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Bearing the Stigma of HIV: Experiences and Coping Strategies in Southwest China

Gender Differences in Self-Reported Heart Disease and Multiple Risk Factors in India: Evidence from the 71st Round of the National Sample Survey Office, 2014

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## From the Editors

n important theme emerging in health services policy is that an individual's health – or lack of – is often attributable to

situations and circumstances far beyond his or her control. We now understand that low levels of education, unemployment, poverty and other socio-economic factors too often also equate with poor health and lower life expectancies. Policy makers seeking to address health inequities will need to look outside of the traditional boundaries of health services to arrive at solutions and strategies to address the issue.

As Marmot and Allen (2014) explain:

"To reduce health inequalities requires action to reduce socioeconomic and other inequalities. There are other factors that influence health, but these are outweighed by the overwhelming impact of social and economic factors – the material, social, political, and cultural conditions that shape our lives and our behaviors"

The authors in this issue of World Health & Population tackle the impact of health inequity with a series of international papers examining inconsistencies in care based on gender, political climate, disease state and birth place. Each paper identifies inequities that lead to poorer outcomes, and thus have important implications for health services planning.

The first article reports on the stigma experienced by many people living with HIV (PLWH) in Southwest China. Yu (2018) and his research partners conducted a qualitative study to look at the impact of

stigma on the daily lives of PLWH, as well as the strategies they use to cope with it. After interviewing PLWH and people in their close communities, the researchers found stigma was an extreme problem for most people. This, in turn, led to decreased self-esteem, and other symptoms including depression, anxiety and psychological distress. The researchers found that the families of PLWH were most often the major factor in stigmatization due to factors such as culture and lack of understanding. The researchers also found that educating families about HIV actually helped to reduce their intolerance. The researchers conclude with a call for the development of culturally tailored programs to help overcome HIV stigma.

In India, Sandeep G. and colleagues (2018) used data gathered in a national survey to look at gender differences in self-reported heart disease and risk factors. Their paper examines gender differences in the prevalence of heart disease in men and women, the attendant socio-economic and biological risk factors, and treatment options that both genders sought. Interestingly, they found that while men and women report similar prevalence rates, there are clear differences in the treatment they seek for their symptoms. Women tend to seek care at lower services levels such as private clinics and physicians, even though they tend to have higher levels of multimorbidity. Men, on the other hand, tended to seek care in private or public hospitals. Since private clinics and physician's offices rarely have sophisticated diagnostic facilities, it may be that the women who frequent them are not diagnosed and treated as accurately or successfully as men. The authors

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recommend further investigation to understand the differences in care-seeking between men and women with heart disease, and the policy implications.

In Brazil, Tovani-Palone (2018) describes inconsistent care provided to people with nonsyndromic cleft lip/ palate (NSCL/P), and some of the reasons that this disparity may occur. There are more than 200,000 people in Brazil with NSCL/P, many of whom have anatomic deformities involving the lip, alveolar ridge and palate. Treatment typically involves multiple surgeries and interventions throughout their lives. As Tovani-Palone describes, although Brazil has a unified health system, there is significant inconsistency in both health coverage and treatment in craniofacial centres across the country – resulting in significant inequity. The author calls for new policy to standardize practice among the various centres as well as increased focus on NSCL/P issues in undergraduate medical education. He also calls for monitoring of redistributed coverage and services to ensure health planners have the data necessary to improve quality of life for NSCL/P patients.

In a Southern area of India, Mony and his team (2018) examined the chronic problem of inconsistent reporting of low birth weights. Low birth weights are estimated for 30 percent of births. However, the authors report that this figure is consistently under-reported by government as 12%, which leads to mismatched resource allocation. As the researchers point out: "Lower birth weight babies experience poor outcomes, not only in terms of morbidity and mortality in childhood and adult life, but also in terms of education and earnings in later life." Because birth weights were under reported, eligible children were not receiving interventions they were entitled to which often lead to life-long difficulties. The researchers sought to address this

imbalance by creating a simple program for validating birth weights. Research nurses with training in proper infant weighting techniques, reweighed babies born in a range of health facilities approximately one day after their birth. Overall, the results showed significant differences in the weights reported by untrained personal compared to those with training. The authors suggested an easy remedy might be to replace the beam scales commonly in use with digital scales. They also recommended standardized training of healthcare personnel. Both measures would ensure more accurate birth weight reporting and concomitant improved flow of supportive resources.

The editors welcome your comments and insights on these or any article published in *World Health & Population*.

## - The Editors

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## Bearing the Stigma of HIV: Experiences and Coping Strategies in Southwest China



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## **Abstract**

Even as the number of people living with HIV (PLWH) is rapidly increasing in China, qualitative studies investigating the effect of HIV stigma on daily lives remain limited. The current study aims to fill this gap in research with attention to not only the experiences but also the coping strategies of PLWH in southwest China. We conducted 90 in-depth interviews in Guangxi, China. Our participants included both PLWH and individuals in their surrounding community (e.g., spouse, children,

health workers). Our interview data showed an intense manifestation of HIV stigma in domestic spheres. Other close community members (e.g., relatives, friends, neighbours) also worked both to discriminate against PLWH and simultaneously thwart possible stigma by association. By explaining how stigma affects both PLWH and their family members, the current study seeks to help both citizens and health practitioners better understand the effects of stigma on PLWH, their friends and their families.

## Introduction

Approximately 501,000 people living with HIV (PLWH) are currently reported in China (UNAIDS, MoH. 2015). In recent years, the trajectory of HIV has changed considerably, with the pharmaceutical advent of medical treatments, including antiretroviral therapy (ART), which prolongs longevity and improves the quality of life for those who are living with the virus (Kalichman 2000; Qiao et al. 2014). As a result, AIDS has become a chronic disease and stigma against PLWH has become an increasingly important issue. Thus, development of evidence-informed stigma interventions with cultural sensitivity will greatly benefit the mental and physical well-being of PLWH and their families. To design and implement such interventions, we first need an in-depth understanding of the very experience of being stigmatized.

Stigma is generally a response to social differences (e.g., class, race, gender) in the context of particular culture and power structures (Parker and Aggleton 2003). Stigma has long been studied in many fields, from psychology and sociology to anthropology. Most researchers have studied stigma in terms of diseases (e.g., leprosy, TB, HIV) and disabilities—chronic statuses that can affect individual identity through an experience of rejection (Krzban and Leary 2001; Miller and Kaiser 2001). In his pivotal work, Goffman (1963) defined stigma as a "spoiled" or devalued identity that discredits an individual. Jones et al. (1984) interpreted stigma as an unwanted attribute that is associated with a bias. Shamos and her colleagues (2009)

added a dynamic component to the perception of stigma – as a social process (stigmatization) that allowed labelling and distinction, which leads to discrimination, loss of status and decreased social power. Drawing upon these previous scholars, we understand the stigma of HIV as a dynamic social mechanism through which individuals with HIV become labelled, discriminated against and then must work at coping within a particular culture and power structure. Therefore, it is imperative to understand the specific social setting in which stigma is produced and reproduced.

Stigma can lead to a severe decrease in self-esteem (Crocket and Quinn 2000) and cause symptoms of depression, anxiety, decreased satisfaction with life (Link et al. 1997), psychological distress and self-hatred (Crandall and Coleman 1992). In particular, the stigma of HIV usually leads to social isolation (Fife and Wright 2000), psychological distress (Chaudoir et al. 2012; Morrison et al. 2002; Reichert 2007; Steward et al. 2008), problems adhering to medical treatments (Abadia-Barrero and Castro 2005; Castro and Farmer 2005), impaired quality of life (Greef et al. 2010; Holzemer et al. 2009; Jurgens 2004; Neely-Smoth 2003) and an increased likelihood of engaging in risky sex (Wegner et al. 1994). HIV stigma is usually extended to and shared by the families of PLWH as well (e.g., Haber et al. 2011; Li et al. 2008; Yu et al. 2016). This phenomenon is conceptualized as "courtesy stigma" (Goffman 1963), "secondary stigma" (Bond et al. 2003) or "association stigma" (Holzemer et al. 2007). Coping strategies to

overcome the stigma of HIV can vary, moreover, according to socio-cultural differences (Yoshioka and Schustack 2001).

Despite the fact that the PLWH population is rapidly growing in Asia, empirical studies of daily experiences and coping strategies for facing the stigma of PLWH have been concentrated in the West, limiting available data from low and mid-income countries such as China; a qualitative, in-depth understanding of lived experiences and daily coping strategies of PLWH has been scant. In addition, previous empirical studies exploring the experience of stigmatization largely drew upon quantitative approaches. The current study examines the experience of HIV stigma, drawing upon in-depth interviews with 90 people in the Guangxi province -both HIV-infected individuals and the people they are close to (e.g., spouse, children, health workers). Our field site presented an ideal site to examine the stigma of HIV, as the province currently ranks second in HIV prevalence in the nation, constituting a 30.12% increase since the end of 2009 (Guangxi CDC, 2011; Zhou et al., 2013).

Drawing upon the interview data, we explored local HIV stigmas, the experience of being stigmatized and individual coping strategies. Through our work, we sought to address the following three questions: First, what is the general attitude towards HIV and PLWH? Second, what are the daily experiences of HIV stigma among PLWH? And, finally, what are the coping strategies of HIV stigma among PLWH and their family members? A more comprehensive understanding of these vulnerable people's daily experiences could both contribute useful insights for future stigma interventions and enrich the literature around stigma by adding a China-based study.

