

Psychoeducation improves the quality of life of informal caregivers of Glioblastoma patients

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OBJECTIVE: To evaluate the impact of a psychoeducational program on the quality of life of informal caregivers of Glioblastoma patients.

METHOD: Twenty informal caregivers (test group) were evaluated before and after attending four sessions of psychoeducation and compared to a group of 10 caregivers (control group), who did not attend the sessions, but were also evaluated in two different equivalent time points. The quality of life was evaluated by WHOQOL-BREF questionnaire developed by the World Health Organization, which was applied by the same interviewer to all the participants. At the end of the study, a blinded interviewer who had no previous contact with the participants applied the tool again to check for any interference bias. The Cronbach's alpha coefficient for consistent evaluation, Student's t-test for parametric, and Wilcoxon test for non-parametric data were applied for statistical analysis.

RESULTS: The questionnaire was shown to be a consistent tool to evaluate quality of life. The test group showed significant improvement in the quality of life, especially in the psychological domain. The control group presented deterioration in all WHOQOL-BREF domains.

CONCLUSIONS: The psychoeducational program improved the quality of life of caregivers of Glioblastoma patients, and revealed to be a valuable support program to be implemented in the treatment of this type of cancer.

KEYWORDS: Glioblastoma multiforme; Caregiver; Psychology; Grief; Quality of Life.

Vainboim TB, Pereira Franco MH, Ciccone AO, Miura FK, Pires de Aguiar PH, Scaff M, Nagahashi Marie SK. Psychoeducation improves the quality of life of informal caregivers of Glioblastoma patients. MEDICALEXPRESS. 2014 June;1(3):158-165.

Received for publication on April 21 2014; First review completed on April 22 2014; Accepted for publication on April 26 2014

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INTRODUCTION

The incidence and mortality of brain tumors have increased worldwide, particularly among the elderly. Glioblastoma multiforme (GBM) is the most frequent brain tumor and represents between 12 and 15% of all intracranial tumors in adults. It comprises about 50 to 60% of all gliomas¹. The death rate from this cancer has increased from 2.24 to 3.35 per 100,000 individuals in the last decades, an increase of nearly 50%².

Standard treatment includes surgical resection, radiotherapy, and chemotherapy, resulting in a survival time of 10 to 12 months³⁻⁵. Patients with high-grade gliomas (Anaplastic astrocytoma and Glioblastoma multiforme) tend to have poor responses to treatment and most patients relapse even when adjuvant treatment is provided^{3,6-9}. The effects of the disease, added to the treatment side effects, severely

impair cognition, especially memory, language, and attention functions¹⁰.

The impact that cancer has on the patient's family is well-documented^{11,12}. It is already known that the news of a diagnosis of a serious illness affects not only the patient but also the family unit. Thus, the cancer patient's family requires special attention, which should be provided from the moment the individual is informed about the diagnosis and maintained throughout the course of the disease¹³. For the family, news of the diagnosis may be a real shock. Individuals may share feelings of guilt, anger, depression and they may also adopt a behaviour of isolation and denial¹⁴.

It has been reported that the cancer patient's family undergoes the same stages as the patient upon receiving the diagnosis of a serious illness¹⁵. The way patients and their families cope with this diagnosis depend on the structure of each family and the relationships established among individuals. A different number of reactions relating to life losses may arise, including anticipatory grieving, feelings of

DOI: 10.5935/MedicalExpress.2014.03.12

ambivalence, fear of seeing the suffering and the decline of the patient, and the feeling of helplessness. The psychosocial impact on family members of patients with brain tumor has two main consequences: it changes family roles and it creates a burden for caregivers¹⁶. Patients with terminal cancer, together with relatives and friends who assume the role of taking informal care of the patient, known as informal caregivers, have been considered a unit of care by the World Health Organization (WHO)¹⁷.

The WHO has organized The World Health Organization Quality of Life Group, a multicenter group involving several countries, to create standard definitions along with an instrument to evaluate the quality of life of individuals¹⁸. Since its creation, the assessment of the quality of life of patients and their caregivers has been used in healthcare. However, only a few studies are available on the life quality of patients with brain tumors and their caregivers^{10,16,19–22}.

