



Clinical and Hospital Level Predictors of Quality of Healthcare for Clients with Epilepsy attending Treatment at Selected Hospitals in Kenya

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Abstract

BACKGROUND

Quality of Healthcare is the degree to which health services increase the likelihood of desired health outcomes of individuals and populations in the context of prevailing professional knowledge. Despite accounting for 1% of the global disease burden, epilepsy care faces significant challenges, and treatment remains inadequate. This study aimed to determine predictors of quality of care for clients at the selected hospitals in the Nairobi metropolis.

METHODS

A mixed methods cross-sectional approach was adopted and quantitative data were collected from 373 sampled epilepsy patients from Mama Lucy, Kiambu, Gatundu, Thika and Machakos Level 5 Hospitals using semi-structured questionnaires. Qualitative data were collected from key informant interviews and focus group discussions in the study sites. Using (SPSS) version 26, quantitative data were analysed using chi-square to determine the distribution of observation between groups, and logistic and multiple linear regression analyses to test for association quality of care and various variables. Qualitative data were analysed into themes using NVIVO.

RESULTS

Predictors of high quality included formal employment with 3.372 OR CI (1.423-7.625) $P=0.005$, similarly, those who did not experience stigma were 1.98 CI (1.123-3.497) $P=0.018$ likely to rate care as high quality. Less than one seizure after beginning treatment was another predictor of high-quality rating OR=2.405 CI (1.017-5.684), $P=0.045$. Additionally, a shorter waiting time was a predictor of a good rating with OR= 2.692 CI (0.353-0.756) $P=0.028$. Patients who could afford treatment were also likely to rate care as high-quality OR=1.79 CI (2.427-3.642) $P=0.045$.

CONCLUSION

Key clinical predictors of quality-of-care rating included the time to treatment initiation, type of anti-seizure medication, seizure frequency after treatment onset, and stigma experience. Hospital-related factors influencing care quality included waiting time, service availability, and affordability. Additionally, individuals with formal employment, seizure control, shorter waiting times, and the ability to afford medication were more likely to rate healthcare quality highly.

Keywords: *Anti-Seizure Healthcare; People Living with Epilepsy; Quality of Care*

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Background

Quality of Healthcare is the degree to which health services increase the likelihood of desired health outcomes for individuals and populations in the context of prevailing

professional knowledge (1). It entails medical science and technology applications to maximize benefits while reducing risks. Some key facets of performance in quality healthcare measurement include structural, process and outcome (2).



High-quality health care boosts and maintains standards of care for individuals, families and communities (3).

Epilepsy is one of the most common neurological disorders, accounting for 1% of the global disease burden. Globally about 70 million people are living with the condition, 10 million in Sub-Saharan Africa, and one million in Kenya (4, 5). Epilepsy has a high economic burden with an average annual cost estimate of €1528 for lost production and disability-adjusted life years (DALYs) due to hospital admissions. Historically, epilepsy has received little public health attention despite poor health outcomes and potentially devastating social consequences from untreated disease, analogously, epilepsy is associated with different cultural beliefs and superstitions (6, 7).

Despite the high global disease burden, epilepsy care faces significant challenges and treatment remains inadequate (8). The vast majority miss treatment often due to the lack of resources, insufficient healthcare infrastructure and stigma surrounding the condition (9). In low- and middle-income countries, where medical infrastructure is limited and common risks such as birth injuries are more prevalent, several factors hinder the effective management and care of epilepsy. These include challenges in diagnosis and treatment access, limited availability of neuroimaging equipment, and a shortage of trained health professionals, all of which may contribute to misdiagnosis, delayed diagnosis, and inadequate treatment (10). Additionally, cultural beliefs and stigma surrounding epilepsy can encourage seeking treatment from traditional healers instead of health professionals. Limited research only conducted in urban settings also impedes the application of evidence-based treatment, leading to gaps in the quality of care, more so in rural setups with constrained healthcare infrastructure (11). In Kenya, there are numerous gaps in delivering the needed services to these vulnerable

patients due to the lack of adequate human resources, diagnosis equipment and anti-seizure medication (10). The limited access to diagnosis and treatment contributes to misdiagnosis and delayed diagnosis and treatment (10). Since 2010, the NGO-led initiative “Shine Epilepsy Support” project, which works to reduce stigma, has been conducting mass sensitization in Nairobi and its environs. Consequently, there has been an increase in the number of patients seeking treatment in local facilities.

