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## **Incidence and determinants of hysterectomy in a low-income setting in Gujarat, India**

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### **Abstract**

Hysterectomy is a leading reason for use of health insurance amongst low-income women in India, but there are limited population-level data available to inform policy. This paper reports on the findings of a mixed-methods study to estimate incidence and identify predictors of hysterectomy in a low-income setting in Gujarat, India. The estimated incidence of hysterectomy, 20.7/1,000 woman-years (95% CI: 14.0, 30.8), was considerably higher than reported from other countries, at a relatively low mean age of 36 years. There was strong evidence that among women of reproductive age, those with lower income

and at least two children underwent hysterectomy at higher rates. Nearly two-thirds of women undergoing hysterectomy utilised private hospitals, while the remainder used government or other non-profit facilities. Qualitative research suggested that weak sexual and reproductive health services, a widespread perception that the post-reproductive uterus is dispensable and lack of knowledge of side-effects have resulted in the normalisation of hysterectomy. Hysterectomy appears to be promoted as a first or second-line treatment for menstrual and gynaecological disorders that are actually amenable to less invasive procedures. Most women sought at least two medical opinions prior to hysterectomy, but both public and private providers lacked equipment, skills and motivation to offer alternatives. Profit and training benefits also appeared to play a role in some providers' behaviour. Although women with insecure employment underwent the procedure knowing the financial and physical implications of undergoing a major surgery, the future health and work security afforded by hysterectomy appeared to them to outweigh risks. Findings suggest that sterilisation may be associated with an increased risk of hysterectomy, potentially through biological or attitudinal links. Health policy interventions require improved access to sexual and reproductive health services and health education, along with surveillance and medical audits to promote high quality choices for women through the life cycle.

### **Introduction**

Hysterectomy, the removal of the uterus, is the leading reason for non-obstetric surgery amongst women in many high-income settings (Stankiewicz et al., 2014, Whiteman et al., 2008, Spilsbury et al., 2006). Medical indications for hysterectomy include fibroids, dysfunctional uterine bleeding, uterine prolapse and chronic pelvic pain (Carlson et al., 1993). Physicians' views on the appropriate use of the procedure diverge widely – contributing to variation in rates, and suspected misuse in some settings (Bickell et al., 1995, Bernstein et al., 1993, Gimbel et al., 2002, Broder et al., 2000). Variations in hysterectomy rates have been associated with women's demographic characteristics such as race, education and socioeconomic status and insurance status, as well as their physician's gender, training and geographical location, suggesting that the procedure is related to the broader social and health

system environment as well as to biological risk (Bickell et al., 1994, Gimbel et al., 2002, Einarsson et al., 2010, Materia et al., 2002, Palmer et al., 1999, Dharmalingam et al., 2000, Byles et al., 2000). Further, particularly in settings with a high lifetime risk of hysterectomy – such as the United States where one in three women undergoes the procedure – hysterectomy has been scrutinised and contested as a symbol of a wider culture of unnecessary medical intervention in women’s bodies (Cloutier-Steele, 2003, Angier, 1997, West and Dranov, 1994).

The incidence of hysterectomy, like caesarean section, varies between and within countries. An estimated 5.1 women per 1,000 women above age 15 underwent hysterectomy in 2004 in the United States, compared to 3.1 per 1,000 women in Australia (Whiteman et al., 2008, Hill et al., 2010). Within Germany, incidence varies across states, ranging from 2.1 to 3.6 per 1,000 women (Stang et al., 2011). Until recently, research and debate on hysterectomy have largely been limited to high-income settings: there are no published estimates of incidence, and only nine of prevalence, in low and middle income countries. Community-based research in India, El Salvador and Jordan has reported hysterectomy prevalence estimates of between 1.7 to 9.8 percent of adult women (Sarna et al., 2013, Barghouti et al., 2013, Desai et al., 2011, Bhasin et al., 2011, Singh and Arora, 2008, Ozel et al., 2007, Patel et al., 2006, Shakhathreh, 2005, Kaur et al., 2004). While none of these estimates were age-standardised, the prevalence of hysterectomy is considerably lower than in high-income countries such as the United States (26.2%), Australia (22.0%) and Ireland (22.2%)(Erekson et al., 2009, Byles et al., 2000, Ong et al., 2000), but closer to prevalence in Taiwan and Singapore (8.8% and 7.5%, respectively) (Lam et al., 2014, Hsieh et al., 2008).

In 2012, media reports in India raised suspicion of increasing misuse of hysterectomy as a routine treatment for gynaecological ailments, particularly in young, premenopausal women (Singh, 2012, BBC,

2013). Analyses of facility and insurance data suggest that hysterectomy is correlated with profit incentives under the national health insurance scheme and unregulated private health care (Jain and Kataria, 2012, Oxfam, 2013). Earlier research in Gujarat identified hysterectomy as the leading reason for hospitalisation in the prior six months amongst both insured and uninsured women, but the cross-sectional nature of the data prevented comparison with other settings or conclusive findings related to predictors associated with the procedure (Desai et al., 2014). A recent study in rural Andhra Pradesh found that hysterectomy, conducted at an average age of 29 years, also included removal of both ovaries (and thereby induced premature menopause) in 59% of cases (Kameswari and Vinjamuri, 2013). In response to such findings, two states in India have already restricted publicly-funded insurance coverage for hysterectomy in private facilities (Majumdar, 2013). Despite widespread media coverage and policy changes regarding insurance, there is limited population-level data on hysterectomy to inform policy. Accordingly, the aim of this paper is to estimate incidence of hysterectomy and identify predictors and the underlying determinants of hysterectomy in a low-income setting in Gujarat, India.

