Original Article

Burden and quality of life of caregivers of children and adolescents with chemotherapy treatment for cancer*

Sobrecarga e qualidade de vida de cuidadores de criança e adolescentes com câncer em tratamento quimioterápico

Sobrecarga y calidad de vida de cuidadores de niños y adolescentes con cáncer en tratamiento quimioterápico

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ABSTRACT

Objective: To evaluate the burden of care and quality of life (QOL) of caregivers of children/adolescents with cancer during chemotherapy treatment, and to relate them to each other and sociodemographic data. **Methods:** A transversal study, with 160 caregivers. We collected sociodemographic data, burden of care using the *Caregiver Burden Scale* and QOL using the SF-36. **Results:** 88.7% of caregivers were mothers, with the mean age of 34.9 years, overall burden score 2.09 ± 0.04 and the SF-36 scores most compromised were: emotional aspects, vitality, mental health and physical aspects. The regression model accounted for 36.0% of the burden. **Conclusion:** The QOL of caregivers and burden of care experienced showed compromise in various domains, and these alterations may affect the quality of care provided to children and adolescents, and lead to imbalances in their own health.

Keywords: Caregivers; Quality of life; Neoplasms/drug therapy; Child care; Adolescent

RESUMO

Objetivo: Avaliar a sobrecarga de cuidado e a qualidade de vida (QV) de cuidadores de crianças/adolescentes com câncer durante tratamento quimioterápico e relacioná-las entre si e aos dados sociodemográficos. **Métodos**: Estudo transversal, com 160 cuidadores. Foram coletados dados sociodemográficos, sobrecarga de cuidado, conforme "Caregiver Burden Scale" e de QV pelo SF-36. **Resultados:** 88,7% dos cuidadores eram mães, idade média 34,9 anos, escore geral de sobrecarga 2,09±0,04 e escores do SF-36 mais comprometidos: aspectos emocionais, vitalidade, saúde mental e aspectos físicos. O modelo de regressão respondeu 36,0% da sobrecarga. **Conclusão**: A QV dos cuidadores e sobrecarga de cuidados vivenciada mostram-se comprometidas em diversos domínios, e essas alterações podem afetar a qualidade da assistência prestada às crianças e adolescentes e propiciar desajustes na própria saúde.

Descritores: Cuidadores; Qualidade de vida; Neoplasias/quimioterapia; Cuidado da criança; Adolescente

RESUMEN

Objetivo: Evaluar la sobrecarga del cuidado y la calidad de vida (CV) de cuidadores de niños/adolescentes con cáncer durante el tratamiento quimioterápico y relacionarlas entre sí y a los datos sociodemográficos. **Métodos:** Estudio transversal, realizado con 160 cuidadores. Fueron recolectados datos sociodemográficos, sobrecarga de cuidado, conforme "Caregiver Burden Scale" y de CV por el SF-36. **Resultados:** 88,7% de los cuidadores eran madres, edad promedio 34,9 años, scores general de sobrecarga 2,09±0,04 y scores del SF-36 más comprometidos: aspectos emocionales, vitalidad, salud mental y aspectos físicos. El modelo de regresión respondió a 36,0% de la sobrecarga. **Conclusión:** La CV de los cuidadores y sobrecarga de cuidados vivenciada se muestran comprometidas en diversos dominios, y esas alteraciones pueden afectar a la calidad de la asistencia prestada a los niños y adolescentes, propiciando desajustes en la propia salud.

Descriptores: Cuidadores; Calidad de vida; Neoplasias/quimioterapia; Cuidado del niño; Adolescente

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INTRODUCTION

Cancer is a disease that affects millions of people each year. In Brazil, the estimates from the National Institute of Cancer (NIC), for 2012, are for 518,510 new cases, which is the second cause of death, second only to cardiovascular diseases (1). Although cancer in children, when compared to adults, is considered a rare disease, corresponding to between 2% and 3% of all cases in different age groups, affecting one in every 600 children or adolescents, it is classified as the first cause of death by disease in those over 5 years, second only to deaths from violence and accidents. The NIC forecast for 2012 was 11,530 new cases of cancer in children and adolescents, up to 19 years of age (1).

