DOI 10.18471/rbe.v37.51209

ADHERENCE TO ORAL ANTINEOPLASTIC CHEMOTHERAPY, SOCIAL SUPPORT AND WELL-BEING OF PATIENTS WITH BRAIN CANCER: A CORRELATIONAL STUDY

ADESÃO À QUIMIOTERAPIA ANTINEOPLÁSICA ORAL, APOIO SOCIAL E BEM- ESTAR DE PACIENTES COM CÂNCER CEREBRAL: ESTUDO CORRELACIONAL

ADHESIÓN A LA QUIMIOTERAPIA ANTINEOPLÁSICA ORAL, APOYO SOCIAL Y BIENESTAR DE PACIENTES CON CÁNCER CEREBRAL: ESTUDIO CORRELACIONAL

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How to cite this article: Alencar BSX, Macedo BSPM, Teraoka EC, Santos AJ, De Domenico EBL. Adherence to oral antineoplastic chemotherapy, social support and well-being of patients with brain cancer: a correlational study. Rev baiana enferm. 2023;37:e51209.

Objectives: to identify perceptions about well-being, social support, intensity of symptoms and their impact on the daily activities of patients with brain cancers and correlate the findings with levels of adherence to oral antineoplastic chemotherapy. Method: correlational and cross-sectional study, conducted in a university hospital outpatient clinic in São Paulo, Brazil, between 2019 and 2020. An instrument was used to characterize the sample, in addition to specific scales. Results: 26 participants, median 36.5 years, 61.5% male, 53.9% diagnosed with glioblastoma; 73.1% showed adherence, social support network and high well-being index. The mean symptom intensity score was low to medium, with a worse score for worry in the worst state. Greater adherence was related to affective support, information support, social interaction and emotional support. Conclusion: most reported positive levels of well-being, social support and few symptoms. The perception of social support and well-being positively influenced drug adherence.

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Descriptors: Medication Adherence. Administration, Oral. Brain Neoplasms. Social Support. Psychological Well-Being.

Objetivos: identificar as percepções sobre o bem-estar, apoio social, intensidade dos sintomas e o seu impacto nas atividades diárias de pacientes com cânceres cerebrais e correlacionar os achados com os níveis de adesão aos quimioterápicos antineoplásicos orais. Método: estudo correlacional e transversal, realizado num ambulatório hospitalar universitário de São Paulo, Brasil, entre 2019 e 2020. Utilizou-se instrumento para caracterização da amostra e escalas específicas. Resultados: 26 participantes, mediana de 36,5 anos, 61,5% sexo masculino, 53,9% diagnosticados com glioblastoma; 73,1% apresentaram adesão, rede de apoio social e índice alto de bem-estar. O escore médio de intensidade dos sintomas foi de baixo para médio, com pior pontuação para preocupação no pior estado. A maior adesão relacionou-se ao apoio afetivo, apoio informação, interação social e apoio emocional. Conclusão: a maioria declarou níveis positivos de bem-estar, suporte social e poucos sintomas. A percepção de apoio social e bem-estar influenciaram positivamente na adesão medicamentosa.

Descritores: Adesão à Medicação. Administração Oral. Neoplasias Encefálicas. Apoio Social. Bem-Estar Psicológico.

Objetivos: identificar las percepciones sobre el bienestar, apoyo social, intensidad de los síntomas y su impacto en las actividades diarias de pacientes con cánceres cerebrales y correlacionar los resultados con los niveles de adhesión a los quimioterápicos antineoplásicos orales. Método: estudio correlacional y transversal, realizado en un ambulatorio hospitalario universitario de São Paulo, Brasil, entre 2019 y 2020. Se utilizó un instrumento para la caracterización de la muestra y escalas específicas. Resultados: 26 participantes, mediana de 36,5 años, 61,5% sexo masculino, 53,9% diagnosticados con glioblastoma; 73,1% presentaron adhesión, red de apoyo social y índice alto de bienestar. El puntaje promedio de intensidad de los síntomas fue de bajo a medio, con peor puntuación para preocupación en el peor estado. La mayor adhesión se relacionó al apoyo afectivo, apoyo información, interacción social y apoyo emocional. Conclusión: la mayoría declaró niveles positivos de bienestar, apoyo social y pocos síntomas. La percepción de apoyo social y bienestar influyó positivamente en la adhesión medicamentosa.