## **Setting**

Gujarat, a state of 60 million people on India's western border, is amongst India's wealthier states (MoSPI, 2015). Health indicators, however, remain close to national averages (IIPS/ORCMacro, 2006). The National Rural Health Mission (NRHM), India's flagship health programme to improve rural health infrastructure and human resources, was initiated in 2005, followed by Rashtriya Swasthya Bima Yojana (RSBY), the national health insurance scheme that provides hospitalisation coverage up to Rs.30,000 in public and private hospitals for families with "below poverty-line" cards. Fifty-seven percent of births in Gujarat occur in health facilities, with institutional birth being more common among higher-income, educated urban women (IIPS, 2010). Forty-four percent of currently married women have undergone

sterilisation by tubal ligation, accounting for 70 percent of all contraceptive use amongst reproductive age women. Lower-income women are more likely to utilise sterilisation as a contraceptive method, with 85 percent of sterilised women obtaining the procedure in a government facility (IIPS, 2010).

We conducted our study alongside a two-year evaluation of a community health intervention implemented by the Self-Employed Women's Association (SEWA) in Ahmedabad district and city in Gujarat between 2010 and 2012. SEWA, a trade union of over 1.5 million women workers in the informal economy, works towards members' full employment and self-reliance. It operates a voluntary health insurance scheme (VimoSEWA) that offers coverage for hospitalisations that exceed 24 hours. Previous research based at SEWA identified hysterectomy as a leading reason for insurance claims, showed that it occurred at an average age of 36 and identified care provided to women for gynaecological ailments and surgery was of poor quality (Ranson and John, 2001, Desai et al., 2011).

## **Methods**

This study utilised two data sources: (i) a quantitative, population-based cohort of adult women and (ii) in-depth qualitative research amongst women, health care providers and key informants. While the quantitative survey could estimate measures of frequency (prevalence and incidence) and some predictors of hysterectomy, understanding the complexity of social and behavioural factors that influenced women to undergo hysterectomy required integration of a qualitative approach (Lingard et al., 2008, Creswell, 2007). All interview participants reviewed a study information form with researchers and consented to participation and sharing of findings including publication. Identities of all sources were anonymised. The Executive Committee of the SEWA Health Cooperative and the ethics committee of the London School of Hygiene and Tropical Medicine provided ethics approval for the quantitative and qualitative components.

### *(i) Cohort study*

Quantitative data came from four household survey rounds that collected demographic, health and treatment-seeking information in a cohort of adult women, as part of a two-year cluster randomised trial to evaluate the effect of a health education intervention designed to reduce insurance claims and hospitalisation for diarrhoea, fever and hysterectomy amongst adult women. The trial was conducted in 28 clusters over two years. Seventy households were selected in each cluster, 35 of which were randomly selected from SEWA's insurance membership database. The remaining 35 were randomly selected from household listings. An adult woman over the age of 18 in each household was selected for interview, with no maximum age limit. In insured households, the primary VimoSEWA insured member was surveyed. No selected households had more than one primary female insured member. In uninsured households, the primary SEWA member or wife of the male head of household was selected. At the time of recruitment, women were given general information about the study topic but not told about the health education intervention on hysterectomy. Of 1,960 households selected, 1,934 women

were recruited in the first survey round; 26 insured households were excluded due to non-availability of the eligible household or member, with no replacement found. After analysing baseline findings on the prevalence of hysterectomy, we added survey questions pertinent to hysterectomy and reproductive health history to subsequent rounds and decided to initiate a qualitative study to explore individual, social and health systems determinants of hysterectomy, described below.

Analysis of the trial found no evidence of an effect of the intervention on rates of claim submission (RR 1.03; 95% CI 0.81,1.30;  $p=0.81$ ) hospitalisation (RR:1.05; 95%CI 0.58,1.90;  $p=0.88$ ) or morbidity (RR: 1.06, 95% CI 0.87,1.28;  $p=0.58$ ) related to diarrhoea, fever and hysterectomy (Desai, 2015). Accordingly, a cohort analysis to estimate incidence and identify predictors of hysterectomy included data from both treatment and control areas over all four rounds of the household survey, rather than from non-intervention areas only. Data were entered into a Microsoft Access database and analysed using Stata 11. The svyset command was utilised to account for the cluster sampling and the different sampling fractions for insured and uninsured households across clusters. Two sampling weights, inversely proportional to the sampling fraction, were defined for each cluster: one for insured women and one for uninsured women. All tables except Table 2 present weighted proportions; findings therefore represent the study population with respect to health insurance status. Women who reported hysterectomy prior to the period covered by the baseline survey were excluded. The incidence of hysterectomy, based on cases reported by the primary adult respondent over the two-year survey period, was estimated using the exponent of the Poisson regression coefficient. Crude rate ratios for a range of demographic characteristics such as income, urban/rural location, education, insurance status, number of living children and sterilisation history, were estimated using Poisson regression. Wald tests were utilised to obtain p values for variables with more than one level. A multivariable Poisson



regression model was fitted to identify predictors of hysterectomy using forward regression, which included variables with crude rate ratios observed to be associated with hysterectomy ( $p \leq 0.10$ ).

### *(ii) Qualitative study*

Qualitative fieldwork was conducted in two rural blocks that were also covered by the quantitative study. We identified participants over time and through interactions in the community, as well as through health workers and referrals from other interviewees, rather than from the survey sample. This approach helped to ensure variation in the length of time that elapsed since women underwent hysterectomy. Women were recruited and interviewed until no new analytical themes emerged. Thirty-five women with previous hysterectomy were interviewed. Five gynaecologists, who had performed the hysterectomy for 20 of these 35 cases, were interviewed along with 16 other key informants who included midwives, health workers and family members. Three women with gynaecological ailments who did not proceed with hysterectomy were identified and interviewed. Interviews were conducted and transcribed in Gujarati. Findings were coded into primary and sub-themes to identify drivers of hysterectomy. Women were compared across sub-themes and variables in a framework analysis. Interview content was also specifically analysed to examine if SEWA health insurance affected the decision to undergo hysterectomy.

