The drowned and the saved

Raphaël Brenner

In recounting their personal stories, cancer patients are not only sharing their experiences and feelings – they are providing practical support to others and are gradually influencing the way cancer is perceived and treated.

IN August 2002 Ivan Noble’s life was turned upside down. While working as a science journalist for BBC News online in London, 35-year-old Noble was diagnosed with a malignant brain tumour. The “strong urge to fight back” against the powerlessness of his condition inspired Noble to chronicle his struggle against the disease in a diary, which he courageously decided to share with readers of BBC News. Noble’s blog (short for weblog), in which he combined his knowledge as a science journalist with his personal story, became an instant hit and triggered thousands of e-mails from readers. It has now been published as a book together with a selection of the e-mails he received.

Noble’s narrative is a straightforward chronicle of how a rational, atheistic journalist courageously fought cancer, while continuing to work and pursue family life with his baby daughter, and of how he finally succumbed. “Dealing with cancer became my job,” writes Noble. The journalist in him did not prevent Noble from expressing his pain – as he swayed between hope and despair, remission and relapse, life and death.

One cannot but feel sympathy when reading about the clumsy manner in which he was told of his illness. “A few more encouraging words would have made that first week so much less painful,” writes Noble as he recalls how his oncologist announced the bad news. He suggests that oncologists spend more time with patients, explaining to them what is actually taking place in terms of the illness and what may happen next, and he wishes they would have the courage to look patients in the eye, rather than looking at their own feet. He reminds us that “it is easy for doctors to lose sight of what it is like to be a patient.”

As is evident from the e-mails received by Noble, cancer patients found his diary inspiring and supportive. Noble’s blog hit a chord. It expressed the unvoiced feelings of the silent mass of cancer patients and exposed their need to share their experiences, talk freely and be comforted by others.

All profits from Like a Hole in the Head go to Médecins Sans Frontières.

Stéphanie Honoré and Carolyn M. Kaelin, both mothers of two children, were 32 and 42 respectively when they were diagnosed with breast cancer. They survived and their books belong to the testimonial-cum-guide genre that offers practical tips and advice to women diagnosed with cancer. Honoré wrote her book in order to enable women to understand and...
express their feelings as cancer victims, as well as to familiarise them with the coded jargon of the medical profession. In concise, easy-to-read chapters, she explains the different stages of treatment and provides a wealth of explanations and useful advice on all aspects of the disease, from how to announce the bad news to one’s family and talk about death with one’s children, to the intricacies of breast cancer imaging and modern forms of treatment, including psychological therapies and alternative medicine.

What makes her book noteworthy is its personal touch: Honoré brings an inner dimension to whatever she discusses, whether it is man/woman’s survival instinct, the brutality of hospitals, the negative way in which the medical establishment deals with cancer patients or reconstructive surgery. At the end of each chapter, we are given boxes called ‘antidotes’ with advice on how to survive in the hostile environment of hospitals. “Oncologists use many protocols and guidelines,” she writes, “it is now time for patients to write guidelines for use by doctors.”

Like Honoré, Kaelin – one of America’s top female breast health specialists – aims to demythologise breast cancer by explaining every step of the disease in plain English. As director of the Comprehensive Breast Center at Brigham and Women’s Hospital, Boston, Massachusetts, and surgical oncologist with the Dana Farber Cancer Institute, also in Boston, Kaelin is superlatively qualified to provide a scientific guide for women undergoing breast cancer treatment.

Her book, replete with illustrations, offers more in-depth information on breast cancer, particularly on the side-effects of chemotherapy, sexuality, surgery, reconstructive surgery and the need to obtain a second opinion. She also covers sensitive issues relating to women’s body image, which are rarely discussed, such as breast forms, ways of dealing with loss of hair, eyebrows, pubic hair and teeth, skin care, exercise and nutrition. On the negative side, she levels no criticism whatsoever at her own profession, and could have dealt more thoroughly with the needs of survivors following completion of treatment – an element also lacking in Honoré.

Certain topics will interest only US readers, nonetheless this highly comprehensive book makes an important contribution to breast cancer literature. The daughter of a breast cancer victim and a professor of English, Marcy Jane Knopf-Newman has produced an excellent book (much better written than the above two) on the history of breast cancer, in which she reveals “the deep impact that narratives can have on a person’s experience and, in turn the significant effect literature can have on political and public culture.”

Knopf-Newman argues that the way breast cancer is perceived and treated, at least in the US, has been shaped by the narratives and public disclosures of a few key people such as biologist Rachel Carson’s book Silent Spring, and her testimony at a Senate hearing in the 1960s on the influence of the environment on cancer. At around the same time, surgeon George Crile published a book challenging the widespread use of Halsted’s radical mastectomy. In 1974 Betty Ford became one of the first major figures to publicly disclose that she suffered from breast cancer. She was followed by activist Rose Kushner, whose watershed book “led to new relationships and better communication between doctors and patients.” Kushner’s book helped empower women to make their own decisions about their bodies, and request the specialists and forms of surgery they desired. In her congressional testimony, Kushner also noted the economic incentives that discouraged surgeons from offering women alternative choices to the Halsted mastectomy.

Finally, in the ’80s and ’90s, poet activist Andre Lorde wrote a book which questioned the dominant medical practices in breast cancer treatment, galvanised women to take a more active role in their healthcare and helped widen the range of choices available to women – particularly black, lesbian and disadvantaged women. Lorde’s influence is clearly felt in Dr. Susan Love’s Breast Book, the number one bestseller on breast cancer in the US.