Quality of life is a subjective and multidimensional issue including positive and negative views. It is based on individual perception, and is embedded in a cultural, social and environmental context^{18,23,24}. Therefore, we endeavored to determine whether a psychoeducational program given to GBM patients' informal caregivers could impact the quality of life of these individuals.

■ MATERIAL AND METHODS

This was a case-control study performed at the Department of Neurology of Hospital das Clínicas, the tertiary hospital of the School of Medicine of the University of São Paulo, Brazil.

The quality of life of 20 informal caregivers of GBM patients (test group) was evaluated before and after attending four sessions of psychoeducation and the results were compared with results obtained from a group of 10 caregivers (control group) who did not attend the sessions, either because they lived too far from the hospital or because their working hours did not allow their participation in the program. Participants in the control group were unaware of the possibility of participating in the psychoeducational program because they would not have been able to attend the service once a month. The control group of caregivers was also submitted to two sequential evaluations of quality of life and the intervals between evaluations were similar to that of the test group.

In order to be included in this study caregivers had to be at least 21 years old and possess adequate cognitive functions to appropriately answer the questions in the psychoeducational interviews. Informal caregivers who manifested unwillingness to know about patient's diagnosis and/or prognosis were excluded from the study.

The psychoeducational program was divided into four sessions of 45 minutes, once a month. The content of these sessions was as follows:

- *Session 1:* Explanation of the principles and aims of the psychoeducational program, information about GBM and the impact the disease could have on patients and their informal caregivers;
- *Session 2:* Care at home, information about disease treatment and side effects, highlighting the role of the family throughout the course of the disease and the importance of communication among all individuals involved, how to improve communication at home and with the healthcare team;

- *Session 3:* Listening and validating the emotions and feelings developed by caregivers due to the impact of the disease on their quality of life, explanation of the steps that patients and family members go through after receiving the news of the patient's diagnosis and prognosis, according to Kübler-Ross²⁵;
- *Session 4:* A debate about quality of life, self-aid opportunities for caregivers; participants evaluated the psychoeducational program.

Before attending the first session of the psychoeducational program, each of the 30 informal caregivers participated in a semi-structured psychological interview (Phase I). The information collected during these interviews was recorded on audio tape with consent. The interviews evaluated the social and demographic aspects of participants and also questioned them about their perception of the disease, how they were coping with it, how they reacted to patients' symptoms, which support they could rely on, and their ability to communicate with others (Appendix A). Following the interview, participants filled out the Portuguese version of the WHOQOL-BREF²⁴. This tool is a short version developed by the WHOQOL Group. In all areas, the psychometric characteristics of the Portuguese version are similar to those of the original version²⁴. It contains 26 questions with answers presented in a Likert scale from 1 to 5. The first two questions represent isolated dimensions and refer to the general perception of the individual about his/her QoL (question 1) and health (question 2). The remaining questions are distributed in sections that evaluate four domains: physical, psychological, social and environmental. The same interviewer applied the questionnaire individually to each participant with a duration of approximately 45 minutes.

Following Phase I, twenty caregivers attended the four sessions that comprised the psychoeducational program whereas the 10 caregivers in the control group did not.

Following participation in the psychoeducational program, participants were again interviewed and asked to fill out the WHOQOL-BREF (Phase II). This time, the questionnaire also included questions related to changes that might have occurred, and that may have become permanent, in the informal caregiver life. At this point, participants had the opportunity to share their experiences with the interviewer (Appendix B). Phase II was applied 3 to 4 months after Phase I. The same questionnaire was applied to the control group within the same interval of time as the test group.

Phase III took place 3 to 4 months after Phase II and comprised a replication of Phase II by a blind interviewer. 24 participants were interviewed in Phase III.

Statistical analysis

The data analysis was performed using SPSS 12.0 (Statistical Package for the Social Sciences) for the WHOQOL-BREF, according to the instructions for its application and evaluation provided by the WHOQOL Group in Brazil. We used SPAD (Système Portable d'Analyse des Données) for factor analysis and SPAD.t (Système Portable pour l'Analyse des Données Textuelles) for analysis of open questions.

