Inherent Bias? Patients Who Use the Internet to Find Information on CAM

Michael Baum

University College London, UK

Dear Sir,

Krebskompass sounds like an exemplary platform for informing patients about the harms and benefits of complementary and alternative medicine (CAM) and the provision of a 'chat room' for dialogue between patients. Unfortunately, as the authors hint, there is a strong bias inherent in this website to use it as a basis for generalizable findings in qualitative research. Those involved are the younger, educated CAM users, and the forum appears to be dominated by a vociferous minority. Their results from an online questionnaire are based on a numerator of 80, but I have no idea of the denominator so I cannot work out the percentage of respondents. As a result, I have to conclude that however interesting the findings, they cannot be extrapolated beyond this very small, self-selected minority. I was appalled at the ignorance of the respondents concerning the basic principles of carcinogenesis, but perhaps that has to be a prerequisite for those who embark on treatments that are, for example, used to 'boost the immune system'. I also believe that the 'satisfaction index' with the CAM experience has nothing to do with the specifics of the therapy as they are mostly placebos or of no proven efficacy; the satisfaction the patients experience therefore is more likely to be linked to the charisma of the practitioner, the time they are kept waiting, and the environment where the placebo is offered, rather than the treatment itself. I discount prayer from this generalization, as it should not be included in the lexicon of CAM. Prayer provides spiritual solace at a time of existential crisis and should be in the hands of the faith groups that the patients belong to and their priests or mullahs. Such services should be available in the context of support services for our clinics where evidence-based medicine is practiced. That aside, the only worthwhile message I take away from this paper is the failure of orthodox practitioners to be willing to enquire about their patients' use of

CAM, but even that might be based on a very small and biased sample who might have their own agenda. Finally, I find these words in the opening statement somewhat quaint: '... use of CAM during or after the disease'. Surely that can only apply to acute conditions like bacterial infection or trauma.

Author's Reply

We are fully aware that our collective is not representative for the whole population. Yet, it represents an important group, namely those who use the internet, which without doubt will gain importance in medicine. Thus, it is important to analyse and understand the attitudes and needs of those patients who already use this medium.

Regarding patients' concepts of aetiology, we are not convinced that the answers from participants of a chat forum are far from those that other patients have. In fact, this would be an interesting research question. Concepts of aetiology most probably will have strong impact on patients' treatment decisions, not only for CAM but also for conventional therapy.

We included prayer in our questionnaire, as religion or spirituality are considered part of CAM in the international literature. Whether this is reasonable or not is open to discussion. If CAM comprises all methods the patient can choose by himself and is responsible for by himself, prayer, as meditation or other methods could be regarded as CAM. On the other hand, the high user rate could point to an important concept that is missing in current modern medicine: the concept of meaning of life, disease and death. One could speculate that the high attractiveness of CAM partly stems from this deficit. Whether CAM really are adequate to convey meaning is another question.