RESEARCH ARTICLE

Implementation of social protection schemes for people living with HIV in three districts of Rajasthan state, India – a mixed methods study [version 1; peer review: 1 approved with reservations, 1 not approved]

B Gowthamghosh ¹, Rosenara Huidrom², Visvanathan Arumugam², Neeraj Pathak³, Neetu Purohit⁴, Hemant Deepak Shewade ^{5,6}, Anoop Khanna⁴, Poonam Ramesh Naik ⁷

¹Institute of Health Management Research (IIHMR), Bangalore, 560105, India

²India HIV/AIDS Alliance, New Delhi, 110048, India

³Hindustan Latex Family Planning Promotion Trust, Noida, Uttar Pradesh, 201309, India

⁴IIHMR University, Jaipur, 302029, India

⁵International Union Against Tuberculosis and Lung Disease (The Union), Paris, 75006, France

⁶The Union South-East Asia Office, New Delhi, 110016, India

⁷Department of Community Medicine, Yenepoya Medical College, Yenepoya (Deemed to be University), Mangaluru, 575018, India

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Abstract

Background: In India, public social protection schemes for marginalized populations are extended to people living with HIV (PLHIV) and their households. Care and Support Centres (CSCs) linked to antiretroviral therapy (ART) centres play a key role in linking PLHIV to the schemes. In three districts of Rajasthan, India, we assessed the linkage of PLHIV registered at CSCs (2016–18) to social protection schemes and explored PLHIV and provider perspectives into barriers and suggested solutions for improving linkage.

Methods: This was an explanatory mixed method study involving a descriptive quantitative phase using secondary data, followed by a descriptive qualitative phase involving face-to-face in-depth (five PLHIV) and key informant (three CSC staff) interviews.

Results: Of 1123 registered PLHIV at CSCs, 1026 (91%) expressed willingness to avail social protection schemes. Of 1026, 94% were linked to any one scheme; 52% to *Palanhar*, 51% to bus fare concession and 42% to widow pension schemes. The perceived barriers were: authenticating *Aadhaar* number (unique identification number provided to all Indians using their registered mobile phone number), cumbersome application processes for each scheme, limited utility of travel concession, delayed and/or irregular disbursement of benefits and non-availability of comprehensive information, education

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and communication material with details of all schemes and their application processes. Reaching out to all PLHIV in the designated district was a huge task for outreach workers. Another important barrier was the potential disclosure of positive status to various stakeholders in order to avail the schemes. Suggested solutions were a single window default application process at ART centres with a smart card and a single pamphlet at ART centres with all the required details.

Conclusions: Bus fare concession, *Palanhar* and widow pension schemes were the most widely accepted and linked schemes by PLHIV. Implementation barriers were identified that need to be addressed to improve the linkage.

Keywords

Social support schemes, utilization, HIV patients, social support, operational research, SORT IT

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Corresponding author: B Gowthamghosh (ghoshbg@gmail.com)

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Introduction

Globally, 36.9 million people are living with HIV (PLHIV). New HIV infections reduced from 3.4 million in 1996 to 1.8 million in 2017¹. HIV/AIDS can push people and households into poverty by reducing household labour capacity and increasing medical expenses. The average household income is lowered by 34% in households with a PLHIV when compared to households without a PLHIV². Households with PLHIV are thus more vulnerable to suffer socioeconomic shocks. HIV-related stigma and discrimination further marginalize the households affected by the virus and exclude them from essential services².

While free and decentralized HIV services remove important barriers to access, other economic barriers like increased expenses for nutritious food and transport expenses, wages lost due to visits for antiretroviral therapy (ART) and social barriers, stigma and discrimination may exist^{3–5}. Social protection helps PLHIV in overcoming these barriers⁵. According to the UNAIDS national composite policy index (2017), 109 countries stated that they had an approved social protection strategy, policy or framework; 99 were implementing various social protection schemes, and 85 countries' strategies were HIV-sensitive at least to some extent⁶. Social protection refers to *“all public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks and enhance the social status and rights of the marginalized; with the overall objective of reducing the economic and social vulnerability of poor, vulnerable and marginalized groups”*⁷.

There are around 2.1 million PLHIV in India. The significant impact of the national AIDS control programme (NACP) has been highlighted by a decline of more than 50% in the number of new annual HIV infections during the last decade⁸. Under NACP phase IV, social protection schemes are expected to play an important role in mainstreaming PLHIV⁹. Some schemes are for all vulnerable groups (HIV sensitive), while some schemes have been started specifically for PLHIV (HIV specific)¹⁰.

Chapter VII, Section 15.1, of the recent HIV and AIDS Prevention and Control Act 2017 guaranteed PLHIV access to welfare schemes¹¹. In 2013, the review commissioned by the International Labour Organization on social protection for PLHIV identified 26 studies on access to social protection and its impact on people living with and affected by HIV, although no studies from India were included. A report by the United Nations Development Programme on HIV sensitive social protection in four Indian states aimed to understand the utilization, facilitating and constraining factors¹². Since then, the social protection schemes under NACP-IV have been mainstreamed with a Care and Support Centre (CSC) linked to ART centres. The CSCs facilitate PLHIV upon ART registration to avail the social protection schemes. There is limited information from India about linkage to social protection schemes among PLHIV registered at ART centres and CSCs. Even though efforts are made to mainstream and provide various services to PLHIV, there is a huge gap in evidence on the reach

and effectiveness of these services. Understanding the linkage to the social protection schemes quantitatively and qualitatively is crucial for planning appropriate interventions to improve the coverage of PLHIV availing the schemes.

