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Truth Disclosure in Medical Settings

By Blake Rosenthal

In 2001, a forty-nine year old father and chemistry professor by the name of Scott¹ checked himself into the emergency room of a Pennsylvania hospital, complaining of severe stomach pain. Five days later, Scott underwent explorative surgery in order for his physicians to pinpoint the cause of his acute pain. During the operation, Scott's surgeon found masses upon masses of dead small intestine, which was later to have been found to be caused by a small blood clot in the patient's duodenum (first section of the small intestine.) Upon discovering this destruction in Scott's body, the surgeon left the operating room to discuss with Scott's family about the gravity of the situation. The surgeon proceeded to disclose the truth about Scott's prognosis; he bluntly stated to the family that the hopes of Scott making a recovery from this type of devastation were slim to none, and that he could either try and salvage some of the existing small intestine, or simply close Scott up, place him on a morphine drip, and let nature take its course. The family, although in grave shock and distress at the surgeon's disclosure of such a hopeless prognosis, told the surgeon to do everything he could to give Scott a chance at recovery. Against the odds, Scott made an almost full recovery; yet, for many years to come, his family was left tormented and depressed over the surgeon's initial disclosure of Scott's prognosis, which in the end, turned out to be incorrect. This case study brings to

¹ Note: the names in this interview case study have been changed in order to keep those involved anonymous. Interview performed September 20th, 2012.

light the negative effects that complete "truth telling" in medical settings can sometimes inflict on patients and their families.

Historian of medicine Olivio Galeazzi in his "Truth, Disease, and Prognosis: a historical anthropological analysis" defines, in philosophical terms, several aspects of "truth telling" or truth disclosure in the context of unfavorable diagnoses; Galeazzi's definitions of terms such as truth and prognosis shape the way one might reason through the ethical dilemma of truth telling in the medical profession. Significantly, Galeazzi comes to the conclusion that physicians should always practice completely honesty when disclosing difficult diagnoses to patients due to the "eternal trust in the relationship between doctor and patient" (49.) Other contemporary authors writing on this dilemma such Lesley Fallowfield in her 1997 "Truth Sometimes Hurts but Deceit Hurts More" similarly deem full truth disclosure absolutely necessary, albeit for slightly different reasons than Galeazzi. Although these contemporary authors make convincing arguments as to why full and truthful disclosure is integral to the functioning of the medical profession, examining the shift the dilemma has undergone of over the past fifty years— from concealing painful aspects of diagnoses to disclosing all features diagnoses—lends an added historical perspective that serves to qualify present-day notions about the necessity of absolute disclosure in all situations.

Tradition philosophical arguments can be made for or against full truth disclosure, and these arguments are vividly illuminated through Scott's case. It is important to recognize these traditional philosophical arguments for the reason that they are connected to and taken up by contemporary authors writing on the dilemma in order to validate their own viewpoints. Lewis Vaughn in his *Bioethics: Principles, Issues, and Cases* thoroughly defines and discusses these traditional philosophical arguments. One significant and traditional argument to consider is the

consequentialist line of reasoning. As defined by Vaughn, a consequentialist, specifically a utilitarian, would maintain that the best actions are always the ones that result in the maximization of good over bad consequences for all those involved (34.) In Scott's case therefore, a utilitarian might argue that it was wrong of the physician to prematurely tell the family that the Scott would most likely not survive. The reasoning behind this argument is that the consequence of the disclosure had the potential to create more harm than good to the majority of those involved, particularly to the mental health of the Scott's family.

In opposition to this utilitarian argument, a deontologist would argue that right and moral actions do not depend on consequences or the maximization of the happiness of all those involved; rather, as Vaughn describes, "rightness" for a deontologist lies within those actions that follow a universally applicable morally rule (34.) In this specific case, a utilitarian might argue that if the surgeon had genuinely believed that Scott was terminally ill, and also that he believed it to be his moral duty as a doctor of medicine to disclose the absolute truth to the family, the surgeon acted in the right and moral manner, regardless of whether Scott would actually get better, or whether this truth telling would have a lasting negative impact on Scott's family.

