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RESEARCH

Health care for children and adolescents with HIV: a comparison of services

Atenção à saúde de criança e adolescente com HIV: comparação entre serviços

Atención de salud del niño y el adolescente con HIV: comparación entre servicios

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ABSTRACT

Objective: compare the quality of different types of health care for children and adolescents with HIV, in the experience of family members and caregivers. **Method:** a cross-sectional study was conducted with 71 family members and caregivers, using the children's version of the Primary Care Assessment Tool (PCATool-Brazil). The Mann-Whitney or Student's t-test and Pearson's chi-square or Fisher's exact test were used for the analysis. **Results:** primary care services and, predominantly, specialized HIV services, were identified as the regular health care sources. There were no significant differences in quality, since their scores were close to the ideal level. **Conclusion:** the attributes of these services need to be improved, which would entail reformulating their structural and performance aspects. In addition, it is imperative to recognize primary health care as an integral place for promoting the health of children and adolescents with HIV.
Descriptors: Child Health; Adolescent Health; Primary Health Care; Health Services Assessment; HIV.

RESUMO

Objetivo: comparar a qualidade da atenção à saúde das crianças e dos adolescentes com HIV entre os tipos de serviços, na experiência dos familiares/cuidadores. **Método:** estudo transversal desenvolvido com 71 familiares/cuidadores utilizando-se o Instrumento de Avaliação da Atenção Primária (PCATool-Brasil) versão criança. Para análise utilizou-se o Teste de Mann-Whitney ou T student e Qui-quadrado de Pearson ou Exato de Fisher. **Resultados:** foram apontados como fonte regular de atenção os serviços de Atenção Primária à Saúde e, majoritariamente, o serviço especializado ao HIV. Não houve diferenças significativas na qualidade de ambos, visto que seus escores atingiram valor próximo ao ideal. **Conclusão:** evidencia-se a necessidade de aprimorar os seus atributos, o que implica em reformulações de seus aspectos de estrutura e desempenho. Além disso, é imperativo o reconhecimento da Atenção Primária à Saúde como espaço integrante da promoção à saúde das crianças e adolescentes com HIV.
Descritores: Saúde da Criança; Saúde do Adolescente; Atenção Primária à Saúde; Avaliação de Serviços de Saúde; HIV.

RESUMEN

Objetivo: comparar la calidad de atención de salud de niños y adolescentes con HIV entre los tipos de servicio, según experiencia de familiares/cuidadores. **Método:** estudio transversal desarrollado con 71 familiares/cuidadores, utilizándose el Instrumento de Evaluación de la Atención Primaria (PCATool-Brasil), versión niños. Para el análisis, se aplicó Test de Mann-Whitney o T Student, y Chi-cuadrado de Pearson o Exacto de Fisher. **Resultados:** fueron considerados como fuente regular de atención los servicios de Atención Primaria de Salud y, mayoritariamente, el servicio especializado en HIV. No existieron diferencias significativas entre la calidad de ambos, alcanzando ellos puntajes cercanos al ideal. **Conclusión:** se evidencia la necesidad de mejorar sus atributos, lo cual implica reformulaciones de sus aspectos de estructura y desempeño. Además, el imperativo el reconocimiento de la Atención Primaria de Salud como espacio integrante de la promoción de salud de los niños y adolescentes con HIV.
Descriptores: Salud del Niño; Salud del Adolescente; Atención Primaria de Salud; Evaluación de Servicios de Salud; HIV.

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INTRODUCTION

Infection by human immunodeficiency virus (HIV) in children and adolescents is categorized as infection by vertical and horizontal transmission. Vertical transmission characterizes newborns infected due to the HIV-positive serological status of their mothers. Horizontal transmission involves infection through exposure through sexual activity or blood. In Brazil, from 1980 to 2013, 18,807 cases of acquired immunodeficiency syndrome (AIDS) were reported in the age group of 0 to 9 years old (children) and 15,480 in the age group of 10 to 19 years old (adolescents). Taking recent years into account, there has been a reduction in the number of cases reported among children (640 in 2011 and 584 in 2012). However, there has been an increase in relation to adolescents (887 in 2011 and 923 in 2012)[1].

