and infection to those of a more noninfectious nature [1] As this transition continues, we are seeing a rise in the awareness of surgical interventions as a means of preventing, treating, curing, and palliating these conditions [2,3]. Surprisingly, little is known about the volume of surgeries worldwide, let alone the burden of surgical disease. Recently, burgeoning interest has led to many sentinel explorations into these topics. A conservative estimate showed that the global burden of surgical disease accounted for 11% of the world's current disability-adjusted life-years (DALYs). To address these conditions, there are an estimated 234.2 million major surgical procedures performed annually worldwide [2]. Yet, even more striking is the fact that the wealthiest third of the world's population receives 73.6% of those surgical procedures while the world's poorest third received only 3.5%.² Further, it is estimated that approximately one third of the world's population has no access to basic surgical care [4]. Experts in the field of global surgery state that there is no difference in the underlying determinants of the need for surgery between resource-poor and –rich countries; therefore we are faced with overwhelming evidence that there is an enormous inequity in surgical care provision between

developed and developing countries [5]. This has lead surgery to be labeled “the neglected stepchild of global health” [6].

1.2 The need for surgical care globally

If one hopes to begin to prioritize access to surgical services, one must first define what necessitates surgery. The accepted definition of a surgical condition – minor or major – is “any condition for which the most potentially effective treatment is an intervention that requires suture, incision, excision, manipulation, or other invasive procedures that usually, but not always, requires anesthesia” [2,7]. To address this admittedly broad field, however, one must be realistic. Due to current real limitations of resources, prioritization of necessary services must be considered. There are certain procedures that have been deemed to be the highest priority by virtue of the fact that they are feasible and cost-effective. Ideally, these are the services that would be available to all citizens of the world [8]. These include emergency and essential surgeries, some examples of which are surgical airways, exploratory laparotomies, external fixations of fractures, treatment of traumatic joint dislocations, cesarean sections, irrigation and debridements, and repair of club foot [9,21]. The morbidity and mortality of these conditions can be very high and addressing these surgical components will also make great strides toward addressing many of the UN Millennium Development Goals, specifically Goals 1, 4, and 5 [8]. For example, obstructed labor is one of the leading causes of not only maternal death but also of obstetrical morbidity in Sub-Saharan Africa

and Southeast Asia. Globally, over 500,000 women die each year of pregnancy-related complications and many more are forced to live with ostracizing sequelae such as obstetrical fistulas or uterine prolapsed which are amenable to surgical correction [3,9,19]. Furthermore, high death rates accompany ectopic pregnancies and intentional abortions [3], and yet it is estimated that 99% of deaths from these conditions in low-income countries can be prevented through improvements in surgical care [7]. Similarly, traumatic injuries account for nearly 5.1 million deaths worldwide or, when put in perspective, 1 in 10 deaths [10]. It has been shown that one-third of these deaths occur in individuals aged 15-44 years who are noted to be the most economically productive segments of the population, often the sole income provider in the family [11,12]. As further evidence of the disparities in resource-poor settings, more than a quarter of the aforementioned deaths due to traumatic injury occur in the countries that comprise the WHO Southeast Asian Region (SEARO) [13]. In India, where a trauma-related death occurs every 1.9 minutes [14], there were nearly 800,000 deaths in 2001 from all causes of injuries, making it the fifth leading cause of death [13]. Given these examples, one can easily see how nearly one-third of the 11% of the global DALYs attributable to surgical disease is borne by the SEARO alone [15].

1.3 Historical Misconceptions

Despite the large inequities in global surgery, the predominant obstacles impeding the progression of this nascent area have been financial deficiencies. Surgery

is often mistakenly cast as a fiscally imprudent intervention available only for wealthy populations and not appropriate for inclusion in a national public health agenda [12,16]. Yet, essential and emergency interventions in general, trauma, and obstetrical surgery have proven to be as cost-effective as other public health interventions in the developing world [17,18,19]. The estimated cost per surgical DALY averted by access to all surgical care in rural Sierra Leone was US\$33.18 For emergency obstetrical care specifically, the cost at a rural hospital in Bangladesh was found to be US\$11 per DALY averted [20]. These figures are comparable to the cost of measles immunizations (US\$30 per DALY averted), management of acute lower respiratory illnesses (US\$20 per DALY averted), and vitamin A distribution (US\$9 per DALY averted) [12,18,21]. The WHO has recently responded to these data and the emerging role of surgery on the global health stage is continuing to gain support [16]. Therefore, it is paramount that we actively pursue research into the causes of surgical care imbalances and the role of surgery in future policy decisions.

1.4 India and the growing field of global surgery

Within SEARO, India is among the countries targeted by the WHO Global Initiative for Emergency and Essential Surgical Care (GIEESC) in order to reduce “death and disability from road traffic accidents, trauma, burns, falls, pregnancy-related complications, domestic violence, disasters, and other emergency surgical conditions”[9,22]. This novel public health strategy prioritizes horizontal health systems

strengthening by way of universal access to essential surgeries as a component of primary care. The project assesses surgical capacity at the first level referral provider as opposed to more specialized secondary and tertiary providers [9]. This is especially poignant in India where the healthcare system has a marked rural-urban disparity; 65-70% of the total population resides in the rural regions – half of whom live below the poverty line – yet only 25% of the medical infrastructure is available to them. While the urban middle class in India has access to medical care that is comparable to many parts of the developed world, at least 135 million of India’s rural and tribal people are without access to even minimal health facilities [23]. Importantly, these disparities are in the context of a healthcare system that is already stretched thin, with the physician-to-population ratio of 6 per 10,000 nationally [24]. With pressure to staff the large, urban centers, 75% of the allopathic providers practice where the minority of the population resides leading to a growing number of non- or under-qualified practitioners in the rural areas [23]. And yet, the availability of surgeons in the rural regions is even bleaker: less than 20% of the surgical workforce practices in rural India [25]. Most of these rural surgeons are responsible for more than just the surgical aspects of medical care and the primary health centers or regional sub-centers in which they work are understaffed, under-stocked, and over capacity [26].

In order to prioritize access to surgery on the public health agenda both globally and in India, we must first acknowledge that the current information is severely lacking.

What is needed is a comprehensive, systematic approach to the measurement of the burden of surgical conditions, the current met and unmet needs for surgical care within the population at risk, and an understanding of the quality of care that the system currently provides. So while the notion of universal access to essential and emergency surgeries is well-founded, it remains an idea still in its infancy. The first step towards its realization is thorough reviews of existing local data for effective coverage of selected surgical conditions. In the context of this framework, this project was designed around previous studies conducted at a rural NGO hospital (SEARCH) in Gadchiroli, India [Belle J. and S Lagoo, unpublished, 2008-09]. SEARCH, in combination with a single civil hospital, provide the primary level surgical referral care in Gadchiroli for a population of 970,000 of which 93% live in rural areas [27]. The district is characterized as undeveloped, with forest covering 76% of the landmass. Additionally, Gadchiroli is designated as Tribal, with this unique community comprising 38.3% of the total population. In this region, 53.5% of families live below the poverty line and there is substantial political instability owing to a longstanding Maoist insurgency [27].

SEARCH (Society for Education, Action, and Research in Community Health) was established in Gadchiroli in 1985 with the joint goals of improving the health of the local population and serving the global community by impacting health policy through rigorous research. The campus of this non-governmental organization consists of a hospital for the rural and tribal communities, a training and research center, and

housing quarters for most of its staff. The research model that is embraced by SEARCH is one that approaches community health by identifying the needs of and from the people, developing models that empower the community, testing these models in a rigorous environment, and then motivating change within the community. Their research has been published in several peer reviewed journals and has had substantial impact on several public health programs of the Government of India. One very unique feature of the medical care provided at SEARCH is that the hospital was built to target the rural and tribal populations who infrequently accessed the government hospital system. After consultation with the tribal leaders, many features of the communities, culture, and religion were incorporated into the design of both the physical structures and the healthcare delivery model. The hospital is staffed by 4 physicians who provide both outpatient and inpatient medical care to over 20,000 patients annually, with daily clinic encounters sometimes topping 300 patients. They have basic laboratory, radiographic, and ultrasound technology available on site, as well as a fully functional pharmacy and two operative theatres. Through surgery camps, SEARCH functions as the primary surgical referral center for the region though outside of these camps it is not staffed by a surgeon and therefore does not have emergency surgical capabilities.

In the continuum from disease existence to care provision, the main drivers are the disease epidemiology, patient-specific drivers and social constraints, and health policy. These three factors work together like the cogs of a machine, with each variable affecting

the other and the sum of the parts needed to transition to effective surgical care. The dilemma that arises in this scenario is the vast lack of data about the surgical burden of disease, which leads to a systemic breakdown, preventing improvement in surgical care policy and provision. Prior work in Gadchiroli focused on identifying the specific surgical disease burdens that would present during the course of periodic surgery camps and the subsequent outcomes for those patients [Belle J., unpublished data]. The surgery camps follow an urban-to-rural care shifting model of surgical care. While the initial study evaluated the surgical burden of disease that was addressed, or met, in the course of rural surgery camps, further research was necessary to evaluate the needs still unmet. Knowing that large unmet surgical need in a community can lead to high morbidity and mortality in the population, the purpose of this study was to assess the level of surgical conditions in rural Gadchiroli, India as well as to conduct a quantitative assessment of the barriers to surgical care. Our hypothesis was that a high level of surgical disease existed in Gadchiroli, India. It was further hypothesized that quantifiable barriers were contributing to disparities in care- and surgery--seeking behaviors in the context of surgical conditions. Therefore, we sought to categorized these factors through primary data collection and use these insights to guide barrier reduction by direct and indirect actions.

Having previously established the surgical care that is provided by SEARCH to the Gadchiroli community and the outcomes experienced by these patients [J. Belle and

S. Lagoo, unpublished data], this descriptive study aimed to identify the levels of surgical conditions and predictors of barriers to surgical care in this rural region by investigating four distinct research questions for rural Gadchiroli:

Question 1: What surgical diagnoses are most prevalent in Gadchiroli?

Aim 1: Estimate the frequency of indicators of surgical conditions.

Question 2: Are patients willing or able to seek evaluation by a healthcare provider?

Aim 2: Document care-seeking behaviors of individuals with surgical conditions.

Question 3: Are patients willing or able to undergo surgery?

Aim 3: Determine if evaluation individuals who have been diagnosed with a surgical condition who underwent surgery for that condition.

Question 4: What types of barriers make it difficult or prevent surgical treatment?

Aim 4: Characterize possible barriers to surgical care and treatment.

2. Method and Materials

To address these four aims, we focused on access to specific, high-prevalence, definable conditions amenable to emergency and essential surgeries in the realms of general, obstetrical, and trauma care. We aimed to characterize the prevalence and outcomes of cases that do not or cannot receive care and use this characterization to help determine the barriers to care that are facing the population. The study and survey administration was conducted at the SEARCH non-governmental hospital in the region of Gadchiroli, India from June 2010 until November 2010. This entire project was crafted in conjunction with a community partner, Dr. Rani Bang.

2.1 Study design

This study was designed to be a retrospective, cross-sectional needs assessment via a paper survey. Owing to the high illiteracy rate in Gadchiroli (39.9% overall, 51.9% for women) [27], a written survey was not feasible or appropriate therefore this was accomplished through supervised, standardized verbal administration in the local language.¹ For the purpose of this study, members of the household were considered to be all those who reside in a given home for most of the year. Per established customs of survey administration in this region, the gold standard of community-based door-to-

¹ *Most individuals regardless of caste or education spoke the State language of Marathi. Individuals who spoke only the National language of Hindi or the Tribal language of Gondi were excluded.*

door sampling could not be undertaken without direct invitation by the community leaders, which was not available at the time of this study.² Therefore, the sampled study population was comprised of individuals accompanying patients presenting for care at SEARCH. An initial clinic-based pilot study utilizing a snowball sampling method was conducted to test the research tool and to elucidate community-specific barriers to care via open-ended questioning. The results were incorporated into further refinement of the survey design, structure, verbiage, and flow as well as the project design.