## **Methods**

## Research site

This current study is a secondary analysis of data originally designed to study parental

HIV disclosure, a study which yielded much information regarding the experiences and perceptions of PLWH. The qualitative study was conducted in a province (Guangxi) in southwest China. HIV prevalence has increased substantially in the province since its first case in 1996 (Qi et al. 2013). Furthermore, Guangxi ranks second among China's 31 provinces in the number of documented HIV seropositive cases - and the epidemic is still growing steadily in the province (Zhou et al. 2013). As of October 30, 2015, Guangxi reported a total of 106,001 HIV/AIDS cases, which represented a 52.41% increase since June 2011 (69,548 HIV/AIDS cases) (Zhang 2014).

## **Participants**

We conducted in-depth interviews with 90 people in Guangxi, China, in 2012. To obtain a comprehensive understanding of HIV experience, our data were collected from multiple groups of people (e.g., HIVinfected individuals, their children, healthcare workers and community leaders). The number of participating parents who disclosed their HIV infection status to their children was equal to parents who did not. We interviewed 42 (46.7%) parents living with HIV, 20 (22.2%) children, 18 (20.0%) healthcare providers and 10 (11.1%) other community members. The majority of the participants were of ethnic minority (Zhuang) (70.0% vs. 13.3% Han majority). As to the household registration, 46 participants were from rural areas (51.1%), 31 were from suburban areas (34.4%) and 5 were from urban areas (5.6%) (8 [8.9%] were missing). Twentyeight participants were men (31.1%), 42 were women (46.7%) and 20 were children (22.2%) (Table 1). We interviewed the children who were knowledgeable about their parents' HIV status. The children's age ranged from 6 to 15 years old. Unfortunately, the routes of infection were not asked.

Table 1. Demographic characteristics of survey participants

Characteristics	п	%		
Composition				
Parents	42	46.7		
Children	20	22.2		
Healthcare providers	18	20.0		
Other community members	10	11.1		
Gender (adults)				
Men	28	31.1		
Women	42	46.7		
Geographic origin				
Rural	46	51.1		
Suburban	31	34.4		
City	5	5.6		
Missing	8	8.9		
Ethnicity				
Majority ( <i>Han</i> )	12	13.3		
Minority ( <i>Zhuang</i> )	63	70.0		
Missing	15	16.7		

## Study procedures

Our semi-structured interview guide was developed based on literature reviews, informal discussions with PLWH, local community leaders, healthcare providers and government officials. The final interview guide consisted of questions covering: (1) demographic information; (2) experiences related to HIV infection; (3) resources used or perceived to be of need and (4) personal preference for HIV interventions. We received IRB approval from Wayne State University, USA, and the Guangxi Center for Disease Control and Prevention (CDC) in China.

To ensure confidentiality for these vulnerable people, we conducted all interviews in a private room at a local CDC office in Guangxi. Each participant provided a written informed consent (parental informed consent and assent from children) before each interview. As our interviews were designed to be semi-structured, we were able

to inquire about interviewees' perceptions, experiences and attitudes towards PLWH in multiple realms such as stigma, disclosure, social support and coping strategies. Each interview lasted a minimum of 30 minutes. Each participant or parent-child dyad received 50 CNY (equivalent to US\$8) to compensate for their time.

## **Data Analysis**

All of the 90 interviews were audiotaped and transcribed. Data analysis followed the procedure outlined by Ryan and Bernard (2000): identifying themes, building codebooks, marking texts, constructing models and testing these models against empirical data. Preliminary coding started with reading and re-reading the Chinese transcripts by research team members. Coding themes were developed from the theoretical framework of stigma (Herek et al. 2009), and new themes emerged during the interviews as well as the coding process (Rubin and Rubin 1995).

In order to analyze the interview data, we adopted thematic content analysis (Green and Thorogood 2013). According to a coding directory, two team members first independently coded all transcripts before coding differences were discussed and reconciled. Detailed summaries with substantial retention of original quotes were prepared in English to facilitate further discussion and elaboration among both American and Chinese investigators. Quotes, excerpts, and summaries were then categorized by participant characteristics and coding themes; they were further compared and assessed for interrelationships and correspondence with coding and the theoretical framework (Rubin and Rubin 1995; Ryan and Bernard 2000). We used qualitative data analysis software (Dedoose) for coding, as it had some unique features that fit with our analytic plan and budget (e.g., more appropriate and effective for our team collaboration and data integration during

coding and analysis). Relevant quotes were then grouped together, which enabled us to develop interpretive memos (Saldana 2012) for a greater understanding of the stigmatic experiences of Chinese PLWH. We then conducted cross-case analysis (Hult et al. 2012) by discussing, comparing, and summarizing cases. Most of the research team members are fluent in both English and Chinese, so translations were often discussed among the team members to ensure the accuracy of the translations between the two languages. There is an equivalent and mostly accepted translation of "stigma" in Chinese (qishi).

## **Results**

## Local context of HIV stigma

HIV stigma was so prevalent in this region that, as in many other parts of China, people generally heard, observed and internalized the stereotype prior to getting infected with HIV. Our interviewees mentioned that the concept of HIV stigma was closely associated with high contagiousness and fatality, which makes people fear contact with PLWH. In addition, the locals presented the idea that PLWH somehow deserved suffering given the immoral behavior that caused the illness.

For example, a 39-year-old rural man who was HIV-positive commented, "People around me are usually afraid when they hear about this kind of disease [AIDS]. It's normal, because if they know you have the disease, they'll usually not interact with you." Another 39-year-old rural male patient added, "When you have a contagious disease, who'd not be afraid of contacting you!" Misunderstandings of the routes of HIV infection translate into stigmatization of PLWH. In many locals' minds, PLWH were immoral people who deserved their intense suffering. Often, PLWH first learned about the stigmatization from their local networks and thus predicted strong HIV stigma and discrimination against them.

## **Experiences of HIV stigma**

Indirect experiences of HIV stigma
According to our data, a clear sense of HIV
stigma usually developed from either
hearing or observing secondary experiences
of patients' peers or relatives. Many of our
participants observed intense HIV stigma,
which reinforced their internalized stigma of
HIV. The observed experiences were
expressed as "being neglected," "excluded"
and "displaced." For instance, a 33-year-old
rural woman pointed out that family was
not an exception in exerting HIV stigma,

... Anyway I have a friend, after he got the disease [AIDS], his family knew it and really treated him this way. When he ate, they wouldn't dare to eat together. He was 30 years old, used drugs, and his family isolated him. When eating, he ate by himself. He took a stool and went off to one side; and every time this happened he felt very lonely; during holidays he was especially lonely. When he spoke [about this], tears fell down.

Among our participants, such preemptive experiences were more prominent than first-hand experiences because many of them did not disclose their status. The examples and stories of their peers made PLWH feel depressed and confirmed their anticipation of strong stigma if their status was revealed. Consequently, these indirect experiences of strong HIV stigma against others shaped their coping strategy of concealment.

Domestic experience of HIV stigma
The most distinctive experience of stigma
among our participants was the intense HIV
stigma – exclusion and discrimination
– exerted by family members. The level of
stigma within families in the current study
was substantial; nearly every participant
who reported experiencing the manifestation of stigma discussed being discriminated

against and excluded by their families. A 33-year-old rural woman explained, "Everyone [in the family] ignores me, dislikes me a lot. My mother in-law even advised my husband to divorce me." A 37-year-old rural woman explained her lack of family support:

[The biggest difficulty] should be being ill, being sick with no one to help. At the time I got sick not a single person dared to stay with me; I couldn't walk, but I still had to grab and take medicine myself. At that time my brother said he'd ask my mom to come. Later they learned I had this kind of disease [AIDS], and my brother didn't even let my mom come to take care of me.

While HIV-infected people expressed their understanding of family members' discrimination, within the local context of strong HIV stigma, they also expressed disappointment at their loved ones' attitudes. A 35-year-old rural man expressed his loneliness saying, "I live alone in our court-yard. They [family members] all moved out. Whoever was able moved out, and kept away from me."

In particular, encounters with exclusion in daily activities, such as sharing meals and utensils, space/housing sharing, chatting, shaking hands and family gatherings were frequently mentioned in our interviews as especially painful experiences for PLWH. A 28-year-old rural woman commented, "My clothes are washed in another washer, even clothes can't be cleaned together." In the families' eyes, the possibility of "polluting" or transmitting the fatal infection to other family members posed a threat to the fundamental unit of the society - making it necessary to isolate the infected individuals. A 39-year-old rural woman expressed her deep sense of isolation and exclusion originating from HIV stigma in domestic spheres:

Everyone in my family knows. But they don't understand this. Even when we have meals or something, no one dares to eat with me or include me. When they get married, they don't ask me to come. They bring out dishes and let me eat alone. I really feel very lonely, very uncomfortable!

Patients with HIV were indeed shocked, saddened and felt abandoned by close and personal rejections from those relationships that were once their most-trusted, intimate or romantic.

Ubiquitous encounters of HIV stigma While families are the primary source of stigma against PLWH, there were also other sources that motivate this stigma. According to our participants, friends, colleagues and neighbours were the quickest actors in rejecting and excluding PLWH. Close acquaintances were often the least ambivalent about ending the relationship while reinforcing HIV stigma in the region. For example, a 28-year-old rural woman infected with HIV said, "They [friends and colleagues] estranged themselves from me ..." A 36-year-old rural man also shared this idea, saying:

In the past I lived in the countryside and cut cane. We did it as a group. But later I got this disease [AIDS], and folks didn't engage with me in the group anymore. Now I don't grow cane. No one dares to be with you, people don't visit, you eat at home yourself. How can you do it without others? I have no way to grow cane, I mean. Things you can do by yourself, do it yourself. Don't be with others or work together, I mean.

