

SUBMISSION TO THE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PERSONS WITH CANCER

by

THE QUEENSLAND INSTITUTE OF MEDICAL RESEARCH

The Queensland Institute of Medical Research (QIMR) is a statutory body established under the QIMR Act (1945). The mission of the QIMR is to remote the well being of human kind through medical research, to maintain within the state of Queensland an internationally recognized centre for medical research, to develop that centre as the primary focus of medical research within the state and to cooperate, and where possible assist other medical research establishments within Queensland and Australia, and throughout the world.

An important focus of research at the QIMR is the translation of research discoveries into beneficial patient outcomes. All divisions of the QIMR participate in this research enterprise within Queensland and Australia, as well as collaborations with numerous countries around the world. The QIMR undertakes early phase clinical trial development of therapeutic products and has a joint venture with Q-Pharm to undertake pharmacological studies in phase I clinical trials and bioequivalence studies of established drugs. The QIMR also has a major research program in indigenous health. The QIMR does not provide a patient treatment service for the daily care of oncology patients and consequently Part A of the Terms of Reference are outside the scope of its mission and research activities.

Research into outcomes of cancer and the use of complimentary and alternative treatments is an area of research interest at the QIMR.

There is a large evidence base documenting the use of less conventional and complimentary treatments of cancer but, until recently, there has been little evaluation about the risks and benefits of such treatments. Even less is known about the fundamental issue as to why people with cancer seek complimentary and alternative treatments.

In a study conducted in collaboration with researchers at the Queensland University of Technology, 149 patients with advanced cancer and a limited life span were assessed to determine their use of alternatives to conventional medical treatments, how committed they were to the use of these alternatives (defined as the perception that alternative treatments were a core part of their overall treatment), the beliefs they had about the outcome of their advanced cancer and their need for control over treatment decisions. The results of this study showed:

- Alternatives to conventional medical treatments were more likely to be used in patients from higher socioeconomic groups. The committed use of these treatments was not associated with lower levels of education.
- Of the 149 patients with advanced cancer who had been informed as part of their routine medical care that their cancer was incurable, 27% believed their cancer was curable.
- Although this could be attributed to poor communication, studies of communication in advanced cancer have not evaluated patient beliefs. Furthermore, the following cluster of characteristics in this sample suggests that poor communication was not the explanation for this belief.
 - Patients who believed their cancer was curable were more likely to be committed users of alternatives to conventional medical treatment.
 - Patients who believed their cancer was curable were more likely to have a higher need for control over decisions about treatment.
 - Of the 27% of patients who believed their cancer was curable, over one-third acknowledged that their oncologist had informed them that their cancer was incurable. Furthermore, need for control over treatment decisions was greatest in this group.
- A further finding, published as a separate article, indicated that patients with advanced cancer often have a very strong will to live and this is associated with a perception of better quality of life.

The findings of this research suggest that some patients do not accept a communication by their doctor that their cancer is incurable but rather undertake actions necessary to support their belief of cure.

Illusions are part of normal psychological make-up and some patients with advanced cancer have unrealistic expectations of benefits from treatment. Alternatives to conventional medical treatments often support unrealistic expectations since they are promoted as cures and are supported by individual testimonials of claimed success. More research is urgently required to further assess why people use alternatives to conventional medical treatments.

Beadle G.F., Yates P.M., Najman J.M., Clavarino A., Thomson D., Williams G., Kenny L., Roberts S., Mason B., Schlect D. "Beliefs and practices of patients with advanced cancer: implications for communication". Br J Cancer 91: 254-257: 2004.

Beadle G.F., Yates P.M., Najman J.M., Clavarino A., Thomson D., Williams G., Kenny L., Roberts S., Mason B., Schlect D. "Illusions in advanced cancer: belief in curability, will to live and quality of life". Psycho-Oncology 13 (1): 26-36; 2004.

Yates P., **Beadle G.**, Clavarino A., Najman J., Thomson D., Williams G., Kenny L., Roberts S., Mason B., Schlect D. Patients with terminal cancer who use alternative therapies: their beliefs and practises. Sociology of Health & Illness; 15: 199-216, 1993.

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