Early diagnosis and treatment of children and adolescents with HIV are a health care priority. Although domestic public policies to counter the AIDS epidemic have received international recognition, there are still barriers to achieving quality health care in this area, whether due to regional diversity or lack of communication in governmental spheres[2]. Strengthening of the health care system occurs through investments in accessible services, which provide a continuum of care, in addition to coordinating the flow of users through shared responsibility among professionals[3].

The affiliation of children and adolescents with HIV seeks to identify the health care services that act as a reference for the continuity of their care, regardless of the existence of an established health care network, and may be any type of health care service or professional[4]. However, health care for this population often centers on the need for a team of professionals with experience, and structured services and technology for clinical and laboratory follow-up[3]. These are overloaded in terms of demand, because of lack of human resources and adequate infrastructure[5].

Therefore, activities related to specialized HIV/AIDS services need to be decentralized and expanded into the area of primary health care (PHC), as a way to recognize it as a care coordinator and to qualify this care[6-7]. Primary health care constitutes a key component of the health care system due to its strategic role in the structuring of actions. It is primarily characterized by its essential attributes (first contact access, longitudinality, comprehensiveness and care coordination) and derivative attributes (cultural competence and family and community orientation). On the basis of these attributes, it is possible to determine the quality of services and promote better health care indicators, greater patient satisfaction and lower costs[8].

It is important to assess the quality of health care received by this population in an effort to identify care gaps and promote improvement in the structure and performance of the care provided[9]. This assessment involves the relationship between the needs of the population and the services provided, in order to produce reliable data and enhance decision-making and the reorganization of care actions[10]. The objective of this study was to compare the quality of different kinds of health care services for children and adolescents with HIV, in the experience of family members and caregivers.

METHOD

This was a cross-sectional study that was conducted in a specialized outpatient service for children and adolescents with HIV in the city of Santa Maria, Rio Grande do Sul, Brazil. This service was chosen for data collection because it provided access to the population through their regular follow-up visits.

The population of family members and caregivers of children and adolescents with HIV (N = 80) was used, but a sample size calculation was not performed. The inclusion criteria were: family members and caregivers of children (0 to 9 years old) and adolescents (10 to 19 years old)[1] with HIV receiving follow-up care in a specialized health care service. The following were excluded: family members and caregivers with limitations that hindered verbal communication and those who reported private services as the regular health care source. There was a total of 80 potential participants. Three people refused to participate, four family members and caregivers were excluded because they reported private services as the regular health care source, and two were no longer receiving follow-up care. That left a final total of 71 participants.

The data collection was carried out from January to September 2013. The family members and caregivers were approached in the health care service when they accompanied the children and adolescents on the day of their appointment. The data collectors used a research protocol containing: Part 1 – questionnaire to characterize the population, including sociodemographic, clinical and health care service use data; and Part 2 – Primary Care Assessment Tool (PCATool-Brazil) - children's version (applied to family members and caregivers)[8,11].

This instrument measures the presence and extent of PHC attributes, which each include a component related to structure and performance, forming an assessment of how much the health care services are guided by the defining PHC attributes, i.e., their quality. The instrument is composed of a Likert scale with the following possible responses for each item: "definitely" (value = 4), "probably" (value = 3), "probably not" (value = 2), "definitely not" (value = 1) and "I don't know/I can't remember" (value = 9). The score can range from 1 to 4 for each attribute[9].

The preferred type of health care service for the children and adolescents was defined by the family members and caregivers based on the three initial questions from the PCATool-Brazil establishing the strength of affiliation: 1) in relation to the health care services that were sought in light of the needs of the children and adolescents; 2) who knew the children and adolescents best; and 3) who was more responsible for the health care of the children and adolescents[8]. The rest of the instrument was answered based on the services reported in the strength of affiliation. For the data analysis, the responses were characterized into "specialized HIV services" and "PHC services". The following were considered to be PHC services: Primary Health Units and the Family Health Strategy.