Given this corroborating and sustained stigmatization from the community, very few

participants reported maintaining relationships with their friends and neighbours after their diagnoses.

HIV stigma exerted by medical practitioners was also reported; the health professionals in the area may be torn between following the social norm (i.e., HIV stigma) and acting on the basis of their professional role/knowledge. A 33-year-old rural woman complained about her doctor's discrimination against patients with HIV:

But doctors also discriminate against people with this kind of disease [AIDS]. They really do ... at the time I knew a doctor. She [doctor] said, "If it wasn't for my job, I'd certainly discriminate against you." ... I don't know why she talked like that at that time. I wanted to ask her then, but she's a doctor after all. I thought, then why are you still doing this. You want to do this, you shouldn't discriminate ...

A 34-year-old woman from a city also complained about the phenomenon saying: "Even some doctors, when they know you have this kind of disease [AIDS], they won't see you." Such HIV stigma enacted by health professionals both confused and upset patients with HIV profoundly. These responses indicate a need for further research into care providers' struggles with strong HIV stigma in China.

## **Coping with HIV Stigma**Coping strategies of PLWH

The great majority of our participants reported concealment as their predominant coping strategy, a strategy explicitly in response to the substantial level of HIV-related stigma in the region. A 39-year-old rural man said, "I dare not, dare not to talk to people ... If everyone knew that I have AIDS, they wouldn't want to deal with me, and if they don't want to interact with me, my life will be over!"

One concealment strategy was to misinform people regarding their illness. A 38-year-old rural woman attempted to thwart stigma by (mis) representing her illness as something other than AIDS:

They don't know I have AIDS. When I take medicine, I don't want to let them know and I take it secretly. If they see me and ask why I take the medicine, I say my throat hurts because my voice is not good, I need a surgery but have no money. I want to take my medicine, but I don't tell people I take AIDS medicine.

The most concerning issue among the PLWH was the way its stigma extends to their children. Efforts to protect their children from possible HIV stigma by association catalyzed concealment strategies and made this concern the dominant motive among our participants. The strategies included hiding HIV infection from the children themselves, as the parents were concerned their children may accidently reveal their parents' infection to peers. Female patients were also worried about losing custody once their infection was revealed.

It is worth mentioning that, other than concealment, some participants took a more adaptive coping strategy to normalize HIV and PLWH. For instance, a 37-year-old rural man mentioned that he had a more proactive perspective to decrease HIV stigma: "I advocate for propaganda, disseminate more vigorously, let everyone understand this kind of disease is not fearful at all and won't be contagious. This way we won't get supplanted or discriminated."

## Coping strategies of family members

HIV stigma was a critical issue for families of HIV individuals as well as for HIV-infected individuals themselves. Our participants made it clear that their families had experienced extended HIV stigma

by association. Intense HIV stigma in the region often forced the family members and relatives of PLWH to distinguish their health status from the patients and thus prevent themselves from the possibility of extended HIV stigma. In this sense, family members became active agents in crystallizing stigma in daily lives. Only a few participants mentioned that their families were appropriately educated about HIV (e.g., routes of infection) and continued the close relationship with them; they also added that the level of HIV stigma in domestic spheres (e.g., exclusion) also depended on their previous relationships and individual context (e.g., only child).

The children who were aware of their parents' infection largely chose a concealment strategy for avoiding association stigma as well. In particular, they were most concerned about the possibility of exclusion from their peers. Depending on age, the children had heard of negative social discourse about HIV and tended to be distressed at the prospect of relatives or neighbours judging their parents. For instance, a 14-year-old rural girl commented:

A schoolmate wanted to play at my home, so I said I didn't have time this week or gave other excuses ... [cry] ... Since my junior-high years, I have known my dad was like this; I didn't want to let my classmates know. [cry] ... When I was in class, my dad came to see me and asked me to come out. I don't know if my classmates would ask me something ... Classmates could ask, and I don't know how to answer them [cry]. They may ask who it was, and what he came for ... So I don't know how to answer the questions. And a classmate may look at me with unusual sight [cry].

A 16-year-old son of an HIV-infected parent from a rural area pointed to

association stigma saying, "No one knows. I can't tell. If I tell, people won't interact with my family, even kids will be criticized." Another 16-year-old son of HIV-infected parents also commented on concealing his parents' illness saying:

I can't tell others about the disease. If you do, they'll look down upon your family. Even a little kid won't play with you. How can you dare to say? You can't talk about this kind of thing ... If you got a disease like TB and tell others, they might help you a bit, but this kind of disease, people will distance themselves from you.

The considerable degree of HIV stigma realized by family members may be rooted in the familism prominent in Chinese culture. Family members (e.g., grandparents) of our participants often took the children of the HIV-infected individuals from their parents to protect the future generation from those deemed "extremely contagious." Beyond having to cope with losing their children, critical support was also lost as the children did not generally hold or exert stigma against their HIV positive parents and expressed pain because of their illness.

## **Discussion**

In this paper, we have demonstrated that PLWH in southwest China suffer substantially from HIV stigma exerted by close community members. In particular, given the dominant concealment strategy, the dynamic process of HIV stigma in domestic spheres represents the manifestation of HIV stigma in the daily lives of PLWH in China. Because the concept of HIV stigma in the region was closely associated with high contagiousness and fatality, which led to fear and exclusion of PLWH in the community, intervention programs should focus on stigma reduction through spreading knowledge of HIV. At the same time, they

will need to address the prevalent practice of blaming infected individuals by dismantling the understanding of HIV infection as a result of immoral behavior.

The current study indicates that family dynamics are a key component when examining the mechanism of HIV stigma. Some researchers have suggested culture as an important factor in determining the level of HIV stigma in a location. They argued that HIV stigma was stronger in Asian cultures because of the traditions of collectivism and familism (Chin and Kroesen 1999; Mason et al. 1995). As a result, PLWH in Asia usually conceal their infections to protect their families from shame and stigma, as it extends to the family and the larger local community (Yoshioka and Schustack 2001). Some previous studies also found that family members who took care of HIV-infected individuals suffered from stigma, such as ostracism, rejection and loss of friends (Scott 2009). As a result, families of PLWH were generally afraid of extended stigma (Bogart et al. 2008). A few studies conducted in other parts of China also showed that families of PLWH felt shame and humiliation (Songwathana and Manderson 2001), experienced exclusion from their neighbours (Alubo et al. 2002; Busza 1999) and felt stigma-driven shame towards HIV-affected families; this led to the families' social networks shrinking (Li et al. 2008). In the context of southwest China, which has a strong tradition of familism, an individual member could very likely bring shame and HIV stigma to the whole family.

However, the extended stigma of HIV problematizes a helpful link to aiding PLWH, as family can be the best source of social support for HIV-infected individuals in the cultural context of familism. Thus, outreach programs for the families of patients with HIV should be perceived as critical in the region. Previous studies have pointed to the positive effects of family support for patients with HIV. For instance, supportive

relationships with family members could reduce the level of HIV stigma that patients face (Lee et al. 2002) and families are the most important resource for female patients (Lekganyane and du Plessis 2012). In the same vein, the few cases of reduced HIV stigma within families among our participants indicate the possibility of alleviated HIV stigma in China. In addition, PLWH who are ostracized by their family have a higher level of internalized stigma and tend to have severe anxiety-related symptoms (Lee et al. 2002). Compared to other cultural contexts, the prevalence of families excluding HIV-infected family members as a proactive strategy to thwart extended HIV stigma seems considerably high in the Chinese cultural setting with its strong tradition of familism. Thus, the development of outreach programs targeting families is urgently needed.

Furthermore, culturally tailored programs need to be designed and implemented so that healthcare providers can completely overcome HIV stigma in the region. Some of our interviewees suggested that people in the region highly respected the opinions of medical doctors and commented that it would be very useful if these professionals talked to families. A few interviewees also mentioned positive effects of media, propaganda and education. Consequently, an effective HIV stigma reduction program will need to include various parties such as medical practitioners, health workers and schoolteachers.

While concealment appealed to the majority of our PLWH participants as the most feasible strategy in the social context, it posed various difficulties in the process, such as psychological distress, emotional hardship and mal-adherence to medicine regimens. Simultaneously, the fear of HIV stigma made people withdraw from possible social interactions and alienate themselves further, often leading to critically inadequate amounts of social support (Herek 1999; Holt et al. 1998). Our interviews indicated that

networking with other patients with HIV helped PLWH to normalize their disease and provided a certain level of relief. Because concealment of HIV infection usually leads patients into an isolated state (Herek 1999), creating a support system for PLWH seems necessary. A few studies have suggested the positive effects of networking among patients with HIV (e.g., Makoae et al. 2008), such as reducing the level of stigma (Lee et al. 2002); men who have sex with men (MSM) often have support networks and experience reduced levels of stigma as a result (Lichtenstein et al. 2002). PLWH in southwest China are also in need of help in forming their own networks. HIV stigma intervention programs in the future will need to focus on creating a strong support network for this marginalized population.

Loss of employment and a lack of social support further exacerbate the negative psychological effects of stigma (Altman 1986). Adequate social functioning and support has been shown to be vital for the healthy development of all human beings (Simon 2002). HIV-affected people often face economic difficulty, especially given the lack of support from their families and their societies (e.g., insurance, employment). Patients with HIV tend to experience exclusion from economic activity and thus experience financial instability (Braveman et al. 2006; Martin et al. 2003). Free distribution of ART to patients with HIV who are unable to pay for treatment will help to eliminate a critical component of HIV stigma - fatal mortality - and thus diminish the public perception that HIV is a chronic disease.