With epilepsy prioritized under Universal Health Coverage (12), there is an urgent need to strengthen health systems to deliver quality care. This entails adequate human resources, funding, logistics, and infrastructure, guided by strong policy frameworks and leadership that supports training, supervision, performance monitoring, and provider motivation (13). Therefore, this study aimed to determine predictors of quality of care for clients at the selected hospitals in the Nairobi metropolis.

Materials and Methods

Study design and site

This was a mixed-methods study conducted between May and September 2021 in selected level five (5) hospitals. This study was conducted in Mama Lucy Nairobi County, Kiambu Level 5, Kiambu County, Gatundu and Thika Level 5 in Kiambu County, and Machakos Level 5 in Machakos County based on the ongoing epilepsy community sensitization and mobilization campaigns in Nairobi Metropolis and its environs since 2010.

Sample size determination

The sample size was calculated by Fisher's formula based on the assumption that the three counties are one system and that the prevalence of epilepsy varies with the population.

$$n = Z^2 p(1 - p) D / d^2$$

Where:

Z = standard deviation, 1.96 at 95% confidence interval

n = is the desired sample size

p = proportion of population estimated to have epilepsy = 0.5 (50 % was assumed as the prevalence is unknown)

$q = 1 - p (1 - 0.5) = 0.5$

d = degree of accuracy = 0.05

Thus, $n = \frac{1.96^2 \times 0.5 \times 0.5}{0.05^2} = 385$

Sampling techniques

The sampling technique was a census, and we recruited all available participants due to low patient flow and the difficulty in accessing the target population until we achieved the sample size.

Data collection

Quantitative data was collected from patients using semi-structured questionnaires adopted from the WHO SF-36v2™ clinical factors. A semi-structured questionnaire was used to collect data on clinical factors, while the WHO SF-36 Health Survey Form (HSF), aligned with the Donabedian Model, was employed to assess process indicators.

The Donabedian Model guided the evaluation of quality of care in clinical practice (14). The quality rating covered multiple domains, such as communication, treatment effectiveness, affordability, accessibility, counselling, geographical access, privacy, and promptness of care. It also encompassed a comprehensive approach involving medical treatment, adherence support, follow-up care, health education, and efforts to reduce stigma.

Qualitative data was collected through key informant interviews and from selected patients using focus group discussion guidelines. Examples of questions in the guide: “*During your hospital visit, did the health provider explain how to take the medication?*” “*Has the health provider talked to you about any signs that should warn you about an attack or complications of a seizure?*” There were five (5) Key Informant Interviews in each station and two (2) focus group discussions of 6-9 selected clients each in every study site. The interviews were conducted under strict COVID-19 public health protocol.

Ethical considerations

Approval to conduct this study was obtained from Jomo Kenyatta University of Agriculture and Technology Ethics Committee Approval Number JKU/IERC/02316/0039. The license to conduct the study was obtained from the National Commission for Science, Technology and Innovation (NACOSTI) Ref No: 691998. All eligible research participants were adequately briefed, and consent forms were issued to them. Only those who gave written consent were recruited to participate in the study. Confidentiality of the participants was maintained and the information obtained was used for the sole purposes of the study.

Data management and analysis

We analysed data using Statistical Package for Social Sciences (SPSS) version 26. Descriptive analysis was used to display the data. The univariate analysis determined the association between clinical characteristics and the quality of care as well as the hospital level factors and the quality of care rating. Multivariate logistic regression assessed if the significant demographics, clinical characteristics and hospital-level factors were predictors of high-quality rating. The statistical significance was set at $P = < 0.05$ with a CI of 95%. Qualitative data was analysed based on the study themes and reported verbatim.

Techniques to minimize bias

Double data entry of quantitative data into the spreadsheets and the use of a variety of sources of primary data from key informant interviews and focus group discussions were used to minimize bias and improve the validity.

To ensure the interval validity of the questionnaires, a thorough literature review on the key constructs of quality of care along with expert review by the supervisors was done to ensure that the questions captured all the intended domains.