Descriptores: Cumplimiento de la Medicación. Administración Oral. Neoplasias Encefálicas. Apoyo Social. Bienestar Psicológico.

Introduction

Central nervous system (CNS) tumors are classified by the World Health Organization (WHO) as primary, secondary or metastatic. In this classification, in addition to the usual morphological criteria, information regarding molecular markers that, despite their relative rarity, have significant morbidity and mortality is also considered(1). In Brazil, the estimated gross rates for 2023 per 100,000 inhabitants vary between 1.77 and 11.74 for men and between 3.41 and 8.16 for women, depending on the state. Among the main causes are changes acquired over time due to genetic predisposition or exposure to risk factors such as ionizing radiation, environmental exposures (arsenic, lead and mercury), occupational exposures, as workers in the petrochemical, rubber, plastic and printing industry, in addition to immune system deficiency and obesity(1-2).

Among the primary malignant tumors, gliomas are the most frequent, especially in their most aggressive form, glioblastoma. The clinical picture of primary CNS tumors is variable and depends on the type, location, size and speed of growth. Seizures may occur and signs and symptoms of increased intracranial pressure (HIC), such as headache, nausea, vomiting and papilledema, are frequent and often accompanied by focal, usually progressive, subacute deficits. Clinical presentation may also occur in an acute manner, as in patients with intratumor hemorrhages(3).

Regardless of the clinical condition, the current therapeutic approach for patients with malignant brain tumors involves a broad multidisciplinary team performance, with the participation of neuro-oncologists, clinical oncologists, neurosurgeons, nurses, nutritionists, physiotherapists, pharmacists, speech therapists, social workers, among others, necessary for multidimensional care(3).

In the vast majority of cases, the surgical procedure is the therapy of choice with the intentions of total tumor resection or as much as possible, collection of material for biopsy or for prevention or treatment of complications. Associated with surgery, antineoplastic pharmacological clinical treatment is practically given orally, intermittently or continuously, and invariably with drugs called lomustine or temozolomide(4).

Among the therapeutic options usually used, oral antineoplastic chemotherapy (OAC) is a breakthrough in relation to traditional treatments, allowing the continuity of treatment in the home environment, favoring the quality of life, the need for hospitalization or attendance to outpatient infusion therapies. On the other hand, it also presents challenges such as the management of side effects, the period of prolonged treatment and problems related to drug non-adherence(5).

The World Health Organization defines adherence as the degree of correspondence of a person's behavior with the recommendations of a doctor or health professional, including medication intake, attendance at appointments, dietary follow-up, lifestyle changes, adjustments in self-care actions, among others(6). According to government health guidelines in Brazil, adherence is a dynamic and multifactorial process, whose management presupposes a shared therapeutic relationship, guided by negotiation, with specific responsibilities, aiming at patient autonomy for self-care(7).

A study conducted with patients using OAC identified the importance of patient-centered care coordination, education and counseling of people treated with OAC, as well as psychosocial support and involvement of family and friends, at the beginning and during treatment(8).

Patients in use of OAC are responsible for organizing their own treatment at home in relation to correct daily intake and management of toxicities. Thus, the achievement of adequate levels of self-management, understood as the skills required for assertive decision-making, becomes predominant(9).

In addition to health education, other aspects not directly related to disease management, such as interaction and social support, contribute to coping and adaptive states in the cancer journey, favoring quality of life and well-being(10). In this perspective, the present study brings as justification the need to characterize the therapeutic adherence of a specific group of people with cancers in the CNS, using OAC, with possible losses of physical and emotional functionality, and who, as social beings, have their own perceptions of their support networks.

Thus, the study aimed to identify perceptions about well-being, social support, intensity of symptoms and their impact on the daily activities of patients with brain cancers and correlate the findings with levels of adherence to oral antineoplastic chemotherapy.

Method

This is a cross-sectional, correlational, quantitative study conducted in an outpatient service of Neuro-Oncology Hospital São Paulo (HSP), *Universidade Federal de São Paulo* (UNIFESP), São Paulo Campus Unit. The study used the criteria of observational studies in epidemiology Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (11), for the qualification of design and writing.

