

Providing Information to our Patients: Published and Personal Perspectives

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In this issue of the *Canadian Journal of Neurological Sciences*, Bramall and Bernstein present qualitative research that explores how neurosurgical patients obtain medical information and how treating physicians might take steps to improve how that information is provided¹. Although the article specifically studies neurosurgical patients who have undergone craniotomy for brain tumour, it draws attention to issues that might pertain to information provision in regards to any type of neurological disorder. The authors conducted semi-structured, qualitative face to face interviews in 31 patients who had undergone craniotomy for resection of a brain tumour (either benign or malignant). They were able to obtain themes that were categorized into two groups: 1) ways in which patients seek information, and 2) ways in which physicians might improve information provision to patients. The study uses validated methods in the field of qualitative medical research. However, there are a number of limitations to the study, many of which the authors allude to themselves. These include a relatively small population of patients all cared for by a single neurosurgeon (the senior author, Mark Bernstein), the selection of only patients who underwent surgery (non-operative cases were excluded), and the length of time between interview and operation (which exceeded one year for some patients). Nevertheless, the themes that emerged in each of the two groups are useful and relevant to the aims of the study. I will briefly discuss each theme below and offer some personal perspectives, especially as they relate to the treatment of patients with a brain tumour, which is one of my areas of interest.

Group 1: Ways in which patients seek information

Theme 1: The Internet was the most widely used resource for seeking medical information.

To me this is not a surprise. The authors found that almost all 31 of the studied patients used the Internet to obtain information regardless of age, gender, educational attainment or self-perceived socioeconomic status. Patients not only used the Internet to obtain purely medical information, but also to search for information that could attest to surgeon's competence and skill, factors which can have a strong influence on a patient's trust in the surgeon². Interestingly, those patients who trusted their surgeon indicated that they spent less time searching the Internet for medical information. Also not a surprise to me was the difficulty that patients had trying to find Internet sites that they could trust. Much has been published on this, including difficulties navigating the Internet as it pertains to cancer in general^{3,4} as well as other disorders with neurosurgical implications such as low back pain⁵.

To me what is a bit of a surprise, and disappointment, is the indication that few patients consulted books, journals and other

printed materials. This to me is disappointing because I am aware of a number of very good publications from reputable organizations in both Canada and the United States that strive to provide patients and their families with accurate and readable information on brain tumours. Specifically in Canada I refer to the Brain Tumour Foundation of Canada (www.braintumour.ca), a not-for-profit organization that has for over 30 years provided a number of free publications including the Adult Brain Tumour Handbook⁶, the Pediatric Brain Tumour Handbook⁷ and the Non-Malignant Brain Tumour Handbook⁸. The vision of the Brain Tumour Foundation of Canada is to find the cause and a cure for brain tumours while improving the quality of life for those affected and its mission is to reach every person in Canada who is affected by a brain tumour through support, education, information and research [Disclosure: the author of this editorial has been a volunteer with the Brain Tumour Foundation of Canada for over 20 years and served as the volunteer Chair of the Board for the past six years.] The Brain Tumour Foundation of Canada is not the only organization to provide very good patient-oriented information regarding neurological disease. Others include publications from societies involved with amyotrophic lateral sclerosis⁹, Guillain-Barre syndrome¹⁰, stroke¹¹, and multiple sclerosis¹². I encourage health care providers to supply their patients with these society's publications and encourage them to take advantage of the patient services that they provide, including patient support groups and educational events such as information days.

Theme 2: In addition to classifying the tumour as benign or malignant, patients sought information about tumour biology, etiology and anatomy of the brain.

This is an encouraging finding. It supports the concept that patients seek to be empowered in regards to their disease¹³. To this end, when I am in consultation with a patient and family members, I often try to explain concepts such as malignant, non-malignant, benign, slow-growing, fast-growing, etc. I try to provide a basic overview of tumour biology and tumour causation using simple terminology and diagrams. I use the Brain Tumour Foundation of Canada handbooks in which are printed basic figures showing brain anatomy.

Theme 3: A malignant diagnosis changed information-seeking behaviour in three ways: 1) patients were less likely to use the Internet; 2) patients felt more anxious with online information; and 3) patients were more likely to consider alternative therapies.

These were interesting and thought-provoking findings. They address not only the information-seeking behaviour of patients but hint at coping mechanisms used by patients¹⁴. Information about malignant disease may be more confusing, contradictory

and fear-inducing. It may drive patients towards alternative therapies making it more important for physicians to have at least some knowledge of these therapies.

Group 2: Ways in which physicians might improve information provision to patients

Theme 1: Patients should be allowed to view their own imaging with the surgeon.

I am of the opinion that all physicians that treat patients with a brain tumour (and especially surgeons) should review neuroimaging with the patient and accompanying family, especially on initial diagnosis (unless the patient declines). I do this review with all my patients in order to help them better appreciate the anatomy, how the tumour causes symptoms, the surgical approach and how post-operative deficits may result. There is no reason why this neuroimaging review could not be applied to other neurological disorders such as vascular malformations, stroke, multiple sclerosis, spinal disease, etc.

Theme 2: The surgeon should be forthright about information, providing specific names whenever possible and avoiding the use of medical jargon.

This is inherently sensible and is supported by the literature¹⁵. Though I already try to be forthright in the course of a consultation with a patient who has a brain tumour (and try to avoid the use of medical jargon), this publication has drawn attention to an apparent flawed expression that I have used in the past and endeavour to avoid in the future – the occasional use of the technically accurate term “lesion” instead of the less confusing term “tumour”.

Theme 3: Surgeons should be aware of how perceived time constraints may influence patient’s willingness to ask questions.

The concept that a patient might perceive that a surgeon’s time is so precious that he or she may be reluctant to ask questions is, unfortunately, a concept that often may be true. For my part I try to spend as long as necessary during the initial consultation with a patient with a newly diagnosed brain tumour. This may require an hour or more, but I feel it is time well spent. I allow the patient and family members the opportunity to ask as many questions as they wish and I leave a contact number in case they have questions that they might want to ask in the future.

Theme 4: Surgeons should consider 1) ways to provide a permanent record of the surgical consultation; and 2) guiding patients to reliable online information resources.

Both of these observations are important. During an initial consultation with a patient and family members, I write a summary of my discussion and am happy to have the consultation recorded. Some versions of the Brain Tumour Foundation of Canada handbooks have a tear-out insert that provides an opportunity to write this summary in duplicate – one copy that is given to the patient as a permanent record and one copy that is retained in the physician’s medical chart. These can be used for future reference by both individuals. The Brain Tumour Foundation of Canada also has free standing note-pads that contain multiple copies of these summary sheets available free for use by physicians. As discussed earlier it is important to

patients that they be guided to reliable Internet websites³⁻⁵. Some centres create their own list of such websites; the Brain Tumour Foundation of Canada can also be helpful in this regard.

In summary, this paper provides valuable information for those who treat patients with a brain tumour. It has certainly served as a useful checklist for me.

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