

ORIGINAL ARTICLE

## ASSESSMENT OF FINANCIAL TOXICITY (FACIT-COST) OF PATIENTS WITH CANCER IN SOUTHERN BRAZIL

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### ABSTRACT

Objective: to assess financial toxicity and associate the total score with the sociodemographic and clinical profile of cancer patients assisted in public and private institutions. Method: descriptive cross-sectional research conducted from September 2018 to January 2020 with 126 patients undergoing chemotherapy in the state of Paraná, Brazil. A sociodemographic and clinical instrument and the COMprehensive Score for financial Toxicity were used; Student's t-test and Scoring Guidelines were used for analysis. Results: the mean score of financial toxicity in the public institution sample was 16.33, in the private one 24.02. Combining the samples, the average score was 18.95. In the correlation analysis, statistical significance was found with the income in the public institution (p-value=0.002); in the private institution, having comorbidity (p-value=0.003) and use of medication (p-value=0.042). Conclusion: recognizing financial toxicity as an adverse event will help professionals to develop a care plan according to the patient's conditions.

**DESCRIPTORS:** Financial Toxicity; Neoplasms; Financial Resources in Health; Health-Related Quality of Life; Quality of Life.

### HOW TO REFERENCE THIS ARTICLE:

Nogueira L de A, Reis BK dos, Ribeiro C de O, Guimarães PRB, Kalinke LP. Assessment of financial toxicity (FACIT-COST) of patients with cancer in Southern Brazil. *Cogitare Enferm.* [Internet]. 2022 [accessed "insert day, month and year"]; 27. Available from: <http://dx.doi.org/10.5380/ce.v27i0.79533>.

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## INTRODUCTION

The occurrence of financial toxicity in cancer patients may be caused by the high costs that the disease causes, going from diagnosis, treatment to follow-up, impacting the patients' and families' lives. It was defined as one of the consequences experienced by patients who cannot pay for the treatment or have difficulties. They often use their savings, change their lifestyle, make loans and often declare bankruptcy<sup>(1)</sup>.

The impacts generated by financial toxicity can go from the diagnosis and continue for months or years after the end of treatment. This is because it includes expenses with medicines, medical appointments, exams and hospitalizations, transport, and expenses linked to possible changes in well-being, caused by the life change and increased expenses. Because of these repercussions, it has been considered a new adverse event of cancer treatment<sup>(2)</sup>.

This adverse event has been measured by different authors<sup>(3-5)</sup> and contexts. Its impact can overcome financial problems, causing psychological disorders, such as increased anxiety and depression, as well as changes in the clinical progress of the disease, as well as worsening of the condition due to non-adherence to the proposed treatment.

Studies<sup>(6-9)</sup> have associated financial toxicity with a poor health-related quality of life (HRQoL). The repercussions are wide and can encompass the domains that make up the concept of quality of life, such as physical and psychological well-being, level of independence, social relationships, among others<sup>(10)</sup>, causing the disease to worsen or complications.

Attention should be given to the consequences of financial toxicity by managers and health teams, to create interventions that lessen patient suffering. According to some authors<sup>(11)</sup>, it can be more critical than physical, emotional, social, or family suffering. It exists among populations served by the public<sup>(4)</sup> and private health systems<sup>(12)</sup>. Identifying patients who suffer from it is the first step towards implementing measures to reduce its effects.

In Brazil, there are three types of health care for the population. The first is access through the public system, called the Unified Health System (SUS), in which every Brazilian citizen, according to the current laws, has the right to health services, and the state must provide them. No patient treated by the SUS spends money. The second type is the entry through private health insurance made by patients or companies; these may have co-payment, which, as the services are used, a percentage is added to the invoice. The third type is the option of payment for the treatment, a condition in which the patient pays his expenses at the time of the assistance.

In an attempt to measure the experience of cancer patients related to financial difficulties, in 2014, the North American group Functional Assessment of Chronic Illness Therapy (FACIT), developed the COMprehensive Score for financial Toxicity – COST questionnaire, which measures the financial toxicity of patients with cancer<sup>(13)</sup>. This questionnaire was validated for the North American culture in 2017<sup>(9)</sup> and has been employed in different cultures and health care models. The COST was translated, validated and adapted to the Brazilian culture in 2020<sup>(14)</sup>.