The treatment of childhood cancer is complex and includes various treatment modalities, such as surgery, radiation and chemotherapy, or a combination of two or more of these therapies. Chemotherapy is the most common, and consists of a set of drugs that act at various stages of cellular metabolism, affecting more than the malignant cells and moving into the healthy body, and is responsible for diverse reactions such as anemia, fatigue, leukopenia, apathy, loss of appetite, hair loss, weight loss, diarrhea, bruising, mucositis, nausea and vomiting. Despite all of these side effects, it is important that the frequency of the cycles is maintained in order to have successful treatment.(2) All these factors are causes of discomfort, stress and suffering, as well as possible prolonged hospitalizations. (3)

Studies have demonstrated psychological compromise of parents, especially mothers of children diagnosed with cancer, who carry out specific treatments. In general, parents confronting the child's illness and the many difficult moments they encounter, eventually require medical and psychological assistance, among others.(4,5)

Although caregivers recognize the importance of participation during treatment, they may exhibit caregiver burden as a consequence of the care provided consistently to children / adolescents, which is still poorly studied and understood. The impact experienced by caregivers of children with other chronic diseases has been investigated, and some studies have related the existence of caregiver burden to the impairment of quality of life (QOL) of caregivers,(6-8) because the requirements deriving from the care may lead parents to neglect their own health. (9)

In our country, there are few studies using validated instruments adapted for assessment of quality of life (QOL) of parents of children / adolescents in cancer treatment, compared with other chronic diseases. (6,7) Based on these data and the necessity to clarify the reality of caregivers of children / adolescents with cancer during chemotherapy treatment, the objective of this study was to evaluate caregiver burden and quality of life (QOL) of caregivers of children / adolescents with cancer during chemotherapy treatment, and relate them to each other and to sociodemographic variables and morbidities.

METHODS

A cross sectional study was conducted in the Pediatric Oncology Service of the Federal University of São Paulo – UNIFESP, and the Cancer Hospital of Mato Grosso, both considered reference services in the treatment of pediatric cancer. The population consisted of caregivers of children / adolescents with cancer, whose diagnosis was confirmed by pathological examination or myelography, and who were undergoing chemotherapy for a minimum of two months. We considered the person to be the family caregiver if they: were older than 18 years, provided care to the patient for the majority of the time, lived in the same house, and agreed to participate in the study.(7)

The sample (n = 160) was obtained using the stratified random sampling method, proportional to the average number of children / adolescents served in the six months preceding the interview. The period of data collection corresponded to November 2007 and May 2008. The time of each interview varied between 20 and 40 minutes, and they were conducted by two trained researchers by means of individual interviews. We used a location reserved for the childhood chemotherapy unit to collect social, demographic and morbidity data; caregiver burden was collected using the instrument, *Cargiver Burden Scale (CBS),* composed of 22 questions and divided into five dimensions: *general tension*, *isolation*, *disappointment*, *emotional involvement* and *environment*. This scale includes partial and total scores that range from 1 (no burden) to 4 (worst burden). (10) Data for assessment of QOL was derived from the *Medical Outcomes Study 36 – Item Short-Form Health Survey* (SF-36) instrument, with 36 items grouped into eight dimensions: *physical functioning*, *role limitations due to physical health*, *bodily pain*, *general health perceptions*, *vitality*, *social functioning*, *role limitations due to emotional problems*, and *mental health*; the scores of the dimensions range from 0 (worst state) to 100 (best state). (11)

The research project was approved by the Committee on Ethics in Research of UNIFESP, under number 0555/07, and all participants were informed about the objectives of the study and signed the Terms of Free and Informed Consent form.

To characterize the sample, data were analyzed using descriptive and inferential statistics. The correlation between the dimensions of the CBS and the SF-36 was verified by means of the Pearson's correlation coefficient. A multiple linear regression analysis for the total CBS (dependent variable) was performed on the basis of the independent sociodemographic variables, morbidities and dimensions of the SF-36. The variables that presented with a significance level of $p < 0.05$ remained in the regression model. Statistical analyses were performed using the SPSS version 14 and MINITAB version 14.

RESULTS

The mean age of the caregivers was 34.96 years; the majority of them were female (88.7%) and married (71.2%). The majority of the caregivers dedicated, on average, 141.5 hours / week to care for the child / adolescent, or spent considerably more time involved with the affairs of the sick child. The other data characterizing the quantitative variables of the caregivers and their children are presented in Table 1.

