

Accountability of the Community in Rendering HIV Care

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Abstract: *The study investigates community accountability in HIV care by assessing leadership structures and preparedness in families and communities. Conducted as a cross-sectional study in the Kancheepuram District, it analyzed data from 1,800 participants. Findings reveal significant gaps in HIV knowledge, including misconceptions about transmission and limited awareness of care resources. Despite these gaps, focus group discussions indicate a willingness among community groups to address stigma and support HIV-affected individuals. The study highlights the need for targeted educational interventions to empower communities and promote effective HIV care.*

Keywords: HIV care, community preparedness, stigma reduction, public health, HIV awareness

1. Introduction

HIV-related stigma remains one of the most significant barriers to effective care and management of the disease, particularly in home-based settings. This stigma not only perpetuates secrecy and denial but also contributes to the continued transmission of HIV by discouraging individuals from seeking testing and treatment [1] [7]. Understanding the prevailing knowledge and misconceptions about HIV/AIDS within communities is essential to addressing these barriers and fostering a supportive environment for those affected [5] [8].

This study aims to evaluate community knowledge, attitudes, and preparedness in providing care for HIV/AIDS-affected individuals. By identifying gaps in understanding and readiness, the study seeks to empower communities to take an active role in combating the stigma and misconceptions surrounding HIV. Furthermore, the findings are intended to inform targeted interventions that can strengthen home-based care initiatives and enhance community involvement in HIV care and prevention [1] [3].

The present research highlights the critical role of community empowerment in reducing stigma, improving care outcomes, and fostering a proactive approach to managing the disease at the grassroots level [2] [6].

2. Objectives

- To assess perceptions regarding HIV/AIDS among the people aged more than 13 years of age
- To identify the leadership structure in the families and community to assess the preparedness of the community for rendering care when the need arises.

3. Review of Literature

USAID publication (2019) "Leadership at the Community level for improved access to care, support and treatment" has identified 2 basic things in mobilising resources to support community empowerment for improved access to care, support and treatment. They are (a) availability of resources and (b) skills. Following are the identified list of main groups of list of resources: - human resources, material goods, free service and facilities, technical assistance, money, contacting NGOs /local governments and submitting proposals, asking for donations, running a small business, running fund raising events and advocating for public resources to be made available. It is considered essential to bridge the gap between prevention, care, support and treatment.

Xiaodong Tan et al (2021) in his Study on "HIV/AIDS Knowledge, Attitudes and Behaviors Assessment of Chinese Students" had the objective to assess students' knowledge, attitudes and practices on HIV and AIDS. Study results indicated that the majority of Undergraduates had a moderate level of HIV and AIDS knowledge, acceptance and attitudes towards people with HIV and AIDS. Boys had more acceptance and positive attitudes towards people with HIV and AIDS than girls. A peer educational program to talk about self-esteem, healthy sexual attitudes, being human-accepting and loving should be developed in the near future.

Mercy Nahmo (2023) conducted a study on obstacles to local level HIV competence in rural Zimbabwe; putting HIV prevention in context. Objective was to highlight how pre-existing social dynamics may have influenced community "readiness" to derive optimal benefit from the intervention, using the concept of "the AIDS competent community". Methodology: We analysed 44 interviews and 11 focus groups with local people. Results and Discussion: Despite high levels of HIV/AIDS-related knowledge, there were

several ways gender, poverty and low literacy may have undermined its perceived relevance to peoples' lives. There were many potential community strengths and resources. There were high levels of HIV/AIDS - related knowledge. Public denial of HIV/AIDS masked huge reservoirs of private support and kindness to AIDS - affected family and friends. There were many strong community organisations and clubs, potentially forming the springboard for more empowered community responses to HIV/ AIDS. It was concluded that HIV/AIDS programmers should pay greater attention to community readiness for interventions, especially around: (1) identifying and anticipating pre - existing obstacles to programme success and (2) mobilising the social assets that exist, even in contexts of poverty and gender inequality.

4. Methodology

This study was a cross - sectional study design, conducted in the coverage limits of primary health centre, Kancheepuram District. The Primary Health Centre (PHC) caters to a population of approximately 38, 736, people living in 520 villages. A total of 1800 samples were selected using cluster sampling technique [2] [4].

