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PERCEPTIONS OF COMMUNITY WORKERS IN THE PROVISION OF PSYCHOSOCIAL SUPPORT FOR INDIVIDUALS LIVING WITH HIV/AIDS IN INDIA

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ABSTRACT

Psychosocial support is a critical component in the promotion of physical and psychological health for individuals managing the challenges of living with HIV/AIDS within the Indian context. The role of community workers in assisting individuals living with HIV/AIDs in India is of significance given the growing population affected by the epidemic. This paper reports on the findings of 11 in depth qualitative interviews exploring perceptions of community workers engaged in a local non-government organisation (NGO) established to assist children and families living with HIV/AIDs. Discussion emphasises the significance of the role of community workers as a vital ingredient in enhancing the lives of HIV/AIDs affected individuals within the Indian context.

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

Introduction:

Since 1981 when the first official case of the human immunodeficiency virus (HIV) was documented, the World Health Organisation (WHO) has reported over 30 million people have lost their lives to acquired immunodeficiency syndrome (AIDS) (UNGA 2011; WHO, UNAIDS & UNICEF 2011). From 2004-5 there has been a decreasing trend in the incidence of deaths caused by AIDS despite the availability of anti-retroviral therapies (ART) since 1996 (UNAIDS 2010). According to United Nations estimates, in 2010 34 million people were living with HIV/AIDS globally (WHO, UNAIDS & UNICEF 2011).

97% of the world's population living with HIV/AIDS is drawn from low and middle-income nations (UNAIDS/WHO 2010). The impact of HIV/AIDS for this population are compounded by a range of factors such as poverty and its associated affects, societal stigma, limited educational opportunity, gender inequality and discrimination; complexity in accessing ART and insufficient medical care (Pradhan & Sundar 2006).

Since the new millennium the incidence of HIV/AIDS infection has declined by 19% worldwide with the instigation of a range of global initiatives to combat the prevalence of the disease (UNAIDS 2010). One of these initiatives is the increasing access to ART, which has led to the decrease of annual deaths resulting from HIV/AIDS-related infections from an estimated 2.2 million people in 2005, to approximately 1.8 million deaths in 2010 (WHO, UNAIDS & UNICEF 2011). WHO (2011) have reported a corresponding increase in the population of people living with HIV/AIDS (PLHA). This increase in prevalence represents a range of challenges for communities worldwide including widening access to equitable and timely HIV/AIDS treatment (UNGASS 2010).

This paper explores the experiences of community workers supporting individuals and families living with HIV/AIDS within a targeted population in a major urban Indian city. The impacts of HIV/AIDS within India will be initially presented focusing on factors that have promoted the rise in HIV/AIDS infection as well as government responses to the epidemic nationally. A brief focus on the role of community workers to address some of the challenges in combatting the affects of HIV/AIDS in India will also be delineated to highlight the efficacy of community-based support in addressing the needs of PLHA. The findings of ten in-depth interviews involving community workers involved in a local NGO in an urban setting will also be presented to highlight some of the successes and challenges in supporting PLHA and emphasise key factors to promote the ongoing utility of this intervention approach. Finally, recommendations for future research focusing on the provision of psychosocial support for PLHA through approaches such as community-based support will be presented to address gaps in knowledge focusing on working with individuals and families living with HIV/AIDs in India.

HIV/AIDS: The Indian Context

India is the second largest nation in the world with a current population of over 1.2 billion people. The rates of HIV/AIDS infection have been of epidemic proportions since the first case of HIV was initially discovered in Chennai, India in 1986 (Steinbrook, 2007). In 1992 the Indian government launched a national response to HIV that demonstrated early success in some states (Chandrasekaran, Dallabetta, Loo, Rao, Gayle & Alexander, 2006). According to recent reports (UNAIDS, 2011) it is estimated that 2.4 million PLHA are located in India, representing approximately 0.36% of the population (NACO 2009; UNAIDS 2007).

Female sex workers, injecting drug users, and men who have sex with men are identified as specific populations most susceptible to HIV/AIDS (Bhatia & Anand, 2009; Claeson & Alexander 2008; NACO 2011). Commercial truck drivers, street children, refugees, and prisoners are also at greater risk of HIV transmission (NACO 2011; WHO/UNAIDS/UNICEF 2011). HIV/AIDS infection is also spread by men accessing the services of sex workers with many wives being infected who would otherwise be categorized as at low risk of contracting HIV/AIDS (NACO 2011; Pallikadavath, Garda, Apte, Freedman & Stones 2004). It is estimated that 39% of females and 61% males are currently living with HIV/AIDS in India (UNAIDS 2011). It is well documented that the low status of women in India increases their susceptibility to infection and that recent trends indicate that HIV/AIDS infection is spreading from urban to rural settings and from high-risk to general populations (Mitra & Sakar 2011; NACO 2011; Pradhan & Sundar 2006; Solomon, 2009).

