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## Livelihood intervention and mental well-being among women living with HIV in Delhi

Kalei R.J. Hosaka<sup>a</sup>, Ezer Kang <sup>b</sup>, James Huff<sup>c</sup>, Sheeba Shaw<sup>d</sup> and Savita Duomai<sup>d</sup>

<sup>a</sup>John A. Burns School of Medicine, University of Hawaii at Manoa, Honolulu, HI, USA; <sup>b</sup>Department of Psychology, Howard University, Washington, DC, USA; <sup>c</sup>Human Needs and Global Resources Program, Wheaton College (IL), Wheaton, IL, USA; <sup>d</sup>Emmanuel Hospital Association, New Delhi, India

### ABSTRACT

Poverty-alleviation programmes aimed to improved mental well-being among persons living with HIV (PLWH) in low and middle income countries have underscored the importance of understanding how and why such programmes work. We present findings from a six-month ethnographic process evaluation of *Kiran*, an economic livelihood programme locally designed to improve mental well-being among women affected by HIV in Delhi, India. In addition to benefits of improved economic standing, we found that supportive relationships cultivated among participants ( $n=9$ ) and with providers ( $n=3$ ) provided respite from worry about their illness and reframed what was relationally and practically possible in the context of living with HIV. In acquiring marketable craft skills with peers, participants challenged internalized scripts of being socially devalued and regained agency about their abilities to contribute to their community and support their children's immediate and future needs. We found that the benefits of *Kiran* weighed less on the direct alleviation of mental distress and more on the instillation of hope for their children. Our findings exemplify the importance of re-visiting a priori theories that inform interventions for PLWH and highlight the methodological merits of ethnographic approaches that underscore how theory and intervention praxis are bidirectionally informed.

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HIV/AIDS; livelihood; India; ethnography; stigma; women

There is a growing consensus that theory-informed livelihood interventions can improve mental and physical well-being of persons living with HIV (PLWH) (Tsai et al., 2017; Weiser et al., 2017). The demands of managing poverty and HIV illness in resource-limited contexts such as India can contribute to increased morbidity, diminished quality of life, and heightened stigma (Kang et al., 2016; Schensul et al., 2009; Zelaya et al., 2012). The link between food insecurity, economic stress, and mental health have been well-established (Lund et al., 2010; Tsai et al., 2016). As such, livelihood interventions aimed at improving the economic standing of PLWH may reduce stigma through poverty reduction and have the potential to reframe perceptions of PLWH as contributing members in the community (Tsai et al., 2013). These interventions also dispel associations often made between HIV and imminent mortality and immorality, thereby reducing the stigma commonly internalized by PLWH (Tsai et al., 2017).

Several other pathways have explained how livelihood interventions improved mental health among

PLWH (Hardee et al., 2014; Hatcher et al., 2020). Some of these pathways have been formative in creating interventions and programming (Lauby et al., 2000). A cross-sectional study of 196 HIV-seropositive adults who received medical services at a community HIV support center in Delhi, India, for example, showed that ownership of fewer household assets was associated with higher levels of food insecurity, which in turn was associated with higher psychological distress. These findings suggest the need to design, evaluate, and refine HIV mental health interventions that are integrated with economic livelihood programmes (Kang et al., 2016). However, few theories have been informed and iteratively shaped by interventions, including livelihood programmes (Schensul et al., 2009).

This paper presents findings from an ethnographic process evaluation of *Kiran* – a theory-informed programme aimed to improve mental well-being among women affected by HIV in Delhi by supporting means to improve their economic livelihood. The theory underlying the intervention was that mental and

physical wellbeing is improved by reducing economic insecurity (Kang et al., 2016; Tsai et al., 2017; Weiser et al., 2017) and strengthening personal agency and life purpose (Hatcher et al., 2020; Weiser et al., 2011). Longitudinal, qualitative methodology may help clarify how livelihood interventions potentially affect mental wellness among PLWH (Hatcher et al., 2020). Informed by an ethnographic approach, we explored how participants experienced HIV and poverty and how the intervention may have influenced their mental well-being.

## Methods

Since its inception in 2001, the organizational mission of Shalom has been to provide medical and supportive services for persons living with HIV in socioeconomically disadvantaged communities in Delhi. Staffed by Indian physicians, nurses, and community outreach workers, Shalom provides in- and outpatient medical services to persons with acute HIV-related illness at their 10-bed Health Centre located in northern Delhi. Shalom piloted *Kiran* in 2015, a livelihood intervention for women<sup>1</sup> affected by HIV. Participants were trained with requisite skills to manufacture, market, and sell craft products and received a monetary stipend. Informed consent was obtained. Two Institutional Review Boards at each participating site approved the research protocols.