Results

Characteristics of the study participants

A total of 373 out of 385 questionnaires issued were completed and included in the analysis, this was a response rate of 96.9%. The mean age of participants was 29.51 ± 11.79 years with a range of 2–71 years. The age category

composition was as follows; 0-5yrs constituted 2.7% (n=10), 6-12 years were 3.5% (n=13), 13-28 years were 15.5% (n=58), 19-28 years were 35.5% (n=132), 29-49 were 37.5% (n=140) and those aged 50+ comprised of 5.4% (n=10). More than half of the respondents (51.2%) were males, three-quarters (67.6%) were married, and more than half (53.6%) had attained a primary school level of education and below.

Table 1
Association between Clinical Factors and Quality of Care

Factor	Categories	N (%)	High quality		Low quality		χ^2	p-value
			n (%)	CI	n (%)	CI		
Time from Seizure onset (N = 373)	< 1 year	70 (18.8)	41 (58.6)	46.3-70.0	29(41.4)	30.0-53.8	6.072	0.048
	1 – 3 years	131(35.1)	77 (58.8)	50.3-66.7	54(41.2)	33.3-49.7		
	> 3years	172(46.1)	79 (45.9)	38.3-53.1	93 (54.1)	46.9-61.7		
Anti-seizure Medication (N = 373)	Yes	329(88.2)	180(54.7)	49.0-60.0	149(45.3)	40.1-51.1	4.024	0.045
	No	44 (11.8)	17 (38.6)	23.8-53.8	27 (61.4)	46.2-76.2		
Co-morbidities (N = 310)	Yes	173(55.8)	86 (49.7)	42.2-56.6	87 (50.3)	43.45-57.8	0.137	0.712
	No	137(44.2)	71(51.8)	43.3-60.1	66 (48.2)	38.9-56.7		
Stigma experiences (N = 356)	Yes	219(61.5)	106 (48.4)	41.5-54.6	113 (51.6)	45.4-58.5	5.022	0.025
	No	137(38.5)	83 (60.6)	52.8-68.8	54 (39.4)	31.2-47.2		
Level of knowledge on Epilepsy (N = 357)	Low (1-2)	167(46.8)	98 (58.7)	51.4-65.8	69 (41.3)	34.2-48.64	3.803	0.149
	Mod (3-4)	160(44.8)	78 (48.8)	40.8-56.5	82 (51.3)	43.5-59.2		
	High (5-6)	30(8.4)	14 (46.7)	28.6-64.0	16 (53.3)	36.0-71.4		
Seizure frequency before the onset of Rx (N = 355)	< 1/week	96 (27.0)	55 (57.3)	47.6-66.7	41(42.7)	33.3-52.4	1.289	0.525
	1 – 4/weeks	155 (43.7)	79 (51.0)	42.7-59.1	76 (49.0)	40.9-57.2		
	>/ 4 weeks	104 (29.3)	52 (50.0)	40.1-60.2	52 (50.0)	39.8-59.5		
Seizure frequency after the onset of Rx (N = 352)	< 1/week	216(61.4)	122 (56.5)	49.8-63.8	94 (43.5)	36.2-50.2	7.337	0.026
	1 – 4 /weeks	99 (28.1)	52 (52.5)	42.9-62.6	47 (47.5)	37.4-57.1		
	> 4 /weeks	37 (10.5)	12 (32.4)	17.3-48.0	25 (67.6)	52.2-86.4		
Treatment regimen (N = 311)	CBZ	204 (65.6)	107 (52.5)	45.6-59.3	97 (47.5)	40.7-54.5	10.464	0.015
	Val	60 (19.3)	39 (65.0)	52.8-77.9	21 (35.0)	22.1-47.2		
	Others	3 (1.0)	0(0.0)	*	3 (100.0)	*		
	No regime	44 (14.1)	17 (38.6)	24.5-54.8	27 (61.4)	45.3-75.5		



Most of the participants were Christians (77.2%) and almost half of the respondents were in informal employment. In Table 1 people who had less than one seizure per week and waited less than 30 minutes were 2.405 (p = 0.029) and 2.692 (p = 0.029) times more likely to rate the quality of care as high, respectively. Patients who could afford epilepsy medication were 1.790 times more likely to rate care high (p = 0.4045). There was a significant relationship between anti-seizure medication use and quality of care ($\chi^2 = 4.024$, p = 0.045), with 52.8% rating care as high. Those taking anti-seizure medication had a 1.401 times higher likelihood of rating care highly (p = 0.037). While seizure onset after treatment was significantly associated with care ratings ($\chi^2 = 7.337$, p = 0.026), these patients were 0.816 times less likely to rate care highly (p = 0.046). Stigma perception also had a significant impact on care ratings, with 48.4% of those perceiving stigma rating care highly, compared to 60.6% of those without stigma ($\chi^2 = 5.022$, p = 0.025). Overall, 53.1% rated care as high.

