

Infertility in Uganda: a missed opportunity to improve reproductive knowledge and health

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Introduction: Fertility care is an important unmet need in sub-Saharan Africa and considered low priority by donor countries and agencies. Understanding the social context of infertility may increase effectiveness of reproductive health programs.

Methods: We conducted a cross-sectional study of fertile and infertile women in Kampala, Uganda, evaluating reproductive knowledge, quality of life (QOL), and infertility-related social morbidity using validated instruments and survey techniques.

Results: QOL scores were lower than previously reported scores in Europe ($P < 0.001$). A majority of respondents (53%) reported that they would rather contract HIV than live with infertility. In all, 46.7% of women listed "family planning" or a reversible contraceptive as a cause of infertility. Reproductive knowledge was low, with only 16.7% of women able to give 3 accurate causes of infertility. Infertile women reported higher rates of interpersonal violence, but these differences were not statistically significant.

Conclusions: Infertility in Uganda decreases QOL comparably to other severe medical conditions and more than in prior studies. Common beliefs linking infertility to contraception may hinder implementation of family planning, though the infertility evaluation may help correct misconceptions. The connections between infertility, low reproductive knowledge, contraceptive uptake, and violence demonstrated here merit further study and may assist in designing culturally competent basic reproductive health programs in communities with limited resources.

Key Words: Fertility, Infertility, Contraception, Family planning, Patient counseling

Of an estimated 40 million couples who are actively seeking treatment for infertility, 34 million live in the developing world^[1]. In these settings, harsh social, emotional, and health consequences accompany childlessness. Indeed, data derived from multiple studies have found higher rates of psychological distress, including depression and anxiety, among infertile women, with the desire to achieve a live birth being an existential concern^[2-8]. Despite this reality, infertility in the developing world remains an understudied and neglected topic^[9-11].

In addition to the associated stigma and emotional distress, studies in South Asia and the Middle East have demonstrated that infertility can be associated with increased interpersonal violence (IPV) among

infertile women^[12,13]. In addition to domestic violence, desperation to achieve pregnancy may lead infertile women to pursue extra-marital sexual relations and other high-risk sexual behaviors, and indeed, multiple studies have shown an increased prevalence of HIV among infertile women in sub-Saharan Africa^[14-17].

Despite other pressing health and social priorities, infertility is among the most common reasons women obtain gynecology consults in Nigeria, Kenya, and other African countries^[18,19]. Unfortunately, few resources or trained personnel are available for patients, leading many to look for care outside the conventional, regulated medical community^[10]. Although fear of side effects is an acknowledged barrier to contraceptive uptake, we do not know which side effects are most concerning to women and there has been scant mention of any possible connections between fear of contraception and fear of infertility^[20]. Although fertility care is perceived as a lower priority by donor countries and organizations, tremendous efforts are exerted on addressing the unmet need for family planning to promote birth spacing and reduce unplanned and undesired pregnancies^[8,9]. Providing modern contraceptives to promote birth spacing and smaller family size advances current policy priorities, including those of the Sustainable Development Goals issued by the United Nations, as well as Family Planning 2020^[21].

In Uganda, as in much of sub-Saharan Africa, overcoming infertility is a critical need despite a high national fertility rate of 5.96 births per women in 2014, and a national health priority to increase uptake of family planning^[22]. Therefore, we sought to quantify the morbidity of infertility on quality of life (QOL) in Ugandan women and compare its perceived morbidity against an accepted health priority, HIV. We also sought to examine the knowledge and beliefs surrounding infertility, as well as its association with IPV and HIV prevalence.

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Methods

Study setting

The study was conducted in the public infertility and antenatal clinics at The Mulago National Referral Hospital in Kampala, Uganda between March and September 2013. IRB approval was obtained at both Makerere University and The Albert Einstein College of Medicine.

Study population

Females aged 20–45 who gave verbal consent to complete a survey while waiting to see a provider at the Mulago National Hospital were eligible for participation. Two groups of women were recruited. The first group, fertile women, was drawn from pregnant patients presenting to the antenatal clinic between March and July 2013, without any history of infertility. The second group, infertile women, was recruited from patients presenting to the infertility consultation clinic at Mulago National Referral hospital with a diagnosis of either primary or secondary infertility, defined as sexually cohabiting with a man for over a year without a conception. As this was a pilot study, without prior data regarding fertility knowledge and beliefs in the community, a formal power analysis could not be completed; however, we estimated that inclusion of 100 women in both the fertile and infertile groups would afford sufficient power to appropriately characterize these populations and compare our variables of interest.