60% of PLHA are distributed across six high prevalence states in India. The southern states of Andhra Pradesh, Karnataka and Maharashtra, as well as north-eastern states including Manipur, Nagaland and Mizoram represent geographical locations with comparatively high HIV/AIDS prevalence rates (NACO 2011). Within the broader Indian context, 87.4% of HIV infections are transmitted through heterosexual intercourse and 5.4% through parent-to-child transmission (NACO 2011). In 2004 the Indian government instigated a national campaign involving the target to establish 250 ART centres by 2011 as a means of providing free ART therapy to treat individuals with HIV (NACO 2007). According to research by Médecins Sans Frontières (2011) 293 ART centres currently exist and 424 802 individuals received ART in 2010 (MSF 2011; WHO/UNAIDS/UNICEF 2011).

Community Based Support for PLHA in India

While there has been some significant research exploring the efficacy of community-based HIV prevention programs both in India and internationally (Pegacao, 1991; Panos Institute, 1992; Schoef, 1993; Asthana & Oostvogels, 1996; Campbell, & Mzaidume, 2001; Basu, Jana, Rotheram-Borus, Swendeman, Lee, Newman & Weiss, 2004; Chattopadhyay & McKaig, 2004; Cornish & Ghosh, 2007; Evans & Lambert, 2008) limited studies have investigated the influence of community-based interventions within India to assist PLHA. A study by Kabore et al. (2010) explored the effectiveness of community-based support combined with medical care for individuals with HIV/AIDS in four locations in sub-Saharan Africa. The study revealed that individuals receiving community-based support experienced improved health outcomes in comparison to individuals subjected to usual care. Jana, Basu, Rotheram-Borus & Newman (2004) reported on the findings of the Sonagachi Project, a community-based intervention program based in Calcutta focusing on HIV prevention and treatment. The study revealed the program's utility and its broader application for communities beyond the sample population. Given the dearth of research focusing on community-based approaches to supporting PLHA in India, a recent qualitative study was undertaken to explore the efficacy of the services of a team of community-based workers providing psychosocial support to a community of PLHA in an urban setting in North India. The following section provides an introduction to the general study and methodology of the research undertaken.

Method

To examine the effectiveness of a community-based initiative in supporting PLHA in an urban Indian context a qualitative methodology was employed. 11 community workers working in a full-time capacity in a non-government organization (NGO) were recruited for the study. Prior to recruitment all participants were given comprehensive information delineating the purpose of the study and the extent of participant involvement through an information sheet and a face-to-face meeting with the researcher. Full ethical approval was given to undertake the research. Following consent to participate in the investigation, the researcher facilitated 11 in-depth qualitative interviews through the use of ten open-ended questions focusing on HIV/AIDS in India, the role of each participant in the NGO, their perceptions of the overarching function of the NGO and their specific work in supporting PLHA. The duration of each interview was between 60 to 90 minutes, providing the researcher with a rich data source with which to analyse emergent themes specific to the NGO's function and the community workers' roles in providing psychosocial support to individuals and families living with HIV/AIDS.

Participants

To protect the anonymity of the 11 participants recruited for the study and the population receiving support from the NGO, the name of the NGO and its location and the names of participants is not contained in this manuscript. The NGO was established in 2012 with the primary function of supporting the psychosocial and basic health care needs of children and families living primarily in three slum communities in a major urban city of north India. The founder and current director of the NGO established the service with the support of five foundation community workers who had been engaged previously in HIV/AIDS support work in a regional NGO providing routine medical care and psychosocial counseling services for PLHA. The need for the NGO emerged given that there was no existing services for the population that the NGO currently serves and team members witnessed the deaths of a significant population of individuals to AIDS within their residing community.

The NGO's model primarily focuses on home-based care, although there is an NGO centre where the NGO team can meet together and engage in case work associated with the beneficiaries receiving support from the service. The home-based outreach work involves two key components: meeting with individuals and families on a weekly basis to facilitate basic health checks including monitoring of blood pressure, weight and ART; and providing psychosocial counseling and support to assist individuals and families in navigating the challenges of living with HIV/AIDS in an urban setting. It is the NGO's policy that in the majority of cases at least two community workers conduct home visits together to provide optimal support for individuals and families and to ensure the safety of all individuals during the home visit service.

