



Sociodemographic Profile and Treatment-Seeking Behavior of HIV Infected Children Accessing Care at Pediatric ART Clinic of a Tertiary Care Hospital in Delhi

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Abstract

Background: Acquired immunodeficiency syndrome (AIDS) has emerged as one of the most serious public health problems in India. The parents of HIV-infected children are more likely to die and thus render the children orphan. The sociodemographic characteristics of children with HIV infection are different than the other children of the same age group. With the diverse range of manifestations, the symptoms of HIV/AIDS can appear in children at any time during the course of infection. After appearance of various signs/symptoms, the parents wander to various health agencies for relief and thus lose their vital time.

Aims: The present study was conducted (1) to study the sociodemographic profile of children living with HIV/AIDS and (2) to know the treatment-seeking behavior of HIV/AIDS patients before coming to the tertiary hospital.

Materials and Methods: The study was a hospital-based cross-sectional study where 216 children registered at the pediatric ART clinic of a tertiary care hospital in Delhi and their caregivers were included in the study. Semi-structured, pretested interview schedule was used for data collection through face-to-face interviews.

Results: Out of the 216 children, males outnumbered females in the ratio of 2.48:1. Most of the children were in the age group of 10–14 years (48.1%) and the majority belonged to urban areas (63.4%). Most of the children were going to school. Majority of children (46.3%) belonged to social class-4. Hospitals (62.5%) were consulted first followed by private practitioners (33.3%) by these patients after appearance of earliest symptoms. Presenting symptoms of HIV in children were not specific and the most common symptom was fever (79.1%) followed by not gaining weight (69.4%), recurrent diarrhea (65.3%), cough (41.7%) and vomiting (30.6%). The average number of consultations sought by these patients before coming to this hospital was 2.34 per patients. Hospitals (39.8%) and prior experience at same hospital (33.3%) were the most common source of information about the ART center.

Conclusion: The study shows multiple sources of consultation with delay in seeking care in the tertiary hospital.

Keywords: HIV/AIDS, Private practitioners, Symptoms, Treatment-seeking behavior

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Introduction

HIV (Human Immunodeficiency Virus) continues to be a major global public health issue, having claimed more than 39 million lives so far.¹ HIV has infected men, women and children in developed as well as in developing countries. Children differ from adults as they have higher rate of viral replication with resulting high viral load and higher rate of CD4 cell destruction.² According to United Nations Programme on HIV and AIDS (UNAIDS), the total estimated number of children under the age of 15 years living with this virus globally was 2.6 million at the end of 2014 with 0.22 million children newly infected and 600 children being infected daily.³ In 2014, 0.15 million children died from HIV-related causes globally.³

In India, the estimated number of people living with HIV/AIDS were 0.21 million in 2013 according to UNAIDS. Of these, children comprised 7% of total cases (0.14 million).⁴ With the availability of antiretroviral therapy (ART) since 2004, HIV infection, which was once considered a progressively fatal illness, has now become a chronic treatable condition in children, as in adults.⁵

Sexual transmission of HIV/AIDS being the commonest cause of infection in most of cases, children remain the least focused group but they share the burden of the epidemic at early age. In many families they act as caregiver for sick parents who have AIDS. Family which is most effective structure for responding to children's need is disrupted in most of the cases because of HIV infectivity of parents.⁶

Due to lack of awareness, most caregivers do not seek help from any healthcare system for their children until they were terminally ill. All this leads to loss of vital time in early diagnosis for halting the disease progression and make visible impact on the financial expenses associated with medical treatment of individuals that are borne by the households to whom they belong.⁷

In spite of the accumulated knowledge about the disease in India in the last decades, our knowledge about some of the pre-diagnosis treatment seeking behavior of pediatric patients is fragmentary. To frame future strategies and for evidence based policy making for care and support for pediatric HIV patients, it is imperative to understand the demographic profile of families to which they belong and their treatment-seeking behavior. This will help in identifying the delay (if any) in health seeking and scope for interventions at health system level as well as at the level of beneficiaries. Therefore, the present study was conducted with an objective to examine the

sociodemographic factors and treatment-seeking behavior of HIV infected children enrolled at the pediatric ART Clinic in a tertiary care teaching hospital in Delhi.