Survey administration

After informed consent was obtained, questionnaires were administered in a private room adjacent to the clinic waiting area. A medical translator assisted women who were unable to read or speak English.

Survey design

The survey had 5 components. First, basic demographic information was collected, including HIV status, which is routinely assessed at both clinical sites. Second, a portion of the FertiQoL, a 36-item instrument for assessment of the impact of infertility on QOL, was utilized^[23]. In this instrument, each item asks the respondent to rank the impact of various consequences of infertility on a range of 0–4; 24 items measure impact on QOL in each of 4 domains (emotional, mind-body, relational, and social subscales), with the remaining 10 questions addressing fertility treatment. Subscale and total scores are generated, with higher values indicating better QOL. This instrument, the most widely used disease-specific measure for infertility-related QOL^[24], has been found to have strong internal consistent reliability, with Cronbach α values ranging from 0.72 to 0.92, and convergent reliability in 5 studies validating 28 different language versions. Only the nontreatment questions were utilized for this study.

Third, participants were asked to state their preference between “being unable to have children” or “contracting HIV.” Fourth, basic knowledge and beliefs surrounding the causes of infertility were assessed. Participants were asked to report their personal understanding of causes of infertility, with numbered spaces for them to list up to 3 most common causes of infertility, and a separate yes/no question of whether males can contribute to infertility. Finally, we measured the incidence of IPV using the revised Conflict Tactics Scale (CTS2), which has been validated to

assess the prevalence, type, and degree of IPV experienced by women^[25]. Participants also answered a series of questions about potential sources of other nonviolent social morbidity related to infertility.

Data analysis

Descriptive statistics were computed and compared between the infertile and fertile groups using the Student *t* test, Mann-Whitney *U*, Spearman ρ and Pearson χ^2 tests, as appropriate. Mean FertiQoL scores for each subscale, as well as the total mean score, were compared between the infertile and pregnant groups, and then between the Ugandan infertile group and published data of Dutch infertile women^[26], using Student *t* test. Preference for HIV versus infertility, differences in reproductive knowledge and beliefs, and experience with sex-based violence were analyzed using Pearson χ^2 test. All statistical analysis was performed using Stata version 12.1 (College Station, TX). Data were stored anonymously using unique alpha-numeric identifiers and maintained on a password protected computer.

Results

A total of 212 women were included for analysis, 108 infertile and 104 fertile women (Table 1). Participants in both groups were similar with regard to age and income. There were no differences in education or income, with the median reported income being equivalent to US\$4.38/day (> US\$ 14,000 in 2016). Fertile women were less likely to be nulliparous, and the 2 groups also differed with respect to education and religion. Infertile women were more likely to have completed a higher level of education and identify as Protestant, while fertile women were more likely to have completed a lower level of education and identify as Muslim. Among all participants, 12.7% were HIV-positive, with no difference between fertile and infertile women. Infertile women had received limited evaluation, particularly for male factor, as less than half of couples were able to complete a

Table 1
Participant demographics.

Variables	n (%)		P
	Fertile (N = 104)	Infertile (N = 108)	
Age (y)	27.9 ± 5.8	29.1 ± 5.0	0.10
Parity			< 0.001
0	30 (28.9)	58 (53.7)	
1	21 (20.2)	32 (29.6)	
≥ 2	53 (51.0)	18 (16.7)	
Education			0.03
No school	3 (2.9)	3 (2.8)	
≤ Primary	39 (37.5)	26 (24.1)	
≤ Secondary	50 (48.1)	52 (48.2)	
> Secondary	12 (11.5)	27 (25.0)	
Median income (USD)	1600 [800,2400]	1600 [800,2500]	0.98
Religion			< 0.001
Catholic	37 (35.6)	38 (35.2)	
Protestant	20 (19.2)	48 (44.4)	
Other Christian	19 (18.3)	11 (10.2)	
Muslim	28 (26.9)	11 (10.2)	
HIV-positive	15 (14.4)	12 (11.1)	0.47

