

Compassionate care: a socially inclusive model for the routine medical care of people living with HIV/AIDS in India

Stephen Larmar
Griffith University

Abstract

Routine medical care for people living with HIV/AIDS (PLHA) in India can present a challenge for service users given the significant stigma associated with living with these conditions. This paper reports on a small qualitative research project exploring an alternative approach to routine medical care that emphasises a socially inclusive model that serves to reduce the marginalisation experienced for PLHA accessing medical treatment. Six medical practitioners working in an outpatient clinic in a central city in India were recruited for the study and were engaged in in-depth interviews to investigate alternative approaches to medical treatment that emphasise compassionate, patient-centred care. The findings of the research indicate that compassionate care for PLHA in India promotes a socially inclusive model of support to increase beneficiary hope and reduce the stigma associated with this population. Such findings emphasise the need for major reform in service delivery in India for this population to ensure that they are treated with dignity and respect.

Key words: compassion, social inclusion, stigma, PLHA, HIV, AIDS, medical support, India.

Introduction

India has one of the highest rates of human immunodeficiency virus (HIV) infection, with an estimated 2.1 million adults and children living with HIV (UNAIDS, 2013). Stigma associated with HIV has been a major issue and area of interest since the rise of the global epidemic in the early 1980s (Zelaya, Sivaram, Johnson, Srikrishnan, Solomon & Celentano, 2008). Research into the impacts of HIV/AIDS related stigma are consistent across a range of settings (van Brakel, 2006). Within the context of India, the stigma associated with HIV has a major impact on people living with HIV/AIDS (PLHA) (Larmar, 2018; Larmar, 2016; UNAIDS, 2013) and may influence access to medical treatment (Steward, Bharat, Ramakrishna, Heylen & Ekstrand, 2012). Unfortunately, the stigma for PLHA in India also has implications for practices in routine medical care for this already marginalised population (Thomas, Ahuja et al., 2007).

Corresponding author: Stephen Larmar (s.larmar@griffith.edu.au)

This paper reports on the findings of a small qualitative study drawn from a larger investigation exploring the lived experiences of PLHA in India. The study examined the perceptions of six medical practitioners drawn from a community clinic in a regional centre of a large city in central India. The enquiry focused on the lived experiences of PLHA but gave emphasis to the significance of the provision of compassionate routine medical care in promoting greater social inclusion for individuals and families personally affected by HIV/AIDs. The findings of the study highlight the importance of social reform in the delivery of medical care for PLHA in India in order to reduce marginalisation and stigma as it is commonly experienced within this population.

HIV/AIDS in India

The first identified cases of HIV in India were detected in a population of female sex workers in Chennai in 1986 (Steinbrook, 2007). The current prevalence rate for HIV in India is approximately 0.26%, with the global average being 0.2%. However, the prevalence rate for high risk groups is 7% (Paranjape & Challacombe, 2016). Such groups include female sex workers, truck drivers, IV (intravenous) drug users, street children, refugees, prisoners and men who have sex with men (MSM) (Bhatia & Anand, 2009; Claeson & Alexander 2008; NACO, 2011, WHO/UNAIDS/UNICEF, 2011). HIV infections also commonly occur in married women whose male partners procure sex from commercial sex workers (NACO 2011; Pallikadavath, Garda, Apte, Freedman & Stones 2004). Further, Indian women of low status are over-represented among people with HIV (Mitra & Sakar 2011; NACO 2011; Solomon, 2009).

Transmission of HIV in India largely occurs through commercial sexual transaction, heterosexual intercourse, IV drug use and unprotected anal sex between MSM (Paranjape & Challacombe, 2016). The stigma associated with HIV in India has significant ramifications for the everyday lives of PLHA (Larmar, 2018; UNDP, 2017; Larmar, 2016; NACO, 2011). A range of factors influence the stigma experienced by PLHA in India including fear of contagion and death as well as a general lack of education and awareness about HIV (Paranjape & Challacombe, 2016). The impacts of stigma and marginalization more broadly include rejection and social exclusion which may culminate in discrimination and violation of an individual's human rights (Heijnders & Van Der Meij, 2006).

Current Approaches to Routine Medical Care for PLHA in India

Since the rise of the HIV epidemic in India including the peak of new HIV infections in 1998, a range of government led strategies including a national campaign to provide free ART (Antiretroviral therapy) as well as pensions and food subsidies have emerged with varying effectiveness (UNDP, 2017; NACO, 2011). However, the stigma associated with HIV/AIDS creates significant barriers to treatment and support services for PLHA (Kumar, Unnikrishnan et al., 2017; Larmar, 2016; Thomas, Ahuja et al., 2007). This issue is reflective of patterns of stigma and marginalisation internationally for PLHA impacting upon their access to health-related services (UNDP, 2017). A range of medical services exist for PLHA in India, including Integrated Counselling Testing Centres (ICTC). However, there is consistently high reporting of both government and non-government-based service providers overtly discriminating against this population, which has deleterious effects for individuals seeking support including PLHA experiencing a sense of marginalisation and reduced confidence in accessing medical support services (Larmar, 2018; Steward et al., 2012; Beattie, Bhattacharjee, Suresh, Isac,

Ramesh & Moses, 2012; NACO, 2011; Mawar, Sahay, Pandit & Mahajan, 2005).