In addition to these utilitarian and a deontological arguments, a slippery slope argument could also be made in the dilemma of full truth disclosure. Vaughn describes slippery slope arguments as a series of premises involving unstated assumptions that may or may be unfounded are accepted, this leads to a conclusion that is also is inevitable (25.) In the case of Scott, a slippery slope argument could be made both for and against the surgeon's disclosure of the full truth. One might contend that if it was morally permissible for the surgeon to keep aspects of Scott's prognosis hidden, this could lead the surgeon down a slippery slope of failing

to disclose prognoses and diagnoses until this surgeon regularly lied to his patients. However, a slippery slope argument could also be made against the surgeon's full disclosure of Scott's diagnosis. In this "against" reasoning, one could argue that if it was ethically permitted for Scott's surgeon to disclose preemptively a prognosis that might not be true and also had the potential to severely harm Scott's family, then the surgeon would also find it morally permissible to disclose any sort of diagnosis or prognosis to a patient and the patient's family, regardless of whether or not the diagnosis was founded in certainty or if it was merely a speculation.

A last ethical position pertaining to the dilemma of full disclosure under all

circumstances is the "case-by-case" moral stance. This case-by-case argument forms the basis of Isle Wolff's 1955 article entitled "Should the Patient Know the Truth." Her argument will be elaborated on further during the "historical perspectives" of this essay.

The case-by-case position essentially reasons that the best moral actions come from carefully considering each case as if it were an individual entity and then deciding on the basis of the pros and cons of the individual situation, what the most moral course of action should be. In Scott's situation, an ethicist following a case by case stance might argue that if the physician was not completely certain of his prognosis, in addition to being aware of the specific family needs of the patient and the psychological strain that a very negative prognosis would elicit from the family, the physician might pause before foreshadowing a very hopeless conclusion. In another case, however, wherein an extremely elderly patient suffering from severe Alzheimer's was placed in the same situation as the interviewed patient, it might be morally permissible for the physician to proceed in telling the family his negative prognosis, provided

that the family members were in a healthy state in both mind and body, and were prepared for the loss of a loved one.

Despite the fact that each of these moral arguments, utilitarian, deontological, slippery slope, and case by case, are all valid ways of approaching the ethical dilemma of truth telling, it is difficult to deem which argument is the most convincing in light of Scott's particular case. In order to evaluate these arguments more fully, it will be useful to recognize current ethical arguments of the dilemma from both historians of medicine as well as researchers, writers who incorporate aspects of these traditional arguments in their papers. As mentioned in the introduction, Galeazzi in his 1997 article defines the meaning of truth, of illness, and of prognosis in order to "...shed light on three crucial elements in this complicated (delicate) task of communicating the truth about cancer" (44.) One of the fundamental aspects in Galeazzi's definition of truth is that truth and reality are two separate entities, and that reality only becomes truth when it is verbally communicated. In terms of medicine, "[c]linical reality certainly exists, discovered by scientific medicine (clinical and technical,) but this reality is different from the truth...the truth comes after and within the act of communicating not the other way around" (41.) Therefore, when a physician discloses the truth about a negative or unwanted diagnoses, he or she illuminates an unpleasant part of medical reality. Galeazzi asserts that although all science involves communication in one way or another, this "full, constant, mutual communication required between the subject [physician] and the object [patient,]" is present only in the practice of medicine, as the communication lies between two human beings who are fundamentally alike (42.) Galeazzi goes on to define the meaning of illness and the meaning of prognosis, which he describes again in terms of this fundamental communication between doctor and patient; these definitions, although important in

Galeazzi's subtler points, will be less integral to the argument of this paper. Galeazzi's discussion about the communication of truth and the revealing of certain aspects of reality, however, is hugely important to his position regarding the essential trust between physician and patients.

