ORIGINAL RESEARCH ARTICLE

Rates and determinants of HIV-attributable mortality among rural female sex workers in Northern Karnataka, India

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Summary: Female sex workers (FSWs) have among the highest rates of HIV infection in India. However, little is known about their HIV-specific mortality rates. In total, 1561 FSWs participated in a cohort study in Karnataka. Outcome data (mortality) were available on 1559 women after 15 months of follow-up. To gather details on deaths, verbal autopsy (VA) questionnaires were administered to key informants. Two physicians reviewed the VA reports and assigned underlying causes of death. Forty-seven deaths were reported during the follow-up (overall mortality rate was 2.44 per 100 person-years), with VA data available on 45 women. Thirty-five (75.6%) of these women were known to be HIV-positive, but only 42.5% were on antiretroviral therapy (ART). Forty deaths were assessed to be HIV-related, for an HIV-attributable mortality rate of 2.11 deaths per 100 person-years. Absence of a current regular partner (incidence rate ratio: 2.79; 95% confidence interval [CI]: 1.39–5.60) and older age (1.06; 1.01–1.11) were associated with increased HIV-attributable mortality. Reported duration in sex work was not related to HIV-attributable mortality. We found a high HIV-related mortality rate among this cohort of FSWs; nearly 10 times that of national mortality rates among women of a similar age group. Older age, but not reported duration in sex work, was associated with increased mortality, and suggests HIV acquisition prior to self-reported initiation into sex work. Despite significant efforts, there remain considerable gaps in HIV prevention near or before entry into sex work, as well as access and uptake of HIV treatment among FSWs.

Keywords: HIV, female sex workers, India, mortality, mobility, risk

BACKGROUND

The HIV epidemic in south India is mainly driven by heterosexual transmission, with unprotected paid sex work contributing significantly to the ongoing epidemic.[1–4] Female sex workers (FSWs) have among the highest rates of HIV in India, with recent sentinel surveillance data estimating an overall prevalence of 5.1%, but ranging as high at 59.2% among FSWs in some areas.[5] Karnataka, a state in south India, has an estimated HIV prevalence among FSWs of 16.3%.[6] Despite an understanding of increased HIV vulnerabilities associated with sex work, little is known about the differential mortality rates among FSWs.

In Karnataka, there is a particular form of traditional sex work that is associated with the *Devadasi* tradition.[7] The *Devadasi* tradition, centred in several northern Karnataka districts, dates back several centuries and involves the dedication of young girls through marriage to different gods. Girls were traditionally required to perform various temple duties, including the provision of sexual services to priests. Over time, the practice has become more commercialized, but sex work associated with the tradition is socially accepted and culturally sanctioned.[7,8] *Devadasi* sex workers, in contrast to other FSWs, more commonly report initiating sex work at a younger age and migrating outside their home state for sex work, characteristics which potentially increase their vulnerability for acquiring HIV.[4,7]

Migration is a significant feature of the *Devadasi* tradition.[4,7,8] *Devadasi* FSWs from northern Karnataka migrate to nearby southern Maharashtra for sex work. Most sex work engaged in by *Devadasi* FSWs in Maharashtra is brothel-based,[9] whereas most *Devadasi* FSWs who stay in Karnataka work out of their homes.[4,6,7] There is evidence to suggest that HIV prevalence among brothel-based sex workers is greater than home-based sex workers.[6,10]

Antiretroviral therapy (ART) can dramatically decrease morbidity and mortality related to HIV.[11–13] The government of India began rolling out free ART services in 2004. By 2009, it was estimated that 45.3% of adults requiring ART were receiving it.[14] Despite tremendous efforts in the scale up of therapy, there remains a significant gap in the coverage of ART. Further, there is evidence to suggest that despite a significant burden of disease among FSWs, these women are not accessing ART through the government programme due to a number of individual, societal and structural level barriers.[15,16] Specifically, concerns include stigma and discrimination, and the potential social and economic consequences resulting

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from disclosure of HIV status. Consequently, FSWs tend to postpone initiating ART until they are quite ill. This has serious implications from both a public health perspective, in terms of onward HIV transmission, as well as for the wellbeing of the FSWs.