Given the stigma and marginalisation PLHA in India experience in accessing medical intervention, the significance of this study, while small in scale, cannot be underestimated in terms of informing an alternative approach which promotes compassionate medical care as routine. The significant barriers that PLHA experience in India in seeking medical support necessitates the dire need for the development and implementation of alternative models of routine medical treatment that compassionately support this vulnerable population. To this end, the study described below served to highlight an alternative approach to routine medical care for PLHA in India that reduces barriers to treatment that are influenced by the stigma and marginalisation this population face.

Method

Primary research question: To address the research gap identified above, the following research question was developed to guide the investigation: What are the key approaches the clinic under investigation takes in its commitment to facilitating compassionate routine medical care for its beneficiaries as perceived by its medical practitioners? From this question a series of subsidiary questions were developed which formed the structure of an in-depth interview protocol consisting of ten open-ended questions which was utilised for the research participants recruited for the study. Subsidiary questions explored themes including: participant knowledge of the impacts of HIV for PLHA in India, key services for PLHA and challenges and successes associated with supporting PLHA. The interview protocols are discussed in a latter section.

Background of the clinic under investigation: In order to explore an alternative approach to medical support for PLHA in India that gives emphasis to widening the participation of this often-marginalised population an investigation was undertaken to focus on the services of a specific HIV clinic that provides a compassion centred approach to routine medical care. The research was conducted during a two-week field trip to India. The clinic was selected as the primary site for the investigation through the recommendation of a local non-government organisation (NGO) that provides support for PLHA in a community area in close proximity to the clinic. The NGO personnel of this organisation also regularly refer their beneficiaries to the clinic for any routine medical care and volunteer approximately eight hours of their time each week to work in the clinic. The researcher has had an ongoing partnership with the local NGO since 2007 which assisted in gaining permission from the clinic managers for their medical practitioner staff to participate in the research.

The clinic has been operating for over fifteen years and provides a free drop-in outpatient service for PLHA and their families. Beneficiaries of the service receive monthly access to one-on-one support from a medical practitioner who undertakes general health checks including: CD4 (cluster of differentiation 4) count levels, blood pressure, medication and general health monitoring. Access to free medication is also included as part of the clinic's service, with a fully functioning medication dispensary. As well as the six medical practitioners, other clinic staff include qualified nurses and trained support personnel who provide counselling and general health checks prior to seeing an allocated medical practitioner.

All clinic staff, including volunteers, are orientated to the values and practices of the service prior to employment. The values and practices of the clinic are underpinned by a Judeo-Christian tradition. However, this religious orientation maintains an inclusive approach regardless of an individual's age, gender, marital status, religious affiliation, cultural/ethnic

background, socio-economic status, caste, sexual preferences and levels of cognitive and physical ability. The principles that underpin the clinic's operation include: love for all people; compassion centred care; quality service; a non-judgemental approach, acknowledgement of beneficiary personal agency and an overarching commitment to social justice and human rights. Such an approach aligns with the orientation to compassionate medical care as described by Lown, Rosen and Marttila (2011).

All clinic service delivery gives emphasis to beneficiary self-determination, with a central focus on widening beneficiary participation in terms of decision making for all routine medical care and psychosocial support related activities included within the clinic's service. All staff attend one-hour morning meetings prior to the clinic being opened to the public each day in order to give focus to the values and principles central to the clinic work and to educate the group on current advances in HIV/AIDS treatment. Staff also receive monthly supervision to discuss their practice with a senior clinician as a means of maintaining professional standards of practice and to ensure that practitioner values align with those of the clinic.

The clinic receives limited financial support through government sources, however the majority of financial resources are sourced through private donations. Due to the stigma associated with PLHA in India, the clinic building contains no identifying information to protect the anonymity of its beneficiaries. Individuals accessing the clinic, learn of the service through referral from partner NGOs and government hospitals as well as through word of mouth.