Materials and Methods

Study Design, Settings and Participants

It was a hospital-based cross-sectional study conducted over a period of one year from January to December 2015 in Antiretroviral Treatment (ART) Centre of a tertiary care hospital in New Delhi, India. All first-line and second-line ART drugs are available at this ART center. Investigations related to HIV are available. Separate counseling rooms are there with male and female counselors. All children aged up to 14 years of age who were enrolled at ART center constituted the study population. According to previous records, there were a total of 260 cases registered at ART center till 2013. All cases registered at ART center were enrolled for the study. Caregivers of 44 patients refused to give consent. Efforts like complete explanation about the study, harm and benefits for future research were explained again to increase the participation in the study but they refused to give consent due to various reasons like stigma, unavailability of time, etc. So, total 216 pediatric cases diagnosed with HIV and receiving treatment and care for HIV/AIDS at ART clinic of tertiary care hospital, New Delhi, were enrolled for the study.

Data Collection

The caregivers of the study subjects attending the pediatric ART clinic were interviewed after taking informed written consent. Assent was taken from children aged 7 to 14 years in addition to written consent from the parents or legal guardians. For children less than 7 years, only written consent from the parents or legal guardians was taken. The interview was taken in a separate personal counselor room and confidentiality was maintained at the time of interview.

Study Tools

A semi-structured interview schedule was designed in English, pretested and used for data collection to study socioeconomic and demographic profile and treatment-seeking behavior regarding HIV/AIDS. Information regarding (a) sociodemographic profile of child and caregiver, i.e., age, gender, religion, educational status, area of residence, socioeconomic status of the parents, parents' occupation, parents' HIV status, (b) treatment-seeking behaviour, i.e., information about initial symptoms of the child, date of onset of symptoms, type

of health agency first contacted, reason for preference, any subsequent change in healthcare provider and the reason for the same were collected from caregivers.

Socioeconomic status was assessed by Modified B. G. Prasad Socioeconomic status scale using updated current price index of 2015.⁸ The schedule in English was translated in the local language (Hindi) and retranslated back to English for validation. It was pretested on 20 patients in similar setting. Appropriate modification was done after pretesting. Average time duration of each interview was approximately 20–25 minutes.

Statistical Analysis

Data were analyzed and statistically evaluated using SPSS software, version 17 (Chicago II, USA).⁹ Quantitative data was expressed in mean, standard deviation while non-normal data was expressed in median and IQR. Difference between two comparable groups was tested by Mann Whitney 'U' test while qualitative data were expressed in percentage. 'P' value less than 0.05 was considered statistically significant.

Ethical Issues

All participants were explained about the purpose of the study. Confidentiality was assured to them. Assent was taken from subjects 7 years to 14 years along with informed written consent from their parents or caregivers. The study was approved by the Institutional Ethical Committee.

Results

Sociodemographic Profile

Out of the subjects surveyed, half (n=104; 48.1%) of the children were in the age group of 10–14 years while only 38 (17.6%) were less than 5 years old (Mean age=8.62±3.82 years). More than two-thirds (71.3%) of the study subjects were males. Majority (n=162; 91.0%) of the study subjects were going to school.

The majority (n=137; 63.4%) of the study subjects were living in urban areas, and more than two-thirds were Hindus (n=178; 82.4%) by religion. Nearly half (n=100, 46.3%) of the study subjects belonged to class-IV socioeconomic status according to modified BG Prasad's (2015) socioeconomic classification.⁸

Details of sociodemographic profile are given in Table 1.

About the caregivers, both the parents of majority (n=136, 63.0%) of the study subjects were alive at the time of the study. Nearly one third (80, 37.0%) of the study subjects had lost either single or both parents.

The majority (n=178; 82.4%) of the study subjects were taken care of by their parents. Some were (17.6%) cared for by relatives including grandparents, elder brother, paternal uncle, maternal uncle, etc.

The mean age of caregiver was 35.36±9.69 (Range 17–65). Nearly half (n=100; 46.3%) of the caregivers were between the age of 31 and 40 years, and gender distribution was almost equal (male:female=1:1.2). More than one-fourth (n=62, 28.7%) of the fathers and half of the mothers (n=114, 52.8%) of the study subjects were illiterate. Less than 15% of the parents were graduates or postgraduates. Less than 5% (n=8, 3.7%) of the fathers and most of the mothers (n=176, 81.5%) of the study subjects were unemployed. The men were employed in most of the cases either as an unskilled (n=88, 44.7%) or semi-skilled worker (n=80, 37%).

