

## **Enhancing Community Based Support for People Living With HIV/Aids in India: The Role of Community Care Centres**

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### **Abstract**

*The emergence of community care centres in India in recent decades has facilitated the provision of outreach services including psycho-social support and routine medical care to assist individuals living with HIV/AIDs. Since 1992 a range of government initiatives have been implemented that have led to an increasing trend focusing on community-based care. This paper focuses on the current role of community care centers in India, highlighting key services in addressing the needs of individuals and families in managing the challenges associated with HIV/AIDs. The paper also highlights barriers to access of patient-centered services for the treatment of HIV/AIDs within the Indian context.*

**Keywords:** HIV/AIDs, psychosocial support, community based care, India.

### **Introduction**

Acquired immunodeficiency syndrome (AIDS) and its causative agent, the human immunodeficiency virus (HIV), has been responsible for the death of over 30 million people since the first official case was recorded in 1981 (UNGA 2011; WHO, UNAIDS & UNICEF 2011). Although life-saving anti-retroviral therapies (ART) have been available since 1996, it is only since 2004-5 that deaths from AIDS-related causes have decreased (UNAIDS 2010). The United Nations estimated that in 2010 there were 34 million people living with HIV/AIDs (hereafter referred to as PLHA) worldwide (WHO, UNAIDS & UNICEF 2011).

Low- and middle-income nations, where 97% of PLHA reside, are most affected by the ongoing and devastating impact of the HIV/AIDs epidemic (UNAIDS/WHO 2010). There are numerous political, cultural and structural complexities which compound this burden for individuals and their communities, including; poverty; stigma and discrimination; lack of education and awareness; gender inequality; limited access to ART; and inadequate medical care (Pradhan & Sundar 2006).

Despite the global imbalance in access to treatment and support, a concerted global effort seems to have resulted in the overall decline of new incidences of HIV/AIDs infection by 19% since 1999 (UNAIDS 2010). As access to combination ART improves, annual deaths from HIV/AIDs-related causes have also been decreasing steadily, from a peak of approximately 2.2 million people in 2005, to an estimated 1.8 million deaths in 2010 (WHO, UNAIDS & UNICEF 2011). There has been a corresponding increase in the number of people living with HIV/AIDs (WHO 2011), which partly reflects global attempts to meet the Millennium Development Goal of universal access to HIV/AIDs treatment (UNGASS 2010). The increasing number of PLHA poses new challenges for governments, communities and health-care providers internationally.

This paper focuses on the role of Community Care Centers in India. An initial exploration of the impact of HIV/AIDs within the Indian context including significant contextual factors that have influenced the spread of the epidemic will be presented to delineate the Indian government's responses in recent decades to this phenomenon. Community Care Centers as a healthcare model that recognizes the need for outreach services and psychosocial support beyond conventional hospital environments will also be investigated. A number of studies within the current literature focusing on community care centers in India will be identified as a means of highlighting the benefits, as well as the complexities, associated with this model of service in the provision of holistic approaches to the treatment of HIV/AIDs. A range of factors are listed that serve as barriers to patient-centered engagement. Finally, recommendations for future research are identified to decrease the knowledge gap associated with service provision for individuals and families living with HIV/AIDs in India.

### ***India and HIV/AIDs***

As the second-largest nation in the world with a growing population of more than 1.2 billion (Government of India 2011), India's response to HIV/AIDs represents an important case study. Although estimates and projections of PLHA in India have been historically contentious (Claeson & Alexander 2008), expanded surveillance measures and improved methodologies have demonstrated that the incidence of HIV/AIDs is much lower than first calculated (Jha, et al., 2010; UNAIDS 2007). For example, in 2006 incorrect assumptions were made by UNAIDS estimating the number of PLHA at 5.6 million. By 2009 however, the organization concurred with the National AIDs Control Organisation's (NACO) revised estimate of between 2 and 3.1 million people (NACO 2009). A recent UNAIDS (2011) report estimated that India was home to 2.4 million PLHA, with approximately 170 000 AIDs-related deaths in 2009, and between 110-160 000 new infections. This number represents approximately 0.36% of the population (NACO 2009; UNAIDS 2007). HIV/AIDs is classed as low endemicity in India because less than one percent of the population are infected. However, India's population size means that it is home to one of the world's largest populations of people living with HIV/AIDs (UNAIDS 2011).