### *Mixed methods analysis*

The mixed methods analysis was both inductive and deductive, combining data in an iterative approach and through using triangulation (O’Cathain et al., 2010). The quantitative cohort data were analysed first to estimate incidence and identify predictors of hysterectomy. A thematic analysis of qualitative data was conducted next to examine processes and determinants. Next, findings from both sets of data were triangulated to identify convergence, dissonance and gaps. New analytical themes in either set of data also led to further analysis in the others. Finally, predictors and underlying determinants were examined together to identify intersections.

## Results

Of the 1,934 women recruited into the study, 191 women (10% of women interviewed at baseline) had undergone hysterectomy before the period covered by the baseline survey and were excluded from the cohort analysis. Surveyed women contributed 3,268 woman-years at risk. Mean follow-up time was 1.9 years. While 94% of women were retained for three survey rounds, unanticipated slum demolitions and occupation-related migration resulted in higher loss to follow up in the final round. In total, 83% of women were followed up for the full two years (Table 1).

**Table 1 Numbers of women surveyed, by round**

	<b>Baseline</b>	<b>Round 2</b>	<b>Round 3</b>	<b>Round 4</b>
Cumulative loss to follow-up	0	73	107	294
Women surveyed	1743	1670	1636	1449

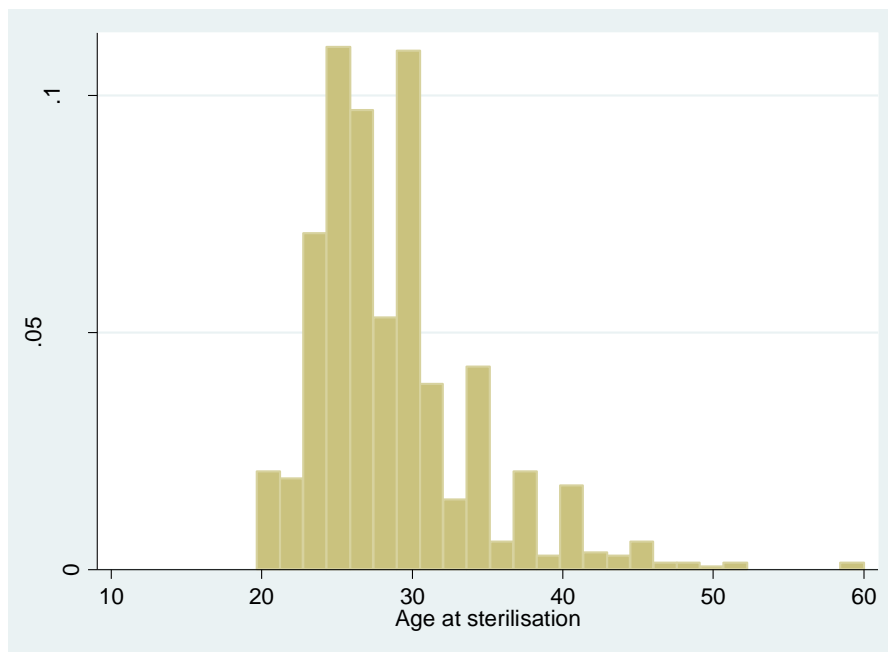
Women surveyed were typically low-income women workers of the informal economy, most between the ages of 25-44, and married with at least two children (Table 2). Sixty-one percent of women who were surveyed in round 4 reported having undergone sterilisation through tubal ligation, with mean age at time of sterilisation of 27.5 years (Figure 1).

**Table 2 Overview of study sample at risk of hysterectomy at baseline**

Overview of study population	n	%
	1,743	(unweighted)
<i>Age group</i>		
<25	132	7.6
25-34	541	31.2
35-44	596	34.4
45-54	359	20.7
55+	115	6.6
<i>Demographic characteristics</i>		
Insured	908	52.4
Rural location	986	56.9
Hindu	1,543	89.0
Currently married	1,536	88.6
Have 2+ children	1,598	92.2
Have undergone sterilisation*	884	61.0
Never attended school	932	53.7
Agricultural worker	697	40.2
Annual income <Rs. 60,000	790	45.6
Partial mud & solid house	1,040	60.0
Report average health	1,254	71.9

\*Data only collected in survey round 4; 294 cases that were lost to follow-up are missing

**Figure 1 Mean age at sterilisation (n=884)**



### *Epidemiological findings*

Sixty-two women reported undergoing hysterectomy during the two-year study period, an incidence of 20.7 per 1,000 woman-years (95% CI: 14.0-30.8 per 1,000 woman-years), at a reported mean age of 36.0 years (95% CI: 33.8-36.2). Crude analyses (Table 3) yielded little evidence that hysterectomy rates varied by insurance status, rural or urban location, religion, education, occupation, house type, latrine ownership or perception of one's own health ( $p \geq 0.2$  in all cases). The incidence of hysterectomy was highest amongst women older than 25 and younger than 54 years, and very low amongst women older than 55 (0.06/1,000 person-years). There was strong evidence that the incidence of hysterectomy was higher amongst women with relatively lower incomes (RR=0.12 for annual household income of Rs. 120,000+ compared to those with an income of Rs. 0-60,000;  $p=0.01$ ). There was also strong evidence that women who have two or more surviving children had a higher rate of hysterectomy than women with fewer children. Further, married women reported higher rates than unmarried (RR=0.07, 95% CI: 0.01,0.66) or widowed women (RR=0.53, 95%CI:0.08,3.66;  $p=0.06$ ). Women who had not been sterilised (RR=0.41, 95% CI: 0.14,1.21;  $p=0.09$ ) reported lower rates of hysterectomy than sterilised women, but evidence for these two associations was relatively weaker.

