Original Article

Primary care for children with type 1 diabetes *mellitus*: caregiver perspectives

Atenção primária à criança com diabetes *mellitus* tipo 1: perspectiva de cuidadores

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Abstract

Objective: To evaluate and compare the quality of primary care provided for children with type 1 diabetes *mellitus*, among the types of public health care services, based on the experience of their main caregivers.

Methods: Cross-sectional study, grounded in health assessment, using interviews with 55 caregivers of children with type 1 diabetes *mellitus*, based on the *Primary Care Assessment Tool*-Child Version.

Results: Most of the attributes of primary health care presented unsatisfactory scores, including the general and essential scores. A greater link with the specialized service (pediatric endocrinology clinics) was found. Although the general and essential scores did not attain satisfactory values, the specialized services achieved better results than the primary health care services, showing, from the perception of the consumers, relevant differences between services. Specialized services were perceived as regular sources of care, and better providers of primary health care practices. This point may be related to the greater contact of the participants with the professionals from the specialized services, and the readiness of these services to care for children with type 1 diabetes mellitus, suggesting fragilities in the primary health care services.

Conclusion: The health care of children with type 1 diabetes mellitus, in the studied municipality, shows little presence and extension of primary care attributes, with fragmented and disconnected actions, leading to losses in the integration and expansion of the care network.

Resumo

Objetivo: Avaliar e comparar a qualidade da atenção primária ofertada às crianças com diabetes *mellitus* tipo 1 entre os tipos de serviços públicos de atenção à saúde na experiência dos seus principais cuidadores.

Métodos: Estudo transversal, fundamentado em avaliação em saúde, a partir de entrevistas com 55 cuidadores de crianças com diabetes *mellitus* tipo 1, com base no instrumento de avaliação *Primary Care Assessment Tool*-versão criança.

Resultados: Grande parte dos atributos da atenção primária à saúde apresentou escores considerados insatisfatórios, inclusive os escores Geral e Essencial. Foi encontrado maior vínculo com o serviço especializado (ambulatórios de endocrinologia pediátrica). Apesar dos escores Geral e Essencial não terem alcançado valores satisfatórios, os serviços especializados apresentaram melhores resultados que os serviços de atenção primária à saúde, mostrando, na percepção dos usuários, diferenças relevantes entre os serviços. Os serviços especializados foram percebidos como fontes regulares de atenção e melhores fornecedores de práticas de atenção primária à saúde. Tal apontamento pode estar relacionado ao maior contato dos participantes com os profissionais dos serviços especializados e prontidão desses serviços na atenção às crianças com diabetes *mellitus* tipo 1, sugerindo fragilidades nos serviços de atenção primária à saúde.

Conclusão: A atenção à saúde das crianças com diabetes *mellitus* tipo 1 no município estudado apresenta pouca presença e extensão dos atributos da atenção primária, com ações fragmentadas e desarticuladas, levam a prejuízos na integração e ampliação dos cuidados em rede.

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Introduction

Chronic noncommunicable diseases are a global health problem, and the burden of these diseases relies especially on low-and middle-income countries, which makes it extremely important to improve strategies to adequately manage public health services.[1,2]

Type 1 diabetes *mellitus* (T1DM) is a chronic disease that occurs in children and adolescents, and represents between 5 - 10% of cases of this disease, [3,4] with a continuous increase in several regions of the world.[3] It is associated with long-term complications, with repercussions on quality of life, in addition to high morbidity and mortality.[3]

Monitoring and health surveillance of children with T1DM are extremely relevant, and require regular evaluation and support for children and families.[5] Access to health services for children with T1DM requires coordination within the health system, to avoid an increase in the number of hospitalizations and serious complications.[5,6]

Primary Health Care (PHC) plays the central, structuring role of health systems, with coordination of the Health Care Network (HCN), including for chronic health conditions.[7] The PHC assessment, proposed by this study, used the Starfield model[8] which considers the characteristics of the PHC as essential attributes (first contact, longitudinality, coordination, and comprehensiveness) and derivatives (family and community guidance). It is based on the theoretical framework of Donabedian, with the triad to evaluate quality in the health area: structure, process and outcome. Considering the relevance of peoples' opinions about the continuity of health care, [9] and that health services have had difficulties offering solutions to the disabilities and injuries that chronic diseases generate, [1] the present study aimed to evaluate and compare the quality of primary care provided to children with T1DM, among the types of public health care services, from the experience of their main caregivers.

