

POSITIVITY AND PROSPERITY GO HAND-IN-HAND: THE STORY OF UNSUNG HEROES FROM PUNJAB

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ABSTRACT

Background: With approximately 24.7 lakh people living with HIV in India, and nearly one lakh HIV positive people in Punjab, the role of outreach workers becomes crucial in providing support, linking patients to medical care, and combating discrimination. **Aim:** The current study is based on the concept that someone who has gone through a situation and has been successful in overcoming it can be instrumental in assisting others to recover from a similar situation. The exploration delves into the personal experiences of HIV-positive outreach workers exhibiting their motivations, struggles, and the unique insights they bring to their communities. **Methods and Materials:** Through in-depth interviews, the study highlights the experiences of three outreach workers (a woman, a man, and a transgender woman). **Results and Conclusion:** The study aimed to understand the critical role these workers play not only in their own lives but also in the lives of those they assist by understanding peer support models and stigma prevailing in society.

Keywords: HIV/AIDS, outreach workers, stigma, resilience

INTRODUCTION

World Health organisation (WHO) in its 2013 report had accepted that since the AIDS epidemic begun, close to seventy million people have been infected with virus and half of them have already died of AIDS. It also listed Sub-Saharan Africa as the most severely affected, with nearly one in every twenty adults living with HIV. After more than ten years we see that HIV remains global concern and has also affected people in India in large numbers. According to the estimates provided by National AIDS Control Organisation in 2023, India has an estimated 24.69 lakhs persons living with HIV. In state

of Punjab closer to one lakh persons are affected by HIV. The exact number is stated to be 1, 05,791. Among the states, the rate of positivity among the injection drug user (IDU) population is most pronounced in Punjab (Swain et al., 2017). IDU population is very hard to track and deal with and they are at higher risk of contracting infections (Rahimian & Pach, 1999). Various government and non-government organisations and staff are working in sync to sustainably deal with its sustainable management which involves a combination of preventative and curative measures. As the HIV stigma related to HIV

in India is ubiquitous, acknowledging and documenting the field experiences of the volunteers working with AIDS patients becomes extremely important. Outreach workers are very important given their significant role at the ground level and are considered to play a central role in combating the HIV situation in India (Hidalgo et al., 2011). The most vital role they play is in tracking and bringing back the patients for the treatment. This can be life saving for the patients battling economic and social hardships. The main functions of outreach workers is creating linkage and referral to medical facilities. Outreach workers promote Tuberculosis (TB) screening and HIV testing (India HIV/AIDS Alliance). Here it is important to highlight that the outreach workers who are HIV positive tend to be more efficient and successful in counselling as it involves the peer support. But at the same time, HIV positive outreach workers have to face more challenges than others while working on the ground.

OBJECTIVES OF CURRENT STUDY

The current study is based on the concept of empathy that someone who has gone through a situation and has been successful in overcoming it, can be instrumental in assisting others to recover from similar situation. The exploration delves into the personal experiences of HIV-positive outreach workers exhibiting their motivations, struggles and the unique insights they bring to their communities. We can better understand the critical role these workers play not only in their own lives but also in the lives of those they assist by understanding peer support models and stigma prevailing in the society. Case studies illustrate the transformative power of hope and advocacy depicting how personal journeys can ignite change and foster resilience in the fight against HIV/AIDS.

METHODOLOGY

This study employs a qualitative approach to explore the experiences of HIV-positive outreach workers of the state of Punjab. The identity of workers as well as care centre visited is kept as confidential as per norms. In-depth interviews and provided a deeper understanding of their personal journeys, motivations and challenges. Participants were selected based on their roles within Care and support centres (CSCs). Representation of every gender was taken into consideration and those participants were selected who are HIV positive themselves and were considered good performers in the centre. Exploratory research methodology aimed to provide rich insights into the lived experiences of these individuals and the broader implications for HIV outreach work and support.