By taking this position that the innate, mutual trust between human doctor and human patient is absolutely essential to the communication of the truth, Galeazzi effectively calls upon a deontological argument; the rightness of this action of truth telling, in Galeazzi's opinion, depends entirely on a fundamental rule that physicians and their patients share a special kind of trust, a trust that upholds communicating the full truth in all situations. Galeazzi states that "...the eternal question of trust in the relationship between doctor and patient is a logical consequence of the prognosis that the patient demands from the doctor and that the doctor cannot avoid giving the patient' (49.) Therefore, the trust that binds a patient and his or her doctor supports and enforces the physician's duty to disclose fully the patient's diagnoses and or prognosis, and the trust is absolutely necessary because without it, the patient will find "..no information, not truth about the illness...it [the diagnosis] will seem provisional, weak, and doubtful (49.) This doubt in the patient is, of course, extremely undesirable because it could forecast further skepticism of the trust between patient and doctor.

The argument from Galeazzi certainly seems to be valid in that his premises about the fundamental trust between doctors and patients, as well as the duty of the physician to communicate truth to the patient, lead to a conclusion that a doctor should disclose the truth to his or her patients in all circumstances, so as to not lose the trust of the patient. His argument also seems to be sound in that both of the premises hold true. Yet, the one important piece that remains lacking from Galeazzi's work is the historical perspectives of the

dilemma. As alluded to earlier, historical contextualization is extremely important because it allows for the complication of otherwise straightforward ethical dilemmas, which, by themselves, are only informed and supported by philosophical arguments.

Before delving into the historical perspectives on the dilemma of truth disclosure, this paper will first discuss two other contemporary authors who make the case for full disclosure. Lesley Fallowfield in her "Truth Sometimes Hurts but Deceit Hurts More" includes a very powerful quote from Tolstoy prior to the introduction of her article. The quotes reads, "[w]hat tormented Ivan Ilyich most was the pretense, the lie...that he was merely ill and not dying, and that he only need stay quiet and carry out the doctor's orders and then some great change for the better would result" (Leo Tolstoy, The Death of Ivan Ilyich.) Although Fallowfield does not discuss this quote from Tolstoy in her article, it completely embodies her frustration with the idea that physicians should conceal the full truth of a prognosis or diagnosis in order to somehow protect their patients. To argue the point that physicians should practice full disclosure, Fallowfield expands on the many problems that can occur when the full truth is not disclosed. She argues that when a doctor fails to use accurate terminology in a diagnosis of cancer, or when he or she uses euphemisms to temper the difficult truth, the patient eventually "...sees through the lie...further distress may be created, as euphemisms serve only to reinforce the idea held by many that cancer is an unspeakably awful disease" (527.) In this instance, Fallowfield turns the original line of thinking (a doctor should do no harm, and if telling a patient a poor diagnosis creates lasting harm for them, the doctor should temper the diagnosis,) completely on its head. She states that in actuality, if a physician withholds information or tempers a diagnosis through the use of euphemisms, the physician harms his or her patients more than if he or she had simply stated the truthful diagnosis, due to the fact that

a patient is bound to discover the truth eventually. Again, this argument seems to be the same as the traditional deontological argument in favor of full truth disclosure, in that a physician's utmost duty is to "do no harm," and therefore a physician is required to disclose the entire truth to avoid doing harm.

Fallowfield also makes the case for full truth disclosure by introducing some of the significant consequences of a physician's failure to discuss death openly with patients. Although the discussion of death is extremely difficult for a physician in that a physician's generally mindset is to always save life, it is important to identify, as Fallowfield argues, that failing to recognize the inevitable in some cases leaves a patient wholly unprepared and miserable for the future. Indeed, Fallowfield states that it is often impossible to conceal the truth from patients as they can observe the "deterioration of their own bodies" (532.) Therefore if physicians try to maintain an empty optimism about a patient's future, the patient is likely to feel both confused and afraid. Additionally, preserving a mask of confidence prohibits a patient from making informed decisions about planning for the time that is left, and also planning for the future once he or she has passed away. Fallowfield accurately states that by concealing the truth about a prognosis, patients "...cannot reveal their fantasies about death and their anxious ruminations about what lies ahead. Consequently, unnecessary fears cannot by allayed" (533.) These arguments about the fear and unpreparedness wrought on a patient if the full truth is not disclosed, essentially return to Fallowfield's deontological point that a physician "does no harm" by disclosing the complete truth in all situations. This deontological argument presented by Fallowfield, although insistent to the extreme at times, is quite convincing. Like Galeazzi, her premises seem to be both valid and sound. The fact

remains, however, that Fallowfield's argument, similar to Galeazzi's, seems to be almost too "perfect."

