

# Evidence-Based Medicine: Is It Relevant To Patients?

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## ABSTRACT

Patients obtain information about their illness from many different sources including Complementary and Alternative Medicine (CAM) sources. This study aimed to identify cancer patients' preferences in health information sources and to find out about secondary sources of information used in making treatment decisions. Thirty cancer patients were interviewed about the sources of information they consulted when choosing treatments. Patients consulted a wide variety of sources of information of which oncologists, nurses, and written hospital information were rated as the most useful sources. The responses showed that many patients would choose a conventional, or evidence-based, treatment ahead of a CAM treatment, but that they would also be willing to use both conventional and CAM treatments concurrently. This study showed that patients placed high importance on evidence-based scientific information, but other considerations were also significant in choosing cancer treatments.

## INTRODUCTION

Evidence-Based Medicine (EBM) and patient-centred care<sup>1</sup> are two concepts integral to medical decision-making. EBM is increasingly emphasised in today's medical practice and this could potentially lead to tension between these concepts. A current trend towards the practice of the Evidence-Based Patient Choice (EBPC) attempts to successfully combine EBM with patient-centred care.<sup>1</sup> EBPC upholds patient autonomy and allows patients to take an active role in their treatment. In order for EBPC to be effective, doctors need to satisfy the information needs of patients while also considering their personal values and beliefs.<sup>2,3</sup>

Despite the emphasis that doctors place on EBM, patients obtain health information from many places. Hospital consultants and GPs are frequently cited sources of information by patients.<sup>4</sup> The majority of patients also consult secondary sources of information such as friends and family.<sup>4,5</sup> Previous studies have shown that younger patients prefer more information than older patients,<sup>6</sup> and that patients also prefer shared decision-making between doctors and patients.<sup>5</sup>

In New Zealand in 2003 almost half of cancer patients used CAM<sup>7</sup> and a 2005 study showed that a third of New Zealand adults believe an alternative therapy could be used instead of a conventional cancer treatment.<sup>8</sup> Most (68 per cent of) New Zealanders believe that CAM could help cancer patients who are also receiving a conventional treatment.<sup>8</sup>

There has been little research on the preference and use of secondary information sources in New Zealand patients, and more research is needed to better serve patient requirements. Thus, the aims of this project were to identify cancer patients' preferences in health information sources, particularly in relation to presentation of evidence, and also to find out about the range and preference of secondary sources of information used by patients in making treatment decisions. This study will provide New Zealand data that will assist in the training of medical students by raising awareness of patient needs and preferences.

## METHOD

Thirty patients currently receiving chemotherapy at Dunedin Hospital Oncology Department were interviewed in the day unit during December 2005 and January 2006. Oncologists identified patients as being suitable for the study. Information sheets explained the study and participants gave written consent before beginning the interview. The Lower South Regional Ethics Committee approved this study.

The interview consisted of five sections:

### 1. Demographic Information.

**2. Sources of Information:** participants indicated the information sources they had used in making choices about their own cancer treatment from a list of 30 possible sources (Appendix 1). Respondents marked on a linear analogue scale (Figure 1) how useful they found the information sources they consulted.

**3. Hypothetical Scenarios:** five scenarios (Appendix 2) described cancer patients with a choice between conventional treatment and a CAM approach. Participants responded by marking on a linear analogue scale (Figure 2) the advice they would give to someone in the scenario situation.

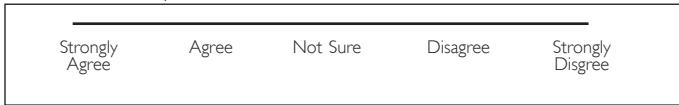
**4. Open Question:** participants commented on their own experience of choosing a cancer treatment and described the factors and advice that they found valuable.

**5. Statement-Based Questions:** patients responded to four general statements about factors used when choosing cancer treatment by marking a linear analogue scale (Figure 2).

**Figure 1:** Linear analogue scale for the usefulness of sources of information



**Figure 2:** Linear analogue scale for scenario responses and statement-based questions



Data were entered into an Excel spreadsheet for analysis. Analysis included finding the mean response, range, and most common responses. The responses to the open question were recorded verbatim. These responses formed the basis for a typology of respondents in which patients were grouped according to the amount and type of information sought out. This typology was subjective and was performed in the manner described because this best matched the aims of the study.