Those communities most vulnerable to the epidemic include female sex workers, injecting drug users, and men who have sex with men (Bhatia & Anand 2009; Claeson & Alexander 2008; NACO 2011). Groups placed in the second highest category for risk include long-distance transport drivers, street children, refugees, and prisoners (NACO 2011; WHO/UNAIDS/ UNICEF 2011). Men who purchase the services of sex workers play a key role in transmitting the disease, often to wives who would otherwise be at low risk of infection (NACO 2011; Pallikadavath, Garda, Apte, Freedman & Stones 2004). There is increasing recognition that the low status of women in India increases their vulnerability to the virus, making gender imbalance a key factor in the transmission of the disease (Mitra & Sarkar 2011; Pradhan & Sundar 2006, 2008). An estimated 39% of PLHA are female (prevalence in men is 61%) (UNAIDS 2011). A recent review asserts that "gender disparities in literacy, educational attainment, labour force participation and exposure to media" prevent women from exercising autonomy over their sexual health (Mitra & Sarkar 2011). Thus, although recent trends show a decline in the overall number of people contracting HIV/AIDs in India (UNAIDS 2010), this decline is less evident in rates of female infection, and HIV/AIDs has spread from urban to rural regions and from high-risk to general populations (Mitra & Sakar 2011; NACO 2011; Pradhan & Sundar 2006; Solomon et al., 2009).

The geographic distribution of HIV/AIDs in India is heterogenous and centered upon key states, with up to 60% of PLHA living in just six high prevalence states. One cluster of these high HIV-prevalence states exists in the southern bordering states of Andhra Pradesh, Karnataka and Maharashtra, while a north-eastern cluster is comprised of the bordering states of Manipur, Nagaland and Mizoram (NACO 2011). Injecting drug use is the primary route of infection in this latter north-eastern region, while in other parts of India HIV/AIDs is primarily sexually transmitted (Chandrasekaran, Dallabetta, Loo, Rao, Gayle, & Alexander 2006; NACO 2009). Nationwide, heterosexual intercourse represents 87.4% of new infections, while parent-to-child transmission accounts for 5.4% (NACO 2011).

Known as the "pharmacy of the developing world", between 2003-2008 Indian manufacturers supplied over 80% of ARTs purchased by donors for use in developing countries (Médecins Sans Frontières 2011b; UNAIDS 2011). Competition amongst multiple generic pharmaceutical manufacturers in India has been critical in reducing the cost of ARTs worldwide in the past decade (MSF 2011b; UNAIDS 2011). Free ART therapy was launched by the Indian government in 2004, with the stated aim of establishing 250 ART centers to treat 300 000 adults and 40 000 children infected with HIV by 2011 (NACO 2007a).

These aims appear to have been closely met; a survey conducted by Médecins Sans Frontières (2011) reported 293 existing ART centers, while the Universal Access Report indicated that 424 802 people - or 39% of those eligible - received ART in 2010 (MSF 2011a; WHO/UNAIDS/UNICEF 2011). This 39% figure is potentially misleading; in addition to the cohort of PLHA who aren't yet deemed to need ART, sources estimate that only 5-10% of Indians infected with HIV/AIDS are aware of their status. This represents a significant problem in terms of treatment and prevention, thus necessitating more widespread initiatives to facilitate comprehensive screening (NACO 2007b; Solomon 2008).

### ***Community Care Centers***

In 1992 the Indian government launched its National AIDS Control Program (NACP), aiming to control the spread of HIV/AIDS. The Indian government is now in its third phase of the NACP, with the fourth phase beginning in 2013. Twenty percent of the 2.5 billion dollar budget for the third phase of the National Aids Control Program (NACP-III) was allocated to care and support of PLHA (NACO 2006; Claeson & Alexander 2008). A significant portion of this included government investment in Community Care Centers to “provide psycho-social support, outreach services, referrals and palliative care” (NACO 2006). Set up under the second phase of NACP with a mandate to treat opportunistic infection (OIs) and offer psychosocial support, the arrival of ART has seen CCCs adapt to offer a wider range of community-based treatment, care and support to PLHA. NACP-III targets mandate that each CCC be linked to an ART center - with CCCs “act[ing] as a bridge between PLHA households and ART centers, focusing on management of opportunistic infections as well as adherence counseling for ART” (NACO 2011).

Ideally, the centers adopt a strategically co-ordinated approach to ensure that PLHA can access; counseling for ARV drug adherence, nutrition advice and prevention of transmission to others; referral and outreach services for such matters as higher medical care and legal advice; social and psychological support; and treatment of OIs (NACO 2007b; Sogarwal & Bachani 2011). CCCs are generally located in districts with a high HIV/AIDS prevalence, and in cases with high registrations for HIV care there may be more than one CCC linked to the same ART center. NACO (2009) lists 254 “functioning” community care centers, while a progress report submitted to the UN General Assembly listed 287 CCCs (UNGASS 2010). The NACP-III target for 2011 was the establishment of 350 centers (NACO 2007). The CCCs function under the ‘Operational Guidelines for Community Care Centres’ (NACO 2012). These guidelines...focus on the objectives, criteria for selection, required infrastructure, equipment, supplies and human resources, monitoring tools and financial guidelines for CCCs’ (NACO 2007, p.8).