Given the current substantial level of HIV stigma and that patients' preference for concealment and isolation is unlikely to change soon, we need to develop services that can ensure patient confidentiality. Our interviews showed that PLWH were very sensitive and did not feel secure, even at local CDC offices. To that end, the adoption of new technologies, such as mobile devices (e.g., cell

phone, internet, phone services) as a means of outreach services (e.g., reminders for medical adherence, tracing health conditions, information about welfare and networking) may be a useful way to closely monitor whether patients take their medicine as well as support their mental health in the context.

While these conclusions stand, we need to be cautious with interpreting the results of the current study because of several limitations. First, the current study was a secondary analysis of data that was originally designed to study parental HIV disclosure. Consequently, the data might not be comprehensive about different experiences of stigma and various strategies for responding to HIV stigma. As pointed out in previous studies (Crandall and Coleman 1992; Bunn et al. 2007; Lee et al. 2002), there may be varying levels of perceived stigma among individuals affected by HIV in China. Second, our sample in this rural area may not be representative of PLWH in other regions (especially big cities in China). Third, our interviews were subject to reporting or recall bias. Despite these limitations, the current study is one of the few qualitative studies on HIV stigma experiences among family members in China and thus provides important insights for possible intervention strategies. More studies that clarify the link between HIV stigma and risk and protective behaviors for intervention, are needed.

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## Gender Differences in Self-Reported Heart Disease and Multiple Risk Factors in India: Evidence from the 71st Round of the National Sample Survey Office, 2014



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## **Abstract**

This study examined gender differences in the prevalence of heart disease in India in terms of type of care sought and biological risk factors. The analysis included 142,620 people aged 30 and above from the National Sample Survey Office's 71st round of 2014. While men and women have the same prevalence of seven per 1,000 persons, using a form of prevalence odds ratio the analysis indicated that women were likely to seek care at lower levels of service provision, even though they carried a higher level of multiple morbidities. This difference is not because of the survival effect of women living longer with heart diseases when compared to men. It is possible that women with heart disease complicated by multiple co-morbidities have limited treatment options. Nevertheless, these constraints are not entirely biological and therefore whether these are a consequence of gender discrimination in care options needs further examination.

## Introduction

Cardiovascular disease is the leading cause of morbidity and mortality in South Asia in general (Yusuf et al. 2004). India, a major component of the South Asian region, has experienced rapid health transition, demonstrated by the increasing prevalence of chronic diseases (Yadav and Arokiasamy 2014). This process of transition can be seen with the shifting of the onset of cardiovascular diseases to younger ages, especially working ages in India (Chauhan and Aeri 2013; Prabhakaran et al. 2016; Srivastava and Mohanty 2013) and also increasing prevalence of Non-Communicable Diseases (NCDs) in rural areas (Joshi et al. 2006).

Gender differences in heart disease have been widely discussed (Maas and Appelman 2010; Milner et al. 1999; Möller-Leimkühler 2007; Ryan et al. 1994) and are an established fact globally. The social labelling of heart disease as a male or overtly masculine disease has led to ignoring the burden of heart disease among women (Emslie et al. 2001; Lockyer and Bury 2002). The exposure to endogenous oestrogen during the premenopausal period delays the onset of heart disease among women (Lerner and Kannel 1986) but this effect tends to taper off after menopause

and the risk of having heart disease becomes more or less the same for both men and women (Habib 2011; Prabhayathi et al. 2014). This natural protection for women from cardiovascular disease at younger ages results in relatively higher incidence of heart disease among men (Lerner and Kannel 1986). However, after the reproductive ages for women, the risk of developing heart disease is more or less similar for both males and females (Swiger et al. 2014). Some risk factors of heart disease, such as smoking and alcohol, are seen as predominantly male behaviours but recently the importance of non-traditional risk factors of heart disease in women, such as pre-term delivery, gestational diabetes, hypertensive disorders in pregnancy, etc., are receiving greater importance (Garcia et al. 2016).

Gender and sex are used synonymously in epidemiological and social science literature, but sex refers to factors that are biologically determined whereas gender explains the socially constructed norms, behaviours and attitudes. It is possible that women are not diagnosed with heart disease as frequently as men are because of the known biological differences. In addition to this, the risk factors are not same for men and women.

Women with heart disease tend to report more co-morbidities when compared to men and this causes difficulties in choosing treatment options (Möller-Leimkühler 2007). After middle age, women may experience a higher buildup of risk factors such as diabetes or hypertension which results in a complicated diagnosis for heart disease (Ramachandran et al. 2003). Women with diabetes mellitus may have a higher risk of cardiovascular disease, and women tend to have higher prevalence as well as less control of hypertension (Garcia et al. 2016). Women with coronary artery disease tend to report atypical symptoms when compared to men (Kumar et al. 2011). Gender-related factors also play a role in diagnosis and treatment for heart disease (Barrett-Connor 1997; National Heart Foundation of Australia 2011: Ramakrishnan et al. 2011).

Women seem to experience heart disease at younger ages with a burden of higher co-morbidity (Kalra et al. 2016). The process through which socio-economic disadvantages operate for long-term ailments are very different for men and women (Sen and Iyer 2012). Gender differences manifest in variations in economic status, marital status and position within the household including marital status. These characteristics affect purchasing power and thus health-seeking behavior and therefore health outcomes (Vlassoff 2007). Women are less likely to use household resources for their healthcare (Kumar et al. 2011). There is reason to believe that women receive less than optimal care in terms of guideline-directed medical prescriptions for cardiovascular disease when compared to men (Kalra et al. 2016). Marital status also affects men and women differently, and the burden of care-giving was found to increase the risk of coronary heart disease among married women (Lee et al. 2003; Eaker et al. 2007). The intersections of biology, socio-economic characteristics and systemic bias seem to produce gendered variations in men and women's experiences of heart disease (Wenger 2012).

It is imperative that the gendered nature of the disease experience, especially for heart disease that are endured life long and need continuous care, be explicated. With this perspective, the specific objectives of this paper are to examine gender differences in the prevalence of heart disease in India, the attendant socio-economic and biological risk factors and treatment options sought.

## **Data and Methods**Data sources

The required data were obtained from the National Sample Survey Office (NSSO)'s 71st round, 2014 "Social Consumption in India: Health." The NSS is a multistage sample survey conducted all over India during January-June 2014. It includes 333,104 individuals of all ages. The survey collected self-reported morbidity, hospitalization and healthcare-related expenditure details of all members of the selected households. Acute ailments had a reference period of 15 days prior to the date of survey and hospitalizations had a reference period of 1 year prior to the date of survey (NSSO 2015). There are 60 morbidity categories included under the NSS, and the category "Heart disease: chest pain, breathlessness" was used for this analysis of heart disease. These self-reported symptoms are indicative of heart disease but there is no means of directly establishing clinical disease from this data source. Moreover, they include congenital and rheumatic heart disease, but these conditions are likely to comprise a negligible proportion of this group. For this reason, we will refer to the reported heart disease from the NSSO data as "heart disease-like symptoms." The same disease category has been used by others to study heart disease in India (Karan et al. 2014).

## Methods

Individual unit level data were extracted from various blocks and merged to create the required data files for analysis. The analysis file included individual characteristics of those who were alive at the time of survey and those who had died during the reference period of one year prior to the date of survey and their reported morbidity. Those aged 30 and above were considered for the estimation of the prevalence of self-reported heart disease and its associated risk factors. The prevalence rate for heart disease (proportion of persons with heart disease) was calculated by including the morbidity status of those who had died.

A total of 142,620 persons including 1,919 who were dead were included in the analysis. There were 72,908 males and 69,712 females in the data set. The prevalence of heart disease by age-sex, marital status, educational status, caste, household size and expenditure class based on Monthly Percapita Consumer Expenditure of the household of the sick person were estimated.

The distribution of people with heart disease by gender, the type of treatment sought, the site of treatment and the experience of co-morbidities by sex were examined to identify variations indicative of gendered differences. To enable comparisons by gender, we have computed a form of prevalence odds ratio (POR) by specific characteristic/multiple morbidity for each sex.

The odds of people with heart diseaselike symptoms by care-seeking sites and multiple morbidity experiences for each level of a characteristic is standardized against the characteristic-free odds to express the effect of the specific characteristic. By characteristic-free odds, we mean the overall odds of using that health site for care or having the specific multiple morbidities with heart disease-like symptoms on the whole (regardless of any specific characteristic). Thus, the PORs for each care-seeking category/experience of multiple morbidity category as the ratio of the odds of seeking care/having multiple morbidities by age, marital status,

educational status, caste, household size and household expenditure against the overall odds of seeking care at that facility/ having that specific set of multiple morbidities for each sex was computed. These ratios, therefore, are not the conventional conditional ORs, but are averaged out across the population to render comparisons possible across multiple variables.

When making comparisons of effect modifiers on prevalence using cross sectional data both POR and prevalence rate ratios have been used (Thompson et al. 1998). This choice depends on the relevance of measure, its meaningfulness and the availability of appropriate software (Zocchetti et al. 1997). Here we preferred POR because they are a function of both the prevalence of the condition and the exposure (Osborn and Cattaruzza 1995; Zocchetti et al. 1997; Bhopal 2008). The exposure here represents the various socio-economic characteristics and existing co-morbidities. The effort is to examine the variation in exposure by sex and therefore we chose POR. In addition, PORs better demonstrate Incidence Density Ratios when dealing with chronic conditions (Zocchetti et al. 1997). This does not, however restrict confounding, but here PORs are being computed for each level of known confounders, viz. socioeconomic characteristics and experience of co-morbidities. Unknown confounders may still affect the PORs, but the aim of the exercise is to compute PORs across men and women and unravel the gendered nature of the outcomes.