The scenario of the study is characterized by the service to users of the Unified Health System (UHS), assisted by two teams of oncology residency programs - medical and multiprofessional (nurses, nutritionists, physiotherapists, pharmacists, social workers, psychologists and dentist) -, as well as members of a university extension project entitled *Acolhe-Onco*, which maintains a telephone counseling service, continuous and for 12 hours daily, for patients and family members throughout the journey of cancer treatment(12).

Data collection was performed between February 2019 and August 2020, the period of composition of the convenience sampling. The inclusion criteria were: patients aged over 18 years, with diagnosis of brain cancer in oral antineoplastic chemotherapy treatment for at least 3 months, with prescription and start date confirmed in electronic medical records, and with the administration of oral chemotherapy under their own self-report control. The exclusion criteria were: having cognitive deficit or some psychiatric disorder described in medical evolution.

Five instruments were used, one for sociodemographic and clinical characterization, with structured and semi-structured questions, about personal, clinical, disease and drug treatment data; the Medical Outcomes Study Social Support Scale (MOS-SSS)(13), the World Health Organization Well-being Index (five) (WHO-5)(14), the eight-item Morisky Medication Adherence Scale, to assess therapeutic adherence, translated and validated, Portuguese version(15-16), and the MD Anderson Symptom Inventory (MDASI) Scale, validated in Portuguese(17).

The instruments were interpreted according to the criteria set out in the literature, namely:

Medical Outcomes Study Social Support Scale: For the calculation of standardized scores for each of the five dimensions of social support, points were assigned to each response option, ranging from 1 (never) to 5 (always). The scores were obtained by the sum of the points totaled by the questions of each of the dimensions and divided by the maximum possible score in the same dimension.

WHO Well-Being Index (five) (WHO-5), 1998 version: The gross score was calculated by the sum of the values of the five responses, whose values can vary from 0 to 25, in which zero represents the worst and 25 the best well-being possible.

Morisky Medication Adherence Scale: Contains eight questions with closed answers of dichotomous character yes/no. Each item measures a specific adherent behavior, with seven questions that must be answered negatively and only one positively, the last question being answered according to a scale of five options: never, rarely, sometimes, often, always. The degree of therapeutic adherence was determined according to the score resulting from the sum of all responses, considering patients with scores equal to eight as adherents.

MD Anderson Symptom Inventory Scale: Evaluates the intensity of symptoms and daily impact in cancer patients in the 24 hours prior to investigation. It consists of two components: intensity of symptoms (pain, fatigue, nausea, sleep problems, worries, dyspnea, difficulty remembering things, lack of appetite, drowsiness, dry mouth, sadness, vomiting, numbness/tingling); and symptoms that interfere with life (general activity, mood, work, relationships, walking and pleasure of living). All on a scale from zero (no symptoms) to 10 (as strong as ever).

For data analysis, descriptive, mean, median and standard deviation and analytical statistics were used. According to the scores of each scale, a cluster analysis was made through the mean linkage, in which people were divided into four groups, with the mean and standard deviation of the scales being observed. A multiple correspondence analysis was performed and the relationships of the variables were verified by the perceptual map.

The project was approved by the Research Ethics Committee of UNIFESP, under n. 1224/2018, Certificate of Presentation of Ethical Assessment (CAAE): 01506918.5.0000.5505.

Results

The study included 26 patients, aged between 18 and 68 years, median 36.5 years (SD 14.14), being 14 (53.8%) aged between 18 and 39 years; 16 (61.5%) male; 13 (50%) participants self-reported brown and black; most, 18 (69.3%), with completed high school and/or higher education; 17 (65.4%) were single, widowed and divorced; 14 (53.8%) were Catholic; 14 (53.8%) with 1 or 2 children; all were accompanied at the appointment; 12 (46.2%) were unemployed.