Descriptive analysis of continuous variables was performed by calculating the minimum and maximum values, means, standard deviations, and medians. Qualitative

Table 1 - Caregivers Characteristics

Demographics	Test group	Control group
Total participants	20	10
Female	19	4
Parenthood		
Wife	7	2
Daughter	6	1
Sister	4	-
Husband	1	3
Son	0	3
Mother	1	1
Daughter-in-law	1	-
Age (years)		
21 to 30	5	1
31 to 50	7	5
51 to 65	7	2
65 and above	1	2
Educational Level		
Incomplete Primary school	3	0
Primary school or incomplete College	7	1
High school and College	10	9
Religion		
Catholic	15	6
Evangelic	3	3
Spiritual	1	1
None	1	0
Ethnic, <i>n</i>		
Caucasian	17	9
African-Brazilian	2	1
Asian	1	0

variables were analyzed by means of absolute and relative frequencies. The Cronbach Alpha coefficient was used to analyze the internal consistency of the questions of the WHOQOL-BREF, which refers to the range of interrelated items. The Kolmogorov-Smirnov test was used to assess

adherence to the normal distribution of quantitative variables. If distribution was normal, the parametric Student's *t* test was used. Otherwise we applied the non-parametric Wilcoxon test. Factor analysis and Hierarchical Classification for building typologies using the results of domains were used for the scale of the WHOQOL-BREF. The level of significance was set at $p < 0.05$.

This study was performed in accordance with the ethical standards of the 1964 Declaration of Helsinki and approved by the Ethics Committee for Analysis of Research Projects – CAPPesq Board Clinic Hospital and the School of Medicine, University of São Paulo, according to Research Protocol No. 0434/08. All participants received and signed an informed consent form prior to their inclusion in the study.

■ RESULTS

Characteristics of subjects

Table 1 summarizes the characteristics of the 30 caregivers. Most patients were female (76.7%), with a high educational level (63.3%), catholic (70%), and caucasian (86.7%). The mean age was 44.3 ± 14.1 (SD) years.

Impact of the psychoeducational program

The answers obtained from the first two questions in each group provided before and after applying the psychoeducational program (and which are not included in any of the four domains of the WHOQOL-BREF) are represented in Fig. 1 and Fig. 2. These two questions are: 1) How would you rate your quality of life? and 2) How satisfied are you with your health?

Before attending the psychoeducational program, nine of the 20 caregivers considered their quality of life "good." After attending the program this number increased to 14

How would you rate your quality of life?

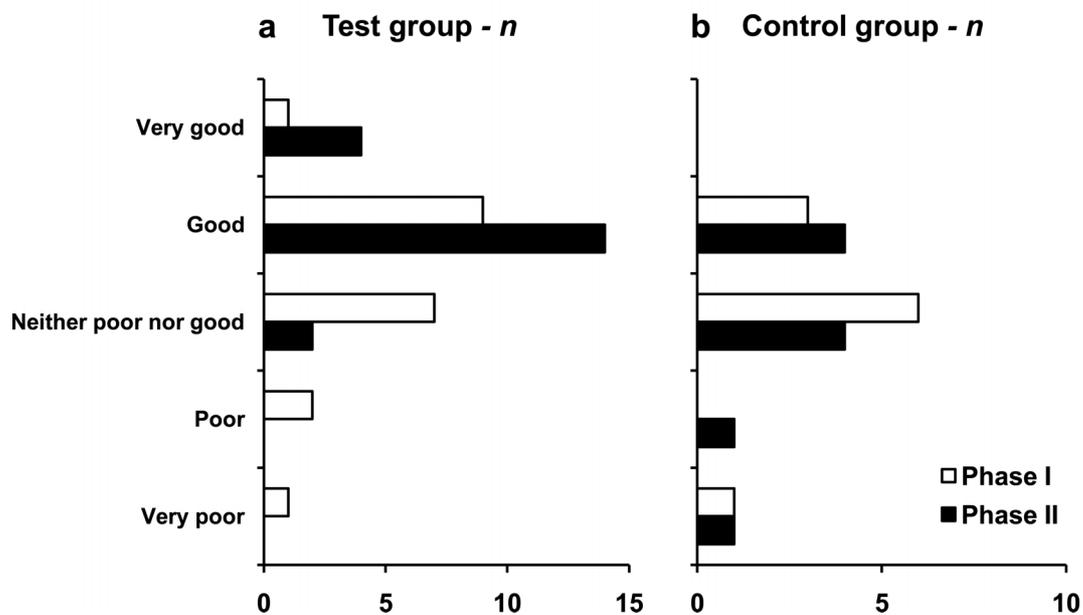


Figure 1 - The answers obtained with the first general question of the WHOQOL-BREF: "How would you rate your quality of life?" a. test group, and b. control group.