Although the COST has been validated for the Brazilian culture, research in the country that measures the financial toxicity of cancer patients is scarce. Thus, this study aimed to evaluate the financial toxicity and correlate the total score with the sociodemographic and clinical profile of cancer patients assisted in public and private institutions in southern Brazil.

## METHOD

This is a descriptive cross-sectional study conducted with 126 cancer patients undergoing antineoplastic chemotherapy. Data collection took place in two institutions, a public one (n=83) and a private one (n=43) in a capital of southern Brazil.

The public institution provides assistance fully supported by the SUS. Services include chemotherapy, blood transfusions, minor procedures, and treatment-related complications. Patients come from referrals from Primary Care or Emergency Care in the city and, to a lesser extent, from other locations. The private institution offers care to patients who have private health plans or are paid by the patient.

The inclusion criteria for participating in the research were to have cancer diagnosis within six months or more, to be undergoing chemotherapy treatment, being 18 years old and over. Patients undergoing chemotherapy for a condition other than cancer were excluded. Patients from both institutions were approached individually, in a private environment, during chemotherapy. The response time ranged from five to 10 minutes.

Data collection took place from September 2018 to January 2020, with two instruments: 1) sociodemographic and clinical data, prepared by the researchers, with questions on age, sex, profession, education and information about comorbidities, use of medications, and life habits; 2) COST, with questions related to the cancer patient's financial issues, including questions about future financial concerns, frustration for not being able to contribute with income as before the disease, satisfaction with the current financial condition, among others. The COST responses were given on a five-point Likert scale ranging from zero (not at all) to four (very much).

Data were double entered in Microsoft Excel version 2010, analyzed by SPSS software, and presented in tables and graphs with mean and standard deviation (SD) values. For the COST score, the questionnaire's Scoring Guidelines were employed, which ranges from zero to 44 – the higher the score, the greater the financial well-being, that is, the lower the financial toxicity. Question number 12 was ignored as it was a summary item and questions numbered two, three, four, five, eight, nine, and 10 were inverted. Results were presented as mean and standard deviation (SD).

To measure the impact of financial toxicity, we decided to adopt the division performed by a Japanese study<sup>(15)</sup>, which categorized the COST score into four degrees of greater or lesser financial toxicity: degree zero with scores above 26 (no impact); degree one with scores from 14-25 (mild impact); degree two with scores from one-13 (moderate impact); degree three with score zero (high impact). Thus, patients with degree two or three have financial toxicity.

We compared the total score of financial toxicity and the sociodemographic and clinical data of the sample from the private and public institutions and the total sample, using Student's t-test. The assumption of normality test was confirmed by the Shapiro Wilk test. To assess the financial toxicity score, the analysis was performed separately.

This research was considered by the Ethics Committee in Research with Human Beings of the Federal University of Paraná, for both institutions, and approved with opinion number 3,969,798. For the use of COST, authorization was granted by the FACIT group.

## RESULTS

A total of 162 patients were approached, with 36 refusals to participate in the research. The sample consisted of 126 patients undergoing cancer treatment. Of these, 75 (59.52%) were women, 67 (53.17%) were aged between 31 and 59 years old, 76 (60.32%) were married or declared a domestic partnership; the most mentioned occupation was "retired" for 44 (35.48%). Family income ranged from US\$ 194.59 to US\$ 583.79, equivalent to one to three Brazilian minimum wages, which was the most found in 54 participants (43.20%) (Table 1).

Regarding the clinical data and life habits of the patients in the total sample (n=126), Table 1 shows that 59 (47.58%) patients had no comorbidity, however, 76 (60.32%) used medication regularly. As for the type of tumor, 79 (62.70%) patients were treated for solid tumors. In terms of lifestyle habits, 88 (69.84) did not practice physical activity regularly, 121 (96.03%) did not drink alcohol regularly and 119 (94.44%) did not smoke.