As part of a prospective cohort study of FSWs in a region with longstanding *Devadasi* traditions (the *Payana* cohort, meaning 'journey' in the local language Kannada), we sought to measure the rates and determinants of HIV-attributable mortality in this population.

METHODS

Study design

The *Payana* project was a prospective cohort study of FSWs in northern Karnataka. Following completion of the cohort study, structured verbal autopsy (VA) questionnaires were completed to gather details on deaths of participants.

Study setting and population

Using existing FSW mapping data of the rural areas in the three study districts (Bagalkot, Belgaum and Bijapur), 15 taluks (administrative areas within a district) with high percentages of migrant FSWs were selected. Within the selected taluks, 144 villages with large numbers of migrant FSWs were selected for recruitment of cohort members based on the presence of high numbers of migrant FSWs. Following validation of the mapping estimates of the FSWs population, a full listing of the FSWs in the sampled villages was conducted to develop a sampling frame. To achieve a target sample size of 600 migrant FSWs, all migrant FSWs were eligible. Selection of non-migrant FSWs was based on a target number from each taluk to achieve a total of 900, with a geographic distribution proportionate to the estimated size of the non-migrant FSW population by taluk. Only FSWs aged 18 years and above and actively practicing sex work were included in the cohort.

Data collection

Cohort study

The total cohort at inception consisted of 1561 participants: 643 migrants and 918 non-migrants. Written informed consent was obtained, and detailed questionnaires were administered by trained community researchers in *Kannada*, the official language of Karnataka state. Baseline and follow-up questionnaires collected information on the women's sociodemographic characteristics, mobility/migration pattern, sexual behaviour and exposure to intervention both in the village of origin and the places of destination, HIV knowledge and risk perception. The cohort study was conducted between January 2008 and November 2009. Baseline and follow-up data are available for 1561 cohort members. Interviews were conducted at baseline, three, nine and 15 months. Of the 1561 women enrolled in the study, outcome data (mortality) were available on 1559 women by 15 months of follow-up.

Verbal autopsy

If participants were lost to follow-up, the study team identified the reason for loss to follow-up through discussions with family members and friends. Overall, loss to follow-up was minimal, and the reason for dropout was ascertained in all but two cases. A list of participants who had died during the follow-up period was compiled upon completion of the study. Further information was obtained on the deaths of the participants by use of a structured VA questionnaire.

During the study period, 47 deaths were reported, with data missing for two persons (4.3%). The study team identified the individual who served as primary care-giver prior to the cohort participant's death. Trained interviewers administered a structured VA questionnaire to the primary care-giver, following informed consent. If the primary care-giver was unavailable, a close neighbour or friend was interviewed. In addition, the community health worker who worked closely with the participant during the cohort study was interviewed with a second VA questionnaire, to ascertain further details. The study team conducted the VA component of the study between May and July 2010.

Data were collected on signs, symptoms and health-care-seeking behaviour in the weeks prior to the deaths. The VA questionnaire was based on a modified version of a previously published tool.[17] Two independent physicians determined if the underlying cause of death was HIV-related (probable, uncertain, unlikely). Discrepancies were resolved by consensus between the two physicians. Deaths due to injury incurred in the two weeks prior to death or direct maternal deaths were classified as non-HIV related.

Statistical analysis

To assess determinants of HIV-related mortality in this cohort during the measured follow-up period (from baseline interview to approximate date of death), we conducted univariate and multivariate Poisson regression (after assessment for over-dispersion). If the approximate date of death was not available from either the primary or secondary key informant, we used the midpoint between the most recent interview and scheduled interview when the participant was identified as lost to follow-up by the original study team.

Ethical considerations

Ethical approval was obtained from the Institutional Review Boards of the University of Manitoba, Winnipeg, Canada and St John's Medical College and Hospital, Bangalore, India.