How satisfied are you with your health?

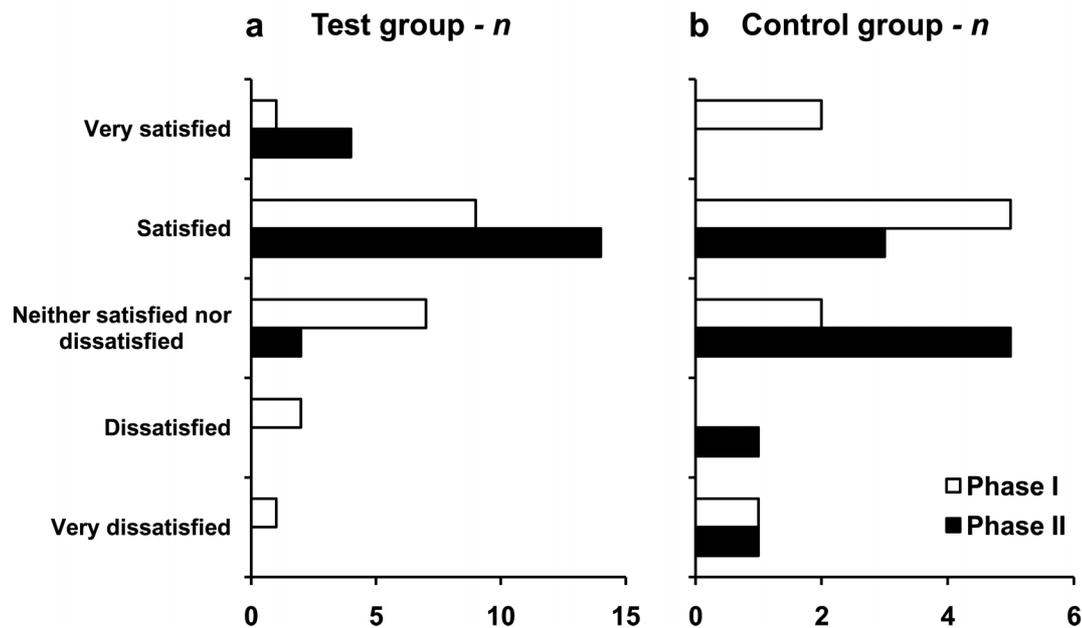


Figure 2 - The answers obtained with the second general question of the WHOQOL-BREF: “How satisfied are you with your health?” a. test group, and b. control group.

individuals. The number of caregivers who considered their quality of life “very good” also increased from one to four caregivers. It should be noted that after attending the program no caregiver considered his/her life quality as “poor” or “very poor”. On the other hand, in the control group no caregiver considered his/her quality of life as “very good”.

Regarding the number of responses given to the second general question related to quality of life, the number of responses from people “satisfied” with their health increased from five to twelve. After attending the psychoeducational program no caregiver considered him/herself to be “dissatisfied” or “very dissatisfied” with his or her own health.

In Phase II, no caregiver in the control group was “very satisfied” with his or her own health. The number of responses from those who were “satisfied” with their health between Phase I and II, decreased from five to three.

According to the score system described in the WHOQOL-BREF¹⁸, we observed that an improvement in the quality of life was obtained for all four domains in the test group (Fig. 3) while in the control group the quality of life

worsened in all four domains (Fig. 4). Note that in all cases a statistically significant difference was found between the values obtained before and after applying the program.

A total of 16 out of 20 participants expressed a desire to continue the psychoeducational sessions after the psychoeducational program was over.

WHOQOL-BREF

The consistency of our evaluation was tested by means of the Cronbach’s alpha coefficient, and satisfactory results were obtained for all 26 questions. For each phase the values were 0.84 (Phase I), 0.86 (Phase II), and 0.87 (Phase III) showing that the application of the WHOQOL-BREF showed no significant variability when applied in all phases of our study. This indicates that this tool was adequate for assessing the quality of life.

Reproducibility

When we compared the differences in each group for the answers provided in Phase II and Phase III, no significant differences were observed (Table 2).