Table 1 – Distribution of patients, according to sociodemographic data. São Paulo, São Paulo, Brazil – 2019-2020. (N=26)

(continued)

Variables	n	%
Sex		
Male	16	61.5
Female	10	38.5

Table 1 – Distribution of patients, according to sociodemographic data. São Paulo, São Paulo, Brazil – 2019-2020. (N=26)
(conclusion)

Variables	n	%
Age group		
18 - 29 years	5	19.2
30 - 39 years	9	34.6
40 - 49 years	4	15.4
50 - 59 years	5	19.2
60 or more	3	11.6
Self-reported skin color		
White	11	42.3
Brown and Black	13	50.0
Yellow	2	7.7
Marital Status		
Single	12	46.2
Married	9	34.6
Widowed	1	3.8
Divorced	4	15.4
Schooling		
1 - 4 years of study	4	15.3
9 - 12 years of study	16	61.6
Over 13 years of study	6	23.1
Current Occupation		
Unemployed	12	46.2
Employed	2	7.7
Informal work	2	7.7
Retired	1	3.8
Own-account worker	2	7.7
Leave	5	19.2
Others	2	7.7

Source: created by the authors.

Regarding life habits, 14 (53.8%) participants were non-smokers and, of those with smoking history (46.2%), 5 (19.2%) remained smokers; 23 (88.5%) were not alcoholics; 17 (65.4%) did not have comorbidities. Regarding the frequency of medication intake, 21 (80.8%) took 1 to 2 drugs a day to control comorbidities and 15 (57.7%) patients with a frequency of only 1 medication taken a day.

Concerning the oncological medical diagnosis, 14 (53.9%) people had glioblastomas, followed by 8 (30.8%) with astrocytomas. Regarding the time elapsed since diagnosis, for 20 (77%) participants, this was 3 to 6 months, for 3 (11.5%), the time was 7 to 9 months, and the others (11.5%), above 9 months. About the therapeutic plan, 19 (73.1%) participants performed adjuvant therapy with concomitant radiotherapy and antineoplastic chemotherapy, receiving the medication temozolomide or lomustine. Combined or isolated radiotherapy was performed by all participants in the brain region. Surgical procedures were performed in 23 (88.5%) participants.

The results of the MOS-SSS scale revealed that most patients answered always and/or often for all questions (Table 2).

Table 2 – Medical Outcomes Study Social Support Scale, according to the mean, median and standard deviation. São Paulo, São Paulo, Brazil – 2019-2020. (N=26)

Medical Outcomes Study Social Support Scale			
Questions	**Mean**	**Median**	**Standard Deviation**
1. Someone to help you if you were confined to bed	3.58	5	1.75
2. Someone to take you to the doctor if you needed it	4.46	5	1.14
3. Someone to prepare your meals if you were unable to do it yourself	4.11	5	1.37
4. Someone to help with daily chores if you were sick	3.73	4	1.48
5. Someone who shows you love and affection	4.77	5	0.71
6. Someone who hugs you	4.77	5	0.59
7. Someone to love and make you feel wanted	4.73	5	0.67
8. Someone you can count on to listen to you when you need to talk	3.92	4.5	1.32
9. Someone to confide in or talk about yourself or your problems	4.08	5	1.41
10. Someone to share your most private worries and fears with	3.42	4	1.55
11. Someone who understands your problems	3.88	4.5	1.37
12. Someone to give you god advice about a crisis	4.08	5	1.41
13. Someone to give you information to help you understand a situation	4.08	5	1.38
14. Someone whose advice you really want	3.85	4.5	1.43
15. Someone to turn to for suggestions about how to deal with a personal problem	3.54	4	1.50
16. Someone to have a good time with	3.96	4	1.34
17. Someone to do something enjoyable with	3.73	4.5	1.54

Source: created by the authors.

The results of the evaluation of the well-being index by the WHO-5 scale showed that most of the patients answered to the five questions: more than half the time or most of the time or all the time, conforming to a high state of well-being. The complete data are presented in Table 3.

Table 3 – Descriptive measures of the World Health Organization Well-being Index scale – Five, according to the mean, median and standard deviation. São Paulo, São Paulo, Brazil – 2019-2020. (N=26)

Questions	**World Health Organization Well-Being Index 5**		
	Mean	**Median**	**Standard Deviation**
1. I have felt cheerful and in good spirits	4.19	5	1.69
2. I have felt calm and relaxed	4.35	5	1.74
3. I have felt active and vigorous	3.92	4	1.57
4. I woke up feeling fresh and rested	4.27	5	1.80
5. My daily life has been filled with things that interest me	4.04	5	1.77
Overall mean	20.77	-	-

Source: created by the authors.

Note: Conventional sign used:
- Numerical datum not applicable.