The sociodemographic variables were: age, city of origin, years of education and income. The clinical variables were: infection category, diagnosis and treatment. The health care service use variables were: knowledge of the health care service

closest to the home, type of service and if the child or adolescent was taken to this service. To characterize the quantitative variables (age, years of education, diagnosis time and income), a median was used as a cut-off point, given the asymmetrical distribution of the data.

The data was organized in the program Epi info® 6.04, entered in separately two times, followed by correction of any errors or inconsistencies. The data analysis was performed with the software Statistical Analysis System (SAS), Version 9.3. The normality distribution of the variables was assessed by the Shapiro-Wilk test. The internal consistency of the PCATool-Brazil, children's version, was assessed by Cronbach's alpha ($\alpha = 0.874$). The attributes and their components were analyzed by calculation of the scores: the essential attributes, derivative attributes and overall score for each attribute, according to the guidelines from the PCATool-Brazil Manual[8]. The scores were transformed into a continuous scale ranging from 0 to 10, where ≥ 6.6 was considered a high score. This score is equivalent, on a scale from 1 to 4, to a score of 3 ("probably"), which corresponds to an appropriate extent of the attribute[8].

For the association analysis of the variables (sociodemographic, clinical and use of the service) for the service that regularly cared for the child or adolescent, the Chi-square test or Fisher's exact test was used. To compare the means of each attribute between the types of service, the Mann-Whitney or Student's t-test was used. For the proportions analysis, the Pearson's chi-square or Fisher's exact test was used, in an effort to identify the variables (sociodemographic, clinical and use of health services) that could be associated with the quality of the service cited as the regular health care source. Thus, the group was dichotomized in relation to the assigned score, into high or satisfactory (≥ 6.6) or low (< 6.6) scores. The assumed level of significance for the tests was 5%.

The ethical aspects were based on the guidelines of Resolution 196/96, in force at the time of the study[12]. The objectives of the study were explained to the family members and caregivers, who were asked to sign two copies of the Free and Informed Consent Form. The study was approved by the Research Ethics Committee of the Federal University of Santa Maria in January 2013.

RESULTS

Of the 71 participants, 56 reported the specialized HIV service as the regular health care source. The specialized service was indicated as the service generally sought when there was a new health problem (43); as the one that best knew the child or adolescent (45); and as the service most responsible for the health of the child or adolescent with HIV (60). Table 1 presents the sociodemographic, clinical and health service use characteristics, according to the regular care source reported by the family members and caregivers.

Among the sociodemographic, clinical and health service use variables, the following were statistically associated with the service that regularly cared for the child or adolescent: age of the child or adolescent, years of education of the family member or caregiver, time since diagnosis, child or adolescent receives treatment, and family member or caregiver takes the child or adolescent to the service closest to home.

Table 2 presents the scores for the attributes in relation to the health care of children and adolescents with HIV, establishing a comparison between the types of service.

In the assessment of attributes according to type of service, both had satisfactory scores (≥ 6.6) for the attributes: strength of affiliation; first contact access – use; first contact access – accessibility; longitudinality; coordination – care integration; coordination – information system; comprehensiveness – services available. There were no statistically significant differences between the two. In the combined analysis of the attributes, neither service had a satisfactory overall score.

An analysis was performed of the association between the characteristics (sociodemographic, clinical and health service use) and best care assessment (high overall score), according to the type of service (specialized or PHC) established by the strength of affiliation (Table 3).

In the assessment of the population characteristics associated with the overall score of the specialized service, no statistical difference was noted that could be associated with the high score. The same occurred with the PHC service. In other words, no characteristic was associated with the high score of either PHC or the specialized service, indicating that the population characteristics did not affect the care assessment of the services.