Hence, we aimed to understand the linkage to key social protection schemes among PLHIV registered with CSCs and explore the barriers and suggested solutions to improve linkage from provider and PLHIV perspectives.

Methods

Study design

This was an explanatory mixed methods study where the descriptive quantitative phase using secondary data was followed by a descriptive qualitative phase¹³. The theoretical framework underpinning the qualitative phase was content analysis¹⁴. In addition to the experiences and challenges faced by the PLHIV in availing the schemes, the qualitative phase explored the reasons for the findings of quantitative phase.

Setting

This study was conducted in three districts (Jaipur, Sikar, Churu) of Rajasthan, a state in north India during 2018–19. The estimated prevalence of HIV among general population in these districts is 0.75%, 0.0% and 0.5%, respectively. As of 2017, the total number of people on ART in the study districts was 37,092⁸. If a person is HIV-positive, post-test counselling is done and the person is referred to the nearest ART centre for clinical and immunological assessment and treatment. Treatment to PLHIV is provided through district level ART centres and all services are given free of cost.

All PLHIV are eligible to avail the state and/or central government provided (public) social protection schemes. There are seven widespread social protection schemes for PLHIV in Rajasthan and these schemes are extensions of schemes intended for vulnerable populations (Table 1). The CSCs support the health and wellbeing of all PLHIV and their affected families, with special effort to reach those from underserved populations, including women, children and members of high-risk groups, such as female sex workers, men who have sex with men, transgender people and people who inject drugs. The ‘Vihaan’ project by India HIV/AIDS Alliance is a national initiative establishing and managing 350 CSCs across India, and it manages the CSCs in the three study districts (there are a total of 17 CSCs in Rajasthan). Working in coordination with nearby ART centres, CSCs serve as safe spaces for PLHIV offering services that include counselling, outreach and follow-up support, health referrals, and linkages to social welfare schemes¹⁵.

PLHIV are counselled at the time of registration at the ART centre about the government sponsored welfare schemes and referred to the Vihaan-CSC. If the PLHIV is willing to avail any scheme, he/she will give consent to the in-charge of the Vihaan-CSC to process his/her application form on their behalf and becomes registered at the CSC. This process is voluntary. The PLHIV are given all details about the process of accessing the schemes and also informed about necessary supporting documents required (Figure 1).

Table 1. Social protection schemes for BPL that are extended to PLHIV in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Scheme	Who are eligible	What is the benefit	Documents required	Renewal
<i>Antyodaya Anna</i> scheme	HIV/AIDS		<i>Aadhaar</i> card*, Electoral identification card, Ration card, Bank passbook copy, Bamashah card**, ART diary copy, photograph	
Widow pension scheme	PLHIV woman	Monthly Rs. 750	Husband's death certificate copy, <i>Aadhaar</i> card*, Electoral identification card, Ration card, Bank passbook copy, Bamashah card, ART diary copy	
<i>Palanhar</i> scheme	Children of PLHIV	Monthly Rs. 500 for children under five years Monthly Rs. 1000 if the child goes to school and Rs. 2000 yearly for school dress	<i>Aadhaar</i> card*, Bank passbook copy, Bamashah card, School enrollment certificate, birth certificate, ART diary copy, Bonafide certificate by panchayat	Yearly
Bus fare concession	PLHIV	75% concession	ART diary	Yearly
Rail fare concession	PLHIV	50% concession	ART diary	Yearly
Bamashah scheme	PLHIV	Free diagnosis, free drugs, full treatment	<i>Aadhaar</i> card*, Electoral identification card, Ration card, Bank passbook copy, Bamashah card, ART diary copy	
Mahatma Gandhi National Rural Employment Guarantee Scheme	Adult PLHIV	Preferential work	Written or verbal communication to gram panchayat	

PLHIV, person/people living with HIV; ART, antiretroviral therapy; BPL, below poverty line.

**Aadhaar* card is a unique identification card used for various government purposes.

** Government of Rajasthan started this scheme to transfer financial and non-financial benefits of governmental schemes directly to recipients in a transparent way. The Bamashah card and number is made for a family with a female member as the head of the family.

Figure 1. Flow of PLHIV from ART registration to linking to social protection schemes in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018. PLHIV, people living with HIV; SPS, social protection schemes; CSC, Care and Support Centre; ARTC, antiretroviral treatment centre.

Data related to key variables at registration and details on linkage to various schemes is routinely recorded in a paper-based register and single-entered into an MS Excel database at Vihaan CSC. Aggregate data is also available on a centralized Vihaan server.

Study population

For the quantitative phase, the study population was all PLHIV on ART who registered at CSCs between January 2016 and December 2018 from the study districts. For the qualitative phase, from the January to June 2018 (six months) cohort, PLHIV receiving benefits and not receiving benefits were purposively selected. To understand the experiences from the provider perspective, we included the following service providers (key informants) as they were routinely involved in contacting the PLHIV and linking them to social protection schemes: Vihaan staff at state and CSC level and outreach workers. The study participants were contacted over the phone and there were no refusals. The enrolment was stopped once saturation of findings was reached.