**Table 3 Baseline characteristics associated with incidence of hysterectomy**

<b>Variable</b>	<b>n with hysterectomy</b>	<b>Rate/1,000 woman yrs</b>	<b>95% CI</b>	<b>Unadjusted rate ratio</b>	<b>95% CI</b>
<i>Overall incidence</i>	62	20.7	(14.0,30.8)		
<i>Insurance status</i>					
Uninsured	30	20.9	(13.7,31.2)	1.00	
Insured	32	20.8	(13.9,32.0)	1.01	(0.62,1.64)
<i>Location</i>					
Rural	45	24.3	(13.9,42.4)	1.00	
Urban	17	15.8	(10.2,24.7)	0.65	(0.33,1.29)
<i>Age group</i>					
<25	4	7.4	(13.0,4.16)	0.33	(0.05,2.14)
25-34	16	23.5	(12.6, 44.1)	1.06	(0.46,2.43)
35-44	28	22.2	(1.32,37.4)	1.00	
45-54	13	26.9	(1.38,52.5)	1.21	(0.62,2.34)
55+	1	0.06	(0.06,5.0)	0.03	(0.003,0.21)

<i>Religion</i>					
Hindu	55	21.5	(15.1,30.5)	1.00	
Muslim	7	16.1	(3.5,73.2)	0.75	(0.20,2.75)
<i>Marital status</i>					
Married	58	21.9	(14.7,33.0)	1.00	
Unmarried	1	1.5	(0.1,15.7)	0.07	(0.01,0.66)
Widowed	3	11.6	(1.8,74.8)	0.53	(0.08,3.66)
<i>Number of surviving children</i>					
0-1	1	0.5	(0.1,0.2)	0.03	(0.002,0.20)
2-3	36	24.7	(16.5,36.8)	1.00	
4+	18	25.4	(13.9,51.5)	0.80	(0.37,1.71)
<i>Sterilisation history*</i>					
Yes	45	27.9	(17.8,43.7)	1.00	
No	10	11.5	(5.1,25.8)	0.41	(0.15,1.16)
<i>Education</i>					
Never attended school	32	19.6	(13.7,28.1)	1.00	
Attended (primary+)	30	21.7	(12.6,36.9)	1.10	(0.67,1.81)
<i>Primary occupation</i>					
Self-employed/service	22	17.3	(11.1,26.6)	1.00	
Agriculture	36	29.1	(15.6,54.5)	1.69	(0.94,3.04)
Salaried	4	11.3	(2.5,5.1)	0.66	(0.13,3.35)

<i>Mean annual HH income (INR)</i>					
0-60,000	29	27.0	(15.9,45.8)	1.00	
60,001-120,000	26	20.3	(10.8,38.0)	0.75	(0.33,1.70)
120,001+	7	3.2	(1.0,97.0)	0.12	(0.03,0.44)
<i>House type</i>					
Mud house	15	33.4	(20.2,55.0)	1.00	
Partial mud and solid	31	20.4	(12.3,33.7)	0.61	(0.29,1.27)
Solid construction	16	15.1	(5.2,43.6)	0.45	(0.13,1.60)
<i>Individual latrine</i>					
No	30	25.5	(15.6,41.8)	1.00	
Yes	32	17.6	(11.3,27.4)	1.45	(0.87,2.41)
<i>Perception of own health</i>					
Very poor	1	9.3	(0.9,94.6)	1.00	
Average	48	20.8	(11.1,38.9)	2.23	(0.23,22.15)
Very good	13	21.2	(9.6,46.9)	2.27	(0.22,23.46)

*\*Data only collected in survey round 4; 294 cases missing*

Multivariable regression (Table 4) indicated strong evidence that the incidence of hysterectomy was independently associated with age, with highest incidence amongst women between 25 and 54 years, with lower income status and with having at least two surviving children. Neither sterilisation history nor marital status emerged as independent predictors of hysterectomy incidence when adjusted for number of surviving children, income level and age. There was little evidence of clustering of hysterectomy rates in a random effects model not adjusted for location strata or sampling weights ( $p=0.12$ ). Nearly two-thirds of women (62%) utilised private hospitals for hysterectomy, while the remainder used government (34%) or non-profit trust hospitals.

**Table 4 Baseline characteristics associated with hysterectomy; multivariable regression**

<b>Risk factor</b>	<b>Unadjusted RR</b>	<b>95% CI</b>	<b>p value</b>	<b>Adjusted RR*</b>	<b>95% CI</b>	<b>p value</b>
<i>Number of surviving children</i>			0.006			0.01
0-1	0.03	(0.002,0.20)		0.02	(0.002,0.22)	
2-3	1.00			(b)		
4+	0.80	(0.37,1.71)		0.81	(0.40,1.66)	
<i>Income level</i>			0.01			0.01
0-60,000	1.00					
60,001-120,000	0.75	(0.33,1.70)		0.71	(0.33,1.53)	
120,001+	0.12	(0.03,0.44)		0.12	(0.03,0.45)	
<i>Age at start of follow-up</i>			0.01			0.006
<25	0.33	(0.05,2.14)		0.56	(0.09,3.23)	
25-34	1.06	(0.46,2.43)		1.08	(0.48,2.43)	
35-44	1.00			(b)		
45-54	1.21	(0.62,2.34)		1.43	(0.77,2.64)	
55+	0.03	(0.003,0.21)		0.03	(0.003,0.23)	
<i>Marital status</i>			0.06			0.32
Married	1.00					
Unmarried	0.07	(0.01,0.66)		0.18	(0.02,1.90)	
Widowed	0.53	(0.08,3.66)		0.65	(0.09,4.61)	
<i>Sterilisation history</i>			0.09			0.24
Yes	1.00					
No	0.41	(0.15,1.16)		0.54	(0.19,1.54)	