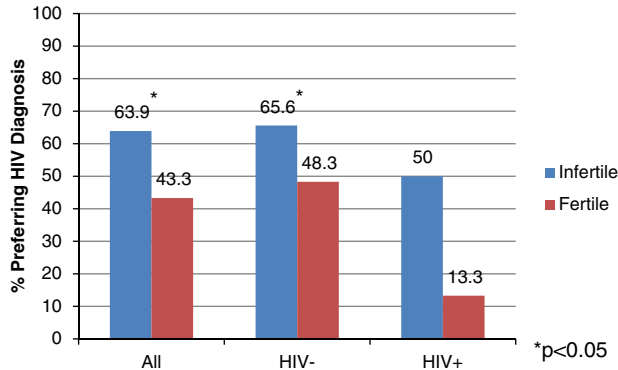


Figure 1. Preference for HIV over infertility diagnosis. Participants stated they would prefer an HIV diagnosis to a diagnosis of infertility.

semen analysis; however, the majority (68%) were diagnosed with tubal occlusion by hysterosalpingography.

Preference for HIV versus infertility

Among the whole group, 53.1% reported that they would rather be diagnosed with HIV than infertility. The fertile and infertile groups had a similar HIV prevalence (11% and 14%, respectively). When broken down by fertility status (Fig. 1), infertile women were more likely to state that infertility would be worse than being HIV-positive (63.9% vs. 43.3%, $P=0 < 0.01$). Among HIV-negative women, infertility was seen as less desirable than HIV, with 65.6% of the infertile participants stating that they would have preferred contracting HIV, as compared with 48.3% of fertile women ($P < 0.01$). Twelve women were HIV-positive and infertile, and of these, half expressed a preference for primary infertility over HIV, compared with 2 of the 15 fertile HIV-positive women, though this observation did not reach statistical significance ($P=0.087$).

QOL

Infertile women scored low in all 4 domains of the FertiQoL (Fig. 2). These results were significantly lower than scores

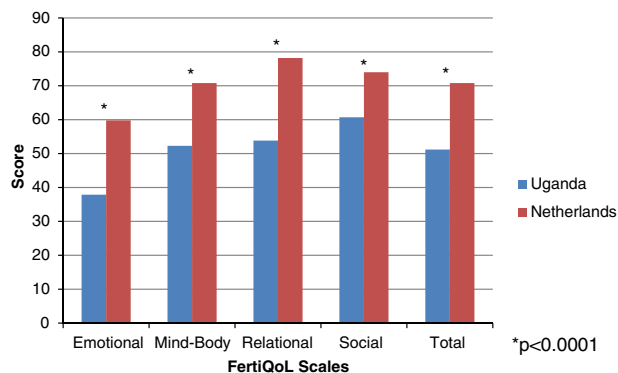


Figure 2. FertiQoL scores among infertile women in Uganda and the Netherlands. Baseline scores for the FertiQoL survey were obtained among infertile Dutch women as part of the initial creation and validation of this tool^[26]. This data is presented alongside the current data collected in Uganda.

Table 2
Fertility knowledge.

	n (%)		P
	Infertile	Fertile	
Listed 3 presumed causes of infertility	90 (83.3)	82 (78.9)	0.40
Listed 3 correct causes of infertility	31 (28.7)	4 (3.9)	0.001
Listed modern contraception	43 (39.8)	56 (53.9)	0.04
Contraceptive methods listed			0.34
Depo-Provera	22 (51.2)	20 (35.7)	
OCPs	3 (7.0)	3 (5.4)	
Implantable	0	1 (1.8)	
General family planning	18 (41.9)	32 (57.1)	
Listed male infertility in top 3 causes	20 (18.5)	4 (3.9)	< 0.001
Agreed males can have infertility	104 (96.3)	101 (97.1)	0.74
Listed infertility as natural, hereditary or God’s plan	25 (23.2)	49 (47.1)	< 0.001

OCPs indicates oral contraceptive pills.

reported from a Dutch cohort of infertile women, in both total scores (51.2 ± 13.0 vs. 70.8 ± 13.9), as well as in each subscale: emotional, (37.9 ± 14.3 vs. 59.8 ± 18.7), mind-body, (52.3 ± 20.3 vs. 70.8 ± 19.5), relational (53.8 ± 13.3 vs. 78.2 ± 14.5), and social (60.7 ± 17.9 vs. 74.0 ± 13.9), all $P < 0.0001$.