The study also employed the Chi - square test to determine the statistical significance of variations in community knowledge and attitudes across demographic factors, including sex, marital status, literacy, and occupation. This analysis provided insights into the factors influencing community preparedness and highlighted areas for targeted interventions.

4.1 Inclusion criteria

People aged more than 13 years.

4.2 Exclusion criteria

People who were not willing to participate in the study were excluded from this study.

4.3 Study Instrument

To assess the preparedness of the community to assume the responsibility for care, focus group discussions were held with community members listed below.

- 1) Formal and informal Panchayat members – 1 FGD [3]
- 2) Teachers of schools and colleges - 1 FGD [5]
- 3) Youth groups – 1 FGDs
- 4) PHC staffs – 1FGD
- 5) Anganwadi workers – 1 FGD [8]

4.4 Core questions for FGDs for all groups

- 1) What is HIV
- 2) What is AIDS
- 3) How does it spread
- 4) List activities/efforts in your village in place for prevention and control of HIV/AIDS since the last 1 year/10 years
- 5) Supposing more cases of HIV/AIDS occur, how much is community/panchayat/government are ready to face.

A facilitator was provided with a checklist to guide the group discussion. The facilitator was putting down a statement at a time and the members were encouraged to discuss the statement. The investigator was observing the process and noted the points that emerged which were pertinent to the statement proposed by the facilitator. The handouts which were given to the participants and explained by the investigator helped in clarifying the doubts raised by the participants.

4.5 Statistical analysis

Chi - square test is used to test the significance difference between the knowledge with respect to sex, marital status, literacy and occupation [4].

5. Results and Discussion

5.1 Age and Sex Distribution of the study population

Table 1: Numbers in parenthesis denote column percentage

Age Group	Sex		Total
	Male	Female	
13 - 23	386 (21.4 %)	399 (22 %)	785 (43.4 %)
24 - 33	183 (10.2 %)	163 (9 %)	346 (19.2 %)
34 - 43	126 (7 %)	159 (8.8 %)	285 (15.8 %)
44 - 53	203 (11.3 %)	58 (3.2 %)	261 (14.5 %)
>53	87 (5.1 %)	36 (2 %)	123 (7.1 %)
Total	985 (55 %)	815 (45 %)	1800 (100 %)

It was observed that majority 785 (43.4 %) of the subjects in the study population were in the age group of 13 - 23 years and the proportion of males and females in the same age group was observed to be 386 (21.4%) and 399 (22 %) respectively. The least i. e., 7.1 % of subjects were observed to be those aged 53 years and above. Consistent decrease in the number of females over the age of 34 years in the study population was due to lack of willingness to participate in the study

5.2 Distribution of the study population by education and age group

Table 2: Numbers in parenthesis denote column percentage

Education	Age Group					Total
	13 - 23	24 - 33	34 - 43	44 - 53	>53	
Not literate	8	28	35	38	4	113
Primary	12	85	40	65	12	214
Secondary	18	16	48	76	8	166
Higher secondary	331	36	65	32	23	487
PUC	32	0	62	50	28	172
Graduate	242	112	18	0	35	407
Post graduate	142	69	17	0	13	241
Total	785	346	285	261	123	1800

It was observed that majority 487 had education up to higher secondary level. Post graduates constituted 241 of the study population. In the age group 13 - 23, 331 were educated up to higher secondary and only 142 were post graduates. In the age group of 24 - 33, 36 were educated up to higher secondary and only 5 (1.08%) were post graduates. In the age group of 34 - 43, 69 out of 290 i. e. (33.79%) were not literate and only 1 (0.34%) were post graduates. In the age group of 44 - 53, 59 (45.73%) were not literate and only 1 (0.77%) were post graduates. In the age group >53, 28 (36.36%) were not

literate and 4 (1.2%) were graduates. In the present study 335 of 1332 (25%) were not literate. In the present study 470 (35.28%) had studied up to higher secondary.