*\*Final model adjusted for number of surviving children, income and age*

#### *Qualitative findings*

The 35 women interviewed who had undergone hysterectomy had broadly similar demographic characteristics as women in the cohort study, except for variation in the number of years since the procedure (Table 5). Most women and key informants (health workers, midwives and family members) felt the procedure was normal and increasingly common; all easily recounted cases of others who had undergone the surgery in the surrounding areas. All 35 women reported gynaecological morbidity, typically experienced as severe pain, excessive bleeding and disruption to daily life, as the catalyst for seeking care from a gynaecologist. Two local midwives perceived an increase in menstrual disorders in the area, which they ascribed to use of fertilisers in the soil and dietary changes. They also believed

younger women no longer relied on traditional medicines for menstruation-related ailments in particular, as the new generation desired quicker treatment.

**Table 5 Demographic characteristics of 35 women who underwent hysterectomy**

<b>Women interviewed</b>		
<i>Mean age at hysterectomy</i>	35.8	
	<b>n with</b>	
<i>Years since procedure</i>	<b>hysterectomy</b>	<b>%</b>
<1 year	7	20
<5 years	12	34
5-10 years	7	20
>10 years	9	26
<i>Occupation</i>		
Agricultural	18	51
Health worker	3	9
Manual (non-farm) labourer	6	17
Housework	8	23
<i>Any education</i>		
Yes	10	29
No	25	71
<i>Insurance status</i>		
Insured	11	31
Uninsured	24	69

The majority of women (27/35) sought at least two medical opinions for gynaecological morbidity, over a period of several weeks or months, during which time they considered the financial, logistical and familial implications of hysterectomy once it was suggested as an option (See Box 1). Slightly more than half of women used private hospitals, while the remainder used government and trust facilities. All except two women were unsure whether their ovaries were removed with the uterus during surgery. Almost all women shouldered debt, a mortgage or other financial difficulties to finance treatment and surgery.



### **Box 1 Women's experiences with hysterectomy**

Hansaben, an agricultural labourer, age 40 when she underwent a hysterectomy last year:  
*I had severe pain in my stomach for two years, but I was scared to see doctors. I have never even had a bottle (IV fluid). I went to Vasna (private doctor)...and then to a trust [hospital] for a second opinion. The doctor said there was no way out....the cyst was so big it could not be removed alone. I kept crying, and finally went to one more private doctor who said my blood was low and I could not have surgery right away though I needed it. I took iron pills for 12 months...and then finally had the operation.*

Gajaraben, who labours in a brick kiln, age 36 when she underwent hysterectomy four years ago:  
*I had my periods for 15 days at a time, for 4 months. I went to two doctors...They said to do the test (sonography) and then said that if I don't remove it, I will definitely have cancer. You will have problems in the future, whether you take medicines or not....I did not want cancer in the future. Now I am okay again, I can lift big bricks and work. You can have a fever, cold, cough or weakness and go to work. But for this [menstrual problems] you can't work unless you take care of it.*

Gauriben, age 40, who could not have children and had severe pain and bleeding:  
*We didn't know the reason for my problem, and the doctor said the uterus will have to be removed eventually. We also told her that we don't have any kids. She said that, since you don't have that capacity [to have children] there is no point in keeping the kothri [uterus].*

Madhuben, an agricultural labourer was 25 years old when she had a hysterectomy:  
*My periods would stay for 20-25 days. I used to have a lot of pain. I took medicine prescribed at Civil Hospital [large urban govt hospital]...for one and a half years. I then had a cyst, which they told me when went back to Civil. I took medicines for one more year but nothing improved. I went to 2-3 doctors after that. A year later I finally had a hysterectomy.*

Nakviben, an agricultural labourer who was 22 when she had a hysterectomy:  
*I had heavy bleeding and a lot of pain. Working was a problem, so I thought to remove it [the uterus]. I went to three hospitals, who said it was not an emergency but I could remove it later. I tried the medicine but started vomiting. I hate medicines; even if I have a fever, I don't take any [oral] medicine... not even home-based remedies. You see, I had a problem and I didn't want medicine. So at last, out of frustration, I removed it. I needed it [the operation] to be healthy.*

Women’s experiences and attitudes regarding hysterectomy were categorised along a spectrum—last resort, pragmatic treatment/prophylaxis or permanent freedom – based on their reproductive health history, treatment-seeking patterns and representations of hysterectomy (Table 6). While attitudes toward hysterectomy did not appear to be linked to observable socioeconomic or demographic characteristics, history of previous sterilisation appeared to be linked to women’s attitudes towards surgical intervention. Further, women’s desire for work security and freedom from future health risks such as cancer or continued morbidity led most women to view hysterectomy as a ‘permanent solution.’ Women who had undergone sterilisation seemed more comfortable with hysterectomy as a viable treatment option, rather than a last resort. Three women who did not undergo hysterectomy for gynaecological ailments were of similar age and demographic characteristics as the other women interviewed. Each cited fear of surgery as the reason for refusal. One preferred to continue with hormonal treatment, and a second had felt cured once she underwent menopause.

