

A Pilot Study on Educational Workshops for Caregivers of Patients with Brain Tumors Called AGAPE Showed its Feasibility and the Maintain Caregiver's Quality of Life Despite Patient's Disease Progression.

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Abstract

Background

Several studies have highlighted the difficulties faced by caregivers of patients with brain tumors. We created the educational workshops called AGAPE. Their aim is to explain precisely the medical aspects of brain tumors, describe resources available, and allow a moment of exchange between caregivers.

Purpose

To evaluate outcomes of AGAPE.

Methods

This was an observational uncontrolled pilot study. Feasibility was evaluated by the caregivers' attendance of the 2 theoretical scheduled sessions and their satisfaction. Additional outcomes were the percentage of caregivers in favour of AGAPE sustainability and the impact on their quality of life according to CarGOQoL questionnaires (Caregiver Oncology Quality of Life) between baseline before the first workshop and after the last one.

Results

From February 2015 to March 2019, 12 three-month sessions were organized allowing 87 caregivers to participate. 84% of caregivers attended at least 2 theoretical sessions, the level of satisfaction was very high, and all caregivers were in favor of AGAPE sustainability. 36 caregivers submitted completed questionnaires at baseline and after the last workshop attended, separated by more than 2 months. The first workshop took place mostly during or after the adjuvant treatment of their loved ones. Two-thirds of their loved ones had a progressive disease after the first workshop and 21 died. Caregivers' quality of life was stable between the first and last attended workshop.

Conclusion

Our study showed that AGAPE helped to maintain caregiver's quality of life despite patient's disease progression and its feasibility. Moreover, AGAPE may easily be run in other hospitals.

Introduction

In most brain tumor patients, evolution of the disease leads to neurological and cognitive decline. Patients need daily assistance and become dependent on caregivers including spouses, partners,

children, relatives and friends. Caregivers are often the primary source of support, such as nursing. If patients display neurocognitive disorders such as memory loss or dyscalculia, caregivers have to conduct administrative procedures. For patients with behavioral disorders, caregivers have to maintain the social relationship [1]. The caregivers have to cope with the uncertain prognosis despite treatments, the risk of neurological sequelae or progressive changes in neurocognitive functions [2–5]. The caregivers often feel untrained and unprepared to face the adjustment to their new responsibilities and neglect their own needs [6, 7], by reducing their leisure, social and working periods [8, 9]. More than two-thirds of caregivers of patients with brain tumors experience significant stress [10–12], 10 to 50% report depressive symptoms [9] that affect their quality of life (QoL) [10–13].

Patients and caregivers had questions that they considered very important but were not satisfied [14]. Several studies focused on the importance of the nature of delivery information to patients and caregivers [6, 15–17], in maintaining hope, methods of coping, and the importance of relationships [18–20]. Some studies have shown that the information requested was sometimes different between patients with brain tumors and their caregivers, in particular about the crucial question of prognosis [21, 22]. Caregivers appreciated the opportunity to ask sensitive questions about prognosis without their loved one present [23]. They also wanted the opportunity to talk to someone who has been through a similar experience, coping with the changes in their social, work, and family life, in order to help with their anxiety or stress [14].

Assessing caregivers' well-being has to take a central place in medical supportive care [9, 24, 25]. Up until now three self-administered questionnaires were developed to evaluate the QoL in the caregivers' population: the Caregiver Quality of Life Index [26], the Caregiver Quality of Life Index-Cancer Scale [5] and CareGiver Oncology Quality of Life (CarGOQoL) [27, 28]. The CarGOQoL questionnaire has been validated in a large cohort (there were 837 caregivers, 50 of them were brain tumors patients' caregivers. There were also 187 dyades (patients and caregivers) in the validation cohort, 65 of them made all the evaluations).

