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The Trend to Seek a Second Opinion Abroad amongst Cancer Patients in Oman

Challenges and opportunities

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نزعة الحصول على رأي ثان من الخارج في علاج مرضى السرطان في عُمان

تحديات وفرص

اكرام برني

A 55 year-old man was diagnosed as having metastatic colon cancer following an endoscopic biopsy at my university hospital in Oman, and was referred to a medical oncologist. The patient, together with his son, travelled to an other asian country seeking a 'second-opinion.' There he was initially treated with a colonic stent, resulting in the perforation of the colon. He underwent emergency resection of the perforated segment, leading to intestinal obstruction. A second surgery was performed to relieve the obstruction, and combination chemotherapy (including the anti-angiogenic drug, bevacizumab) was started. During the first course of treatment, the patient developed urinary retention, was catheterised, and then went on to develop haematuria. He returned to Oman with severe haematuria, a prescription to continue the combination chemotherapy, and radiographic evidence of a bilateral pulmonary artery embolism.

Stories like this are not uncommon and are frequently encountered during routine medical practice in general, and in oncology practice in particular. What is not mentioned in the above story is the fact that the duration between the diagnosis of cancer in Oman and arriving at the hospital abroad was about 4 weeks, during which time the metastatic disease in the liver had increased considerably and the patient's performance status had declined. Inserting a stent was unnecessary in a non-obstructing bowel, a procedure which ultimately led to two needless surgeries and a further delay in starting standard systemic treatment. The expensive anti-angiogenic drug was contra-indicated in a patient with two recent surgeries, and is definitely contra-indicated following a diagnosis of a pulmonary embolism. The patient spent the equivalent of 28,000 Omani riyals (US$ 45,000) during his 4 week stay abroad. He regretted the decision made by his family members.

What is a second opinion? And why do patients, especially those with a diagnosis of cancer, seek one? What are the challenges that face both patients and health providers when a second opinion is sought? Indeed, is the desire to get a second opinion problematic and, if so, can the situation be improved?

Asking for a second opinion is understandable. When it comes to choice (be it selecting food in a restaurant, buying a car, or purchasing a new house) we all value the opinions of others, and sometimes we may even look for a third or fourth opinion. Seeking a second opinion is a way of making choices. However, it is not quite the same when one has received the diagnosis of a cancer. In such a situation, with the likelihood of extensive surgery, chemotherapy and/or radiotherapy, opinions should be sought to see if alternative forms of treatment or cure were available. From the point of view of the

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oncologist, seeking a second opinion is desirable and, in some cases, obligatory. The vast majority of cases are straightforward, and treatment begins as soon as diagnosis and staging are known. In cases of less common cancers, borderline cases or cancers of unknown primary sites, practising doctors frequently invite a second opinion from their colleagues. Seeking a second opinion is a recognised practice in the specialty of oncology. However, the situation described in the above story is something commonly encountered in oncology-related practice in Oman: the seeking of a second opinion abroad before any treatment at home in Oman. A significant number of patients, especially from small towns, bypass the tertiary care/specialist hospitals available to them in bigger centres and immediately go abroad. Once overseas, they may not be provided with a second opinion, but instead are started on the first stage of treatment even when it is uncalled for. Patients invariably return home to continue the treatment. Although the off-shore clinics are very quick to commence 'treatment', valuable time, not to mention savings or borrowed money, is often lost in the making of travel arrangements.

The tendency to seek a second opinion abroad can endanger the patient's health. The clinical condition may not be fully known to the patient and/or his/her family members, and urgent clinical attention is sometimes delayed. Any delay in travel arrangements may lead to a progression of the disease; this in turn leads to an increased burden of disease and a decline in performance status, both conditions decreasing the chances of successful treatment and a subsequent cure. A decline in performance status by a single grade is an adverse prognostic factor in almost all cases of cancer, and for some, this decline may occur within just a few weeks. Furthermore, the patient's selection of country or medical centre is often not informed by prior knowledge of expertise, excellence in the field or familiarity with the type of cancer, but rather by geographical proximity, convenience of travel or simply by a verbal recommendation. Some patients are known to have arrived at centres in which they have received less than adequate treatment or been the victim of experimental/investigational treatment without their knowledge. In both cases, the chances of any subsequent standard treatment being effective are reduced. Sometimes patients end up in good centres where standard treatment is offered or advised for straightforward cases, but there are complications as a result of travel-related delays. Additionally, cancer treatment overseas is seldom cheaper.

