

# The Role of Autonomy and Information In Patient-Physician Clinical Decision- Making

Anoeil Odisho

Supervisor: Professor Benjamin Handel

University of California, Berkeley, Economics Department

Fall 2018

## Acknowledgments

I would like to thank Professor Handel for assisting me in developing a model for this thesis, as well as guiding me throughout the semester regarding our meetings and discussions. I would also like to thank my mother, my father and my brother for supporting me throughout the development of this thesis. Finally, I would like to thank Stephen J. Dubner and his podcast *Freakonomics Radio* for the initial idea to write this thesis.

## **Abstract**

The patient-physician interaction has changed due to recent trends in medicine that favor more patient autonomy about their own medical decision-making and the onset of multiple sources of medical information outside of the doctor's office. Many papers have examined this issue as to whether or not this is beneficial for the patient's health. The goal of this paper is to develop a model that can accurately describe the expected marginal benefits of the patient having more control over their own medical decisions and their capacity to incorporate their medical information as well as the costs of dealing with such information. This also involves patients having different parameters regarding how detrimental hassle costs are, and how much they value their health. Simulations were run in R software that examined different examples of diseases in order to portray theoretical marginal benefits for the patient given different levels of patient autonomy. These simulations also involved varying patient parameters and varying hassle costs for the patient. R software was used to generate 3D visualizations to accurately portray the relationship between hassle costs, patient autonomy, and hassle cost multipliers, as well as expected marginal benefits, patient autonomy, patient health value multipliers. Visualizations were also used to describe how if patients had more information and autonomy regarding a specific disease, costs of attaining information remain small relative to the increasing marginal benefits. Simulations regarding different diseases were used to make an approximate matrix to describe when certain diseases need patient involvement or not.

# I. Introduction

The patient-physician interaction in clinical decision-making is at the heart of medical treatment and health care systems, and is an intimate interaction between the personal health issues of the patient and the informed, trained experience of a medical professional, and remains the cornerstone of medical care. Such an interaction provides a medium for the gathering of data, interpreting such data into appropriate diagnoses and treatment options, and facilitates healing, compassion and humanity to allow for an effective and therapeutic doctor-patient relationship, emphasizing the science, art and heart of medicine (Goold, 1999). However, more specifically, there has been a very recent resurgence of interest in examining the information gap of the patient and the physician due to increased access to information as a consequence of the Internet. Additionally, contemporary trends in medicine have shifted away from a relationship that previously involved a paternalistic scenario of the physician instructing the patient what to do, and has evolved into increasing patient involvement regarding their own health care decisions, and possible treatment options. Such recent trends have left many researchers examining and trying to understand whether these developments are optimal for the patient's health and for medicine as a whole. We will now examine several aspects of the work that has been done in this field.

## II. Literature Review

### A. Medical Information From the Internet

The Internet has led to an increase in readily available information that can be accessed by patients and consumers, with medical websites such as WebMD.com and health organization

websites providing guidance on a variety of medical ailments. Such websites include the Mayo Clinic, as well as a plethora of medical associations, organizations, and specialty groups, such as the American Association of Neurological Surgeons. Such information may also come from other websites with questionable authority and guidance on illnesses and how to diagnose or treat such illnesses, either through blogs, social media groups, or message boards. Currently, 93 million Americans have used the Internet for a range of health-related topics, ranging from immunizations to mental health (Weaver, 2013). This exponential increase in the availability of medical information, both credible and not has been examined by researchers. Ahmad and Hudak (2006) discuss the negative impacts of Internet-based information by tape-recording several focus groups of patients that brought Internet-based health information to physician appointments, and categorized themes in several conversations. What was discovered was that patients would often be misinformed about their affliction, be more prone to self-diagnosis or self-treatment, and would lead to additional emotional distress, which was verified by Herrle and Moore (2011). Hamm and Smith (1994) also found patients are not very accurate in diagnosing diseases correctly as well. Among medical professionals, there is a difference in whether the professional believed the information was beneficial for the consultation, as Dilliway and Maudsley (2008) found that nurses believed the information was very helpful compared to general practitioners (87.1% to 37.7%). They also found that these patients may also request additional treatments or medications that could lead to a misallocation of medical resources, putting additional costs on an already expensive system. Such patient information also leads to physician stress and exacerbates time constraints, as this introduction of false information to misinformed patients would require the physician to take time to re-inform the patient correctly. Additional concerns are raised where misalignment of the patient's online findings and the

physician's recommendation leads to patient dissatisfaction, and possible physician or treatment plan changes.