Medical information and more communication with healthcare providers could improve caregivers' QoL [20]. More education about the disease, the potential cognitive effects of treatment and support groups is required [29]. Educational programs for caregivers have always been a positive experience; and several teams reported their experience for reducing stress [30–32]. However, very few of them studied their impact on the quality of life of caregivers [13]. A better quality of life for caregivers could positively impact outcomes of patients with glioblastoma [13] and brain tumor patient's physical health [4, 33]. A recent study has even shown that the more glioblastoma patients' caregivers know about the disease, the less likely the patient is to die [34].

We conducted educational workshops for caregivers of patients with primary brain tumors. The objective is to explain precisely the medical aspects of brain tumors, describe resources available, and allow a moment of exchange between caregivers. We asked the caregivers to complete a quality of life

questionnaire after each workshop and retrospectively studied the impact of our educational workshops on caregivers' quality of life.

Material And Methods

Creation of Educational Workshops called AGAPE ("Atelier Goûter pour les Aidants Proches de Patients ayant une tumeur Encéphalique" **for snack workshop for caregivers of patients with brain tumors**)

We developed educational workshops called AGAPE based on the caregivers' feedback who wanted a place for discussion without any psychologist present. Caregivers had been informed about the aims of AGAPE, as indicated on the flyer, to provide them a place for discussion and exchange with peers, in order to prevent exhaustion, whenever possible.

Handbook for Brain Tumor Patients' Caregivers

A handbook for brain tumor patients' caregivers was written by members of our neuro-oncology unit; including 2 neuro-oncologists, 2 nurses specialized in neuro-oncology and educational workshops, a nurse responsible for the supportive care department, a radiation therapist, a social worker, 2 physiotherapists, a pharmacist, a radiotherapy manipulator and a dietician. The authors reviewed and corrected the handbook as well as the interactive PowerPoint presentation. The advantages and disadvantages of the diverse hospital facilities have also been validated by the doctors in these institutions. The handbook for caregivers was given only to participants of the AGAPE session.

AGAPE Workshops

AGAPE took place in a quiet, soothing space in the supportive care department, outside of the treatment and consultation rooms, where snacks and drinks were provided. A medical oncologist and a nurse specialized in neuro-oncology or the nurse responsible for the supportive care department also took part in the AGAPE session. AGAPE was divided into 3-monthly-workshops. All AGAPE sessions began by a round-table that permitted caregivers to introduce themselves and to express their expectations. During the first theoretical workshop, neurological symptoms as well as therapeutics were discussed. The aims were to better understand the brain tumor disease, its evolution, and to manage potential side effects of treatment. In this workshop, an interactive PowerPoint presentation was used where, for instance, the caregivers had to find all the potential brain tumor's symptoms. The second theoretical workshop was dedicated to information on instrumental human resources available (e.g. wheelchairs, walkers, crutches and psychometrics, nutrition, psychologists, social workers) and hospital facilities (e.g. rehabilitation and follow-up care, palliative care units, home hospitalization, mobile support and rehabilitation teams). The website of our Cancer Center was also shown to caregivers, in particular the neuro-oncology unit homepage, with general information about disease, symptoms, treatment, MRI, human resources, and patient associations (<http://www.centre-eugene-marquis.fr/>). The third workshop was run as a support group open for free discussions. Every caregiver had the opportunity to share his/her difficulties and burdens with professionals and could obtain answers personalized to their specific needs. Caregivers of

the previous session, whose loved one was still alive, were invited to participate in this third workshop. To allow more privacy and time for discussion, the first and second workshops were initially limited to six caregivers.

Evaluation of Feasibility of AGAPE

AGAPE feasibility was evaluated by the caregivers' attendance of the 2 theoretical scheduled sessions and their satisfaction according to a questionnaire filled out after the third workshop attended.

AGAPE Outcomes

Additional outcomes were the percentage of caregivers in favour of AGAPE sustainability.