Females in India live longer than males and that in itself could result in females living for longer periods with the disease. To further examine the possibility that there may be a variation in the life years lived subsequently with heart disease-like symptoms for men and women, Sullivan's method (1971) for adjusting years lived into two mutually exclusive states has been used. This serves to estimate the percentage of life expectancy lived with heart

disease-like symptoms to the total life expectancy for males and females. The product of the person years lived and the prevalence rate for each sub-group (agesex) provided the person years lived with heart disease. This product was used to estimate the expected years of life lived with heart disease.

## **Results**

## Prevalence of heart disease-like symptoms

The prevalence of heart disease-like symptoms by age and sex depicts a typical picture with increase in prevalence related to age (Table 1).

Overall, the prevalence of heart disease for men and women seems to be the same. The age pattern of prevalence shows an increasing trend by age as expected for both sexes. Women who were not currently married seem to have a higher prevalence of heart disease when compared to men in the same category (12 vs. 7 per 1,000). Not much variation in prevalence is seen by education status on household size. But, those belonging to other backward castes (OBCs) and higher caste groups have higher prevalence proportions for both men and women. Men in households with expenditure above the 60th percentile seem to have higher prevalence when compared to women.

Table 1. Prevalence (per 1,000 persons) of heart disease-like symptoms in India by background characteristics and sex, 2014

	Heart disease		
Background characteristic	Males	Females	Total
Age			
30–39	2	2	2
40–49	3	5	4
50–59	11	9	10
60–69	18	15	16
70+	24	24	24
Marital status			
Currently married	7	6	7
Others	7	12	11
Educational status			
Up to primary	8	7	8
Secondary	6	6	6
Higher secondary and above	7	6	6
Caste			
SC/ST	4	5	5
OBC	8	7	7
Others	9	9	9
Household size			
1–5	8	8	8
>5	6	5	5
Expenditure			
Up to the 60 <sup>th</sup> percentile	5	6	6
More than the 60 <sup>th</sup> percentile	11	8	9
Total	7	7	7

 $OBC = other\ backward\ caste;\ SC = scheduled\ caste;\ ST = schedule\ tribe.$ 

## Seeking treatment for heart disease-like symptoms

Treatment options do vary by sex with men more likely to seek allopathic care (modern medicine-based care, as defined by NSSO) when compared to women (Table 2).

A higher proportion of women seem to be seeking care using the Indian system of medicine or receive no care at all. Even when care is sought, men are more likely to seek care in better-equipped public or private hospitals when compared to women. Women tend to use public and private units that are more basic. However, women seem to carry a higher burden of multiple morbidities when compared to men. This extra burden of multiple morbidities including hypertension and diabetes mellitus could be a function of age. Therefore, we standardized the distribution of women with co-morbidities using the age distribution of men. The pattern of co-morbidities for women after standardizing using the male age distribution was 82.3% for heart disease only; 5.2% for heart disease and diabetes mellitus: 5.8% for heart disease

and hypertension and 6.7% for heart disease, diabetes mellitus and hypertension. Clearly, the level gets tempered but the pattern of higher burden of co-morbidities among women does not change.

The examination of gendered care using PORs for different levels of care by characteristics indicates that older women with heart disease are more likely to see an ancillary healthcare worker in the neighbourhood when compared to men. Currently, married men and women do not seem to vary by level of care sought for heart disease-like symptoms; women who are not currently married are more likely to use peripheral facilities such as health sub-centre (HSC)/primary health centre (PHC) or a private doctor when compared to similar men. Higher levels of education (higher secondary and above) for women facilitates the seeking of care at private hospitals. Women in scheduled caste/ schedule tribe groups seem to seek care in the better-endowed public and private hospitals when compared to men in the same group. Upper caste men are more likely to use private hospitals when compared to women in the same

Table 2. Distribution of people with heart disease-like symptoms by nature of treatment, level of care and experience of co-morbidities by sex, India, 2014

Treatment options	Males	Females	Total			
Nature of treatment						
Allopathy	97.6 (763)	95.4 (640)	96.5 (1,403)			
Indian system of medicine	0.4 (6)	1.0 (5)	0.7 (11)			
Homoeopathy	0.5 (5)	0.7 (9)	0.6 (14)			
Yoga and naturopathy	0.1 (1)	0 (0)	0 (1)			
No treatment	1.4 (14)	2.6 (7)	2.0 (21)			
Other	0 (2)	0.3 (2)	0.1 (4)			
Total	100 (791)	100 (663)	100 (1,454)			
Level of care						
HSC/AMN/AWW	0.5 (11)	0.4 (9)	0.5 (20)			
PHC/dispensary/CHC/mobile medical unit	2.5 (20)	3.7 (28)	3.1 (48)			
Public hospital	20.5 (181)	15.9 (143)	18.3 (324)			
Private doctor/clinic	34.5 (197)	39.3 (187)	36.8 (384)			
Private hospital	42.0 (350)	40.6 (268)	41.3 (618)			
Total	100 (759)	100 (635)	100 (1,394)			

AMN = auxillary nurse midwife; AWW = angan wadi worker; CHC = community health centre; HSC = health sub-centre; PHC = primary health centre. Note: Figures in parenthesis are an unweighted number of cases.

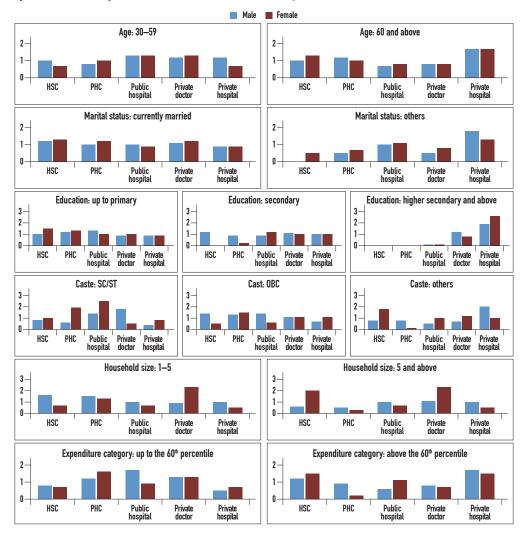
group. Care seeking for NCDs by women in larger sized households (>5 members) seems to be concentrated in smaller public sector healthcare units. When compared to men, women also seem to use individual private doctors across all household sizes, small and large.

Men in households whose expenditure falls below the 60<sup>th</sup> percentile are more likely to use public hospitals when compared to women. In households with expenditure in the higher percentile (>60<sup>th</sup>), women are more likely to use the public facilities and men use private facilities (Figure 1).

## Co-morbidities and heart disease-like symptoms

The POR for co-morbidities experience by characteristics are shown in Figure 2. In the younger ages, multiple co-morbidities seem to affect men but at higher ages (>60) women are more likely to be affected. The burden of co-morbidities of heart disease with diabetes mellitus and hypertension seems to be very high for women not currently married and also women educated up to higher secondary and above when compared to men in similar categories.

Figure 1. Prevalence odds ratio by characteristics for utilization of specific facilities by sex for self-reported heart disease, India, 2014

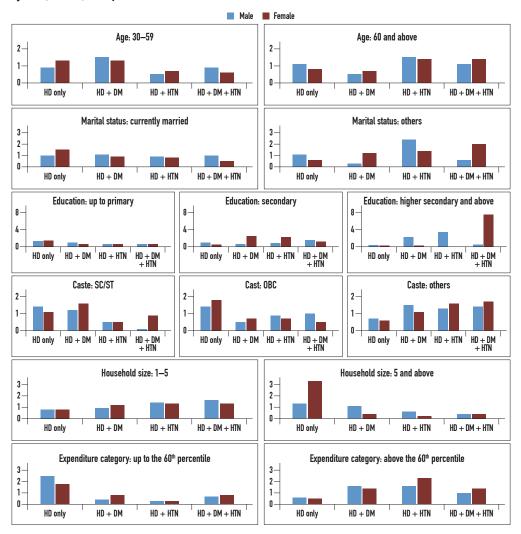


 $HSC = health \ sub-centre; \ OBC = other \ backward \ caste; \ PHC = primary \ health \ centre; \ SC = scheduled \ caste; \ ST = scheduled \ tribe.$ 

The burden of co-morbidities seems to be higher among men of mid-level castes when compared to women. Among the higher castes, the burden of multiple co-morbidities is higher for women. Women living in households with higher expenditure levels (>60<sup>th</sup> percentile) tend to carry the burden of co-morbidities to a greater extent when compared to men in the same group.

The burden of heart disease is more among women especially when one considers the added burden of co-morbidities such as diabetes and hypertension. Older women, currently not married, belonging to middle and upper castes, better educated and in better households carry a higher extent of this burden than their male counterparts. This should mean that such women would seek healthcare in settings with improved facilities such as public and private hospitals rather that HSCs or PHCs or private clinics. But this is not true. Men seem to use facilities providing a higher level of care and women seem to use basic healthcare facilities.

Figure 2. Prevalence odds ratio by characteristics for presence of co-morbidities with HD by sex, India, 2014



DM = diabetes mellitus; HD = head disease; HTN = hypertension; OBC = other backward caste; SC = scheduled caste; ST = schedule tribe.