## B. Shared Decision-Making, Communication and Consumerism in Healthcare

The trend of increasing consumerism in healthcare predated the widespread use of the Internet by approximately one decade, yet still provides clear insight into changing attitudes about the patient-physician relationship. Haug and Levin (1983) analyzed three different surveys, two of which involved the general population and a third involved primary care physicians, with the authors discovering trends that implied the erosion of physician authority, an increased desire to be part of shared decision-making for treatments, and that doctor's visits have become more communicative between the physician and the patient than before. A movement in the 1990s also bolstered the shift in consumerist health care as doctors became increasingly aware of a patient's chronic pain (Lopez, 2015). A consumerist model of healthcare advocated a discussion for what the patient wanted and what the physician could provide, which in this circumstance was pain medication. The desire to treat patient's chronic pain was abetted by pharmaceutical companies developing new prescription opioids that were marketed as less addictive. However, these opioids were still highly addictive, and physicians would have to take their patient's word about their pain because of how subjective such a measure could be. The current ongoing opioid crisis serves as an example of how putting too much decision-making power in the hands of consumers could have negative affects on health for patients and the medical system in general. However, Brédart et al. (2005) analyzed studies that examined different approaches in improving doctor-patient communication in oncology, and pointed out that facilitating such communication has positive benefits for patients' sense of comfort and satisfaction. Additionally, Tongue (2005) emphasizes how better doctor-patient communication leads to increased patient adherence to

medication regimens, and improved clinical outcomes. Such communication is also much more necessary than doctors currently realize, as Canale (2000) presents discrepancies between physicians' perceptions of orthopedic care and communication and patient's perceptions, highlighting that while 71% of physicians believed they were compassionate and caring, only 37% of patients believed so. Similar rates were found regarding the doctor spending adequate amount of time with patients. The research overall indicates the necessity in including the patients' input in clinical decision-making and improved communication, however there are precautionary tales about the role of too much patient autonomy, as well as possible distrust in medical authority.

### C. Discussions of a Shared Clinical Decision-Making Model

Emanuel and Emanuel (1992) developed the initial model to describe patient-physician interactions in a more abstract and sociological context. They lay out a one-dimensional spectrum, where one end involves low patient autonomy and values, and the other end involves high patient autonomy and values. According to their model, autonomy and values are mutually varying, as a certain patients' values have no bearing on the possibility of a shared, clinical decision if the patient has no autonomy to make such a decision in the first place. They advocate four models along this spectrum. Near the low autonomy/values end of the spectrum, there is the *paternalistic* approach, which is more typical of physician appointments and clinical decision-making of the past, as the physician independently decides what intervention is needed for the patient, without much patient input. Increasing levels of patient autonomy and values lead to the *deliberative* approach, involving strong specific recommendations by the physician, but involve the patient's values and inputs more. Following this trend is the *interpretive* approach, where the physician acts more as a counselor to help discover the values of the patient in order to make the

best decision for themselves. At the end of the spectrum is the *informative* scenario, where the patient makes all clinical decisions and the doctor is simply a conduit of information. Other models expand and build upon this spectrum baseline in various capacities, either involving the influence of family and friends in decision-making, or how Agarwal and Murinson (2012) develop a three-dimensional model that involves one axis of autonomy, one axis of values, and one axis of information, all on a somewhat arbitrary spectrum of low to high. The Emanuel and Emanuel model provides a strong baseline for how to approach our own theoretical model, as different patients have different levels of autonomy and values. Charles (1997) improves upon this by explaining that this spectrum is continuous rather than a collection of explicit points on a line. However, additional models simultaneously do not provide a mathematical framework to translate these ideas into models, and overcomplicate the relationship in a way that makes the clinical decision-making difficult to mathematize coherently. We can still use these models to create our own theoretical model that can effectively explain the change in autonomy in a patient-physician interaction as well as involve the differences between patients and their preferences.