Participant recruitment: To investigate the unique approach the clinic adopts in its interface with beneficiaries, six medical practitioners (all medical staff working for the clinic) were individually approached to engage in a face to face interview of approximately one hour's duration. All six medical practitioners consented to participate in the research. All participants were proficient in the use of the English language. Each interview served to capture qualitative data focusing on the perceptions of the medical staff in the delivery of services for PLHA referred to the clinic. A qualitative approach through the facilitation of in-depth interviews was deemed the most effective means to develop a rich narrative about the unique approach of the medical team in their delivery of services to PLHA, a highly-marginalised group within the broader Indian context (Larmar, 2016; Larmar, 2018).

The mean score for years of service to the clinic across the participant sample was 3.3 years, with the minimum period of service for one participant being 6 months and the longest period being 7.5 years. Of the full sample, three participants identified their gender as female and the remaining three, male. The mean age of participants at the time of the interviews was 49 years. All participants were internationally qualified medical practitioners (five Indian nationals and one U.S. dual citizen) with each having at least ten years of experience in the medical field.

Ethics approval: Prior to the facilitation of the research full ethical approval was granted for the project through the Griffith University's Human Research Ethics Committee (approval number: 5545). Each participant was given a full description of the nature and intentions of the research, including notification that participation in the research was voluntary and that they could withdraw from the research at any time. Following a full verbal description of the project for each potential participant delivered by the researcher, including the nature of the participant's involvement in the research, verbal consent to participate was gained.

Interview protocol: Interviews were conducted in a private room within the clinic to maintain the anonymity of the participants, in terms of their engagement in the research. Each interview was conducted between a 45 to 60 minute time period. The names of the city and state of India, as well as the clinic within which the participants were withheld from this paper given the sensitive nature of the service provided, the risks associated with identification of the population for which the clinic serves as well as the need to maintain the anonymity of the clinic

given that it is a confidential service.

The research questions were developed by the researcher in consultation with the coordinator of the local partner NGO mentioned in an earlier section to ensure that the researcher's enquiry was culturally relevant to the participant sample and consistent with the broader aims of the research. Ten key questions guided the in-depth interviews and gave emphasis to the following themes relating to each participant's: involvement in the clinic; knowledge of the Indian context relating to PLHA; level of orientation to key services offered for PLHA; awareness of the role of government in educating people about HIV/AIDs; and the perceptions associated with the nature and impacts of the clinic's service for beneficiaries.

All interviews were recorded and transcribed in preparation for data analysis. Prior to the recording of all interviews, the researcher sought full informed consent of each participant to record each respective interview conversation. The interview content was initially categorised according to the themes outlined above in order to initiate a second data analysis phase which involved organising responses into more refined categories that identified patterns of participant response convergence and deviation. The following section presents the results of the study.

Results

Participant entry into the clinic context

All participants shared an initial interest in working with PLHA prior to engaging as medical practitioners within the clinic. Participant one and six were originally working with leprosy patients in India but became interested in working with PLHA. As a result of their experience in recognising the significant need for alternative medical support for this population they founded the clinic. The combined responses below articulate this background information:

We were originally doing work with leprosy patients until the end of 2003 – we finished the leprosy work at the end of 2003 (Participant One) – we waited for future direction and for 6 months we kept scouting for places to run an AIDs clinic – but because there were no suitable places to carry out the work we started the clinic in our home in June 2004 (Participant Six)

Participant two and four received their medical training in the U.S. and became interested in working with PLHA during that time. Participant two found out about the clinic through a relative and commenced work there shortly after. Participant four had been working in a range of NGOs and subsequently found out about the work in the clinic which led to their recruitment with the team. As participant two stated:

One of my colleagues said that they needed a doctor and I was also looking for work to help people with HIV – I thought in addition to what I want to do I can help with HIV and work in the clinic (Participant Two)

Participant three heard from a colleague in another organisation that the clinic was recruiting medical staff which led to their commencing work with the clinic. Participant five had heard about the work of the clinic through a neighbour while working in a Muslim hospital. They became interested in working in the clinic because they had heard that the staff adopted an alternative approach that was based on compassionate care. The following responses are outlined below:

My husband and I decided we wanted to work with people with HIV – we got special training in the US and then moved to India where we visited various NGOs to work out where we wanted to work - we then came to this clinic and decided this was where we wanted to work (Participant Three)

I am a doctor and I was interested in working with people with HIV (Participant Five)

All six participants indicated that the key motivator that drew them to working for the clinic was the clinic's overarching approach to working with PLHA. This approach was underpinned by a person-centred framework of care, grounded in compassionate support and driven to achieve the primary goal of developing patient autonomy and self-agency. The following participant response reflects this motivation:

Patients will go to other hospitals to get treatment in order to protect their anonymity and they often get the worst treatment even though the medical profession are aware of how the disease is contracted because the health professionals are still concerned that they may become infected... People in our clinic often have to scout around the city to find doctors who are willing to help... patients keep coming back – they know they are receiving great care – they are being physically touched, people care for them – they don't get this treatment in the government hospitals – we show kindness to their children – we help to give them hope! They are not going to get this anywhere else (Participant Three)