Nearly two-thirds of the study subjects (n=140; 64.8%) were diagnosed with HIV at the ART center of Lok Nayak Hospital and another 15.8% (n=34) at other Delhi government hospitals. Only 12% (n=26) of the study subjects were diagnosed in private hospitals. Most of the study subjects (n=196, 90.7%) were on ART treatment and only 9% (n=20, 9.3%) were on Pre-ART. None of the pediatric HIV patient was hospitalized at the time of the study.

Treatment-Seeking Behavior

The first point of contact with the health system for two-thirds (n=90, 62.5%) of the study subjects for initial symptoms was a hospital, while another one third (n=48; 33.3%) went to a private practitioner and only 2 (1.4%) of the respondents went to traditional healers.

Fever was the most common initial symptom for which care was sought (n=114, 52.7%), followed by weight loss (n=100; 46.3%), recurrent diarrhea (n=94; 43.5%), cough (n=60; 27.8%), vomiting (n=44; 20.4%) and breathlessness (n=10; 4.6%). In 72 (33.3%) children no symptom was found but parents were HIV positive so they directly brought their children to the ART center (Table 2).

Table 1. Sociodemographic Profile of Children Living with HIV

Sociodemographic Factors	Study Subjects	
	Number	Percentage
Age (N = 216)		
<5 year	38	17.6
5 year–9 year	74	34.3
10 year–<14 year	104	48.1
Gender (N=216)		
Male	154	71.3
Female	62	28.7
Education (for ≥4 year only)* (N=178)		
Not going to school	16	9.0
Kindergarten	38	21.3
Primary	82	46.1
Above primary below secondary	38	21.3
Secondary	4	2.2
Residence (N=216)		
Urban	137	63.4
Rural	49	22.7
Urban slum	30	13.9
Religion (N=216)		
Hindu	178	82.4
Muslim	32	14.8
Sikh	6	2.8
Socio-economic status (N=216)		
Class I	18	8.3
Class II	18	8.3
Class III	46	21.3
Class IV	100	46.3
Class V	34	15.7

*schooling status of fewer than four years was not assessed as school admissions are done after completion of 4 years of age.

Table 2. Distribution of Subjects according to Presenting Complaints Leading to Seeking Care (n=216)*

Complaints	Number	Percentage
No. symptoms	72	33.3
Fever	114	52.7
Not gaining weight	100	46.3
Recurrent diarrhoea	94	43.5
Cough	60	27.8
Vomiting	44	20.4
Ear discharge	10	4.6
Neurological symptoms	4	1.8
Recurrent skin infections	4	1.8
Others# (Swelling in abdomen, nodular swelling on skin)	12	8.3

*Responses are not mutually exclusive

There were multiple reasons for which a particular health facility was chosen for seeking care. The most common reason cited by the caregiver was accessibility (n=144; 79.2%), followed by better care provision (n=74; 51.4%), trust in the facility (n=76; 52.8%), convenience of their schedule (n=48, 33.3%) and affordability (n=44; 30.6%). Attitude of the staff was also cited as a reason

for care seeking by nearly one-fourth of the caregivers (n=36, 25%). Nearly one-fourth (n=40; 27.8%) of the subjects visited a single health facility before diagnosis, while 43.0% (n=62) of the children visited ≥3 facilities. Mean number of health facilities visited were=2.34±1.62.

Number of consultations was taken as a proxy indicator for preference of a particular health facility. More than two-thirds of all consultations were from hospitals and