Tabela 1. Sociodemographic characteristics of caregivers and children / adolescents with cancer undergoing chemotherapy, São Paulo-SP/Cuiabá-MT, 2008. n = 160

Caregiver characteristics	n = 160
Age (years)	34.96 (18-57)
Gender	
Female	142 (88.75%)
Male	18 (11.25%)
Civil State	
Married/Living together	126 (78.75%)
Separated/Widowed	19 (11.88%)
Single	15 (9.37%)
Skin color	
White	88 (55.05%)
Brown	49 (30.63%)
Black	23 (14.38%)
Level of Education	
Did not complete primary education	29 (18.13%)
Completed primary education	67 (41.87%)
Secondary education	52 (32.50%)
Graduate education	12 (7.50%)
Support received from partner	
Excellent / Very Good	73 (45.63%)
Good	47 (29.37%)
Does not have / Does not receive	24 (15.00%)
Poor / Very poor	16 (10.00%)
Receives help to care for child	
No	119 (74.38%)
Yes	41 (25.62%)
Work situation	
Unemployed	66 (41.25%)
At home	41 (25.62%)
Employed	23 (14.37%)
Other	15 (9.38%)
Self-employed	15 (9.38%)
Lacks services to care for child	
No	127 (79.38%)
Yes	33 (20.63%)
Lives with child	
Yes	152 (95.00%)
No	8 (5.00%)
Has some problem with own health	
No	129 (80.62%)
Yes	31 (19.38%)
What is the problem with your health?	
None	129 (80.63%)
Arterial hypertension	21 (13.12%)
Others	10 (6.25%)
Use of medication	
No	136 (85.00%)
Yes	24 (15.00%)
Consults to a physician this year	
0	57 (35.62%)
1	53 (33.13%)
2	30 (18.75%)
>3	20 (12.50%)
Time of marriage / stable relationship (years)	9.75 (0-36)
Number of children	2.92 (0-13)
Time exercising role function of caregiver, in months	18.26 (3-108)
Extra costs due to the role function of caregiver	
Yes	128 (80%)
No	32 (20%)
Weekly hours dedicated to caregiving for child (hours)	141.52 (12-168)
Times approached the doctor in the last year (mean)	1.36 (0-12)
Characteristics of the child / adolescent	n = 160
Age (years)	9.09 (1-17)
Gender	
Male	88 (55.00%)
Female	72 (45.00%)
Diagnosis	
Leukemias	48 (30.00%)
Osteosarcoma	19 (11.88%)
Neuroblastoma	19 (11.88%)
Lymphomas	17 (10.62%)
Central nervous system	12 (7.50%)
Others	45 (28.12%)

Values expressed as mean ± SD and % number.

Table 2 shows the mean scores, with the respective standard deviations, of each of the SF-36 dimensions, for 160 caregivers of children / adolescents. Of the eight total dimensions, four proved to be compromised: *role limitations due to emotional problems* (48.09), *vitality* (61.84), *mental health* (62.62) and *role limitations due to physical health* (66.09).

Table 2. Mean values of the SF-36 scores of the 160 caregivers of children/adolescents in chemotherapy treatment. São Paulo-SP/ Cuiabá-MT, 2008

SF-36 Dimensions	Mean ± SD
Physical functioning	79,53 ± 1,51
Role limitations due to physical health	66,09 ± 3,61
Bodily pain	70,84 ± 2,17
General health perceptions	70,82 ± 1,50
Vitality	61,84 ± 1,62
Social functioning	72,73 ± 2,26
Role limitations due to emotional problems	48,09 ± 3,65
Mental health	62,62 ± 1,60

In regard to the mean scores for the dimensions of the *Caregiver Burden Scale* (CBS) of the 160 caregivers, the most significant dimensions, respectively, were: *isolation* (2.29 ± 0.07), *disappointment*, (2.22 ± 0.05) and *general tension* (2.17 ± 0.06). These were followed by *environment* (2.12 ± 0.06) and *emotional involvement* (1.45 ± 0.06), and the overall mean was (2.09 ±0.04).