The 11 NGO community workers were originally drawn from a range of contexts within India, but have been residents in local contexts within a five-kilometer radius from the NGO and the beneficiaries accessing support. The median age of the community workers is (*n=32.7*). All workers have received a minimum of one year of intensive training to support PLHA. The minimum level of formal education of the 11 workers is 6^{th} standard and five of the workers have completed at least two years of tertiary studies. The years of working with PLHA in India also varied across the participant group from one year to sixteen years. However, the majority of participants had worked in a capacity that established them as experienced workers in the field. Further, 10 of the participants received weekly professional supervision from the NGO director (participant 11) who has undertaken extensive training in HIV/AIDS education and support over the sixteen years the participant has been working in the field. The NGO Director has established relationships with leading International HIV/AIDS training practitioners and receives regular support and supervision in this role.

The author conducted nine of the interviews during a two-week field trip to India. A research assistant who followed similar protocols to the earlier interviews facilitated the final two interviews. Two ensure that the two interviewers adhered to similar interview protocols, two face-to-face meetings were facilitated to address issues of methodological consistency during the interview process. The interviews consisted of ten open-ended questions focusing on HIV/AIDS and the Indian context and participant perceptions of their engagement as community workers providing support to PLHA. This structure facilitated consistency of data collection across the 11 interviews, as a means of identifying collective emergent themes associated with the community workers' experiences. To ensure the validity and reliability of data collection processes, following each interview, full transcripts were provided to each participant providing opportunity for further elaboration of responses and/or subsequent data to be adapted accordingly.

Data was synthesized through a process of coding involving the in depth study of each participant's response to specific interview questions, identifying core themes associated with each response and organizing these themes into a working document to identify convergent or disparate responses associated with each question. The following section provides a summary of the key themes that emerged through the process of data synthesis.

Results

Experience in the field:

The median length of time that the 11 participants had been working with PLHA was (*n=4.8 years*) with the most inexperienced worker having completed one year of work and the most experienced 16 years.

Experience in entering the field:

The majority of workers had had prior experience working with PLHA through other NGOs and undertook work with the NGO associated with this study because of the uniqueness of the model of service including the emphasis on home-based care. Participants expressed a commitment to contributing to society and acknowledged that there were few services in India providing adequate care of PLHA. This motivated each worker to undertake specific training in HIV/AIDs that ultimately led to their recruitment with the NGO. Three workers had also worked with people living with tuberculosis that led to extending their work to PLHA. Two participants spoke about the influence of personal experience with the GLBT community, fear of contracting HIV/AIDS and exposure to individuals living with HIV/AIDS as influencing factors in their future work with the NGO.

Participant perceptions about HIV/AIDs and its impact within the Indian context:

All participants displayed a comprehensive general knowledge of HIV/AIDS in India with each worker acknowledging the rapid spread of infection and the high population of individuals within India affected by HIV/AIDS. The majority also identified the high prevalence of HIV/AIDS within the state of Andhra Pradesh. Participants also identified the concern with many people in the population not being tested, indicating that the majority of individuals are diagnosed through accessing of alternative forms of treatment including basic surgical procedures, antenatal visits or medical examinations associated with visa requirements. A number of workers identified that the promotion of correct condom use has brought about some changes in rates of infection. However, it was reported that many conservative Christians hold strong views against condom use. There was a convergence of opinion that the majority of people in India do not

have sufficient knowledge about HIV/AIDs or medication to treat the disease. This influenced the significant discrimination against PLHA. Participants reported that many individuals who are infected are migrant workers and labourers and women involved in commercial sex work. One worker reflected on the negative impacts that HIV/AIDS has had on the Indian economy with the challenge associated with managing such a vast population of infected people. Most participants identified issues with the inaccuracy of reporting of PLHA. The Indian government recognised the trend for PLHA to register with multiple agencies and NGOs for different needs, exaggerating prevalence rates of HIV/AIDS. All workers stressed the deleterious impacts of HIV/AIDS in India and the importance of providing support for PLHA and implementing preventative measures to decrease the spread of the disease.