Table 1 - Sociodemographic and clinical profile and life habits of the research samples. Curitiba, PR, Brazil, 2021 (continues)

	Private institution		Public institution		Total sample	
	n=43	%	n=83	%	n=126	%
<b>Sex</b>						
Male	18	41,86	33	39,76	51	40,48
Female	25	58,14	50	60,24	75	59,52
<b>Age</b>						
18 - 30 years	0	0	4	4,82	4	3,17
31 - 59 years	23	53,49	44	53,01	67	53,17
Over 60 years	20	46,51	35	42,17	55	43,65
<b>Marital status</b>						
Married	27	62,79	44	53,01	71	56,35
Single	5	11,63	14	16,87	19	15,08
Divorced	3	6,98	12	14,46	15	11,9
Domestic partnership	2	4,65	3	3,61	5	3,97
Widow/ed	6	13,95	10	12,05	16	12,7
<b>Occupation</b>						
Formal work	11	25,58	16	19,75	27	21,77
Autonomous	12	27,91	13	16,05	25	20,16
Unemployed	0	0	10	12,35	10	8,06
Homemaker	5	11,63	13	16,05	18	14,52
Retired	15	34,88	29	35,8	44	35,48
<b>Family income</b>						
None	0	0	5	6,02	5	4
Up to 1 MW*	1	2,38	16	19,28	17	13,6
1 - 3 MW	3	7,14	51	61,45	54	43,2
4 - 10 MW	23	54,76	11	13,25	34	27,2

10 - 20 MW	8	19,05	0	0	8	6,4
Over 20 MW	7	16,67	0	0	7	5,6
Welfare						
None	13	30,23	22	26,51	35	27,78
Yes	30	69,77	61	73,49	91	72,22
Type of welfare**						
Sickness benefit	10	33,33	27	44,26	37	40,66
Retirement	20	66,67	32	52,46	52	57,14
Other	0	0	5	8,2	5	5,49
Comorbidities						
None	22	51,16	37	45,68	59	47,58
Hipertension	16	37,21	24	29,63	40	32,26
Diabetes	5	11,63	11	13,58	16	12,9
Other	9	20,93	22	27,16	31	25
Use of medications						
None	9	20,93	15	18,07	24	19,05
Analgesics	6	13,95	20	24,1	26	20,63
Anti-inflammatory	0	0	9	10,84	9	7,14
Antibiotic	4	9,3	3	3,61	7	5,56
Other	26	60,47	50	60,24	76	60,32
Smoking						
Yes	1	2,33	6	7,23	7	5,56
No	42	97,77	77	92,77	119	94,44
Routine physical activity						
Yes	15	34,88	23	27,71	38	30,16
No	28	65,12	60	72,29	88	69,84

\*MW – Minimum wage; \*\*These are benefits offered by the government, intended for people without resources or who have contributed to social security.

Source: Authors (2021).

In the public institution sample, the mean COST score was 16.33 (SD=6.57), and in the private institution, the mean score was 24.02 (SD=9.48), showing that the responses of this sample were more varied. Combining the two samples (n=126), the mean score was 18.95 (SD=8.48). The SD was higher in the sample from the private institution due to the differences in the answers about income. Patients from the private institution answered all categories of the income variable, while those from the public institution focused on the three lowest categories.

Figure 1 presents the COST Score of the two samples and shows the difference between them and the variability of the standard deviation of each one. The average score of the private institution was higher than the sample of the public institution, indicating greater financial well-being. Significance was found when the samples' scores were compared ( $p=0.000$ ).