The noted sex differentials noticed in the prevalence of heart disease by characteristics can be explained by the survival effect, wherein more women survive with heart disease compared to men. To check if indeed the survival effect among females affects the proportions of males and females with heart disease-like symptoms, the proportion of life years expected to be lived with the disease for males and females was computed using Sullivan's (1971) method for healthy life expectancy. Computation of the proportion of life expectancy lived with heart diseaselike symptoms to the total life expectancy using Sullivan's approach, enabled a comparison by gender of the expected duration to be lived with the disease. The person years lived at various age intervals is divided into the portion ascribable to disease state and the portion ascribable to diseasefree state. The years spent with the ailment is the product of years lived under various age groups and prevalence of ailments in those age-groups. The years the cohort is expected to spend in the disease state is computed by dividing the total person years spent in the disease state by the number of persons at the exact age.

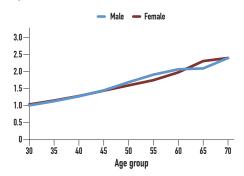
Figure 3 indicates the proportion of life years a person is expected to live with disease for males and females by age. While there is a difference in the duration of life expectancy with disease by age, males and females on an average live approximately the same proportion of their life expectancy with heart disease. The difference in the proportion of life years lived with heart disease by sex is marginal. It means females do not have an advantage over males with respect to living with heart disease-like symptoms. There could however be a sex difference in survivorship with diabetes and hypertension.

## **Discussion and Conclusions**

The study analyzed gender differences in the prevalence of heart disease-like symptoms

and its attendant risk factors and treatment sought using NSSO 71st round, 2014 data for India. Men and women reported the same prevalence rate for heart disease-like symptoms, with a marginal variation by age. The NSSO surveys identify heart disease based on certain symptoms. But selfreported morbidity is reliable in the case of chronic diseases (Dilip 2007). The category includes congenital and rheumatic heart disease, but the predominant condition in this category is likely to be ischaemic heart disease (Finegold et al. 2013). Allopathic medicine is the most accepted treatment for heart disease, but some of the PHCs/ dispensaries may have doctors from other medical streams. There are clear gender differentials in treatment seeking for heart disease-like symptoms. For instance, 2.6 per 100 women did not received treatment for heart disease when compared to 1.4 per 100 men. Women were more prone to seeking care at lower levels of service provision when compared to men, as the proportions seeking treatment from private clinics/ doctors or from PHC/dispensary were relatively higher for women and men were more likely to seek care from hospitals – both private and public. This suggests that women may have lesser access to proper diagnostic facilities such as angiography and treatment options such as fibrinolysis or angioplasty.

Figure 3. Percentage of life expectancy to be lived with heart disease-like symptoms by sex, India, 2014



While men and women have more or less similar rates of heart disease-like symptoms, the complicated presentation of multiple co-morbidities among women limits treatment options for them. The risk of heart disease in diabetic women is reported to be thrice that of diabetic men. Moreover, women are also reported to have lower levels of control of hypertension. (Garcia et al. 2016) It is possible that women live for longer durations with heart disease-like symptoms because of their survival advantage over men but that is not validated by the analysis. There is no gender gap in the percentage of years one is expected to live with heart disease. However, there may be gendered differences in the years a person is expected to live with co-morbidities, but that needs to be elucidated. The treatment options for women seem to be lower levels of healthcare when compared to men. This could be because of differences in presentation, diagnosis and treatment in health systems. Similar findings of higher burden of co-morbidities with cardiovascular disease for women combined with less than optimal care have been reported in the PINNACLE India study (Kalra et al. 2016). Peripheral healthcare units may not have the necessary means to deal with the complicated presentations of heart disease that women seem to have. There is also the probability of limited choice of drugs available at such facilities for tailoring adequate regimens for optimal control of these co-morbidities. Such constraints are not biologically determined and are indicative of the gendered nature of care options used by women. More explanations are needed to determine whether these are a consequence of gender discrimination in care options available to women. There is a need for sex-disaggregated data in health information systems

to monitor the gendered differentials in screening, treatment-seeking and potential outcomes for heart disease. More focused research on the gendered pathways of this experience and care-seeking for it are needed.

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## Treatment of Nonsyndromic Cleft Lip and/or Palate in Brazil: Existing Consensus and Legislation, Scope of the Unified Health System, Inconsistencies and Future Perspectives



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## **Abstract**

Cleft lip and/or palate (CL/P) are the most prevalent craniofacial birth defects in humans, affecting around ten and a half million people across the world and over three hundred thousand in Brazil. Of that, about 70% of the cases occur as a nonsyndromic form, while the remaining 30% are syndromic. In turn, individuals with nonsyndromic CL/P (NSCL/P) often have anatomic deformities involving the lip, alveolar ridge and palate. In this case, the treatments generally require multiple surgeries and various other health interventions throughout childhood, adolescence and adulthood. Another relevant point is that various problems regarding the treatment of NSCL/P in Brazil through the Unified Health System (SUS) have been reported. There are also many inconsistencies in this scenario, including the

territorial coverage of healthcare assistance from the craniofacial centres across the country. However, very little data can be found in the scientific literature about the current situation for the treatment of NSCL/P in Brazil. Thus, the present article discusses the existing consensus and legislation, the scope of the SUS, as well as inconsistencies and future perspectives related to the treatment of these craniofacial abnormalities at a national level.

## Introduction

One of the most common birth defects of the head and neck are the cleft lip and/or palate (CL/P). Such malformations affect approximately 1 in 700 live births worldwide, representing a major public health burden. The related etiology is complex and multifactorial, and is associated with an interaction between genetic and environmental factors (Freitas et al. 2012). In this context, there are contributions from several genes together with inadequate nutrition, use of some medications, exposure to ionizing radiation, viral infections, smoking, alcoholism, pesticides in food and physical or mental stress (Freitas et al. 2012; Tovani-Palone and Saldias-Vargas 2016).

It should be noted that about 70% of CL/P cases occur as a nonsyndromic form, without association to syndromes or malformations. The remaining 30% appear as a syndromic form, which are associated with genetic disorders (Mendelian or chromosomal), teratogenic and sporadic conditions (Freitas et al. 2012). These syndromic characteristics can interfere with the offered treatment, requiring higher demands and complexity for the healthcare.

In turn, individuals with nonsyndromic CL/P (NSCL/P) often have anatomic deformities involving the lip, alveolar ridge and palate. Treatments generally require multiple surgeries (Freitas et al. 2012; Palone et al. 2015; Tovani-Palone et al. 2017) and various other health interventions throughout childhood, adolescence and adulthood (Freitas et al. 2012).

Another aspect that is very important is that various problems regarding the treatment of NSCL/P in Brazil through the Unified Health System (Sistema Único de Saúde – SUS) have been reported. There are also many inconsistencies in this scenario, including the territorial coverage of healthcare assistance from the craniofacial centres across the country (Tovani-Palone et al. in press).

Notwithstanding, there are still very few data available in the scientific literature about the current situation for the treatment of NSCL/P in Brazil. Thus, this article discusses the existing consensus and legislation, the scope of the SUS, as well as inconsistencies and future perspectives related to the treatment of these craniofacial abnormalities at a national level.

## Consensus about the Need for Comprehensive Treatment of Individuals with NSCL/P

In 2002, groups of professionals of renowned centres for rehabilitation of individuals with CL/P, from all over the world, gathered in Geneva (Switzerland) with the support of the World Health Organization (WHO 2004).

On this occasion, they discussed new global strategies aiming to promote advances in offered treatments. The various adopted recommendations recognized the need for improvements in the quality of services for the treatment of NSCL/P, with a focus on the development of methodologies for monitoring and identification of strategies that maximize the healthcare access to appropriate levels (WHO 2004).

Several Brazilian authors (Custódio 2013; Freitas et al. 2012; Raposo-Amaral and Raposo-Amaral 2012), furthermore, have reinforced the need for multidisciplinary care for the treatment of individuals with NSCL/P as a strategy to promote improvements in the quality of life of this population group. In their view, healthcare must always be comprehensive, contemplating guidelines, reconstructive surgeries and various other procedures, such as orthodontics and speech therapy.

## Legislation for the Treatment of NSCL/P in Brazil

Currently, in Brazil there is still no specific legislation for the composition of healthcare teams and of their organizational model (if they are multidisciplinary, interdisciplinary, transdisciplinary or isolated).

However, the Ordinance SAS/MS n. 62/1994 of the Secretary of Health Care and Ministry of Health determines that all accredited hospitals performing integrated procedures for aesthetic and functional rehabilitation of individuals with NSCL/P should provide the following services: anesthesia, aesthetic and reconstructive plastic surgery, otorhinolaryngology, internal medicine, pediatrics, speech therapy, psychology, physiotherapy, nursing, social service, nutrition, general dentistry, pediatric dentistry, orthodontics, prosthodontics and implantology, oral and maxillo-facial surgery, and family care (Tovani-Palone and Bertolini 2017).

## Scope of the SUS for the Treatment of NSCL/P in Brazil

At present, healthcare in the SUS is divided into three hierarchical levels: high complexity, medium complexity and basic health attention (Custódio 2007, 2013). It is thus important to discuss the actions for the treatment of NSCL/P in this arrangement.

The high complexity level refers to the set of procedures in the context of the SUS, which involve high technology and high cost.

Its aim is to provide access to qualified services for the population, integrating them with other healthcare levels of this system. The procedures for the treatment of NSCL/P are contemplated in this care level (Custódio 2007, 2013) and they correspond to the specialized and specific procedures that are performed in outpatient and/or hospital regimen, especially surgical procedures (cheiloplasty, palatoplasty and alveolar graft).

The medium complexity level, in turn, comprises actions and services aimed at solving various problems and health disorders. To this end, the complexity of care in clinical practice involves the availability of trained professionals, as well as the use of technological resources to provide diagnosis and treatment. In this case, the treatment of NSCL/P is achieved through outpatient surgeries, actions in dentistry and speechlanguage therapies, prosthesis and orthosis, clinical pathology, anatomopathology and cytopathology, radiodiagnosis, anesthesia, diagnosis, physiotherapy, nutritional and psychological care (Custódio 2007, 2013).