Perceptions of socio-cultural factors impacting upon PLHA

All participants indicated that there exists a concerning lack of education and awareness about HIV/AIDS. The impacts of this is significant with a range of prevalent social trends including: physical or psychological ostracisation from family and/or community members; children being refused admission into schools, effecting educational opportunity; high rates of infection due to limited understanding about preventative practices; accessing alternative treatment that is often costly and ineffective leading to acute infection and sometimes death; husbands and husbands' families blaming wives for spreading the infection when in most cases the husband is the initial carrier of the infection leading to spousal abuse or forced removal of the wife from the family home; resistance to accessing treatment including initial testing; individuals with higher levels of education failing to acknowledge their HIV status due to social shame and subsequently accessing private treatment options that are less effective than government-based approaches; cases where paternal families remove male children from mothers if the father of the child has died; stealing of property from family members following the death of a relative; death through suicide as a result of the social stigma associated with HIV/AIDS; and economic disadvantage due to the impacts of the disease on individual's capacities to work and the significant reliance on women who are often unskilled having to engage in cheap labour to support a family when a husband is no longer able to work. The majority of participants held the perception that stigma associated with HIV/AIDS is reducing, particularly in the district the NGO is located and this was perceived to be in part due to the work that the team are undertaking in reducing social barriers associated with HIV/AIDS through education and awareness raising.

Services provided by community workers

In response to a key question focussing on the services of the NGO and associated activities of community workers a range of key initiatives were identified. The primary focus of the community workers' responsibilities centred upon the provision of psychosocial support to assist in PLHA adjustment to living with the condition. This support involved working in targeted communities where the prevalence rates of HIV/AIDS were high with a central focus on home-based care. This approach involves workers visiting identified individual's homes on a regular basis (usually on a weekly basis for periods of one to three hours in duration). Participants emphasised that the focus of interaction was person-centred and deviated from highly medicalised models of patient care. Workers described the experience as 'relating like a family' rather than a social worker or counsellor. The focus of the visits included: enquiring about the individual and family's general well-being and medical health; case management focussing on assistance with and adherence to ART; HIV/AIDS education including general experiences of living with the condition and considerations for dealing with stages of illness; discussions about basic nutrition, diet, sanitation and

personal hygiene to promote ongoing health and vitality; referral to appropriate medical treatment and linkage to specific services for PLHA; practical assistance including house cleaning and general property maintenance, provision of basic food items (e.g. dahl, oil, rice etc.), often for widows - this is usually a coordinated effort drawing on contributions from the community; provision of basic psychosocial counselling to assist individuals in coming to terms with their HIV/AIDS status without fear, overcoming depression, suicidal ideation etc.; telephone assistance to discuss personal issues, issues related to their physical state, emotional well-being etc.; building of community toilets to improve hygiene and general sanitation; transportation of very sick individuals to government hospitals and ongoing assistance during the duration hospital admission; assisting in the admission of patients in the last stages of the disease to specific centres (hospices); routine simple medical check ups including monitoring of blood pressure and weight - if the individual is undergoing a particular treatment under a doctor's supervision workers will monitor and administer the treatment for the particular health issue the individual is experiencing; assistance with legal issues as they arise, directing individuals and families to legal services; guidance concerning children's educational needs; assisting infected women to find employment; and sporadic assistance in the provision of finances for low income families to receive treatment.

Along with the home-based care initiatives the NGO also provides a range of training opportunities focussing on HIV/AIDS to institutions, schools, colleges and churches and offers support to clients from the LGBT community including: education focussing on general sexual health and safe sex practices; empowering individuals to live a healthy and fulfilled life through one-on one counselling; specialised care for gay men experiencing the effects of 'double stigma' i.e. living as a gay, HIV/AIDS affected person; and the facilitation of a gay friendly clinic to reduce stigmatisation and broaden the social inclusion agenda focussing on HIV/AIDS and the LGBT community in India.

Perceived focus of NGO and community worker provision?

Participants were questioned on their perceptions about the greatest emphasis given to their work with beneficiaries. All workers acknowledged the central focus on home-based care and its significance to their roles and the NGO's service. The participants emphasised the rich experience of engaging with individuals and families in the home environment and the efficacy of this approach as a powerful tool to reducing social stigma and fear of rejection for PLHA, creating a powerful social space for acceptance, mutuality and personal transformation. Participants also recognised the role of home-based care in the promotion of personal autonomy and self-determination through interpersonal strategies such as psychosocial counselling. Discussion about the utility of telephone counselling was an emergent theme given the ease with which individuals and families could maintain close and ongoing social connection through phone conversation. Another key component identified as a focus of the service was the process of referral to other agencies to facilitate comprehensive and timely support. The role of the NGO as a drop-in-centre was another dimension perceived as a central component of the service.