The data in Table 3 show the morbidity and sociodemographic variables that negatively and significantly affected four dimensions of the CBS: *general tension* was influenced by variables *poor or very poor support from the partner, and having health problems*; *isolation* was influenced by *increased number of children* and *unemployment*; *disappointment* was affected by *poor or very poor support from the partner*, *having health problems*, and a *low educational level*; *environment* was affected by a *low educational level*, *black skin color*, and *does not receive help to care for child.*

By correlating caregiver burden and the scores of the SF-36 dimensions, using the Spearman correlation coefficient (ρ), we observed that only the *bodily pain* domain showed no statistically significant negative correlation with caregiver burden (Table 4).

Table 4. Spearman correlation coefficient with the scores of the SF-36 dimensions and the overall score of burden (CBS), of the 160 caregivers of the children/adolescents with cancer in chemotherapy treatment. São Paulo- SP/Cuiabá-MT, 2008

Dimensão do SF-36	Correlação CBS	Valor de p
Capacidade funcional	-0,159	0,045
Aspecto físico	-0,272	<0,001
Dor	-0,109	0,171
Estado geral de saúde	-0,257	0,001
Vitalidade	-0,391	<0,001
Aspectos sociais	-0,411	<0,001
Aspectos emocionais	-0,354	<0,001
Saúde mental	-0,474	<0,001

SF-36 (“Medical Outcomes Study – 36 item Short- From Survey”). CBS = Cargiver Burden Scale.

The data in Table 5 show the multiple linear regression analysis performed between the total score of the CBS, the scores of the SF-36 dimensions, and the sociodemographic variables and morbidities of the caregivers. The regression model accounted for 36.0% of the caregiver burden experienced by caregivers, and the main variables were general health perceptions (23.3%), social functioning (6.4%), vitality (3.0%) and extra costs due to the role function of caregiver (1.6%).

Table 5. Multiple regression that correlates the average burden of the caregiver, the dimensions of the SF-36 and sociodemographic variables of the 160 caregivers of children / adolescents with cancer undergoing chemotherapy. São Paulo-SP/Cuiabá-MT – Brasil, 2008

Variable	Coefficient	Standard Deviation	R2
General health perceptions	-0.007819	0.001973	23.30
Social functioning	-0.004242	0.001256	6.49
Vitality	-0.004728	0.001869	3.01
Extra costs due to the role function of caregiver	0.163490	0.082470	1.61
Other illnesses	0.208100	0.139500	0.93
Hypertension	-0.108960	0.099250	0.69

Nota: residual analysis was performed to verify the adequacy of this model, after which it was considered appropriate, and the value of $\beta0$ = 3.055100 and the coefficient of determination showed a value of 36.03% (R2 = 36.03) with a sample standard deviation of 0.4167 (s = 0.4167), F6,153 = 2.92 and a p-value of 0.01. The overall model explained 36.03% of the overall burden experienced by caregivers.

Table 3. Dimensions of the Caregiver Burden Scale and variables that affect caregiver burden in a statistically significant way, of 160 caregivers of children / adolescents with cancer undergoing chemotherapy treatment. São Paulo-SP/Cuiabá-MT, 2008

Variables	General tension p-value	Isolation p-value	Disappointment p-value	Emotional Involvement p-value	Environment p-value
Support by partner is poor or very poor	0.014	-	0.042	-	-
Problem with health	0.047	-	0.042-	-	-
Number of children	-	0.05	-	-	-
Work situation	-	0.025	-	-	-
Low level of education	-	-	0.018	-	0.001
Skin color (black)	-	-	-	-	0.002
Does not receive help to care for child	-	-	-	-	0.033

SF-36 (Medical Outcomes Study – Short-Form 36-item Survey); CBS = Cargiver Burden Scale

DISCUSSION

Caregivers of children / adolescents with cancer undergoing chemotherapy, in this study, were primarily young adults, mostly women (mothers) who were not receiving help for the care. These characteristics are similar to those reported in studies involving caregivers of children with cancer conducted in Uberlândia (MG) and recently also in other countries, such as the study of a Children's Hospital – Division of Oncology in Philadelphia (USA), that evaluated the symptoms of parental stress during treatment of children with cancer, and another study involving five oncology centers in Canada (Vancouver, Winnipeg, Ottawa, Toronto and Hamilton), in which the parental impact of caring for a child with cancer was evaluated. (12,13)