## RESULTS

### 1. Demographic Information.

**Table 1:** Characteristics of survey respondents (n=30)

Age	
< 45	4
45 - 64	14
> 65	12
Sex	
Male	13
Female	17
Ethnicity	
European/Pakeha	28
Pakeha/Maori	2
Formal Educational Qualifications	
No tertiary qualification	14
Tertiary qualification	16
Cancer Diagnosis	
Breast	14
Ovarian	3
Lung	3
Bladder	3
Bowel	2
Lymphoma	2
Other	3

### 2. Sources of Information

The sources of information question showed that a range of sources were used by patients in making decisions about cancer treatments and confirmed that many patients do not limit themselves to hospital based information. The number of sources of information used by patients ranged from two to 22 and the mean was 8.6 (Table 3). Demographic trends could be seen in information usage: younger patients tended to consult more sources than older ones, as did female participants and those with a tertiary education qualification (Table 2).

### 3. Hypothetical Scenarios

In the scenarios, participants were first asked whether they would recommend choosing a conventional cancer treatment or taking a CAM approach. They were then asked if they would recommend a CAM treatment concurrently with a conventional one. A number of trends could be seen in the responses to these scenarios (Figure 3, Scenario 1): firstly, most patients chose a conventional treatment over a CAM treatment, and secondly, most patients agreed with the approach of using conventional

**Table 2:** Numbers of information sources used by participants according to demographic groups

	Mean number of sources of information used	Range (min- max number of sources used)
<b>Age</b>		
< 45	13.0	8 - 22
45 - 64	9.5	2 - 21
> 65	5.6	2 - 14
<b>Sex</b>		
Male	6.5	2 - 22
Female	10.3	4 - 21
<b>Formal educational qualifications</b>		
No tertiary qualification	5.6	2 - 14
Tertiary qualification	11.1	5 - 22

**Table 3:** Information sources consulted by more than 25% of participants, and mean usefulness of these sources

Source of Information	% of participants using source	Mean usefulness of source where used (0=not at all useful, 100=highly useful)	Standard deviation of mean
Oncologist	100.0	94.07	8.2
General practitioner	66.7	71.90	31.7
Nurse	66.7	83.90	20.1
Written hospital information	63.3	82.58	16.3
Friends	50.0	43.93	32.3
Family	43.3	66.46	31.2
Internet	43.3	71.00	24.7
Books	43.3	77.92	21.1
Voluntary organisations	40.0	79.25	22.5
Newspapers	33.3	34.64	18.6
Other patients	33.3	61.20	30.6
Alt. Health Care Practitioner	30.0	62.56	39.8
Magazines	30.0	43.00	28.2
Health food shop	26.7	46.88	32.6
TV	26.7	31.88	27.7

**Figure 3:** Scenario 1

*A friend asks you for advice. He has recently had surgery for bowel cancer and the surgeon has recommended postoperative chemotherapy to mop up any remaining but invisible tumour spots. The surgeon stated that large, reliable scientific research studies have shown that chemotherapy results in 10% more cures. However the friend explains that his partner is keen for him to try herbal therapies first to fortify the immune system. This therapy does not appear to have any harmful side effects and seems to be a more gentle way to treat cancer. The partner knows of many people who have used these herbal therapies and have not had any relapse of their cancers.*

medicine and CAM together. These trends are illustrated by the responses to Scenario 1 (Figure 4). All five scenarios showed similar trends in the responses.

### 4. Open Question

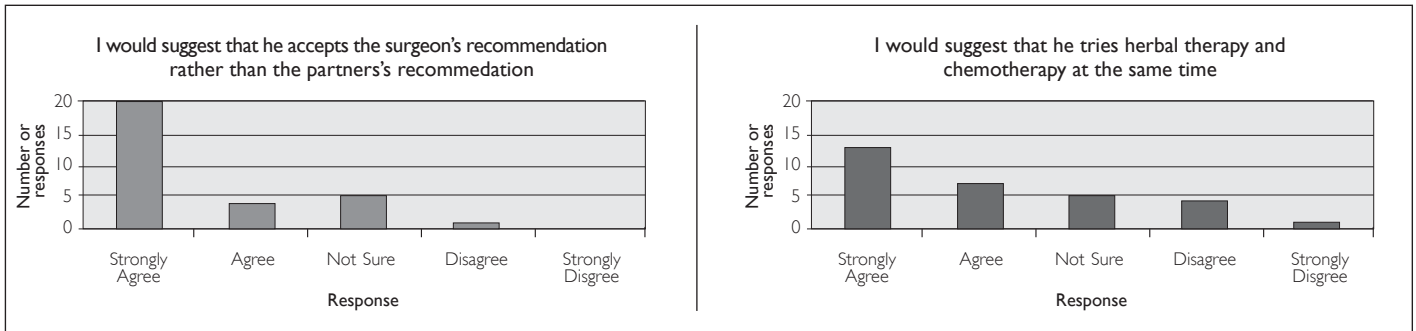
Responses to the open question could be divided into three groups according to the attitude towards information gathering and the sources of information consulted:

**Group 1:** Did not seek further information apart from what they were told or given.

**Group 2:** Looked outside the hospital, but only for scientifically based information.

**Group 3:** Sought all information regardless of its basis.

Figure 4: Histograms showing responses to statements based on scenario I



### Summary of comments from the open question

**Group 1:** These patients felt they were given sufficient information from the hospital, and they trusted medical advice was expert and, therefore, follow recommendations. Typical comments regarding their oncologist included, "If they don't know what they're doing no-one does," and, "I just went along with what the doctors told me, hoping that they knew what they're talking about." There were also differences in opinion amongst this group. Some of these patients expressed a need for scientific evidence and felt this need was met through hospital based information. In some cases, patients did not look further for information as they felt the situation was "cut and dried" with no ambiguity surrounding the best course of treatment to follow. Other comments included that it was "pretty rude to suggest things to specialists" and that you are "making an idiot of them [the oncologist] if you go see someone else," but not all patients in the group held this view.

**Group 2:** The participants in this group searched for information outside the hospital, but stated that "they needed to see research-based evidence." For many patients this did not exclude the use of CAM as they felt enough evidence was available to convince them it would work. The internet was commonly consulted to "find out about different options" and because it "brings about questions, gets discussion going with yourself." Patients read books to find out about CAM therapies, to find hope, and to hear stories about other people with cancer.

**Group 3:** This third group of patients was the smallest, and again, there were differences in opinion amongst these participants. The main characteristics of this group were that they were willing to try anything and would accept all advice, regardless of its origin. Participants mentioned the importance of an "holistic approach" and that they were "open-minded" and would "use as many weapons as they could to fight it [cancer]." The main reason for looking for information was to allow decision-making "on a rounded basis." It is worth noting that all of these patients still placed high trust in their oncologist, and followed the course of treatment recommended by the hospital.

### 5. Statement-Based Questions

The responses to the statement-based questions supported the scenario results. The statement, "When making decisions about cancer treatment I would always put most emphasis on my own instincts," resulted in a fairly equal distribution of responses across the scale. The second statement was, "I would only accept recommendations for treatment of cancer that were based on scientific research," and there was a trend towards agreement with this statement. However, there was a trend towards disagreement with the statement, "I would seek advice from alternative and/or complementary medicine providers before choosing a cancer treatment," with 21 patients either disagreeing or strongly disagreeing with this statement. The final statement, "I would value advice from friends and relatives before choosing a cancer treatment," resulted in a polarised response, with many patients either strongly agreeing or strongly disagreeing. Analysis of the responses to these statements in relation to age and level of education showed no apparent differences.

### DISCUSSION

Several of the findings in this study are supported by previous research: oncologists are frequently consulted and patients consider them to give high quality information;<sup>4</sup> younger patients consult more sources of information than older patients;<sup>1</sup> and about half the patients interviewed felt they received enough information from hospital to decide on treatment. This study indicated that some patients do not actively seek information, some want to see evidence-based information, and some patients are willing to accept information from any source.

Studies have already shown that CAM is perceived to be helpful when used together with a conventional treatment.<sup>8</sup> This study found general agreement with following advice based on scientific evidence and the majority of those interviewed said they followed medical recommendations. Around half of patients were either receiving a CAM treatment or would consider doing so in the future. An interesting result was the finding that patients held strong views about including family and friends in their treatment decisions, with participants strongly agreeing or strongly disagreeing with this concept.

This study was limited by the small sample size. For example, there were only four patients in the under 45 age group. This could impact on the results, because younger patients tend to utilise more information sources than older patients.<sup>1</sup> Within the sample, patients with breast cancer were over-represented, and this could impact on the results if these patients sought information differently from patients with other forms of cancer. Another limitation was that only patients who had chosen to receive anti-cancer treatment at the hospital participated, so those who did not opt for this treatment were not included in the sample. A possible bias was the selection of patients by oncologists: the oncologists may have chosen patients with whom they had a good relationship, and these patients may have found information from their oncologist more helpful than patients who did not participate in this study.