2.1.1 Consent process

Prior to participation, all potential participants were to be informed (i) that the survey was being conducted in conjunction with a research study with SEARCH, (ii) that participation was voluntary, (iii) that they had the right to refuse to participate at any time, (iv) that participation in this study was not a promise or contract to provide surgical services to them or to their family, and (v) that they had the right to ask questions at any time. No data was collected prior to IRB approval.³ Per established customs of survey administration in this region through SEARCH, there was no

² *At the time of this study, the community leaders had expressed interest in the topic of surgical needs in their communities but were not willing to accept a community-based project. There was uncertainty about the extent of the issue. Verbal agreement was reached to permit initial clinic-based work after which time they would review the results to consider a possible community-based approach.*

³ *A local IRB process did not exist therefore Duke IRB functioned as the sole reviewer.*

compensation for participation, neither monetary, material, nor medical. There was no immediate direct benefit to individuals participating in this study.

2.1.2 Referral process

Any individual who was identified to have indicators of a chronic surgical disease were, as per established customs at SEARCH, to be given a referral for evaluation. This would often be the same day and on the standard socio-economic tiered payment scheme without priority over the current queue of outpatients. As with any patient in the clinic, they would be eligible for inclusion in an upcoming surgery camp on the same tiered payment scheme and, again, would receive no preference in the queue. Any individual who was identified to have indicators of an acute surgical disease were immediately evaluated and, if necessary, advised to seek care at the nearest referral hospital.^{4,5} All cases of referrals were documented, including refusals.

2.2 Participant recruitment and criteria

The sample population was compared to the most recent census data (2005) for the SEARCH catchment (N=89,951).⁶ Accepting a margin of error of 5% and a confidence

⁴ SEARCH is equipped with operative theaters but neither a surgeon nor an anesthesiologist outside of scheduled surgery camps, therefore emergency surgical care beyond the basic provision of services necessitates a referral to the Gadchiroli civil hospital which is 15km away.

⁵ Individuals who presented with signs and symptoms of an acute surgical condition were uniformly excluded from this particular study because they were patients. See inclusion criteria.

⁶ SEARCH conducts an internal regional census of each home every 5 years which includes vital and health statistics. The national census occurs every 10 years (latest data available is 2001).

interval of 95% in a random sampling of this population, power calculations predict a necessary minimal sample size of approximately 400 surveys. In order to ensure ample room for incomplete survey data, the target sample size was set at 500 for this study. Via convenience sampling, non-patient visitors (referred to hereafter as Participants) were enrolled for self-reporting as well as proxy responses for randomly selected members of their household (referred to hereafter as Participant by Proxy). The inclusion criteria for Participants were as follows: an adult community member living in the catchment area for SEARCH within the preceding 2 year period. The exclusion criteria for Participants were as follows: any person under the age of 18 years at the time of the survey or a person of any age who was presenting for care on the day of recruitment. Participants were asked to self-report on their personal health experiences as well as to report as a proxy for their family members, up to a maximum of 5 representative surveys per household. Selection criteria for Participants by Proxy were as follows: any household member residing within the SEARCH catchment during the preceding 2 years, even if they were now deceased⁷, including only those about whom the Participant can adequately report health information.⁸ For each given list of potential Participants by

⁷ *Midway through the project it became apparent that the issue of deceased family members was not being addressed voluntarily therefore it was added as an additional verbal question to the survey and queried directly to ensure that this population was not missed.*

⁸ *Information about persons under the age of 18 years was collected when voluntarily provided by a representative adult proxy since many unique surgical conditions exist in that population.*

Proxy, inclusion was selected from a randomly generated number list. This process was repeated until the maximum of four Participants by Proxy per household was reached or the Participant declined to contribute further. Collectively, the Participants and Participants by Proxy comprised the sample population and were used as an accurate representation of the true community.

2.3 Survey Construction

The survey demographic information was modeled after the categories used in the Indian national census (i.e occupation, education) [28]. The survey tool was designed to focus on specific, prevalent, and definable surgical conditions. The diseases selected for inclusion were informed by local case diversity, regional epidemiology (i.e. filariasis), and previous studies on unmet surgical need [3,29,30,31,32]. Two distinct causal diagrams were constructed for the two cause-and-effect scenarios: the effect of surgical symptoms on healthcare evaluation (*Appendix A*) and the effect of a surgical diagnosis on achieving surgical treatment (*Appendix B*). The specific and necessary queries for this study were chosen. based on analysis of these causal diagrams and prior community-based studies.⁹ Per this model, in addition to the barriers to surgical care, the following demographic variables were included: gender, age (continuous), health

⁹ *All non-causal pathways were blocked and therefore unbiased. The colliders were disease severity perception, overall health status, and the barriers of burden of time and cost of care (all measured).*

status, distance traveled for care, and socioeconomic status. Socioeconomic status is at the level of the household and this variable was constructed out of the highest level of education per family and the highest income-generating occupation per family. While caste is a component of socioeconomic status in India, it was not directly involved in any causal or noncausal pathway and therefore was not included in the model. The effect of caste was later investigated via stratification, in addition to occupation, marital status, and gender¹⁰. The survey was designed to inquire about past surgical history as well as four dimensions of surgical disease within only the preceding 2 years: perceptions of current need for surgery, screening for indicators of possible surgical disease, care-seeking behaviors, and willingness to undergo surgery. Potential predictors for barriers to seeking or receiving surgical care were based on open-ended pilot study responses provided by members of the community and the hospital staff. These barriers were related to basic demographics as well as cost, burden of time, emotions and culture, time of the year¹¹, disease severity perceptions, and knowledge deficits. Possible responses were on a 3-variable gradation scale which was shown to be compatible across the educational levels of the population.

So as to minimize the time burden for survey completion, the form was constructed with embedded decision trees assisted by addendums for surgical diseases

¹⁰ While gender was a covariate in the regression model as a potential predictor of the outcome but was also investigated via stratification to explore the interaction between gender and the barriers.

¹¹ Examples include farming-related seasons (planting, harvesting) or the academic school year

pertaining to acute abdomen, trauma/burns, and obstetrical complications.¹² (See *Appendix C* for the final version of the English survey, complete with addendums). The complete English survey was then translated into the local language of Marathi independently by two physicians who were native Marathi speakers with English fluency. After comparing their two independent translations, the two physicians collaborated to produce a single cohesive translation. Consultations were then conducted with the hospital's head nurse to ensure that translations of medical vocabulary were congruent with the vernacular of the local and tribal peoples. Then, the Marathi survey was given to a third native Marathi speaker with English fluency for back-translation into English. This third translator was blinded to the original English version and did not possess a medical background. Many areas for correction and clarification were identified in this manner. Finally, this Marathi survey was administered in the pilot study and adapted based on the subsequent feedback. (See *Appendix D* for the final version of the Marathi survey, minus the addendums which were fully translated but excluded here for brevity). For clarity, the question order and layouts were identical between the English and Marathi versions.

¹² For example, a Participant who denies suffering from sudden, severe abdominal pain within the previous 2 years were not required to complete the addendum on acute abdomen. Likewise, Participants who screen negative for surgical disease were not required to report on potential barriers to seeking or receiving care.

2.4 Survey administration and data management

The surveys were administered by 2 physicians and the head nurse at the SEARCH outpatient clinic. Each surveyor received training by JLH on the purpose of the research project, the rationale behind the questions, and the importance of consistent administration. JLH was present during each survey administration.

The final survey version was used to create a data dictionary in Microsoft Excel and a database in Microsoft Access. All surveys were collected in paper form in Marathi only, were de-identified, and were given two numerical identifiers: one that was unique for the individual and one that was identical for all members of a given family. All of the original forms are stored in the research facility at SEARCH and the electronic database is stored at SEARCH and Duke. All statistical analysis was accomplished via Microsoft Excel and STATA 10.0. Because of the nature of this study design, the statistical techniques utilized were largely descriptive but also included multivariate regression analysis for investigation of the barriers to surgical care for individuals who had a surgical condition and had been evaluated by a healthcare provider. We sought to investigate the role of these barriers as predictors of obtaining surgery. Since a given individual could have more than one surgical diagnosis for which a variety of care-seeking behaviors and unique barriers might apply, the unit of analysis for this model was surgical diagnoses (cases), not individuals and the dependent variable was surgery received.

Overall, this study was novel and unique in several ways, most notably it was a community-initiated research endeavor, it is the first study in this community to examine the burden and barriers of surgical disease, it created concise and accurate data collection tools, and it instituted rigorous monitoring strategies.

3. Results

3.1 Pilot Study

The first survey administration for this project was in a clinic-based pilot study (N=23; 12 females, 11 males) conducted during July 2010. The intention of this study was to test the survey tool itself and therefore the surveys were not uniformly administered, the survey itself changed over time in response to feedback, and the data generated were excluded from the database. The most useful information gleaned from the pilot study pertained to the survey itself as well as needed modifications to the study design. Such alterations include: changes in question order, inclusion of different multiple choice options, introduction of decision trees/skip patterns, improved and uniform instructions for each new block of questions, minor changes to Marathi grammar and syntax, and the need for more direct questioning regarding deceased family members. The other key objective of the pilot study was to create a list of community-specific barriers to surgical care by way of an open-ended question which were then transformed into quantifiable closed-ended questions (see *Appendix A* for final survey).

3.2 Sample population characteristics

The final project survey was administered between August and October 2010 with completion of the targeted sample size of 500 surveys, representing 159 family units. Missing data are rare as each survey was overseen by JLH and checked for completion prior to the conclusion of the interview. Comparison to the census

population showed that our study population was representative in distribution of marital status, caste, and occupation. However, it was noted that within the study population, there was a slight inequality in gender distribution: 55% male (N=275) and 45% female (N=225) in comparison with the 50:50 distribution seen in the census (*Figure 1*). Additionally, there was a greater proportion of individuals over the age of 20 in the study population when compared to the census data, consistent with the exclusion criteria for this study (*Figure 2*)¹³. These data show that there is an increase in the proportion of individuals over the age of 20 years in the study population when compared to the local census. However, the overall gender distribution with each age category is approximately equal between the two populations.

¹³ For the purposes of determining proportions of education, individuals 5 years of age or younger (inclusive) were excluded.

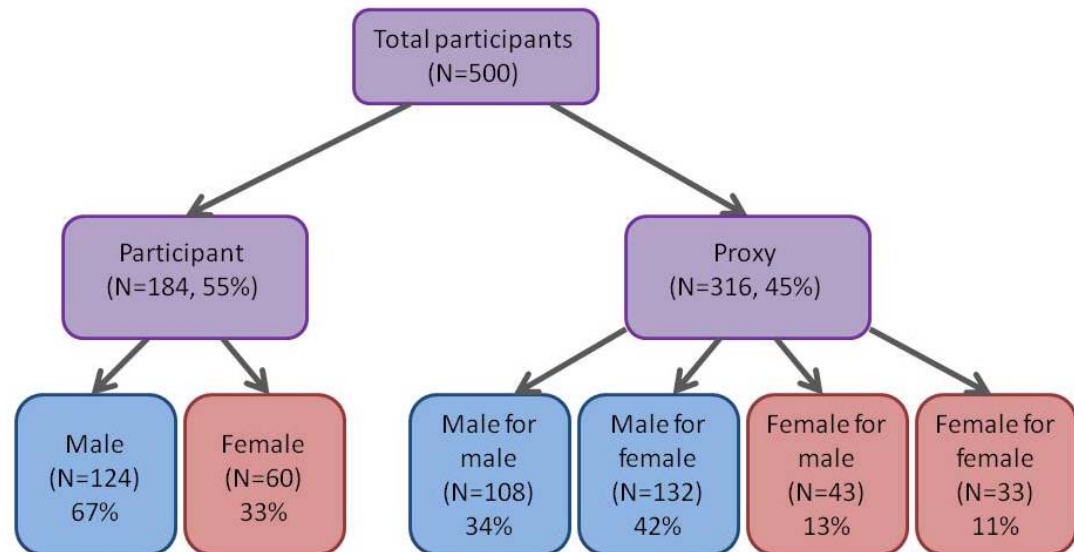


Figure 1: Frequency of gender representation in the study population, stratified by Participant type

There was also a greater proportion of individuals with higher levels of education in the study population when compared to the census data (Figure 3). These data show that the study population is comprised of fewer illiterate individuals and more individuals with higher levels of education when compared to the census data.