In addition, the other care level, basic health attention, represents the first level of care in SUS (preferred contact of the users). It is guided by all the principles of this system, however, using low-density technology (Custódio 2007, 2013). Several actions can be performed for the treatment of NSCL/P in basic health attention, such as primary dental treatment, pediatric monitoring, periodic assessments of general health, treatment of recurrent diseases (recurrent otitis) and social assistance.

In view of all this, the implementation of Healthcare Networks would seem essential. According to the SUS legislation, such Networks are defined as organizational arrangements of health actions and services, with different technological densities, that are integrated through technical support systems, logistics and management intended mainly to provide guaranteed comprehensive care (Brazilian Ministry of Health 2010).

## Consensus about the Political-Territorial Organization of the Craniofacial Centres in Brazil

Another very relevant point of concern to the authorities is the political-territorial organization of the craniofacial centres in Brazil.

According to Trettene et al. (2014), there has been a decentralization trend of outpatient services for the treatment of NSCL/P in the country. They also highlight the need for dissemination of knowledge about post-operative care to health professionals in general. This is because sometimes without assistance in their home cities, individuals with NSCL/P and their families encounter difficulties with care of possible post-operative complications.

Moreover, Custódio (2007) has stated that the existing program of decentralization of services of the Hospital for Rehabilitation of Craniofacial Anomalies of the University of Sao Paulo – Brazil (Hospital de Reabilitação de Anomalias Craniofaciais da Universidade de São Paulo - HRAC/USP) has over the years involved several actions, such as the creation of subcentres, nuclei and associations for treatment of NSCL/P. Their objectives have been to facilitate patients' access to the health services in their home cities, so that the demand for care in HRAC/USP decreases, along with the geographic, financial and social difficulties of many of these patients.

In an interview in 2010, Capelozza Filho defended the existence of multidisciplinary centres for the treatment of NSCL/P distributed in strategic areas, as consistent protocols are respected (Capelozza Filho 2010).

Raposo-Amaral and Raposo-Amaral (2012) have suggested more guidelines to consolidate the centres for treatment of NSCL/P in Brazil based on the planned geographic distribution across the country, i.e., the regionalization of the specialized comprehensive treatment centres.

Therefore, both the effective regionalization of high complexity treatment services and decentralization of outpatient treatment services for individuals with NSCL/P are issues of great interest for all regions of Brazil. This is because there are large geographical distances and long durations of treatment for most of the cases that often come at a very expensive cost to the patients and/or their families, making comprehensive treatment very difficult to obtain (Tovani-Palone et al. in press).

## Inconsistencies and Future Perspectives for the Treatment of NSCL/P in Brazil

Recently, even with the creation of health policies for the treatment of NSCL/P (Tovani-Palone and Bertolini 2017) and implementation of Telemedicine in this field (Custódio 2013), health services and institutions have not been organized in conformity with two of the principles of SUS, regionalization and decentralization. A significant example of this is what happens in the state of Sao Paulo, considered the richest and most populous of the nation, with indications of centralization of highcomplexity surgeries for the treatment of NSCL/P and only a trend toward decentralization of outpatient services (Tovani-Palone et al. in press).

In this sense, it is also important to point out that HRAC/USP (located in the city of Bauru in the state of Sao Paulo) is the largest craniofacial centre in Brazil, and it was the Brazilian establishment that assisted a higher number of patients with NSCL/P in the recent years (Tovani-Palone et al. in press). The attended patients came from all five regions of the country (Freitas et al. 2012).

In contrast, in 2017 members of the University of Sao Paulo (USP), including the Rector and the Superintendent of HRAC/USP, together with politicians, negotiated the transfer of management of HRAC/USP, as

well as a new building of this hospital, to the State Health Secretariat of Sao Paulo. The new building was completed about five years ago and had been intended to be put to use to expand the physical structure of HRAC/USP. Now, however, it will be to set up as a general tertiary hospital. Therefore, from 2018 the contribution of resources to maintain the activities and new hires to HRAC/USP and the new general hospital will be under the responsibility of the State Government and not USP. In both health institutions, the University will only do the academic management. (Assessoria de Imprensa HRAC/USP 2017). I believe that all these changes could affect the quality and maintenance of the service provided by HRAC/USP as well as limit the assistance of new cases.

From that, an important issue arises: Is an immediate regionalization policy to delimit the territorial area for coverage of healthcare assistance from each of the craniofacial centres of Brazil a good option at this time?

I do not think so, because this can result in negative consequences to many patients, including the possibility of discontinuation of treatment for those depending on healthcare assistance from HRAC/USP. First, new specific rules for the organization and operation of craniofacial centres, as well as effective health policies for the treatment of NSCL/P, should be implemented in practice. This is necessary because, although the number of centres accredited by the National Register of Health Establishments as specialized in high complexity treatment for individuals with NSCL/P has increased over the years, several of them provide very few surgical procedures of high complexity or even none at all (Tovani-Palone et al. in press).

It is important that all of these craniofacial centres could, in fact, offer comprehensive care for the treatment of NSCL/P. Other than that, many of them need improvement in their service quality. Thus, the new rules and health policies for the treatment of such

craniofacial malformations should take into consideration mainly these two aspects.

Other measures, such as the incorporation of NSCL/P issues in the curriculum of undergraduate health courses, and the expansion of treatment of these anomalies to specialized care centres for the general population, as well as to the basic health units, are also fundamental actions to be carried out. Thereby, together with improvements in the work process and organization of the reference and counter reference system, they may contribute to the decentralization of outpatient treatment services for individuals with NSCL/P (Tovani-Palone et al. in press). This would lead to advances in the effectiveness of Healthcare Networks.

However, it is worth stressing that such expansion of treatment would only be viable/possible after adequate training of the professionals of SUS to attend the needs of the public, in order to satisfactorily provide both medium complexity healthcare and basic assistance.

In conclusion, new studies should be conducted periodically to verify the impact of the distribution of treatment services for individuals with NSCL/P and their coverage throughout the country, beyond the occurrence of changes in this scenario and their implications. Information of this type may undoubtedly help in health planning aiming to improve the quality of life of this population group.

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# Design and Implementation of a Structured Programme for Validation of Birth Weights in a District of Southern India: A Case Study



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### **Abstract**

In India, though the prevalence of low birth weight (LBW) is estimated to be nearly 30%, routine reporting by the government consistently under-reports it as 12%, with resulting mismatched rectification efforts. We designed a programme comprising weight measurement standardization training, a pilot study-based sample size calculation, re-training and certification of personnel and finally a validation exercise. Paired birth weight readings of 404 newborns by a staff nurse and a research nurse were compared. LBW (<2,500 g) prevalence was 18% and 36% according to staff nurse and research nurse, respectively. Thus, it is feasible to set up simple validation exercises.

# Introduction/Background

Lower birth weight (<2,500g) babies experience poor outcomes, not only in terms of morbidity and mortality during childhood and adult life (WHO 2014), but also in terms of education and earnings in later life (Black, Devereux and Salvanes 2005; Gragnolati et al. 2006). Developmental problems are because of deficits in academic achievement, attention problems and internalizing behavioral problems, poor executive function (Aarnoudse-Moens et al. 2009) and mathematics learning disabilities (Taylor et al. 2009). India, despite its recent economic growth, still accounts for more than 40% of the global burden of low birth weight (LBW) babies, with over two-thirds being born at term showing fetal growth restriction and one-third being born prematurely (MoHFW 2014). Paradoxically, given that low birth weight is also associated with the "double burden of malnutrition" (that is, diseases caused by being

underweight as well as being overweight/ obese), it is even more important for regions in transition such as India (WHO 2017).

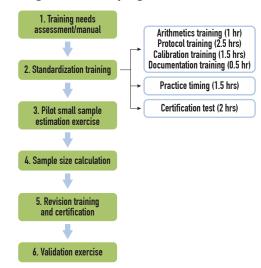
Accurate measurement of birth weight is key to identification of an LBW baby. Birth weight measurement is however prone to error, be it in community settings, hospital settings or in NICU (neonatal intensive care unit) settings (Emmerson and Roberts 2013; WHO 2014). Errors in measurement may be because of subject, observer or instrument (Mony et al. 2016). In India, instruments used to weigh babies at birth are mostly beam balances; in addition, most of the errors are observer-related, owing to poor measurement technique such as "heaping" (Gragnolati et al. 2006; Dubey and Nath 2016). Misclassification is both a health issue, with proven costeffective interventions (e.g., Kangaroo Mother Care) not being offered to eligible infants (Vesel et al. 2015), and a human rights issue, with appropriate healthcare being denied to those who need it the most

(Dickson et al. 2015). In India, though the prevalence of LBW is estimated to be 25-30% (UNICEF 2013; MoHFW 2014), routine reporting by the national health information system consistently under-reports it to be around 12% (NHM 2016), resulting in minimal efforts being undertaken to identify or correct the under-reporting. There is an urgent need for health systems' research that can help identify key deficiencies and propose targeted solutions (Bahl et al. 2012). Validation of routine clinical measurements of anthropometry against those by a researcher in a controlled setting after being trained by a certified anthropometrist is a strategy used in several settings (DiMaria-Ghalili 2006; Leo et al. 2014; Xiao et al. 2017), as it offers both face validity and construct validity as markers of accuracy (Heale and Twycross 2015). The objective of our initiative was to construct a validation system to test the accuracy of the routine birth weight capturing mechanism using the beam balance in a district of southern India.