## III. The Theoretical Model

### A. The Shared Autonomy Between the Physician and the Patient

The interaction between the patient and the physician is that of a typical information asymmetry problem. One party, in this case the physician, has more access to relevant medical information than the other party, in this case the patient. The dynamic of the interaction between the patient and the physician is that the patient needs to buy a certain amount of healthcare in order to no longer be sick, and the doctor needs to provide a certain treatment based on their

information, training, and correct diagnosis. The physician typically spends four years in medical school, in which medically relevant course material spans approximately two years, followed by two years of clinical rounds that vary between specialties that the physician needs as a baseline to be a medical professional, and also pique interest in further medical training. This training is called residency, and encompasses another three to seven years of on-the-job, hands-on experience and work regarding a specific specialty. After such extensive learning and work, the physician may choose to pursue a fellowship or practice medicine after becoming board-certified. This is a stark contrast to the typical patient who, outside of common knowledge treatments for common diseases such as colds or infections, does not have either the extensive information or training as a physician. This highlights the expansive information gap between the physician and the patient, and emphasizes the immense difficulty and impossibility in trying to bridge this gap despite good intentions to do so. The patient could read an entire textbook about a particularly rare disease, such as Cushing's Syndrome, but they may not have the background to understand the disease, much less the training and experience to deal with such an issue at the same level as a doctor. With these ideas in mind, the information the patient provides the physician is still essential for improving medical outcomes, as the physician cannot use their own knowledge and experience without knowing anything about the patient. But the information the patient brings, and the autonomy the patient has definitive costs and benefits to describe.

In the typical interaction between the patient and the physician, there is a varying degree of autonomy, which essentially defines the amount of control the actor has in the interaction, as well as the information held. The logic behind this is that the patient could listen to just what the doctor orders, or the patient could have a certain level of information about the disease and themselves, and that information is only useful if the patient has a certain portion of control on

their own medical decision-making. The patient could have all the autonomy, the physician could have all of the autonomy, or there can be variations in the shared autonomy, as discussed in Emanuel and Emanuel (1992). As a result, we will define autonomy as  $A$ , with  $A_P$  defining patient autonomy, and  $A_D$  defining the doctor's autonomy. In this context, autonomy is the capacity of the actor to have a role in their decision-making and encompasses the information of the actor, since such information has no functional capacity unless the actor has some control or autonomy in the interaction.  $A$  can be written into Equation 1 as

$$A_P + A_D = 1 \text{ (Eq. 1)}$$

as the total autonomy between the patient and the physician must equal 1, or 100%, and whatever autonomy the patient does not have implies that the remaining autonomy belongs to the doctor. This implies a minimum value of 0 for either  $A_P$  or  $A_D$ , or a maximum value of 1 for either  $A_P$  or  $A_D$ . We also assume patients have full insurance, or availability for all treatment options.

## **B. The Hassle Costs of Medical Information and Decision-Making**

Despite information becoming much more readily available through the Internet, information is not free. Information requires inputs of energy and time and effort, and the patient that decides to find additional information about their specific medical condition on the Internet or other sources is engaging in real-time costs. These can be described as hassle costs, costs that we can associate with finding and handling information, as well as the stress and emotional burden carrying such information can have. We can describe this in Equation 2:

$$C(A) = \gamma A_P \text{ (Eq. 2)}$$

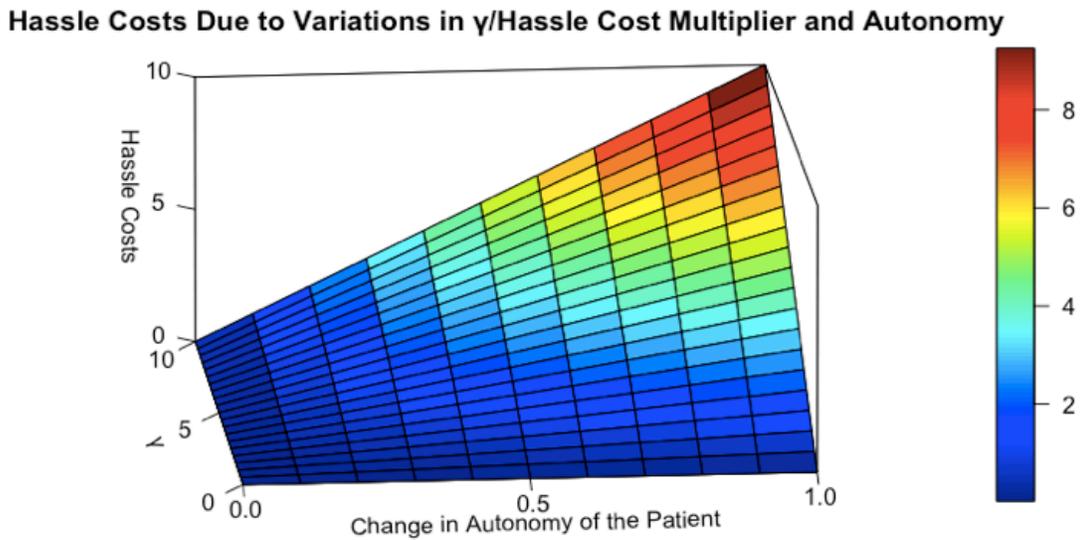
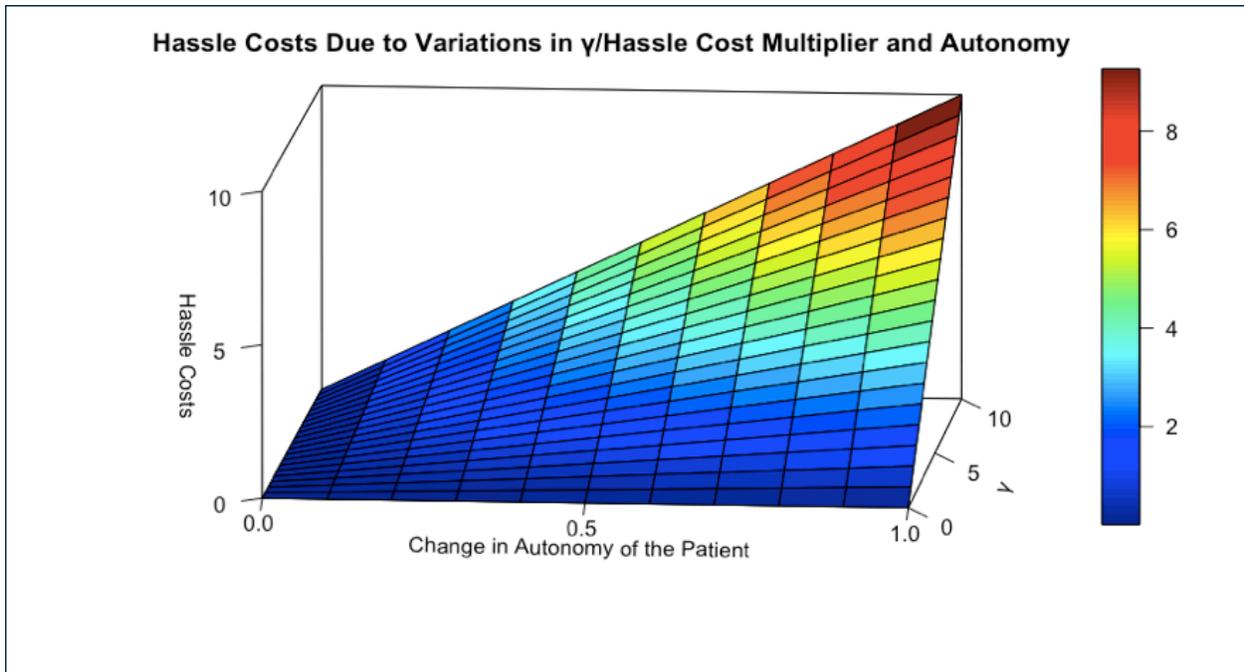
where  $\gamma$  is the hassle cost multiplier of the particular patient. This is necessary to clarify because different patients may not believe it is very costly to spend a significant amount of time learning about certain medical illnesses, while other patients may believe such information creates

significant hassle costs. Through this equation, we can explore hypothetical cases that describe different patients and different levels of autonomy. For someone with no information or autonomy about their medical decision,