Overall, the study population was considered to be adequately representative of the community at large. As such, distinctive features of rural populations including the distributions of occupation¹⁴ and caste were identified in both the study and census

¹⁴ Children were not excluded from this calculation because of the noted school attrition rate and the existence of a child workforce in the region. Therefore, a definitive cutoff was not identified.

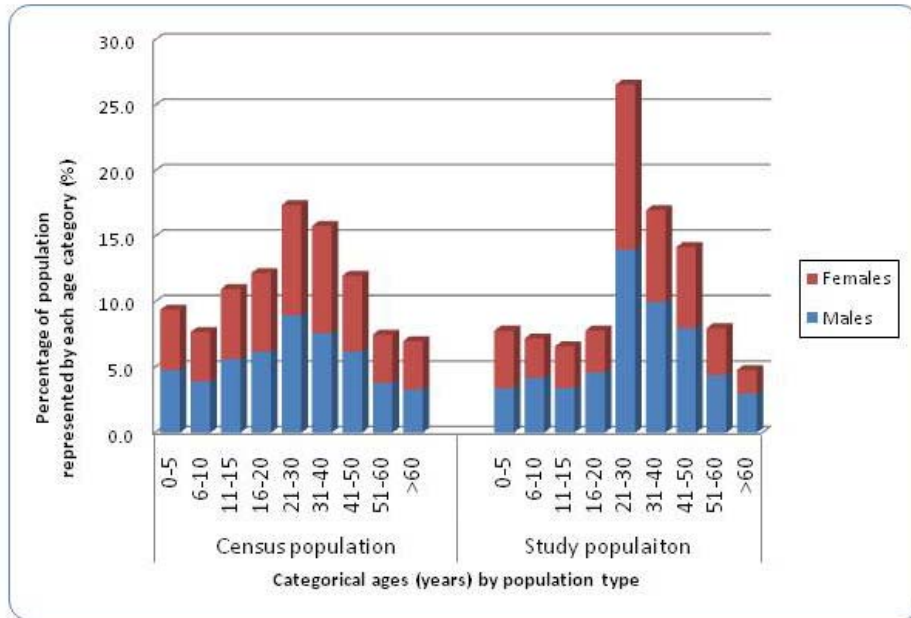


Figure 2: Comparison of categorical ages by population type, stratified by gender. Age categories are in accordance with the Census of India.

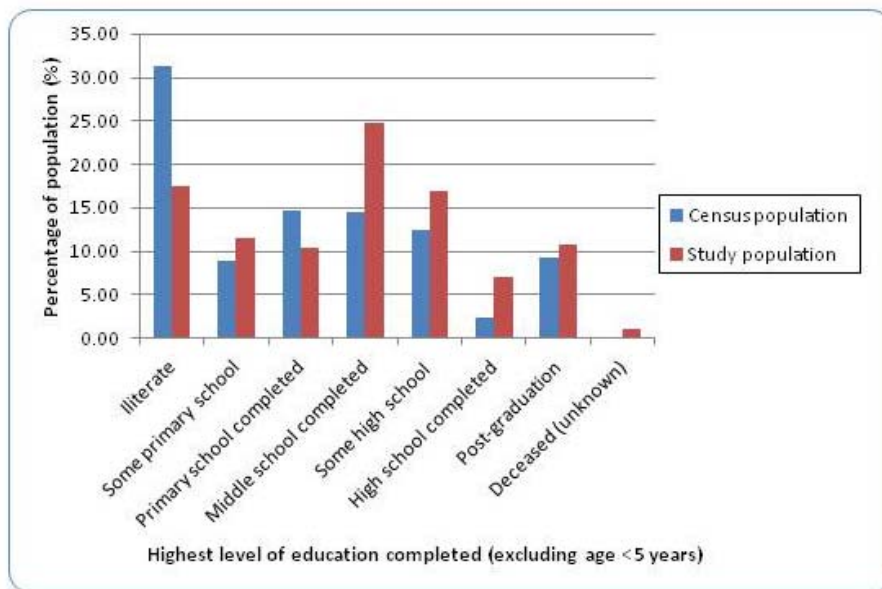


Figure 3: Comparison of categorical educational level by population type. Education categories are in accordance with the Census of India, where primary school is 1st through 4th standard, middle school is 5th through 7th standard, partial high school completion certificates are awarded after 10th standard, and high school diplomas are awarded after 12th standard.

populations. Farming was the predominant occupation, with 40% of males and 40% of females in the study population reporting it as their primary occupation. After farming, the occupations with the highest frequency for males were student (20%), businessman (12%), and laborer (11%) while for females housewife (20%), student (17%), and child under 5 years of age (9%) were the most prevalent. As for the India caste social stratification system, 94.2% self-identified as Hindu while Muslim, foreign refugee, and Christian accounted for 3.4%, 1.8%, and 0.6%, respectively. Within the Hindu caste system, 61.1% were categorized as Other Backwards Castes (OBC), 24.4% as Scheduled Tribe (ST), 12.3% as Scheduled Caste (SC), and 2.1% as the elite Brahman, consistent with the Tribal characterization of Gadchiroli.¹⁵

Regarding prior exposure to surgical care, 126 individuals (25.2%) reported having undergone surgery in their lifetime with 91.3% of those individuals reporting only one surgery. The remaining 8.7% of individuals had undergone 2 surgeries each. Of the 137 surgical cases, most of the individuals were women with the overwhelmingly majority of procedures being an abdominal tubal ligation. For the men, the majority was vasectomies (*Table 1*). In fact, reproductive sterilization measures accounted for 44.5% of the reported past surgical history.

¹⁵ *In comparison, the latest census data reports that India is comprised of 52% OBC, 7% ST, and 16% SC.*²⁸

Table 1: Self-reported lifetime surgical history by condition type, for all participants and according to gender.

Surgery reported (cases)	All participants		Males		Females	
	N	%	N	%	N	%
Total	137	100	58	42.3	79	57.7
General Surgery	125	91.2	57	98.3	68	86.1
<i>Cardiopulmonary</i>	0	0	0	0	0	0
<i>Endocrine</i>	0	0	0	0	0	0
<i>Gastrointestinal</i>	12	8.8	11	19	1	1.3
<i>Genitourinary</i>	93	67.9	*34	58.6	**59	74.7
<i>Musculoskeletal</i>	2	1.5	2	3.4	0	0
<i>Neurologic</i>	3	2.2	3	5.2	0	0
<i>Other</i>	15	10.9	7	12.1	8	10.1
Acute abdomen	4	2.9	3	5.2	1	1.3
Obstetrical	7	5.1	0	0	7	8.9
Trauma	0	0	0	0	0	0
Missing	1		1		0	
* Case variety: vasectomy (N=23)						
**Case variety: tubal ligation (N=53; 38 abdominal, 15 unspecified)						

Finally, 36.8% of the study population was self-reporting Participants (N=184) while 63.2% were Participants by Proxy (N=316). Of the self-reporting Participants, however, 67.4% were male while 32.6% were female. Of the Participants by Proxy, 44.6% were represented by family members of the same gender (i.e. female reporting for another female).

3.3 Final survey results

Aim 1: Frequency of surgical conditions

Of the 500 individuals surveyed, 141 (28.2%) screened positive for surgical conditions in the preceding two years. This was not inclusive and 29 individuals

screened positive for greater than 1 surgical condition in the preceding 2 years. Therefore, the total number of surgical conditions identified in the study population was 175 cases (*Figure 4*).

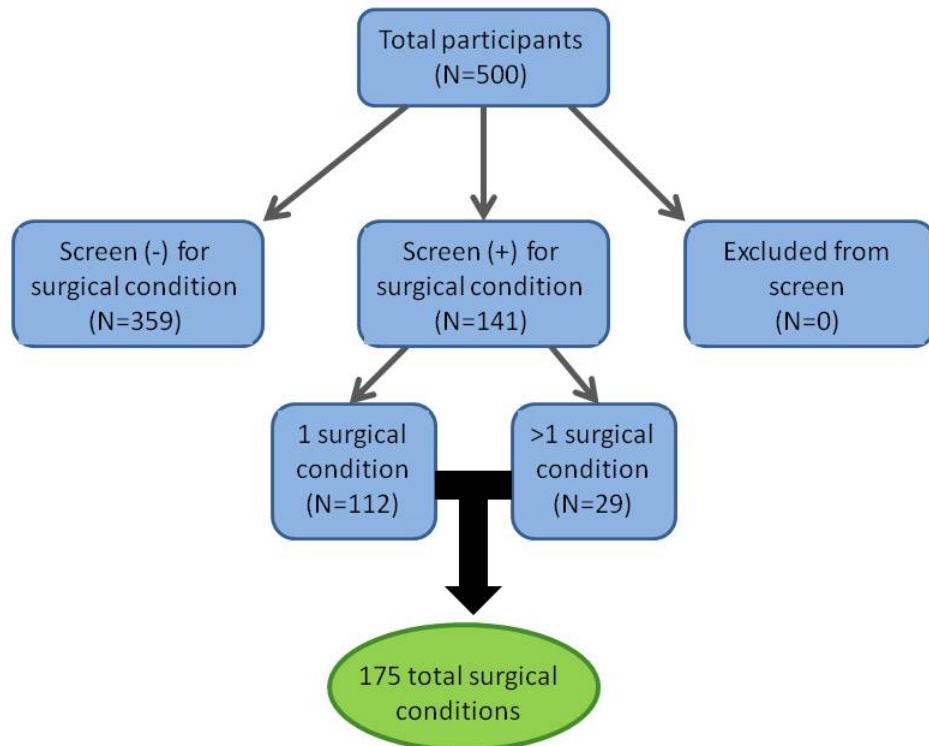


Figure 4: Distribution of screening results within sample population.

Of the 175 surgical cases, 156 (89.1%) were general surgery cases while trauma, obstetrics, and acute abdomen had 8, 6, and 5 cases, respectively. The most commonly reported conditions were hydrocele, anorectal processes, dysfunctional uterine bleeding, cataracts, appendicitis, and spondylosis with neurologic claudication (*Table 2*).

Table 2: Frequency of self-reported surgical conditions identified in the study population of 500 in the preceding 2 years (N=175).

Surgical disease	# of cases	Surgical disease	# of cases	Surgical disease	# of cases
Hydrocele (acquired, congenital)	26	Kidney stone, large	4	Antepartum hemorrhage	1
Rectal bleeding, painful	19	Anatomic anomaly	3	Cryptorchidism	1
Dysfunctional uterine bleeding	13	Breech presentation	3	Esophageal varicies	1
Lump, other	13	Congenital heart disease	3	Gastric ulcer	1
Spondylosis (cervical, lumbar)	11	Hernia, incarcerated	3	Phimosis	1
Appendicitis (acute, chronic)	10	Lump, testis	3	Prolonged labor	1
Cataracts	10	Post-coital bleeding	3	Rectal prolapse	1
Fractures	6	Arthritis, severe	2	Retained placenta	1
Lump, breast	6	Coronary atherosclerosis, severe	2	Small bowel obstruction	1
Hernia, benign	5	Cyst	2	Uterine cancer, abd mets	1
Abscesses	4	Laceration, large	2	Valvular heart disease	1
Anal fissure	4	Post-partum hemorrhage	2	Subtotal	175
Hemorrhoids, internal	4	Thyroid swelling	2	None reported	325
				Total	500

Aim 2: Care-seeking behavior for surgical conditions

For the 175 distinct cases of surgical conditions in the preceding two years, assessment in a healthcare setting was sought in 76.6% (N=133) of all cases. It can be seen that general surgery comprised the majority of cases, largely due to a high number of gastrointestinal and genitourinary conditions. Care seeking behavior varied based on the type and perceived severity/urgency of the condition. (Table 3, Figure 5).

Table 3: Categorical surgical case frequencies identified in the study population of 500, stratified by care-seeking behavior (N=175).