Table 1 – Sociodemographic, clinical and health service use characteristics of children and adolescents with HIV, according to the type of service reported by the family members and caregivers as the regular care source, Santa Maria, Rio Grande do Sul, Brazil, 2013

Variables	Total (N = 71)		Specialized service (n = 56)		Primary Health Care (n = 15)		*P* value
	n	%	n	%	n	%	
Sociodemographic characteristics							
Age of child/adolescent							< 0.001†
Up to 12 years old	35	49.0	35	62.5	0	0.0	
13 to 19 years old	36	51.0	21	37.5	15	100.0	

To be continued

Table 1 (concluded)

Variables	Total (N = 71)		Specialized service (n = 56)		Primary Health Care (n = 15)		*P* value
	n	%	n	%	n	%	
City of origin							0.079†
Santa Maria	35	49.0	31	55.0	4	27.0	
Other	36	51.0	25	45.0	11	73.0	
Main caregiver							0.549*
Mother	38	54.0	31	55.0	7	47.0	
Other	33	46.0	25	45.0	8	53.0	
Income (n = 69)							0.575*
Up to 1,000 BRL	37	54.0	28	52.0	9	60.0	
Over 1,000 BRL	32	46.0	26	48.0	6	40.0	
Years of education of family member/caregiver							0.008†
Up to 6 years	41	58.0	37	66.0	4	27.0	
Over 6 years	30	42.0	19	34.0	11	73.0	
Clinical characteristics							
How the child/adolescent contracted HIV							1.000†
Vertical transmission	64	90.0	50	89.0	14	93.0	
Other	7	10.0	6	11.0	1	7.0	
Time since diagnosis							0.009†
Up to 8.5 years	36	51.0	33	59.0	3	20.0	
Over 8.5 years	35	49.0	23	41.0	12	80.0	
Child/adolescent undergoing drug treatment							0.006†
No	5	7.0	1	2.0	4	27.0	
Yes	66	93.0	55	98.0	11	73.0	
Health service use characteristics							
Knows health service closest to home							1.000†
No	4	6.0	3	5.0	1	7.0	
Yes	67	94.0	53	95.0	14	93.0	
Type of service closest to home (N = 66)							1.000†
PHC	63	95.0	48	94.0	15	100.0	
Other	3	5.0	3	6.0	0	0.0	
Goes to the service closest to home							0.002†
No	40	56.0	37	66.0	3	20.0	
Yes	31	44.0	19	34.0	12	70.0	

*Notes: *Pearson's Chi-square test; †Fisher's exact test.*

Table 2 – Comparison between the means of the attribute scores among the services reported as the regular care source, 2013 (N = 71)

Attributes	Scores (0–10)										*P* value**
	Specialized service (n = 56)					Primary Health Care (n = 15)					
	Mean	SD	Median	Minimum	Maximum	Mean	SD	Median	Minimum	Maximum	
Strength of affiliation†	8.15	2.10	10.00	3	10	8.00	2.10	6.67	3	10	0.763
First contact access – use†	8.41	2.59	10.00	0	10	9.03	1.24	10.00	6	10	0.834
First contact access – accessibility†	7.19	2.03	7.78	1	10	7.70	1.94	7.78	4	10	0.445

To be continued

Table 2 (concluded)

Attributes	Scores (0–10)										
	Specialized service (n = 56)					Primary Health Care (n = 15)					*P* value**
	Mean	SD	Median	Minimum	Maximum	Mean	SD	Median	Minimum	Maximum	
Longitudinality*	8.02	1.12	8.18	5	10	7.67	1.93	7.88	2	10	0.750
Coordination – care integration †	8.09	2.43	9.33	0	10	8.16	2.32	9.33	4	10	0.978
Coordination – information system†	7.71	2.17	7.78	2	10	7.18	2.48	7.78	2	10	0.476
Comprehensiveness – services available*	7.14	1.63	7.41	3	10	6.94	1.67	6.85	3	10	0.872
Comprehensiveness – services provided†	6.57	3.49	7.67	0	10	6.42	4.04	8.33	0	10	0.958
Family centeredness†	5.21	2.93	5.28	0	10	4.48	3.54	4.44	0	10	0.449
Community orientation†	2.53	3.18	1.67	0	10	1.92	3.33	0.00	0	10	0.310
Essential score*	7.02	1.43	7.22	4	9	6.93	1.63	6.45	4	9	0.459
Derivative score†	3.67	2.37	3.33	0	10	3.07	3.04	2.22	0	10	0.178
Overall score*	6.43	1.34	6.49	3	8	6.13	1.61	5.53	3	8	0.341