$$C(0) = 0$$

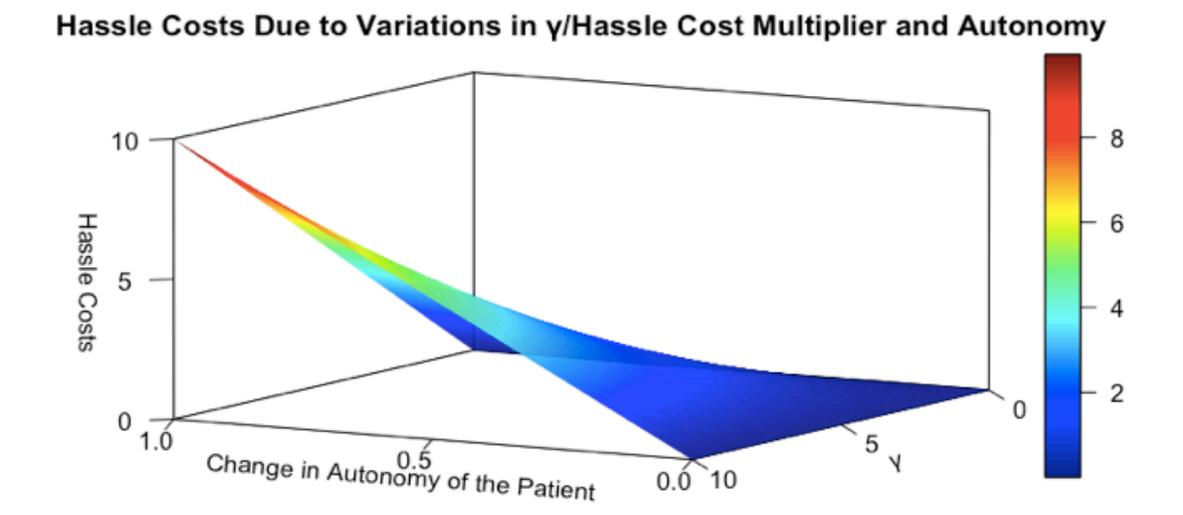
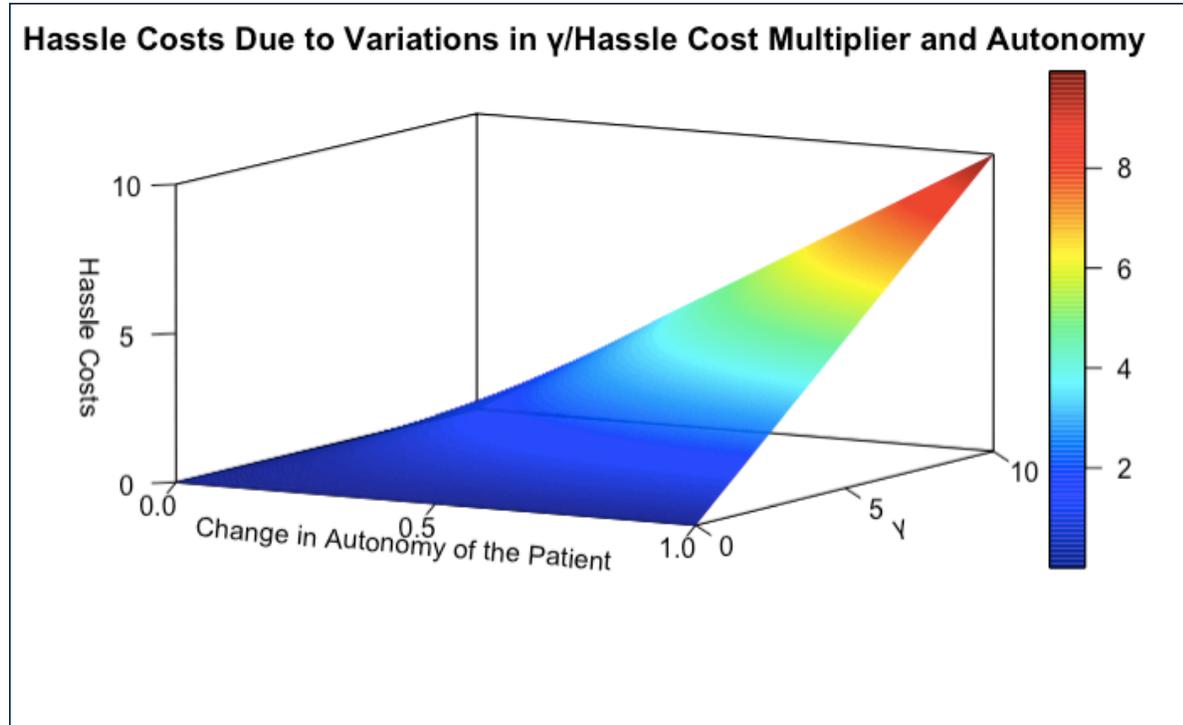
as there are no hassle costs associated with handling no information. In one scenario, we could have a patient with a low  $\gamma$ , where the patient can spend hours looking at information and easily deal with the stresses of such an endeavor. Additionally, the low value of  $\gamma$  means that this person will not see a large difference in hassle costs when dealing with either high  $A_p$  or low  $A_p$ . This parameter can explain different patients, one of whom would like to know substantial information because they know the amount of information will not hassle them significantly (low  $\gamma$ ), or another patient that does not want to deal with significant information and would rather not deal with the hassle (high  $\gamma$ ) because the stress or cost of dealing with such information is high. The high  $A_p$  or low  $A_p$  points out varying levels of autonomy that the patient has in their decision making. High  $A_p$  indicates significant patient control, most like the patient in the *informative* Emanuel and Emanuel model, where the doctors are simply conduits of medical information, and the patient now experiences costs of making a decision and finding information in order to make a better decision. Low  $A_p$  indicates more doctoral authority on the medical decision-making process, more likely directing the patient what to do in the *paternalistic* Emanuel and Emanuel model. If for example, a patient wants to attain a high  $A_p$  and has a high  $\gamma$ , then spending several hours researching their specific ailment will have significant hassle costs due to the patient's personal response to stress and amount of control over their medical decision. 3D graphs were generated in R to show how if a patient becomes more autonomous