RESULTS

The *Payana* cohort consisted of 873, 437 and 251 women from Bagalkot, Belgaum and Bijapur districts, respectively. The median age was 26 years (range 18–55), while the median number of reported years selling sex was nine (range 0–34). Over 80% of women were illiterate, and at entry into the cohort, 1371 women (87.8%) reported moving within or between districts for sex work. Almost all of the women self-identified as Hindu (97.9%), and the majority (73.8%) was *Devadasi*. Fifty percent of women with complete follow-up reported HIV testing during the study period, with 86.1% ever tested for HIV by study completion.

A total of 47 deaths occurred over 15 months of follow-up, with complete follow-up available for 99.9% of women ($n = 1559$).

This represents a mortality rate of 2.44 per 100 person-years for the total cohort, and 1.91 per 100 person-years for women aged 25–34 years. VA data were available for 45 of these participants, with primary and secondary key informant interviews completed for 42 and 43 of these participants, respectively.

Causes of death and descriptors of illness are shown in Table 1. Over 75% of the deaths occurred in the participants' home villages, with the majority of deaths occurring at home. Most of the women with VA data (83.3%) had disclosed their HIV status to their primary care-givers, and almost 60% had disclosed their status to their community researcher. Thirty-five (75.6%) of these women were known to be HIV-positive but only 42.5% of the 40 women were on ART. For these 35 women, informants reported that the deceased knew of their HIV status for a median of six months prior to death. Twenty-six of these women (74.3%) had accessed private clinics for care and support. Very few women (8.9%) belonged to a network of persons living with HIV/AIDS. Tuberculosis (TB) was very common among these women, with 75.6% reporting a history of TB.

VAs confirmed that 40 deaths were HIV-related, for an HIV-attributable mortality rate of 2.11 deaths per 100 person-years of follow-up. Among women aged 25–34 years, the HIV-attributable mortality was 1.46 per 100 person-years. Of the 40 women with HIV-related deaths, 27 had a recent history of TB. In addition, a number of other AIDS indicator conditions were present, including significant weight loss, diarrhoea and oral thrush. Despite significant illness, six women had not sought any medical care. The reasons cited by the informants included distrust of physicians, lack of knowledge on where to access medical care, the cost of treatment and the lack of a friend/family member to accompany them (data not shown). Thirty-nine of these 40 women were actively engaged in sex work within the three months prior to death, and 19 (42.2%) had a lover who was also ill (data not shown).

Table 2 shows determinants of HIV-attributable mortality among participants. On univariate analysis, older age and the absence of a current regular partner were significantly associated with mortality, whereas anytime migration showed a trend to increased risk, and having at least one child at home

Table 1 **Causes of death, descriptors of illness and HIV-related care, among the 45 study participants on whom a verbal autopsy was completed**

	n	%
Death occurred at		
Hospital	11	26.2
Home	29	69.1
On way from hospital	2	4.7
Died in home village	34	75.6
Disclosed HIV status		
Primary key informant	35	83.3
Community researcher	25	58.1
Known HIV-positive	35	75.6
On ART	17	37.8
HIV care (if known HIV-positive)		
Government ART centre	16	45.7
Private clinic	26	74.3
Pharmacy	16	45.7
Community care centre	7	20.0
AYUSH	5	14.3
Quack	3	8.6
Prior or current tuberculosis	34	75.6
Immediate/underlying cause of death		
Injury	2	4.4
Direct maternal	1	2.2
Other (non-HIV related)	2	4.4
HIV/AIDS (probable)	40	88.9
Tuberculosis	27	–
Clinical features		
Herpes zoster	30	66.7
Moderate to severe weight loss	40	88.9
Cutaneous abscess	8	17.8
Oral candida	24	53.3
Diarrhoea	31	68.9
Illness leading up to time of death	42	93.3
Place of seeking treatment during illness (*n* = 42)		
No medical care	6	
Government care facility	31	
Private facility	38	
Sangha/NGO	13	
Pharmacist	25	

NGO = non-governmental organization, ART = antiretroviral therapy

Table 2 **Association between selected characteristics and HIV-attributable mortality rates among female sex workers in northern Karnataka, India**