Data variables, sources of data and data collection

For the quantitative phase, the source of data was electronic records maintained by Vihaan centrally. Baseline socio-demographic (age, gender, education, occupation, income, marital status, number of PLHIV in family) and clinical data (CD4 cell count, alcohol use, tobacco use, risk behaviour) were extracted from the CSC registers. The linkage to the various social protection schemes was assessed as of April 2019. Data analysis was carried out in June 2019.

For the qualitative phase, face-to-face interviews were conducted (June–August 2019) to understand PLHIV (in depth interviews) and provider (key informants) perspectives into the barriers and suggested solutions for improving linkage to schemes. The principal investigator (BG) is a public health professional (M.P.H.) who is trained in qualitative research methods. He conducted the face-to-face interviews in the local language (Hindi) after obtaining their written informed consent to participate in the study. Interviews were conducted at the CSC office in a private room. The principal investigator, though aware of ART services and social protection schemes, was not involved in routine programme implementation and belonged to a public health academic and research institute (external expert). A qualitative interview guide was pilot tested on three PLHIVs from the CSC office, who were not part of the final sample. A few changes were made after the pilot testing; probes were added and local terms used in the final guide. The final interview guide comprised of broad open-ended questions and is available as *Extended data*¹⁶. The interview guide was further modified based on the quantitative phase results. Only the study participant and the principle investigator were present during the interview. Audio recording (after consent) and/or verbatim notes were taken during the interview. After the interview was over, the summary of the interview was read back to the participants to ensure participant validation.

Analysis and statistics

The electronic data obtained from the Vihaan-CSC were cleaned and exported to SPSS (version 21 IBM SPSS) for analysis. Continuous variables were summarized in terms of either mean $\pm$ SD or median (IQR) depending on the statistical distribution of data. Categorical variables were summarized using frequencies and proportions.

For face-to-face interviews, transcription and translation was done the same day based on the verbatim notes and audio recordings. Manual descriptive thematic analysis was done by two investigators (BG and HDS)^{13,17}. The decision on coding rules and theme generation was done using standard procedures and in consensus¹⁸. The themes were derived from the data. The codes/themes were related back to the original data¹⁹.

Themes/categories have been reported below in single quotation marks, verbatim quotes in double quotation marks and italicized, author explanation within quotes in square brackets and respondents' details in round brackets. The findings were reported by using 'Consolidated Criteria for Reporting Qualitative Research' (COREQ) guidelines²⁰.

Ethics

Ethics approval was obtained from the Institutional Ethics Committee of the IIHMR University, Jaipur, India (May 2019/2) and the Ethics Advisory Group of the International Union Against Tuberculosis and Lung Disease (The Union), Paris, France (No 127/18). As the quantitative phase of the study involved secondary data, a waiver for informed consent was sought and approved by the ethics committees. For the qualitative phase, written informed consent was obtained for participation and publication of findings and this process was approved by the ethics committees. Throughout the study, efforts were made to avoid inadvertent disclosure of participants' HIV status with others.

Results

Quantitative phase

Baseline characteristics. The sociodemographic and clinical characteristics of 1123 PLHIV registered at the CSCs, stratified by study districts, are shown in [Table 2](#) and [Table 3](#). The mean age was 34 (± 12.8) years and 46% were female. Of 1123 registered at CSCs, 63.9% had a monthly household income below 70 USD and 53% (n=604) PLHIV had one more person with HIV in the household. At CSC registration, 467 (41.6%) had CD4 count <350 cells/mm³ (median count 364 cell/mm³), 132 (12.0%) consumed alcohol and 25% had daily usage of tobacco (smoking or chewing). Regarding the possible source of HIV transmission, in 478 (42.6%) it was reported to be heterosexual sexual transmission and in 359 (32.0%) it was reported as unknown.

Linkage to social protection schemes. The linkage to the social protection schemes is presented in [Table 4](#). Of 1123 PLHIV registered at CSC, 1026 (91.3%) expressed willingness