This study – conceived after *Kiran* was implemented (between June 2016 and June 2017) – utilized various data collection techniques based on an ethnographic approach. These included participant-observation, semi-structured interviews, and pre–post group meetings with *Kiran* participants. Ethnographic evaluation – which entailed the collection and analysis of qualitative data in the context of long-term relationships – was utilized to assess programme processes and to identify how participants were influenced by programme activities (Holmes, 2006; Odell Butler, 2008). In contrast to a conventional quantitative evaluation design, which are often less feasible for local development programmes operating on small budgets, an ethnographic approach builds on contextual knowledge and allows key stakeholders to generate knowledge of actual programme practice, which in turn can guide programme implementation (Bell & Aggleton, 2012).

An ethnographic approach prioritizes participant-observation as an iterative process that necessitates immersion in the life of a specific sociocultural context, directly observing patterns of ordinary behaviour that occur and listening to everyday conversations of people who inhabit that context. The ethnographic team carefully documented and recorded the experience of

participants by taking extensive fieldnotes, which were used as one key data source for analysis. The first author (KH) completed a six-month internship at Shalom in 2015, volunteering primarily with a home-based visitation programme, wherein community health workers visited families affected by HIV monthly to provide psychosocial support. Over the course of six months in 2017, KH (fluent in English and conversational Hindi) spent 3–4 days per week as a participant-observer at *Kiran*, utilizing a systematic and generative approach to inquiry (Miller et al., 2003). Semi-structured interviews were conducted with each participant in Hindi by SS, while KH recorded responses in English writing (we did not receive IRB approval to audio record the meetings). Participants were asked to describe their experiences living with HIV, involvement with *Kiran*, and identify how the intervention may have affected their overall well-being.

Finally, SS and SD met with *Kiran* participants as a group before the formal start of this project and following the completion of the data analysis. Although these group meetings were not strictly focus groups per se, they were intended to introduce the purpose of the study and to glean initial impressions about their experiences with the programme (Gill et al., 2008; Morgan, 1998). Participants were familiar with each other and their HIV status, which provided a level of comfort and homogeneity in talking about sensitive topics (Bernard, 2005). The first group meeting ( $n = 5$ ) addressed topics related to participants' experiences of living with HIV and illness-stigma, and the second group ( $n = 5$ ), was convened to draw critical feedback and elaboration on the preliminary evaluation findings.

## Data analysis

Following a standard ethnographic approach situated in the field of cultural anthropology and interpretive medical anthropology, data were analyzed in the context of participation, observation, informal conversations, and relationships over a period of six months (Holmes, 2006; Schepher-Hughes, 1990). KH regularly coded and systematically analyzed fieldnotes and interviews. Over a period of three months, KH and senior authors weekly analyzed fieldnotes and written interview transcripts. These findings were carefully discussed as a team, which shaped ongoing generation and exploration of themes.

## Results

The aim of this study was to explore and describe participants' experiences of *Kiran*, a local livelihood

**Table 1.** Kiran participant background ( $n = 9$ ).

	Median (range); $n$ (%)
Age	35 (18–40)
Widow, $n$ (%)	2 (22%)
Education $\leq$ Secondary, $n$ (%)	8 (89%)
Education $>$ Secondary, $n$ (%)	1 (11%)
Family income per month apart from Kiran, Mean (SD)	61 USD (0–273)
HIV-positive, $n$ (%)	6 (67%)
Significant debt <sup>a</sup> $n$ (%)	5 (55%)

<sup>a</sup>Defined as unable to be paid off with 1 year's wage at Kiran.

programme, and how their participation potentially influenced their mental well-being and capacity to cope with stressors related to HIV and poverty. Nine women participated in *Kiran* between June 2016 and June 2017 (median age = 35-years-old; range = 18-years to 40-years). Six were HIV-seropositive and three were HIV-seronegative caretakers of family members who were living with HIV (see Table 1 for background information). All received medical and supportive services at Shalom prior to participating in *Kiran*. Our analysis of interview, field observations, and meeting transcripts with 9 participants and 3 providers at Shalom revealed the following themes that described how participants were affected by the intervention: positive self-appraisal as community member and caregiver, improved relationships, and respite from worry about HIV status.