Challenges in supporting PLHA

A key question of the interview focussed on perceived challenges experienced by workers in their engagement with PLHA. A strong theme that emerged across the interviews was the emotional exhaustion experienced by workers in supporting PLHA. For many of the participants, working with people experiencing loss, depression and other psychological responses associated with living with HIV/AIDS were often perceived as personally taxing. Some workers expressed that they experienced discouragement during times when they perceived that their level of assistance was limited or could not adequately assist

individuals and families in addressing problems. Dealing with individuals who are dying, especially young children, presented as a major challenge to the work. Another common issue experienced was the resistance of some family members to the services of the workers and NGO. Some families are reluctant for the workers to engage with infected familial members due to fear of stigma and social marginalisation. Another key issue is the demands placed on workers due to the perceptions of some affected individuals regarding worker accessibility. The majority of workers acknowledged that many individuals and families placed unrealistic demands on the worker's time, rendering ongoing challenges associated with the home-based model of intervention. For example, many individuals would call workers on their day off or during the evening, even though it was common knowledge that the participants only worked on specific days and at specified times. Participants also identified financial challenges associated with the work. For example, government funding and support from donors to facilitate the work of the NGO is limited and worker's salaries are very low. There was also acknowledgement that patient needs often require costs that are beyond the financial constraints of the NGO. Limited staff to provide comprehensive and sustainable support was also identified as another factor impacting upon the NGO service. This was influenced by financial limitations as well as a lack of motivation to engage in work involving PLHA. Another key issue was the challenges associated with fighting discrimination and stigma. Long held attitudes towards HIV/AIDS as a well as a lack of education create significant challenges in raising awareness about the disease and its implications for individuals and families affected by it – all workers articulated the strong desire for all people within Indian society to accept the status of HID/AIDs patients. Workers also mentioned that many families failed to have access to adequate nutritional support due to significant poverty that affected workers' capacity to facilitate ongoing routine medical care. Finally, participants expressed concern about the limited capacity to maintain the ongoing welfare of children in living with HIV/AIDS and/or supporting their affected parents.

Successes in supporting PLHA

In response to a question focussing on perceived successes associated with the work of the NGO, participants identified the positive changes that have occurred in terms of community attitudes towards HIV/AIDS. Through various educational and awareness raising opportunities the workers have assisted in helping community members to better understand the disease and how individuals can better manage living with HIV/AIDS through approaches such as ART management, boiling water and creating patterns to promote good nutrition. Workers also identified that the home-based care model has served to facilitate the establishment of strong allegiances with individuals and families. The development of trust between workers and beneficiaries has been a strong determinant in facilitating successful outcomes in terms of the NGO's service. The counselling support offered to assist individuals and families both through face-to-face and phone-based interaction has been another perceived success that has been instrumental in the provision of strong and sustainable positive psychosocial change. The provision of patient support in the hospital settings was another key part of the NGO service that was giving hope for people who were close to death. Participants also articulated success in building strong networks with other NGOs as well as partnerships with local community clinics. This served to further enhance the service provided by the NGO. Another perceived success was the development of a positive reputation within the immediate community and internationally. One participant mentioned that the U.S. embassy have recognised the work of the NGO and wish to maintain an ongoing relationship with them. The majority of participants discussed how they have observed individuals and families seeking out their service. Existing beneficiaries are referring new individuals and families in need of support that is serving to reduce the stigma associated with the disease. It was also highlighted that many family members engaged with the work of the NGO are less fearful of providing support to HIV/AIDS affected relatives.

Perceived impacts on beneficiaries

A related question linked to some of the successes of the NGO service focussed on the perceived benefits to beneficiaries. The greatest perceived impacts included: accessing necessary services to manage living with HIV/AIDS; improving sanitation though the building of toilets for people in village locations; increased societal acceptance and reduction of social stigma through worker engagement with families; education and awareness raising about HIV/AIDS within regular community populations; psychosocial support facilitating opportunities for individuals and families to share their difficulties, challenges and sorrows openly with the workers; improving overall quality of life, especially in relation to health outcomes with many service users living longer as a result of the NGO assisting in individuals and families managing ART and providing educational opportunity focussing on the promotion of a healthy lifestyle; helping clients at the final stages of the illness to die with dignity; and helping children to live with hope.