Participant perceptions of the current HIV/AIDS epidemic in India including government responses

All participants understood that there were approximately 2.1 million PLHA in India with the first cases of the disease emerging in the mid 1980s. Participant one highlighted that in recent years HIV rates across India had declined, however the problem is still having major impacts within Indian society:

...curve has flattened in the last few years – a multiple pronged approach has been taken – Government bodies and NGOs are making a difference... some of the spread has occurred through economic changes – lots of movement between cities and regions through lack of jobs – many single men end up coming to the cities to work and utilise the services of prostitutes – they then go back to their place of origin and infect their women (Participant One)

There was the shared perception amongst all participants that HIV infection primarily occurred through sexual contact with commercial sex work being a major factor in the spread of the disease, as well as IV drug use.

Four participants articulated that the spread of HIV was also influenced by the increase in men from rural locations migrating to bigger cities for work and contracting the disease through sexual contact with commercial sex workers. All participants expressed the view that the incidence of HIV/AIDS was highest in the state in India within which the clinic is located, with one participant stressing that the location of the clinic was strategic to combatting the problem within that particular city:

In India and especially in (state deidentified) the incidence of HIV is quite high – a lot of people are affected – this is mainly because of the migrant workers who come from the villages – they are alone working here and they have sex with partners in the city and they contract the disease (Participant Four)

Participant two and six indicated that many people in India have limited knowledge about HIV/AIDs which impacts upon the stigma associated with the condition. However, all participants talked at length about how people in India are becoming more aware about HIV/AIDs through government campaigns. Further, participants emphasised that the government has been developing strategies to support PLHA but were mainly focused on routine medical support in contrast to more holistic approaches that consider the psychosocial needs of PLHA as reflected in the following participant responses:

The government is concentrating a lot of its work in the cities...each hospital is providing HIV medication at no cost to the patient (Participant Five)

Some of the initiatives are educational in intent – conferences with students or other specialist groups...whatever the government is doing, it is not enough (Participant Three)

Participant one mentioned that the government has developed a range of resources (fliers, posters and brochures) as well as media campaigns to broaden societal awareness about HIV/AIDs. They also indicated that medical practitioners are provided with government training to orientate them to key considerations for working with PLHA. Participant two added that while the government provided clinics to offer routine medical care for PLHA, many of the clinics were understaffed and could not meet the significant demands associated with this population or provide personalised quality care:

We need to have more centres to assist patients with HIV because of the population – clinics are understaffed so they are not able to give the attention that the patients need – it is not at all possible for them – [the patients] have no relationship with the Doctors at the government hospitals - and even the help that they give to children is limited – they really can't give the comprehensive treatment necessary to manage the disease because of the limited resources available (Participant Two)

Participant five emphasised that the government was unable to reach all groups, hence the significance of the clinic under investigation. As indicated below, participant five also mentioned that the majority of HIV clinics were situated in major cities, impacting upon the capacity for individuals living in rural and remote locations to seek adequate and timely support.

The government is concentrating a lot of its work in the cities...the government can't reach everybody – that is why the work of this clinic is so important (Participant Five)

Participant perceptions about the socio-cultural dimensions for PLHA

All participants were united in the predominant view that PLHA experience significant stigma, discrimination and abuse. Participant one and four mentioned for example that children with HIV/AIDs are denied access to regular schools and that employees will not disclose their HIV status to their employers due to the fear that they will lose their jobs. Participant two indicated that many PLHA experience rejection from their family members and community:

Many families may go to the extent of chasing the infected person out of their houses and women are forced to go and live with their parents...When the women go to their parents they are facing an equal amount of harassment from their other in-laws (sister/brother in-laws as well as their brothers and sisters) - so life

becomes very difficult for them (Participant Two)

They also shared a recurring observation that women were largely blamed for bringing the HIV infection into the family and as a result were physically ostracised from the family home. Participant three emphasised that many PLHA do not disclose their status even to close friends and family members due to the fear of rejection. They also highlighted barriers to treatment access for PLHA due to the stigma attached to the disease. For example, parents may find it difficult to come up with excuses for children missing school to attend medical appointments or employees may need time off work for follow-up medical appointments but are unable to speak openly with their employers about these appointments for fear of dismissal.

They have to make up excuses to go out and get medication – they may have to take time off work to visit the clinic and their employer may become suspicious...It is difficult for families with children with HIV – they often have problems because they need to take the kids out of school for treatment and the school also gets suspicious wondering what is wrong with the child (Participant Three)

Participant three also described the common occurrence for PLHA having to go to government hospitals for treatment in order to protect their anonymity but in the process receiving poor treatment outcomes and experiencing discriminatory attitudes from medical staff. They also mentioned that some of their patients lost their jobs if their HIV status was revealed to employers.