Evaluation of the Impact of AGAPE on Caregivers' QoL

In order to objectively evaluate the impact of AGAPE, caregivers were asked to complete a Caregiver Oncology Quality of Life (CarGOQoL) questionnaire in the beginning of the first workshop: the baseline and after each workshop. Through 29 items, the CarGOQoL described 10 dimensions of caregivers' QoL: psychological well-being, burden, relationship with healthcare professionals, administration and finances, coping, physical well-being, self-esteem, leisure time, social support, and private life. An index was calculated as the mean of all dimension scores. Each dimension and the index were ranged from 0 to 100, i.e. better QoL corresponding to higher score. We retrospectively analyzed CarGOQoL questionnaire scores for each caregiver during their involvement in the AGAPE workshops. To increase the relevance of our study, we have limited our analysis to CarGOQoL questionnaires between baseline before the first workshop and after the last one attended by caregivers separated by more than two months.

Results

AGAPE workshops

In 2015, oncologists initially proposed AGAPE for recurrent glioblastoma patients' caregivers according to the scoring described in **Annex 1**. Since the most frequent remark of the satisfaction questionnaire was to introduce AGAPE earlier, as of October 2016, the oncologist gave all brain tumors' caregivers the information about the workshops at the initial medical consultation. For each patient, several different caregivers could take part in these educational workshops, but it was initially limited to 6 families. Some caregivers were so eager to take part in AGAPE, that we subsequently agreed, that more caregivers were allowed to attend the first workshop (up to 9 families and 11 caregivers).

In total, between February 2015 and March 2019, 12 three-month sessions were organized allowing the attendance of 87 caregivers from 75 families (Fig. 1).

At the beginning of the first educational session and after each workshop, caregivers had to complete the self-administered CarGOQoL questionnaire (only one per family).

We excluded one caregiver from the analysis as his loved one had brain metastasis. We also excluded 14 caregivers because of the missing data in the CarGOQoL questionnaire due to the fact that some caregivers didn't want to fill it in, others didn't submit the questionnaire after the last workshop, and others never fully completed it, especially the private life section. Only 36 caregivers submitted the baseline questionnaire and at least one other completed and more than 2 months apart CarGoQol questionnaire (Fig. 1).

AGAPE Feasibility

62 out of the 74 families of primary brain tumor patient caregivers (84%) attended the first two theoretical workshops. 1 caregiver didn't take part in the second workshop because of schedule issues (she missed the 2nd workshop scheduled on a Monday from 5 to 7 PM, because of her work, but she attended the 3rd workshop support group several times), one caregiver died before the second workshop, and 11 caregivers didn't attend the 2nd workshop because of their loved one's rapid progressive disease.

The level of AGAPE satisfaction was very high (80%), the most frequent remark was to propose AGAPE earlier, even during adjuvant treatment (not only after the first relapse).

36 Caregivers and Patients Characteristics:

Caregivers were mostly spouses (**Table 1**). Most of caregivers (94.4%) had attended to at least 3 workshops (Fig. 2).

Patients' characteristics are reported in **Table 2**. Two thirds of the patients were male, with a glioblastoma (67%). Most patients were undergoing the first line of treatment or had their first relapse at the time of the first caregivers' workshop (respectively 47.2% and 38.9%). Two-thirds of the patients had a progressive disease after the first workshop and 21 died. The time between the first workshop and the last was up to 4 years.

Additional AGAPE Outcomes

Each caregiver was in favor of AGAPE sustainability.

Impact of AGAPE on QoL Evaluated by CarGOQoL

As indicated in **Table 3**, we compared dimension scores and index obtained after the first workshop to the last workshop that caregivers participated in. Overall, there was no difference in all these scores. Caregivers's CarGOQoL index mean score was 70.0 at baseline before the first workshop and 69.9 for the last workshop they took part in ($p = 0.95$). At baseline and after the last workshop, highest scores were obtained for administration and finances, social support dimensions, self-esteem, and relationship with healthcare professionals. Caregivers reported the lowest scores at the baseline and after the last workshop for leisure time, psychological well-being and private life. There was no statistical decrease in QoL between baseline and the last workshop. Even though these findings are not significant, caregivers

seemed to have a better relationship with healthcare providers and better self-esteem after attending the AGAPE workshops.