These articles by reputable historians and researchers are quite adept at convincing a reader that full truth disclosure in all medical situations, especially in grave diagnoses situations such as cancer, is of the utmost importance. Their arguments also fall in line with the previously discussed moral perspectives of deontology and slippery slope that uphold ubiquitous truth telling. However, because these arguments are based solely upon by philosophical arguments and present day circumstances, their validity and applicability are too uncomplicated, too "neat." In actually, the dilemma of truth telling has had a debated past that is not altogether straightforward. Ignoring this historical influence, therefore, creates situations where enlightening information is left out and arguments fall into neat bundles that make complete sense; although uncomplicated arguments are nice to read, they do not always represent the whole truth.

Historical evidence from the 1950s and 60s, as illustrated through primary sources such as newspaper articles and images, indicate that debate about the dilemma of truth disclosure existed and was important at that time. Some of these sources seem to show support of full disclosure in all situations, whereas others seem to support modified and or incomplete disclosure in certain situations. In his 1965 article "To Tell the Truth," Dr. Neumann replies to another physician's published position (Dr. Rhoads) that a doctor should disclose all painful aspects of a cancer diagnosis to his patient. Neumann's reply to the position of Rhoads is that a physician's first and foremost objective should be to "do no harm" to the patient. Neumann's argument is based on two premises; the first of which is that when a physician's "...efforts to heal fail, he should continue to give hope" (159.) Neumann's second

premise is that human beings rarely wish to know their exact fate. He states that "Man does not like to know how long he is going to live, whether it is a month, a year, or ten years" (159.) These ideas about what exactly the principle "do no harm" stands for in the medical profession, seem to differ quite starkly from Fallowfield and Galeazzi's definitions of the principle. Indeed, researchers such as Klocker, Kaiser, and Schwaninger deem that definitions similar to Neumann's idea of the concept of "do no harm," was the standard of the mid 20th century era. In their article entitled "Truth in the Relationship Between Cancer Patient and Physician" from the 1990s, the researchers state that "[h]ardly a quarter of a century has elapsed since the time physicians were educated to tell compassionate and merciful lies to cancer patients" (56.) It is certainly true, as demonstrated by Neumann's published opinion about the dilemma, that many physicians during the 1950s and 60s upheld the notion that "doing no harm" meant keeping painful details about a diagnosis, or even the entire diagnosis itself, hidden from the patient. However, analysis of other historical primary sources reveals that the above sentiment did not entirely dominate the practice of physicians and other medical professionals during the mid 20th century.

"Should the Patient Know the Truth" was published by Isle Wolff in a May 1955 edition of *The American Journal of Nursing*. Unlike Neumann's article, Wolff argues that a physician should neither disclose the full truth in all situations, nor keep aspects of the truth hidden from patients in all situations. Instead, Wolff states that the best way to approach the dilemma is for a physician to analyze each case as an individual entity, and from there decide whether or not to disclose the entirety of a diagnosis or prognosis to the patient. At the time of her article's publication, Wolff was serving as the head mental health consultant Connecticut State's Department of Health, and previously, Wolff earned her nursing degree from two

nursing schools, one in Germany and one in Kentucky. Due to Wolff's strong nursing background, her article about truth disclosure in the medical profession gives special attention to the role of nurses in diagnosing processes, as they are generally the medical experts most in contact with patients. Wolff's assumes an individualized approach to the question "Should the patient know the truth?" She writes that it would be wrong for a nurse or doctor to "...rationalize that the patient is unable to take it [the diagnosis,] that the shock would cause him to give up prematurely...By reasoning and projecting in this way we confuse identities" (456.) This reasoning falls more closely in line with the reasoning of the contemporary writers Galeazzi and Fallowfield than the reasoning of Wolff's own contemporary, Neumann, indicating that there was perhaps debate surrounding the dilemma of truth disclosure during the 1950s and 60s.