Participant four articulated that many PLHA become too sick to work, which impacts upon their capacity to provide for their families. As a result, they lose hope which can affect their decision making around timely access to treatment. Participant six highlighted the shame that PLHA experience and the subsequent rejection from friends and family. Participant one did acknowledge as evidenced below that, through greater education within Indian society about HIV/AIDs, condition for PLHA are slowly improving, however discrimination remains a serious issue for the population.

Conditions are improving for people with HIV but in general people can't reveal their status to family members – if they do, they do it only with their immediate family...stigma and discrimination is the reason for this (Participant One)

Key services offered by the clinic

All participants highlighted that the clinic gives emphasis to the provision of counselling more generally as well as pre- and post- test counselling, to assist individuals in their psychosocial adjustment to living with HIV/AIDs. This is unique to the majority of HIV services offered in India that are limited to the provision of routine medical care. Counselling services within the clinic focus on patient history, including psychological and physical health status and emphasise a strong educative component to assist individuals in understanding how to best manage the disease. As participant five indicated:

In this clinic we mainly offer patients counselling – and also medical treatment – the treatment is then followed up with further counselling (Participant Five)

All participants indicated that psychosocial counselling was considered a core component of the clinic work that facilitated compassionate care for all patients. Of note, participant four stressed that no other hospital or service gives the same kind of one-on-one focus that places the patient at the centre of their care, highlighting the uniqueness of this approach within the Indian context:

When the patient first enters the clinic, we counsel them – we speak to them – we spend time with them...no other hospital would do that – we spend a lot of time with the patients (Participant Four)

All participants also communicated that the clinic provides free access to a range of medicines and vitamin supplements to promote the health and well-being of each patient. However, free ART can only be accessed via government hospitals due to tight regulations associated with the distribution of ART.

Participant one and two mentioned that the clinic also provides a range of social support initiatives such as assistance with payment of children's school fees, facilitating training for women to develop skills for gaining meaningful employment and support for people with intellectual impairment. All participants indicated that the clinic provides basic routine medical care such as: general physical assessments including HIV testing; early diagnosis of tuberculosis; blood pressure monitoring; blood tests to determine the extent that the disease has progressed; ART adherence protocols; medical assistance for diabetes and asthma; treatment of opportunistic infection as well as management of common symptoms associated with HIV; and referral to specialist care beyond the clinic.

Participant three stressed that the clinic is committed to providing high quality HIV care that was undergirded by current research and quality guidelines and standards. They also highlighted the significance of the clinic service in maintaining a patient centred orientation that was compassionately delivered. Participant six also mentioned that home-based care was provided for people who were physically unable to access the clinic. All participants articulated that clinic staff promote hope in all services offered within the clinic to give dignity to every individual as highlighted in the following participant response:

We also show them hope - that they can look forward to a better future with good treatment and better nutrition (Participant Four)

Challenges associated with the clinic services

Participants were invited to consider what were the greatest challenges facing the clinic service. All participants indicated that there were some major resource challenges for the clinic, particularly given the high population of patients accessing services. Such resource challenges were centred around clinic staff capacity and limitations around access to free medication. Participant one highlighted that such resource challenges also impacted upon the quality of care that could be sustained for all users of the clinic service:

...resources are a challenge – there are never enough resources – financial – personnel (Participant One)

All participants communicated that the government's restriction on allowing the clinic to administer free ART medication presented challenges for patients who were then driven to seek free medication from government hospitals whose services were marked by discriminatory attitudes and sub-standard patient care. Participant two highlighted that patient lack of adherence to ART protocols created challenges in the provision of routine care.

Participant three identified language barriers as a primary challenge given that English is their first language and they have limited capacity to speak local dialects. They also mentioned that some patients have difficulties accessing the clinic due to poor transport options or a lack of resources to fund the journey to the clinic:

Language barriers are significant for me given that English is my primary language – we try to develop relationships that help with the language barrier... there are patients who aren't able to come because of transport – we wish there were easier ways for them to access the clinic – that is a challenge for many – you aren't always able to keep track of what is going on in the patient's lives because they can't get here all the time (Participant Three)

Participant four highlighted some of the challenges in assisting more vulnerable individuals such as those who present symptoms of suicidal ideation or who are experiencing depression due to the stigma associated with the disease. Participant five identified some challenges in developing trust with specific patients due to the stigma and shame the patients carry in living with HIV. They mentioned however, that such barriers were generally overcome as a result of the compassionate orientation of clinic staff towards each individual seeking treatment:

Sometimes it is difficult to develop trust and rapport with the patient but gradually we build trust – by showing them love and acceptance they will open their hearts to us and to the work we are doing (Participant Five)

Impacts of the clinic service for PLHA

All participants indicated that the clinic was increasing hope for PLHA. More specifically, individuals accessing the clinic service experienced a sense of acceptance despite their HIV status and their first-hand experiences of stigma and marginalisation from the broader community. Participants also highlighted how the educational component of the counselling services was changing people's attitudes and behaviours about managing the disease on a daily basis.