Discussion

Information about brain tumors and treatment effects were the first expectations expressed by caregivers at the beginning of the first workshop, as found by Ownsworth and al [35]. Small groups allowed each participant to share his/her own experience of caregiving including difficulties and abilities. AGAPE is a valuable source of information, the caregivers relating easily to a peer who is coping with a similar situation rather than a healthcare provider, as described in the literature [4, 10]. AGAPE was mostly offered to caregivers of patients with glioblastoma, due to rapid neurocognitive decline. AGAPE guide caregivers along several steps of the disease, from the announcement of the diagnosis to palliative care, helping them to accept the changes in the condition of their loved one and their death.

Compared to a similar population of glioma [36], our population had higher scores at baseline in all dimensions and index. Another educational program with 24 caregivers had shown a statistical improvement on knowledge scores testing from baseline to the end of the workshops, but found a decline 4 to 6 weeks after the workshops [30]. Some studies have shown that neurological symptoms at progression [37] and recurrence also have a negative impact on brain tumor patients' QoL [38]. A significant correlation between patients' and caregivers' overall QoL has been shown with similar reductions especially in their emotional and social well-being [10]. Maintain caregivers' QoL is essential, as two thirds of the patients presented neurocognitive decline, physical debilitation or behavioral changes due to disease progression since the baseline. The absence of decline score highlighted one of the positive effects of AGAPE as a resource for caregiver to face the impact of the disease on their loved one.

Caregivers shared that they felt they had become invisible; neither friends nor doctors asked them about their well-being. As caregivers felt valued, AGAPE allowed an increase of self-esteem, coping, and relationship with healthcare providers between the first and the last workshop, but this was not significant. Moreover, confidence increased between caregivers and healthcare providers as a result of the workshops, as caregivers shared their private lives including their personal thoughts and feelings.

Caregivers learned that it was fundamental to take care of themselves in order to take care of their loved one, they reported a stable sense of well-being between the first and the last workshop. Indeed, 2 caregivers from the first workshop (4 years ago), whose loved one was still alive, continue to attend the third workshop. The support group allowed caregivers to feel sometimes overburdened without guilt. The anxiety and worries about the future still predominated, as shown in others teams [21, 22], however caregivers felt that they could express themselves without judgment. The testimony of other caregivers, whose loved one had finished treatment without relapse or responded to bevacizumab after a relapse, maintained some hope of possible stabilization of the disease, even after a possible rapid neurological deterioration. Another team led to the same observation; caregivers appreciated sharing their own experiences with others caregivers [39].

Through AGAPE, we focused on the importance of social support as a crucial endpoint to allow caregivers to take time for themselves without feeling guilty. We insisted on the use of a list of resources to activate, if necessary. In the case of administrative or financial difficulties, caregivers from previous sessions emphasized how our social worker could easily help them in administrative procedures. Social help was appreciated to decrease the perceptual aspect of feeling overwhelmed. Reblin and al. [32] have found an association between greater burden at diagnosis and lower social support. Moreover, lower social support was related to higher depression and anxiety. This underlines the importance of early programs for caregivers in order to ensure low initial levels of burden. Sherwood and al. [9] concluded that researchers might not be able to reduce distress but could focus on preventing an increase of distress over time. Thanks to AGAPE, the caregivers felt that they were not alone in particular with administration difficulties and shared the burden with the support group. The decrease of burden, social isolation, administration and financial dimensions between baseline and last workshop attended was not significant in our study.

Several limitations to our study should be discussed, including the small size of our cohort, due to the low incidence of primary brain tumors and our choice to limit the number of caregivers from different families during the first 2 workshops to 9. As it was a feasibility study, there was no control group, but caregivers were their own control as the score of QoL was compared between baseline and the last workshop attended. Several histologies and stages of disease were included. Initially, we proposed AGAPE only for caregivers of patients with a recurrent glioblastoma, but since caregivers asked us to introduce AGAPE earlier, we then authorized all caregivers whatever stage and histology of brain tumor. Piil and al. [39] have already shown that caregivers wanted interventions to maintain hope after diagnosis, early initiate health promotion activities, strategies for symptoms management and life planning.