### Positive self-appraisal as community member and caregiver

Participants described their work with *Kiran* as stable and respected by their community and families. Such an opportunity for women to receive remuneration for learning a vocational skill was uncommon. BR, a 36-year-old participant, for example, explained that “at *Kiran*, we get paid to learn. And even after we learn, we can keep learning and earning”. When asked what made her most happy since joining *Kiran*, 38-year-old VS responded, “Gaining the skills that I have gained here in the last year have made me most happy. Even if I lose all of my material possessions, no one can take these skills away from me”.

Participants internalized their illiteracy and lack of employment skills, believing they could not contribute to their families or society-at-large. The culture of learning at *Kiran* challenged women to imagine life beyond perceived limitations with HIV, an important aspect of mental well-being. They began to challenge societal scripts that speculated their potential to acquire a skill-set and excel at it. Thirty-five-year-old LD explained, “When I first came to *Kiran*, I never thought I could

ever make a bag with this quality. But now I am able to do this. My goal for the future is to continue improving my skills”.

Their newly acquired skill sets also encouraged participants to believe that they can provide for their children, as 39-year-old PK with four children explained: “[Prior to *Kiran*] my biggest fear was: ‘How will I take care of my children if my husband is ill?’ I am illiterate. ... How will I work?” Although the income generated from their work at *Kiran* was meager, it was symbolic of how they can practically support their children's future – an eminent concern and worry for mothers living with HIV. VS explained that she saves some earnings for her children's education. A clear overall theme that emerged from these responses was that the practical skills gained at *Kiran* bolstered their confidence and appraisals of what they were capable of accomplishing – a stark contrast to prior scripts of self-defeat and futility.

### Improved relationships

Supportive relationships between participants were established largely by informal interactions with each other in a common work space. Casual conversations during work and breaks deepened into personal storytelling of their experiences of living with HIV or caring for family members with the illness – ones that frequently extended outside the work hour. Participants often compared *Kiran*'s work environment with to previous interactions with co-workers and employers at local factories, the main employment option for women with minimal education in poor urban areas. In these factories, a bottom line of production output placed considerable pressure on workers. In contrast, *Kiran* participants worked in a more relaxed manner (*araam se*). PK elaborated that she enjoyed sitting “*araam se* and [talking] while working at *Kiran*, sharing joys and sadness”. Working *araam se* motivated participants to invest in their work and relationships.

*Kiran* also functioned as an extended family for participants. Women often felt isolated from their own families. LD recounted that when her extended family found out her husband died from HIV, they stopped eating and talking with her. HIV ruptured family networks leaving many women feeling alienated. This was particularly debilitating giving the centrality of family as a source of social and practical support in the Indian context. It was understandable that RK considered her co-workers at *Kiran* “like family”. Others described their co-workers at *Kiran* as “companions”, their “support”, and peers who could help them “overcome their sorrow”.

*Kiran* staff also were a source of emotional support. In addition to teaching them how to make high quality crafts, the staff related to participants as HIV seronegative peers. When participants first talked about HIV with *Kiran*'s staff members, they "were confused. They asked, 'How do you feel when you are around us? Are you scared you will get HIV when you eat with us?'" These relationships were experientially corrective in that participants re-considered what was socially and relationally possible. Isolation due to HIV was not their only option.

### Respite from worry about HIV status

The environment at *Kiran* also provided participants with respite from worry and fear of being singled out and stigmatized because of their HIV-status. This was clearly expressed by 40-year-old NS who explained: "Because we talked and shared about being [HIV] positive ... *Kiran* provided me with an opportunity to forget about my illness daily". These conversations broadened the meanings women ascribed to living with HIV.

Participants also did not worry about the effect of HIV on employment stability. The option of returning to the programme after extended leave due to an extended sickness or hospital visits offered women additional security and stability which further reduced distress. Similar to other PLWH in India, participants attend monthly medical appointments to receive highly active antiretroviral therapy at government hospitals (Rai et al., 2017).