**Table 6 Treatment-seeking spectrum amongst women who had hysterectomy**

<b>Grouping (n=35)</b>	<b>Childbirth</b>	<b>Sterilised</b>	<b>Waited to seek treatment</b>	<b>Sought 2+ opinions</b>	<b>Tried Medicine /Alternatives</b>	<b>Perceived risk of surgery</b>	<b>Main drivers of procedure</b>
Last resort (11)	Primarily home	Half	Yes	Yes	Yes	Fear of surgery	No other option – work and health security
Pragmatic (15)	All home birth	All	Yes	Yes	No	Minimal risk; concerned with future morbidity	Work and health security
Freedom (7)	Institutional	Most	No	No	No	None	Relief from menstruation

Very few women related side effects of having a hysterectomy. Almost all women who had the surgery several years ago did not report experiencing any difficulty associated with premature menopause, although none had taken hormone replacement therapy. Only one woman, a SEWA community health

worker, related difficulties with sexual function and hot flushes after her hysterectomy. Midwives and local health workers felt that the removal of the uterus could be dangerous, but each had supported local women and family members in their decision to undergo hysterectomy.

### *Providers' views*

All providers we interviewed primarily provided obstetric care in their practices. They viewed hysterectomy as a one-time cure for menstrual problems, cysts, fibroids and other gynaecological ailments for rural, low-income women (Box 2). In contrast, they felt urban women, as well as wealthier rural women, had the resources and awareness to try medicines or less extreme procedures such as cystectomy. A consistent theme was that, once reproduction was complete or women were sterilised, the uterus was a superfluous organ. With one exception, providers interviewed shared the opinion that side effects of hysterectomy are limited. Private practitioners cited the introduction of a consumer protection act as a stimulus for hysterectomy instead of less invasive treatment, to ensure women would not complain of incomplete treatment if a cyst or fibroid returned. However, one felt the act was a deterrent, due to potential complaints of unnecessary hysterectomy. The two non-profit providers felt the profit motive led private doctors to conduct unnecessary procedures, but felt that women's demand was also a factor.

### ***Box 2 Providers' views***

Dr. Nikhil, non-profit charity hospital:  
*Women are different there [in the city] – more literate, and they know and understand the indications and problems associated with hysterectomy.*

Dr. Samir, private doctor:  
*They start bleeding a lot and don't take the proper [hormonal] treatment course. And they are already sterilised. So somehow, the uterus falls to the wayside, and women ultimately undergo a hysterectomy.*

Dr Gaurang, government doctor:  
*Basically, if a woman is above 35-36 years, with her kids done, I do a full hysterectomy with oophorectomy. I do this to be safe, otherwise if they get a cyst they come back and say what kind of operation was that? So to be safe, I remove everything. [regarding side effects] Premature ovarian failure anyway happens by 37, 38 years.*

Local clinics and hospitals offered few preventive services such as diagnosis of reproductive tract infections through microscopy or less invasive treatment like laparoscopic removal of cysts, either due to lack of equipment or skills to perform such procedures. Pap-smear tests were not available, outside of government-sponsored camps held twice a month. Trans-vaginal ultrasounds that could detect fibroids and cysts were not readily available. All providers related the frequent conduct of hysterectomy as a means for young, particularly rural, government doctors to gain surgical skills. Two providers had conducted many hysterectomies during early career rural postings, to help ‘perfect the surgical hand’.

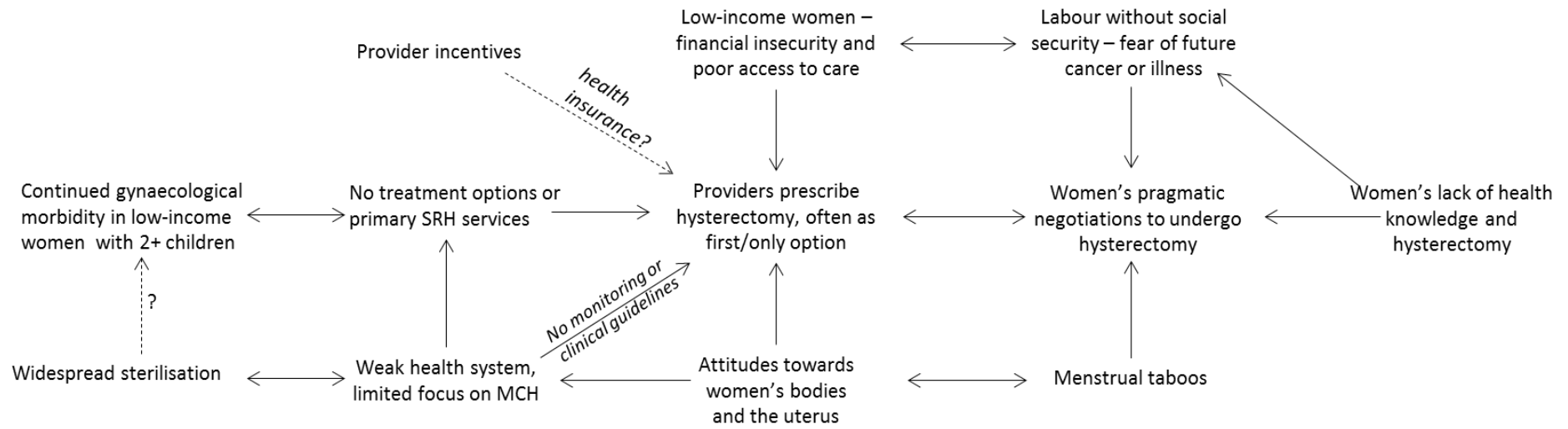
*Pathways to hysterectomy: mixed methods analysis*

Comparing and synthesising findings from both data sets, we identified pathways to hysterectomy that stem from: (i) work and economic insecurity (ii) lack of alternate treatment options for gynaecological morbidity, particularly in the primary health care system and (iii) attitudes towards the post-reproductive uterus and to a lesser extent, (iv) history of sterilisation (Figure 2). Aligned with strong evidence from the survey that the incidence of hysterectomy was higher amongst lower-income women, providers reported that hysterectomy was more likely to be prescribed as a first or second-line treatment option for low-income rural women who would not return for follow-up appointments associated with less invasive treatment. Although women without work security underwent a major surgery at considerable financial and physical risk, they believed removing the uterus – deemed a permanent cure for gynaecological ailments – would in fact secure their future productivity.

