

The Achilles Heel of the Patient-Care Process

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Grant Achatz, a famous chef, once declared in an interview that he would rather die than lose his taste buds, but faced with such a choice Achatz refused to accept either. At 35, he had noticed a white spot on the underside of his tongue and within a few months, half of the tongue was a white, crusty texture. Despite being a young, healthy male with no history of risk factors, five doctors confirmed that he indeed had cancer of the tongue and informed him that his only treatment option was to have his

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entire tongue removed. Adamant that radiation therapy was more suitable, Achatz headed to Chicago where he pursued a course of chemotherapy. The drugs left him weak and, for the better part of a year, Achatz lost all sense of taste. Despite feeling uncomfortable and uncertain at times of his treatment, Achatz persevered and today is not only the head Chef of a restaurant ranked 7th in the world but has also recovered full use of his tongue [1].

Grant Achatz’s story throws into light the involvement that many patients take in their own treatment. Sometimes at-home therapy (particularly after more aggressive treatments) is left in the hands of the individual, with life-altering consequences. Statistically, the repercussions of patient non-compliance are staggering: 10-20% of all hospital and nursing home admissions, totaling 340 deaths per day, are directly due to this phenomenon [2]. Even more worrisome is the number of pregnancies (almost 20%) resulting in patients not taking prescribed contraceptives [3]. In totality, these figures sum to a hefty estimate of between \$100 billion and \$300 billion a year of unnecessary healthcare costs in the US [4-6].

‘Non-compliance’ now has a two-fold definition: first, the failure to follow a drug regimen, and second, the failure to adopt other measures that contribute to improvement in health [7]. There are a variety of techniques that have attempted to control the former, but they have often come with ethical questions. For example, the tendency to provide exhaustive information on healthcare leaflets, especially regarding side effects, may make medications sound more dangerous than they actually are [7]. In a survey of 412 members of the Swedish Society of Oncology, 45% of doctors believed that patients would not participate if fully cognizant of all aspects of the study [8]. Nevertheless, fewer than half of the patients actually understood the concept of “randomization” in a test trial following the explanation by the doctor [8]. Regardless of the amount of information given, non-compliers make up a statistically significant and constant population.

For those with medical conditions that necessitate constant control, such as diabetes, compliance is absolutely vital. For diabetics, failure to take insulin arises in approximately 28% of patients [9]. Furthermore, there is a direct link between poor glycaemia control, acute hospital admission for diabetic ketoacidosis, and acute complications related to diabetes [9]. In one of the most comprehensive studies ever done in the United States, it was demonstrated that males and females are both just as non-compliant. There is, however, a strong age dependence—adolescents from ages ten to twenty report a much lower adherence index than any other age group [9]. Commonly cited explanations for non-compliance were weight loss strategies, manipulation, recklessness, error, or fatigue in the daily battle against diabetes. This study did not even take into account the 5% of patients who—after diagnosis—default from clinical follow-up and are at the highest risk for acute complications. These patients, unlike so many of their fellows, are faced with following medication throughout their entire lives and, perhaps unsurprisingly, are particularly vulnerable to non-adherence. Very little, other than increasing exposure to healthcare professionals and addressing medication in a formal setting (at a higher cost), can be done to ensure that teenagers, as the highest risk group, comply with their medication strategies [9].

One area where information does make a difference is in drug leaflets. Some patients who sit anxiously in the doctor’s office thumbing and re-thumb through the leaflets will even sometimes go online and, after reading the interpretations of other untrained sufferers, decide to only take half the dose for half the time [7]. Lastly, the “nocebo” effect where a patient’s predisposition is the key to physical and psychological side effects has been shown in several studies to have a serious impact on a patient’s choice of continuing treatment [7]. Luckily, there is a fairly clear and well-studied procession for those eager to address the power of the written word: reassess the current recommendations and make them easier to access, more readable in laymen’s term, and, above all, entirely truthful.

