

**Fanny SOUM-POUYALET et Annie HUBERT
et Guy Kantor**

(2010)

“Quality as Viewed and Lived by the Patient.”

Un document produit en version numérique par Jean-Marie Tremblay, bénévole,
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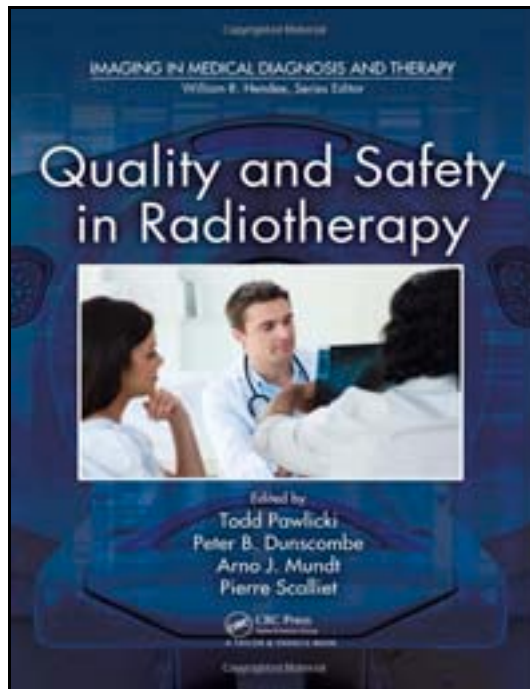
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Introduction

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Analyzing quality, as viewed and lived by a patient undergoing radiotherapy, leads us to consider the main points of sociopsychological quality theories. The concept of quality of life (QOL) is currently used in oncology. However, no systematic overviews or guidelines issued for QOL assessment have been produced yet, even on the international level (Shimozuma et al. 2002). A consensus on QOL has been settled, and this relates QOL to symptoms, functioning, psychosocial and social wellbeing, and even to fulfillment. Thus, the concept has undertaken a multidimensional meaning and has been renamed healthrelated quality of life (HRQOL) (Kaasa and Loge 2003). These new dimensions of the concept of quality lead to linking the very intimate experience of the patient undergoing radiotherapy to the quality of cure and care. It also underlines the close link existing between the following three concepts : quality, satisfaction, and well-being. These are the three keywords around which the question of quality as viewed and lived by patients must be considered. Nevertheless, these criteria have not been taken into account enough in the field of radiotherapy. Many attempts have already been made toward the systematization of toxicity ; however, they were mainly focused on physical and func-

tional criteria rather than on multidimensional ones (Ciabattoni et al. 1997). Perception of quality and patients' satisfaction are closely connected.

Patients' Perceptions of the Environment of Radiotherapy

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Ergonomic and environmental factors of radiotherapy treatments obviously affect patients' perception of quality. It has been underlined that times, spaces, and care coordination have great impact on patients undergoing radiotherapy (Hoarau, Kantor, and Dilhuydy 2000). Some papers point out the importance of waiting times and the variability of local demand of patients, referring to the schedule of treatments (Calman et al. 2008). Other papers stress the impact of the physical environment, which can significantly influence one's sense of well-being (Jarvis 2003). Radiotherapy treatments can cause individual discomfort due to a lack of confidentiality or a lack of privacy, for example, in the waiting areas. Difficulty can occur in sharing private information with the medical team. Several studies underline the importance of the entire hospital organization, and especially the treatment session itself, as the waiting times and the interaction with fellow patients are often considered potentially stressful (Dilhuydy et al. 2002).

As a consequence, considering radiotherapy as an ambulatory treatment neglects the impact of its context on patients' experience, although quality of cure and care are strongly linked to QOL. In fact, several studies demonstrate that the patients' perception of the burden of treatment contributes to coping less well with the radiotherapy treatment itself and could explain the long duration of side effects, such as fatigue, even after the end of treatments (Smets et al. 1998). The subjective dimension of coping with radiotherapy needs to be seriously considered.

Actually, initiatives that stress the improvement of patients' well-being during radiotherapy have demonstrable effects on their experience and evaluation of quality as in, for example, the role of support-

ive care. In radiotherapy, supportive care can integrate the key aspects of diagnosis and treatment and alleviate physical and psychosocial comorbidities inherent to the disease as well as to the treatment (Perez Romasanta and Calvo Manuela 2005).

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Even minor improvements of patients' experience during radiotherapy can have a great effect on their perception of quality. For example, socio-aesthetic care, cosmetology, and relaxation therapy have demonstrated their genuine impact on patients' mood and states of well-being (Jereczek-Fossa, Marsiglia, and Orecchia 2002 ; Titeca et al. 2007), and especially on patients' self-perception of the disease and treatments.

Patients Coping with the Complexity of Radiotherapy

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Radiotherapy has undergone major evolutions during the past three decades. Advanced technology and the necessary multidisciplinary composition of its medical teams set it apart. Modes of treatment are complex and require various medical skills (Hogle 2006 ; Perez Romasanta and Calvo Manuela 2005). This situation makes the patient feel lost and powerless while undergoing treatment. Studies of patients' perceptions of radiotherapy reported that many patients feel alienated by the techniques (Hoarau and Kantor 2000) and could not handle radiotherapy without being stressed or depressed and needed to be helped by one or various members of the clinical team.