REVIEW OF RELATED LITERATURE

Notwithstanding the perceived comfort that can come from someone with the same lived experience, this concept is complicated. Some common wounds might not be an asset, and have been deemed detrimental (Fussell & Bonney, 1990), or unsuitable for example experiences of past criminal convictions, drug and alcohol addictions, and mental health issues (Gleed, 1996). It has been observed that it is only after resolution of painful or traumatic experiences that empathy for others might be available. (Cristy, 2001). McDonald (2001) stressed that empathy was a critical component of participatory research. Recent advances in treatment have improved the health of many people living with HIV/AIDS. The study by Yallop et al. (2002) shows that the changing context of care is also impacting significantly on people who provide services. The study explored four themes: hope and optimism; changing context, roles and identities; changing relationships; and quality of life. Study findings have implications for the wider health care context and the changing

roles and power balances within this arena. Sheppard (2004) argues that a researcher using grounded theory should seek an empathic understanding of the people they are studying, to make sense of their responses by putting yourself in their shoes. When shared understanding and common experiences are discussed in the qualitative research literature, the concept of insider/outsider status is more commonly discussed. The insider/outsider status is understood to mean the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group. A related topic is 'common wound effect' which implies that giving any empathy at all might be determined or undermined by the helpers' own past experiences. Hodgson (2006) acknowledged that the anxiety felt by healthcare workers coming into contact with people living with HIV and AIDS (PLWHA) has been recognized in numerous studies. There is often an amplified notion of threat and a worldview fuelled by stereotypes, which inevitably leads to negative attitudes and stigmatization. Using an ethnographic approach which included a 14-month period of observation and 31 semi structured interviews, and, collecting data for the years 2000 and 2001 in a large teaching hospital in the United Kingdom where the caregivers had a high level empathetic approach accompanied by close engagement with the client group concluded that using nursing staff specially prepared for the care of PLWHA could be the most effective way to minimize stigma and discrimination against this client group in the healthcare sector. Fox et al. (2009) found that doctors who had experienced a significant health condition believed that they felt more empathy, particularly toward those patients who had a similar health condition. In turn, this empathy led them to use more self-disclosure with their patients and to work

in more empowering ways. Lin et al. (2013) in their study aim to investigate health care providers' empathy levels and its association with avoidance in providing service to patients living with HIV/AIDS (PLWHA) in China. A total of 1760 health service providers were randomly sampled from 40 county hospitals in two provinces of China. Using a self-administered questionnaire, participants' demographic characteristics, work history, empathy level, and avoidance attitudes toward PLWHA were collected in a cross-sectional survey. Empathy was higher among participants aged 31–40 years, those who had an associated medical degree, and those who had served in the medical profession for less than 20 years. Nurses, younger providers, and providers with lower education tended to avoid contact with PLWHA. Multiple linear regression model showed that a higher level of empathic attitude toward patients was significantly negatively associated with avoidance attitude toward PLWHA. Service providers' empathy level plays an important role in providing quality care to HIV-infected patients. Future stigma reduction interventions should cultivate empathy as a platform for understanding, effective communication, and trusting provider–patient relationships. PLWHA could potentially benefit from attitudinal change in medical settings. Kumar et al. (2015) conducted an in-depth interview and focus group discussions with members of established support networks to examine the pervasive HIV-related stigma in India and its impact on People Living with HIV/AIDS (PLHA) in Tamil Nadu. The stigma surrounding HIV in India is enhanced by taboos related to modes of transmission and societal attitudes towards certain groups especially sex workers. Several effective coping strategies include clear knowledge and understanding of HIV, social support and family well-being, selective disclosure and participation in positive networks. This study also informs culturally

relevant interventions aimed at reducing stigma and enhancing the coping mechanisms of PLHA in India to promote their well-being and integration into society. Busza et. al. (2018) showed that the reliance on community health workers (CHWs) for HIV care continues to increase, particularly in resource-limited settings. To assess CHWs' experiences delivering the intervention, they conducted longitudinal, qualitative semi-structured interviews with all 19 CHWs at three times during implementation. CHWs expressed strong motivation, commitment and job satisfaction. They considered the intervention acceptable and feasible to deliver, and levels of satisfaction was found to be positively related to empathy. Nugroho et al. (2020) explored the perspectives of men who have sex with men (MSM) and transgender women (waria) on an outreach approach promoting HIV testing in Indonesia. Semi-structured interviews were conducted with 32 participants. This research revealed positive experiences with outreach workers (OWs) who were seen as key motivators for accessing HIV testing and care. Clients valued the accessible HIV information provided by OWs and emphasized the importance of face-to-face contact, particularly for waria. They suggested that outreach should be more engaging incorporating activities that foster professional and life skills while utilizing positive framing around HIV prevention. The study highlights the need for tailored outreach strategies addressing the diverse social and health needs of MSM and waria. Building trust between clients and OWs is essential for effective service engagement and retention in HIV care. Park et. al. (2020) through their study explored the nature of emotional expressions found among patients new to HIV care, how HIV clinicians respond to these expressions, and predictors of clinician responses. Patient-provider encounters were audio-recorded, transcribed, and coded using