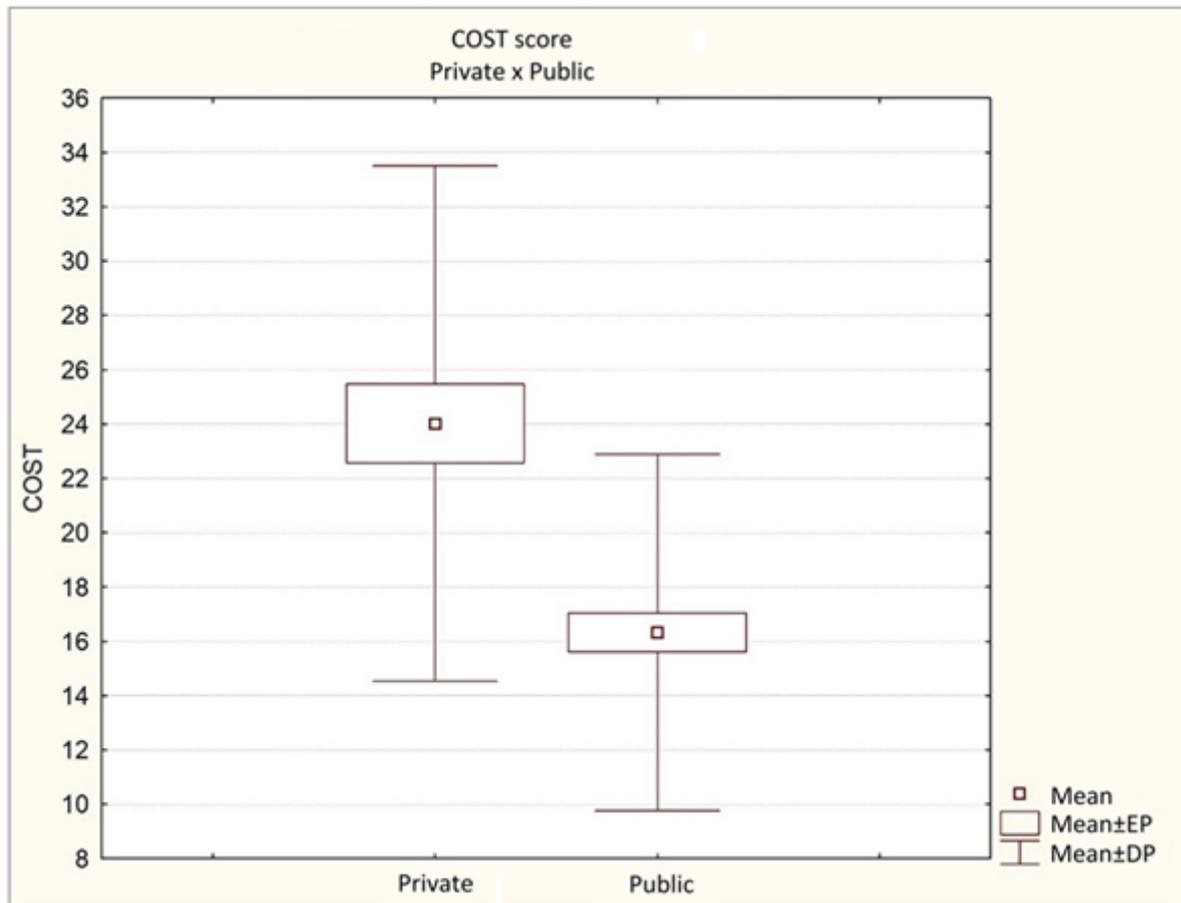


Figure 1 – Mean COST score and standard deviation of the public and private institution samples. Curitiba, PR, Brazil, 2021  
Source: Authors (2021).

By associating the COST and the sociodemographic data of the samples separately (Table 2), it was possible to observe significance between the COST x income in the public institution, COST x comorbidity in the private institution, and COST x medication use in the private institution.

Table 2 – Association between COST and sociodemographic and clinical variables. Curitiba, PR, Brazil, 2021 (continues)

	Mean score	n	SD	Minimum	Maximum	p-value
Sex						
Private institution	24,02	43	9,48	8	44	
Male	23,67	18	10,11	10	44	0,72
Female	24,28	25	9,21	8	40	
Public institution	16,33	83	6,57	1	32	
Male	16,06	33	7,2	1	32	0,9
Female	16,5	50	6,19	4	30	

Total sample	18,95	126	8,48	1	44	
Marital status						
Private institution	24,02	43	9,48	8	44	
Married	22,48	27	8,87	8	40	0
Single	21	5	12,12	10	40	
Married	23	3	10,44	16	35	
Domestic partnership	24	2	4,24	21	27	
Widow/ed	34	6	6,29	26	44	
Public institution	16,33	83	6,57	1	32	
Married	17,82	44	5,55	4	32	0,02
Single	13	14	8,95	1	30	
Divorced	15,5	12	7,5	3	30	
Domestic partnership	16,33	3	5,51	11	22	
Widow/ed	15,4	10	4,95	8	24	
Total sample	18,95	126	8,48	1	44	
Occupation						
Private institution	24,02	43	9,48	8	44	
Formal work	21,82	11	8,67	10	40	0,77
Autonomous	25,25	12	7,35	10	35	
Unemployed		0				
Homemaker	22,8	5	11,08	9	36	
Retired	25,07	15	11,48	8	44	
Public institution	16,48	81	6,53	1	32	
Formal work	19,13	16	7,44	1	32	0,38
Autonomous	14,69	13	5,62	5	22	
Unemployed	15,6	10	6,95	4	27	
Homemaker	15,77	13	6,26	4	24	
Retired	16,45	29	6,34	3	30	
Total sample	19,1	124	8,45	1	44	
Family income						
Private institution	24,38	42*	9,3	8	44	
None	0	0	0	0	0	0,33
Up to 1 MW*	30	1	0	30	30	
1 - 3 MW	21	3	7,21	15	29	
4 - 10 MW	24,39	23	9,15	8	40	
10 - 20 MW	20,88	8	8,46	10	34	
Over 20 MW	29	7	11,43	12	44	
Public institution	16,33	83	6,57	1	32	
None	18,6	5	3,78	13	23	
Up to 1 MW*	11,63	16	5,73	1	22	0