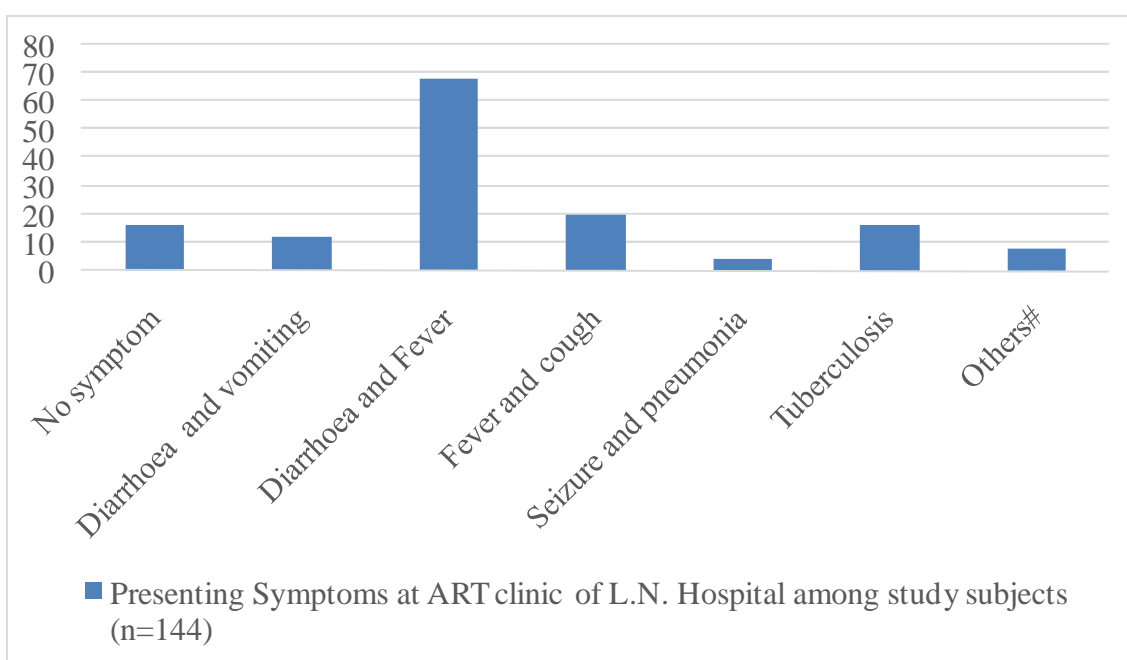
hence they were the most preferred health facility for seeking care. The second most preferred place for seeking care was a private practitioner (Table 3).

Table 3. Health Facility Preferred for Consultation before HIV Diagnosis (n=144)

Type of Health Facility	Total No. of Consultations	
	Number	Percentage
Hospital	228	67.7
Health center (PHC/CHC)	2	0.6
Private practitioner	92	27.3
Traditional healers	13	3.8
Pharmacist	2	0.6

Symptoms at the time of presenting at present ART center were asked. Nearly half of the subjects (n=68, 47.2%) had presented with diarrhea and fever to the

ART center and another 13% (n=20, 13.9%) with fever and cough. Nearly 10% (n=16) had tuberculosis at the time of presentation (Fig. 1).



#Other symptoms include swelling in abdomen, nodular swelling on skin

Figure 1. Presenting Symptoms at Present ART Clinic of Tertiary Care Hospital among Study Subjects (n=144)

In half of the subjects (n=74; 51.4%), symptoms started before the age of 2 years but only one-third were diagnosed as HIV (n=52; 36.1%), others were diagnosed later on. The median age of HIV diagnosis of the children (Median: 3 IQR: 3.4) whose parents were known HIV

cases was lesser than those children (Median 4: IQR: 5) whose parents were unaware of their HIV status. This was found to be statistically significant when tested by Mann Whitney 'U' test (p value <0.001) (Fig. 2).