Qualitative findings pointed to health systems weaknesses, particularly the lack of reproductive and sexual health services, as a reason why hysterectomy was commonly prescribed to treat gynaecological ailments. Lack of knowledge, amongst both women and providers, about side effects of the procedure

further contributed to its normalisation. Notably, approximately one-third of women utilised public services for hysterectomy, and almost all women interviewed in-depth reported seeking at least two opinions before undergoing the procedure – suggesting that privatisation of health services or provider’s profit motivations alone do not explain the pattern of hysterectomies in this setting. Moreover, there was no evidence of an association of being insured by VimoSEWA with hysterectomy. Women did not report seeking services in a primary care setting for gynaecological ailments, due to lack of availability. Findings also suggested that both women and providers viewed the post-reproductive uterus as a dispensable organ, which may explain why women with more than two children were more likely to undergo hysterectomy. Menstrual taboos, either a product of, or contributor to, attitudes towards the uterus, further strengthened some women’s desire to undergo hysterectomy. Lastly, both qualitative and quantitative data suggested an association between history of sterilisation and hysterectomy. From a decision-making perspective, women who had undergone previous sterilisation were less likely to try alternative treatment options such as hormonal medicine for gynaecological ailments. They expressed greater comfort with gynaecological surgery and a permanent solution, despite not having sought medical intervention for other health issues including childbirth.

**Figure 2 Overview of determinants and pathways associated with hysterectomy**



## **Discussion**

Our incidence estimate of 20.7 per 1,000 woman-years (95% CI: 14.0, 30.8), the only estimate of incidence in India to our knowledge, is at least four times higher than the highest global rates, such as the United States (5.1 per 1,000), Germany (3.6 per 1,000) and Australia (3.1 per 1,000) [rates in woman-years] (Whiteman et al., 2008, Hill et al., 2010, Stang et al., 2011). This comparison of overall incidence must be interpreted cautiously, however, due to differences in the demographic characteristics of the cohort population. Over 85% of respondents in the study population were women between the ages of 25-54, comprised mostly of low-income SEWA members who worked in the informal economy. Age-standardised rates based on findings from a nationally representative sample of women in India will allow for more appropriate comparison to findings from other settings where age-standardised data are available. German estimates are available standardised to the German population structure in 2005 (Stang et al., 2011), but published incidence data from other settings do not present age-specific or age-standardised rates (Hill et al., 2010, Whiteman et al., 2008).

### *Predictors and underlying determinants*

Variations in hysterectomy rates by socioeconomic status, ethnicity and education in high-income settings such as Italy, New Zealand and the United States (Erekson et al., 2009, Bower et al., 2009, Hautaniemi and Leidy Sievert, 2003, Matera et al., 2002, Dharmalingam et al., 2000) support the view that hysterectomy is a product of both social and biological processes (Brotherton and Nguyen, 2013). Our data from Gujarat suggests a similar situation in India. Higher rates amongst lower-income women are of particular concern, as they reflect both immediate health risks and embedded inequality. Women workers in India's vast informal economy typically survive on precarious incomes. As women articulated, gynaecological and menstrual disorders disrupt their work security, similar to findings in other low-income settings (Patel et al., 2006, Harlow and Campbell, 2000, Black and

Fraser). They therefore viewed hysterectomy as both pragmatic treatment and prophylaxis, a permanent solution that secured their future earning capacity.

The high proportion of young women sterilised in India, most commonly amongst low-income women, has considerable health and demographic implications (Matthews et al., 2009). In addition, sterilisation appears to be related to an increased risk of hysterectomy. Biologically, tubal ligation has been associated with higher risk of menstrual disorders and gynaecological ailments in some research conducted in the United States, although evidence is mixed (Hillis et al., 1998, Ozerkan et al., 2010, Olenick, 1998, Moradan and Gorbani, 2012, Nankali et al., 2012). Widespread, normalised surgical sterilisation in India may in fact be a precedent for the normalisation of ‘permanent’ solutions to reproductive ailments, for both women and providers. Our findings underscore the need to understand linkages between sterilisation and hysterectomy further.

Further, belief that the uterus and ovaries are productive only when reproductive reflects underlying gender biases, as well as a widespread cultural prioritisation of women’s identity as mothers (Inhorn, 2006). Almost no one interviewed believed the uterus or ovaries performed an essential body function after childbearing was complete. Moreover, women viewed it as a potential site of cancer – a liability – for which hysterectomy represented a solution. These findings concur with emerging research in South Asia on the rationale for hysterectomy to prevent future health problems (Towghi, 2012, Sardeshpande, 2014), as well as reflect women’s pragmatic actions to use bio-medicine as a tool to reduce physical and socioeconomic risk (Lock and Kaufert, 1998).

### *Implications for women’s health*

In this setting, neither women nor providers were aware of potentially adverse side effects of hysterectomy—in accordance with the perception that removal of the uterus and ovaries at young



age was generally beneficial or protective. However, even without removal of the ovaries, hysterectomy has been associated with earlier onset of menopause (Farquhar et al., 2005). Women who undergo hysterectomy at a mean age of 36 are at risk of menopause considerably earlier than the estimated global median age at natural menopause, 51 years (Gold et al., 2001). Evidence on the long term effects of hysterectomy, though inconsistent, also suggests hysterectomy is associated with higher risk of cardiovascular disease, with higher risk amongst younger women and women who have undergone oophorectomy (Rocca et al., 2012, Ingelsson et al., 2011, Yeh et al., 2013, Fletcher et al., 2010). Recent research in Taiwan suggests that women who undergo only hysterectomy before age 45 are at a higher risk of stroke (RR: 2.29, 95% CI: 1.52,3.44) (Yeh et al., 2013). Further, hysterectomy has been associated with urinary incontinence and problems with sexual function (Rodriguez et al., 2012, Hunter et al., 2012, Hoga et al., 2012, Cabness, 2010, Bayram and Beji, 2010, Brown et al.).