Patients visiting the clinic at intervals of less than one month rated care as high quality 57.3% of the time, while those visiting every 2-3 months and over 3 months rated it highly at 51.2% and 50%, respectively ($\chi^2 = 1.385$, p = 0.500). Waiting times significantly impacted care ratings, with 55.7% of those waiting less than 30 minutes rating care highly, compared to

50.3% for 30 minutes to 1 hour, and 53.6% for over an hour ($\chi^2 = 6.490$, p = 0.031).

Equally, service availability was significant, with 52.6% of those receiving timely services rating care highly compared to 53.6% of those who did not ($\chi^2 = 7.137$, p = 0.029). Cost affordability significantly influenced ratings, with 54.1% of those who could afford care rating it highly compared to 46.4% of those who could not ($\chi^2 = 4.034$, p = 0.043), as shown in Table 2.

Waiting time significantly predicted the perceived quality of care ($\chi^2 = 6.490$, p = 0.031). Patients who waited less than 30 minutes were 2.692 times less likely to rate care as high compared to those waiting over an hour (p = 0.028). Those waiting 30 minutes to an hour were 1.177 times less likely to rate care as high (p = 0.041). Similarly, service availability was a significant predictor of quality of care rating; 52.6% of patients who received services when needed rated care highly, while 53.6% of those without access rated it as low. Patients with timely access were 1.930 times more likely to rate care as high (p = 0.050).

Cost affordability predicted care rating, patients who could afford medication were 1.790 times more likely to rate care as high, though the result was not statistically significant (p = 0.4045), shown in Table 3.

Table 2

Association between Hospital-Level Factors and Quality of Care Rating.

Variables	Categories	N(%)	High Quality N (%) (CI)	Low Quality N (%) (CI)	Chi-square	P-Value
Visit Interval	< 1 month	117(31.4)	67 (57.3) (48.3-65.8)	50 (42.7) (34.2-51.7)	1.385	0.500
	2-3 months	172(46.1)	88 (51.2) (43.9-58.8)	84 (48.8) (41.2-56.1)		
	>3 months	84(22.5)	42 (50.0) (39.7-61.1)	42 (50.0) (38.9-60.3)		
Waiting Time	< 30 min	97(26.0)	54 (55.7) (45.2-65.7)	43 (44.3) (34.3-54.8)	6.490	0.031
	30min-1 hr	151(45.0)	76 (50.3) (41.4-59.3)	75 (49.7) (41.7-57.7)		
	>1 hr	125(33.5)	67 (53.6) (44.5-62.3)	58 (46.4) (37.7-55.6)		
Service Availability	Yes	304(81.5)	160 (52.6) (47.0-58.1)	144 (47.4) (41.9-53.0)	7.137	0.029
	No	69(18.5)	37 (53.6) (42.1-65.7)	32 (46.4) (34.3-57.9)		
Cost affordability	Yes	262(70.6)	32 (46.4) (34.3-57.9)	125 (47.7) (41.4-53.9)	4.034	0.043
	No	109(29.4)	59 (54.1) (44.4-63.6)	50 (45.9) (36.4-55.6)		



Emerging themes

Seizure onset. The majority of participants reported a seizure onset of more than three years:

“The first time I was...uum can't really remember but mum told me I was in standard 3. Yes, I have been on medication for so long. it's now so many years down the line.” [FGD-KIAMBUR-02]

“At the age of 10 years...I remember that day well...my grandson was full of life, but (crying)...but I always ensure that he gets medication to suppress the seizures.” [FGD-GATUNDU-03]

One participant reported seizure onset in adulthood, contrary to the expectation that epilepsy only affects children:

“It is so unfortunate...mine began recently...we were made to believe that epilepsy only attacks children. I first ...it's a year ago, and I will be turning 35 next week...but I am hoping the medication will help me.” [FGD-MACHAKOS-01]