Characteristics	Total *n* (%)	Incidence rate ratio	95% CI	*P* value
Age (years)	–	2.24	2.12–2.37	<0.001
Illiterate	1260 (80.7)	1.23	0.48–3.13	0.67
Home district				
Bagalkot	873 (55.9)	Ref.	–	–
Belgaum	437 (28.0)	2.01	1.05–3.87	0.04
Bijapur	251 (16.1)	0.77	0.26–2.27	0.64
Marital status				
Ever married (yes/no)	390 (25.0)	0.87	0.41–1.82	0.71
Among those married (*n* = 390)				
Widowed	136 (34.9)	0.93	0.23–3.72	0.92
Currently married/ divorced/separated	254 (65.1)	Ref.	–	–
Denied a (current) regular sexual partner	755 (48.4)	2.86	1.42–5.71	0.003
Had ≥1 child (biological)	1136 (72.8)	0.56	0.30–1.04	0.07
Dedicated into sex work (*Devadasi*)	1155 (74.0)	0.95	0.46–1.94	0.88
Duration in sex work (years)	–	1.03	0.99–1.08	0.17
Mobility and destination				
Ever travelled to other district for SW	964 (61.8)	1.86	0.91–3.81	0.08
Travelled to *outside district* for SW during follow-up period	994 (63.7)	0.85	0.45–1.61	0.63
Travelled *within district* for SW during follow-up period	424 (27.2)	1.46	0.76–2.79	0.26
Ever gone to Mumbai for SW	213 (23.9)	0.74	0.25–2.21	0.60
First place of destination (Mumbai versus others)	169 (19.0)	0.41	0.10–1.74	0.22
Years since first travelled outside district for SW	–	1.02	0.96–1.07	0.51
Health-care visit (ever visited an NGO, private or government clinic) in home or destination site	1217 (78.0)	1.33	0.59–3.03	0.48
Exposure to HIV prevention programme (at least 1 peer educator visit) in home or destination site	1243 (79.6)	1.02	0.95–1.08	0.54