To receive additional help from other people, for the caregiving, was uncommon in our study (25.6%), possibly because it reflects that 23.7% of primary caregivers were employed or were self-employed and therefore it was not possible for them to assume full care. For those providing all of the care, they did it both day night and still assumed the tasks related to home and the other children, so possibly, there was no spare time to meet personal needs. Most caregivers said that they remained focused on the care of their children with cancer 24 hours/day, and this function was a priority, which contributed to a very high average weekly work hours (141.5 h/wk). The reality of not having anyone to share the patient care and domestic affairs, led to the majority of caregivers losing their jobs (14). Parents of children with cancer are obliged to provide assistance to their children day and night, and this has implications for the amount of time remaining to meet their own needs (9).

Most caregivers in this study had a low educational level, and 60% had only completed primary education. A recent study in the northeast regions of Brazil, assessed the caregiver burden of children with cerebral palsy by means of the Burden Interview, and showed a negative and significant correlation between a low educational, social and economic level and the burden experienced by caregivers (6).

Among caregivers, 19.3% reported some health problem and hypertension was the most common disease; 15% were taking medication; and 31.2% required a medical consultation two or more times in the last year. Research has shown that caregivers generally experience psychopathological disorders more frequently with the physical problems that require more doctor visits, therefore, they use more medications and have poorer health than the general population. (15,16) In another study, it was reported that 41% of caregivers of children with cancer became ill at some point in the child's treatment. (14) The illness or presence of chronic disease at the mean age of these caregivers is not common; research conducted with 218 caregivers of healthy Brazilian children found no presence of any chronic health problem, and 25% of the caregivers of children with cancer reported some type of chronic morbidity. (13)

In this study, the majority of children were suffering from leukemia, with a mean age of 9.09 years and a slight male predominance, corroborating the national epidemiological data. Leukemia is the most common type of childhood cancer in Brazil, affecting more males, and although the treatment of childhood cancer in the country comprises individuals from 0 to 17 years, the mean age varies between 8 and 10 years (1, 9,17).

In our country, there are few studies with quantitative design and the use of validated instruments for assessing quality of life and caregiver burden in the area of oncology. On the other hand, several studies with a qualitative research design and focus on the child with cancer and his family have been performed, and show damage to the caregiver in respect to work, study, sleep, leisure activity, and sexual life. (8, 14) Furthermore, they point to conflicting situations experienced by the child and family members, such as the abandonment of routine activities (school, courses, work, leisure, family life and others), once they begin to start living in the universe of cancer treatment and prognosis. Parents, in general, distance themselves, the mother assumes the care of the sick child and the father, the support the family and the extra expenses resulting from the treatment. (3)

Confronting the disease is influenced by perceptions of quality of life of every individual: the positives are more related to rational strategies, how to design a goal or learn more about the disease, and the negatives relate to avoidant strategies such as denial of illness, acting as if it did not exist. (18)

In assessing the health-related quality of life, using the SF-36, this study indicated compromise of the *role limitations due to emotional problems* (48.09), *vitality* (61.84), *mental health* (62.62) and *role limitations due to physical health* (66.09); however, when comparing our findings to those found in the population of caregivers of healthy children and in the adult Brazilian population, we observed that the scores of all dimensions of the SF-36 in the study were lower than in other studies, including normal adult populations of other countries, whose scores were not lower than 70. (10,13) The QOL of caregivers of children with juvenile myoclonic epilepsy was most affected in *role limitations due to emotional problems* (59), *vitality* (64) and *mental health* (69) of the SF-36.(7) In a Canadian study, mothers and fathers of children with cancer presented lower scores, respectively, in the domains of *vitality* (38.4 x 48.3), *mental health* (53.6 x 60.8) and *social functioning* (54.0 x 59.0) (9).