	Number of cases		No care		Care	
	N	%	N	%	N	%
Total Cases	175	100.0	41	23.4	133	76.0
General surgery	156	89.1	36	23.1	119	76.3
Cardiopulmonary	6	3.4	0	0.0	6	100.0
Endocrine	2	1.1	1	50.0	1	50.0
Gastrointestinal	48	27.4	7	14.6	41	85.4
Genitourinary	55	31.4	18	32.7	36	65.5
Musculoskeletal	3	1.7	1	33.3	2	66.7
Neurologic	10	5.7	1	10.0	9	90.0
Cataracts	9	5.1	4	44.4	6	66.7
Other	24	13.7	3	12.5	19	79.2
Acute abdomen	5	2.9	0	0.0	5	100.0
Obstetrical	5	2.9	3	60.0	2	40.0
Trauma	8	4.6	2	25.0	6	75.0
Missing	0		1			

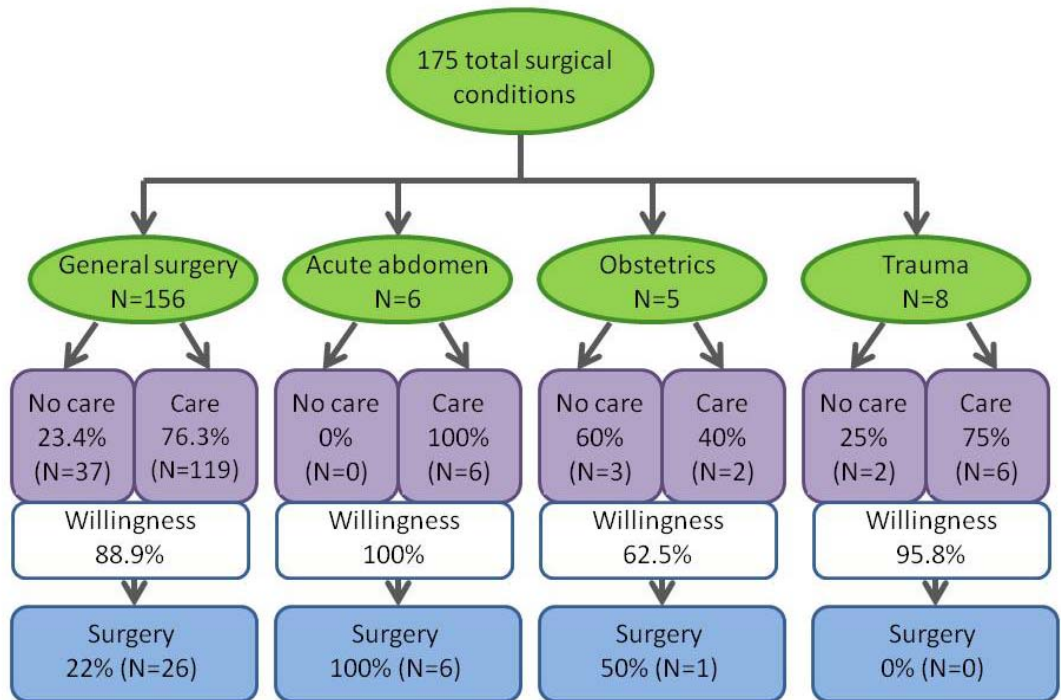


Figure 5: Distribution of care-seeking behavior for those who screened positive for a surgical condition, further subdivided by surgery provision.

For acute abdominal processes, there was complete willingness to undergo surgery and care was sought in 100% of cases, all in less than one day from the onset of symptoms. The diagnoses included small bowel obstruction (N=1), acute appendicitis (N=2), and incarcerated hernia (N=3). Regarding obstetrical emergencies, only 40% (N=2) sought care despite diagnoses of antepartum hemorrhage (N=1), post-partum hemorrhage (N=1), and prolonged labor with breech or transverse presentation (N=3). Of the malaligned presentations, one sought care at the civil hospital and received an emergency cesarean section while another was repositioned by a traditional birth attendant without complication. However, the third was not evaluated by a healthcare

provider and the prolonged labor resulted in fetal death complicated by retained placenta, post-partum hemorrhage, continual bleeding, and a miscarriage of the subsequent pregnancy 3 months later. Of these cases, only 62.5% reported being willing to accept surgical interventions for their condition. In the case of traumatic injuries, 95.8% expressed willingness to undergo surgery, 6 of 8 cases resulted in care-seeking behavior, and, again, all in less than one day from the insult. The trauma-related diagnoses were large lacerations with hemorrhage (N=2), open fractures (N=5, 3 of which were reported as poorly healed), and a hip fracture (N=1). Finally, regarding general surgery conditions, the willingness to undergo surgery was also very high at 88.9% and care was sought for 119 of 156 conditions (76.3%).

Aim 3: Surgical care in the setting of surgical diagnosis

As previously mentioned, 133 of the 175 surgical cases in the preceding two years presented for evaluation by a health professional. Overall, the willingness to undergo surgery for these conditions was very high. However, only 32 (24.1%) underwent surgery during that same time period. The most common surgeries in the sample population were, in order of highest occurrence: Hernia repair, hydrocele repair, cataract repair, cesarean section, and hysterectomy. However, a wide variety of surgical conditions which had been evaluated by a healthcare provider had not been addressed by surgical care during the preceding two years. These conditions were primarily

chronic general surgery and gynecologic in nature whereas acute conditions were, in general, addressed promptly (*Table 4*).

However alarming these data may appear, it should be noted that this proportion includes only those cases of surgical disease that were evaluated by a healthcare provider. While healthcare evaluation is a necessary step to obtain surgical care and given the fact that this survey did not include a confirmatory physical exam, this subpopulation is the most accurate group for exploring barriers to care in this study population. However, from a population perspective, all of the surgical cases identified in the study population are to be considered, not just those which sought care. Therefore, in the preceding 2 years the rate of surgical conditions in the population was an astounding 35% (175 conditions per 500 population) and was addressed by 32 cases of minor or major surgery in 500 individuals (6.4%), extrapolated to 64/1000 individuals.

Table 4: Categorical list of surgical diseases and interventions.

Categorical disease	Surgical disease	Surgery complete	Surgery incomplete
Cardiopulmonary (N=6)	Congenital heart disease	-	3
	Coronary atherosclerosis, severe	-	2
	Valvular heart disease	-	1
Endocrine (N=2)	Thyroid swelling	-	2
Gastrointestinal (N=51)	Anal fissure	-	4
	Appendicitis (acute)	1	-
	Appendicitis (chronic)		10
	Esophageal varicies	-	1
	Gastric ulcers	-	1
	Hemorrhoids, internal	-	3
	Hernia, benign	1	3
	Hernia, incarcerated	2	-
	Laparotomy, abdominal mass	3	-
	Rectal bleeding, painful	1	19
	Rectal prolapse	-	1
	Small bowel obstruction	-	1
	Genitourinary (N=63)	Abortion, medical	1
Cryptorchidism		-	1
Dysfunctional uterine bleeding		3	9
Dysfunctional uterine bleeding requiring blood transfusions		-	1
Hydrocele, congenital		-	4
Hydrocele, acquired		4	18
Imperforate hymen		1	-
Kidney stones, large		2	2
Lump, breast		-	6
Lump, testis		1	2
Obstructed labor requiring cesarean		3	-
Phimosis		-	1
Post-coital bleeding		-	3
Uterine cancer, metastatic	-	1	
Musculoskeletal (N=8)	Arthritis, severe	-	2
	Fractures	-	6
Neurological (N=11)	Spondylosis (cervical, lumbar)	2	9

Cataracts (N=10)	Cataracts	4	6
Other (N=24)	Abscesses	-	4
	Anatomic anomaly	-	3
	Cyst	-	2
	Laceration, large	-	2
	Lump, other	3	10
Total (N=175)		32	143

Aim 4: Barrier to surgical care

Twelve distinct barriers to seeking or obtaining surgical care were elucidated from the participants of the pilot study and were included in the final survey. Any individual who screened positive for an indicator of a surgical condition – regardless of care-seeking behavior – was asked to indicate on a three-point scale how often each of the following barriers made it difficult to get care or prevented them from getting care:

(see *Appendix C*)

1. Cost of medical care
2. Cost of transportation
3. Wages lost while out of work
4. Amount of time spent traveling to the healthcare facility
5. Amount of time needed to stay at the healthcare facility
6. Amount of time without being able to work/go to school
7. Amount of time that family members need to stay at the hospital to help
8. Embarrassment/shyness about the medical problem

9. Did not know that this was a serious problem
10. Did not think that surgery would help this problem
11. Difficulty understanding the information given by the healthcare provider
12. The time/season of the year (ex. Planting, academic, etc)
13. Other (specify)

For those individuals facing acute abdominal emergencies, all 6 immediately presented for evaluation and underwent surgical management. Uniformly, they all denied the influence of barriers to care in the setting of these surgical diseases, though the responses ranged from 0-5 barriers with a mean of 1.

For those facing obstetrical emergencies, as previously stated, 2 out of 5 sought medical care and the willingness to undergo surgery was low. The reported barriers to care ranges greatly (0-11), with a mean of 4.75 barriers. The two seeking care denied having any barriers, stating that the emergency nature of the illness was the most important factor. However, of those who did not seek care, the diagnoses were still serious but on average 6 of the 12 barriers were endorsed as being the drivers of the decision not to seek care. The most frequently reported barriers were cost of medical care, amount of time spent traveling to the healthcare facility, did not know that this was a serious problem, and difficulty understanding the information given by healthcare providers.

Of those individuals reporting traumatic injuries, 6 of the 8 immediately sought evaluation by a medical provider. These specific injuries included long bone fractures, a skull fracture, large lacerations, and traumatic hemorrhage. In each of these cases, the individual reported that the acuity of the injury was the driving factor, regardless of possible barriers to care. However, no surgeries were performed and 3 out of the 4 fractures were reported to be poorly healed. The range of reported barriers to care was large (0-12), with a mean of 4.5 barriers. The most commonly reported were as follows: lost wages and time spent in the hospital by patient and family. Of the two individuals who did not seek care, one was an elderly woman who fell and fractured her hip and the other was a middle-aged gentleman who sustained a traumatic testicular injury on his motorcycle and ultimately suffered from testicular atrophy. They reported 9 and 11 of the 12 barriers to care, respectively which the mutually non-applicable barrier being embarrassment.

For the general surgery disease processed, the wiliness to undergo surgery was much higher (88.9%) than the actual completion rate (22%). The barriers to care which were endorsed were quite variable across an array of disease processes with a range of 0-12 and a mean of 4 barriers. Using STATA 10.0, multivariate analysis inclusive of all 12 barriers was generated as outline in the methods above. The unit of analysis was cases of surgical conditions and included only those cases that had been evaluated by a healthcare professional as that is a necessary step in the continuum of care. Using this

model, we identified lost wages ($p=0.027$), time family members spend providing inpatient care ($p=0.038$), and time away from work ($p=0.045$) as significant barriers to surgical care. Notably, neither education level, nor cost, nor the distance traveled for care was a statistically significant barrier identified in this population. While the residual was sufficient with this basic model ($R^2 = 0.76$), it was improved by combining barrier variables that correlated thematically and statistically. The combinations were as follows: the cost of medical care and cost of transportation became “direct costs of care;” amount of time spent traveling, staying in the hospital, being out of work/school, and time family stayed at the hospital became “burden of time;” and not knowing that this was a serious problem or that surgery could address it became “lack of knowledge.” After clustering thematic barriers into burdens of time, knowledge about surgery, and direct costs, only lost wages ($p=0.004$) and the burden of time ($p= 0.030$) remained as statistically significant surgical care barriers. After univariate stratification for basic demographic variables, additional unexpected barriers were identified, including the effect of shyness about the medical problem for farmers ($p=0.014$), and lack of knowledge in SC ($p=0.024$) and OBC ($p=0.006$). Again, neither education level, nor cost, nor the distance traveled for care was a statistically significant barrier for surgical care in this population.