Participant one mentioned that clinic staff are able to give focus to discussing various social issues that patients experience but that are not able to be explored within services such as public clinics and government hospitals. They also mentioned that they have been able to provide quality medical care, even in the face of mounting resource challenges. Specialist referral to other organisation has also benefited patients:

Also a lot of times they have social issues that the government can't address – familial issues between husband and wife and children issues – we are able to counsel them and offer psychosocial support...we have been able to deal with any medical issues – basic through to complex – we can give vitamins and antibiotics – we then can refer them to other hospitals for more complex conditions (Participant One)

Participant two indicated that clinic staff have been able to improve the health of many children diagnosed with HIV, which has provided a source of hope to primary caregivers as well as other family members as they see their children making incremental health gains that allow them to function within their respective communities. Participant three mentioned that patients continue to return to the clinic. This is a major achievement given that many patients have shared that the lack of support and experiences of discrimination when accessing alternative services created significant barriers to ongoing treatment and general engagement.

Participant four articulated that the focus on compassionate support has been a key driver in the growth of the patient population accessing the service over time (from 700 patients in 2004 to over 5000 + patients in 2017). Further, they indicated that individuals seeking treatment often comment on how the service significantly contrasts other services where compassionate

care is not central:

*The patients realise that they are not rejected – each one of us will show them love
(Participant Four)*

Services for women and children offered within the clinic are also having a significant impact including increasing access to regular schools for school aged children and assisting women in finding gainful employment. Clinic staff liaise with government schools to promote access for child patients as well as reaching out to local businesses as a means of facilitating potential work opportunities for women. Participant six commented on how clinic staff could see the way that patient's lives were transformed through the ongoing commitment of clinic personnel to provide quality medical care that is grounded in a compassionate and holistic orientation, giving emphasis to both the physical as well as the psychological dimensions of each individual's life:

*We want to attain high quality without compromising on core values – that is
compassionate medical care, living life to the fullest, giving hope to the hopeless
and reaching out and touching lives (Participant Six)*

Discussion

The results of the study highlight a number of key themes associated with the routine medical care for PLHA in India that warrant discussion. It was apparent in all of the participant interviews that individuals were specifically drawn to working within the selected clinic due to its overarching orientation to provide medical support that was centred in compassionate client centred care. Such an approach advocated for the rights of individuals and served to increase client self-determination. All participants acknowledged that this approach was unique within the broader Indian context in terms of the delivery of medical services for PLHA. Such findings are consistent with research by Thomson, Mimiaga, Mayer et al. (2012) and Van Brakel (2006).

All participants were well versed in the HIV/AIDS epidemic in India and its impacts upon society at large. Participants acknowledged that the spread of HIV infection occurred primarily through sexual contact and IV drug use and that further education was necessary to promote safe sex practices to reduce the incidence of HIV infection. All participants emphasised the significance of increasing services for PLHA to improve quality of life and to promote social inclusion, particularly for individuals managing the challenges of HIV/AIDS in rural and remote areas where services were limited. Such factors in improving the quality of care provision for PLHA in India are further supported by Mawar, Sahay, Pandit & Mahajan (2005), Steward et al. (2012) and Larmar (2016).

The results of the study also highlight the serious issue of stigmatisation for PLHA. The stigma associated with HIV/AIDS leads to increasing marginalisation across all sociodemographic groups, although research suggests that women and individuals living in abject poverty in India are most vulnerable to social exclusion. Despite the Indian government's commitment to the provision of medical services for PLHA, barriers to effective treatment are still apparent due to the attitudes of medical staff towards PLHA. Further education and ongoing accountability are necessary to improve government services providing routine medical care for PLHA. Further, alternative services should also be considered that promote greater awareness of the issues for people living with HIV/AIDS and that implement models of compassionate service delivery. These findings align with research by Heijnders & Der Meij (2006), Beattie et al (2012), Kumar et al (2017) and Larmar (2018) focusing on the need for further development of services to address the stigma and marginalisation for PLHA in India.