#### *Implications for health policy and programs*

Our findings suggest that hysterectomy is performed without appropriate diagnostic evaluation or alternative treatments tried. Similar to findings of medical audits in the United States, the lack of clear clinical guidelines for hysterectomy may leave it prone to misuse (Farquhar et al., 2005). Differential treatment of lower-income women and use of hysterectomy as ‘practice’ in this setting point to embedded biases in health care for women – and reflect a wider culture, beyond this setting, of unnecessary medical intervention in women’s reproductive systems (West and Dranov, 1994, Cloutier-Steele, 2003, Angier, 1997). The normalisation of hysterectomy also underscores the complex negotiations between women’s agency and medically unindicated procedures, as well as the ethical obligations of providers – both of which require further consideration in the Indian context (de Bessa, 2006, Lopez, 1993, Unnithan-Kumar, 2010).

While SEWA insurance was not associated with higher hysterectomy incidence – women and providers both cited the scheme’s benefit package was too low to be a financial incentive. Research is required to investigate possible influences of more generous coverage offered by government-funded health insurance schemes on increasing the incidence of hysterectomy. Publicly-funded health insurance can arguably skew the health system further away from primary gynaecological care, as it only covers tertiary care procedures or admission that exceeds 24 hours rather than outpatient services (Selvaraj and Karan, 2012).

These findings highlight the need to address the physical and emotional burden of untreated gynaecological morbidity, as reported in several studies in rural and urban India (Bang et al., 1989, Bhatia and Cleland, 1995, Bhatia et al., 1997, Latha et al., 1997, Santhya and Jejeebhoy, 2003, Bhatnagar et al., 2013). Providers’ practices in the private, government and trust facilities were predominantly obstetric; they reported having neither the equipment, time, nor experience to diagnose or treat gynaecological ailments. Moreover, the health system in Gujarat, as reflected in policy documents and observation during this study, focuses on maternal and child health without integrated reproductive and sexual health services at the primary level (NRHM, 2011). Without access to timely treatment in a primary care setting, women may approach gynaecologists only when symptoms worsen, perhaps to a point when only surgical interventions are offered. In the preventive services for cancer, hysterectomy appears to serve as a prophylaxis – similar to findings reported in Mexico (MacLean, 2005). Lastly, the potential linkages between sterilisation, already widely criticised for poor quality of care and coercive policies, and hysterectomy further emphasises the need for comprehensive reproductive and sexual health services (Mavalankar and Sharma, 1999, Das and Contractor, 2014).

### *Strengths and limitations*

A primary strength of this study was its mixed methods design, which identified predictors, suggested pathways for associations, and raised new hypotheses to explain hysterectomy patterns in one setting. The use of a cohort to estimate incidence, is an important contribution to examining hysterectomy in India. However, the study was conducted in a population comprised only of low-income women, limiting generalisability within India or to national estimates in other countries. Similarly, health is a state subject in India and services vary accordingly; these findings may be specific to the Gujarat health system.

Several factors may have affected our estimates of hysterectomy incidence. Self-reported hysterectomy is subject to reporting error, although the short recall periods and importance of a major and well-known surgery likely limited recall errors. The trial in which this study was nested noted a drop in overall reported hospitalisation episodes over rounds consistent with survey fatigue, a known risk in cohort studies (Hayes and Moulton, 2009), which may have resulted in an underestimate of incidence. Further, the primary respondent in the household was selected for participation based on an association with SEWA, a potential source of bias if SEWA members were more or less likely to undergo hysterectomy. Although retention rates were high until round three, loss to follow-up increased in round four. As a result, we may have under or over-estimated population incidence. Lastly, this study would have been strengthened by inclusion of variables related to women's medical histories in the survey as well as a longer follow-up period.

### **Conclusion**

The burden of untreated morbidity, combined with attitudes towards the uterus, and a health system ill-equipped to manage women's gynaecological health needs, has rendered hysterectomy both medically rational, and socially acceptable, for low-income women in this setting. The incidence

and determinants of hysterectomy call for urgent intervention to curb its seemingly common use for conditions amenable to less-invasive procedures. Improved access to sexual and reproductive health services within primary health care services is a first step, along with understanding the links between sterilisation and hysterectomy. Health education on gynaecological ailments and the potential side effects of hysterectomy and oophorectomy, as well as provider training and health financing for alternative procedures also emerge as important needs. Research at the population level on gynaecological morbidity and hysterectomy is required across India to monitor trends, identify local determinants, and track long term health effects. Encouragingly, the National Family Health Survey will initiate collection of population-based data on hysterectomy in its 2014-15 round, from which age-standardised prevalence, facility choice and the association with health insurance can be examined across settings and over time (Kay, 2013). There is no globally recommended appropriate rate of hysterectomy against which to compare Indian trends. However, experience in other settings suggests that national surveillance and medical audits can evaluate appropriateness of the procedure and monitor misuse, as well as support development of clinical guidelines (Dyck et al., 1977, Hansen et al., 2008). Most critically, a rights-based approach to women's health is essential to promote high quality prevention and treatment choices for women through the life cycle, rather than 'permanent' but potentially inappropriate solutions.

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