1 - 3 MW	16,67	51	6,59	3	30	
4 - 10 MW	20,55	11	4,87	14	32	
10 - 20 MW	0	0	0	0	0	
Over 20 MW	0	0	0	0	0	
Total sample	19,03	125	8,47	1	44	
Type of welfare						
Private institution	23	30	9,56	8	44	
Sickness benefit	18,7	10	7,13	9	29	0,07
Retirement	25,15	20	10,04	8	44	
Other		0				
Public institution	15,34	61	6,49	1	30	
Sickness benefit	14,42	27	6,78	1	26	0,53
Retirement	16,37	32	6,33	3	30	
Other	13,25	5	6,18	8	22	
Total sample	17,95	91	8,45	1	44	
Comorbidities						
Private institution	24,02	43	9,48	8	44	
No	20,23	22	8,8	8	44	
Yes	28	21	8,67	14	40	0,003
Public institution	16,3	81	6,62	1	32	
No	16,7	37	7,74	1	32	0,58
Yes	15,95	44	5,59	3	27	
Total sample	18,98	124	8,54	1	44	
Use of medications						
Private institution	24,02	43	9,48	8	44	
No	18,56	9	8,32	8	29	
Yes	25,47	34	9,35	9	44	0,042
Public institution	16,33	83	6,57	1	32	
No	16,73	15	7,85	4	30	0,78
Yes	16,24	68	6,32	1	32	
Total sample	18,95	126	8,48	1	44	

\*one patient did not inform income. \*\*two patients did not answer.

Source: Authors (2021).

In the public institution, the mean score of family income of up to one minimum wage (US\$ 194.59) was significantly lower than the score of one to three minimum wages (US\$ 194.59 to US\$ 583.79) and from four to 10 minimum wages (\$778.39 to \$1,946.00).

In the private institution, the mean score for comorbidities was significantly higher than the score "without comorbidities", indicating a relationship between previous diseases and financial toxicity. In this same sample, the use of medication was significantly higher

than those who do not use daily medication, suggesting that the cost of drugs affects expenses and, therefore, financial toxicity (Table 2).

## DISCUSSION

Among the study participants, women were the majority, and most individuals had a partner, either married or in a domestic partnership. The leadership of women may affect the family nucleus in different areas, as she may be the provider at home and the in-charge of domestic and family obligations. Cancer treatment can limit resources and impair the routine of daily tasks. Having a partner who can cooperate or take over duties and expenses can bring peace of mind. In a study carried out in Canada<sup>(4)</sup>, which found the factors associated with the financial toxicity of lung cancer patients, 56% of the sample was female, with a predominance of married individuals, corroborating our findings.

Regarding the age group of patients, our findings are similar to those found in Australia<sup>(16)</sup>, which determined the extent and factors that affect the financial toxicity of patients with neuroendocrine tumors. However, it differs from the study conducted in California<sup>(17)</sup>, United States of America (USA), which observed a mean age of 63 years and another one<sup>(18)</sup> also carried out in the USA, which evaluated the financial impact of patients with newly diagnosed cancer and had a mean age of 68 years.

The prevalence of patients aged from 31 to 59 years is a condition that can worsen financial toxicity, as this age group is considered economically active with income that can help and/or provide for the family. Thus, a cancer diagnosis may cause impacts that comprise, besides physical and psychological issues, economic problems resulting from decreased earnings and absences, which can affect the budget.