Perceptions associated with government support and education

Participants were questioned about their understanding concerning ways that the Indian government is assisting PLHA. The following key activities were identified: awareness programs about HIV/AIDS using street drama, posters and printed material published in a range of local dialects; preventative campaigns focussing on issues such as safe sex practices and education about ART; increasing access to comprehensive treatment, particularly for individuals and families living in poverty; provision of free ART; and counselling/educational opportunity through established government ART centres and VCTC (Voluntary Counselling and Testing Centres);

While all participants identified positive initiatives the Indian government was taking in supporting PLHA, each shared similar concerns about specific approaches the government was taking to address the HIV/AIDS epidemic. Participants articulated that government endorsed media campaigns often overemphasise the negative impacts of HIV/AIDS that has the potential to instil fear and despair about the disease. All participants recognised that this approach reinforced the stigma of living with HIV/AIDS within India and was influential in developing a distorted view about the affects of HIV/AIDS. While participants also acknowledged that media campaigns were improving, certain initiatives were ineffective. Four of the participants for example, mentioned a government led campaign where community workers and government employees were distributing free condoms to patients within government hospitals and other health services without also providing education about proper condom use. A number of participants also mentioned that the government was not providing effective teaching about the necessary measures to treat HIV/AIDS related health issues. There was a shared concern that many PLHA did not have knowledge concerning the best ways to access services for timely and reputable treatment.

Discussion

A number of key findings based on this small study are of significance in terms of understanding cogent methods for the provision of support for PLHA within a range of community populations in India. It is clear from the various themes that emerged following analysis of the 11 interviews that the role of community workers in the provision of services such as home-based care for PLHA is an efficacious method for responding to the needs of individuals and families affected by HIV/AIDS. Given the social stigma and pervasive discrimination that dominates the lived experiences of PLHA, government and non-government services must consider alternative treatment approaches including community worker engagement to care

for the physical and psychosocial needs of PLHA. It is evident through the stories of the 11 community workers recruited for this study that community workers in India bring dignity to the lives of people who are at greater risk of social marginalisation and poor health outcomes. Through regular social engagement with community workers and routine medical and psychosocial assistance PLHA are better able to manage living with the condition and lead lives that promote social inclusion. Such an approach provides opportunity to teach basic skills that are health promoting including the outlining of safe sanitation and hygiene practices and the communication of principles associated with basic nutrition and personal health.

A key factor in the effectiveness of community workers as an approach to supporting PLHA is the person-to-person contact central to this intervention model. Through regular face-to-face and timely and responsive phone engagement individuals and families managing the challenges of HIV/AIDS are able to experience psychosocial support that recognises each person's humanity and acknowledges the potential for PLHA to live life in all its fullness. Further, such contact serves to educate community populations as they witness first hand the positive affects that community based support can illicit in individuals and families affected by HIV. It is also apparent that community workers serve as powerful conduits to related health care services, assisting in the enhancement of comprehensive treatment approaches for PLHA. Finally, community worker models of engagement such as home-based care provide a cogent framework for assisting in the management of ART through effective and ongoing personalised approaches to case management that allow for timely, cost effective and person centred care.

Limitations

There were a number of limitations associated with this study influenced by the design and central focus of the research. The small sample size of 11 participants and the specific geographical location within which the NGO is based confines the impacts of the study to the services of the individuals employed by the NGO under investigation. This limits the generalisability of the study's findings to broader community populations with contrasting demographic and cultural characteristics. Finally, the study focussed on one model of care for PLHA. Future research should give consideration to alternative models of community based treatment that move beyond preventative measures and that ultimately aim to increase psychosocial support for PLHA. Such research would serve the broader agenda of increasing the quality of life of all PLHA and reducing the stigma and social marginalisation associated with the HIV/AIDS epidemic both in India and in other nations.

Conclusion

This paper has highlighted the effectiveness of community worker centred intervention approaches to provide psychosocial support for PLHA in India through the documentation of the lived experiences of 11 community workers employed in a community district in India. Key findings of the study recognised the positive impacts of community worker support for PLHA including: greater psychosocial adjustment to HIV/AIDS; increasing opportunity to live in regular community populations without fear of discrimination or marginalisation; intensive support that provides routine medical assistance and educational opportunity focussing on managing the challenges associated with living with HIV/AIDS; and the central focus on person centred approaches to community work with PLHA that serves to reduce social stigma and widen participation across a range of community contexts.

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