4. Discussion

As in many part of the developing world, the existing knowledge about emergency and essential surgery in rural India is severely lacking. In a country as large and diverse as India, the first step is thorough reviews of local data for effective regional coverage of selected surgical conditions. What is needed is a comprehensive, systematic approach to the measurement of the burden of surgical conditions, the current met and unmet needs for surgical care within the population at risk, and an understanding of the quality of care that the system currently provides. This cross-sectional assessment of surgical needs in rural Gadchiroli is the first of its kind in the region and provides novel insight into this problem. While, admittedly there are limitations to generalizability imposed by the study design, given the current climate of community leader support, this is the best possible starting point. These data show that the level of surgical disease in the community is much higher than initially anticipated; and while the willingness to be evaluated by a healthcare provider and seek surgical treatment is also high, the surgery rate is quite low.

The study population totaled 500 which gave a robust sample of the community which appeared similar in many ways to the demographics seen in the latest census data. However, in practicality, this population was sampled from visitors of an active healthcare clinic and therefore some potential biases exist. Namely, is it possible that this study population has a self-selecting bias based on the fact that their presence in the

clinic acknowledges that they accept biomedicine, are willing to seek biomedical care for members of their family, know where the healthcare resources are in their community, and have the means to get there. Additionally, this study was conducted via a survey screen and notably lacked an additional confirmatory assessment by physical examination. While these caveats should be considered, they do not negate the potential power of this novel investigation which was conducted within the community constraints.

The first research question dealt with the levels of surgical conditions in the community and the results were higher than expected with 28.2% reporting to have suffered from a surgical condition within the preceding 2 years. This number was driven largely by the high burden of hydrocele and anorectal processes with each accounting for approximately 20% of the disease burden coupled with dysfunctional uterine bleeding, cataracts, appendicitis, and spondylosis with neurologic claudication which evenly split another 40% of the burden. Therefore, 80% of the conditions noted were from these 6 diagnoses. The high prevalence of hydrocele is not surprising because the area of Gadchiroli is endemic to filariasis. Anorectal processes include the diagnoses of rectal prolapse (N=1), anal fissure (N=4), internal hemorrhoids (N=4), and painful rectal bleeding with defecation (N=19). Unfortunately, especially for these complex diagnoses, the questions queried in the absence of physical examination might not definitively separate surgical from non-surgical anorectal processes. While extreme, complete

exclusion of these data still leaves 122 of 481 individuals with positive screens (25.4%), for a total of 147 surgical conditions.¹ Therefore, we conclude that these data are in agreement with our initial hypothesis that a large burden of surgical conditions exists within this community. However, while 1 out of 4 individuals reported a surgical condition in the time frame, it is noted that the representative spread in the data indicate that this burden is largely of chronic disease processes. The reporting of acute surgical diseases was very low: 19 cases with 1 fetal mortality. It is possible that this is an accurate reflection of a rare event but it is also possible that this study design was ill suited to capture cases of surgical mortality which could be improved by community-based surveillance.

The second research question addressed the care-seeking behavior of individuals who reported suffering from a surgical condition in the preceding two years. Of the 175 cases, 76.6% were assessed by a healthcare provider in at least one allopathic facility. Additionally, the data indicate that the conditions of a more acute nature were assessed immediately. However, the unexpected exception was for obstetrical emergencies where failure to seek care resulted in a fetal death in addition to a wide array of maternal sequelae. For this particular case, the home birth was attended by a nurse only and the Participant indicated that the cost of care and time spent traveling to the facility were major barriers to seeking care while the cost of transportation was a

¹ *An anorectal process was the sole reported condition for 19 individuals*

minor barrier. Additionally, the Participant strongly agreed that care-seeking was not undertaken in this case because she did not know that it was a serious problem and furthermore did not know that surgery would help this problem. Further delineation is needed to elucidate the variations in the time interval between the onset of symptoms and care seeking behavior for chronic, general surgery conditions. Finally, preliminary results indicate that a rather interesting trend of care seeking behavior exists for the identified surgical conditions. Many individuals reported seeking initial evaluation in the public or private sector which was followed by a second evaluation at SEARCH after surgery was recommended. The exact mechanisms behind this phenomenon is unknown but one possible explanation for this could be the tiered payment scheme used at SEARCH which is adjusted based on socioeconomic factors, namely the education levels, occupations, and castes within the household. SEARCH also provides a complete waiver of fees for members of Scheduled Tribes which comprise 38.3% of the District of Gadchiroli.²⁷ This lowers the cost of definitive care and may contribute to the creation of an artificially high demographic of patients seeking surgical treatment at the SEARCH facility.

The third research question addressed the transition between evaluation by a healthcare professional and undergoing surgical treatment for a given condition. Informing the expected outcome were the existing data from SEARCH surgery camps

which had completed 1130 surgeries in the preceding 2 year time period.² 30% of these procedures were hydrocele repair, 19% were hernia repair, and 11% were vaginal hysterectomies though a large degree of variety was seen, including some specialist surgeries such as repairs of cleft palate, hypospadias, and obstetrical fistula. Coupled with these surgery completion statistics, the active waiting list for surgery at SEARCH was 485 cases long³, approximately equal to one year of their surgical capacity. Therefore, it was hypothesized that the proportion of surgery needed to surgery completed would be low. Our data suggest that in the preceding 2 years, 35% of the population suffered from a surgical condition for which only 6.4% of the population underwent a minor or major surgical procedure. For these surgical conditions, health care evaluation was sought in 76.6% of the time. Within the population which sought evaluation by a healthcare provider, 24.1% underwent a minor or major surgical procedure in that same time period. It is likely that the true value lies somewhere in between the two estimates. In either case, it is evident that the majority of the cases and therefore individuals needing surgery were unable to receive it. This supports our hypothesis though in itself is not too surprising because prior studies in resource-poor settings have also reported a paucity of surgical care provision [13:14:25:26:29] Thus, our data suggest that there is a lack of surgical care provision to the population in general as

² Data obtained from the SEARCH operative theatre log by JLH. November 2010

³ Collected from medical records placed in procedure-specific waiting lists by JLH. November 2010.

well as to the specific subpopulation that we have identified who are actively seeking surgical care.

In seeking to understand these imbalances, in our fourth research question our study sought to determine the underlying barriers to surgical care. In order to ensure regionally and culturally specific queries, the distinct barriers were created from the open-ended response given in the pilot study and transformed into quantitative closed-ended questions for the final analysis. The results indicate that in this population, the two distinct, statistically significant barriers to surgical care were lost wages ($p=0.004$) and the burden of time ($p=0.030$). And while these two barriers are not uncommon, it is worth noting that the surgery care model at SEARCH may be especially susceptible to exacerbating them for its patients. In particular, the standard of care protocol dictates that patients undergoing a minor surgical procedure remain as an inpatient for 7 days and those undergoing a major surgical procedure remain in the hospital for 14 days. In general, most surgical patients remain at SEARCH from incision to stitch removal. These protocols are driven by a desire to protect patients of very remote villages, far from both emergency and follow up care, during the critical post-operative period. This protocol allows for close evaluation for post-surgical complications, assurance of proper wound hygiene to minimize wound infections, and ensures that stitches will in fact be removed. Therefore, while well-intended, our study suggests that this unique model of patient care may be self effacing, creating significant barriers to surgical care in an attempt to

improve surgical outcomes. And, despite being a foreboding problem, this contradictory model of care presents an opportunity for improvements. The barriers of lost wages and burden of time can potentially be ameliorated by addressing the common thread of time spent in the hospital, which is uniquely prolonged at SEARCH. For example, an uncomplicated repair of a hydrocele is generally conducted under local anesthetic and accomplished in a matter of minutes. Nearly all patients are walking, eating a regular diet, and managing their pain with NSAIDs on post-operative day 1. The remaining 13 days of hospitalization are only punctuated with wound examinations, betadine washings, and the occasional scrotal wrapping all the while the patient (and often their family members) are away from home and work. It may be possible to shift these or similar post-operative care tasks to the community without directly undermining the goals of extended hospital stays, perhaps via home visits by existing community health workers. In this way, patient safety could continue to be a priority with simultaneous acknowledgement of the help and hindrance provided by the surgery. While more investigation would be needed to evaluate the feasibility of such a model, this theory of change is a tangible outcome of this study.

Delving into the expected barriers to care found not to be significant in this population, one finds the cost of care, the distance needed to travel, and the maximum educational level of the household. Even stratification by each of the socioeconomic variables did not indicate that any specific subpopulation endorsed these as significant

barriers. These results were unexpected and provided novel insights into why those who need surgical care do or do not seek care. Regarding cost of care, possible explanation for this unexpected result may lie in SEARCH's tiered payment scheme. In this context, the cost of surgery is much lower on average than care received at the civil hospital which is the sole surgical alternative. A lower cost of surgical care may also play a role in the aforementioned pattern of care-seeking where initial diagnoses were in the public or private sector and then definitive surgical treatment was sought at SEARCH. Therefore, it is possible that the cost of surgical care would prove to be a significant barrier in another setting. It is also plausible that our data suggest that a tiered payment scheme in a mixed-income clinic can effectively help to reduce the affect of this barrier to surgical care.

As for distance needed to travel to the clinic, it is likely that this barrier was not significant in this population because of the selection bias introduced with a clinic-based study design. As each Participant had, by default, already demonstrated the ability to travel to SEARCH, distance would likely not present itself as a barrier. Finally, while we predicted the socioeconomic marker of education to be a negative predictor of surgery completion, our data suggest that this is not a significant barrier to receiving surgical care. One possible explanation is that the outcome variable in the regression analysis was the undergoing surgery after one was instructed to do so by a physician. Based on

societal norms, it is likely that the opinion of the physician would prevail regardless of the educational level of the patient.

While these results shed light on the difficulties faced by individuals in the community who suffer from surgical conditions, there are a number of potential factors that need to be addressed regarding alternative interpretations of the outcomes of this study. This exploratory study indicates that the prevalence of surgical disease conditions was 282 per 1000 population in the preceding two years. Multiple factors suggest that this estimate may over-or underestimate the true burden in the community. One design component contributing to overestimation could be the reliance on self-report without a confirmatory physical examination, leading to potential inclusion of non-surgical conditions or conditions that may only necessitate surgery if the disease severity progresses sufficiently. Additionally, conducting this study in not only a clinic, but more specifically in a clinic that provides the sole low-cost surgery option in the region likely introduced selection bias. However, there are a number of reasons that suggest underestimation of the true community burden as well. Specifically, this underestimate could be driven by the fact that this survey poorly captured the mortality component of surgical conditions, largely capturing diseases of a more chronic nature with minimal reporting of more acute diseases. Additionally, there could be exclusion bias involved because those in the community who most need care, surgical or otherwise, might not have the means to get to the SEARCH clinic and therefore were excluded from this

study. Finally, the use of the non-patient visitor as the participant and as the designated proxy may be contributing to underestimation in two ways. First, a lack of knowledge about the health conditions of family members may lead to surgical diagnoses being missed. Previous studies have used the matriarch of the home as she often holds the largest body of knowledge about the family's health. However, owing to the demographics of the patients in the SEARCH clinic and the exclusion criteria set out for this study, we had a high sampling of men as self-reporting Participants (124 males versus 60 females) which could result in unintentional omissions. Secondly, complete exclusion of all community members presenting for care assuredly missed the segment of the population suffering from surgical conditions who were actively seeking evaluation by a healthcare provider.