and uses energy to find information, their hassle costs increase. Additionally, various  $\gamma$  values have been simulated in order to indicate patients with varying cost multipliers.



In the images above, the Change in the Autonomy of the Patient changes by steps of 0.1 from 0 to 1, and  $\gamma$  (Gamma, the Hassle Cost Multiplier) changes by steps of 0.5 from 0 to 10. This is a

visualization to simulate different hassle costs as due to varying changing levels of patient autonomy and  $\gamma$ . These are additional images regarding more detailed changes in the parameters. For the Change in the Autonomy of the Patient, the changes are by steps of 0.01 from 0 to 1, and  $\gamma$  (Gamma, the Hassle Cost Multiplier) changes by steps of 0.01 from 0 to 10. These are the same graph, just shown at different angles, to clarify the 3D visualizations.



Regarding the cost model, it is important to note not only the increasing costs of the patient as they are given more autonomy, and hence, more capacity to find more information, but it is also important to note that where the patient's autonomy begins and ends also matters. For example, in regards to the common cold, most patients would have a certain level of autonomy above zero, because not only do people know what to do most of the time when they have the common cold, but they also have the capacity to act upon that information. These patients inherently have a high  $A_p$ , at least for the common cold. They do not need to incur the costs of studying for hours at home, since they may already inherently know what to do about the common cold (get rest, drink fluids, take some over the counter medication). This is why in the graphs above, we specify the x-axes as the change in patient autonomy. Therefore, we can include initial values of patient autonomy in Equation 3:

$$\Delta C(A_p^{Disease}) = \gamma(A_p^{Final,Disease} - A_p^{Initial,Disease}) \text{ (Eq. 3)}$$

In reference to our common cold example, a patient may have an autonomy of 0.7, and for this case, the patient has a Hassle Cost Multiplier/ $\gamma$  of 1. If this patient does not put any effort into finding additional information, then this person does not experience any hassle costs of finding that additional information to begin with. However, if they are given more control over their decision-making and decide to find information regarding their disease, in this case, the common cold, then the value of the patient autonomy increases, hypothetically, to 0.8. In our formula,

$$\Delta C(A_p^{Common Cold}) = \gamma(A_p^{Final, Common Cold} - A_p^{Initial, Common Cold})$$

$$\Delta C(A_p) = 1(0.8 - 0.7) = 0.1$$

This means that certain patients have inherent autonomy based on the disease they are impacted with, and whether they choose to pursue additional information about their specific disease

incurs hassle costs depending on the initial level of patient autonomy and information, and the final level. As another example, we can again look at Cushing's Syndrome, a rare disease that affects at most 15 Americans per one million per year, which involves the body producing too much cortisol, or stress hormone, according to the American Association of Neurological Surgeons. The disease can be caused by the patient consuming medication that produces too much cortisol, or by a tumor in the body producing the hormone. With such a rare disease, a patient's initial autonomy or baseline of information is most likely 0. However, with the need to understand what specifically is causing the disease, the patient would more likely do research online to help themselves and the doctor understand what may be causing such symptoms. As a result, the patient would most likely have an initial  $A_p$  of 0, and after spending several hours researching this disease, could have an  $A_p$  of 0.5. Assuming again a Hassle Cost Multiplier/  $\gamma$  of 1,

$$\Delta C(A_p^{Cushing's Syndrome}) = \gamma (A_p^{Final, Cushing's Syndrome} - A_p^{Initial, Cushing's Syndrome})$$

$$\Delta C(A_p) = 1(0.5 - 0) = 0.5$$

The patient has spent much more effort and incurred more hassle costs to deal with such information just because of the rarity of the disease, and such disease rarity inherently means there is less common knowledge about this disease that is available for everyone. Again, we can examine Equation 3:

$$\Delta C(A_p^{Disease}) = \gamma (A_p^{Final,Disease} - A_p^{Initial,Disease}) \text{ (Eq. 3)}$$