Only few studies in neuro-oncology [13, 30, 40, 41] have analyzed the impact of an intervention on the QoL of caregivers of patients with a primary brain tumor. Without any intervention, a significant decline had been found in all dimensions of QoL for patients with a recurrent high grade glioma and their caregivers [13, 42]. An educational program for caregivers found an improvement of knowledge at 4 weeks but scores decreased at 6 weeks, suggesting that information needed to be repeated [30]. In our experience, some caregivers continued to join us for the third workshop, ensuring knowledge and sharing the burden throughout the disease's trajectory from the initial announcement to palliative care. We found the same benefits (e.g. camaraderie, cohesion, motivation etc.) and barriers of support groups, such as logistical factor like transportation as Mallya and al. [43]. A meta-analysis on distress in neuro-oncology caregivers highlighted a feeling of isolation and lack of support from healthcare systems [44]. It is crucial to generalize early caregivers' support to improve psychosocial outcomes [32]. Our educational workshops could easily be developed in other hospitals. Recent studies have demonstrated that caregivers' mastery not only improves their own QoL [42], but increases the overall survival of patients with glioblastoma [34]. These two studies have found that mutual respect, good communication, caregiver mastery, and resilience benefit both patients and caregivers.

Our real-life pilot study shows, in spite of these limitations, that AGAPE workshops have helped maintain caregivers' QoL even though the patients had a progressive disease, which is usually correlated to QoL decline [45].

Conclusion

Caregivers have to modify their everyday life to face new challenges imposed by brain tumors. Integrating them in health care through early educational workshops such as AGAPE is crucial. AGAPE combines 2 theoretical workshops to acknowledge and guide caregivers and a support group to share the burden of their new key role. Our study shows that AGAPE helps maintain caregivers' QoL despite the patient's progressive disease and could be easily developed in other neuro-oncologist teams.

Declarations

Authors' Contributions :

All the authors contributed to the study conception and design. Material preparation, data collection, and analysis were completed by Heloïse Bourien and Elodie Vauléon. The first draft of the manuscript was written by Heloïse Bourien and Elodie Vauléon and all the authors commented on previous versions of the manuscript. All the authors read and approved the final manuscript.

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Compliance with Ethical Standards

Conflict of interest: The authors declare that they have no conflict of interest.

Ethics approval: The study was performed in accordance with the Declaration of Helsinki and was approved by a local Ethics committee of Rennes (IRB-ID: 28.08).

Consent to participate: All participants provided written informed consent prior to study participation.

Consent for publication: Authorization was included in the participation consent.

Availability of data and material : data were collected to comply with the European law of the General Data Protection Regulation (GDPR).

Code availability Not applicable.

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Tables

Due to technical limitations, table 1,2,3 is only available as a download in the Supplemental Files section.