the VR-CoDES. They categorized patient emotional expressions by intensity (subtle 'cues' vs. more explicit 'concerns'), timing (initial vs. subsequent), and content (medical vs. non-medical). Emotional communication was present in 65 of 91 encounters. Clinicians were more likely to focus specifically on patient emotion for concerns versus cues and were less likely to provide space when emotional expressions were repeated, medically-related, and from African American patients. They concluded that the potential areas for quality improvement include raising clinician awareness of subtle emotional expressions, the emotional content of medically-related issues, and racial differences in clinician response. According to study by Iryawan et. al. (2022), in Indonesia, people who inject drugs (PWID) face significant challenges in accessing HIV care, often due to late diagnoses, delayed treatment initiation, and poor retention in care, leading to high morbidity and mortality rates. Contributing factors include legal and systemic barriers, alongside stigma and distrust towards healthcare services. To address these issues, conducted a community-led qualitative study involving in-depth interviews with 20 participants including PWID living with HIV, peer support workers, and service providers in Jakarta and Bandung. The study revealed unanimous support for peer support initiatives were seen as instrumental in improving access to HIV testing, linkages, referrals and adherence to antiretroviral treatment. Participants elaborated about various benefits of peer support, such as enhanced HIV awareness, emotional backing, assistance in navigating healthcare systems, and fostering trust in services. These findings depicted the critical role of peer support in promoting engagement with HIV care for PWID in Indonesia. The study calls for increased prioritization of peer support interventions to connect at-risk populations with essential

health services.

CASE STUDY OF A WIFE: FROM DESPAIR TO STRENGTH

A middle-aged woman of 45 years old served as an outreach worker for an organization in Punjab dedicated to tracking and counselling individuals living with HIV. Her unwavering commitment for guiding patients was commendable given the fact that she was working throughout day at the modest salary of rupees 11,000. Her profound empathy stemmed from her own experience as an HIV/AIDS patient having endured the condition for more than twenty five years. However, she shared that her journey was not without tribulations. At the age of twenty, she was thrust into this harrowing reality and was devastated to discover that her husband who worked as a truck driver was living with HIV/AIDS and soon learned that she had contracted the virus from him. She further shared that the situation worsened when her husband succumbed to the disease and her in-laws subjected her to cruel discrimination by isolating her and refusing to share meals prepared by her. She left their home overwhelmed by this treatment and returned to her parents feeling desolate and devoid of purpose. In her despair, she started questioning the rationale of her existence and wondered why such misfortune had befallen her believing she had committed no wrongdoing. During this tumultuous phase, a cousin encouraged her to shift her perspective from negative to positive. With the support of her mother, he made her realise that she could play a pivotal role in the transformation of lives of others suffering from the same. They inspired her to reclaim her life for herself and for those who believed in her potential. With their encouragement and support, she decided to overcome every obstacle in her path and remained determined to meet the expectations of her supporting family