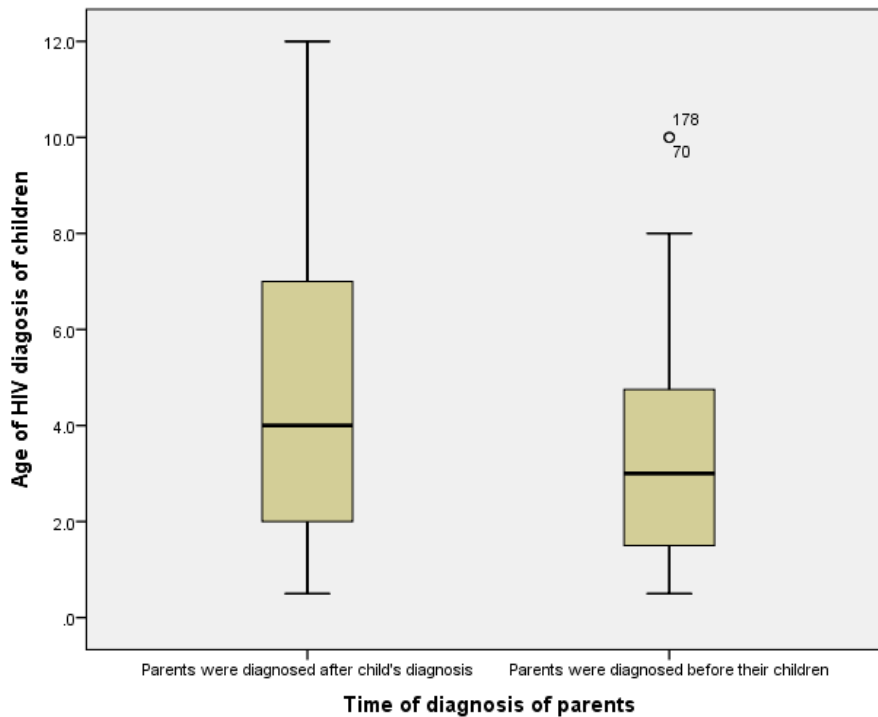


Figure 2. Comparison between Age at Diagnosis of Children and the Time of Diagnosis of Parents (n=216)

Sources of information about present ART center were asked from care givers. Nearly 40% (n=86, 39.8%) of the caregivers of the subjects had heard about the present

ART center from another hospital and another one-third (n=72, 33.3%) had known about the same from their previous experience (Fig. 3).

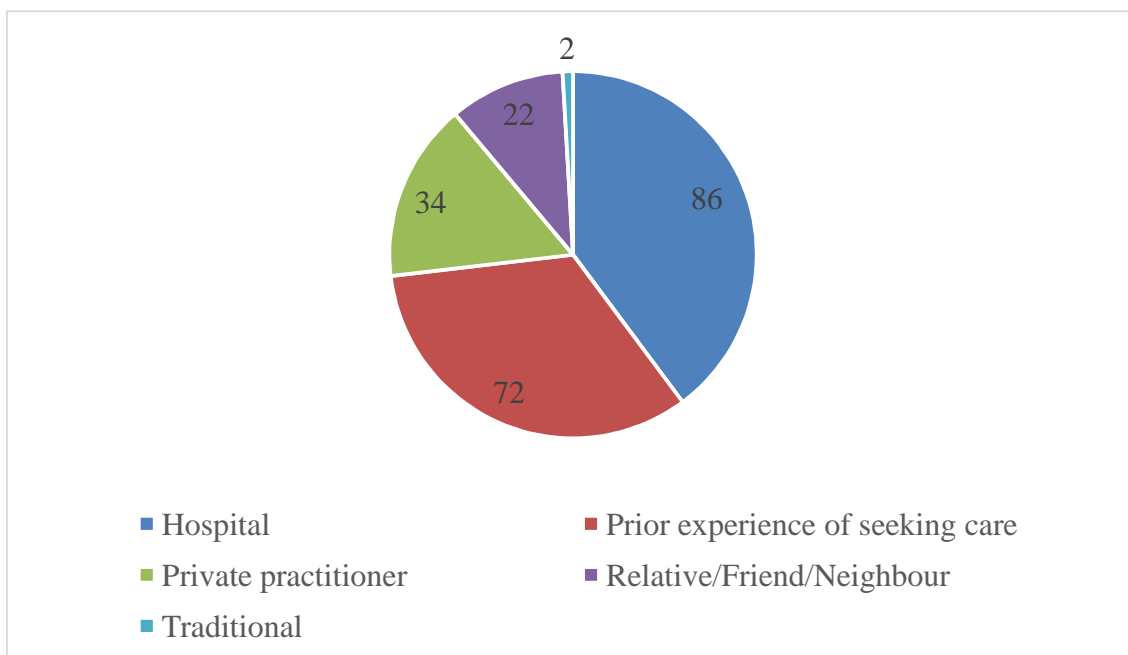


Figure 3. Source of Information about Present ART Center of Tertiary Care Hospital (n=216)

Discussion

The present study was a hospital-based cross-sectional study conducted to assess the sociodemographic characteristics and to find out treatment-seeking

behavior of 216 HIV-positive children, taking treatment and care from ART center of a tertiary care teaching hospital in Delhi. The caregivers of the study subjects attending the pediatric ART clinic were interviewed after taking informed written consent.