Table 4 shows the descriptive results of the MDASI, in which, in part 1, the questions evaluated the intensity of 0 to 10 for each symptom, and in part 2, the intensity of 0 to 10 for the interference of each symptom in daily activities.

Table 4 – Descriptive measures regarding the MD Anderson Symptom Inventory, according to the mean, median and standard deviation. São Paulo, São Paulo, Brazil – 2019-2020. (N=26)

MD Anderson Symptom Inventory			
Part 1 – How severe are your symptoms?	**Mean**	**Median**	**Standard Deviation**
1. Your pain at its worst	4.04	2.5	3.62
2. Your fatigue (tiredness) at its worst	5.23	6.0	3.54
3. Your nausea at its worst	4.58	3.5	3.83
4. Your disturbed sleep at its worst	4.42	2.0	3.98
5. Your feelings of being distressed (upset) at its worst	7.42	8.5	3.58
6. Your shortness of breath at its worst	2.19	1.0	2.40
7. Your problem remembering things at its worst	5.58	6.0	3.79
8. Your problem with lack of appetite at its worst	5.0	3.5	4.20
9. Your feeling drowsy (sleepy) at its worst	5.73	6.0	3.96
10. Your having a dry mouth at its worst	5.35	4.5	3.91
11. Your feeling sad at its worst	5.46	6.0	3.73
12. Your vomiting at its worst	4.42	1.0	4.15
13. Your numbness or tingling at its worst	3.77	2.0	3.39
Overall mean	4.86	-	-
Part 2 – How have your symptoms interfered with your life?			
General activity	6.69	7.0	3.69
Mood	5.23	6.0	3.72
Work (including work around the house)	5.50	5.5	4.03
Relations with other people	4.38	2.5	3.86
Walking	6.27	6.5	3.93
Enjoyment of life	5.81	5.5	4.38
Overall mean	5.64	-	-

Source: created by the authors.

Note: Conventional sign used:
- Numerical datum not applicable.

The evaluation of adherence by MMAS-8 identified that 19 (73.1%) patients showed adherence with a score of 8 points and 26.9%, with mean adherence (7 points). In the analysis by specific questions of the instrument, it was found that 22 (84.6%) patients never forgot to take their medicines, as well, in the last two weeks, did not stop taking; 24 (92.4%) never stopped taking their medicines or decreased the dose without warning their doctor even when they felt worse when taking them and never forgot to take their medicines when they traveled or left home; 96.2% never stopped taking their medicines when they felt well.

The questions with lower scores were: they never felt bothered to follow their treatment correctly 19 (73.1%); and they never had difficulties to remember to take all their medications 20 (77%).

By analyzing the scores of the questionnaires, the WHO-5 score, calculated by the sum of the values of the five responses, the scores of the MOS-SSS questionnaire and the MMAS-8, excluding the MDASI, since many answers did not meet the requirements for the calculation of the two scores and, therefore, were disregarded, the cluster below was obtained, grouping the respondents into 4 groups by mean linkage (Table 5).

Table 5 – Groups formed by mean linkage, related to the domains of the World Health Organization-5 scale, the Medical Outcomes Study Social Support Scale and the Morisky Medication Adherence Scale -8. São Paulo, São Paulo, Brazil – 2019-2020. (N=26)