Here, the parameters involved are  $\gamma$ , which is the hassle cost multiplier of the particular patient, and as discussed earlier,  $A_p$  is the autonomy of the patient, indicating the capacity of attaining medical information and acting upon that personally found. We add the superscripts of *final* and *initial* to indicate changes in patient autonomy from before learning medical information to after,

as well as the superscript of *Disease* in order to specific different patient autonomies for different diseases, as discussed in our previous examples of comparing the common cold, a common illness, to Cushing’s Syndrome, a very rare disease.

### C. The Expected Marginal Benefits of Medical Information and Decision-Making

When examining the marginal benefit of knowing a certain amount of information and having a certain level of autonomy in medical decision-making, it is useful to describe the marginal benefit as any benefit of additional treatment above a standard physician baseline treatment. For this reason, we will consider the standard physician baseline as 0, and any marginal benefit for additional treatment will be a non-negative value that can be determined through expected value. We know that expected value for continuous variables is determined by

$$E[X] = \int_{-\infty}^{\infty} x f_x(x) dx$$

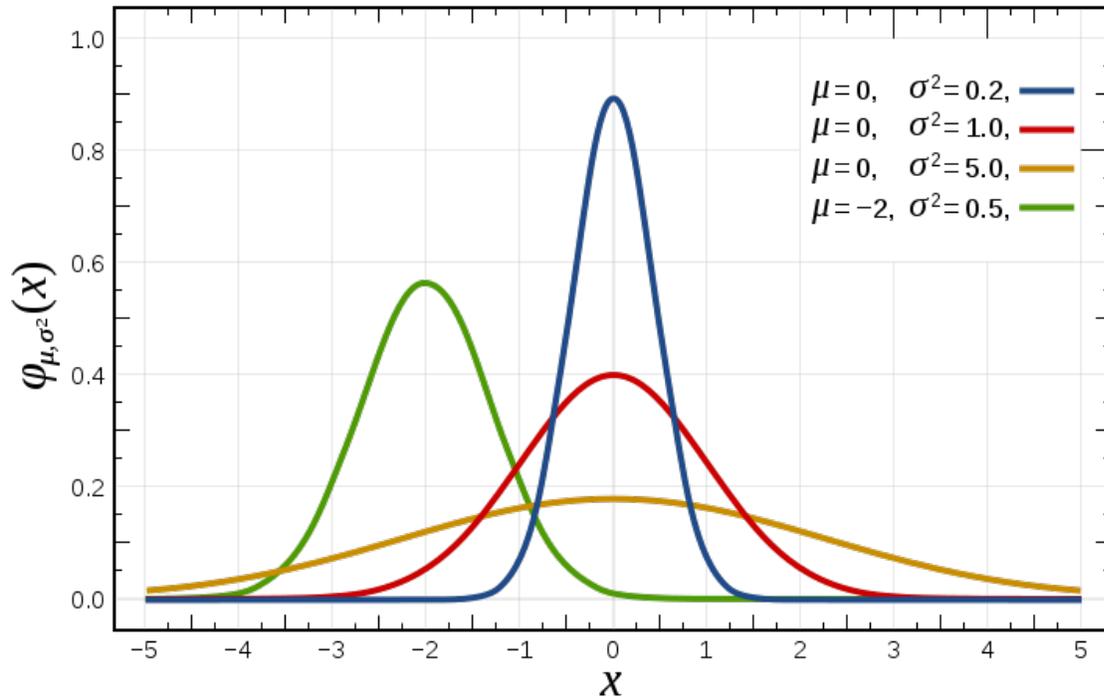
For the expected value of discrete variables, the formula is

$$E[X] = \sum_{i=1}^n x_i p(x_i)$$

We can use similar concepts to apply to our model regarding  $A_p$  and expected values based on  $A_p$ , treating  $A_p$  as the probability that a patient could find a certain value of marginal benefit due to the additional information found outside of the doctor’s appointment. Our goal is to find the expected value of the marginal benefit of additional treatment, given a specific autonomy of the patient. We can use an inverse cumulative distribution function in order to graph this relationship. We start with a baseline to graph a normal distribution, with the formula