Studies of nursing in radiotherapy also pointed out the necessity of guiding patients during the entire process (Carper and Haas 2006). As a matter of fact, recognition of each patient's individual needs is necessary to deal with the treatment and to cope with the disease. Obviously, patients would rather feel like the most important actor of the therapeutic relation than like a medical object (Soum-Pouyalet et al. 2005).

The Importance of the Medical Team Role and the Impact of Communication

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Several studies emphasize the importance of the entire medical team's (physicians, therapists, and other professionals) understanding in helping patients cope with radiotherapy treatments (Gamble 1998). Moreover, the lack of care delivered in some radiotherapy departments has been pointed out (Long 2001). Follow-up during radiotherapy and after completion of treatment appears essential. These deficits are essentially due to the lack of communication and information related to the objectives of the radiotherapy treatment or to the inappropriate attitude of the medical team in meeting the needs of patients. Failure of coordination within the radiotherapy department can also explain why patients may receive confused or contradictory messages, especially about side effects or the care received (Dilhuydy et al. 2002). It appears that, according to the medical referents, improvements are needed to provide the right information to patients (Sandoval et al. 2006). For example, a study about radiotherapy-induced nausea concludes on the high percentage of patients who would have liked to receive more information about this specific side effect (Enblom et al. 2009). This example also stresses the importance of identifying and adequately treating side effects related to radiotherapy. Also, the patients' perception of quality is strongly related to the information given and the means of communication (Hogle 2006).

Quality Related to Information in Radiotherapy

According to the actions of collective patient associations and the evolution of the national laws concerning the rights of cancer patients, the public demand for and interest in information about radiotherapy has increased. Therefore, the necessity of providing patients with adequate information has become more and more difficult for the medical teams (Sch.fer et al. 2005). Many studies are devoted to the issue of informing patients about their illness and treatment. For example, a

pilot study examined patients' understanding of their illnesses and their expectations from palliative radiotherapy. It has been shown that a significant proportion of the patients have misconceptions regarding their illness and unrealistic expectations for their treatment (Chow et al. 2001). Inadequate information can also cause anxiety for the patient and might lead to legal action against the physician (Schfer et al. 2005). The link between anxiety, side effects, and information resources is obvious.

Patient information about radiotherapy has many ethical implications that must also be considered. The most important ethical principles of patient information are truth, autonomy, informed consent, and hope (Schafer and Herbst 2003). For each of these, a detailed discussion of various typical situations while undergoing radiotherapy (such as adjuvant therapy or palliative treatment) is desirable. Besides patient information, expectations seem to be the most important in the biophysiological, functional, and social fields (Siekkinen et al. 2008). The necessity of informing patients of the possible side effects of their radiotherapy treatments has already been underlined (Chow et al. 2001).

Many studies mention the specific question of delivering information to patients. Some regional variations on the topic have also been studied. The question of information requires an entire development in itself. Information expectations may vary from time to time during the duration of the treatments (Siekkinen et al. 2008). Therefore, it is very difficult to point out the true information needed for particular and singular maturation of patient status (Hoarau and Kantor 2000).

Although the types of information provided to patients appeared to fit their needs, health professionals and patients placed different levels of importance on information. The priority given to specific information may not be optimal from the perspectives of patients, as can also be the case for a wide range of information deliveries (Halkett, Short, and Kristjanson 2009).

The Impact of Information Materials

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Educational booklets (Dilhuydy et al. 2003 ; SFRO 2000) and educational strategy concerning information appear to be a [9] strong necessity. Improvements are needed in counseling and education of patients and their relatives, especially concerning the different sequences of radiotherapy and the follow-up care required after completing the treatment (Sandoval et al. 2006).

In fact, educational bases are highly regarded by a large majority of patients, especially when they are based on patients' experiences (Bonnet et al. 2000 ; Dilhuydy et al. 2002 ; Hoarau and Kantor 2000). The practical and technical knowledge provided by booklets and other patient information materials give reassurance about treatments and the medical teams (Fervers et al. 2003). Satisfaction with information materials in general leads patients to consider them as real necessities (Bonnet et al. 2000 ; Dunn et al. 2004). At this point, forums and medical information on the internet do not seem to substitute for the traditional information modes, even if they have great impacts on the therapeutic relationship between patients and physicians (Siekkinen et al. 2008).

However, educational materials that have excellent face validity and that are well received by patients may fail to fit the information expectations of the patient regarding his or her specific needs (Dunn et al. 2004). Information is best accompanied by professional caregivers (especially physicians) (Hubert et al. 1997). As a matter of fact, oral and direct communication remains the preferred mode of information delivery (Bonnet et al. 2000).

Summary

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The whole context of radiotherapy has a deep impact on the quality perceived and experienced by patients. The high technical specificity and complexity of radiotherapy contribute to make the patient feel powerless during treatments. On top of that, the coordination between the different members of the medical team may not be well identified by the patient and that could contribute to making that person feeling lost. In spite of the progress made in the field of patient education and information, the singular relationship between patient and physician for the quality of communication in the different therapeutic steps is still considered a conclusive factor in the satisfaction and wellbeing of the patient. The very specific needs and expectations of each patient during the different periods of treatment and the great variability of each radiotherapy department should lead to develop a sharper view of each and every context to improve the quality perceived and experienced by a patient undergoing radiotherapy. From this perspective, the particular approaches of the social sciences could provide a useful contribution (Soum-Pouyalet, Hubert, and Dilhuydy 2008).

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