Phase III was applied by a collaborator psychologist who had no prior contact with the caregivers. This was done in order to avoid interviewer bias; the result confirmed the robustness of our study.

The results show that psychoeducational intervention impacted the quality of life of informal caregivers of patients with GBM, especially in the psychological and physical domains.

DISCUSSION

In our study, most caregivers were female, which is the same finding as reported in other studies^{26–36}. Nine of the

Table 2 - Mean of the difference for the answers provided in Phase II and Phase III

Domains		Mean	SD	Mean difference	p
Physical	Phase II	70.2	3.62	1.34	0.083
	Phase III	68.9			
Psychological	Phase II	66.0	7.05	1.74	0.24
	Phase III	64.2			
Social	Phase II	64.6	-	-	-
	Phase III	64.6			
Environmental	Phase II	62.0	3.53	0.52	0.477
	Phase III	61.5			

SD standard deviation

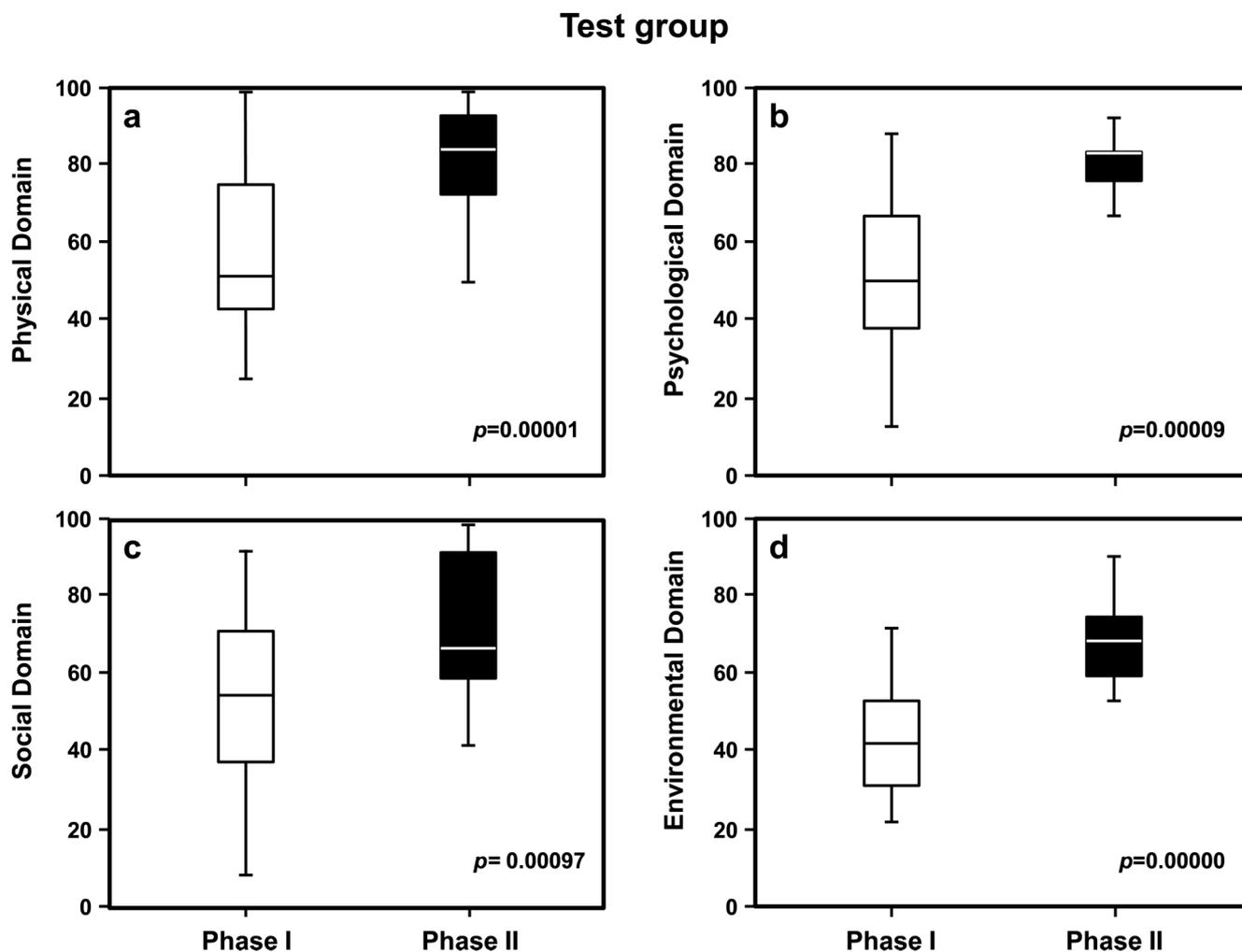


Figure 3 - The median value of the total score obtained in each of the four domains of the WHOQOL-BREF, before and after the psychoeducational program was applied. a. physical domain: $p = 0.00001$ (Student's t test), b. psychological domain: $p = 0.00009$ (Wilcoxon), c. social domain: $p = 0.00097$ (Wilcoxon), and d. environmental domain: $p = 0.00000$ (Student's t test). P values < 0.05 were considered statistically significant.

caregivers were the wives of the patients, seven were daughters, three were sons, four were sisters, two were mothers, four were husbands and one was a daughter-in-law. A study by Minchillo²⁸ showed a higher incidence of wives or daughters in the population of caregivers.

As for the level of education of the caregivers, 19 had completed either high school or college, eight had completed primary school or did not finish college, two did not finish the primary education. This indicates that all caregivers were capable of understanding all the information transmitted although we cannot rule out the effect of other factors such as psychological factors.

In a study by Golimbet & Trubnikov³⁷, the authors found that education showed a significant association with psychological health, and the higher the education level the higher the score in that domain. It should be noted that the psychological domain is possibly the one domain that expresses the subjectivity inherent to the concept of quality of life.

After participating in the psychoeducational program, all participants showed improvement in their quality of life,

especially in the psychological domain. As regards the controls, their quality of life, in all domains, worsened. It is believed that psychotherapeutic interventions, applied either individually or in a group, offer an environment where individuals can express their feelings, and share knowledge and life experiences related to illness. This environment is seen as a place for sharing experiences related to caring for sick individuals and a place where caregivers may identify with each other. Family members are usually eager for information as a way to better understand the disease and guide them in questioning decisions related either to treatment or to its side effects^{16,21}. As already proposed by others, psychotherapy for support and/or for clarification aims to "promote a therapeutic environment in which the family can be helped to understand their own experiences and reorganize themselves to face the demands of the new reality"³⁸.

The fact that our program consisted of a psychoeducational instead of a psychotherapeutic program apparently added an overall benefit to the program. Frequently, caregivers choose not to question doctors because they