members. She also sought alternative treatments in 2002, invested close to thirty thousand rupees in ayurvedic treatment which unfortunately yielded no improvement. Disheartened by the available treatments, she turned to an Antiretroviral Therapy (ART) Centre seeking stability, where she began to feel a sense of balance. She later found employment at a toy shop, deriving joy from the laughter of children and the satisfaction of their parents. It seemed as though her life was finally on an upward trajectory until a neighbour disclosed her HIV status leading to her dismissal from the job. She reveals that it was a difficult phase as again found herself engulfed in uncertainty. However, life had other plans. She learned of a vacancy for an outreach worker at an organization while collecting her medication from the ART Centre. She was encouraged by her mother and cousin to apply for the job. Ultimately, she secured the position which allowed her to connect with many individuals living with HIV. Inspired by her own journey and the stories of others, she realized her capacity to effect change through tracking, counselling and guiding patients. This newfound purpose became essential at a time when she teetered on the precipice of hope and despair. Today, she is fulfilled in her role dedicating her heart and soul to improve the lives of those affected by HIV. She affirms that dedication is the result of her struggles and she is relentlessly working to express her gratitude and transmit an indomitable will to live and learn in others like her. She acts as a beacon of hope for those who had either lost faith or were teetering on the brink of despair. Her journey is profoundly inspirational demonstrated by resilience and positivity despite the challenges life presented. Interacting with her made us convinced that her vibrant aura imbued with positivity and she has the power to impact lives.

CASE STUDY OF A YOUNG ATHELETE: A MAN LIVING ONCE IN THE DARK LEADING OTHERS TOWARDS THE LIGHT

A young 24-year-old youth from Punjab having attractive attributes including tall height, beautiful turban, well-groomed moustaches, polite tone, glooming eyes, well-mannered etiquettes, muscled body and perfect physique was the one who has been serving Care and support centre since one and half year profoundly. An informative and productive discussion between the researchers and Care and support centre outreach workers was continuing when he was asked by the researcher, "What made you join Care and support centre and how is your experience?" Nobody was prepared for what his answer professed. It was unexpected and shocking as well. He answered the question very undauntedly that he is HIV Positive, and this has inspired him to work with Care and support centre. There was not even the slightest hesitant tone in his voice which reflected his acceptance and positive approach towards the status of HIV Positive. He revealed that he was a young 18-year-old Kabaddi athlete pursuing diploma in Physical education. As he was a very good athlete he had won a bike, many medals and laurels with his outstanding performance in Kabaddi tournaments. In 2017, during a hospital visit for some ailment he got the shock of his life as he was diagnosed with the HIV Infection in 2017. He revealed that at that time he felt that all he had was lost and nothing can repair the void that has been created in his life. In his words, "my heart ached and brain was unable to respond to the situation". The heaviness of thoughts gave birth to suicidal thought. Soon, this thought was changed into reality and he attempted suicide in 2017. He now believes that it was the grace of God that he was unsuccessful in giving up his life with his own hands. His parents tried to help him with their love, care and compassion which

convinced him to take the treatment of HIV but his hope and actions were not consistent all the time. He was among the lost to follow up patients at Antiretroviral therapy Centre. As the care and support centre he was going to, kept keen eye on follow up patients who fail to report back, he was traced and was counselled well. Through them he also got to know about the vacancy in Care and support centre as the Outreach Worker. He applied for the vacancy and got selected, which acted as a turning point in his life. He took up this job to get involved in productive tasks to avoid indulging in the negative thoughts that constantly pushed him to the deep dark world. Eventually, he started working on the ground and realised he is more fortunate than most of the HIV infected population. He felt inspired by his participation and the protagonist role he was playing in people's lives. He got involved in this profession whole-heartedly to bring a positivity in the lives of other patients. Now, he is also pursuing a Bachelor of Arts simultaneously with his profession. Even the meagre salary of rupees 13000 is not a concern for him as he thinks that all his good deeds will bring him good health and a good future. Now he is considered at his workplace as a role model who holds the hands of HIV positive patients in the dark and guides them to the light.

CASE STUDY OF A TRANSGENDER WOMAN: DANCING THROUGH ADVERSITY

In her late twenties, a transgender woman in Punjab identified as she found joy in dancing and singing at auspicious occasions, such as for a newborn, in lohri celebrations and weddings. She bestowed blessings upon newborns and newlyweds with genuine warmth. During this vibrant period, an NGO organized an HIV/AIDS testing camp in 2009 near her locality. She decided to undergo testing alongside others in her community as she was aware of her vulnerability due to her