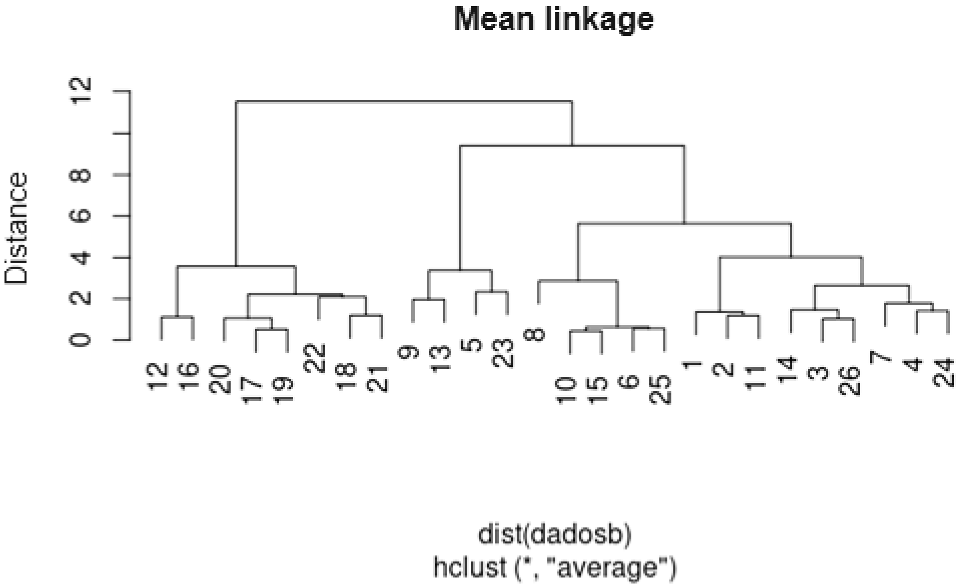
Group	**WHO-5 mean (standard deviation)**	**Medical Outcomes Study Social Support Scale mean (standard deviation)**					**MMAS-8 mean (standard deviation)**
	Well-being	**Material support**	**Affective support**	**Emotional support**	**Information support**	**Positive social interaction**	**Adherence**
1	28.50(1.69)	0.77(0.25)	1.0(0.0)	0.81(0.27)	0.79(0.27)	0.82(0.21)	5.25(0.89)
2	12.20(5.17)	0.63(0.28)	0.89(0.20)	0.62(0.33)	0.62(0.30)	0.64(0.29)	5(1.87)
3	22.60(0.89)	0.85(0.19)	0.91(0.17)	0.74(0.22)	0.79(0.15)	0.81(0.11)	6.4(0.89)
4	17.22(2.22)	0.89(0.14)	0.96(0.07)	0.83(0.20)	0.85(0.21)	0.80(0.20)	5.55(0.73)

Source: created by the authors.

WHO World Health Organization; MMAS Morisky Medication Adherence Scale.

It is noted that the groups differ more in the mean of *well-being* than in relation to the other means of other scores of support and adherence. Group 2 had a slightly lower mean than the other groups for the variables of support and social interaction. Comparing the mean adherences, group 3 had the highest mean (Figure 1).

Figure 1: Mean link with the scores of the World Health Organization-5 questionnaires, the Medical Outcomes Study Social Support Scale and the Morisky Medication Adherence Scale-8 (disregarding the MD Anderson Symptom Inventory scores).

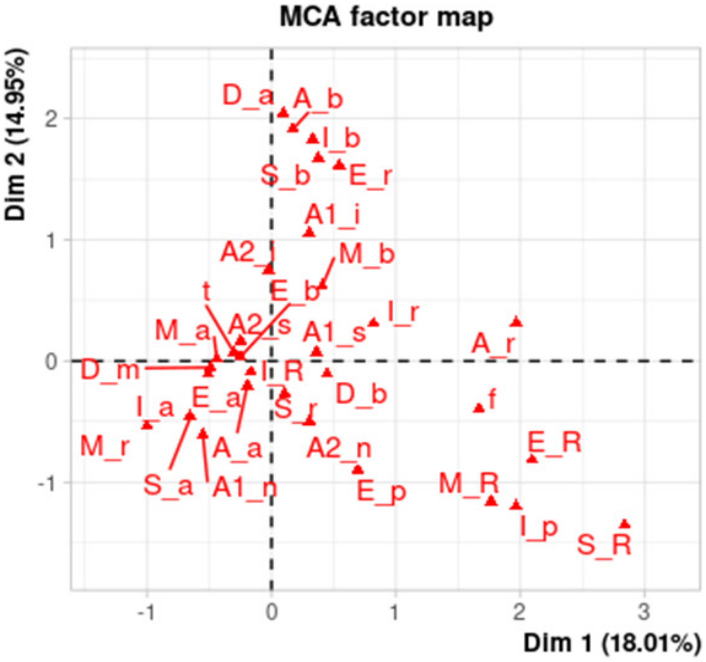


Source: created by the authors.

After verifying the possible associations, the multiple correspondence analysis was performed without considering the variable score of part 2 of the categorized MDASI, which evaluates the intensity that symptoms interfere with life. The first two dimensions explained 32.9% of the data variability.