As there are individual deprivations caused by high expenses and little resources, the economic losses caused by cancer also harm society. The estimate made by the economic group BRICS (Brazil, Russia, India, China, and South Africa), with data from 2012, calculated the loss of work rate due to the deaths of individuals of working age; the yearly loss totaled US\$ 46.3 billion<sup>(19)</sup>.

Regarding the existence of other diseases, it was possible to observe the predominance of patients with comorbidities, the main one being systemic arterial hypertension (SAH). This result is similar to a finding<sup>(18)</sup> that, when investigating the financial impact of cancer among newly diagnosed patients in the USA, had SAH as the main health problem.

By observing the value of the COST score of the two samples, we could evidence a higher score in the sample of the private institution, which may be an indication of greater financial well-being among those who have a private health plan or pay for treatment. This outcome reveals that in the population with higher purchasing power, the impact of new costs tends to be lower.

Although the results of the private institution sample showed less financial toxicity, it is important to assess its existence, as it may show signs of financial concern. According to the categorization made by Japanese researchers<sup>(15)</sup>, both samples of this study had financial toxicity with a minor impact. This outcome reinforces that, although, with different purchasing power, the two samples suffer from the effects of financial toxicity. Authors who used COST in different samples have found similar results to this study. Research<sup>(4,12)</sup> conducted in Canada and the USA found a mild impact (first degree) with a mean score of 21 and 24, respectively, when assessing the financial toxicity of their samples.

Concerning different degrees of financial toxicity, the issue of having or not having health insurance may considerably affect the financial suffering experienced by the patient. Those with health insurance may suffer as much or even more than those who rely exclusively

on the public system. Depending on the therapy adopted, the costs of medicines and tests are high, charged to the insurance contractor, through co-payments. In this regard, a study<sup>(16)</sup> carried out in Australia found that having health insurance was the main reason for higher direct costs.

By making the associations between the COST and sociodemographic data, we could observe that, in the public institution, patients with a lower family income had a score significantly lower than the ones with higher income ranges. This finding indicates that the portion of the sample with a purchasing power of up to one minimum wage had a lower COST score, that is, greater financial toxicity. This condition is expected, considering that, even in public health care systems, in which the patient has no treatment expenses, the family budget may still be intended to indirect costs, such as transportation and food expenses. For those with lower incomes, a small budget change can cause or worsen financial toxicity, a situation already described<sup>(20-21)</sup>.

In the private institution, the variables "comorbidities" and "the use of medications" had an impact on the COST score. The patients from this sample, who have underlying diseases and/or use medication frequently, are impacted by the costs arising from these conditions, worsening financial toxicity. This association can lead to non-adherence to the prescribed medication, as a way to save money<sup>(22)</sup>. The fact that the "comorbidities" and the "use of medication" impact the level of financial toxicity of the private institution sample reinforces the conception that financial toxicity can be found in samples of different socioeconomic conditions, excluding the possibility of being associated with scarcity.

The main study limitations are the non-use of other questionnaires, which would allow for the association between financial toxicity and other constructs, such as HRQoL. Furthermore, the sample is composed of patients with different types of cancer does not express the financial toxicity of specific groups.

## CONCLUSION

The results of the COST scores of all samples reveal the existence of financial toxicity in the patients surveyed in different degrees/levels. Regardless of income, both samples show a significant degree of financial toxicity, being greater in the participants of the public institution. Those with lower income have greater financial suffering related to cancer treatment.

Although both samples present a low degree of financial toxicity, we could observe a contradictory issue. In the private institution, financial toxicity was associated with comorbidity and the use of medication, while in the public institution, financial toxicity exists without this association.

We believe that this study contributes to the practice, as it reveals financial toxicity among cancer patients from two important oncological treatment institutions in southern Brazil. It is suggested to develop research using COST associated with other questionnaires, to verify the association between financial toxicity and quality of life and types of cancer in the Brazilian population.

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\*Article extracted from the doctoral thesis "Translation, cross-cultural adaptation and validation of the COMprehensive Score for Financial Toxicity (COST) questionnaire for Brazilian culture". Universidade Federal do Paraná, 2021.

Received: 22/02/2021

Approved: 24/07/2021

Associate editor: Cremilde Aparecida Trindade Radovanovic

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ISSN 2176-9133



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