Participants also highlighted the current resource challenges associated with services for PLHA. The growing population of PLHA represents a major challenge for medical service providers in terms of resource constraints. Limiting access to free ART to government hospitals for example increases the burden for non-government services in the provision of quality care. Limited transport services for people living in remote locations also represents real barriers to engagement. The need to prioritise the physical health needs of clients due to resource constraints also limits the capacity of health workers to address the psychosocial needs of PLHA. This is of major concern given the impacts of stigma and the growing trend of social exclusion faced by PLHA and is consistent with research by Thomson, Mimiaga, Mayer et al. (2012) and Larmar (2016).

Finally, the research findings highlight the positive impacts of compassion centred routine medical care for PLHA. Such an approach promotes a sense of hope for a community living with the daily challenges of survival in a society that largely discriminates against PLHA. The work of the clinic practitioners is increasing the agency of clients through: education that promotes autonomous health management, facilitating greater access for women and children; and an emphasis on the psychosocial dimensions of health care.

Strengths and Limitations

There were a number of strengths and limitations to the study. However, before focusing specifically on the strengths and weaknesses specific to this investigation, it is important to acknowledge more broadly the unique opportunities and challenges in utilising a qualitative research design for a study of this kind. One of the most significant advantages to the facilitation of a small study is the opportunity to develop a more nuanced and complex understanding of the lived experiences of a specific population or group. Larger quantitative inquires, while gaining useful data that can be generalised to broader population, often do not generate more in-depth understandings of the lived experiences of individuals or groups. Major challenges in utilising predominantly qualitative research methods with a small cohort is the non-generalisability of findings, and challenges with legitimising their validity given the propensity for researchers, particularly in the hard sciences, to favour quantitative over qualitative data sources.

One of the strengths of this research was in amplifying the often-silent voices of health practitioners located in services that provide alternative models of care for PLHA. Another strength lay in the focus of the unique service the clinic provides. There is a current lack of services that facilitate compassionate centred care that address both the physical and psychosocial needs for PLHA in India. A major limitation of the study was the small sample size of participants. While only six practitioners were interviewed for the study, this sample represented the entire medical staff working in the service. Another limitation was that the service represented one specific orientation to the delivery of routine medical care for PLHA within one location in an urban centre of India. These study limitations impact upon the generalisability of findings to other geographical locations and health service providers in India.

There are a number of lessons learned through this study that may serve to guide future research and practice in best supporting PLHA in India. Future research should give consideration to amplifying the voices of individuals providing alternative forms of medical support for PLHA that are specifically focussed on eliminating discrimination and marginalisation through further qualitative studies of this kind. Research targeting larger sample populations in both urban and rural settings within India could also be undertaken to broaden understandings about the most effective ways to provide holistic support for PLHA. In terms of improving practice for supporting PLHA in India, services must consider approaches to working with PLHA that locate humane responses into service provision. The inclusion of psychosocial counselling within general medical practices, access to affordable service care

free of discrimination and distribution of community-based resources to raise awareness of the lived experiences of PLHA are important steps in improving routine medical care for this specific population.

Conclusion

The findings of this research highlight the significance of a model of routine medical care that strengthens the agency of PLHA in India and promotes greater social inclusion for a traditionally marginalised population. The stories of the medical practitioners recruited for the study provide a resounding narrative that celebrates the significance of applying a compassionate model of care to best support PLHA. The study emphasises the need for alternative models of medical support for PLHA in India that encourages client self-determination and highlights the importance of socially inclusive practices in public health.

References

- Beattie, T.S.H., Bhattacharjee, P., Suresh, M., Isac, S., Ramesh, B.M. & Moses, S. 2012. "Personal, Interpersonal and Structural Challenges to Accessing HIV Testing, Treatment and Care Services Among Female Sex Workers, Men who have Sex with Men and Transgenders in Karnataka State, South India." *Journal of Epidemiol Community Health*, 66: 42 – 48.
- Bhatia, N. & Anand, P. (2009). Barriers to Sustainable Access of Children and Families to ART Centers in Rural India: A report on operations research conducted in Maharashtra and Manipur. India HIV/AIDS Alliance.
- Claeson, M. & Alexander, A. (2008). Tackling HIV in India: Evidence-based priority setting and programming. *Health Affairs*, 27, 1091-1102.
- Heijnders, M., Van Der Meij, S. (2006) The fight against stigma: an overview of stigma reduction strategies and interventions. *Psychology Health Medicine*, 11, (3): pp. 353–363.
- Kumar, N., Unnikrishnan, B., Thapar, R., Mithra, P., Kulkarni, V., Holla, R., Bhagawan, D. & Kumar, A. (2017) Stigmatization and discrimination toward people living with HIV/AIDS in a coastal city of South India, *Journal of the International Association of Providers of AIDS Care*, 16, (3), pp. 226 – 232.
- Larmar, S.A. (2018). Men who have sex with men (MSM) living with HIV in India: Challenges and Opportunities for Community Support, *International Journal of Interdisciplinary Social and Community Studies*, 13, (1), pp. 13 – 24.
- Larmar, S.A. (2016). Perceptions of community workers in the provision of psychosocial support for individuals living with HIV/AIDS in India. *European Journal of Business and Social Sciences*, 4, (10), pp. 61 - 72.
- Lown, B.A., Rosen, J. & Martilla, J. (2011) An Agenda For Improving Compassionate Care: A Survey Shows About Half Of Patients Say Such Care Is Missing. *Health Affairs*, 30, (9), pp. 1772 – 1778.
- Mawar, N., Sahay, S., Pandit, A., and Mahajan, U. 2005. The third phase of HIV/AIDS pandemic: Social consequences of HIV/AIDS stigma and discrimination and future needs. *Indian Journal of Medical Research*, 122: 471 – 484.
- Mitra, A. & Sarkar, D. (2011). Gender inequality and the spread of HIV-AIDS in India. *International Journal of Social Economics*, 38, 557-572.