Although Knopf-Newman’s book is written from a US perspective, it has much that is relevant to European patients. In Europe too, breast cancer patients have had to fight not only their illness but also the medical establishment. To what extent patient narratives will influence public policy and medical practice remains to be determined, but if the US is anything to go by, patient activism is a force to be reckoned with.
Written by an associate clinical professor of medicine at the American University of Beirut Medical Center, this is the first book of its kind in Arabic. Addressing itself to the lay public, it presents in simple terms the main medical information pertaining to the health and diseases of the breast and provides answers to questions that can cross the minds of women as well as a list of relevant Arab, European and US websites. Saghir’s book offers much useful information, support and guidance for women with breast cancer, and discusses the problems resulting from surgery, radiotherapy and chemotherapy. The book is lavishly illustrated in four-colour printing, and each indication is accompanied by a list of the most recent references. For French-speaking (radio) oncologists, this is the ultimate reference book on medical imaging of prostate cancer.

Cornud’s book depicts the prostate pathologies (including normal prostate and benign prostate hypertrophy) as they appear in all the imaging techniques currently available: microscopy, ultrasonography, MR imaging, MR lymphography, lymphoscintigraphy, PET-CT, spectroscopic imaging, etc. It also discusses the indications of these techniques for each stage of a malignant evolution (for diagnostics and therapeutics), and analyses the role of imaging in radiotherapy of localised prostate cancers. The book is lavishly illustrated in four-colour printing, and each indication is accompanied by a list of the most recent references. For French-speaking (radio) oncologists, this is the ultimate reference book on medical imaging of prostate cancer.

The popularity of complementary and alternative medicine (CAM) in the western world continues to grow, especially among cancer patients. In Europe, 30% of patients on average use at least one type of CAM, while in Germany and Switzerland the figure is over 50%. Despite the fact that most physicians do not approve of CAM as a whole, the practice has become a reality. Hence the pragmatism of Unger and Weis – both professors of oncology in Freiburg, Germany – and their goal to acquaint physicians and other professionals involved with cancer with the fundamental principles of non-conventional therapies. Such knowledge, it is hoped, will help to ensure professional control over non-conventional methods, protect patients from charlatan practitioners and prevent detrimental interactions of plants with chemotherapy or radiotherapy. The book is thoroughly comprehensive: the authors analyse the most popular CAM methods, explaining their indications, pharmacology and side-effects, and discuss the available
scientific data, with a wealth of references. The first part of the book deals with the various therapies – sport and physical activity, diets (fruits and vegetables), psycho-oncology, and anti-tumour immune response (IL-2, TNF-\(\alpha\), etc.), while the second part is devoted to non-conventional drugs. Mistletoe (widely used in Germany), anti-oxidants, melatonin, enzymes, thymic hormones, Boswellic acids (against brain tumours) and aloe vera are some of the main remedies reviewed in the book. The authors note that these products cannot be recommended according to the rules of evidence-based medicine, and they call for more prospective studies, but they also note that they are not harmful and can often improve a patient’s quality of life.

German-speaking readers interested in psycho-oncology will find a good overview of this discipline in the textbook edited by Hermann Faller. According to Faller, psychological therapy is highly effective for cancer patients, as it strengthens their ability to cope with the illness, gives them hope, and facilitates communication with their oncologist. Although cancer causes great psychological stress and suffering in patients and their families (including depression, anxiety and somatoform symptoms), psychological therapies regrettably remain underused.

**Textbook of Neuro-oncology**
Edited by Mitchel S. Berger and Michael D. Prados
Elsevier Saunders, 876 pp, £134.00

**Principles of Neuro-oncology**
Edited by David Schiff and Brian Patrick O’Neill
McGraw-Hill, 768 pp, £95.00

**Minimally invasive Neurosurgery**
Edited by Marc R. Proctor and Peter M. Black
Humana Press, 448 pp, £103.00

Despite the impressive advances in molecular biology and brain imaging, these methods are “still short of achieving major improvements in patient care and survival”, acknowledges Nicholas Vick in *Principles of Neuro-oncology*. This is why brain tumours remain “the most dreadful form of cancer”. The two textbooks by Berger/Prados and Schiff/O’Neill provide an encompassing study of neuro-oncology, catering to all those who wish to understand more about brain tumours, from neuro-radiologists to students. They successfully decipher the complex issues behind brain tumourigenesis and enhance the reader’s intellectual curiosity. Both books cover first the scientific underpinnings and principles of diagnosis and treatment, before addressing specific tumours. However, Berger/Prados is more beautifully produced, in four-colour printing, and benefits from a clearer layout and a richer iconography than Schiff/O’Neill. The content is also richer, containing a more detailed discussion of rare diseases such as glioblastoma multiforme and Lhermitte-Duclos, and is presented in a more coherent manner. This is especially true of the section devoted to paediatric neuro-oncology.

For their part, Schiff/O’Neill provide useful summaries at the beginning of the chapters and include an interesting chapter on the neurological complications of radiotherapy and chemotherapy. Both books deal at length with cerebral metastases, a subject under-represented in other textbooks even though metastases are the most common form of brain tumour in adults.

The advances in imaging of the central nervous system (CT, MRI) have been crucial to the development of minimally invasive neurosurgery (MIS), which means surgery through small openings or surgery that is minimally disruptive to the patient. In part I of *Minimally Invasive Neurosurgery*, clinical neurosurgeons and neuroradiology experts review cutting-edge techniques and technologies. They offer a comprehensive survey of neurosurgical endoscopic equipment, one of the mainstays of MIS, as well as of gene-based and viral-based therapies. Part II is devoted to the application of MIS in the different fields of neurosurgery, including brain tumours. This is a fast-moving field. Where image-guided neurosurgery dominated the advances of the last decade, laser hypothermia and focused ultrasound may radically change our ability to treat specific tumours in the future. A highly recommended book for clinical neuroscientists interested in MIS.