SW = sex work; NGO = non-governmental organization; CI = confidence interval

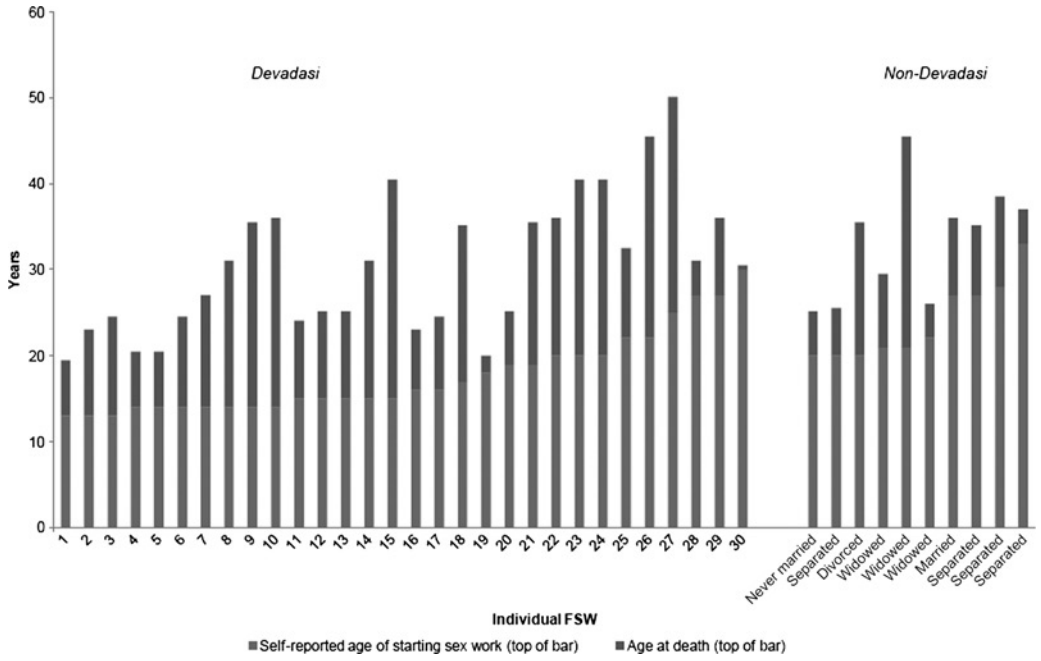

Figure 1 **Reported age of starting sex work and age at death (years)**

showed a protective trend. On multivariate analysis, absence of a current regular partner (incidence rate ratio: 2.79; 95% confidence interval [CI]: 1.39–5.60) and older age (1.06; 1.01–1.11) were associated with increased HIV-related mortality. Interestingly, reported duration in sex work was not related to HIV-related mortality, even after adjustment for potential confounders (age, dedication into sex work, mobility, healthcare visit, exposure to HIV prevention programme). To further explore this, we examined age at entry into sex work and age at death (Figure 1). There are a mix of women who entered into sex work later in life and died shortly thereafter and women who may have been infected during sex work and died after a longer sex work career.

DISCUSSION

We found an overall mortality rate of 2.44 per 100 person-years, and an HIV-related mortality rate of 2.11 deaths per 100 person-years of follow-up among FSWs in northern Karnataka. To our knowledge, this is the first report of mortality among FSWs in India and, in particular, HIV-attributable mortality. Recent census data from India indicate that among women aged 25–34 years in southern India, where our study took place, the mortality rate is about 0.18 per 100 person-years,[18,19] more than 10-fold lower than the mortality rate among FSWs of a similar age. In a recent survey of cause of deaths in India among the general population, among women aged 25–34 years, 4.2% of all deaths were attributable to HIV;[19] in contrast, our study revealed that almost 90% of deaths among women in the cohort were attributable to HIV.

Older age and lack of a regular partner were associated with mortality. Lack of a regular partner may indicate lack of social and financial support, resulting in increased need for more active engagement in sex work. Of interest was that duration in sex work was not associated with mortality. The lack of a consistent relationship between duration of sex work and mortality is likely the result of heterogeneity in the sexual life course of FSWs: some women may have been infected by their partner and enter sex work later in life, after their partner is ill or has died, whereas others become infected after starting sex work. In the latter case, HIV acquisition may result from unprotected transactional or non-transactional sex. There is also anecdotal evidence that among this community of *Devadasi* women, there may be a time gap between when a girl enters sex work and when she self-identifies as a sex worker. Unfortunately, data on age at first sex were not available from this study to determine the length of this time gap. Further study is required to explore the relationship between duration in sex work and HIV-attributable mortality, including measurement of HIV prevalence and uptake of ART by duration in sex work. We are conducting further research to understand this early time period in an FSW's life history and to understand when infections may be taking place.

Through the use of the VA questionnaire, cause of death was determined to be HIV related in 40 deaths. Although HIV testing was quite common among this high-risk group of women, it was often done quite late in their course of disease. Further, although disclosure of one's status was also common, very few women sought HIV treatment services. Despite the availability of free ART provided through the public health system in India, very few women in this study accessed services, and only did so only at a very late point in their illness. In addition, many women were reported to have been actively selling sex immediately prior to their deaths. Lack of treatment and late treatment during end-stage HIV infection can result in prolonged periods of time with very high levels of viral load, with increased potential for onward HIV transmission.[20] The majority of women who sought care accessed private clinics rather than receiving HIV treatment though the public health system. This is of concern because HIV care is not standardized in the private system, and is often not sustainable due to its associated cost.

There were several limitations of the study. Although not all women who participated in the study were accounted for at the end of it, retention in the cohort was excellent, with only 0.1% of women on whom mortality data were not available. Cause of death was not determined at time of death by medical practitioners, but through the use of VAs. However, we were able to conduct VAs for 45 of the 47 deaths, and VAs have been shown to be very effective tools in determining cause of death in resource-limited settings.[17,19,21–24]

FSWs constitute one of the highest risk groups for HIV infection. This study highlights the importance of ensuring that health-care services are appropriate and accessible for FSWs. Despite significant efforts and scale up of ART services in India in recent years, there remains a considerable gap in access and uptake of HIV treatment among FSWs. Innovative strategies and ongoing work is required to ensure that HIV prevention and care services are available for mobile and rural FSWs in India.

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