- National AIDS Control Organization. (2011). Annual Report 2010-11. <http://aidsdatahub.org> (last accessed 2 August 2018).
- National AIDS Control Organization and Institute of Health and Family Welfare. Annual HIV Sentinel Surveillance Country Report. Last modified June 14. 2006. https://www.who.int/hiv/mediacentre/2006_EpiUpdate_en.pdf?ua=1
- Pallikadavath, S., Garda, L., Apte, H., Freedman, J. & Stones, W. (2004). HIV/AIDS in rural India: context and health care needs. *Journal of Biosocial Science*, 37, 641-655.
- Paranjape, R.S. & Challacombe, S.J. (2016). HIV/AIDS in India: an overview of the Indian epidemic, *Oral Diseases*, 22, (1), pp. 10 – 14.
- Solomon, S. (2008). Challenges in the Management of HIV disease in India. <http://www.cgdev.org/content/calendar/detail/15481/> (last accessed 2 August 2018).
- Steinbrook, R. (2007). HIV in India; A complex epidemic, *The New England Journal of Medicine*, 356, 1089 – 1093.
- Steward, W.T., Bharat, S., Ramakrishna, J., Heylen, E. & Ekstrand, M.L. (2012). Stigma is associated with delays in seeking care among HIV-infected people in India, *Journal of the International Association of Providers of AIDS care*, 12 (2), pp.103 – 109.
- Thomas, B., Mimiaga, M.J., Mayer, K.H., Closson, E.F., Johnson, C.V, Menon, S., Mani, J., Vijaylakshmi, R., Dilip, M., Betancourt, T. & Safren, S.A. (2012) Ensuring it works: A community-based approach to HIV prevention intervention development for men who have sex with men in Chennai, *India AIDS Education and Prevention* 24 (6), pp. 483-499.
- Thomas, K.M., Ahuja R.C., et al. (2007). Screening for HIV infection by health professionals in India. *National Medical Journal India*. 20 (2): pp. 59 - 66.
- United Nations Development Programme HIV, Health and Development report. Retrieved August 2, 2018, from http://aidsdatahub.org/search/node/general%20HIV%20treatment%20type%3Areference_library_item
- United Nations Joint Programme on HIV/AIDS. Global report: UNAIDS report on the Global AIDS Epidemic. Modified at June 7. 2013: Available at: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf.
- Van Brakel, W. H. (2006). *Measuring health-related stigma: A literature review*, *Psychology, Health and Medicine*, 11, pp. 307 – 334.
- World Health Organization, UNAIDS & UNICEF. (2011). Global HIV/AIDS response: Epidemic update and health sector progress towards Universal Access - Progress report. http://www.who.int/hiv/pub/progress_report2011/en/ (last accessed 2 August 2018).
- Zelaya, C.E., Sivaram, S., Johnson, S.C., Srikrishnan, A.K., Solomon & Celentano, D.D. (2008). *HIV/AIDs stigma: Reliability and Validity of a new measurement instrument in Chennai, India*.

Biographical Notes

Stephen Larmar's research focuses on children and families with a strong emphasis on child protection and engagement with vulnerable populations. Over the last six years his research has been directed more broadly towards international work with projects in India centring on the psychosocial adjustment of individuals living with HIV/AIDs and Nepal where he has been working in a consulting capacity with Terre des hommes, focussing on exploitative and hazardous labour in child populations. Dr Larmar is currently employed as a senior lecturer working in the School of Human Services and Social Work, Griffith University. He is a qualified counsellor and psychotherapist and over the last fifteen years has consulted in an advisory capacity for a range of organisations focussing on training and development in counselling and

working with children and families. In 2011 Dr Larmar was awarded a National University Teaching Award in recognition for his teaching excellence in a range of disciplines including counselling, psychology and social work.