5.3 Perceptions regarding HIV - AIDS among the study population

Table 3

Variables	Yes	No	Do not know
1) HIV is a virus	715	220	865
2) Are the words HIV and AIDS one and the same	708	180	912
3) How a HIV person is diagnosed	658	346	796
4) Is there complete cure	698	260	842
5) Is treatment available to prolong life	543	768	489
6) If you need HIV test, do you know where to go	323	559	918
7) If you need HIV treatment, do you know where to go	276	657	867
8) Do you fear your child becoming infected with HIV if he/she plays with a child with HIV	298	766	736
9) Do you buy vegetables from a shop keeper living with HIV/AIDS	198	909	693
10) Should a child living with HIV be able to attend school	234	712	854
11) Would you be embarrassed to be seen in public with a friend who is known to have HIV/AIDS	567	414	819

N=1800 Numbers in parenthesis denote percentage of N

5.4 Focus Group Discussion

All the groups participated in focus group discussion, were willing to address their communities through staging drama and role plays to eliminate wrong beliefs related to HIV/AIDS. Further they volunteered to promote the use of condoms in their community. They strongly felt that the testing for HIV should be made compulsory for all those intending to marry. They felt an urgent need to screen all antenatal mothers for HIV and strongly felt that it should be a routine testing.

Panchayat members, teachers, anganwadi workers and youth groups were ready to address the commercial sex workers and help them to change their behaviour. They even volunteered to get them some other occupation for their livelihood. Thus it was inferred from focus group discussion that the community is willing to provide care and support for HIV affected individuals either in their own homes or any other community based initiatives. Only one group expressed prejudice, suggesting that HIV/AIDS - affected individuals be housed a kilometre away from the village.

It was perceived that it was possible to build up on these strengths in the community and at the same time take appropriate measures to address the prevailing misconceptions in order to improve the care and support initiatives.

6. Conclusion

It was concluded that the neighbourhood groups, village groups, self help and women's group are likely vehicles for the effective spread of knowledge in the community. From the focus group discussion, it was observed that there is a positive attitude among the study subjects in providing care and support to the individuals affected with HIV/AIDS.

The findings emphasize the urgent need for community education and targeted interventions to address prevailing misconceptions and empower communities to provide effective HIV care and support [6] [7].

7. Recommendations

- A lot of misconceptions are prevailing in the community with respect to HIV/AIDS. So with these prevailing misconceptions the home based care will be inappropriate at this stage in the community [3]. So, it has to be addressed by conducting a need based, targeted, and focused Information, Education and Communication activities in the villages as a priority primary measure.
- The local groups in the community like Teachers of the schools and colleges, youth groups and the Anganwadi teachers etc. should be first educated regarding these misconceptions and later they can be involved in conducting Information, Education and Communication (IEC) activities to the community [5] [8].

8. Limitations

- The Restriction in asking questions concerning sexual beliefs and behaviours as was observed in the pilot study, made me to slightly change the questionnaire.
- Because of the nature of the questionnaire, the honesty of individual's responses may be questioned.

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References

- [1] USAID. (2020). *Leadership at the Community Level for Improved Access to Care, Support, and Treatment: HIV/AIDS in South Africa*.
- [2] Nhamo, M., Campbell, C., & Gregson, S. (2009). Obstacles to local - level HIV competence in rural Zimbabwe: Putting HIV prevention in context. *AIDS Care*, 22 (2), 1662–1669.
- [3] USAID. (2020). *Leadership at the Community Level for Improved Access to Care, Support, and Treatment: HIV/AIDS in South Africa*. [Duplicate reference, consider removing].
- [4] Yazdi, C. A., Aschbacher, K., Arvantaj, A., Naser, H. M., Abdollahi, E., Asadi, A., et al. (2006). Knowledge,

attitudes, and sources of information regarding HIV/AIDS in Iranian adolescents. *AIDS Care*, 18 (8), 1004–1010.

- [5] Tan, X. (2007). HIV/AIDS knowledge, attitudes, and behaviors assessment of Chinese students: A questionnaire study. *International Journal of Environmental Research and Public Health*, 4 (3), 248–253.
- [6] WHO. (2023). *The Global AIDS Strategy*.
- [7] Sudha, R. T., Vijay, D. T., & Lakshmi, V. (2005). Awareness, attitudes, and beliefs of the general public towards HIV/AIDS in Hyderabad, a capital city from South India. *Indian Journal of Medical Science*, 59, 307–316.
- [8] Al - Serouri, A. W., Takioldin, M., Oshish, H., Aldobaibi, A., & Abdelmajed, A. (2002). Knowledge, attitudes, and beliefs about HIV/AIDS in Sana'a, Yemen. *Eastern Mediterranean Health Journal*, 8 (6).