In the study, 71.3% were boys and only 28.7% were girls. Nearly half of the pediatric HIV patients were in the age group of 10–14 years, i.e., 104 (48.1%) cases. Similar age and sex distribution was found in other hospital-based studies by Gupta et al., Venkatesha et al., Dachew et al. and Shah et al.^{5,10-12} As the most common route of transmission is vertical (mother to child transmission), it is expected that the proportion of children living with HIV (CLHIV) on ART should be almost equal in both genders. However, it was not so in the present study and this could be due to lower level of utilization of services among girls as compared to boys.

An important finding was that most of the infected children (91.0%) older than 4 years were going to school. This could be because nearly 90% of the children were on HAART and hence were able to cope with school activities. It was a positive finding that timely ART initiation helps HIV positive children to study like other children and helps to lead a normal life.

In the study, nearly half of the children (46.3%) belonged to social class-IV (according to modified B.G. Prasad's social classification), which was comparable to other studies from Ahmedabad by Thakor et al. (56.4% from social class-IV) and from Karnataka by Shettar et al.^{13,14}

The main symptoms for which pediatric HIV subjects started seeking care was fever (79.1%) followed by cough (41.7%), not gaining weight (69.4%), recurrent diarrhea (65.3%) and vomiting (30.6%). Other Indian studies by Solunke et al., Pol et al., Parthasarathy et al. and Lodha et al. also reported same pattern of complaint for seeking care.¹⁵⁻¹⁸ Studies from other countries also reported similar findings.^{19,20}

It was revealed from this study that after appearance of various signs and symptoms, patients preferred to seek care from a nearby hospital (62.5%) or private practitioner (33.8%). Reasons given by caregivers for accessing these facilities were accessibility (79.2%), more trust or reliability (52.8%), provision of good care (51.4%), convenient schedule (33.3%), affordable services (30.6%) and better attitude from health center (25.0%). In this study, since there was no improvement in symptoms or due to repeated sickness of child, pediatric HIV children were found to seek care from different health agencies like hospitals (80.6%), private clinics (29.2%) before diagnosis and thereby lose their vital time. It was also observed that before diagnosis of HIV on an average, every child sought treatment from more than two treatment sources. This focuses on need for training of health providers in identifying symptoms of pediatric HIV/AIDS so that they can get patients

diagnosed timely. In contrast Shettar et al. from Karnataka reported that 65% had taken treatment from government hospitals while 13% from private hospitals for the symptoms of HIV.¹⁴ This showed lack of knowledge among communities about etiology of minor signs and symptoms and importance of seeking healthcare at appropriate place. This study has provided valuable insights about prevalent pattern of seeking care and deficiencies which needs to be considered for framing future approaches for healthcare for pediatric HIV patients.

Conclusion

It can be concluded from the study that gender discrepancy was present in health seeking with more of male than female pediatric patients were enrolled at ART center. Presenting symptoms of HIV in children were not specific and the most common symptom was fever followed by not gaining weight, recurrent diarrhea, cough and vomiting.

Most common health facilities visited by the subjects for their presenting complaints were hospitals followed by private practitioners and traditional healers.

On an average, more than two health facilities were visited by the subjects for relief of symptoms before diagnosis of HIV. Hospitals and private prior experience at the same hospital were the most common source of information about the present ART center of tertiary care hospital.

Recommendations

Since the presenting symptoms of pediatric HIV patients were non-specific and often overlapped with other common childhood illnesses, it is recommended that all healthcare providers at all levels should be adequately trained in identification and referral of cases suggestive of HIV so that any child presenting with malnutrition, chronic diarrhea, or recurrent respiratory tract infection, or disseminated tuberculosis need be screened for HIV infection in order to ensure early diagnosis and management.

Limitations

Health-seeking behavior and delay in treatment seeking was recorded based on history of the caregivers. Recall bias by study subjects was an important limitation of the study. The present ART center was a center of excellence. Facilities available at this center are difficult to replicate at all ART centers across the country. Hence the results have limited generalizability.

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Conflict of Interest: None

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