Figures

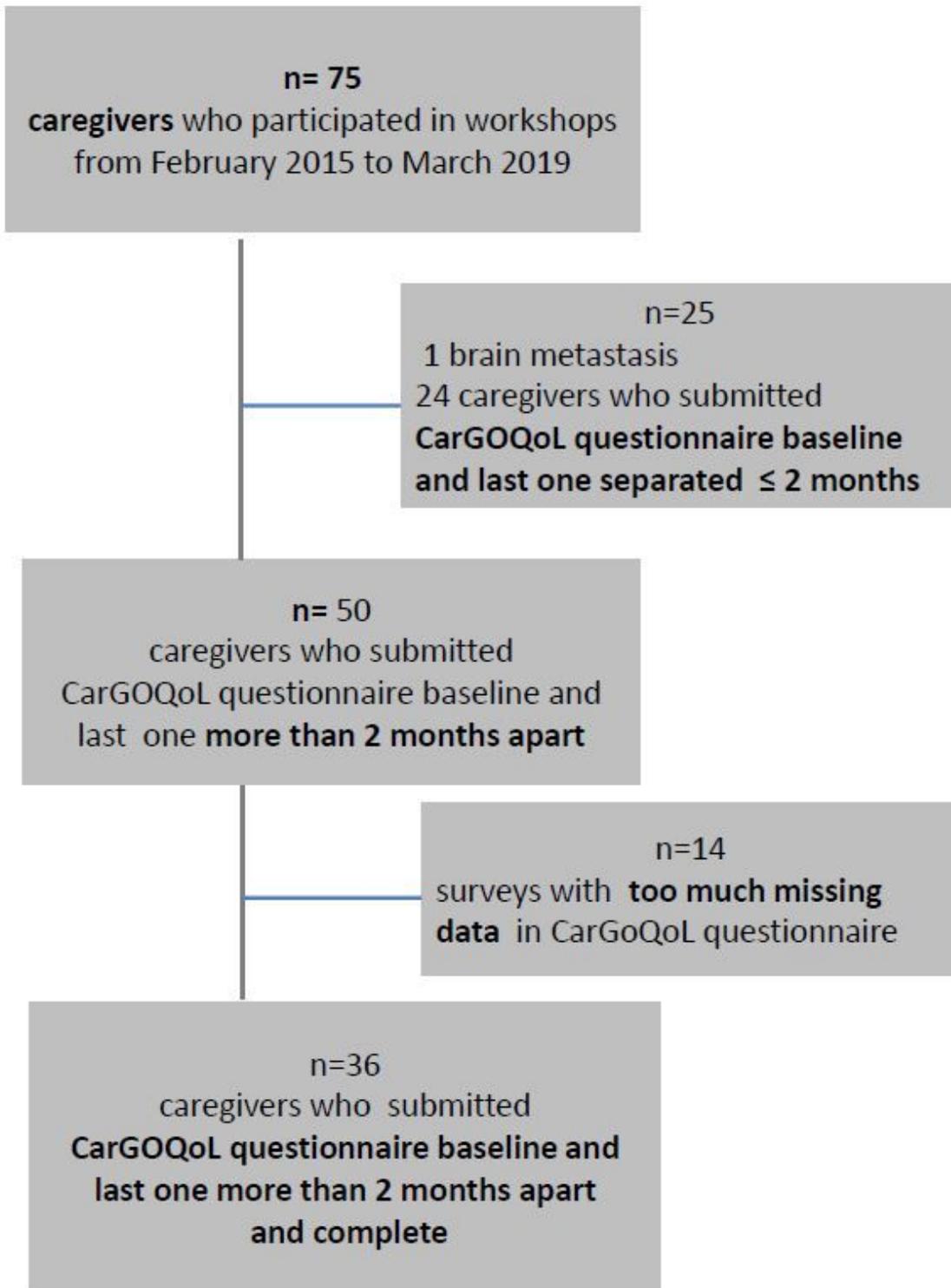


Figure 1

Flowchart

Numbers of workshops attended by caregivers

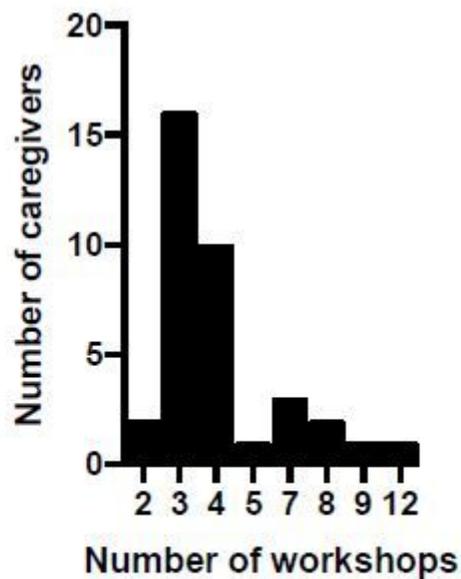


Figure 2

Numbers of workshops attended by caregivers

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