These studies have sought to identify factors that contribute to compromised QOL of caregivers and point out that the presence of chronic disease, longer time of diagnosis, decreased quality of sleep, younger age, lower income, lack of physical activity, among others, are indicative of a lower QOL (9, 15); in addition, more hours of care per week and living with the patient also contribute to the compromise of the caregiver's QOL. (19)

The subjective burden perceived by caregivers in this study measured by the CBS was the highest in the dimensions of: *isolation*, *disappointment*, *general tension* and *environment*. Studies using rating scales in caregivers of children with chronic diseases are scarce. A study conducted with caregivers of patients with epilepsy due to mesial temporal sclerosis and juvenile myoclonic epilepsy, using the burden scale, *Zarit Burden Interview*, consisted of 22 items and assessed the activities of care and impact on social life, physical well-being, emotional and finances of the caretaker, (7) and showed mild to moderate burden in both groups (23 and 30 points). In the correlation between the SF-36 domains and caregiver burden, there was a statistically significant correlation to the *general health perceptions* ($p = 0.011$), *role limitations due to emotional problems* ($p = 0.037$) and *mental health* ($p = 0.002$), that is, the lower the means in domains of the SF-36, the greater the caregiver burden (7) .

As to the sociodemographic variables and morbidities that affect timely and significant statistics, different domains of caregiver burden were: *poor or very poor support from the partner*, *having health problems*, *greater numbers of children*, *u*nemployment, *low education level*, *black skin color*, and *not receiving help to care for the child / adolescent patient*. Numerous studies conducted with caregivers of patients with various chronic diseases (6,7,9,12,16) in different countries, and with a variety of instruments that measure the burden, demonstrated similar findings, that is, caregivers often experience similar situations that cause burden.

In univariate analysis, significant correlation was observed between the lowest scores of the dimensions of QOL and high perception of burden, except in the *bodily pain* domain. Sociodemographic variables and morbidities that showed significant correlations with the total score of the CBS were: partner support poor or very poor, having health problems, increased number of children, being unemployed or a home maker, being illiterate or having incomplete elementary education, to be black, and not receiving help to care for the child / adolescent patient. Other studies conducted with parents of children with chronic diseases such as cerebral palsy and epilepsy also highlighted similar variables as responsible for the increased caregiver burden and for changing the daily activities of parents(6,7).

The main objective of this study was to evaluate caregiver burden experienced by caregivers of children with cancer undergoing chemotherapy treatment and their QOL, and thus to know the variables that affect this burden. Multivariate analysis of the data allowed us to identify psychosocial and physical independent predictors of perceived caregiver burden by the caregivers (general health perceptions, social functioning, vitality, role limitations due to physical health, and extra costs due to the role function of caregiver), and that responded to 36.0% of this burden.

In a study conducted with caregivers of patients with juvenile epilepsy, that assessed caregiver burden and QOL, found a negative and statistically significant correlation between the domains of *general health perceptions*, *mental health*, and *emotional involvement*, and *caregiver burden*(7).

The caregiver burden may reflect not only the psycho-role limitations due to emotional problems of the caregiver, but also of patients linked to them. Other additional factors could possibly affect the QOL and caregiver burden, such as: family involvement in care, the couple's relationship, adjustment to a new living situation, personal satisfaction, guidelines for care, social and psychological support, age of the child / adolescent, and type of tumor.

The fact that there is no history of contact between the researcher and the family may have been a limiting factor for answering some questions, although the caregivers appeared to be comfortable during the interviews.

FINAL CONSIDERATIONS

We understand that caring for children / adolescents with cancer during chemotherapy generates caregiver burden and compromises the caregiver's QOL, therefore, the multidisciplinary team that serves this clientele with cancer should direct proposals and strategies to ensure a relationship of empathy with the caregiver, as well as basic information relevant to the treatment and its peculiarities. Interventions must be implemented to promote and protect the health of caregivers in the physical, social and emotional aspects, to reduce the caregiver burden, and maintain their QOL. Further studies should be conducted, with different designs with caregivers of children / adolescents with cancer, aimed at better understanding and clarification of the variables already identified, along with the search for other factors that, possibly, are responsible for the burden experienced by them.

CONCLUSIONS

Most caregivers were unemployed women or home makers with low educational levels, who received no help for providing care.

The QOL of the caregivers was significantly diminished in the SF-36 domains: *role limitations due to emotional problems*, *vitality*, *mental health,* and *physical functioning*.

Caregivers of children with cancer undergoing chemotherapy treatment, have caregiver burden, demonstrated by the compromise of the scores of the CBS scale: *isolation*, *disappointment* and *general tension*.

The variables that independently interfered in the perceived caregiver burden by caregivers in this study responded well to the model.

The decrease in QOL and caregiver burden experienced by these caregivers may compromise the care they provide to children / adolescents, as well as providing their own health imbalances.

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