In order to influence the behaviour of persons seeking a second opinion abroad, one needs to study the mechanisms underlying this phenomenon. First, it is important to understand the motives and expectations of the patients. Second, in a society where decision-making in health care is often shared, it is important to consider the point of view of all the decision-makers involved. Patients do not always make their own decisions. They are often influenced by the care-givers/well-wishers who, in some cases, are the only ones involved in important decisions.

Although many patients with cancer seek second opinions, there is a dearth of literature on the subject. Only a few have looked at the phenomenon, even fewer have tried to assess its incidence and outcomes.[1,2] The actual incidence of seeking a second opinion is likely to differ from country to country, and amongst different groups of patients. With an increase in the knowledge of disease and improvements in communication, an increasing number of patients seek second opinions. For example, 56% of more than 1,500 cancer patients in the United States sought a second opinion in a single year.[3] The incidence in Oman is unknown. It would be useful to know how often a second opinion has impacted upon the course of treatment. In a survey done in Holland of 403 patients, the majority with breast cancer, the investigators found that in 84% of cases the advice given was comparable. Not everybody had a review of either histological or radiological diagnosis and when this occurred, a major change in treatment was observed in only 3% of patients and a change in prognosis in just 2%.[4]

Who are the people more likely to travel abroad to seek a second opinion before the first? Are they the well-informed, the well-read or the wealthy? There is insufficient information on this subject. However, a common observation is that the phenomenon transcends the boundaries of information and financial resources as much as it transcends national boundaries. For example, Kangas reported on the behavior of not-so-rich Yemeni patients with various diseases seeking biomedical treatment in other countries, and noted that their behaviour did not differ significantly from that of relatively well-

off Saudis.[5]

In the absence of published data concerning Omani patients, the motives for seeking second opinions before the first remain hypothetical. The motives may be intrinsic or extrinsic, or a combination of both.[6] Intrinsic motives could include: seeking reassurance and more certainty about the diagnosis; seeking a treatment other than the conventional one 'usually' offered to cancer patients; the desire to be treated in a different environment - perhaps to maintain 'confidentiality'; or the belief that 'paying more' will produce better treatment. Extrinsic motives are more varied. These could include: experiences from the patient's past; doubts about the health care services in the home country; market forces, such as dynamic advertisements by external health care organisations; social and societal pressures; or merely word of mouth information that a 'cure' is available elsewhere, and hence borrowing or spending large amounts of money might bring positive results. Common extrinsic motivators for seeking a second opinion may not be applicable in the case of Omani patients, since a 'first' opinion has not yet been sought. These may include: the lack of effective communication by and with the oncologist; dissatisfaction with the primary oncologist; seeking an opinion on a rare cancer; concern about the side-effects of a particular type of treatment; an ambivalent attitude towards the care provided resulting in the need for more information, or the desire to participate in a clinical trial.

Is there a solution? First of all, the phenomenon needs to be studied, and the motives and expectations of the local population explored. This would provide a wonderful opportunity not only for examining patients' and families' motives, but also to investigate the health services offered. A lack of communication between health care providers, a delay in diagnosis (especially at the point of primary care), or simply the unavailability of resources (actual or perceived) may contribute to the need for a second opinion. In cases of the latter, these could be easily rectified by better utilisation of our material resources. On the other hand, if the major motivations are intrinsic (or social), then the solution may lie in sustained and concrete efforts aimed at enhancing public awareness and confidence-building through a process of education and information dissemination. The ultimate winners should and would be the patients and society at large.

In conclusion, seeking a second opinion amongst cancer patients in Oman poses certain challenges for the health of our patients and provides the health care profession with opportunities to study the problem and to aim for practical solutions. First of all, it must be recognised that seeking a second opinion is not only justified, but also desirable in many situations. Oncologists themselves should support patients in their efforts to obtain an opinion. However, seeking a patient-initiated second opinion abroad, especially in the case of cancer management, may have an adverse effect on the outcome of the disease, both because of the delay it causes in diagnosis, and because of the chance of receiving sub-optimal treatment or advice elsewhere. In order to overcome the challenge, there is an urgent need to study patients' or their decision makers' motives and expectations. Meanwhile, it may help Omani patients diagnosed with cancer and their families, who are seeking a cure wherever it may be found, to know that the World Health Organization (WHO) has ranked Oman as the most efficient 'health care system in the world in terms of outcomes'.[7] Furthermore, patients should be advised that second opinions can be easily and quickly sought at little or no cost through fax, email, and telemedicine from places in Oman or abroad that are widely perceived to be centres of academic and clinical excellence. This will avoid the need for cancer sufferers to seek opinions from more profit-oriented health care centres which may not have the necessary expertise to provide the best advice.

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