

## “Evidence of me” in evidence based medicine?

Susan Lockwood

Evidence based medicine provides independent, validated advice about treatment options, but does it take sufficient account of individual patients' values to provide them with an optimal health outcome?

Sackett et al define evidence based medicine as “the integration of best research evidence with clinical expertise and patient values.”<sup>1</sup> Although there is extensive literature about the role that patient values do and should play in evidence based medicine, most of this has been written from the perspective of clinical and research communities (see appendix on [bmj.com](http://bmj.com) for a discussion of the literature on this topic). Virtually no articles consider the topic from the patients' perspective.

Clinicians tend to emphasise the rational, scientific, “objective” view of the world. Patients usually do not approach their decision making about their lives on this basis. Although they make decisions based on evidence, they view this evidence through a filter that is based on their own individual values. These values are derived from their lifetime experiences. Thus the values that patients bring to a clinical situation may be very different from the values of their clinicians.<sup>2</sup>

This variety of attitudes, approaches to life and decision making, and values makes the use of evidence based medicine at the individual level difficult for patients and for the clinicians working with them.

### Data sources

This article is based on my 12 years' experience with treatment for breast cancer and eight years' experience as a consumer representative on many different committees, including the development of guidelines for the treatment of advanced breast cancer and ductal carcinoma in situ in Australia. As chair of the Breast Cancer Action Group, I have had many conversations with clinicians and with patients and their families about their experiences of breast cancer. The opinions expressed are my own and not necessarily those of the Breast Cancer Action Group.

Because of the paucity of evidence of patients' views of patient values, my article is mainly based on “patient expertise.” The illustrative quotes all come from women with breast cancer who participated in various consumer focus groups held as part of a joint research project between Monash University School of Information Management and Systems with Breast-Care Victoria, and Breast Cancer Action Group (Victoria). This project, which is funded by the Australian Research Council, is looking at the information needs of women with breast cancer and setting up a website to meet these needs. For details of the research project see [www.sims.monash.edu.au/research/eirg/bcko.html](http://www.sims.monash.edu.au/research/eirg/bcko.html)

The values expressed by these patients may be different to those of other patients, in particular male patients, in a similar situation.



MAURO FERRARELLO/SPL

As well as the basic evidence about their illness, patients want information based on values that they can understand and relate to: “Personal experiences I found much more useful than just bland brochures.”

### How important is evidence based information in patients' decision making?

In the treatment of breast cancer, it is clear that evidence based medicine can reduce variation in clinical practice and inform patients, allowing them to make their own decisions about their treatment. The National Breast Cancer Centre in Australia developed evidence based treatment guidelines, producing the first of these guidelines in 1995.<sup>3</sup> Clinical and consumer guidelines have now been produced on all aspects of breast cancer, including psychosocial issues. Consumers have been extensively involved in the drafting of all the guidelines. In the state of Victoria a study compared medical practice before the introduction of the guidelines for early breast cancer with practice at five years after and showed that practices are incorporating the principles advocated in the guidelines.<sup>4</sup> As clinical expertise incorporates best practice, outcomes are improving.

We also know that the existence of the consumer version of guidelines for early breast cancer has

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A discussion of the research literature on this subject appears on [bmj.com](http://bmj.com)

encouraged women to make their own decisions about their care (personal communication, K Luxford, programme director, National Breast Cancer Centre). Most women want to have some involvement in the decisions made about their care.<sup>5</sup> Other studies have shown that the provision of “adequate information is related to increased psychological well-being.”<sup>6</sup> Women patients in the focus groups have commented favourably on the consumer guidelines for early breast cancer:

“I found it really helpful. I read it through so that when I went in to that first interview and [started] talking about going in for a lumpectomy, at that stage I said, ‘Right. That’s all you’re doing, and then I’m coming home. I want to think about what else.’ . . . I don’t think I would have known to say that if I hadn’t had the book before all of that started.”

Outcomes are improving, and mortality is declining in Australia. It is clear that from a clinical perspective and a patient perspective, evidence based information is important for making decisions and for patients’ physical and psychological wellbeing.

There is a vast literature on evidence based choice, communicating evidence based information, and ethical considerations of evidence. This literature seems to assume that, given the evidence in an understandable form, patients will make the same decisions as their clinicians. However, patients often have an entirely different view of the world, based on a different set of values to those espoused by evidence based medicine, and these values influence their decisions.

### How important are patients’ values in their decision making?

Sackett et al define patients’ values as “the unique preferences, concerns and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions if they are to serve the patient.”<sup>1</sup> These individual patient values are a major part of decision making by patients, as shown by comments made in the focus groups:

“I think somehow your pathway is a bit self directed in the sense that, all of us sitting around this table, I don’t think any of us would have sought identical information because we all do it in different ways, and our personalities handle it in different ways, and we progress at a different speed with the level of information that we want.”

There is a stark difference between the empirical basis of evidence based medicine and the value systems of individual patients. Evidence based information is based on samples and populations, not individuals:

“I find the help from doctors is less informative, probably because they tend to talk in general terms. They are talking about groups of people rather than individuals. And because they’ve had no experience of the illness, they don’t really understand what you’re looking for in terms of information—as to how it affects you personally.”

For many patients, statistics are esoteric concepts with little relevance to their daily lives. Presenting them with figures that they do not understand produces confusion and resentment that clinicians cannot speak “their” language:

“Then I think at another point, when I knew I was about to have my treatment—it was a very bad time in my life for per-

sonal reasons—it just got very depressed, because the doctor told me I had a 1 in 100 chance of dying from the treatment . . . and I guess if I had at that stage some more useful information about the treatment and could talk [about it to someone else].”