Methods

This was a cross-sectional study, based on the theoretical methodological framework of health evaluation, proposed by Donabedian.[6-10] The Primary Care Assessment Tool (PCATool) - Child Version, validated in Brazil and provided by the Ministry of Health,[11,12] is based on the assumptions of structure, process and outcome.[10]

The study was conducted in the city of Uberlândia-MG-Brazil. The inclusion criteria for the study included: mother and/or guardian of children in the age group of zero to 11 years, 11 months and 29 days, counted from the date of beginning of the data collection, whose children had a medical diagnosis of T1DM, who attended follow-up appointments at outpatient clinics specializing in children's T1DM, were residents in the municipality, and who declared themselves as the the child's primary caregiver. Exclusion criteria were: follow-up in supplementary or private health services, caregiver under 18 years of age, missing the appointment, and not being located after three attempts at a home visit.

All the children with T1DM were enrolled in the Municipal Center for Diabetes Care (MCDC), to receive medicines and supplies. Children with T1DM received follow-up at the MCDC or Pediatric Outpatient Clinic of the *Hospital de Clínicas* of the Federal University of Uberlândia. At the time of data collection, the PHC services in the municipality had 45 Family Health Strategy teams, nine Basic Health Units, and eight Integrated Care Units.

In order to select the study participants, we used the MCDC cadastral data; 84 children who met the inclusion criteria were identified. Among these, 25 children were receiving care at concomitant supplementary or private health services. Thus, a total of 59 children were appropriated for inclusion; however, one mother refused, and three were not located after three attempts at home visits at different times. Therefore, 55 mothers/guardians were included.

Data collection was performed from July of 2013 to February of 2014, in the waiting rooms of outpatient clinics specialized in pediatric endocrinology, on the day of medical consultations. Interviews were

conducted by one of the researchers, with an average duration of 20 minutes. In addition to the PCATool, a questionnaire prepared by the researchers, containing socio-demographic data on the family, was used.

In relation to the PCATool, the items on the PHC attributes enable the development of scores ranging from responses on a four-point Likert scale (rated one to four) for each attribute. The final score of each of these attributes is derived from the mean of the responses of their items, which also vary from one to four. The sum of the means of the values of the four essential attributes, and their sub-dimensions, combine with the mean of the user's degree of affiliation to the health service to produce the Essential Score. The means of these essential scores added to the means of the derived scores produce the General Score. In order to determine the cut-off point for the scores, the answers "probably yes" and "certainly yes" (values three and four, respectively) were considered to demonstrate a positive aspect of the PHC. Thus, scores ≥3 indicate a strong presence and extension of the evaluated attribute. The value of the scores obtained for each attribute was transformed into a scale from zero to ten, using the following formula: [(Obtained Score-1)x10]/3. The score is considered satisfactory when it attains a value greater than 6.6.[12] The first item of the PCATool is the Degree of Affiliation. When obtaining the answers to the first three questions for this item, it is possible to establish the service with greater affiliation, and thus to direct the other questions in the script to this service, that is, the participant evaluates the service to which she/he has the highest degree of affiliation.[12]

All attributes were presented using means, standard deviations, and medians. Data from the PHC and specialized service groups were tested for normality using the Shapiro Wilk test. When both groups presented normality, their means were compared for homogeneous or heterogeneous variances using the Student's t-test. When at least one of the groups did not present normality, the medians of the groups were compared using the Mann-Whitney test. A Cronbach's alpha was calculated for the entire data set. For all analyses, a 5% level of significance was adopted. The analyses were performed using the SPSS statistical program, version 20.0.

The research was approved by the Research Ethics Committee of the University of São Paulo at Ribeirão Preto College of Nursing, under protocol nº 405818.

Results

Among the 55 study participants, 45 were mothers and ten were other caregivers, ranging in age from 18 to 61 years. Among the children, 30 (55%) were males, and 25 (45%) were females; ten (18%) were under five years of age, 15 (27%) were between 6-9 years, and 30 (55%) were between 10 years and 11 years, 11 months and 29 days. The mean time since the T1DM diagnosis of these children was three years and six months, with a minimum of two months, and a maximum of ten years.

Table 1 presents the PHC evaluation using the PCATool- Child Version, based on the experiences of the caregivers of children with T1DM, with the scores of each PHC attribute.

Only Longitudinality, Degree of Affiliation, and Coordination related to Information Systems achieved scores greater than 6.6.

Table 1. Values obtained for scores of PHC attributes, in the context of children with T1DM

Component	Mean	Standard deviation
Degree of affiliation	7.76	2.29
First contact - Use	6.29	2.55
First contact - Acessibility	4.84	2.55
Longitudinality	7.21	1.99
Coordination - Integrated care	5.18	2.09
Coordination - Information system	6.71	2.17
Comprehensiveness - Available services	2.23	1.42
Comprehensiveness - Services provided	5.43	3.22
Family orientation	3.86	2.64
Community orientation	0.90	1.58
Essential attributes	5.78	1.37
Derivative attributes	5.06	1.31

In this study, the majority of the participants (76.36%) were affiliated with specialized services, and the other 13 (23.63%) were affiliated with PHC services; that is, the majority were referencing the specialized services when they responded to the questionnaire. The results were stratified into two groups according to the service that was evaluated, and comparison through statistical analysis was performed (Table 2).