To include the scores of the complete MDASI, the scores of the different questionnaires were categorized as follows: for the scores of support and social interaction, the scores of 0.8 to 1 were considered category **a**; category **b** the scores of 0.6 to 0.8; category **r** scores from 0.4 to 0.6; category **R** scores from 0.2 to 0.4; category **p** scores from 0 to 0.2. For the well-being index, the score below 13 was categorized in **f**; and the score greater than 13 in **t**; for the adherence score, the score of 8 points was categorized as **a**; **m** the score from 6 to less than 8 points; **b** the score below 6. For the MDASI scores, part 1 was categorized as **i** for less than 85 points; **s** as higher than 85 points. For part 2, below 39 was categorized as **i** and **s** above 39. The data are in Figure 2.

Figure 2: Perceptual map of the first two dimensions: support and social interaction



Source: created by the authors.

As shown in Figure 2, people with poor well-being scores are associated with emotional support between 0.2 and 0.4, material support between 0.2 and 0.4, and information support between 0 and 0.2. However, people with well-being scores above 13 had material support between 0.8 and 1, mean adherence score, emotional support between 0.6 and 1, information support between 0.2 and 0.4 and MDASI score in part 2 higher than 39. Moreover, respondents with high adherence also reported affective support between 0.6 and 0.8, information support between 0.6 and 0.8, social interaction between 0.6 and 0.8 and emotional support from 0.4 to 0.6.

Respondents with good adherence score were associated with MDASI score in part 1 over 85, social interaction between 0.4 and with emotional support from 0 to 0.2. Cronbach's alpha, for the first dimension of multiple correspondence analysis, indicated a good reliability, value of 0.853.

Discussion

The results of the present investigation gathered patients diagnosed with glioblastoma, in the age group of young adults, most men, schooling equal or superior to nine years of formal study, no work activity in the period and receiving the oral antineoplastic chemotherapy temozolomide or lomustine. Drug adherence was high and dependent on better perceptions of well-being and social support.

In the evaluation of adherence, in the majority of the sample, the respondents presented a score of 8, which means absolute, leading to the reflection that the applied care model has contributed to the generation of good results. Adherence to OAC is an important indicator of antineoplastic therapeutic response related to personal, social and structural factors(18). A systematic review highlighted that the monitoring of OAC should include personal contact with patients in the first weeks of therapeutic care, due to the need to build skills for self-management, monitoring and adoption of personal and environmental safety measures(19).

As portrayed, the participants of the present study are assisted by a multidisciplinary team, in an integral and continuous way and, in addition to the periodic outpatient consultations, they also have a telephone counseling service for the clarification of doubts regarding home care, including the intake of OAC. Corroborating the importance of adopting multiple strategies, a randomized study in cancer patients using OAC identified that strategies that individualize care, such as the participation of a navigator nurse and a web portal for distance communication, offer opportunities to improve adherence and quality of patient care(20).

It is relevant to consider the well-being of patients diagnosed with a tumor in the central nervous system, in the various spheres, since this diagnosis has high complexity and average survival of less than two years, despite multimodal procedures, as surgical, radiotherapy and antineoplastic chemotherapy available(21-22). It should be noted that, in this sample, most had already completed the phase of submission to surgical and radiotherapy procedures or were performing radiotherapy concomitant to OAC.

The results of the social support scale show that patients have fragile social bonds due to various vulnerabilities. In contrast, it was noticed that, in the social environment, there are people who are willing to give advice and information. A qualitative study conducted in Rio Grande do Sul, Brazil, among women with breast cancer, identified four themes for the social support network: family and friends, therapeutic groups, health team and religiosity, faith and spirituality. These supports are important allies of quality and safety of care to the patient, because religiosity, faith and spirituality are necessary for coping with the disease throughout the treatment process; the health team influences the recovery, support for adherence and motivation so that they can persist in treatment, as well as for the hope that everything will work out(23).

Social and family supports are indispensable when it comes to favorable responses to treatment and life prospects of people with cancer. Continued access to psychosocial support is important for maintaining the well-being of people with brain cancer and their families, as attested in a qualitative study that characterized the challenges for people to enter psychosocial care systems and how brain cancer affects the whole family(24).

