Diagnosis Disclosure Process in Patients With Malignant Brain Tumors

Elsa Magro, MD, Lydie Bergot, Solenn Cuchard, Sylvie Lebreton, MSc, Marie-Bénédicte Coutte, MD, Ghislaine Rolland-Lozachmeur, PhD, Phong Dam Hieu, MD, PhD, and Romuald Seizeur, MD, PhD

Background: The way to disclose a cancer diagnosis has evolved, and psycho-oncology has developed a more prominent place in cancer care. The diagnosis disclosure process was established to improve the overall quality of patient care and the communication about a cancer diagnosis.

Objectives: The aim of this study was to assess the implementation of the disclosure process in a neurosurgical unit.

Methods: This study was conducted prospectively during a one-year period. All patients were diagnosed with malignant brain tumors and received their diagnosis using the disclosure process. The communication between the provider and the patient during diagnosis disclosure was recorded for analysis, and patients completed a satisfaction survey.

Findings: Ninety-one patients with a brain tumor diagnosis participated in the study. Twenty-six were unable to complete the satisfaction survey because they were either deceased or close to the end of their lives. In total, 65 questionnaires were sent to patients and their families, and 43 responded. Patients were satisfied with the quality of the disclosure process regarding information given, psychological support, and communication with all healthcare providers. This assessment allowed the authors to better characterize the impact of the disclosure process on the overall care of patients and to measure the effect of the components of the disclosure process on patient satisfaction.

Modalities for announcing bad news in medicine, particularly in cases of incurable disease, have been evolving (Dolbeault & Brédart, 2010; Institut National du Cancer, 2003; Parker et al., 2001), and the concept of psycho-oncology is now a specialty (Holland, 2003). Baile et al. (2000) proposed a protocol for disclosing unfavorable information to patients with cancer about their illness, and Hoerni (2004) provided recommendations on the modalities for breaking bad news in oncology. De Haes and Koedoot (2005) have analyzed feelings and viewpoints of patients with cancer in palliative care. In their article, the quality of the end of life appeared to be more important than survival time. A qualitative assessment by Schaepe (2011) stressed the importance of the words chosen by the physician to disclose a diagnosis and the influence of these words on the patient’s real-life experiences and ability to face the disease. The ability of patients to cope with a diagnosis is individual and depends on a patient’s psychological profile, environment, and sociocultural background, and all of those elements should be taken into consideration when breaking bad news (Kai, Beavan, & Faull, 2011).

Malignant brain tumors are characterized by short-term survival (Ricard et al., 2012). Glioblastoma multiforme is the most frequent (Rigau et al., 2011; Zouaoui et al., 2012) of primitive brain tumors in adults, and its prognosis remains poor (mean survival of 14 months) despite therapeutic advances (Stupp et al., 2009). Therefore, the manner and process of divulging this diagnosis and average time for survival...
represents a very difficult task for the neurosurgeon (Marcoux, 2012). A prospective study by Marcoux (2012) assessing the modalities of diagnosis disclosure in patients with high-grade brain tumors reported that patients had been well informed regarding diagnosis and treatment. However, information related to prognosis had rarely been given, leaving patients and their families with many unanswered questions. Brain tumors are also characterized by patients having neurologic deficits (Schuhart, Kinzie, & Farace, 2008) or cognitive difficulties (Joly, Rigal, Noal, & Giffard, 2011), which could impair quality of life and autonomy. These factors require careful assessment and specific management. In addition, most patients with brain tumors experience high levels of anxiety (Goebel, Stark, Kaup, von Harscher, & Mehdorn, 2011) and often develop depression (Wellisch, Kaleita, Freeman, Cloughesy, & Goldman, 2002) following diagnosis disclosure.