Control group

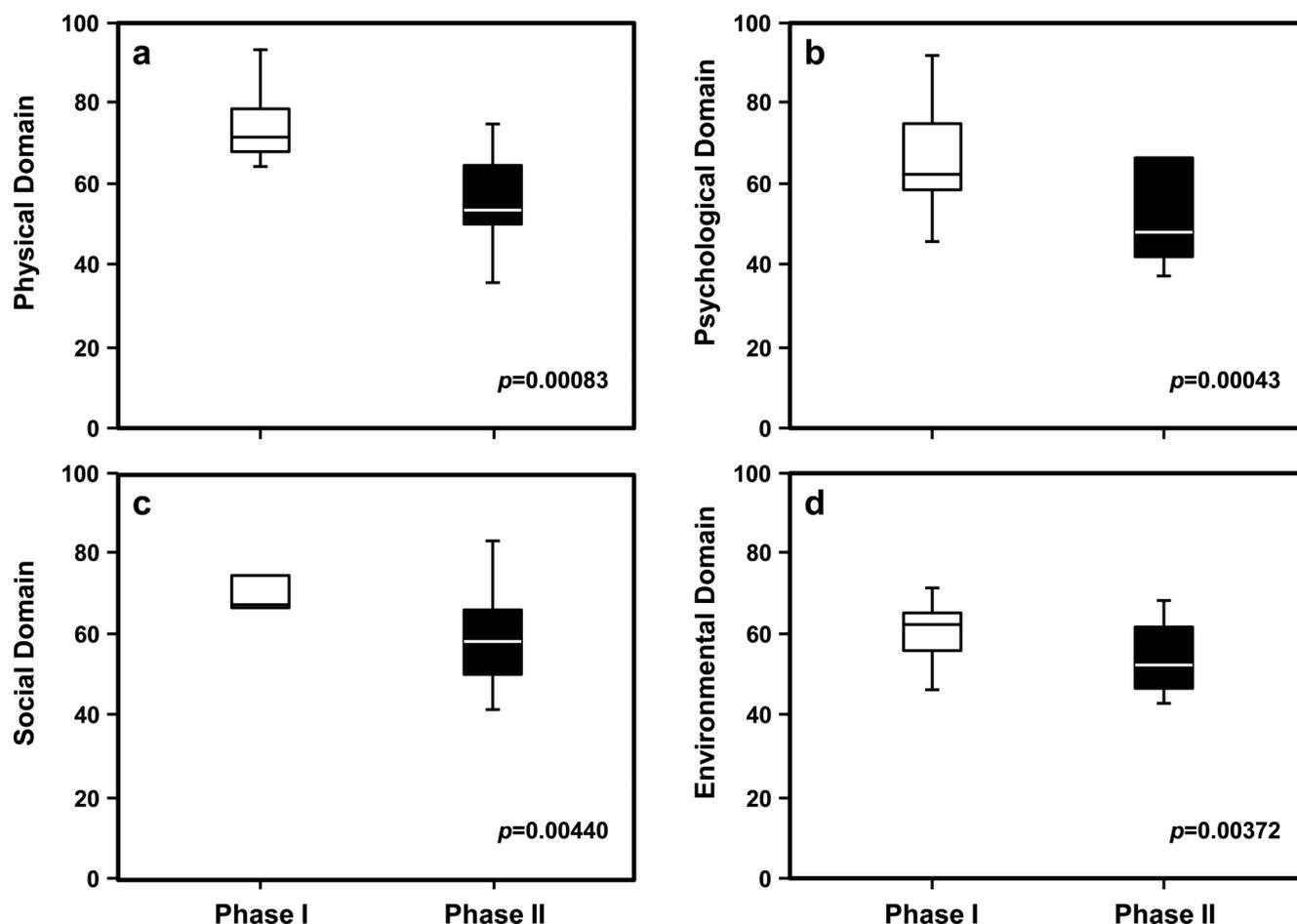


Figure 4 - The median value of the total score obtained in each of the four domains of the WHOQOL-BREF (control group). a. physical domain: $p = 0.00083$, b. psychological domain: $p = 0.00043$, c. social domain: $p = 0.00440$, and d. environmental domain: $p = 0.00372$, based on Student's *t* test. *P* values < 0.05 were considered statistically significant.

usually have contact with doctors when they are accompanying patients to exams or appointments. This may create a conflict in which the caregiver omits his/her questions as a way to protect the patient from answers that might be too hard for the patient to cope with.

Our program represented an open space where caregivers could ask their questions knowing that the psychologist would work as an important channel of communication between them and the health team. Additionally, the program seems to have also fulfilled an important need previously identified by Costa Neto³⁹, who stated that the patient's family should have one main reference person in the healthcare team who can be reached by other family members for additional information. In many cases the psychologist is the professional indicated to play this role.

Indeed, 16 out of 20 participants expressed a desire to continue the psychoeducational sessions after the psychoeducational program was over, which indicates that caregivers perceived a benefit in attending the sessions.

In regard to the worsening of quality of life observed in the control group, we cannot rule out that this finding may relate to health deterioration conditions of the patients under the

care of these caregivers. Participants in the control group were unaware of the possibility of participating in the psychoeducational program because they were out of São Paulo and could not attend the service once a month.

We could not detect significant differences between the answers obtained in Phase II and Phase III in both groups. This indicates that the methodology applied was consistent and that the answers given by the caregivers did not suffer interviewer-related bias effects. Instead, the answers seemed to reflect the caregivers' perception of their quality of life throughout the study period. Psychoeducational care seemed to benefit glioblastoma informal caregivers.

Testing one's quality of life is still a challenge. According to Bleger⁴⁰, the semi-structured psychological interview done in the hospital is characterized by its ease of application and adaptability, allowing individuals a spontaneous expression of their emotions and opinions. It also allows the quantitative and qualitative assessment of the scientific content of the interview through a categorization scheme of the responses.