Table 2. Comparison between means and medians of the attribute scores among the types of services referred to as the service with highest affiliation, by caregivers of children with T1DM (n=55)

Attributes of primary health care	Primary health care services (n = 13)			Specialized services (n = 42)			Statistics	p-value
	Mean	SD	Median	Mean	SD	Median		
Degree of Affiliation	5.38†	2.56	6.67	8.49†	1.68	10.00	*Z*=-3.87	<0.001
First contact - Use	7.69£	2.00	7.77	5.84£	2.60	6.67	*t*=2.35	0.023
First contact - Acessibility	4.66£	2.51	5.57	4.91£	2.62	5.00	*t*=-0.29	0.770
Longitudinality	5.22£	2.87	4.83	7.82£	1.15	7.87	*t*=-3.19	0.007
Coordination - Integrated Care	3.64£	1.54	3.33	5.65†	2.06	6.10	*Z*=-2.68	0.007
Coordination - Information System	6.41£	1.77	6.67	6.80†	2.32	7.22	*Z*=-0.79	0.426
Comprehensiveness - Available Services	2.45£	1.47	1.87	2.16†	1.44	1.87	*Z*=-0.88	0.378
Comprehensiveness - Services Provided	2.05†	2.52	0.67	6.48†	2.71	6.67	*Z*=-4.12	<0.001
Family Orientation	2.86†	3.33	1.67	4.18†	2.39	3.33	*Z*=-2.19	0.029
Community Orientation	1.25†	2.29	0.00	0.79†	1.36	0.00	*Z*=-1.22	0.903
Essential Attributes	4.72£	1.53	4.80	6.11£	1.18	6.12	*t*=-3.44	0.001
Derivative Attributes	4.20£	1.63	4.00	5.32£	1.11	5.18	*t*=-2.84	0.006

Notes: £ - Normal distribution and † - Asymmetric distribution based on the Shapiro-Wilk test; Z - Z statistic based on the Mann-Whitney test, t - t statistic based on the Student's test; SD - Standard deviation

It is observed that the Degree of Affiliation, Longitudinality, and Coordination related to the Information Systems reached the satisfactory values only for the specialized services, with the first two demonstrating a statistically significant difference. The attribute, First Contact – Use, was higher for PHC, where it achieved a satisfactory score. The Coordination attributes, related to Integrated Care, Comprehensiveness of Services Provided, Family Orientation, Derivative Attributes and Essential Attributes were higher for the Specialized Service with statistical significance, but did not reach a satisfactory mean score.

The internal consistency of the instrument showed a value of α=0.757 with Cronbach's Alpha. For individuals who chose PHC services as a regular source of care, the value was α=0.784; for the individuals who selected the specialized services, the value was α=0.749.

Discussion

The specialized services were indicated as a regular source of health care for children with T1DM by the majority of participants. The choice of a service of medium complexity and technological density, as a reference, reveals weaknesses of actions and services within the scope of PHC.

The score values of the Use and Accessibility components showed that the city's health services, in general, were not recognized by the caregivers as a primary access point for the child with T1DM. Access to health care is limited, with difficulties in obtaining appointments, extended waiting time, a week reception experience, and instability in ability to meet the most urgent needs. When stratifying the results, it was noted that the Use component obtained a satisfactory score among those who chose PHC as a regular source of care, suggesting that PHC services offer greater access for new health problems and acute processes of chronic conditions. A Brazilian study showed that many emergency situations could have been resolved in PHC, and that many patients prefer to go straight to emergency services, often because they value the services of greater technological density, distorting the concept of complexity, in which PHC is characterized as "basic care", conceived of as "elementary" or "less complex."[13]

The mean score for the Longitudinality attribute was satisfactory, and reached the highest value of the study. This can be attributed to the higher Degree of Affiliation with specialized services, as a regular source of follow-up for these children over time. This study indicates, despite the contextual difficulties of the health services, that once access is obtained, longitudinality is assured, and a positive evaluation of this attribute indicates the loyalty to services.[14] Authors[9] point out that the experiences of people with continuity of care are directly related to information provision, trust, and safety during the care, as well as a relationship

of trust with the professional, which anchors the continuity. The present study demonstrated the lack of recognition of longitudinality among patients who presented a higher degree of affiliation with PHC services. It should be emphasized that the performance of the professionals and health care services can make it difficult to monitor people with specific health needs.[15]