Disclosure Processes

In France, the disclosure process is integrated within defined cancer plans targeting the management of cancer (Institut National du Cancer, 2003). In 2005, the French Cancer Institute and the French National Cancer League formulated recommendations to implement the disclosure process in hospitals (Institut National du Cancer, 2005). A year-long experiment was conducted in 58 hospitals throughout the country (Institut National du Cancer, 2006; Tivoli et al., 2005) and resulted in the establishment of quality criteria, including more time to carry out consultations, professional psychologists being available to listen to disclosures, explanations with the patient at the right time, and additional consultants before or after the diagnosis disclosure by the doctor to better meet the different needs and expectations of patients (Bettevy, Dufranc, & Hofmann, 2006). The main objective of the disclosure process is to improve the process of announcing a cancer diagnosis by coordinating the involvement of medical and paramedical staff (PujoL, Bruere Dawson, & Tirefort, 2008). In 2007, the Ministry of Health enacted a regulation requiring hospitals to set up a disclosure process for patients with cancer (Légitfrance, 2016). In 2011, the French medical board proposed an obligational basis for disclosure process (Conseil National de l’Ordre des Médecins, 2011), and the second cancer plan includes measures to facilitate access for patients to the disclosure process (Institut National du Cancer, 2013). Setting up a disclosure process is mandatory in all hospitals; however, each hospital is free to organize disclosure processes in its own manner (Institut National du Cancer, 2005). Therefore, the operating mode of a disclosure process may differ from one hospital to another and from one specialty to another.

In the neurosurgical unit of the authors’ university medical center, the disclosure process has been progressively implemented since 2007 by a team composed of nurses, a psychologist, and a social worker who work with all neurosurgeons. Announcement was coordinated by all contributors with a particular time devoted to (a) cancer announcement by the neurosurgeon, (b) reformulation with a disclosure process nurse, and (c) other healthcare providers.

Since 2011, it has been a legal obligation to inform all patients of the existence of the disclosure process in a hospital. In the authors’ hospital department, nurses explain the role of the disclosure process team to patients and identify all members who are available to assist patients and their families.

The aims of this study were (a) to conduct an assessment of the implementation of the disclosure process team as mandated by the French cancer plans in a neurosurgical unit, (b) to characterize the impact of the disclosure process on the overall care of patients, and (c) to describe challenges and elements amenable to change.

Methods

This prospective study occurred during a one-year period from September 2011 to August 2012. All patients managed for malignant brain tumors and receiving their diagnosis by the disclosure process were eligible for the study. The assessment was conducted based on data collection and a patient satisfaction survey.

The ethics commission of the university medical center approved the study, as well as validated the questionnaire and each step of the process used. A verbal consent to participate was obtained for each participant after they received an information letter about the study. Inclusion criteria were participants aged 18 years or older with primary or secondary malignant brain tumors who were receiving management by disclosure process at the time of diagnosis or recurrence in the department of neurosurgery. Exclusion criteria were participants aged younger than 18 years with a nonmalignant brain tumor or other cancer who were being managed by disclosure process prior to the beginning of the study or, for the satisfaction survey only, were deceased.

Data Collection

The data were collected prospectively for all new patients during a one-year period of communication between patients and their healthcare providers in relation to the receipt of the diagnosis. The database included patient information (age, gender, date of diagnosis, date and type of surgery, tumor histology, other treatment), information related to the role of the physician (date and place of the diagnosis disclosure visit, people present, duration and content of the visit), information related to the role of the nurse (number, place and date of the visit, people present, duration and content of the visit, orientation toward other healthcare providers), social workers, psychologists, and healthcare providers not assigned to the disclosure process (dietitians, physiotherapists, speech therapists), connection with the oncology network, link to the oncology department’s disclosure process, and links to disclosure processes at other hospitals.

Satisfaction Survey

The satisfaction survey was based on a questionnaire completed by patients about the key elements of receiving a diagnosis. When patients were not able to complete the questionnaire, the family member who was present when the patient received the diagnosis completed the form. The questionnaire was sent to patients and their families within one month after the receiving the diagnosis.