Despite these caveats, this study provided novel data for this region and was conducted in the most scientifically sound manner permitted. Many aspects of this study worked very well, including the survey translation into Marathi, the verbal administration by trained providers, the institution of the surgical referral system, and the permission of the community. Our data contribute to the growing body of literature in this burgeoning field and indicate that despite the current surgical care provisions by SEARCH, the surgical disease burden in rural Gadchiroli is worse than we had anticipated. Certain factors appear to predict difficulty in seeking or receiving surgical care. Targeting these factors is a first step towards addressing the surgery needs in this

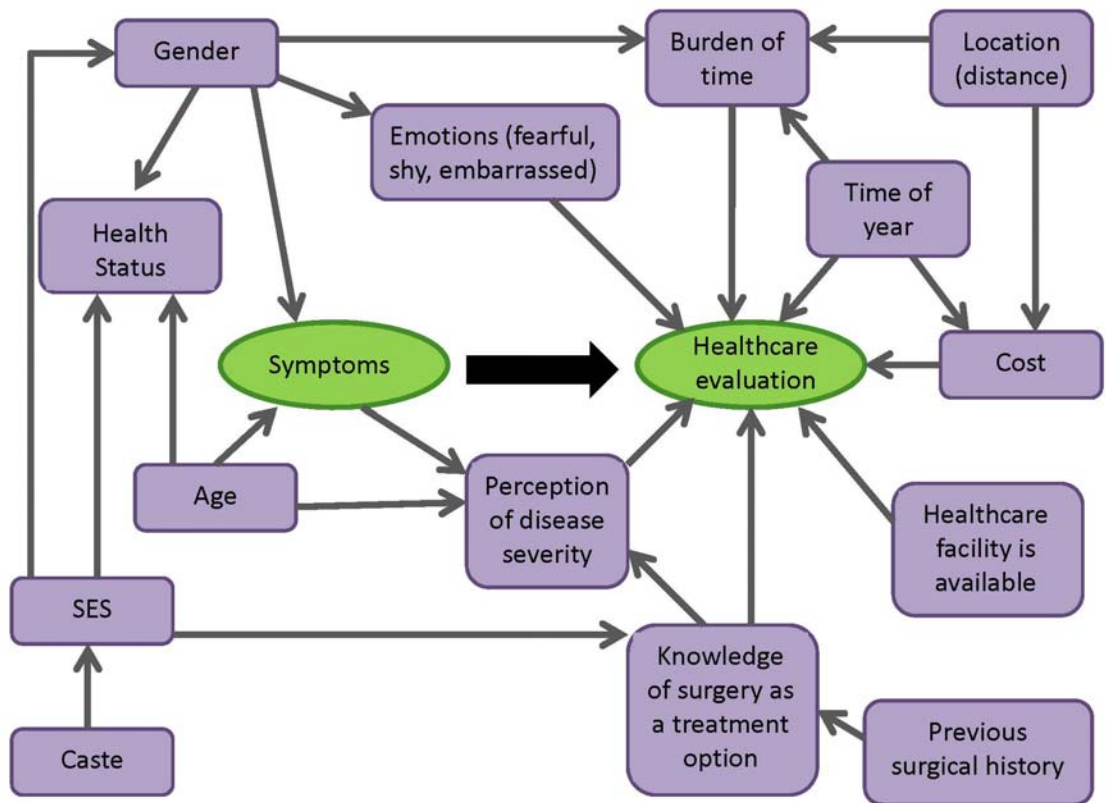
community. Importantly though, this study served to meet the request of the community leaders for further insight into the burden of surgical disease in their communities and hopefully will open the door for future community-based studies.

Possible future endeavors include repeating this study in a community-based setting with random, proportional-to-population sampling resulting in a less biased population, possibly in conjunction with the existing SEARCH verbal autopsy database which has captured all deaths in the past 15 years. While this database is still being processed, it is a possible source of confirmation of the mortality associated with untreated surgical conditions in the community. Additionally, there is ongoing work in the United States and the United Kingdom to create a standardized research tool and methodology to capture more accurately the surgical disease burden via community-based studies which may be a useful alternative to revamping the tools of this study. Given the emergence of a more accurate assessment of the community disease burden, our future objectives would be to determine if SEARCH could provide care for the identified community surgical conditions, and, if not, to investigate potential modifications needed to create a more successful district-level surgical referral center. We believe that it is through this decentralized care model that emergency and essential surgery will become available to the individuals in need both in the SEARCH catchment and beyond.

Appendix A: Causal Diagram 1

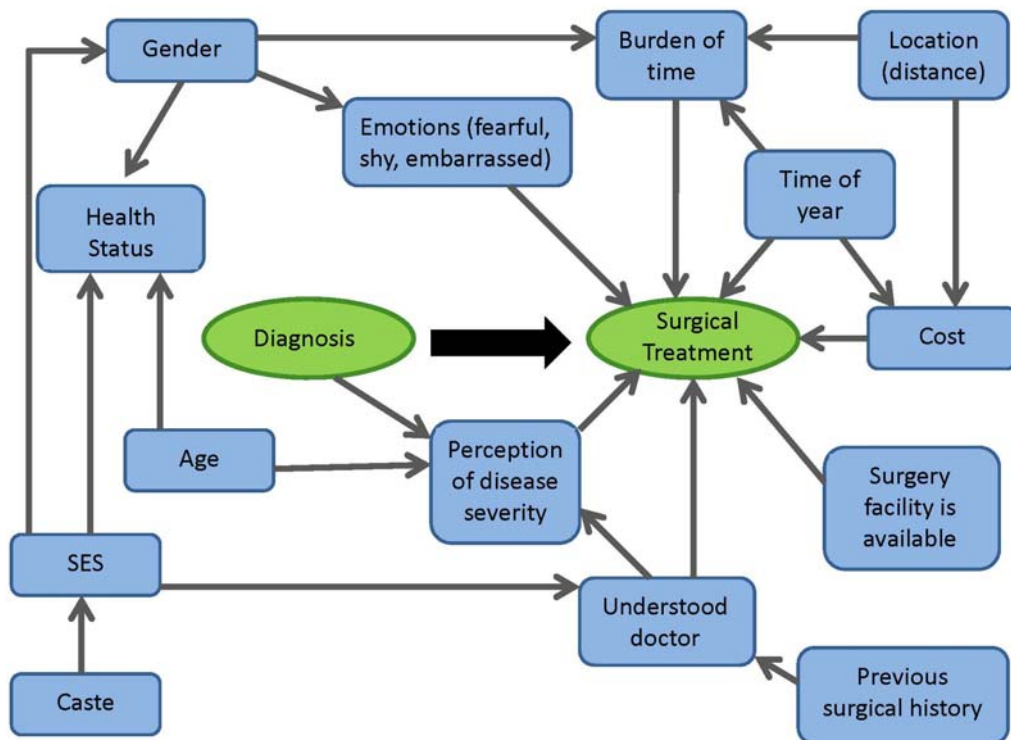
Effect of symptoms of surgical disease on care-seeking behavior, where exposure is symptoms, outcome is healthcare evaluation, 33and population is total study sample.

[This form was created by JLH.]



Appendix B: Causal Diagram 2

Effect of surgical disease diagnosis on actual surgery received, where exposure is surgical diagnosis, outcome is surgery treatment, and population is those individuals with a surgical disease who have been evaluated by healthcare professional [This form was created by JLH.]



Appendix C: English Survey

Final survey in English, with addendums (acute abdomen, trauma/burns, OB)

[This form was created by J LH].

ASSESSMENT OF UNMET SURGICAL NEED IN RURAL INDIA: A POPULATION-BASED STUDY (*PARTICIPANT SURVEY*)

SEARCH, GADCHIROLI 442 605

1. Description of investigation

You have been asked to participate in a survey designed to investigate the prevalence of diseases in your community that might benefit from surgery. Your participation is entirely **voluntary** and you can stop at any time without penalty. Participation in this survey **does not constitute a promise by the researcher to provide you or your family with surgical care**, though a referral to a healthcare provider might be given. If you have questions, you can ask the researcher at any time or contact them at the address listed above.

Completed this survey before?: Yes No

Date: ___/___/___ (dd/mm/yyyy)

Signature of oral consentor: _____

2. Demographics of primary household reporter

Gender: (0) Female (1) Male Caste: _____

Birthday: ___/___/___ (dd/mm/yyyy) (if unknown, enter age: _____)

District: _____ Taluka: _____ Village: _____

Marital Status: (0) Never Married (1) Currently Married
 (2) Separated (3) Widowed

Below you will find a list of categories for education and occupation with number indicators on the left. Please select the response that best describes you and the indicated family members. Write the correct numbers in the boxes below. If more than one answer applies, choose the one best answer. If the family member is deceased, enter 99.

Highest education level		Occupation	
0	Illiterate	0	Farming
1	Literate, < primary school complete	1	Laborer
2	Primary school complete (Pass through 4 th standard)	2	Business
3	Middle school complete (Pass through 7 th standard)	3	Civil service
4	Some higher secondary (not completed)	4	Housewife
5	Higher secondary complete (Pass through 12 th standard)	5	Student
6	Beyond higher secondary	6	Not working in past 12 months

Participant:	Highest education level	<input type="checkbox"/>	Occupation	<input type="checkbox"/>
Spouse:	Highest education level	<input type="checkbox"/>	Occupation	<input type="checkbox"/>
Father:	Highest education level	<input type="checkbox"/>	Occupation	<input type="checkbox"/>
Mother:	Highest education level	<input type="checkbox"/>	Occupation	<input type="checkbox"/>

3. Overview of Past Surgical History

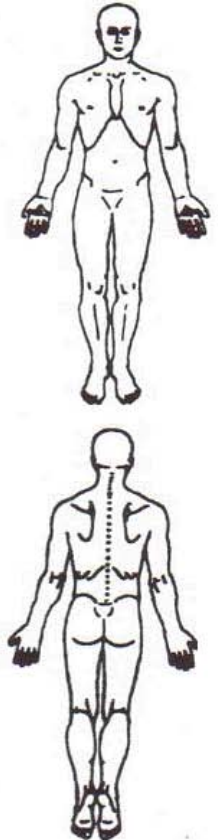
USN ___ //FAM ___

3A. PLEASE DESCRIBE YOUR CURRENT OVERALL STATE OF HEALTH: _____ %

100% (very good) 75% (good) 50%(fair) 25%(poor) 0% (very poor)

3B. HOW MANY TIMES HAVE YOU HAD SURGERY?: _____

If zero/none, skip to question 4:



SURGERY DETAILS: (if yes)	Surgery #1	Surgery #2	Surgery #3
1. Type of surgery? (Mark scars on diagram to the right)			
2. When did you first notice the symptom? (mm/yyyy)			
3. How much time passed before you went to a healthcare provider?			
4. After you first went to the healthcare provider, how much time passed before you were told that you needed surgery?			
5. After you were told that you needed surgery, how much time passed until you decided that you wanted to have the surgery?			
6. After you were decided that you wanted to have the surgery, how much time passed until you had the surgery?			
7. Where did you have surgery? (ex. Civil hospital, private hospital, SEARCH)			

4. In-Depth Review of Surgical Disease History

4A. A LIST OF BODY PARTS WILL BE READ TO YOU. FOR EACH, PLEASE INDICATE IF YOU CURRENTLY HAVE A PROBLEM WHICH YOU THINK NEEDS SURGERY:

	Yes	No	Specific problem details
1. Head or face			
2. Neck or throat			
3. Lungs			
4. Heart			
5. Abdomen			
6. Urinary system or bladder			
7. (if female) Breast, uterus, cervix, ovary, or vagina			
8. (if male) Penis, testes, or breast			
9. Shoulders, arms, wrists, or hands			
10. Hips, legs, ankles, or feet			
11. Back or spine			
12. Other			

4B: IN THE LAST 2 YEARS HAVE YOU HAD ANY OF THE FOLLOWING?

FOR BOTH MALES AND FEMALES	Have this problem?		Saw healthcare provider?	
	Yes	No	Yes	No
1. Lump in abdomen?				
2. Lump anywhere else? (Specify: _____)				
3. Hernia? Circle: epigastric, surgical scar, inguinal				
4. Skin abscess which you thought needed surgery?				
5. Vomiting blood >volume of cupped hand?				
6. Cataracts?				
7. Swelling or lump in front of the neck/throat?				
8. Blood in bowel movement/motions?				
9. Pain at anus with bleeding during defecation?				
10. Abscess with discharge at the anus?				

FOR MALES ONLY	Have this problem?		Saw healthcare provider?	
	Yes	No	Yes	No
1. Lump in or on testes?				
2. Hydrocele?				
3. Missing one or both testes in scrotum?				
4. Phimosis?				

FOR FEMALES ONLY	Have this problem?		Saw healthcare provider?	
	Yes	No	Yes	No
1. Lump in breast?				
2. Lump in or on vagina?				
3. Menstruation requiring >3 pads per day?				
4. Blood-stained vaginal discharge?				
5. Bleeding after menopause?				
6. Urinary dribbling?				
7. Inability to control micturation at all?				
8. Passage of feces per vagina?				