Medication adherence and its significance. Participants have remained on anti-seizure medications for extended periods:

“Yes, I have been on medication for so long... it's now so many years down the line.” [FGD-KIAMBUR-02]

“I always ensure that he gets medication to suppress the seizures.” [FGD-GATUNDU-03]

Table 3

Multivariate Analysis for High Quality of Care for PWE

Variables		Odds ratio	Confidence Interval		P value
			Lower	Upper	
Occupation	Formally employed	3.372	1.423	7.625	0.005
	Unformal employed	0.990	0.523	1.876	0.976
	Unemployed (REF)	1.00	*	*	*
Onset	< 1 year	1.172	0.587	2.339	0.625
	1 – 3 years	1.325	0.769	2.283	0.310
	> 3 years (REF)	1.00	*	*	*
Anti-seizure Medication	Yes, had medication	1.401	1.669	2.934	0.214
	No, it wasn't necessary (REF)	1.00	*	*	*
Stigma	Yes, had stigma	1.00	*	*	*
	No, didn't have (REF)	1.98	1.123	3.497	0.018
Seizure frequency after onset of Rx	Had in < 1 /week	2.405	1.017	5.684	0.045
	1 – 4 /week	1.932	0.769	4.858	0.161
	> 4/ weeks	1.00	*	*	*
Regimen	CBZ	1.00	*	*	*
	Val	1.654	0.880	3.109	0.118
	No regime	0.000	0.000	*	0.999
Waiting time	< 30 min	2.692	0.353	0.756	0.028
	30 min – 1hr	1.177	1.372	2.231	0.041
	> 1hr (REF)	1.00	*	*	*
Service availability	Yes	1.939	1.492	4.795	0.050
	No (REF)	1.00	*	*	*
Cost affordability	Yes	1.790	2.427	3.642	0.045
	No (REF)	1.00	*	*	*

Stigma associated with epilepsy. Participants faced stigma in relationships, including rejection by potential partners:

“The man who was supposed to marry me went for another girl when he realized that I am epileptic.” [FGD-02]

Stigma in the workplace. Some participants lost jobs due to their epilepsy condition:

“Yes, I lost a job.... I was a house girl...I was hoping to help my grandmother who was sick but my boss fired me when she learnt I was epileptic.” [FGD-MACHAKOS-06]

Social stigma: Some participants reported stigma affecting their children or grandchildren at school.

“My grandson came crying that no one was willing to sit with him in class...I had to transfer him from that school.” [FGD-LUCY-01]

Absence of stigma. A few participants reported not experiencing stigma due to supportive social networks:

“So far all my friends know that I am epileptic and they support me.” [FGD-THIKA-02]

“My husband and my mum support me...but the other people around me are not aware that I am epileptic since my seizures do not occur frequently.” [FGD-KIAMBU-03]

Awareness of medication side effects. Some participants were aware of the side effects of anti-seizure medication.

“I do experience blurry vision and headache...at times the headache takes long that I can't work well.” [FGD-04]

Lack of knowledge of warning signs. Some participants lacked knowledge of warning signs indicating an impending seizure.

“The provider did not explain to me some of the warning signs...so I don't know.” [FGD-THIKA-01]

“One feels drowsy, irritable...I also experience gum hypertrophy but warning signs I can't remember any.” [FGD-MACHAKOS-03]

Integration of qualitative and quantitative data

Duration of seizures. Quantitative: The participants rated care differently depending on the duration they experienced seizures. 45% of those who had seizures for over three years rated care as high compared to those who had seizures for one to three years, 54%, as shown in Table 1. Qualitative: Management of epilepsy is challenging, as noted by a participant who had been on medication for a lengthy period. Another participant expressed difficulty in adjusting to the new medicine.

Stigma and perceived quality of care. Quantitative: Patients who did not experience stigma (60%) rated care quality as high compared to those 44% who rated care as low quality in Table 1. Qualitative: Participants reported various forms of stigma; for example, loss of employment due to epilepsy, reiterating the qualitative that stigma negatively influences the perception of care.

Knowledge of epilepsy and medication. Quantitative: The levels of knowledge about epilepsy did not significantly correlate with care ratings, $P=0.149$ in Table 1. Qualitative: Some participants were very knowledgeable about the medication's adverse effects, others lacked this knowledge in addition to a lack of knowledge on the warning signs of seizures.

