

TESTING TREATMENTS

Chapter 12, 12.3.9 TESTING TREATMENTS

Question 8: Are there reliable sources of information that can be recommended? (See also Additional Resources)

There is no single information source for all diseases and treatments. To apply the principles in this book, readers may want to develop some skills themselves. For example, in addition to Chapters 6-8 in this book, the book *Smart Health Choices*⁵ gives some tips on how to find good information, and what to check for.

Of the websites available, few are largely based on systematic reviews. Some that are include the Cochrane Database of Systematic Reviews (www.cochrane.org/cochrane-reviews), which has lay summaries, and the IQWiG website (in German, but also translated into English at www.informedhealthonline.org). In addition, there are many websites that generally provide good information but are not always based on systematic reviews of the best available evidence – for example, NHS Choices (www.nhs.uk) and PubMed Health (www.pubmed.gov/health) both provide high-quality information.

Of course, there is also a lot to be wary of. In particular, watch out for conflicts of interest, such as sites that might financially benefit from people believing the information or others that try to sell something. This can be hard to detect, however – for example, as we mentioned in Chapter 11, some patient groups have undeclared funding from pharmaceutical companies and that can taint the information provided.

Question 9: How should people avoid being ‘labelled’ with an ‘illness’ and getting unnecessary treatments?

Medicine has made amazing advances: vaccines and antibiotics for preventing and treating infections; joint replacements; cataract surgery; and treatment of childhood cancers, to name but a few. But that success encourages medicine to extend its reach to areas of less benefit. To a person with a hammer, the whole world looks like a nail; and to a doctor (or a drug company!) with a new treatment everything looks like an illness. For example, as better treatments for diabetes and high blood pressure have become available, the temptation is for doctors to suggest their use to patients with only slightly abnormal results. This dramatically increases the number of people labelled as

diabetic or hypertensive, ‘medicalizing’ many people who once would have been classed as normal.

In addition to any adverse effects of (sometimes unnecessary) treatment, this ‘labelling’ has both psychological and social consequences, which can affect a person’s sense of well being, as well as creating problems with employment or insurance. So it is important for patients and the public to recognize this chain of events; to pause and consider the likely balance of harms and benefits before too hastily agreeing to a treatment. As we discussed in Chapter 4, screening commonly causes these problems of labelling through overdiagnosis, and potential overtreatment.

The first defence is to be wary of labels and proposed further investigations. The seemingly flippant remark that a normal person is someone who has not been investigated enough has a very serious side to it. So it is always wise to ask whether the

WHO HAS DIABETES?

So how do we decide who has diabetes? When I was in medical school, our numerical rule was this: if you had a fasting blood sugar over 140, then you had diabetes. But in 1997 the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus redefined the disorder. Now if you have a fasting blood sugar over 126, you have diabetes. So everyone who has a blood sugar between 126 and 140 used to be normal but now has diabetes. That little change turned over 1.6 million people into patients.

Is that a problem? Maybe, maybe not. Because we changed the rules, we now treat more patients for diabetes. That may mean we have lowered the chance of diabetic complications for some of these new patients. But because these patients have milder diabetes (relatively low blood sugars between 126 and 140), they are at relatively low risk of these complications to begin with.

Welch HG, Schwartz LM, Woloshin S. *Overdiagnosed: making people sick in the pursuit of health*. Boston: Beacon Press, 2011: p17-18.

illness is considered high or low risk. And, as we suggested earlier, also to ask what would happen if nothing immediate was done: how might the condition be monitored, and what would be the signal for action? Some doctors are relieved that patients don't want immediate treatment or tests. But other doctors fall into the labelling trap – label = disease = mandatory treatment – not realizing that the patient may be quite happy to wait and see if the problem gets better or worse by itself.

WHERE DO WE GO FROM HERE?

The issues discussed above – about individual concerns and values, about understanding statistics and how they apply to individuals, and about the concerns of extending effective treatments to increasingly milder degrees of disease – all speak to a need for better communication between patient and doctor, and between the health sector and the citizens it serves. So we will finish this chapter with the Salzburg Statement on shared decision making, which sets out an agenda for different groups to improve how we work together.^{6,7}

Salzburg statement on shared decision making

We call on clinicians to:

- Recognize that they have an ethical imperative to share important decisions with patients
- Stimulate a two way flow of information and encourage patients to ask questions, explain their circumstances, and express their personal preferences
- Provide accurate information about options and the uncertainties, benefits, and harms of treatment in line with best practice for risk communication
- Tailor information to individual patient needs and allow them sufficient time to consider their options
- Acknowledge that most decisions do not have to be taken immediately, and give patients and their families the resources and help to reach decisions