The NACP-III report the incidence of adults registered for ART as 1, 371, 232 and children, 97, 208 indicating promising treatment advances for PLHA (2012). While the overarching focus of CCCs is to facilitate links between ART centres and the families of PLHA, specific services include:

- one-on-one and group based counseling to provide psychosocial support for individuals and families;
- development of ART individual treatment plans that can be monitored over time;
- education-based information sessions that focus on management of HIV/AIDS including prevention of the spread of infection as well as personal health and nutrition and home-based care;
- facilitating stronger educational links for school-aged children;
- advocacy against stigma;
- delivery of basic medical services to address low level medical issues; and
- coordination of more complex medical treatment through referral to alternative services such as NGOs and government hospitals (NACO, 2007).

One coalition of Indian CCCs advocates that CCCs emphasise a patient-centered approach that aims; “to deliver a continuum of care at low cost, to promote early detection of HIV, to focus on the effective treatment of common opportunistic infections, to reduce maternal and fetal transmission wherever possible, and to offer a non-stigmatizing, caring, and confidential environment to all” (Horizons Program, YRG CARE, & International HIV/AIDS Alliance 2004). Whether or not such aims have been realised is the subject of a number of limited studies focusing on CCCs in India and services that they offer. Some centers focus on quality of life for patients and/or broader issues affecting the lives of PLHA who visit the centers, while others evaluate the effectiveness of the centres themselves and particular services offered.

One key study was a process evaluation conducted in 197 centres, making it the largest evaluation conducted on CCCs in India (Sogarwal & Bachani 2011). Critical issues identified by the study included; high workload and client volume impacting on services; poor co-ordination with ART centres leading to potentially adverse affects; shortage of medicines for OI treatment; the need for further training of counselors, particularly given that some counselors have been reported to receive a minimum of two weeks training at a designated institution, and thus lack in-depth knowledge on subjects such as drug addiction counseling, infant feeding, and prevention between discordant couples (i.e. one HIV positive and one uninfected); difficulty experienced by outreach workers due to long distances, incorrect addresses, client migration and objections raised by patients who refuse a home visit due to fear of stigma and risk of disclosure of HIV-status to others; difficulties transporting clients to ART centers by CCCs who require government grants to hire, rather than buy, vehicles; low salary and/or delayed payment amongst staff; and lack of training on monitoring and evaluation (Sogarwal & Bachani 2011). Despite these identified issues, the study reported that patients were for the most part satisfied with available CCC services. However, Claeson and Alexander's 2008 research into government policy and response regarding HIV/AIDS in India, "identified the need for... disaggregate analysis about the needs of the poor, better targeting of these needs, and better community ownership of interventions" (Claeson & Alexander 2008).

Other evaluations of the effectiveness of HIV/AIDS care in India highlighted the importance of synergistic programming between CCCs and other key programs. Integration and co-ordination across diverse services and programs related to HIV/AIDS - including tuberculosis treatment and maternity care - is crucial to effectively meet common objectives (Bhatia & Anand 2009; Horizons Program, YRG CARE, & International HIV/AIDS Alliance 2004; MSF 2011). Removing adult-bias is also important to provide a safe space for children and their parents to access treatment (Bhatia & Anand 2009). The significant number of women infected by their husbands was noted by one study, which then advocated "strengthening partner-notification strategies" (Gangakhedkar et al., 1997).

A consistent theme in the literature is the role of regular contact with a clinic, and particularly accessing counseling services, in increasing life quality and longevity amongst PLHA. One longitudinal study at a CCC in southern India measured 136 patient's subjective evaluation of five key aspects of their quality of life - classified as physical, sexual and psychological well-being, their relationship with their partner, and social support (Solomon et al., 2009). Although the study was conducted before ART was readily available, it still found that a multidisciplinary approach to managing HIV/AIDS "significantly improved" individuals' sense of psychological well-being and social support. Specifically, it found that counseling services which "broadly address patient concerns" positively impact upon the quality of life of PLHA, and recommended that comprehensive clinical care incorporated counseling "at every patient encounter". These findings were reinforced by a later study that examined mortality rates amongst 100 patients affected by HIV/AIDS in resource-poor settings (Rajagopalan et al 2009). It found that counseling that focused on adherence to ART significantly increased life expectancy, partly because regular and ongoing interactions with the clinic staff helped to ensure early prevention, prompt diagnosis and treatment of OIs - which are often the cause of death for PLHA. The study concluded that 'HAART alone without proper OI management and nutrition did not prevent mortality among PLHA' - reinforcing the importance of services offered by CCCs (Rajagopalan et al., 2009).