*Notes: * Normal distribution; † Asymmetric distribution; **Mann-Whitney test or Student's t-test; SD = Standard deviation.*

Table 3 – Association of the sociodemographic, clinical and health service use characteristics with low/high scores, according to the regular care source for children and adolescents with HIV, 2013 (N = 71)

Variables	PCATool-Brazil									
	Specialized service (n = 56)					Primary Health Care Service (n = 15)				
	High overall score (≥ 6.6)		Low overall score (< 6.6)		*P* value	High overall score (≥ 6.6)		Low overall score (< 6.6)		*P* value
	n	%	n	%		n	%	n	%	
Age of child/adolescent					0.094*					-
Up to 12 years old	12	50.0	23	72.0		-	-	-	-	
13 to 19 years old	12	50.0	9	28.0		5	100.0	10	100.0	
City of origin					0.351*					0.230†
Santa Maria	15	62.5	16	50.0		0	0.0	4	40.0	
Other	9	37.5	16	50.0		5	100.0	6	60.0	
How HIV was contracted					1.000†					0.333†
Vertical transmission	21	87.5	29	91.0		4	80.0	10	100.0	
Other	3	12.5	3	9.0		1	20.0	0	0.0	
Time since diagnosis					0.084*					0.505†
Up to 8.5 years	11	46.0	22	69.0		0	0.0	3	30.0	
Over 8.5 years	13	54.0	10	31.0		5	100.0	7	70.0	
Child/adolescent receives treatment					1.000†					0.560†
No	0	0.0	1	3.0		2	40.0	2	20.0	
Yes	24	100.0	31	97.0		3	60.0	8	80.0	

To be continued

Table 3 (concluded)

Variables	PCATool-Brazil									
	Specialized service (n = 56)					Primary Health Care Service (n = 15)				
	High overall score (≥ 6.6)		Low overall score (< 6.6)		*P* value	High overall score (≥ 6.6)		Low overall score (< 6.6)		*P* value
	n	%	n	%		n	%	n	%	
Main caregiver					0.698*					0.282†
Mother	14	58.0	17	53.0		1	20.0	6	60.0	
Other	10	42.0	15	47.0		4	80.0	4	40.0	
Years of education of family member/caregiver					0.221*					0.230†
Up to 6 years	18	75.0	19	59.0		0	0.0	4	40.0	
Over 6 years	6	25.0	13	41.0		5	100.0	6	60.0	
Income					0.967*					1.000†
Up to 1,000 BRL	12	52.0	16	52.0		3	60.0	6	60.0	
Over 1,000 BRL	11	48.0	15	48.0		2	40.0	4	40.0	
Knows health service closest to home					1.000†					1.000†
No	1	4.00	2	6.0		0	0.00	1	10.0	
Yes	23	96.0	30	94.0		5	100.0	9	90.0	
Type of service closest to home					0.258†					-
PHC	21	100.0	27	90.0		5	100.0	10	100.0	
Other	0	0.0	3	10.0		-	-	-	-	
Goes to the service closest to home					0.103*					0.241*
No	13	54.0	24	75.0		2	40.0	1	10.0	
Yes	11	46.0	8	25.0		3	60.0	9	90.0	

*Notes: *Pearson's Chi-square test; †Fisher's exact test.*

DISCUSSION

For most of the interviewees, the specialized service was identified as the regular health care source. Another study corroborates this result and attributes it to the organization of the health care system and the experience of the professionals from this service[13].