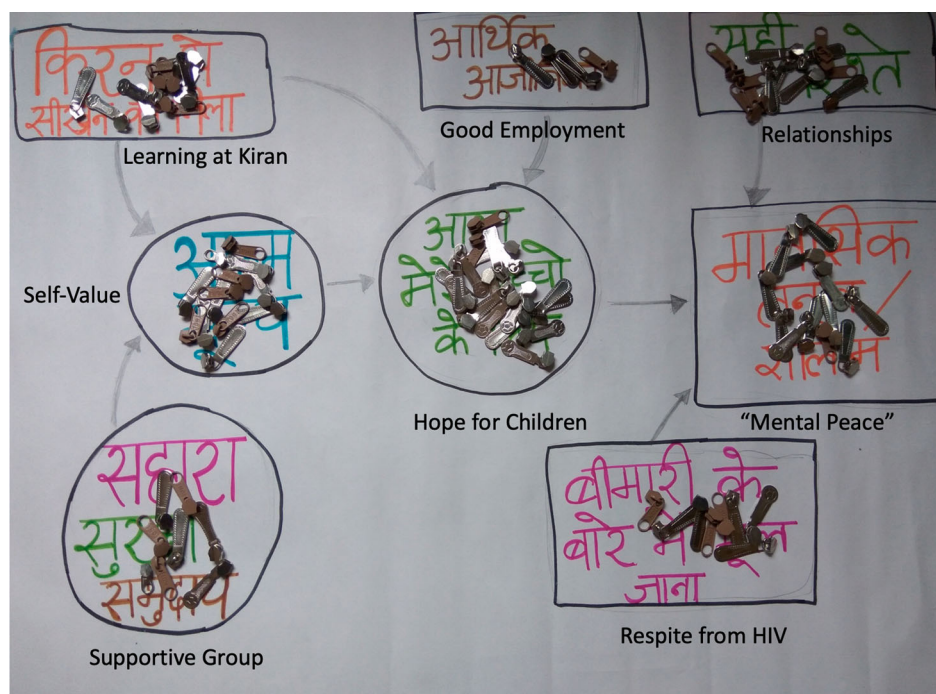
Participants reported dealing with unpredictably long queues at such appointments. In previous work settings, several participants fabricated reasons for missing work for medical visits out of fear of inadvertent disclosure of their HIV status. Removing the fear of losing employment because of illness offered additional reprieve.

### Thematic model

We (SS, EK, KH) presented the themes identified from the interviews and field observations to the participants. At this second group meeting, they elaborated on the nature and strength of relationships between the themes and placed zipper tags on the diagram that denoted how they were most affected by the programme (Figure 1). The women underscored how their relationships with each other chiefly instilled confidence in their ability to attend to their children's immediate and future needs. In addition to achieving a moderately stable livelihood, the women emphasized their positive shift in self-appraisal as parents and persons living with HIV and how this was a source of hope and "mental peace". Based on these group findings, we revised our model to reflect areas emphasized (Figure 2).

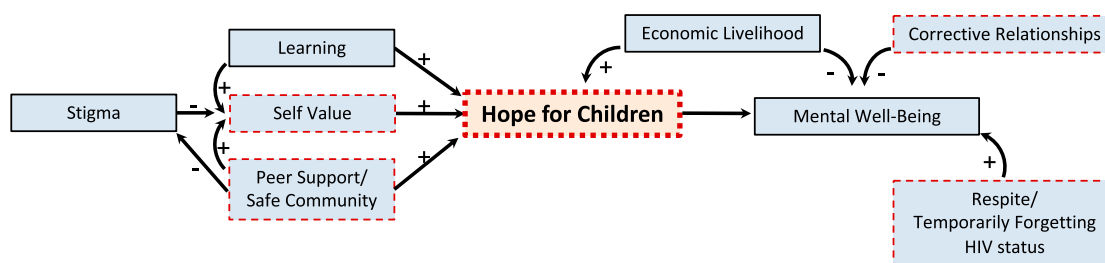
### Discussion

Results from this process outcome evaluation showed that in addition to the benefits of improved economic



**Figure 1.** Visual thematic model: participant feedback. Note: Participants placed zipper tags in circles/boxes representing themes that resonated with them most.





**Figure 2.** Experiences of participating in Kiran: Revised and final thematic model after post-evaluation feedback from participants ( $n = 9$ ). Note: (+): positive relationship; (-) negative relationship. Thickness of squares with dotted outline denotes level of emphasis participants indicated for a theme (drawn from second group meeting).

livelihood, the supportive relationships cultivated among participants and providers reframed or corrected what was relationally and practically possible for the women and their families in the context of living with HIV. Prior studies of livelihood interventions for PLWH in African regions have similarly found that improved economic standing was coupled with “social reintegration and reversal of status loss” (p. 134; Hatcher et al., 2020; Tsai et al., 2013). Longitudinal evaluation findings in Kenya and Uganda, for example, highlighted that improved sense of self-efficacy and social standing collectively improved mental health for PLWH above and beyond improved short-term livelihood gains (Hatcher et al., 2020; Tsai et al., 2012). Our findings aligned with these important conclusions by emphasizing that the process of acquiring livelihood skills with peers living with HIV increased personal agency and challenged stigmatizing scripts of what were deemed acceptable and possible for women living with HIV in Indian society.