Alternately, Wolff is also of the opinion that it would be wrong for a nurse or physician to decide to always tell a patient the complete truth in every situation because "...the patient's needs are by bypassed, and the nurse's [or physician's] own needs take precedence" (547.) In both cases, therefore, absolute and inflexible reasoning on the nurse's part is unethical because the nurse effectively removes the individual patient's autonomy from the situation and instead inserts her own interests, either intentionally or not. Wolff offers that the best and most ethical route in truth telling is to "...take cues from the patient himself," thereby operating on a case-by-case basis (547.) She reasons that this route allows a patient to maintain full autonomy and dignity. Wolff's argument as asserted in this 1955 article is extremely interesting in that she disagrees with concealing the truth about a difficult diagnosis from a patient and also in that she introduces questions of patient autonomy, a valid ethical point that is neither discussed by Fallowfield nor Galeazzi.

Historical context may give clues as to why Wolff emphasizes patient autonomy in her argument for the case-by-case stance for truth disclosure. "Should the Patient Know the Truth" was published in the mid 1950s, post World War II and on the precipice of the Civil Rights Movement. This era in America is generally thought of as one of optimism and confidence in American government, family dynamics, and technology, while also trending toward the increased defense of individual freedom and autonomy. In terms of the medical profession, high levels of patient faith in physicians and in medical technology (or perceived faith) led to paternalistic doctor patient relationships. However, Wolfe's reasoning slightly contrasts with this paternalist doctor patient relationship of the 1950s in her recognition of the importance of separating the medical expert's needs and desires from the patient's own wishes. Wolff's rather non-paternalistic and individual centered decision-making approach could of course be a result of her status a woman in the medical field. Despite the fact that women in America had gained the right to vote nearly forty years earlier, women were still vying for an evening footing with men in terms of social status and professional equality in the 1950s and consequently Wolff, as an educated and influential woman, may have been partial towards non-paternalistic methods due to paternalism's tendency to ignore the role of the patient's choice. Regardless of Wolff's gender, her article when compared to Neumann's piece, reveal that historical perspectives on the dilemma of truth disclosure were not uniform. This variation in thought during the mid 20th century serves to inform modern day notions about the dilemma by illustrating that beliefs about the importance of truth telling have not progressed from some "uniformed" and incorrect belief to some later "enlightened" belief; rather, debates about the dilemma occurred in the 1950s and 60s, and most likely those debates still exist today.

Still, as evidenced by the articles by Galeazzi and Fallowfield, as well as other modern images that will be discussed later, there has been a noteworthy change over time in attitudes toward the dilemma of truth disclosure. The dominant attitude of the 21st century seems to be one of complete and full disclosure, whereas there appears to have been more debate in the 1950s and 60s about the degree of truth to disclose in severe diagnosis/prognosis situations. This shift in attitude may be accounted through social and technological developments. The researchers Bass et al, in a 2006 article about the relationship between internet health information access and cancer diagnoses, state that the modern boom in technology has built a "communications revolution," which has created an environment where access to health information is equalized throughout the population. According to the researchers, "201 million individuals are accessing the Internet, 68% of the United States population" (220.) Indeed these new technological resources that have grown steadily in accessibility over the past decade, have begun to shape and change the traditional relationship between patient and doctor. Bass et al. emphasize that information about disease symptoms and treatments, which was once privy only to health care professionals, is now available to the larger population through the internet. Although this paper is less concerned with how newly diagnosed cancer patients' access to a massive medical bank of knowledge previously unavailable to them has altered their sense of agency and self-efficacy, the main point about technology shaping the way that patients and doctors interact is significant. It is noteworthy in the context of the truth disclosure dilemma in that, if patients have a greater sense agency due to increased availability of self-found knowledge, physicians may be more likely to disclose the full truth because 1) patients will almost certainly find the truth of their diagnosis themselves and 2) patients may be better equipped to deal with a severe diagnosis if they themselves can seek out aid and information.