Table 2. Sociodemographic profile of PLHIV registered at CSCs of Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Characteristics	Jaipur N=503		Sikar N=477		Churu N=173		Total N=1123	
	n	(%)	n	(%)	n	(%)	n	(%)
Socio-demographic characteristics								
Age group								
≤25years	11	(22.9)	81	(18.1)	24	(13.9)	220	(19.6)
26–35	178	(35.4)	142	(31.8)	63	(36.4)	383	(34.1)
36–45	140	(28.3)	132	(29.5)	56	(32.4)	328	(29.2)
46–55	46	(9.1)	69	(15.4)	20	(11.6)	135	(12.0)
>55	24	(4.8)	23	(5.1)	10	(5.8)	57	(5.1)
Gender								
Male	271	(53.9)	230	(51.5)	106	(61.3)	602	(54.1)
Female	231	(45.9)	217	(48.5)	67	(38.7)	515	(45.9)
Transgender/transsexual	1	(0.2)	0	(0.0)	0	(0.0)	1	(0.1)
Education								
Illiterate	162	(30.6)	152	(31.9)	58	(31.5)	372	(31.2)
Primary	140	(26.4)	112	(23.5)	53	(28.8)	305	(25.6)
Secondary	159	(30.0)	163	(34.2)	58	(31.5)	380	(31.9)
Higher secondary	29	(5.5)	21	(4.4)	6	(3.3)	56	(4.7)
College and above	28	(5.3)	22	(4.6)	7	(3.8)	57	(4.8)
Marital status								
Unmarried	46	(8.7)	73	(7.3)	7	(3.8)	88	(7.4)
Married	348	(65.7)	328	(68.8)	127	(67.4)	803	(67.4)
Widowed	77	(14.5)	73	(15.3)	37	(20.1)	187	(15.7)
Divorced/separated	10	(1.9)	1	(0.2)	1	(0.5)	12	(1.0)
Live-in	0	(0.0)	1	(0.2)	0	(0.0)	1	(0.1)
Not applicable	49	(9.2)	39	(8.2)	12	(6.5)	100	(8.4)
Monthly income (in Rs.)								
Below 5000	337	(67.0)	265	(59.3)	116	(67.1)	718	(63.9)
5000–25000	146	(29.0)	171	(38.3)	47	(27.2)	364	(32.4)
25001–50000	3	(0.6)	3	(0.6)	2	(1.1)	8	(0.7)
50001–75000	1	(0.2)	0	(0.0)	0	(0.0)	1	(0.1)
Occupation								
Student	47	(9.3)	37	(8.3)	15	(8.7)	99	(8.8)
Unemployed	5	(1.0)	24	(5.4)	4	(2.3)	33	(2.9)
Home maker	194	(38.6)	200	(44.7)	66	(38.2)	460	(41.0)
Salaried professional	42	(8.3)	43	(9.6)	26	(15.0)	111	(9.9)
Salaried non-professional	70	(13.9)	64	(14.3)	14	(8.1)	148	(13.2)
Non-salaried	84	(16.7)	23	(5.1)	37	(21.4)	144	(12.8)
Petty business/large business/small shop/self employed	61	(12.1)	24	(5.4)	3	(1.7)	88	(7.8)
Agriculture	0	(0.0)	30	(6.7)	8	(4.6)	38	(3.4)
Other (retired)	0	(0.0)	2	(0.4)	0	(0.0)	2	(0.2)
Number of PLHIV in the family*								
None	242	(48.1)	173	(38.7)	101	(58.4)	516	(45.9)
1–2 members	252	(50.1)	267	(59.7)	72	(41.6)	591	(52.6)
3–4 members	6	(1.1)	7	(1.5)	0	(0.0)	13	(1.1)

CSC, Care and Support Centre; PLHIV, people living with HIV; ART, antiretroviral therapy.

*Number other than the registered.

Table 3. Clinical profile and risk factors of PLHIV registered at CSC of Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Characteristics	Jaipur N=503		Sikar N=477		Churu N=173		Total N=1123	
	n	(%)	n	(%)	n	(%)	n	(%)
CD4 count/ mm ³								
<100	43	(10.9)	71	(20.6)	14	(9.3)	128	(14.0)
100–500	220	(56.0)	195	(56.7)	99	(65.6)	514	(57.9)
>500	130	(33.1)	78	(22.7)	38	(25.2)	246	(27.7)
Alcohol use -Yes	69	(14.5)	33	(7.4)	30	(17.3)	132	(12.0)
Tobacco use -Yes	118	(24.7)	102	(22.8)	60	(33.7)	280	(25.5)
Type of risk behaviour								
Heterosexual	154	(30.6)	203	(45.4)	121	(69.9)	478	(42.6)
Men having sex with men	6	(1.2)	2	(0.4)	1	(0.6)	9	(0.8)
Blood transfusion	7	(1.3)	7	(1.6)	2	(1.2)	16	(1.4)
Mother to child	49	(9.7)	40	(8.9)	13	(7.5)	102	(9.1)
Unsafe syringe	4	(0.8)	5	(1.1)	5	(2.9)	14	(1.2)
Unknown	208	(41.4)	132	(29.5)	19	(11.0)	359	(32.0)
Commercial sex-work	1	(0.2)	0	(0.0)	2	(1.2)	3	(0.3)
Migrant	16	(3.2)	35	(7.8)	5	(2.9)	56	(5.0)
Trucker	7	(1.4)	22	(4.9)	5	(2.9)	34	(3.0)
Not disclosed	16	(3.2)	1	(0.2)	0	(0.0)	17	(1.5)

PLHIV, people living with HIV; CSC, Care and Support Centre.

Table 4. District wise distribution of PLHIV registered at CSC and linked to social protection schemes, in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Linkage to schemes [^]	Jaipur		Sikar		Churu		Total	
	N	(%)	N	(%)	N	(%)	N	(%)
Number of PLHIV registered at CSC	503	(100)	477	(100)	173	(100)	1123	(100)
Number expressed willingness to avail social protection schemes	475	(94.4)	391	(87.4)	160	(92.4)	1026	(91.3)
Proportion of PLHIV linked to social protection schemes	475	(100.0)	346	(88.4)	140	(87.5)	961	(93.6)
Proportion linked to <i>Palanhar</i>	329	(69.2)	99	(28.6)	70	(50.0)	498	(51.8)
Proportion linked to bus fare concession	34	(7.1)	346	(100.0)	108	(77.1)	488	(50.7)
Proportion linked to AAY	95	(20.0)	20	(5.8)	28	(20.0)	143	(14.8)
Proportion linked to widow pension ⁺	37	(72.5)	10	(19.2)	07	(26.9)	54	(41.8)

PLHIV, person living with HIV; CSC: Care and Support Centre; AAY, Antyodaya Ann Yojana.