Another longitudinal study also demonstrated the beneficial effects of longer-term counseling - in this instance in reinforcing behaviour change. Demonstrated outcomes included 'safer behaviors, especially reduction in partners, and consistent condom use with spouse and other partners' (Mawar et al., 2011). The researchers also advocated the need for a capacity building and gender-sensitive approach for sustained behaviour change. Identified issues included alternative sources of income, women's right to property, and education for children (Mawar et al., 2011).

In summary, evidence focusing on the positive impacts of CCCs in India indicates that:

- patients reported high levels of satisfaction with CCC service delivery;
- multidisciplinary approaches to managing HIV/AIDs promoted individual psychosocial adjustment; and
- longer-term counseling services positively impacted PLHA quality of life, including life expectancy;

Limitations of CCC services included:

- lack of resourcing to accommodate high rates of access, including CCC personnel and medical supplies for OI;

- limited coordination with ART centres;
- minimal training of counselors working in CCCs;
- barriers to outreach work, including adequate transportation; and
- Lack of evaluation of services (Sogarwal & Bachani 2011; Rajagopalan et al 2009; Mawar et al., 2011).

Although some research has been undertaken to determine the efficacy of CCCs in India, further studies are necessary to assist in the generation of research outcomes to assist in the enhancement of CCC service delivery and render such services sustainable over time.

### ***Discussion: Barriers to Accessing Patient-Centered Services***

Addressing issues such as those identified by Mawar et al. (2011) are critical in resolving barriers to living a fulfilled and healthier life as a PLHA. These barriers are exacerbated in resource-poor settings; the socio-economic status of a person, which is negatively affected by the contraction of HIV/AIDS, severely impacts upon their ability to access treatment and live well. The personal impacts of HIV/AIDS are exacerbated by the financial burden of illness, gender inequality, and stigma and discrimination experienced from medical staff, family members and the broader community.

Yet widespread poverty means that access to life-saving ART centres and CCCs is not guaranteed. Despite the Indian government's 2004 launch of free ART, costs associated with travel, medicines, loss of wages, and treatment of OIs can be a significant obstacle to accessing treatment (Horizons Program, YRG CARE & International HIV/AIDS Alliance 2004). Beyond these immediate costs is the long-term and often significant loss of income for the PLHA and his or her caregiver/s - further entrenching poverty (Kumarasamy, Venkatesh, Mayer & Freedberg 2007). Unsurprisingly, one study of 100 PLHA found that unemployment increased after the onset of disease (Singh, Garg, Nath & Gupta 2009). This underscores the need for alternative income streams, with some CCCs initiating programs to assist PLHA generate income (India HIV/AIDS Alliance 2007; Snehacare 2011).

There is an unfortunate wealth of international research on the pervasive discrimination experienced by PLHA, whether in the workplace, health care system, family structures or the broader community (Ambati, Ambati & Rao 1997; Bharat, Aggleton & Tyrer 2001). Ignorance and stigma are significant barriers for many PLHA in accessing vital services and treatment (Bharat, Aggleton, & Tyrer 2001; Bhatia & Anand 2009). One study in Mumbai in 2000 reported that "only 15% of doctors agreed to admit HIV positive women for delivery at their clinics" (Sing et al., 2009). For women in particular, HIV/AIDS-related discrimination "reinforces pre-existing economic, educational, cultural, and social disadvantages" and impedes equitable access to treatment and services (Parker, Aggleton, Attawell, Pulerwitz & Brown 2002; Pradhan, Sundar & Singh 2008). Often infected by their husbands, they are also more likely to be the primary carer for their partner in the more advanced stages of HIV/AIDS. Within a patriarchal culture, studies show that women of all income levels frequently sacrifice their own treatment and care needs in order to care for male partners and children (Kumarasamy, Venkatesh, Mayer & Freedberg 2007). Further, one study found that women were more likely to be misinformed about their HIV status by both medical staff and family (Pallikadavath, Garda, Apte, Freedman & Stones 2004).