The questionnaire was developed in collaboration with neurosurgeons, disclosure process nurses, and a disclosure process psychologist. It was composed of three parts: the
medical disclosure, the nurse disclosure, and satisfaction. The first part concerned the medical disclosure and was comprised of five yes-or-no questions on information given about the diagnosis, the disease and its side effects, treatments and their side effects, and the clarity of terms used. The second part concerned the nurse disclosure and was comprised of five yes-or-no questions on information given about the diagnosis, the disease and its side effects, treatments and their side effects, and location where the diagnosis disclosure takes place. It also had two multiple-choice responses and three open-ended questions. The third part concerned satisfaction after the diagnosis disclosure, with questions about the role of the disclosure process at this time. Open- and closed-ended questions were used, but only the correct answers are included in the current article. The questionnaire was given in French. Responses to the questionnaire were analyzed, and descriptive statistics were performed using Access software, version 2007.

Results

Sample

From September 2011 to August 2012, 148 patients were diagnosed with malignant brain tumors in the neurosurgical department of a university hospital. Of this sample, 91 patients were eligible for the diagnosis disclosure process. Fifty-six participants were men, and 35 were women. The mean age was 59 years (range = 29–85). Forty-six patients underwent complete removal of the tumor, 19 underwent partial removal, and 26 underwent biopsy. Surgery was performed for tumor recurrence in seven patients. Sixty-seven patients were undergoing adjuvant therapies (e.g., chemotherapy, radiotherapy).

Medical Disclosure Visit

The disclosure visit with the neurosurgeon took place, on average, 11 days (range = 7–14) after surgery. In all but five cases, family members were with the patient during the disclosure visit with the neurosurgeon.

Nurse Disclosure Visit

The disclosure visit with disclosure process nurses took place, on average, 12 days (range = 7–15) after surgery in the hospital. The visits occurred on the same day as the neurosurgeon’s visit for 82 patients and within 48 hours for the other 9 patients. In all but nine cases, family members accompanied the patient during the nurse disclosure visit. At this visit, patients were referred to disclosure process psychologists (n = 32), social workers (n = 29), physiotherapists (n = 5), speech therapists (n = 4), and dietitians (n = 2). Among the 91 patients, 46 patients were managed in the authors’ hospital within the oncology department after the initial management in the neurosurgical department. Forty-five patients were managed in the neurosurgical department, and then transferred to other hospitals closer to the patients’ homes for oncology treatment. A psychologist or a social worker within the disclosure process network monitored 26 patients. Patients had the opportunity to establish contact with oncology networks in 25 cases and with communities of patients with cancer in 4 cases.

Satisfaction Survey Results

Among the 91 patients included in this sample, 26 did not participate in the satisfaction survey because they were either deceased or close to the end of their lives. A total of 65 questionnaires were sent to patients, and 43 completed surveys for a response rate of 66%. Questionnaires were filled out by the patient independently in 21 cases, by the patient and family together in 5 cases, and by the family in 17 cases.

The consultation with the neurosurgeon provided patients with information regarding diagnosis and disease (n = 37), as well as potential treatments and their side effects (n = 35). In 35 cases, patients indicated that the time spent with the neurosurgeon was adequate. The visit was considered too short in one case. In 18 cases, patients would have preferred to have written information in addition to the verbal information at the end of the consultation. Nineteen participants did not feel they needed written information, and six did not respond.

Initial information regarding the existence of the disclosure process was given by the neurosurgeon in 23 cases, by a neurosurgical nurse in 12 cases, by the head nurse in 2 cases, and by the disclosure process nurse in 2 cases. The visit was considered as having been scheduled at the right moment in 31 cases and too early in 8 cases; in these cases, the visits took place an average of 12 days after surgery. Patients met with the disclosure process nurse in the neurosurgery department prior to the operation in 15 cases and after the operation in 8 cases. Patients met with the neurosurgeon before the neurosurgical visit in 14 cases and after the neurosurgical visit in 2 cases. After being informed of the existence of the disclosure process visit, patients felt reassured in 19 cases, surprised in 14 cases, and anxious in 6 cases. Among the 23 patients who had met with the disclosure process nurse prior to the neurosurgical visit, 15 felt reassured and 8 felt surprised. The location of the visit with the disclosure process nurse was adequate in 41 cases.