[^] Individual patient data not available for Mahatma Gandhi National Rural Employment Guarantee Scheme, Bamashah and Rail concession were excluded.⁺ Current marital status as widow.

to be linked to schemes and of them 93.6% (n=961) were linked to at least one scheme; 51.8% (n=498) to *Palanhar* (cash assistance for children of PLHIV), 50.7% (n=488) to bus fare concession, 14.8% (n=143) to *Antyodaya Ann Yojana* (meaning scheme to provide subsidized food to the socio-economically weakest) and 41.8% (n=54) to widow pension (among 129 widows living with HIV). Overall, linkage to the social protection schemes is good, but the individual scheme linkage varies among the districts. In the case of bus fare concession, the linkage is good in Sikar and Churu, but in Jaipur it is very poor. Linkage to *Palanhar* and widow pension schemes are good in

Jaipur but poor in the other two districts. The variation in the linkages to the schemes prompted questions about the barriers in linking the schemes at a PLHIV and CSC level.

Qualitative phase

Table 5 depicts the participant characteristics and duration of each one-to-one interview. In the context of linking and accessing the social protection schemes, we present the results in two parts: perceived barriers and suggested solutions by the PLHIV and program staff.

Table 5. Study participant characteristics and duration of data collection activity in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Method of data collection	CSC staff	Demographic details	Experience in the position (in years)	Duration in minutes
One to one interview				
	State level staff	39 years, Female	3	44
	CSC staff	42 years, Male	7	42
	Outreach worker	27 years, Male	3	21
Method of data collection	PLHIV	Demographic details	Linked with SPS scheme	Duration in minutes
One to one interview	PLHIV-1	42 years, Male	No	32
	PLHIV-2	30 years, Female	Yes	26
	PLHIV-3	30 years, Male	Yes	38
	PLHIV-4	46 years, Male	No	36
	PLHIV-5	25 years Female	Yes	33

PLHIV, people living with HIV; CSC, Care and Support Centre; SPS, social protection schemes.

Figure 2. Thematic analysis showing barriers in availing the social protection schemes from the perspective of PLHIV registered at CSCs in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018. PLHIV, people living with HIV; CSC, Care and Support Centre; IEC, information education and communication.

Perceived barriers - PLHIV perspective. Thematic analysis showing barriers in availing the social protection schemes from the perspective of PLHIV are depicted in **Figure 2**. We identified five themes, broadly grouped into two categories: system level and patient level.

System level

Four themes were categorized here. 'Linking *Aadhaar* with bank and cumbersome application process' was consistent among all participants. The common issue was in authenticating

the *Aadhaar* number [unique identification number provided to all Indians that is linked to a bank account] through a one-time password sent to the registered mobile number of PLHIV. The *Aadhaar* number facilitates the direct benefit transfer of schemes like the widow pension and *Palanhar* scheme. If the PLHIV changes his or her registered mobile number, then this authentication is delayed. One participant mentioned about the inconsistency of basic information in other government documents (like name from school records did not match with *Aadhaar*) causing delay in scheme linkage. As the bank account

information needed the child's name, the name mismatch in records resulted in delay.

"For Aadhaar update my mobile number registered with Aadhaar got lost, I have updated my new mobile number and received message but I don't understand the message [message with one-time password details which has to be shared with the concerned department]" (Male PLHIV)

"The child's name in school record varies with the name recorded in Bamashah document [Government of Rajasthan started this scheme to transfer financial and non-financial benefits of governmental schemes directly to recipients in a transparent way. The Bamashah card and number is made for a family with female member as the head of the family]. I have updated the name in Bamashah." (Male PLHIV)

'Limited utility of travel concession' was observed. The concession for the bus fare was limited to one trip per month. For an additional trip in the same month, the PLHIV had to pay the full fare. 'Delayed receipt of benefit due to budget delay' was a common observation.

"I have submitted the form for Palanhar scheme nearly 12 months ago, but due to lack of budget, I am still waiting to receive the money". (Female PLHIV)

'Non-availability of comprehensive IEC material' was noted. One of the important elements in accessing the schemes is the availability of the information, education and communication (IEC) material. However, there was no comprehensive IEC material available from the government and most of the PLHIV did not have adequate knowledge of all schemes. The only printed handout available was from the Vihaan containing the list of schemes and required documents.

"I know Palanhar Yojna [scheme] only. [That too,] Once [after] I heard from the other patients about this scheme". (Female PLHIV)

Patient level

'Lack of family support' in linking to the schemes is a barrier due to stigma and discrimination at the family and community level. Apart from the system level support, the PLHIV need significant support from the family in overcoming the economic burden caused due to loss of employment and social stigma.