If no problems, skip to question 4C:

Are you still having problems from this condition, even if you received care? Please list:

A list of things will be read to you that for some people make it difficult to get care or prevents them from getting care. For each, please indicate how often each statement made it difficult for you.

	Most of the time	Some of the time	Rarely/never
1. Cost of medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Cost of transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Wages lost while out of work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Amount of time spent traveling to the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Amount of time needed to stay in the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Amount of time without being able to work/go to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Amount of time that family members need to stay at hospital to help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Embarrassment/shyness about the medical problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Did not know that this was a serious problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Did not think that surgery would help this problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

USN ___ //FAM ___

11. Difficulty understanding the information given by the healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12/ The time/season of the year (ex. planting, academic, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Imagine that the medical care was free to you. How willing would you be to accept surgical care for the PROBLEM LISTED ABOVE? 100% 75% 50% 25% 0%

If yes care received, then: Where did you get care? _____
 How much time passed before you went to a healthcare provider? _____

4C: IN THE LAST 2 YEARS HAVE YOU HAD SUDDEN, SEVERE ABDOMINAL PAIN?

YES NO **If no, skip to question 4D. If yes, then insert acute abdomen addendum**

4D: IN THE LAST 2 YEARS HAVE YOU HAD A BURN OR TRAUMATIC INJURY?

YES NO **If no, skip to question 4E. If yes, then insert trauma/burn addendum**

4E: (If male, proceed to question 5) IN YOUR ENTIRE LIFE:

pregnancies had? _____ # children born preterm? _____
 # children born alive? _____ # abortions? _____

IN THE LAST 2 YEARS, HAVE YOU BEEN PREGNANT? YES NO

If no, skip to next question. If yes, then insert obstetrical addendum:

5. FAMILY DEMOGRAPHICS

5A: Now that you have finished this survey, would you be able to answer most of these questions about another person in your home? Yes No

5B: Please list the people other than yourself who have lived in your home during the LAST 2 YEARS:

Relation to you	Age	Gender	Relation to you	Age	Gender

For researcher use only:

- Referral to healthcare provider needed? Yes No Suspected condition: _____
- Referral to healthcare provider given? Yes No Location: _____
- If emergency, is transportation available? Yes N/A
- Additional notes: _____

ASSESSMENT OF UNMET SURGICAL NEED IN RURAL INDIA: *ACUTE ABDOMEN*

4C: IN THE **LAST 2 YEARS** HAVE YOU HAD **SUDDEN, SEVERE ABDOMINAL PAIN?**

YES NO

Location of the abdominal pain: _____

If yes, then did you also have:	Yes	No	# of times
1. Duration >6 hours?			
2. Profuse vomiting?			
3. Extensive abdominal distension (hardening and larger)?			
4. Shock (2 of 3): cold hands, rapid heart beat, fast breathing			
5. Bleeding from rectum?			
6. Blood in urine, scanty urine, or obstruction of urine flow?			
7. Complete stoppage of feces and flatus/gas >24 hours?			
8. Hernia that became tender and firm?			
9. (If female) Missed menstruation/period?			

Are you still having problems from this condition, even if you received care? Please list:

A list of things will be read to you that makes it difficult for some people to get care or prevents them from getting care. For each, please indicate how often each statement made it difficult for you.

	Most of the time	Some of the time	Rarely/never
1. Cost of medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Cost of transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Wages lost while out of work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Amount of time spent traveling to the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Amount of time needed to stay in the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Amount of time without being able to work/go to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Amount of time that family members need to stay at hospital to help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Embarrassment/shyness about the medical problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Did not know that this was a serious problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Did not think that surgery would help this problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Difficulty understanding the information given by the healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. The time/season of the year (ex. planting, academic, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Imagine that the medical care was free to you. How willing would you be to accept surgical care for the **SUDDEN, SEVERE ABDOMINAL PAIN?** 100% 75% 50% 25% 0%

Did you go to see a healthcare provider about the **SEVERE ABDOMINAL PAIN?** YES NO

If yes care received, then: |

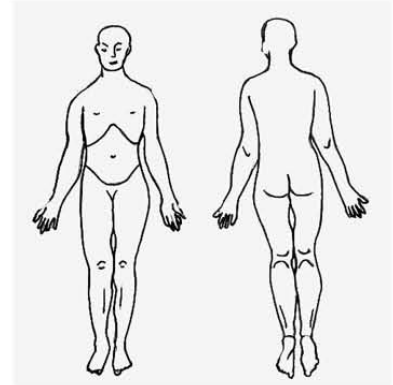
Where did you get care? _____

How much time passed before you went to a healthcare provider? _____

USN ____ // FAM ____

**ASSESSMENT OF UNMET SURGICAL NEED
IN RURAL INDIA: BURN/TRAUMA**

4D: IN THE **LAST 2 YEARS** HAVE YOU HAD A **BURN OR TRAUMATIC INJURY**? YES NO Mark on diagram



DID YOU HAVE THIS BURN AND:	Yes	No	# of times
Breathing difficulties/throat swelling?			
Dry, black patches over the burn?			
Burn contractures?			
Pus formation with fever?			

Cause of the BURN INJURY: _____

THIS INJURY AND:	Yes	No	# of times	Specify
Open wound > size of one outstretched hand?				
Fracture: Long bone, skull, spine, pelvis, or ribs?				
Abdominal pain or distention, vomiting, blood in feces or urine, or urinary retention?				
Penetrating injury?				
Amputation?				
External blood loss > volume of cupped hand?				

Cause of the NON-BURN INJURY: _____

Are you still having problems from this condition, even if you received care? Please list: _____

A list of things will be read to you that makes it difficult for some people to get care or prevents them from getting care. For each, please indicate how difficult each statement made it for you.

	Most of the time	Some of the time	Rarely/never
Cost of medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cost of transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wages lost while out of work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amount of time spent traveling to the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amount of time needed to stay in the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amount of time without being able to work/go of school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amount of time that family members need to stay at hospital to help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Embarrassment/shyness about the medical problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did not know that this was a serious problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did not think that surgery would help this problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty understanding the information given by the healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The time/season of the year (ex. planting, academic, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Imagine that the medical care was free to you. How willing would you be to accept surgical care for the BURN OR TRAUMATIC INJURY? 100% 75% 50% 25% 0%

Did you go to see a healthcare provider about the BURN OR TRAUMATIC INJURY? YES NO

If care received, where did you get care? _____

How much time passed before you went to a healthcare provider? _____

ASSESSMENT OF UNMET SURGICAL NEED IN RURAL INDIA: *OB ADDENDUM*

FOR ALL PREGNANCIES WITHIN THE **LAST 2 YEARS**, DID YOU ALSO HAVE:

DURING PREGNANCY:	Yes	No	# of pregnancies with this event
1. Bleeding per vagina before 7 complete months of pregnancy?			
2. Bleeding per vagina after 7 complete months of pregnancy but before delivery?			
3. Seizures/fits during pregnancy?			
4. Passage of grape-like forms per vagina?			
5. > 24 hours of strong contractions?			
6. > 40 weeks gestation?			

DURING DELIVERY:	Yes	No	# of pregnancies with this event
1. Bleeding after delivery that caused dizziness or loss of consciousness?			
2. Tear in vaginal and/or rectal region?			
3. Retained placenta?			
4. Prolapse of the uterus per vagina?			
5. Breech presentation/transverse lie of baby?			

If no problems skip to question 5 (main form):

Are you still having problems from this condition, even if you received care? Please list:

A list of things will be read to you that for some people make it difficult to get care or prevents them from getting care. For each, please indicate how often each statement made it difficult for you.

	Most of the time	Some of the time	Rarely/never
1. Cost of medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Cost of transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Wages lost while out of work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Amount of time spent traveling to the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Amount of time needed to stay in the healthcare facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Amount of time without being able to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Amount of time that family members need to stay at hospital to help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Embarrassment/shyness about the medical problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Did not know that this was a serious problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Did not think that surgery would help this problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Difficulty understanding the information given by the healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. The time/season of the year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Other (specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

USN ____ //F AM ____

If the medical care were free to you, how willing would you be to accept surgical care for the COMPLICATED PREGNANCY OR DELIVERY?

Circle one: 100% 75% 50% 25% 0%

Did you go to see a healthcare provider about the COMPLICATED PREGNANCY OR DELIVERY?

YES NO

Where did you go for care? _____

Who delivered this baby? _____

Where was the baby delivered? _____

How much time passed before you went to a healthcare provider? _____

Appendix D: Marathi Survey

Final survey in Marathi (addendums translated but not shown). [This form was created by JLH. Translation & back-translation was accomplished by Dr. Sona Deshmukh, Dr. Pawan Patil, and Ms. Aditi Tembe.]

ASSESSMENT OF UNMET SURGICAL NEED IN RURAL INDIA: A POPULATION-BASED STUDY (PARTICIPANT SURVEY)

SEARCH, GADCHIROLI 442 605

1. सर्वे बदलची माहिती

तुमच्या भागात शस्त्रक्रियेने उपचार होऊ शकणाऱ्या आजारांच्या प्रमाण शोधण्यासाठी एक सर्वे होत आहे. त्यात सहभाग घेण्यासाठी तुम्हाला विचारले जात आहे. ह्या सर्वे मध्ये तुमचा सहभाग हा पूर्णपणे तुमच्या मर्जीवर अवलंबून आहे आणि तुम्ही कुठल्याही क्षणी कुठलाही दंड न भरता सर्वे थांबवू शकता. या सर्वेतील तुमच्या सहभागासाठी तुम्ही किंवा तुमच्या कुटुंबाला संशोधकाकडून शस्त्रक्रिया सुविधा पुरवण्याचे वचन देण्याचा सहभाग नाही. तरीही गरज असल्यास डॉक्टरकडे रेफर केले जाऊ शकेल. तुम्हाला सर्वेबद्दल काही प्रश्न असल्यास तुम्ही संशोधकाला कधीही विचारू शकता किंवा वर दिलेल्या पत्त्यावर संपर्क साधू शकतात.

तुम्ही हा सर्वे ह्याच्या पूर्वी पूर्ण केलेला आहे का ? :

हो नाही

दिनांक ___/___/____ (dd/mm/yyyy)

माहिती घेणाऱ्याची सही _____

2. तमच्या बदलची माहिती

लिंग : (0) स्त्री (1) पुरुष

जात : _____

जन्म तारीख : ___/___/____ (ता/महीना/वर्ष, जर माहित नसेल तर वय : _____)

जिल्हा : _____ तालुका : _____ गाव : _____

वैवाहिक स्थिती : (0) कधीच लग्न झालेले नाही/ अविवाहित (1) विवाहित (सध्या)

(2) विभक्त

(3) विधुर / विधवा

खाली दिलेल्या टेबल मध्ये तुम्हाला शिक्षण आणि व्यवसायाच्या काही केटेगरी (वर्गवारी) दिलेली आहे आणि डावीकडे त्यासाठी डाव्या बाजूला काही क्रमांक दिलेले आहेत. कृपा करून तुम्ही तुमच्या आणि खाली निर्देशित केलेल्या तुमच्या कुटुंबातील सदस्यासाठी सर्वात उपयुक्त असा पर्याय निवडा. प्रत्येक पर्यायाचा क्रमांक हा खाली दिलेल्या डब्यात लिहावा. जर एकापेक्षा जास्त पर्याय योग्य वाटल असेल तर सर्वोत्तम पर्याय निवडा. जर परिचारातील एखाद्या सदस्याचा मृत्यु झाला असेल तर 99 लिहावे

	आतापर्यंत चे घेतलेले उच्च शिक्षण		व्यवसाय
0	अशिक्षित	0	शेती
1	4 थी पेक्षा कमी	1	मजुरी
2	प्राथमिक शिक्षण (4 पास)	2	व्यवसाय
3	माध्यमिक शिक्षण (7 वी पास)	3	सरकारी नोकरी
4	10 वी पास	4	गृहिणी
5	हायस्कूल (12वी पास)	5	विद्यार्थी
6	12 वी पेक्षा जास्त	6	मागच्या 1 वर्षात काम केलेले नाही