# Intervention

We developed a conceptual framework for a validation system consisting of a series of sequential steps (Figure 1). The first step was to develop a specific training manual for accurate weighing of newborns, drawing from existing generic anthropometry training manuals (Zerfas 1985; Lohman et al. 1988; InterGrowth-21st 2009) and based on common errors noted in literature review (Blanc and Wardlaw 2005; Gragnolati et al. 2006; Dubey and Nath 2016). This was used in a standardization training and certification programme for research nurses over a duration of nine hours. These trained and certified research nurses were to undertake a pilot study to estimate proportion of low birth weight in a small convenient sample to be able to perform a formal sample size calculation. After a revision session of re-training or re-certification as needed, the definitive validation exercise was undertaken.

Figure 1. Conceptual framework for a birth weight validation programme



# Methodology/Change Process/Results

The programme was undertaken in the northeastern region of Karnataka in India, a region with a population of 16 million spread over eight districts and having suboptimal coverage of Emergency Neonatal Care (EmNC) at the district and sub-district levels (Mony et al. 2015), typical of most parts of India. The prevalence of LBW in Karnataka for the year 2015–16 was 13% according to the government records (HMIS 2017).

Nurses with diploma/graduate qualification [General Nurse Midwife (GNM) or Bachelors in Nursing] trained as Nurse Mentors in a previous maternal and neonatal health project (Fischer et al. 2015) were the research nurses for this study. A package comprising a training manual/ training schedule was designed to address common errors in birth weight anthropometry measurements (de Onis et al. 2004; Blanc and Wardlaw 2005). The training and operations manual covered topics such as Standard Operating Procedure (SOP) for weighing newborns, calibration procedures, a checklist for weight measurement and wrapping of newborn and the birth weight validation and calibration dummy sheets. The total duration of the training was for nine hours: 5.5 hours on day 1 and 3.5 hours on day 2 (Figure 1).

Eight research nurses underwent the standardization training. This comprised four components: arithmetics training, protocol training, calibration training and documentation training. Arithmetics training was focused on teaching the resolution of different weighing scales (50 g or 100 g) and reading pictorial representations of birth weights ranging from 500 g to 4,500 g. Protocol training comprised teaching the accurate method of weighing newborns using digital and manual weighing scales and practical demonstrations and return demonstrations using both scales first on mannequins in the classroom setting and then on babies in the postnatal ward of the hospital. Training was provided on both types of scales because although most health facilities had manual weighing scales, a few government and private neonatal care centres had digital scales, and although digital scales are more accurate, errors could arise if there were differences in adherence to protocol (such as weighing the newborn with or without clothes). This was followed by training on calibration of the weighing scales using standard weights, and lastly on correct documentation of birth weight in a standardized format ("grams"). After the training, we allotted time for practising weight measurements on nearly a dozen babies. Subsequently, they attended a certification test comprising two parts: a classroom-based theory test of reading still photographs of newborns (weight range = 500-4,500 g) and a practical test of comparing their measurements on a set of 10 live newborns against those of a certified anthropometrist. Weightage of 30:70 was accorded to the theory:practical components of the test for the calculation of the overall scores and ≥67% was considered as pass marks. A non-probability-based sample of 76 babies born in January 2016 in five hospitals from the three tiers (one district hospital, two subdistrict hospitals and two primary health centres) of Bagalkot district were weighed by

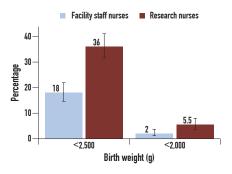
the research nurses. Nearly one in five babies were found to have low birth weight; so assuming 20% expected prevalence (from the pilot exercise) and 20% relative precision, we calculated the sample size for the validation exercise to be 400 babies. Based on observations made during the certification test and the pilot exercise, we undertook a revision training of about two hours to fine-tune the measurement skills of the research nurses.

The 405 newborns included in the study were born during August-September 2016 from the three tiers of health facilities in Koppal district in the ratio of 3.5:5:1.5 (primary:secondary:tertiary), proportionate to the delivery volumes in different facilities. The study instrument was the beam balance (a manual weighing scale) commonly used in the delivery rooms of all health facilities. Research nurses visited health facilities to measure birth weights of babies born the previous day and recorded their weights on the validation worksheets. In addition, they also noted the values obtained for the same babies, usually within an hour after birth and recorded in the parturition registers. Measurements by research nurses were taken at a median of 10 hours after birth (range = 1-144 hours); so for purposes of comparison, we inflated these weights obtained by research nurses, assuming a rate of ~1% loss in body weight per 24 hours (Noel-Weiss et al. 2008).

Seven of eight research nurses passed the certification test in the first attempt; one nurse mentor required additional training and passed in the second attempt. For the validation exercise, a total of 405 babies had paired readings recorded. During the validation exercise, it was noted that checking of birth weights in the health facilities was by staff nurses in 75% (304/405) of cases and by "unauthorized staff" in 25% (101/405) of cases. Further, they all followed a variety of different procedures for obtaining the weights. Overall LBW (<2,500 g)

prevalence was 18% (73/404; 95% confidence interval (CI):[15, 22]) according to facility staff and 36% (145/404; 95% CI:[32, 41]) according to research nurses. While it was 12%, 23%, 17% and 3% in the government district, subdistrict, primary care facilities and private health facilities, respectively, according to the facility staff, it was found to be 35%, 40%, 35% and 28% by the research nurses in the four types of facilities respectively; the differences between the two personnel were statistically significant (p < 0.05). LBW (<2,000 g) prevalence was 2% (8/404; 95% CI:[1.0, 3.8]) according to facility staff and 5.5% (22/404; 95% CI[3.6, 8.1]) according to research nurses (Figure 2). About a quarter of those with birth weights ≥2,500 g according to health facility staff were identified as LBW by the research nurses; more specifically, nearly two-thirds of those with birth weights recorded exactly as 2,500 g by the facility staff were identified as LBW by the research nurses. Weights recorded by facility staff revealed a marked digit preference, by about 200 g. In addition, it was also seen that differences in weights obtained by facility staff were about 150 g higher than that obtained by the research nurses. This error was however random and spread across all birthweight levels rather than just around different cut-off levels, as seen in the Bland–Altman plot (Figure 3).

Figure 2. Proportion of newborns identified as low birth weight in a district of southern India, by type of workers (n = 400)



### **Discussion**

One of the global nutritional goals is to achieve a 30% reduction in LBW incidence by the year 2025 (WHO 2014). While total deaths and age-standardized death rates because of maternal disorders and certain communicable diseases (malaria and HIV/ AIDS) have declined significantly during the period of 2005-2015, progress has been slower for nutritional/perinatal disorders (GBD 2015). Not being able to quantify the problem accurately and acting upon that on a day-to-day basis in birthing facilities of developing countries could partly explain this gap because of substantial misclassification and missed opportunities for offering proven and cost-effective child health interventions (Grove et al. 2015; Vesel et al. 2015).

Health systems aiming to strengthen measurement strategies linked to maternal and child health programmes should accord priority to ensuring that the first set of measurements taken soon after birth are accurate and reliable. Our strategy of employing a trained and certified third-party research team enabled independent assessment of the quality of birth weight measurement. Using such trained personnel to conduct a pilot exercise helped us in arriving at a logistically feasible sample size for the main validation exercise than would have been possible with the LBW proportion from routine reporting.

One option for overcoming deficiencies in weight measurements would be for health departments to replace all the beam balances in labour rooms, newborn care areas and in post-natal wards of hospitals with digital weighing scales; the 10-fold or higher costs of such an exercise may however be prohibitively expensive for several jurisdictions. In the interim, quality assurance (QA) steps such as standardized training of healthcare personnel and calibration of weighing equipment will help minimize errors in anthropometric

measurements. In addition, such validation exercises also have a role in improving health systems (Grove et al. 2015). Investing in a dedicated team identified by the health department, preferably an independent third-party monitoring and evaluation unit, can help identify rates of misreporting of birth weights at regular intervals for quality control (QC) purposes.

Accuracy of birth weight measurements however appeared to be assessed more often among community health workers than among hospital nurses (Amano et al. 2014). Such quality improvement process efforts can be established with minimal budgets even in hospitals and can contribute substantially to professional development, quality of care, better documentation and overall effectiveness of health systems (Peabody et al. 2006).

Strengthening the quality of perinatal data monitoring systems should thus be pursued vigorously in low- and middle-income countries (Grove et al. 2015), including India currently ranked at 143 out of 188 countries on Sustainable Development Goals indicators (GBD 2015), if avoidable causes of deaths are to be identified early and accurately for implementation of preventive and curative care services.

# **Conclusions**

LBW (<2,500 g) prevalence was 18% and 35% according to facility staff and research nurses respectively while LBW (<2,000 g) prevalence was 2% and 5.5% by the two sets of workers respectively. Mostly, the misclassification was because nearly two-thirds of babies with birth weights recorded exactly as 2,500 g by facility staff were classified as low birth weight babies by the research assistants. Setting up simple quality control systems for validation of key health indictors, such as birth weight, by independent evaluators is feasible in resource-constrained settings.

# **Acknowledgement**

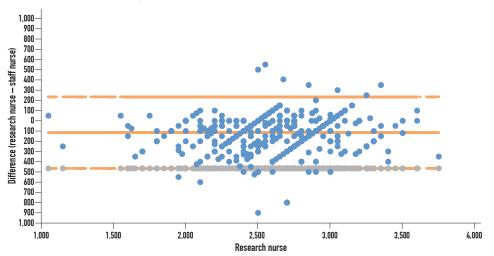
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Figure 3. Bland-Altman plot of birth weights obtained by research nurses against the differences in birth weights



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