"Nobody is there to look after the children. My mind is not working. No assistance at home". (Male PLHIV)

Perceived barriers - provider perspective. Thematic analysis showing barriers in availing the social protection schemes

Figure 3. Thematic analysis showing barriers in availing the social protection schemes from the perspective of CSC programme staff in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018. PLHIV, people living with HIV; CSC, Care and Support Centre; ART, antiretroviral therapy; IEC, information education and communication.

from the providers' perspective is depicted in [Figure 3](#). We identified ten themes, broadly grouped into two categories: system level and patient level.

System level

As expressed by the PLHIV, the program staff also expressed the same barriers related to - 'linking Aadhaar with bank and cumbersome application process', 'limited utility of travel concession', 'delayed/irregular disbursement of benefit' and 'lack of availability of comprehensive IEC material'.

'Renewal' of certain schemes [*Palanhar*, Bus fare concession] is essential for receiving continued benefits. The program staff reported that many PLHIV forgot to submit the renewal documents, after which the benefit was discontinued.

"Every year they [PLHIV] have to submit the school enrollment certificate through online, failing to which they [beneficiary] cannot receive the benefit". (Male program staff)

The application process also required repeated visits to offices by PLHIVs after their application, leading to long periods of time between application and linkage. PLHIV and outreach workers had to make multiple visits to the office due to non-availability of the staff.

"The department has few staff to run the office so once the form is filled and submitted, we [program staff] have to visit again and again to the offices whether the scheme started or not." (Male outreach worker)

"Pension has a long lead time, it will take 3 to 4 months to get the pension". (Male program staff)

The ART centres had single hoardings / posters summarizing all the schemes, but handouts that could be given to PLHIV were unavailable at ART centres. Reaching out to all the PLHIV in the designated district by the outreach worker was a huge task.

"We do not have much resources for mobilization, somehow this is one of the reasons of clients lost to follow-up". (Female program staff)

Another important barrier was the potential 'disclosure of positive status'. The PLHIV did not want to disclose their status due to fear of discrimination and social exclusion and preferred to travel to far away health facility, resulting in the burden of transportation expenses^{21,22}. Though all the schemes applicable to below poverty line families have been extended to PLHIV, in many times the status had to be disclosed to avail the scheme.

"PLHIV has to appeal to SDO [sub-divisional officer] for Khadya Suraksha Yojana [Food security scheme], SDO asks

why they want to avail the schemes and they have to disclose the HIV status". (Male program staff)

"Collector [District administrator] also ordered that other than the gram sachiv [village government official] the PLHIV need not disclose their HIV status to anyone else, because the sachiv [secretary of local administrative body] is appointed by the government and the sarpanch [elected village representative] is a political post. Sachiv will think about disclosing the status before telling others, he cannot risk his job". (Male program staff)

'Reluctant doctors', as described by the program staff, discriminated against the PLHIV and this is a major barrier in accessing health care services. Evidence suggests that the PLHIV are prone to being discriminated against by the health workers at health facilities²³⁻²⁶.

"Big challenge is with the government hospital. The doctors are not operating the PLHIV after knowing the HIV status". (Male program staff)

Patient level

The program staff perceived that 'non- disclosure of HIV status to spouse causing in delay of treatment^{27,28}, delay in submitting the renewal documents' for schemes like *Palanhar* that need annual renewal and 'irregular visits to ART centre' due to transport charges were barriers in linking the schemes.

"We have many instances reported in which the wife is unaware of the husband's HIV status". (Female program staff)

"Irregularity in applying for renewal for the scheme, may be due to community ignorance" (Male program staff)

Suggested solutions. The suggested solutions are described as two themes from the PLHIV perspective ([Table 6](#)) and seven themes from provider perspective ([Table 7](#)).

Documentation

The PLHIV suggested a simpler process for scheme application and the providers suggested a centralized process at ART centre. A procedure change was suggested by the providers in which a unique smart card could be issued at ART centre. This smart card should be linked with Aadhaar or a bank account and used for availing all the schemes. Special camps for PLHIV run by the government to redress the issues and barriers in linking and availing the schemes by the PLHIV were other suggested solutions.

Accessibility

In the process of continuous and uninterrupted disbursement of scheme benefits, adequate budget allocation is necessary. Awareness generation among the PLHIV, officials and at the community level about the schemes through strong comprehensive IEC material [all schemes' related information

Table 6. Suggested solutions in availing the social protection schemes from the perspective of PLHIV registered at CSC in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Categories	Themes	Verbatim quote
Documentation	Need simpler process	"The scheme should be run in a single umbrella. I heard from some of the patients facing problems to submit the form at different offices. I saw them in pain and sad". (Male PLHIV)
		"And once the doctor confirmed about the diseases, and after the registration at ART center, there should be no need of any report like Ward member [local body representative] or Surpanch [local body representative] report". (Female PLHIV)
Accessibility	Information needs to be available widely	"By increasing the amount of different financially beneficial schemes, like pension. The amount currently I am getting is not sufficient". (Female PLHIV)

PLHIV, people living with HIV; CSC, Care and Support Centre.

Table 7. Suggested solutions in availing the social protection schemes from the perspective of CSC program staff in Jaipur, Sikar and Churu districts, Rajasthan, India, during January 2016 to December 2018.