Discussion

In many countries, the management of patients with cancer represents a major issue in terms of public health. In Europe, improving the quality of life, particularly by providing psychological aid, is one of the main goals of caregivers within the European Society for Psycho-Oncology (Keller, Weis, Schumacher, & Griessmeier, 2003). In Italy and the United Kingdom, concerns relating to cancer diagnosis disclosure have been stressed (Locatelli et al., 2010; Loge, Kaasa, & Hytten, 1997). In France, the Ministry of Health formulated regulations in 2007 to create disclosure processes in hospitals where oncology care is given (Institut National du Cancer, 2003, 2013). The second cancer plan made the management of patients with cancer by disclosure process mandatory (Institut National du Cancer, 2013; Légifrance, 2016). The disclosure process serves a paramount role in terms of psychological support to patients (Conseil National de l’Ordre des Médecins, 2011). In the United States, the American Cancer Society is developing a health policy aiming to improve the management of patients with cancer (Blum & Sherman, 2010; Holland, 2003).
Modalities for breaking bad news and supporting patients and their families are in constant evolution. In 2008, Dolbeault and Holland (2008) published a retrospective study reporting the 25-year evolution of psycho-oncology in New York, New York. They reported the high prevalence of psychopathological disorders in patients with cancer and stressed the necessity for adapted psycho-oncology management. Burden and depression among caregivers and family have also been studied, and support of these people represents a concern (Given et al., 2004). Specific methods for disclosing diagnosis of intractable disease have been proposed by Harvey-Knowles and Kosenko (2012). In non-Western countries, management of patients with cancer is also evolving. In Iran, the experiences of cancer disclosure by patients, their families, and physicians were studied by Zamanzadeh et al. (2013). A majority of the patients reported they had been poorly informed, and the authors of the study stressed the necessity to improve this initial step of disease management (Valizadeh et al., 2012). In China, a study regarding the attitude of health professionals toward diagnosis disclosure in patients with cancer concluded that healthcare professionals should learn more about informed consent and that special guidelines and methods compatible with Chinese cultures should be developed (Tieying, Haishan, Meizhen, Yan, & Pengqian, 2011).

The onset of brain tumors may cause tremendous upset for patients and their families. Therefore, diagnosis disclosure is a therapeutic act with direct repercussions on the patient’s psychological state and quality of life (Dolbeault & Brédart, 2010). The current study enrolled 91 patients during a one-year period, which is more than half of the total number of patients (N = 150) diagnosed annually with brain tumors in the authors’ department. The authors include measures facilitating access for patients to a disclosure process, as recommended by the cancer plan in France (Institut National du Cancer, 2013).

In the current study, despite information given to the patients regarding the advantages of being accompanied by family at the time of the disclosure visit, the results showed that some patients still chose to go alone to the medical disclosure visit and disclosure process nurse visit. Healthcare providers should respect the patients’ desire to be alone when bad news is broken. However, when possible, the presence of family or caregivers at the disclosure visit should be strongly encouraged. In neuro-oncology, the role of the patient’s family and caregivers is important (Schubart et al., 2008).

All the patients who had low-grade gliomas and sent back the questionnaire had responded alone. In contrast, among the 51 patients diagnosed with glioblastoma multiforme, 42 patients received the questionnaire, and 27 patients completed and returned the questionnaire, but only 12 patients were able to answer the questions themselves. A large proportion of those with high-grade tumors required help from others, which was not surprising. This further highlights that, with this population, healthcare providers in oncology are dealing with not only the patient, but also a network of family and caregivers.

The development of the satisfaction questionnaire was complex because of the immediate negative repercussions of glioblastoma on quality of life and the rapidly fatal evolution. Weitznner and Meyers (1997) reviewed the cognitive functioning and quality of life in patients with malignant gliomas and provided recommendations for the appropriate assessment of these patients. Lobb, Halkett, and Nowak (2011) identified the difficulty of patient recall when discussing prognosis soon after major surgery for high-grade gliomas.