Fertility knowledge

When asked about causes of infertility, basic knowledge was extremely low. Although 81% of respondents provided 3 possible etiologies, only 20.3% of those respondents (16.5% of the total group) actually gave 3 medically accepted causes of infertility (Table 2). Forty-seven percent listed “family planning” or a specific modern reversible hormonal contraceptive among the 3 leading causes of infertility; 51% named “family planning” generally, 42% specified Depo-Provera injections, 6% oral contraceptives, and 1% specified subcutaneous, implantable contraceptives. Participants with a prior infertility consultation were more likely to provide accurate responses, compared with women with no history of infertility (28.7% vs. 3.9%, $P < 0.001$) and were less likely to report contraceptives as a leading cause of infertility (39.8% vs. 53.9%, $P=0.04$).

Similarly, infertile patients who had seen a medical doctor for infertility evaluation were more likely to list a male factor among the 3 leading causes of infertility (18.5% vs. 3.9%, $P < 0.001$) and less likely to report nonbiological causes such as “God’s plan” (23.2% vs. 47.1%, $P < 0.001$). Although few patients listed male factors among the top 3 causes of infertility, 65% stated that both partners should undergo an evaluation.

Psychosocial morbidity and IPV

The majority of women reported that infertile women were excluded socially and this perception seemed to be even more prevalent among fertile women than infertile women (89.4% vs. 78.7%, $P=0.03$) (Table 3). Despite this social exclusion, the majority of all participants (70.3%) felt that infertile women are emotionally supported by their male partners. The majority (64.6%) also felt that both partners would be willing to undergo evaluation, though this number was higher among the infertile women (71.3% vs. 57.7%, $P=0.04$). Over 90% of respondents in each group would want a medical evaluation if they

Table 3
Interpersonal violence and social morbidity due to infertility.

Question	n (%)		P
	Infertile	Fertile	
Has your partner insulted you?	25 (23.2)	22 (21.4)	0.87
Has your partner threatened you?	22 (20.4)	17 (16.5)	0.48
Has your partner physically hurt you?	14 (13.0)	11 (10.7)	0.61
If yes to any of prior 3 questions, related to infertility?	13 (44.8)	1 (4.6)	0.001
Has your partner raped you?	8 (7.5)	4 (3.9)	0.26
In sum, any abuse?	36 (33.6)	26 (25.2)	0.18
Does your partner have other female partners?	39 (36.1)	24 (23.3)	0.04
Are you having sex with other men?	8 (7.6)	0	0.007
Are infertile women socially excluded?	85 (78.7)	93 (89.4)	0.03
Are infertile women supported by their male partner?	79 (73.2)	70 (67.3)	0.35
Will both partners undergo infertility evaluation and treatment?	77 (71.3)	60 (57.7)	0.04
People would want diagnosis if no treatment available?	98 (90.7)	93 (89.4)	0.75
People would want diagnosis if they could not afford treatment?	93 (86.1)	99 (95.2)	0.02
How much would you spend for 50% chance of baby?			0.002
Not sure	8 (7.4)	8 (7.7)	
0–40	24 (22.2)	28 (26.9)	
41–200	42 (38.9)	23 (22.1)	
201–1000	25 (23.2)	18 (17.3)	
1001 +	7 (6.5)	11 (10.6)	
Any amount I could afford	2 (1.9)	16 (15.4)	

experienced infertility, even if treatment was unavailable or too expensive.

Although there was no difference in IPV, infertile women were more likely to report that their partner had sex with other women (36.1% vs. 23.3%, $P=0.03$). While no fertile women reported having sex with men other than their husband/partner, 7.6% of infertile women did. There was no statistically significant difference in the likelihood of suffering verbal abuse, threats, violence, or rape between infertile or fertile populations, 33.6% versus 25.2%, respectively ($P=0.18$), though in each case the absolute numbers suggested a higher prevalence among infertile women.

Discussion

Infertile women in Uganda experience severe social and emotional morbidity, which is underscored by the finding that a majority of women responded that it was worse to experience primary infertility than to be diagnosed with HIV. These responses are further supported by the finding of low fertility-related QOL when compared with infertile patients in European populations. Although our primary hypothesis utilized the initial Dutch validation cohort for comparison purposes, subsequent studies in European populations have also shown average FertiQOL scores higher than what we noted in the Ugandan population^[27,28]. Studies of infertile women in other developed nations, such as Korea, also showed lower distress than in our study^[29].