Larger social issues may have also contributed to the change over time regarding the truth disclosure dilemma, a change that has occurred over the span of fifty years. As alluded to earlier, the civil rights movement took place directly following the 1950s. Although this movement most likely did not have a direct effect on the dilemma of truth disclosure, it perhaps indirectly affected the dilemma by altering the general mindset of the US population to one more focused on the individual rights and freedoms of all citizens. This modern emphasis on individual autonomy has possibly led to the evolution of a doctor patient relationship that has a greater emphasis on the rights of the patient, privileges that include a patient having the right to know exactly what a medical procedure entails, more commonly know as informed consent. Specifically, in 1973, the Patient's Bill of Rights was approved by the AHA House of Delegates, and within it were specific legal guidelines which delegated a patient full rights to know the exact details of his diagnosis, treatment, and prognosis. Consequently, doctors today are required to tell a patient the truth of his or her diagnosis. These legal proceedings, of course, have had a substantial effect on the ways in which physicians approach disclosing diagnosis information to patients. Although these social changes and subsequent legal proceedings have improved aspects of the medical system in terms of standardized informed consent and accessibility, the standardization has not necessarily resulted in patients' understanding their diagnoses more fully, or understanding their full range of treatment options. These failings in modern-day medicine have been critiqued widely by many authors, researchers, and artists.

An excellent portrayal of this present day critique of the patient doctor relationship and of informed consent can be found in contemporary cartoons. The cartoon entitled "Give it to me nuanced Doc," published in a 2010 edition of *The New Yorker* by Mike Twohy is one such cartoon. The setting of the carton is a sterile medical examining room, with the only adornment on the wall being the physician's diploma. Twohy deftly portrays the middle aged male patient as an intimidated child-like character; his dressing gown is whimsical with swirled designs and neat bow ties in the back, and his feet are nestled together, with his long socks emphasized through dark shading; his hands are placed earnestly on his knees and his eyebrows are arched upwards, indicating anticipation of the doctor's next words. In comparison to the patient, the physician looks rather haughty and intimidating with his square glasses, bushy mustache, pointy nose, and downward peering gaze; his receding hairline in concurrence with these other details highlight his age and experience. Interestingly, the patient actually asks the physician to "nuance" the negative diagnoses, thus tempering any information that could be painful or difficult. This request seems to indicate a disillusionment of the present day full and "harsh" disclosure of the truth in diagnosing situations. Whether or not the physician replies with that patient's request, one cannot say. However, this cartoon very accurately portrays both the lack of connection between doctor and patient that has been critiqued by many, as well as a satirization of the modern day emphasis on full truth disclosure in all situations.

Although this cartoon's main purpose is, of course, to be funny, the larger message reveals a certain degree of the discontent that seems to be felt by modern society about the doctor patient relationship and truth disclosure. Returning again to Fallowfield and Galeazzi's arguments for the case of full disclosure in all diagnosing situations, there does seem to be a

disconnect in the way in which these authors view the trust in the doctor patient relationship and the way that other individuals in today's society view that same relationship. Additionally, the lack of historical perspective in the modern day articles analyzed for this essay, as well as the assumption that the historical attitudes were homogeneous, reflects poorly on these authors' arguments. Indeed, it seems as though an account of the historical perspectives on the dilemma of truth disclosure is absolutely necessary, as this account reveals that there were debates surrounding the dilemma and that those arguments vying for compromised disclosure or case-by-case truth disclosure were supported and valid. The modern author Fallowfield, however, does make one short statement that admits to the importance of "delicate" truth telling in difficult diagnosis situations. She states that "[b]lunt, brutal truth telling is not acceptable either, and patients also have rights to more limited information if they have been given an opportunity to express the preference clearly" (534.) Despite the fact that this statement is tucked away at the conclusion of her piece, it speaks to the place of the comprised disclosure or case-by-case disclosure in certain situations, even in modern day medicine. Revisiting Scott and his family once again, their personal interaction with the ethical dilemma of truth disclosure especially illustrate the consequences of full and harsh truth disclosure. The interview with Scott truly represents that full and immediate truth disclosure in all situations is perhaps not the best ethical stance, and also that modern day notions of the dilemma are flawed in someway. This dilemma is extremely difficult to work through; it is hard to imagine that there exists a true right or wrong answer. Yet, Scott's case in addition to the historical perspectives on the dilemma, seem to indicate that ubiquitous truth disclosure should not be taken for "truth."

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