Extensive training and awareness raising amongst medical staff has been found effective in increasing workers' commitment to patient-centered procedures; which in turn encourages patient engagement and diminishes, rather than reinforces, stigma (Bhatia & Anand 2009; Bharat, Aggleton & Tyrer 2001; Hemlata et al., 2007; Mahendra et al., 2006). One process evaluation of discriminatory practices in hospital settings - which culminated in a training manual designed and delivered in collaboration with PLHA - defined 'patient-centered' medical practices as those in which;

*PLHA receive appropriate care (i.e. humane, thorough, timely, clinically appropriate, and respectful); where there is an absence of stigma and discrimination against PLHA; and where staff are confident, competent, and assured of a safe working environment in order to care for patients of unknown or HIV-positive status (Bharat, Aggleton & Tyrer 2001).*

Millennium Development goals also advocate the greater involvement of people with HIV/AIDS (GIPA) at all levels of policy and implementation as critical in eradicating stigma and fear through the provision of positive role models and bringing valuable lived experience to the education and health sector (Paxton & Stephens 2007).

HIV testing and adherence counseling is in the process of “task-shifting” to lay health care workers (MSF 2011a), introducing a peer support component to treatment at the same time as supporting employment options for PLHA. This is strongly supported by Bharat and Mahendra (2007), who assert in their research that, “providers, some of whom may themselves be HIV positive, can make an important difference, especially if they are supported in their working conditions, are knowledgeable about HIV and sexual and reproductive health and have the skills to provide good quality care.”

Although little attention has been drawn to the eradication of barriers in accessing CCCs, the NACO (NACO 2012) have implemented a range of community based initiatives to ‘...create an enabling environment that encourages HIV related prevention, care and support activities and to reduce stigma and discrimination at individual, community and institutional levels’ (NACO, 2012, p. 21). Such innovations include specific community based projects focusing on prevention of HIV/AIDs, multi-media campaigns including radio and television national broadcasts and dissemination of HIV/AIDs educational literature, special events linked to World AIDs Day, National Youth Day etc., training for frontline workers and community based drop in centres.

### ***Future Research Recommendations Focusing On Community Based Care And Services***

With recent advances in the prevention and treatment of HIV/AIDS, there is great need for CCCs to address the issues explored within the literature, in order to build communities and medical systems that can enable PLHA to live longer and healthier lives than has previously been possible. A range of future research agendas have been identified that focus on community-based support in India that would serve to reduce the gap in understanding the impacts of such services within a range of community contexts. Key priorities for future research should include:

- 1) Ongoing evaluation of existing services to ensure that patient needs are being adequately addressed. Given that community based care initiatives can provide immediate and accessible services that maintain the confidentiality of PLHA, rigorous and sustainable short and long-term evaluation practices need to be facilitated as a means of ensuring services are comprehensively addressing the needs of clients. There is currently a dearth of research focusing on the efficacy of CCCs. The ongoing development of valid and reliable research instruments that can be readily applied within a range of settings and to a diverse population of clients will assist in accessing both qualitative and quantitative data focusing on the ongoing experiences of individuals engaging with community based support such as CCCs to achieve this end.
- 2) Examination of the efficacy of organizational partnerships such as hospitals and community care centres in the coordination and delivery of health related services. Current models of community based service delivery for PLHA include coordination of care between government hospitals and relevant NGOs including CCCs. Such investigation would lead to the identification and implementation of health care priorities that could be actualized through coordinated partnerships, thus decreasing the duplication of services and maximizing the roles of personnel working across a range of government and non-government health care settings.
- 3) Investigation of the lived experiences of PLHAs and community care workers. Given the significance of the ‘central voice’ of PLHAs, as well as community based workers that have the potential to illuminate the lived experiences associated with health care provision, further studies need to be undertaken that focus on the experiences of both individuals working within community care centres, in concert with patients accessing health care and psychosocial support. The findings of such studies would further assist in the evaluation and ongoing refinement of services as a means of ultimately improving the lives of PLHA.

### ***Conclusion***

This paper has focused on community-based care for PLHA in India. A review of current literature was presented that delineated the nexus of HIV within the Indian context including government initiatives to address societal concerns associated with the epidemic as a means of highlighting the role of CCCs in addressing the psychosocial and health care needs of PLHA. Key studies centering upon the benefits as well as the complexities of CCCs were examined that advocate for models of community engagement that widen participation and provide sustainable services that increase the quality of life for individuals managing HIV/AIDs. Recommendations for future research were also acknowledged to assist in continuing the HIV/AIDs research agenda within India and more generally within the International community focusing on psycho-social and medical support to combat the potentially deleterious affects of the HIV/AIDs epidemic.

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