The results of this study may not apply to other parts of New Zealand because of differences in ethnic diversity. The sample in this study was predominantly European/Pakeha, and therefore the results may not reflect regions of the country with a different ethnic makeup. To extend knowledge in this area, research should be done on samples representing the range of ethnicities in New Zealand. Further research is also needed to increase knowledge about patients' reasons for trusting different types of information, and their reasons for using CAM. Furthermore, research should be done to explore the differing information needs between patients so that care can be individualised.

In conclusion, the results of this study indicate that EBPC could be an effective model of medical decision-making to follow in New Zealand. EBPC advocates evidence informed patient choice,<sup>1</sup> and the results of this study show that patients wish to make scientifically based choices about their treatment. Following an EBPC model of care would satisfy patients by giving them access to evidence-based information. It also gives patients the autonomy to make their own treatment decisions,<sup>1</sup> potentially including the use of treatments that are not yet evidence based. EBPC allows a partnership between doctors and patients, where clinical decisions are made using scientific evidence, while also taking into account the patients' individual situations.

The findings of this study may also give guidance for effective medical education in New Zealand by increasing awareness of information preferences of patients. These results also give insight into the factors that are important to patients in deciding on treatments, and about patients' views regarding CAM. It is important for doctors to gain an understanding of patients' views and beliefs so that they help patients make informed choices about treatments.

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## APPENDIX 1: SOURCES OF INFORMATION

Oncologist	Magazines
General practitioner	Health food shop
Nurse	TV
Friends	Radio
Family	Newspapers
Other patients	Cancer/medical journals
Support groups	Research articles
Voluntary organisations eg Cancer Society	Citizen's Advice Bureau Clergy
Alternative Health Care Practitioner eg	Helplines Dietician
Naturopath/Homeopathist	Social worker
Written hospital information	Physiotherapist
Internet	Occupational therapist
Books	Other (please specify)

## APPENDIX 2: HYPOTHETICAL SCENARIOS

### Scenario 1

A friend asks you for advice. He has recently had surgery for bowel cancer and the surgeon has recommended post-operative chemotherapy to mop up any remaining but invisible tumour spots. The surgeon stated that large, reliable scientific research studies have shown that chemotherapy results in 10% more cures. However the friend explains that his partner is keen for him to try herbal therapies first to fortify the immune system. This therapy does not appear to have any harmful side-effects and seems to be a more gentle way to treat cancer. The partner knows of many people who have used these herbal therapies and have not had any relapse of their cancers.

### Scenario 2

A friend asks you for advice. She has recently been informed of a diagnosis of incurable lung cancer which has spread to the liver. Your friend is keen to try high dose vitamin C as she has heard of remarkable improvements in cancer when the

doctors have given up. She has asked her oncologist about using high dose vitamin C and he indicated that a large scientific study has failed to show any benefit in patients with cancer. The oncologist offered your friend a copy of the research report.

### Scenario 3

A friend asks you for advice. She has recently been diagnosed with breast cancer and has sought opinions from two breast surgeons about the choice between total mastectomy and partial mastectomy. One surgeon was very positive about partial mastectomy and recommended this with only a brief mention of the other options. The other surgeon explained the pros and cons of both procedures, including evidence from scientific studies, and indicated the final decision lay with the patient. Your friend is not sure which advice to accept.

### Scenario 4

Your cousin wants advice from you as to what she should do. She has been diagnosed with breast cancer several weeks ago and had surgery to remove the breast lump. A few days ago she saw the cancer specialist who told her the best outcome for her situation would come from several courses of radiotherapy followed by hormone tablet treatment. He explained that his recommendation was based on scientific research studies in which different treatment options had been compared, and that the treatment would cause only minor side-effects. However, a neighbour of your cousin had given her a book written by a woman scientist who had also suffered from breast cancer. This scientist wrote that she had successfully combated her breast cancer simply by staying off dairy products. She not only told her personal, first-hand story in the book but also gave some very attractive theories why a dairy free diet would be so successful. Your cousin is not sure which approach to take.

### Scenario 5

A friend has had bowel cancer, which was successfully operated on. However, he was later told that a scan showed incurable secondary tumours in the liver. He had recently found out about a new treatment which was still at the experimental stage. This treatment consisted of cryotherapy [a freezing technique] to the tumours, which involves a major operation followed by a course of chemotherapy. Even though there were no final results from research studies on this treatment, there were some promising early results. Your friend does not know whether to make further enquiries about cryotherapy.