The results on well-being obtained in the present investigation revealed that most of the patients studied felt, *most of the time*, cheerful and well-disposed, and calm, active and energetic, renewed and rested after waking up and with the day filled with interesting things, indicating good mood of patients even during treatment.

The factors that affect well-being and the symptoms that most affected the population studied were changes in sleep pattern, inappetency, pain, fatigue, sensory changes such as dry mouth, shortness of breath, nausea, numbness or tingling, difficulty remembering things, and the feeling of sadness. It should be noted that the concern in its worst state, fatigue and difficulty to remember things were scored as higher averages.

The MDASI scale has been widely used to evaluate the symptoms related to systemic chemotherapy, as exemplified by a study conducted in a university hospital chemotherapy service(25). Among 79 cancer patients, the study showed that fatigue and lack of appetite were symptoms reported by 64.6%, followed by nausea, with 58.2%, and that the greater the interference of symptoms in general life activities, the higher the self-care score presented(25).

In the present study, the monodrug scheme may have been in favor of the low complaint of physical symptoms for most symptoms. However, it is known that any physical symptom is a risk for drug non-adherence, as well as polypharmacy, higher age and social vulnerability(26). Thus, the education for self-management of symptoms is particularly important during treatment with OAC, for prolonged periods and with less contact with health professionals compared to infusion treatments.

Results that reveal the particularities of people in the journey of cancer, as the present study, can help professionals plan better educational interventions and measure results with instruments that sharpen the intervening factors for the risk of failure of the therapeutic plan, in a systematic way. This data set can also strengthen multiprofessional care and generate better adaptive responses in people assisted(27).

In the study that assessed socioeconomic factors affecting the survival of glioblastoma patients in a developing country, most of the patients diagnosed with glioblastoma, 38 (79%), worked full-time, 6 (13%), part-time, and the minority, 6 (13%), was unemployed and 3 (6%) were retired. The authors cited high treatment costs and a government support deficiency in infrastructure and logistics of adjuvant treatment(28).

Therefore, this research revealed another reality in relation to patients because despite most being in the working age group, they were on sick leave or retired. Even though the causes are not revealed in this investigation, the literature shows possible explanations about the difficulties that people with cancer still find to remain active in the labor market, factors related to physical and psychological limitations caused by illness or treatment, or even by labor market prejudices(29).

A limitation of the study concerns the reduced sample size, although all patients using the study site and eligible were included. Another limitation refers to the type of study, which provided data on a specific moment and resulting from the sum of all respondents. Since the phenomenon studied is a continuous treatment, the comparative analysis of data from different temporal moments could indicate variabilities of adherence in the same respondent, enriching the interpretation of the phenomenon.

The study has important implications for the practice, by helping to unveil the multidimensionality of people with brain cancer in OAC treatment and thus offer data for the resizing of care priorities, including the participation of several indispensable multidisciplinary team members in addition to the oncologist, such as nurse, pharmacist, nutritionist, social worker, physiotherapist and psychologist, according to the nature of the problems evidenced.

Conclusion

Most participants reported well-being status and satisfaction with social support. However, there was a negative impact on daily life for performing activities in general and walking of some symptoms such as fatigue, drowsiness, dry mouth, memory difficulty, worries and sadness.

The evaluation of adherence to oral antineoplastic chemotherapy proved to be absolute for most participants, and it was possible to verify that the variables with the greatest positive impact on drug adherence were the perceptions of support in the affective and emotional aspects, in addition to being satisfied with the information received and their social interactions.

Collaborations:

1 – conception and planning of the project: Barbara Santos Ximenes de Alencar, Bárbara Stéphanie Pereira Macedo, Adrialdo Jose Santos and Edvane Birelo Lopes De Domenico;

2 – analysis and interpretation of data: Barbara Santos Ximenes de Alencar, Eliana

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3 – writing and/or critical review: Barbara Santos Ximenes de Alencar, Eliana Cavalari Teraoka, Adrialdo Jose Santos and Edvane Birelo Lopes De Domenico;

4 – approval of the final version: Adrialdo Jose Santos and Edvane Birelo Lopes De Domenico.

Competing interests

There are no competing interests.

Funding sources

Institutional Scientific Initiation Scholarship Program (PIBIC) of the National Council for Scientific and Technological Development (CNPq).

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Received: March 23, 2023

Approved: October 27, 2023

Published: November 22, 2023