Categories	Themes	Verbatim quote
Documentation	Need centralized process	"There should be a centralized place to submit the forms. The ART center is best place instead of different offices". (Male program staff)
		"If ART is the single window, the client can get the medicines and avail schemes information and linked with the help of e-mitra near to ART and the issue of visiting to different department will be addressed". (Female program staff)
	Unique smart card	"With the help of all government departments one unique card could be issued. The same card will be used at all places wherever eligible". (Male program staff)
		"We will do advocacy to issue a smart card to PLHIV, based on the smartcard they can regularly visit ARTC whenever required. And the regularity will be increases they can live healthy". (Female Program staff)
Accessibility	Special camps	"Program from government level, like in 2010, prasaran gaon sang, we got several problems solved. They inform about the camp date and place in newspapers. We used to go there and collectively all PLHIV linked to the schemes". (Female program staff)
	Sufficient budget	"There should be adequate budget in the departments. Many time the because of lack of funds the PLHIV has to wait for months to receive the benefit" (Male program staff)
	Mainstream and sensitization	"Efforts are made by the government and the NGOs are trying to sensitize the officials". (Female program staff)
	Strong IEC	"If you want to remove these challenges, field level awareness is essential and strong IEC required. At PHC level basic IEC should be available, if any client from rural area wish to avail schemes they can go for them". (Female program staff)
	Resource book on social protection schemes	"After registration the client could be handover one resource booklet on schemes" (Female program staff)

PLHIV, people living with HIV; CSC, Care and Support Centre; ART, antiretroviral therapy; IEC, information education and communication; NGO, non-governmental organization; PHC, primary health centre.

in single pamphlet] should be made available widely. In addition, a resource book on social protection schemes was also recommended.

Discussion

This is one of the few mixed methods studies on this topic conducted in India. All PLHIV are eligible to avail the state and/or central government provided social protection schemes. These

schemes are extensions of schemes intended for marginalized populations. Of all other schemes available in Rajasthan, bus fare concession, pension and the *Palanhar* scheme were the most widely accepted and linked schemes by PLHIV. Even with certain limitations like limited travel (one trip in a month using bus fare concession), long period of time before the receipt of benefits (2–3 months for pension) and complex documentation process (*Palanhar*), PLHIV are considering these schemes.

Verification of *Aadhaar* and the complicated application process for linking to the schemes and renewal were the key barriers. A PLHIV has to submit 7-9 different supporting documents for availing the schemes over repeated visits, and delayed benefit and the need for renewal of certain schemes are causing distress to PLHIV. Both PLHIV and the program staff reported that the process is not user friendly.

The ART centre is the first point of information on social protection schemes and CSCs play a key role in linking to the schemes. Very limited comprehensive IEC material related to social protection schemes was available at the ART centres and CSCs.

One of the key areas of the CSCs is community mobilization. Due to lack of adequate funds and human resources, the program staff (CSC) were not able to visit all the PLHIV at village level in a timely manner. The care and support centre has done an impressive job in linking the social protection schemes to the PLHIV who consented to them; however, since the ART centre is the first point of contact and also a sustained point of interaction, it is felt that ART centre must play a lead role in facilitating the linkage of social protection schemes.

Recommendations and policy implications

The investigators recommend the following. First, a single window default application process at ART centres could be established, providing PLHIV with a smart card. The registration at this window can enable the PLHIV to access multiple schemes as per their eligibility with the help of smart card. This window can help the PLHIV in choosing and applying to the schemes with ART registration as a basic requirement.

Second, a state or national level direct benefit transfer (DBT) scheme for PLHIV upon registering at the ART centre could be considered, like *Nikshay Poshan Yojana*, where all the notified tuberculosis patients under treatment are eligible for incentives^{29,30}. The DBT may be in the form of conditional or unconditional transfers (cash/food). Evidence from South Africa^{31,32} revealed that the HIV-risk has been reduced among adolescent girls and boys with the model of “cash plus care” (cash transfers with psychological support). A cross-sectional study in Cameroon found that financial barriers decrease ART adherence³³. Household economic strengthening interventions can help the PLHIV in meeting the direct non-medical and indirect costs (loss of wages due to sickness absenteeism)³⁴. Recently, initiatives of the state government for relaxation of the age criteria for the widow pension scheme to all HIV positive widows has been an important enabling factor for widows to avail the scheme.

Limitations

There are some limitations of the study. We did not have data for PLHIV who did not register at the CSC; therefore, the true

picture of linkage among PLHIV registered at ART centres may be even lower and we were not able to make observations on that aspect. Delays in linkage were not captured quantitatively. We did not interview the key stakeholders (the government departments) who are responsible for delivering the schemes.

Future research

More studies need to be conducted on the impact of linkage to social protection schemes on the lives of PLHIV. A pilot intervention to test the suggested solutions and the impact on linkages to the schemes is recommended.

Conclusions

The study was able to identify the barriers perceived by the PLHIV and providers. CSCs have been by far the major facilitators in linking the schemes. The ART centres did not seem to play a significant role in facilitating the social protection schemes, except providing ART. Comprehensive IEC need to be developed and widely circulated at all levels of service delivery. There is an urgent need to address these barriers to enhance linkage to social protection schemes.