Coordination obtained an unsatisfactory score in relation to Integrated Care, and a satisfactory score for the Information System, which presupposes fragility in the coordination of care as a whole, in opposition to the proposal of the PHC as a health care provider, with a commitment to the management and continuity of care. These results are in line with crisis situations in the health care system, particularly in the context of chronic diseases, which detect fragmentation with hierarchized services by levels of 'complexity', organized in isolated places without cross-site communication, with difficulties in providing continuous care for the population.[7] In this way, the integration between levels of care and the establishment of a carenetwork that supports communication and the processes in health are fundamental. In addition, it is important to increase the number of Family Health Teams and to reflect about new arrangements for a PHC designed for a coordinating effort.[7-16]

In relation to Integrality, the score values were low in both the available services and the provided services. Specialized Services performed better than PHC services. In the Brazilian health system, there is often a greater search and valuation of services with technological equipment, which may compromise comprehensiveness of the system.[15] Thus, it is fundamental that professionals and health managers exercise the responsibility of identifying health care needs, in order to provide and to coordinate the services and actions available in the different health centers and institutions, or those in other social sectors.[17] Other authors stated that child care that departs from comprehensiveness generates a vulnerable framework, fragmented and unequal, and does not allow opportunities for the existence of fruitful therapeutic relationships.[18]

The attribute, Family Orientation, presupposes greater interaction between health professionals and the family, and the recognition of the potential of the family context being of extreme importance for comprehensive care..[14] In the present investigation, this attribute attained an unsatisfactory score, indicating that health actions aimed at the family context are fragile and poorly recognized, corroborating other evaluative studies related to the child's health, which obtained similar results. [14,19-22]. Family health care with poor orientation can also lead to fragility of comprehensiveness; if the life contexts of individuals and their families are not perceived or known, the involvement and concern for extended care, with commitment to all their needs, may not be effective.[23,24]

In relation to the Community Orientation attribute, the scores were the lowest in the study, which instigates the reflection that the health services in question do not recognize the health specificities of the community, nor do they have a direct relationship with the surrounding population.[14] It is important that children with chronic conditions are also monitored in the PHC, in order to balance the demand for emergency services, to facilitate the actions of the specialized services, and strengthen the attributes of PHC. Actions such as home visits allow greater health surveillance, strengthening of bonds, educational activities, and identification of risk situations.[25] These findings are in agreement with other studies with a context of children's health.[19,14,20-22]

Although the Derivative and Essential Elements scores did not attain satisfactory values, the specialized services presented better results than the PHC services, showing that, from the perception of the consumers significant differences between the services. The specialized services were perceived as regular sources of care, and better providers of health practices, based on the attributes of PHC. This may be related to the greater contact of the participants with the professionals of the specialized services, and greater involvement of the specialized service professionals with the children with T1DM, suggesting fragilities in the PHC services.

The results of this study are limited to the studied population; it is impossible to generalize the re-

sults to other contexts and populations. In addition, the study was limited to families that used only the public health services.

The scarcity of studies on the subject makes it relevant to rethink and reformulate public actions and policies, for the management of care among, higher authorities managers, professionals and consumers.

Conclusion

The opinions and experiences of the caregivers of children with T1DM indicated a health care system with little presence and extension of PHC attributes, with fragmented and disconnected actions. The specialized services, with which the interviewees had a higher affiliation, presented better results in their evaluations. However they are focused on pathology and follow the traditional health model, with weaknesses in access and little integration with other services, compromising the care network. This may be related to the greater contact of the participants with the professionals of the specialized services, and greater involvement of the specialized services with children with T1DM, suggesting fragilities in the PHC services. In the context of children with T1DM, PHC can act in the promotion, prevention, treatment, and recovery of health, reducing the demand for emergency services, with a view to comprehensive care, resolution and longitudinality. As coordinator of the network, PHC has the function of integrating the services, establishing the flow of patients in the health system, and referral to the specialized services, without a loss of continual follow up. From this perspective, it is fundamental to strengthen the PHC and the effective implementation of HCN, with a special focus on children in situations of vulnerability during a chronic health condition, especially T1DM. More studies and discussions need to be conducted among health professionals, population, students, and management bodies on this issue, in order to overcome the challenges in caring for these children.

Contributions

Wolkers PCB contributed to the project design, data analysis, writing and interpretation; Macedo JCB, Pina JC, Mendes-Rodrigues C and Furtado MCC contributed to data analysis and relevant critical review of the intellectual content; Mello DF contributed to the project design, writing, data analysis and interpretation, and final approval of the version to be published.

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