Waiting time and service availability. Quantitative: The participants who waited for less than half an hour rated care highly, as did those who had better access to care, with $P=0.028$ and $P=0.050$ in Table 3. Qualitative: The qualitative data confirmed the quantitative, with participants expressing frustration over lengthy waiting times and difficulty in accessing services.

Cost affordability. Quantitative: The ability to afford medication was associated with a higher likelihood of rating care despite the marginally significant correlation $P=0.045$ in Table 3. Qualitative: Sentiments of the ongoing



strain of treatment were highlighted, underscoring how affordability influenced the patients' overall experience and satisfaction with care.

Discussion

The majority of the clients had been ill for more than three years, were not on anti-seizure medication and had experienced stigma. The delay in seeking treatment may have been due to a lack of awareness of the signs and symptoms. This finding concurred with Gasparini and colleagues (15), who reported an average delay of seven years before surgery, despite findings that a shorter duration of epilepsy is linked to more favourable seizure outcomes post-surgery (16), furthermore, Antiseizure medications prevent seizures in about 70%, with 51.1% becoming seizure-free (17).

Many respondents were already on medication but continued to experience seizures; approximately 61% were getting less than one attack per week. Nasir and colleagues (18) similarly observed that though anti-seizure drugs are the primary therapeutic modalities for epilepsy management, one-third of the patients continued to experience seizures despite being on appropriate medication, and these patients remained at risk of seizure-related injuries at home, on the streets or at their places of work.

We also found a significant association between stigma and the quality of care, concurring with Kanner, who reported that stigma was significantly associated with higher levels of psychological distress symptoms and lower quality of life (19). Participants who experienced treatment delays or perceived stigma were less likely to rate the quality of care as high. This finding highlights the significant impact of stigma perception on care quality, aligning with Ibinda's 2017 study, which found that stigmatized individuals may have poor adherence to AED therapy, leading to reduced seizure control (20).

Knowledge about the causes of epilepsy did not affect the perceived quality of care,

contradicting the findings elsewhere, reporting that stigma from a lack of public and family understanding of epilepsy can hinder treatment seeking due to its negative effects on social and emotional well-being (19). Furthermore, the duration of the presence of co-morbid conditions significantly influenced the quality of care, hence disagreeing with Szarflarski's (21). However, a meta-analysis published recently indicated that comorbid depression and epilepsy were associated with a poor quality of life (22); similarly, neurological conditions may have long-term negative downstream effects on schooling and employment prospects (23). We noted a statistically significant relationship between the quality of care and the patient's regimen, indicating that the quality of care was affected by the choice of the regimen. Haag and Bauer (24) corroborated this by stating that continuous administration of some AEDs highly controls seizures.

Our findings indicated, that the waiting times affected the perception of the quality of care, and these findings were in line with Bleustein and colleagues, who reported that long waiting times hurt the metrics as well as the overall satisfaction with the management process. Additionally, waiting time also influenced how participants perceived information, directions and overall care offered at the facilities. Similarly, another study reported that the waiting time was negatively associated with clinical provider scores of patient satisfaction, and patient confidence and a negative correlation with the perceived quality of care (25). Patients who faced difficulty in accessing services had a lower likelihood of rating care highly. These results concur with the findings by Olkiewicz and Bober (26). Equally, patients who could afford medication had a higher likelihood of rating the quality of care high, consistent with findings from Ostendorf and Gedela, who noted that the cost of treatment affected the quality of care the patients received (27).



Limitations of the study

Given that it was interviewer-dependent, the language barrier had the potential to blur communication, for which translators proficient in local dialects were deployed.

Conclusion

The study concluded that the duration before the onset of treatment, antiseizure medication, seizure regimen seizure frequency after onset of treatment and stigma experience were the major clinical predictors of quality-of-care rating. Waiting time, service availability and affordability were the major hospital factors that determined the rating of the quality of healthcare services.

Recommendations

We recommend a well-coordinated public awareness programme aimed at sensitizing patients, relatives and families to seek treatment soon after the onset of symptoms. Hospitals providing care should increase the number of clinic days and increase staff empowerment programmes to lower the staff-patient ratio and seek partnerships with agencies that can provide patient support and thus lower the cost of treatment.

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