For the majority of patients in this study, patients reported that the information given by the neurosurgeon was adequate and sufficient. This positive result is encouraging; however, room for improvement exists concerning the modalities of diagnosis disclosure, which should be considered to be a therapeutic act (Hoerni, 2004; Parker et al., 2001; Schaepe, 2011).

The current study showed that anxiety reported by patients after the visit with the disclosure process nurse decreased when patients had previous contact with the nurse before diagnosis disclosure. These results stress the positive impact of early and patient-tailored psychological support coordinated by disclosure process nurses and psychologists before the neurosurgeon discloses the diagnosis. These visits allow the disclosure process nurses to meet with patients and their families, anticipate their concerns and needs regarding quality of life, and facilitate the intervention of other caregivers after the disclosure. This particular time period, when the patient is still unaware of the diagnosis, allows the disclosure process nurses to prepare the patient for the moment of diagnosis disclosure. Two studies have focused on the distress of patients with newly diagnosed brain tumors (Goebel et al., 2011; Wellisch et al., 2002). Goebel et al. (2011) documented high levels of distress among newly diagnosed patients with brain tumors and concluded that sources of distress should be assessed in these patients during the period after disclosure. Wellisch et al. (2002) conducted a descriptive study to identify determinants of major depression in patients with brain tumors and reported a higher incidence of major depression in this population.

The results of the current study demonstrate that most patients were satisfied with additional information related to disease and treatment given by the disclosure process nurse. The interview with the disclosure process nurses prepared the patient for the diagnosis disclosure, and it provided psychological support and additional information regarding therapeutic management and practical modalities.

Receiving bad news in neuro-oncology may provoke such a tremendous emotional shock that the patient and family are unable to process all of the information given at the first visit (Pujol et al., 2008; Schaepe, 2011; Wellisch et al., 2002). To

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<th>Implications for Practice</th>
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<td>- Provide early and patient-tailored psychological support coordinated by disclosure process nurses before physician disclosure of the diagnosis.</td>
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<td>- Anticipate the needs and concerns of patients and their families regarding quality of life with a disclosure visit, and use that information to facilitate the intervention of other healthcare providers.</td>
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<td>- Use the time when the patient is unaware of the diagnosis to prepare the patient for the difficult moment of diagnosis disclosure.</td>
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address the individual patient and family issues more precisely, a second interview should be systematically conducted within a few days of initial diagnosis disclosure.

Inpatients within the authors' neurosurgical department come from a population base covering a wide geographic area. Only one-half of patients are managed in the oncology unit of the hospital. The other half are managed in local hospitals 50–150 kilometers from the unit. One of the tasks of the disclosure process is to ensure a close follow-up of the patient in collaboration with other healthcare providers, particularly when they receive care at distant hospitals. Despite the distance, most patients were satisfied with the quality of communication and the collaboration between the different teams. How a patient is transferred from one hospital to another is crucial to the quality of care and, consequently, their survival (De Haes & Koedoot, 2003). Mattarozzi et al. (2012) showed that diagnosis disclosure of a severe neurologic disease (multiple sclerosis) presented by a disclosure process team had a positive effect on quality of life.

Conclusion

For a patient receiving the diagnosis of a malignant brain tumor, the neurosurgeon is at the forefront before care is transferred to oncologists, oncology nurses, and radiotherapists. Therefore, setting up a disclosure process in each neurosurgical unit is strongly recommended. Disclosure process nurses should be involved before and after the disclosure of the diagnosis. Although the current prospective study showed encouraging results, new measures are needed to facilitate access for patients to disclosure process teams. In addition, the team can plan for the disclosure process for patient before the diagnosis disclosure and propose a second visit with the disclosure process nurse within a few days of initial diagnosis disclosure to discuss adjustment, identify problems, and review treatment planning.

References


Mattarozzi et al. (2012) showed that diagnosis disclosure of a severe neurologic disease (multiple sclerosis) presented by a disclosure process team had a positive effect on quality of life.


Schaepe, K.S. (2011). Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis. Social Science and Medicine, 73, 912-921. doi:10.1016/j.socscimed.2011.06.038