The findings related to the sociodemographic characteristics indicate greater vulnerability of the population that uses the specialized service as the regular care source. This vulnerability lies in the prevalence of the age group up to 12 years old and the low educational level of their family members and caregivers. This result is similar to that of another study, which reinforces the pauperization trend of the epidemic, due to the increased number of cases in individuals with a low educational level, which is also a socioeconomic status marker[14]. With regard to the clinical characteristics, the length of time since the original diagnosis was longer among those who indicated the PHC as the regular care source than among those who reported the specialized service and were undergoing drug treatment. This confirms the importance of care being shared with the PHC service, regardless of whether treatment is being carried out. This coincides with a study conducted in Africa, where users at a less advanced and clinically stable stage of the disease were cared for by PHC teams, and the rest by specialized services[15].

As for use of the services, those who reported the specialized service did not use the service closest to home for the provision of health care for children and adolescents with HIV, corroborating the findings of another study, which affirms that the closest health service is generally not used to promote health among this population[16]. On the other hand, in the case of other infectious diseases, such as tuberculosis, there have been proposals to control them at the PHC level through the incorporation of diagnostic, treatment and prevention actions. Primary health care services are also responsible for the diagnosis and control of other chronic conditions, such as high blood pressure[18]. What makes it difficult to implement actions to affiliate HIV patients with PHC services is the lack of professional preparedness to care for this population and the stigma attached to the disease[19].

In relation to the scores for the attributes of the services identified as the regular care source by family members and caregivers, most of the attributes obtained high scores. For the attribute first contact access, the scores were satisfactory and similar between the services, indicating that this population is able to

access health services. The components accessibility and access obtained higher scores at the PHC level, unlike the findings of other studies that assessed PHC in relation to the general population, where the scores were lower[20-21]. This may be because PHC services are often closer to users' homes than specialized services and, therefore, are the first services sought[21].

The satisfactory score for the longitudinality attribute for both services shows that it is essential for the health care of children and adolescents with HIV, since it seeks to have a care source, maintain regular use and constitute a link that reflects mutual cooperation between users and health professionals[9]. It is important to note that the difficulty of providing continuity of health care results in high proportions of HIV tests not being performed and people with HIV not taking antiretroviral treatment[22]. The higher score for the specialized service may be due to the continuous follow-up that occurs there because of the chronic nature of the disease.

The care coordination attribute also obtained a satisfactory score for both services. The fact that the care integration component received a higher score in the PHC service suggests that this service focuses on referral and communication with other health services. The high score for the information system component in the specialized service indicates that this service is much better organized and informational in relation to the documents and medical records of its patients. It is worth noting that referral to specialized services often results in disconnecting users from PHC services and transferring the responsibility for their follow-up[13]. Therefore, for users, specialized services may represent the place where care is provided for their health condition, suggesting that they have no need to disclose their diagnosis to PHC teams[6]. This is a mistaken notion, since specialists may provide more appropriate care for the disease itself, but PHC professionals can integrate the care with the range of other health problems affecting individuals[10].

In the analysis of the comprehensiveness attribute, the available services component obtained a satisfactory score for both services, demonstrating that family members and caregivers believe that the services care for the basic needs of the population, including supplies such as vaccines and medicine. However, the services provided component yielded a score below that considered ideal, indicating the need to invest in promotion and prevention activities, so that they can be effectively executed by health services. One study points out that PHC professionals report obstacles in caring for people with HIV, such as work overload, lack of privacy for providing care, and the stigma attached to the disease[13,19,23]. Professionals need to be trained in terms of early diagnosis, clinical aspects, diseases associated with HIV, treatment, and the need to refer users to specialized services[13].

The family centeredness attribute did not achieve a satisfactory score for either of the services assessed, despite high longitudinality scores. However, the specialized service, which obtained a higher score than PHC, tends to enhance the life context of children and adolescents and their insertion into their families and communities [24].