स्वतः आतापर्यंतचे घेतलेले शिक्षण व्यवसाय

जोडीदार आतापर्यंतचे घेतलेले शिक्षण व्यवसाय

वडील आतापर्यंतचे घेतलेले शिक्षण व्यवसाय

आई आतापर्यंतचे घेतलेले शिक्षण व्यवसाय

3. भूतकाळातील शस्त्रक्रियेची माहिती

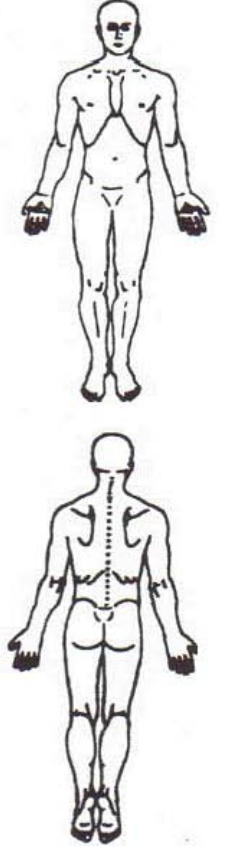
USN____ //FAM_____

3A: तुमची तब्येत जेव्हा खूप चांगली होती तेव्हाचा विचार करा. आणि अशा तब्येतीला 100 % म्हणून अंदाज करा .
कृपया तुमच्या मते तुमच्या सध्याच्या आरोग्य स्थितीचे वर्णन करा: एक पर्याय निवडा : _____%
100% (खूप छान) 75% (छान) 50% (बरी) 25% (वाईट) 0% (खूप खराब)

3B तुमची आतापर्यंत किती वेळा शस्त्रक्रिया झाली आहे : _____

जर 3B चे उत्तर 0 किंवा नाही असेल तर सरळ प्रश्न क्रमांक 4 चे उत्तर द्या.

(जर हो तर) झालेल्या शस्त्रक्रियेबद्दलची माहिती	शस्त्रक्रिया 1	शस्त्रक्रिया 2	शस्त्रक्रिया 3
1. कुठली शस्त्रक्रिया ? (कृपया उजवीकडच्या चित्रावर ऑपरेशनच्या जागी खूण करावी जेव्हा आपल्याला झालेल्या ऑपरेशन बद्दल माहिती नसेल)			
2. तुम्हाला सगळ्यात पहिले आजारची लक्षणं कधी लक्षात आली ? (mmmm/yyyy)			
3. (लक्षणं दिसण्यापासून) तुम्ही दवाखान्यात जाण्यापर्यंत मधे किती कालावधी गेला?			
4. तुम्ही डॉक्टर पहिल्यांदा गेल्यावर किती वेळाने तुम्हाला त्याने ऑपरेशनची गरज आहे अस सांगितलं			
5. डॉक्टरने ऑपरेशनची गरज आहे अस सांगितल्यावर तुम्ही किती वेळा नंतर ठरवलं की तुम्हाला ऑपरेशन करवून घ्यावयाचं आहे ?			
6. तुम्ही ऑपरेशन करायचे ठरवल्यावर प्रत्यक्ष ऑपरेशन होण्यामधे किती वेळ लागला ?			
7. तुमचे ऑपरेशन कुठे झाले? सर्ज/खाजगी दवाखाना / सरकारी दवाखाना			



4. ऑपरेशन करण्यायोग्य आजाराचा पूर्व इतिहास

4A मी आता तुमच्या पुढे कही शारीरिक अवयवांची नाव वाचून दखवणार आहे तुमच्या मते सध्या तुमच्या ज्या शारीरिक अवयवाला ऑपरेशनची सध्या गरज आहे त्याबद्दल मला सांगावे.

	हो	नाही	त्रासाबद्दलची सखोल माहिती
1. डोक , चेहरा			
2. मान , गळा			
3. फुफुस			
4. हृदय			
5. पोट			
6. मुत्रसंस्था किंवा लघवीची पिशवी			
7. (फक्त स्त्रियांसाठी) स्तन , गर्भपिशवी, गर्भपिशवीचे तोंड अंडाशय, योनी			
8. (फक्त पुरुषांसाठी) लिंग, वृषण किंवा गार, स्तन			
9. खांदे ,भुजा, मनगट , हात,			
10. कंबर , पाय , घोटे , किंवा , तळपाय.			
11. पाठीचा कणा/ कणा			
12. ईतर			

4B: मागील 2 वर्षात तुम्हाला खालील पैकी कुठलाही त्रास झाला होता का ?

स्त्री आणि पुरुष साठी	त्रास होता का		डॉक्टर ला दाखवत का	
	हो	नाही	हो	नाही
1. पोटगत गाठ / गोळा/ आला होता का ?				
2. शरीरात ईतरत्र कुठे ही असाणारी किंवा आलेली गाठ ? (गाठेची जागा_____)				
3. हिनिया? गोल करावे : बेंबीच्या वर, ऑपरेशनच्या जागी , जांघेच्या वर ?				
4. शरीराच्या कुठल्या भागात झालेलं बॅंड ज्यासाठी तुम्हाला ऑपरेशनचा विचार करावा लागला ?				
5. उलटीत रक्त पडले होते का ? हाताच्या ओंजळीचं माप करून अदांजे सांगा किती रक्त गेलं असावे ?				
6. मोतीबिंदू झाला होता का ?				
7. मान किंवा घशासमोरची सूज ?				
8. संडासातून रक्त पडणे ?				
9. संडासाच्याजागी संडास करताना कधी रक्त गेले आहे का / खूप दुखले आहे का?				
10. संडासाच्या जागी कधी पू झाला होता का/ संडासाच्या जागेतून कधी पू गेला आहे का?				

फक्त पुरुषांसाठी	त्रास होता का		डॉक्टरला दाखवत का	
	हो	नाही	हो	नाही
1. गार/शिरेमधे किंवा तिच्यावर गाठ				
2. हायड्रोसील ?				
3. अंडपिथवीमधे एक किंवा दोन्ही गार/ शिरा गायब असणे				
4. लिंगावरच्या चमडीचे तोंड लहान असणे, चमडी मागे न जाणे.				

फक्त स्त्रियांसाठी	त्रास होता का		डॉक्टर ला दाखवत का	
	हो	नाही	हो	नाही
1. स्तनात गाठ ?				
2. लघवी सारखी गळत असते का ?				
3. लघवीवर नियंत्रण करता येते का?				
4. योनी मार्गातून शौचाला होते का ?				
5. योनीत किंवा योनीवर गाठ ?				
6. मासीक पाळीत 1 दिवशी 3 पेक्षा जास्त वेळ घडी/ पॅड बदलावा लागतो का?				
7. तुम्हाला संबंधानंतर योनीतून रक्तस्राव होतो का? ?				
8. मासीक पाळी थांबल्यावर (रजोनीवृत्ती) पुन्हा रक्तस्राव?				

जर 3B चे उत्तर 0 किंवा नाही असेल तर सरळ प्रश्न क्रमाक 4C चे उत्तर या.

तुम्ही वरती सांगितलेल्या त्रासाने तुमच्या रोजच्या जीवनात काही त्रास कींवा अडचणी जातात का ? ज्या अडचणी जातात त्या नमुद कर .

मी काही गोष्टी तुम्हाला वाचून दाखवणार आहे की ज्याच्यामुळे काही लोक आजाराचे उपचार घेऊ शकत नाही किंवा त्यामुळे आजाराचे उपचार घ्यायला त्यांना अडचण येते. तुम्ही खाली दिलेल्या प्रत्येक पर्यायासाठी कृपया हे नमुद करा की त्याच्यामुळे तुम्हाला किती अडचण किंवा त्रास झाला तुमचे पर्याय खालील प्रमाणे आहेत खूप वेळा, 2. कधी कधी, आणि 3. क्वचित / कधीच नाही.

	खुप वेळा	कधी कधी	क्वचित / कधीच नाही
1. वैद्यकीय उपचाराचा खर्च	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. हॉस्पिटल मध्ये येण्या जाण्याचा खर्च	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. कामावरून गैर हजर असल्यामुळे कापला गेलेला पगार	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. हॉस्पिटल मध्ये येण्या जाण्यात जाणारा वेळ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. हॉस्पिटल मध्ये राहावं लागत असल्याने जाणारा वेळ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. काम न करता येत असल्यामुळे रिकामं राहावं लागणारा वेळ / बुडालेली शाळा	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. परिवाराच्या सदस्यांचं हॉस्पिटल मध्ये मदत करण्यासाठी राहावं लागत असल्याने जाणारा वेळ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. आजाराबद्दल वाटत असलेली लाज/	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. आजार ईतका गंभीर आहे असं वाटलं नव्हतं ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. ऑपरेशनद्वारे ह्या आजाराचा ईलाज होते हे माहीत नव्हते	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. डॉक्टराने सांगितलेली माहिती पूर्णपणे कळली नव्हती	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. वर्षाचा तो रूतु / काळ (ex. पेरणी / शाळा ...ईतर)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. ईतर (सविस्तरपणे सांगा)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

कल्पना करा जर तुमच्या आजारासाठी ऑपरेशन / वैद्यकीय सेवा ही मोफत पुरवली तर तुम्ही किती स्वखुशीने वरती सांगितलेल्या त्रासासाठी ऑपरेशन करवून घ्याल ? 100% 75% 50% 25% 0%

जर होणार-या त्रासासाठी उपचार घेतले असेल तर कुठून घेतले? _____

तुम्ही वरती सांगितलेल्या त्रासासाठी किती वेळा नंतर किती वेळाने डॉक्टरकडे गेलात ? _____

4C: मागच्या 2 वर्षात तुम्हाला अचानक खूप जोरात पोटात दुखलं आहे का? हो नाही

जर 4C चे उत्तर नाही असेल तर सरळ प्रश्न क्रमांक 4 D चे उत्तर द्या.

जर उत्तर हो असेल तर पोट दुखीची माहिती असणारा फॉर्म जोडा

4D: मागच्या 2 वर्षात तुम्हाला कुठे अपघाताने दुखापत किंवा भाजले / जळाले आहे का? हो नाही

जर नाही तर सरळ प्रश्न 4E चे उत्तर द्या. जर हो बाजूच्या चित्रात ती जागा दाखवा .

जर उत्तर हो असेल तर अपघात किंवा जळण्याची माहिती असणारा फॉर्म जोडा

4E: (जर पुरुष असेल तर सरळ प्र 5 विचारावे)

तुमच्या पूर्ण आयुष्यात तुम्ही आतापर्यंत कितीवेळा गरोदर होता ? _____

किती मुलं जीवंत जन्माला आली ? _____

किती मुलं 9 महिन्यांच्या पूर्वी जन्माला आली? _____

किती गर्भपात झाले ? _____ (MTP _____ natural _____)

तुम्ही मागच्या 2 वर्षात कधी गरोदर राहिलात का? हो नाही

जर नाही तर पुढचा प्रश्न विचारा अथवा गर्भावस्थेची माहिती विचारणारा फॉर्म

5. परिवाराची माहिती

5A: आता तुम्ही ह्या सर्वे मध्ये विचारलेली माहिती दिली स्वतः साठी दिलेली आहे . तुम्ही अशीच जास्तीस जास्त माहिती आपल्या परिवारातील दुस-या सदस्याबद्दल देऊ शकाल का ? हो नाही

5B: मागच्या 2 वर्षात तुमच्या घरी राहणारे तुमच्या परिवाराच्या सदस्याबद्दल माहिती सांगा. जर मागच्या 2 वर्षात तुमच्या घरात रहणा-या कुटुंबातील सदस्या पैकी कुणी मरण पावला असेल तर त्याची पण माहिती सांगा

तुमच्या सोबतचे नातं	वय	लिंग		तुमच्या सोबतचं नातं	वय	लिंग

=====

For researcher use only:

1. Referral to healthcare provider needed? Yes No Suspected condition: _____
2. Referral to healthcare provider given? Yes No Location: _____
3. If emergency, is transportation available? Yes N/A
4. Additional notes: _____

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