“ **Healthcare leaflets may make medications sound more dangerous than they are** ”

The question then naturally arises—why do so many individuals knowingly postpone, skip, or stop taking medications that could save their lives? In a complex study involving at-home leg physiotherapy, patients were interviewed through an initial phase with a therapist and then on their own as the study progressed [10]. In the beginning, most attempted to comply either out of an altruistic sense of responsibility toward the study or in order to please the therapist. When the therapy moved to the home, however, most patients only



Medical advice leaflets - encouraging hypochondriacs? Reproduced from [14]

incorporated the exercises that were easiest, that showed some immediate benefit, or that fit in with their lifestyle [10]. Some struggled to complete any whatsoever. This result corroborates with current sociological thinking—that patients follow treatment based on their experiences, their beliefs, and how the treatment fits into their daily routine, and this behavior does not bode well for a society-wide culling of non-compliance [10].

Finally, the most harrowing reason for patient non-compliance is historical instances of negligence by healthcare providers. Between the years 2000 and 2002 an estimated 195,000 patients died in hospital due to medical malpractice [11]. 400,000 preventable drug-related acts of negligence occur each year. A further 800,000 occur in long-term care settings, and roughly 530,000 occur just among patients over the age of 50 placed in outpatient clinics [12].

In the United States, the Tuskegee Syphilis Trial shook the trust of African Americans in healthcare providers—particularly as regards clinical studies. In Tuskegee, nearly 400 patients were observed until death for nearly 40 years in order to assess the clinical effects of long-term syphilis [13]. The patients were not told that they had a specific disease that is transmitted through sexual intercourse nor that the disease could be passed from mother to child. Furthermore, the men were deliberately denied treatment (penicillin) when antibiotics emerged after World War II. In the modern context, the result of deep-seated fear led major African American newspapers as well as some doctors and even a

television programme to assert, in 1991, that AIDS was a form of genocide created by mankind to curb their population. As a result, the SCLC (Southern Christian Leadership Conference), a civil rights group set up by Martin Luther King, was given funding by the Centre for Disease Control in order to provide HIV education. In their studies, they discovered that, at the time, while 35% believed that AIDS was a genocide (with 30% believing that HIV was a manmade virus), another 30% were unsure, and 44% believed that the government was lying about HIV while another 35% were unsure [13]. In particular, when HIV-infected women were encouraged not to have children and to use contraception, they misinterpreted this as a suppression of reproductive rights [13]. These results prompted the SCLC to report to the CDC that mistrust from African Americans could be a cause for serious concern for health officials. Within this context, the SCLC advised that healthcare professionals must be aware of the levels of mistrust and be informed about the details of the Tuskegee trial [13].

While this discussion has attempted to address what—on a global level—the caregiver can do in order to address noncompliance, patients such as Grant Achatz provide an example of how the patient-provider relationship has changed. Although the professional is almost always more informed and more experienced, patients are able (due to the internet, extensive publications, and speedier methods of communication), to learn about all of their options and make decisions accordingly. Just as patients must play an active partnership

role in their treatment, so too must healthcare professionals know their patients' medical care rights and act on them. It has been recommended that, while professionals should be entirely truthful about potential and clinically relevant side effects, so too must patients ask for a record of the drugs they have been prescribed including a print record of all medication [8]. Patients should also maintain a list of dietary supplements, over-the-counter medications, and hormonal contraceptive methods that may affect their patient care [8]. Fundamentally, if a trustworthy relationship is to be built, personal responsibility exists on both sides.

Given that each individual follows a course of action that seems in keeping with his or her lifestyle, it is somewhat surprising that non-compliance is such a pervasive outcome that consistently affects around 30% of those administering treatment to themselves [2]. Millions of pounds have gone into addressing non-adherence from a medical standpoint, as it is widely accepted that increased compliance will lead not



Antibiotics - how many of us actually complete the course? Reproduced from [15]

strains, it is becoming increasingly difficult to find panaceas for today's society like penicillin was in the 1950s. Despite better-phrased leaflets, more patient contact, and a number of other strategies all aimed at increasing face contact with patients, it is ultimately the individual's responsibility to consider not only what is best for his or her own health, but also what can ultimately affect the world-wide population. The solution is almost painfully simple: finish a treatment course, unless otherwise advised by a doctor. ■

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“Mistrust could be a cause for serious concern for health officials”

only to better patient health, but also to greater drug efficacy. With the rise of multi-resistant HIV and tuberculosis

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