Our findings further highlighted that this recategorization ushered a sense of relief and reprieve from worry about social stigma, livelihood security, and caring for children. Although the cumulative alleviation of these stressors over time offered overall respite, reversal of discredited social status and assurance in participants’ ability to support their children’s immediate and future needs was a primary source of “mental peace”. In addition to the merits of strengthening stigma reduction components of integrated HIV and livelihood programmes, we learned that many women prioritized their children’s well-being, which underscored a focal point for guardians in the Indian context (Roopnaraine et al., 2012). Exploring the long-term intended and unintended effects of integrated programmes on women and their families is needed to understand the broader range of outcomes including ART adherence, family interactions, and community perceptions of HIV.

Our findings also underscored the importance of revisiting a priori theories that inform interventions for PLWH – especially those who contend with dual

stressors of HIV and poverty. In addition to guiding how an intervention is implemented, ethnographic process evaluations that iteratively explore participants’ experiences of the intervention with depth can help researchers and practitioners critically examine the theory underlying the programme. Findings from our second group meeting with the participants, for example, reframed our understanding of *how* the women benefited from the intervention. The benefits weighed less on alleviation of mental and physical distress, as expected, and more on the instillation of hope for their children. The valid importance of theory-informed intervention should not overshadow the contributions of *intervention-informed theory*. Theory and intervention praxis are bidirectionally informed. Our study highlighted that ethnographic process evaluation holds promise in locating new patterns, understanding existing narratives, and listening to participants explain how HIV affects them from their perspective and in their sociocultural context (Brunson & Suh, 2020). These factors must be taken into account when designing and evaluating the effectiveness of interventions.

### Limitations

Several limitations of this study and its design are noteworthy. First, the women in our convenience sample were active participants of *Kiran* before this study was formally conceived. This may have constrained more forthright reporting of their experiences in the programme. Also, the homogeneity and self-selection of the group may further limit the generalizability of findings – particularly for women with relatively more support and economic resources. By not including women who previously discontinued the programme, for example, there was less scrutiny of the programme (Roopnaraine et al., 2012). In efforts to minimize potential sampling biases, we employed various methods to verify the information gathered from groups, individual interviews, and field observations. The use of participant-observations and semi-structured interviews,

however, raised a second methodological limitation. The emergence of mixed findings from various data collection sources introduced the challenge of deciding which interpretation to highlight – a common constraint in ethnographic research that cannot be fully resolved despite recursive analysis of findings (Case et al., 2014). Third, data was not analyzed by independent, unbiased coders – a conventional practice in qualitative research. This further highlighted the challenge of balancing methodological rigour (e.g., random-sampling, comparison group) with the realities of implementing livelihood programmes which may not necessarily adhere to ethnographic evaluation standards. Nevertheless, care was taken to minimize bias. Analysis was informed by feedback from senior scholars in the field of cultural anthropology (JH), HIV medicine (SD), and community-clinical psychology (EK). Also consistent with common practices in cultural and social anthropology to decrease external bias, study participants were invited to critique the analysis formally in the follow-up group session (Clifford, 1983). Fourth, the cross-sectional design of this study which did not include repeated measures of outcomes (i.e., mental health, economic standing) limited our understanding of how women and their communities are affected by integrated programmes over time – warranting the need for longitudinal mixed-method studies (Kadiyala et al., 2009). Lastly, we did not *directly* assess for participants' mental health functioning as we had initially intended. Although related themes of well-being and stress that emerged from participant interviews and observations were interpreted as proxy indicators for mental health, we could not conclusively draw implications of how Kiran affected by mental health.

## Conclusion

Notwithstanding the tempered interpretation of our findings, we believe that the themes that emerged from multiple data sources in the context of our long-term relationships with women who participated in *Kiran* provided an important starting point to address the *continued* involvement of participants in clarifying causal pathways and programme processes of livelihood interventions for women living with HIV in India. The unremitting dialogue between sound theory and intervention praxis is critical to achieve impact.

## Note

1. Primarily HIV-infected wives of labourers (former migrants) with children.

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## Disclosure statement

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## ORCID

Ezer Kang  <http://orcid.org/0000-0001-7857-2656>

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