This study describes one way through which help and support may be provided to caregivers of patients with

Glioblastoma multiforme and other cancers. We suggest the incorporation of programs like the one we described here into the routine of neuro-oncology centers and other cancer centers in order to improve the quality of life of caregivers of cancer patients. It is possible that programs containing additional sessions would improve the quality of life of these individuals even more. The design and development of new psychoeducational programs that explore other aspects related to the quality of life of caregivers of cancer patients, especially for the caregivers of terminal cancers such as Glioblastoma multiforme, is highly recommended.

CONCLUSIONS

Although quality of life is a subjective parameter, our findings indicate that the semi-quantitative methodology here presented is a reproducible and measurable approach for establishing the quality of life of the individuals tested. The psychoeducational program showed itself to be a powerful instrument to improve the quality of life of the informal caregivers of the Glioblastoma patients and the inclusion of such a program may add real benefit for a unit of care managing these patients.

ACKNOWLEDGEMENTS

This study was supported by grants from Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES).

RESUMO

OBJETIVO: Avaliar o impacto de um Programa Psicoeducativo na Qualidade de vida de cuidadores de pacientes portadores de Glioblastoma Multiforme.

MÉTODOS: Vinte cuidadores (Grupo Experimental) foram avaliados antes e depois de participar de quatro sessões de um programa psicoeducativo e comparados com um grupo de dez cuidadores (Grupo Controle) que não participaram do programa, mas que também foram avaliados em dois momentos diferentes. A qualidade de vida foi avaliada pelo questionário *WHOQOL-bref* desenvolvido pela Organização Mundial de Saúde, que foi aplicado pelo mesmo entrevistador. Houve reaplicação dos instrumentos por uma investigadora cega para os parâmetros analisados na tentativa de garantir que os resultados não sofressem contaminação pelo viés do contato com a entrevistadora anterior. O coeficiente *Alfa de Cronbach* foi utilizado para análise da consistência interna das questões do *WHOQOL-bref*. Quando as variáveis apresentaram distribuição normal foi utilizado o teste paramétrico Teste t e quando não apresentaram distribuição normal foi utilizado o teste não-paramétrico de *Wilcoxon*.

RESULTADOS: O questionário mostrou ser uma ferramenta consistente para avaliar qualidade de vida. O grupo experimental apresentou melhor significância na qualidade de vida, especialmente no domínio psicológico. No grupo controle houve uma piora da qualidade de vida em todos os domínios.

CONCLUSÕES: O programa psicoeducativo melhorou a Qualidade de vida dos cuidadores de pacientes com Glioblastoma Multiforme, e revelou-se um valioso programa de apoio a ser implantado no tratamento deste tipo de câncer.

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■ APPENDIX A

Below is the list of questions asked to caregivers before they attended the psychoeducational program, in Phase I.

1. What is your relationship with the patient?
2. How did you become a caregiver? When? Why?
3. How did you react when you learned that the patient was ill?
4. What do you think of this disease?
5. As a caregiver, has something changed in your life? What has changed and how?
6. How do you take care of the patient?
7. Do you talk at home about the disease?
8. If the previous answer is no, would you like to talk at home about the disease?
9. If yes, how would you like this conversation to be?
10. Say a word that represents how your life has been since you became a caregiver.

■ APPENDIX B

Below is the list of questions asked to caregivers after the psychoeducational program was applied, in Phase II. Questions 2, 3, 10, and 11 were slightly different depending on whether or not the caregiver participated

in the program. The alternative questions (asked to caregivers who did not participate in the program) are presented just below questions 2, 3, 10, and 11.

1. How have you spent the past few months?
2. Did you experience changes after attending the psychoeducational interventions? If the answer is yes, what changes?
 2. Alternative. Did you experience changes in the last three or four months? If the answer is yes, what changes?
3. Have you noted any changes in your relationship with the patient after attending the psychoeducational interventions?
 3. Alternative. Have you noted any changes in your relationship with the patient in the last three or four months?
4. Are there new difficulties?
5. Are there difficulties that still remain?
6. What kinds of feelings does caring for someone trigger in you?
 7. Do you talk at home about the disease?
 8. If the previous answer is no, would you like to talk at home about the disease?
 9. If yes, how would you like this conversation to be?
10. What suggestions do you have for psychoeducational care?
 10. Alternative. What type of support is necessary besides the support already offered to you?
11. Say a word that represents the experience of having participated in the psychoeducational interventions.
 11. Alternative. Say a word that represents your experience during this 3-4 month period post-Phase I.