In isolation, these findings may appear unfortunate for infertile women in Uganda given the lack of resources or support from donor countries or agencies for providing fertility evaluation and treatment. However, given the commonly perceived association between infertility and family planning use among participants in our study, we suggest that a fear of infertility may be a barrier to contraceptive uptake among young women who desire future

pregnancies. Similarly, the increased incidence of extramarital relations among infertile couples may exacerbate the HIV epidemic as infertile couples with few options through conventional medical systems might seek additional partners to increase their chances of conceiving. Indeed, significantly more male partners of infertile women had extramarital affairs, and, even more striking, only the infertile women sought sexual relations with other partners. This finding echoes work done in Nigeria and Ghana that has similarly suggested that infertile individuals seek additional sexual partners^[30–32].

Patients who accessed infertility care were less likely to attribute contraception to infertility, suggesting that obtaining such consultation improves reproductive knowledge and may serve to disseminate this information to their communities. The consultation also raised awareness of male factor etiologies and decreased the role of superstition as it pertains to reproductive physiology. Research subsequent to ours in rural Uganda has demonstrated the persistence of myths relating to contraception and the need for improved education on this topic^[33]. Providing infertility training to providers and counseling to patients may reduce widespread community misconceptions around contraceptives and infertility and decrease patient resistance to performing semen analyses, thereby resulting in a broad improvement of reproductive knowledge and health relating to both fertility and contraception.

The paradox of increasing access to infertility care and decreasing population growth has been observed in many affluent countries^[9]. Furthermore, the overwhelming majority of respondents in our study reported that both partners would be willing to undergo evaluation, and they saw a benefit to receiving a diagnosis even without access to treatment, suggesting that reproductive health programs could offer education, consultation and diagnostic examinations as a first step until cost-effective treatments become available.

While we share the concern of policymakers who are hesitant to advocate for infertility coverage due to the cost of providing care and other more immediate health priorities, we must also give credence to the health priorities of the communities involved. The effectiveness of any public health campaign depends critically on willingness to understand and value the specific local cultural context. When communities do not trust or feel valued by a health care team, they are less likely to accept the recommendations of public health providers and experts, a phenomenon witnessed repeatedly across the globe.

The fact that we did not find any significant associations between IPV and infertility suggests that social morbidity may not routinely manifest in violence. Among the 36 infertile women who experienced IPV, however, 13 (36.1%) attributed the violence to infertility. A post hoc power analysis suggests that, given the prevalence of IPV in our study population, we would have had to enroll at least 3 times more women to uncover a statistically significant increase in any of these behaviors. Further, as our study population included only those women with resources and support to access infertility consultation at the national referral hospital, there is likely a selection bias toward those infertile women who have more supportive partners and social networks. Further work is needed to quantify and validate the impact of infertility on violent behaviors and physical trauma.

Although our study is the first to apply the FertiQOL in Uganda, and generates novel hypotheses, there are also limitations to this work. Although English is one of 2 official languages in the country, limitations in reading proficiency and health literacy could theoretically have generated misunderstandings. Although a medical translator was

available to assist as needed, some participants may not have answered completely accurately, particularly given that the interpreter was male, and interpretation may have been imperfect, especially at conveying colloquialisms or abstract concepts. In addition, though the FertiQOL, the most important measure in this study, is an established instrument, the other items are not as well-validated. Better tools to assess participants' thoughts on the sensitive topics broached in our work, namely fertility, IPV and sexual activity, may also improve accuracy. Finally, as we expected, many infertility patients could only access a limited medical evaluation, whereas a uniform experience for all participants in this group would have been preferable.

Infertility and its psychological and physical sequelae have been recognized by the World Health Organization (WHO) as a major public health concern. The long-term economic benefits of a desired and productive citizen may someday justify the costs of providing infertility treatments even in low and middle income countries^[34]. Further broadening of reproductive health programs to include infertility counseling may achieve a synergistic effect with other programs, not only improving QOL and reduce social morbidity for some women, but also enhancing communal reproductive knowledge and decreasing both unplanned pregnancies and HIV/STI transmission.

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Conflict of interest disclosures

The authors declare that they have no financial conflict of interest with regard to the content of this report.

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