profession. Her world shattered when she received the news of her HIV-positive status. She reveals that it felt like an unbearable addition to the discrimination and ridicule she faced because of her sexuality. She struggled to maintain hope as the virus took a toll on her physical health and emotional well-being. However, her mother and siblings remained steadfast in their desire for her to live a life filled with joy. In the moments of thoughts and reflection, she often wished that her father had not passed away at a young age. Then perhaps she would not have been compelled to pursue sex work as she believed that the virus had been transmitted through encounter with HIV-positive clients. Her family came in support and encouraged her to take treatment. Finally she embarked on a journey of treatment at an antiretroviral therapy centre with the support of her family and the compassionate counselling from the NGO staff. She diligently followed her treatment regimen leading to a gradual improvement in her condition which allowed her to continue her work. Finally she aspired to inspire others driven by a newfound purpose and applied for the position of outreach worker for HIV and her prior education led to her successful appointment. She now reveals that the sense of accomplishment in serving others invigorated her spirit. She now passionately counsels individuals and encourages them to pursue treatment. She is also actively involved in spreading awareness for safe sex practices. She further reveals that even amid mockery by many in the society and her personal hardships such as the loss of her mother, she persevered and later moved in with her paternal uncle while supporting her partner through health struggles. She reveals that she had decided to move in with her paternal uncle after her siblings got married and settled. Her partner lived with them for a few years but eventually chose to return to his own family due to deteriorating health

from HIV. While talking about support of family, she shared that during a difficult period marked by partial hearing loss and speech issues from the virus, her sister stood by her side, offering support and solace. She also reveals that throughout this, she remained dedicated to her role as an outreach worker, and for them, her energy and passion never waned. She continued to sing and dance at events while fulfilling her outreach responsibilities undeterred by her modest salary of rupees 10,000. Her unwavering zeal and enthusiasm for both (entertainment as a profession and outreach as a social responsibility) illustrate a remarkable blend of passion and compassion while serving as an inspiration to all who encounter her journey.

GENDER AND HIV

The detailed analysis of all three case studies reveals that the challenges related to their HIV status are identical in all three. The differences based on gender roles, were not affected by HIV status in the current study. The main challenges were:

Stigma and Discrimination: All three individuals faced significant stigma related to their HIV status. The woman experienced isolation from her in-laws, the young man dealt with societal perceptions of masculinity and vulnerability, and the transgender woman faced discrimination due to her sexuality. Each overcame this stigma through personal growth and community support.

Mental Health Struggles: The young man struggled with suicidal thoughts after his diagnosis, while the transgender woman faced depression and feelings of despair. Their journeys illustrate the importance of mental health support and the power of community in fostering hope and resilience.

Socioeconomic Challenges: Despite modest salaries, all three individuals found meaning in their work. Their commitment to helping others outweighed financial concerns, showcasing their desire to contribute to society despite economic limitations.

Health Management: Each person navigated the healthcare system seeking treatment and support. The woman transitioned from Ayurvedic treatments to Antiretroviral Therapy, which highlighted the importance of effective medical care. The young man also pursued consistent treatment after initially falling out of the healthcare loop.

Role of Family and Support Systems: Family played a crucial role in their journeys. The woman received support from her cousin and mother, the young man was encouraged by his parents, and the transgender woman had her family rally behind her after her diagnosis. This support was vital in helping them reclaim their lives.

EMPOWERMENT THROUGH ADVOCACY Each individual transitioned from being a patient to an outreach worker. This role not only allowed them to help others but also empowered them by transforming their own experiences of hardship into tools for advocacy and support. It helped them in two main ways:

Overcoming Past Trauma: The transgender woman particularly navigated her trauma related to her profession and loss of family. Her journey illustrates resilience in the face of a challenging past, emphasizing healing and personal growth.

Community Impact: They aimed to uplift others in similar situations, breaking the cycle of despair and providing guidance by becoming outreach workers. Their stories

serve as beacons of hope for those facing similar struggles.

CONCLUSION

These case studies exemplify how individuals can rise from adversity and become agents of change in their communities. Their stories demonstrate how personal journeys can inspire hope and resilience which tend to transform not only their own lives but also those of the communities they serve. Each individual's narrative reveals the multifaceted issues they confront which includes stigma, mental health struggles, socioeconomic hardships and the pivotal role of family support. Their transformative journeys exhibit how personal adversity can lead to empowerment and community impact apart from fostering hope and change within their communities while reinforcing the importance of empathy.

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