A basic principle of evidence based medicine is that of giving information on chance, probability, and risk. Most patients have difficulty with the consequent concept of uncertainty that underpins all the information presented:

“I guess I handed over the medical stuff to the medical people because I really didn’t understand enough about what was going on there. And I would say that it’s not until the last three or four years that I have understood a lot more about the medical stuff . . . Then I started doing the reading and stuff and understanding the jargon about confidence intervals and things like that.”

Often, the research that is carried out, and becomes part of the evidence base, does not include issues that are important to individuals. The young woman quoted below was bemoaning the lack of interest by researchers in her need to maintain her fertility. It is known that chemotherapy often induces menopause, but there has been little research interest in premature menopause because the bulk of women who have breast cancer are postmenopausal. For most women less than 40 years old, however, maintaining fertility is a vital issue:

“They don’t consider all the extra areas, and for younger women, you’re right. They still see it as this old woman’s disease. And you say, ‘Look, there are younger women.’ They’ll just dismiss it with ‘There aren’t big numbers.’”

Evidence based medicine gives individuals information based on a philosophy of life or values that they often cannot relate to. No wonder patients make decisions through the filter of a different set of values. Although the production of guidelines or other information for individuals tries to minimise these issues, patients are still very aware that they cannot relate to the basic values underpinning the information that is offered to them:

“The doctors are limited—they can only give you the medical information. They cannot go beyond that point.”

Naturally, patients prefer information based on a philosophy that they can understand and relate to and which addresses their personal values:

“Personal experiences I found much more useful than just bland brochures. Testimonials from people, face to face, or written. It just seems more personal. There are clinical books on the process, and you’re just another individual in the process, which has happened to thousands and thousands of people, but it’s happening to you.”

Some patients acknowledge the need for both types of information, but it is not clear whether the evidence based information they read actually determines the decision they might make:

“So at different times people are going to want to know different information . . . straight up when you’re diagnosed and you have to make decisions, you’re going to want to know the scientific; but then, later on, it becomes more personal and you want to know other people’s experiences and what they went through. It’s good to know that other people have been through it before you.”

## How do we know what a patient's values are?

Most people learn to understand the world around them from stories, not statistics. Fairy stories, myths, legends, and historic poems have been used from time immemorial by people to help them understand and to locate themselves within the "big issues" in society. For patients, a diagnosis of cancer is a big issue. It brings into sharp relief issues of mortality, the importance of family, and acknowledgements of love and commitment, and lack of love and commitment.

We explain to ourselves, and others who will listen, our situation by talking about the important matters at hand. We look for people who have been in a similar situation or who have similar beliefs to see how they handled a particular problem:

"Actually, when I think about it, one of the things I was really wanting about that time was to meet people, to hear stories about people who had lived."

We look to stories or experiences of people in our own families, we look to spiritual beliefs, usually told as stories or parables. We look to books about other individuals, to gain inspiration for the difficult tasks ahead:

"At about that stage I found someone who I could talk to who had had it, but she subsequently died, but it was very useful. Yes."

We sort out our own values by looking to the values of those around us and then reflecting on them. We state our values through stories about ourselves and our families.

Recognition of the role of stories as a means of understanding what is happening to us has developed from the work of sociologists. Listening to groups of cancer survivors is enough to convince even the most devoted advocate of evidence of the value which these survivors place on the stories they hear.

Some medical sociologists have developed the concept of the narrative and its importance to our understanding the meaning of events in our lives. The DIPEX website also uses the narrative voice as a means of helping both patients and their doctors to understand what different experiences of clinical care mean to individual patients.<sup>7</sup> Only by listening to the stories that patients tell can clinicians understand their patient's values.

## Conclusions

Evidence based medicine has been a great boon for patients. It has provided independent, validated advice about treatment options. But, like all tools, it has its limitations. As individuals, we are all a mixture of our inclinations to know why things happen; in some cases these lead us to seek explanations through science, and sometimes we also use the deep seated cultural, philosophical, and spiritual parts of our being to understand the world. Evidence, as moderated by clinical expertise and filtered by our basic individual values, will be the basis of excellent health care.

## Summary points

Patient values are the beliefs that patients bring to discussions about treatment options

Evidence based information is important for both clinicians and patients in making decisions about treatment options, but it is only part of the picture

Patient values are a filter through which patients view the evidence that they are presented with

Patients express their values by talking about their life experiences, by telling their stories

I am a part of all that I have met;  
Yet all experience is an arch wherethrough  
Gleams that untravell'd world, whose margin fades  
For ever and for ever when I move.

Alfred Lord Tennyson, *Ulysses*

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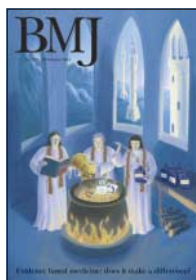
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- 2 Bastian H. Speaking up for ourselves. The evolution of consumer advocacy in health care. *Int J Technol Assess Health Care* 1998;14:3-23.
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- 7 DIPEX.org: personal experiences of health and illness. [www.dipex.org](http://www.dipex.org) (accessed 13 Oct 2004).

## Evidence based medicine: does it make a difference?



### Webchat

At 4 pm local UK time, Thursday 4 November, we're hosting a one hour webchat devoted to the topic.

Go to <http://quest.bmj.com/chat> to register and read the rules of engagement.