The family members and caregivers also assigned low scores to the community orientation attribute for both services. It is important to note that PHC services should address community health needs through direct contact with the population and knowledge of its epidemiological profile[10]. The difficulty of promoting health is due to the limitations of public policies related to HIV prevention and control, which need planning and investment. Specialized services meet growing demand by individuals suffering from the disease; however, they are not designed to provide community orientation. This population also needs to receive care in PHC services, in order to balance the demand and enable more concrete actions in specialized services[25]. To achieve this attribute in PHC services, household visits can be carried out by health professionals and community agents, resulting in health surveillance, strengthening of ties, educational activities and identification of risk situations[26].

In the essential score analysis, it was found that both services were providing care that was aligned with PHC attributes. As for the derivative score, it indicated that health services still need to improve actions that focus on families and communities. The combined analysis of the attributes (overall score) indicated that the services were below the level considered as ideal, although they were close. This result coincides with other studies that have assessed PHC[27] and reinforces the importance of the role of health care services in boosting the quality of life of this population[28]. There was no statistically significant difference in the assessment of the services, indicating that family members and caregivers may consider them as having similarities. In addition, no characteristic was associated with a high score for either the PHC or specialized service, demonstrating that the characteristics of the population did not affect the care assessments for the services.

Through the results analysis, it can be inferred that the family members and caregivers noted positive aspects in the care provided in the specialized service as the regular care source, primarily in terms of more contact with the professionals from this service. This result indicates that specialized services are striving to serve this population. On the other hand, users should place more trust in PHC and view the integration of the services as a care continuum. One study indicates that care is often disconnected from PHC services, either due to the unpreparedness of professionals or the organization of the operation of the services[13]. It must be borne in mind that, in some cases, PHC professionals are unfamiliar with the actions performed by specialized HIV services, and also do not identify infected users as being within their scope of work[13]. In fact, primary health care should play an important role in receiving and counseling this population on how to handle their chronic condition, mainly in reference to social and family interactions, health care routines and family planning[6].

CONCLUSION

This study revealed the importance of assessing health care for children and adolescents with HIV within the context of health care services, since the results indicated that the specialized service was the regular care source; this highlights the need to recognize PHC services as a place where health can

be promoted. The results of this study also emphasize the need to improve certain attributes of PHC and specialized services, which would entail reformulating some aspects of their structure and performance, in order to provide the intended quality.

Although children and adolescents with HIV are often referred to specialists, they should continue using PHC services for their chronic condition and other health needs related to longitudinality and care coordination. The services should define the responsibilities for meeting the health needs of this population and decide when referral is indicated. Specialized services are dedicated to specific care for the disease, including clinical and therapeutic needs, but it is the role of PHC to coordinate care and follow-up of users in their communities, in order to promote their health. In this regard, it is imperative to integrate the services, which can be established through a flow of users in the health care system.

It is recommended that PHC carry out the following activities: engaging in needed information campaigns to change behavior regarding prevention of infection and reinfection; diagnosing new cases of HIV; serving as a point of reference for specialized services so as to maintain an ongoing flow of care; monitoring childcare and pubertal changes in children and adolescents with HIV; complying with the immunization calendar; promoting health based on the family and social context; helping people sign up for treatment and resolve nonspecific complaints and comorbidities; actively seeking users; and sharing information systems between services.

To integrate services, PHC professionals could be required to receive training (through short courses and continuing education) aimed at a collaborative care model to provide ongoing training and support. Integration also requires strengthening communication between services, clear definition and distribution of their activities, collaboration with other non-health-related government sectors, commitment from the government to a formal policy and legislation to legitimize actions that integrate services, and commitment to infection care in the long term.

It is worth noting that, in this study, the attributes were assessed through the experience of users (family members and caregivers), who tend to have a more critical view of health care services, which illustrates the need to include other social actors. A limitation was the population size of the study. Because it was conducted with a population that was linked to the specialized service, the study ended up excluding other children and adolescents with HIV who were receiving follow-up in other services, which statistically affected the chances of association in comparing the services. It should be emphasized that the results are restricted to a single city, so any generalization of the data must be done with caution. However, the lack of national studies on the subject suggests that similar assessments would be relevant and could serve as input to improve actions and public policies through discussions with users, professionals and managers, acting as a tool to guide implementation in the health care system.

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