Data availability

Underlying data

The quantitative and qualitative data that support the findings of this study can be obtained from India HIV/AIDS Alliance. These data are not publicly available due to concerns that the data could potentially disclose individuals' identities. Data are, however, available upon request to researchers for the purpose of further academic research from the corresponding author (ghoshbg@gmail.com) and with permission of India HIV/AIDS Alliance.

Extended data

Figshare: Annex 1.pdf. <https://doi.org/10.6084/m9.figshare.11889630.v1>¹⁶.

Data are available under the terms of the [Creative Commons Zero “No rights reserved” data waiver](#) (CC0 1.0 Public domain dedication).

Acknowledgements

We would like to thank the participants who kindly agreed to participate in the study and share their experiences. We are also grateful to have received the encouragement and support by the IIHMR University, Jaipur management.

Disclaimer: The contents of this paper do not necessarily reflect the views of the Government or Non-Governmental Organizations or The Union

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Georges Nguefack-Tsague

Faculty of Medicine and Biomedical Sciences, University of Yaoundé 1, Yaoundé, Cameroon

1. Please update the number of people living with HIV (PLHIV) and also new infections in 2020 globally and in India.
2. Clearly justify the choice of the three districts.
3. Table 3, justify the choice of CD4 count cutoffs; I would rather prefer that you use WHO or UNAIDS cutoffs.
4. Tables 2-4, please insert a column on p-values to statistically compare variables across districts, i.e. statistical significance. We understand that the quantitative phase was descriptive, but it would be great to consider significance.
5. In addition to sex, please add age to the Verbatim quote

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Partly

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Statistics, Modeling, Health Informatics, Health Information System (HIS), SGD monitoring and evaluation, public health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 14 October 2020

<https://doi.org/10.5256/f1000research.24584.r71736>

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Mulamuli Mpofu

FHI 360, Gaborone, Botswana

Article summary:

- The study assessed access to social protection schemes by PLHIV in three districts of Rajasthan State in India. This was a mixed methods study integrating secondary data analysis to assess access rates of the different social protection schemes by district. The qualitative component through interviews (Vihaan staff, outreach workers and PLHIV) were conducted to understand the system and individual barriers to access to social protection schemes. The authors concluded that ART centers did not play an important role in facilitating access to social protection schemes.

Comments by section:

Abstract:

- Abstract is consistent with the main body. As in the description of the qualitative phase; indicate what was assessed in the secondary data analysis.

Introduction:

- Paragraph 4 - it will be important to list the type of schemes that PLHIV are entitled to per the HIV/AIDS Prevention Control Act.

Methods:

- Study design: This was a mixed methods study

- Setting - The HIV prevalence for Sikar is given as 0.0% and this brings to question where the PLHIV came from. Maybe increase the decimal places for the percentage if it is less than 0.1.
- Table 1: Provide description of the purpose of each SPS. Are these schemes exclusively for PLHIV or beyond? This is not coming out clearly.
- Figure 1: Everyone ends up accessing the SPS whether consented or not. Perhaps more details on those who did not consent so that its clear how they end up getting SPS.
- Analysis - Only descriptive analyses were conducted but it would have been good to also assess for statistical difference in these measures by sex, district etc. This will help understand the observed trends.
- Interviews - its not clear how the questions were translated. Were they translated after transcription or during? Its also not clear how the individuals interviewed were selected. The authors also indicate that 'The enrolment was stopped once saturation of findings was reached', its highly unlikely saturation can be reached by interviewing three or five individual using an open-ended tool.
- Ethics section - how was the confidentiality of the interview participants, particularly the PLHIV protected? While the authors indicate that an NRD was obtained for the secondary analysis, it will be worthwhile indicating that: 'non of the authors interacted with the data that contained personal identifying information'.

Results:

- The results are presented as three separate studies - secondary analysis, qualitative study for PLHIV and qualitative study for providers. The purpose of a mixed-methods study is to triangulate the results where the qualitative explain the quantitative; and qualitative results from different sources get analyzed together. The authors should revisit the results section.

Discussion:

- The discussion does not interpret and explain the findings. It does not integrate literature to make comparisons with other areas.

Conclusions:

- The conclusions should be directly related to the results. There wasn't much analysis done from the quantitative data and the sample size from the interviews may not have sufficient power for such conclusions to be drawn.

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

No

If applicable, is the statistical analysis and its interpretation appropriate?

No

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Public Health, HIV/AIDS, Malaria, Integrated Vector Management, Health Information Systems, Epidemiology

I confirm that I have read this submission and believe that I have an appropriate level of expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Comments on this article

Version 1

Reader Comment 05 May 2020

Sateesh Gouda M, Govt. First Grade College, Hunnur, Bagalkot. Karnataka, India, Jamkhandi, India

The study is an good effort to highlight the gaps in service provided by the Govt. and NGOs specially high risk and marginalized population and suggesting the measures to address the problems. Another advantage of this study is; this is exploratory mixed method study. Some of my suggestions to authors are; justify the reason for selecting the particular districts, another suggestion is; though it is mixed method, the study conclusion and suggestions are dominated by qualitative data, I mean utilization of quantitative is not as equal to qualitative data.

Competing Interests: None

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