

PROLOGUE

“I believe that patients will do better with their treatment when their doctors communicate information more effectively to them.”

Ever so often I meet a patient who looks me in the eye and smiles inappropriately and almost mockingly, who then suggests that I should rephrase myself so that I could be better understood. Whilst this is certainly not an unfamiliar situation for many doctors, I will not make excuses for our breed for our inability to communicate with the layperson. Let's admit it guys, we doctors are often so easily carried away by the science and jargon of our world that we unconsciously leave our poor patients behind at the starting blocks to figure things out on their own. We don't seem to realize that when we communicate information that is difficult to comprehend, patients are forced by our insensitivities to come to their own conclusions about their health. You cannot blame your patients if they come to a flawed conclusion or one with a wild twist. But fortunately for us, most of our patients ultimately find the correct answers. The problem is we doctors are not living in the real world. Many of us literally don't even see the lights of day. To make things worse, medical science has of late become frenetic in churning out new knowledge. There's barely enough time for the dust to settle before more data comes in. I am thoroughly convinced that it is frankly impossible for the layman to figure things

out. Despite all that's on the internet; or more precisely because of all that's (misleading) on the internet, laypeople shouldn't even try. There are less painful ways of doing this. I know all patients want to have everything and have it in a logical package. But manage your expectations, the logic is at best 80%, the rest of the 20% is still chaos. This book will hopefully give you enough of the ground-work to start some logical reasoning. If you can't even understand this book, take heart that you're normal and get on with the more important issues of getting well.

This book is deliberately written in everyday English and in a lighter mood for the benefit of those of us who visit doctors but don't really understand what the doctor said. It is meant primarily for patients with multiple myeloma^a (MM). However, this book may also be a valuable resource for family members, friends, doctors, nurses, as well as anyone else who is interested in considering a more-than-worthy alternative mode of therapy for MM, i.e. other than standard therapy. The author has the opinion that what has been loosely termed as "standard therapy" is (frequently) not necessarily the best form of treatment at all for patients with MM. In his experience, patients come in all shapes and sizes, so having only one size of whatever therapy will certainly not work for every patient.

Serendipitously, MM patients are spoilt for choice today. Exponential increases in bench-to-bedside (translational^b) research spending by academic and commercial agencies have greatly: (i) increased our current understanding of MM biology, (ii) accelerated the pace

^a My mentor in Harvard Medical School, Prof Kenneth Anderson, considered MM to be totally evil, and would not tolerate capitalization of the term "multiple myeloma" when written; as that would give the disease more respect than necessary. Ken was often right...

^b Basic Research refers to very fundamental studies performed usually in a laboratory. When the results of such research (e.g. a molecule) is used (or applied) to create a product (e.g. a drug) that can be used for clinical treatment, this is often called Applied Research. The final step of bringing this product from the research bench to the patient requires rigorous testing in the laboratory (*in vitro* testing), perhaps in research animals (*in vivo* testing), and finally in human clinical trials. This complex process is also called Translational Research.

of novel drug discovery, (iii) improved therapeutic drug targeting, and (iv) expanded patient access to these novel therapies. In other words, patients now have the luxury of picking and choosing from not just a few, but numerous new “designer” therapeutic compounds that have recently flooded the market. Accordingly, patients (and their doctors) can tailor their treatments to suit their diseases, their lifestyles, and most importantly, their pockets. Without a doubt, “boutique” medicines are the IN things for patients with MM. Costs aside, patients are no more bothered by treatments that might not work; today, they can “swatch” (mix and match) confidently between different highly-effective compounds to achieve: (i) better disease control, (ii) better adverse effects profiles, and (iii) more holistic healthcare programs that potentially result in “cure”.

The key to better therapeutic outcomes via individualizing of anti-MM therapy is an in-depth understanding of the group dynamics that dictate the algorithms surrounding the way doctors decide therapy. This is a no-brainer; things do not happen alone, they always affect the group. Enhancing or suppressing an aspect of treatment and/or response to treatment will lead to group effects within that single individual. It is vital to separate this concept from what the author considers as the most confounding information that can be gleaned (especially from the internet) by patients. It is what we know of, and unfortunately strive for in healthcare accreditation exercises, as evidence-based medicine (EBM) i.e. the artificial world of clinical trials.

Patients undergoing clinical trials are a highly-selected group of individuals who are required to fulfill stringent eligibility criteria. They are then subjected to fixed treatment regimens that have been designed by groups of investigators (usually renowned doctors) and representatives from the pharmaceutical (sponsoring) companies. Because of tight controls during the conduct of these trials, including strict rules that govern how data should be collected, one size is made to fit all, or else patients simply fall-out of the study. The data so obtained, with all these and more biases built in, is now deemed as medical “evidence”. When in actual fact what it is,

is nothing really more than a statistical valuation of that regimen in a highly confined cohort of patients.

Unfortunately, this information is then marketed as “truth” (for want of a better word), and frequently extrapolated to all patients, regardless of shape and/or size. Sadly, the actual physicians who advocate EBM might in fact be the most ill-informed lot; believing that they are doing their best at convincing patients to undertake certain therapies that could well be totally inapplicable. The author does not in any way discount the value of doing good clinical studies. He is in fact the principal investigator of a number of clinical trials. The author is only cautioning against the random extrapolation of such information, and the potential “accidental” misinformation that could occur when these study results are quoted to patients, who are by-and-large ignorant of the clinical trials processes. This fundamental point cannot be over-stated. Ultimately, a patient’s treatment is a very personal thing, and it has to be individualized, regardless of the clinical evidence. As a patient, the best treatment for you is simply the one that works, regardless of formal clinical evidence. And vice versa, the worst treatment you can receive will be the one that is thought to work for you but in reality does not fit you at all. You are you, an individual, and to you treatment must be individualized to suit you first.