$$F(x) = \frac{1}{\sigma\sqrt{2\pi}} e^{\frac{-(x-\mu)^2}{2\sigma^2}}$$

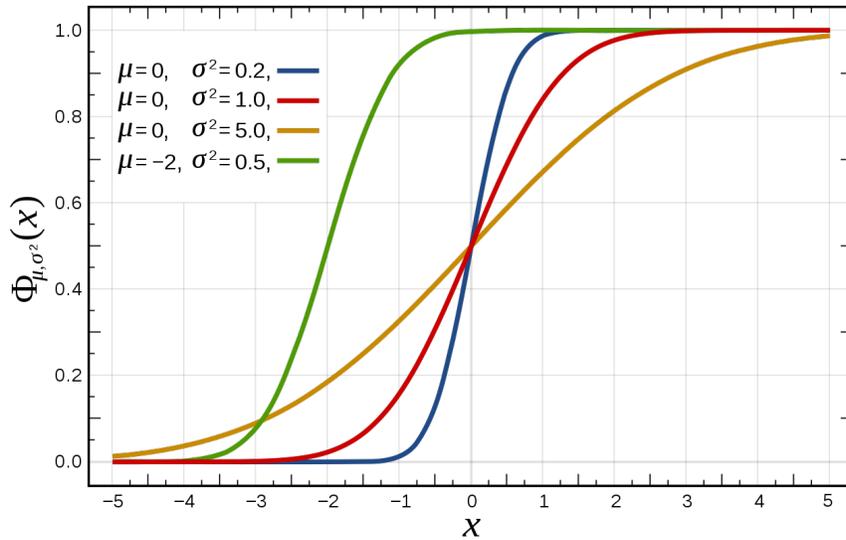
Variations in  $\mu$  and  $\sigma$  allow for different normal distributions to be graphed, such as indicated below.



Converting the normal distribution to a cumulative distribution function involves an integration to find the cumulative distribution function formula, indicated here

$$\Phi(x) = \frac{1}{\sigma\sqrt{2\pi}} \int_{-\infty}^x e^{-\frac{(t-\mu)^2}{2\sigma^2}} dt$$

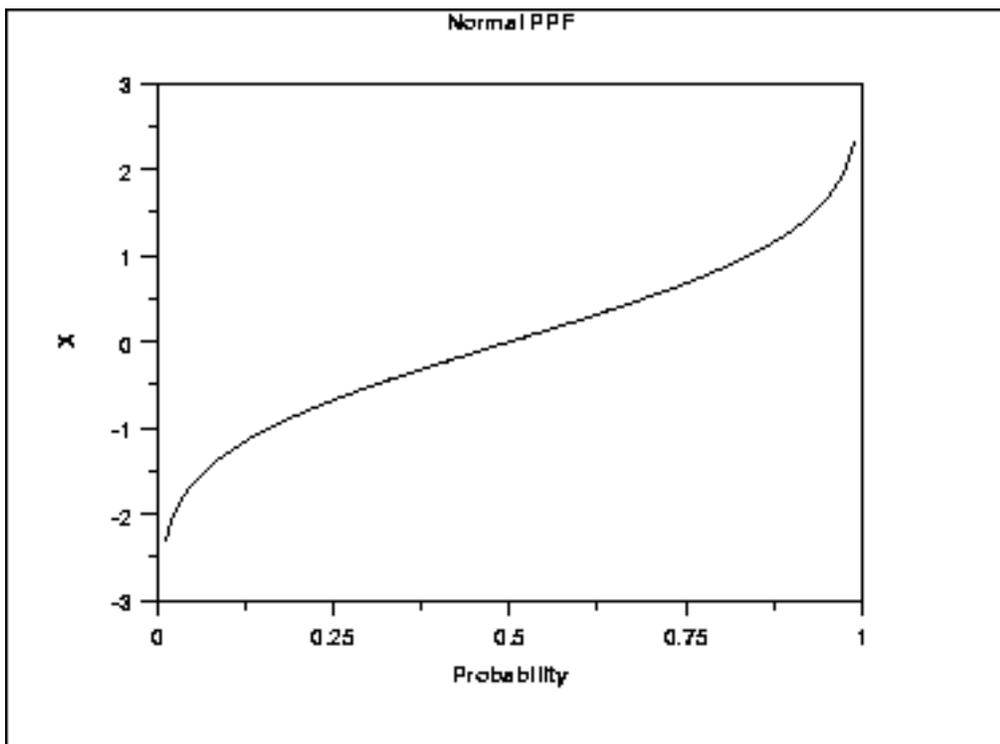
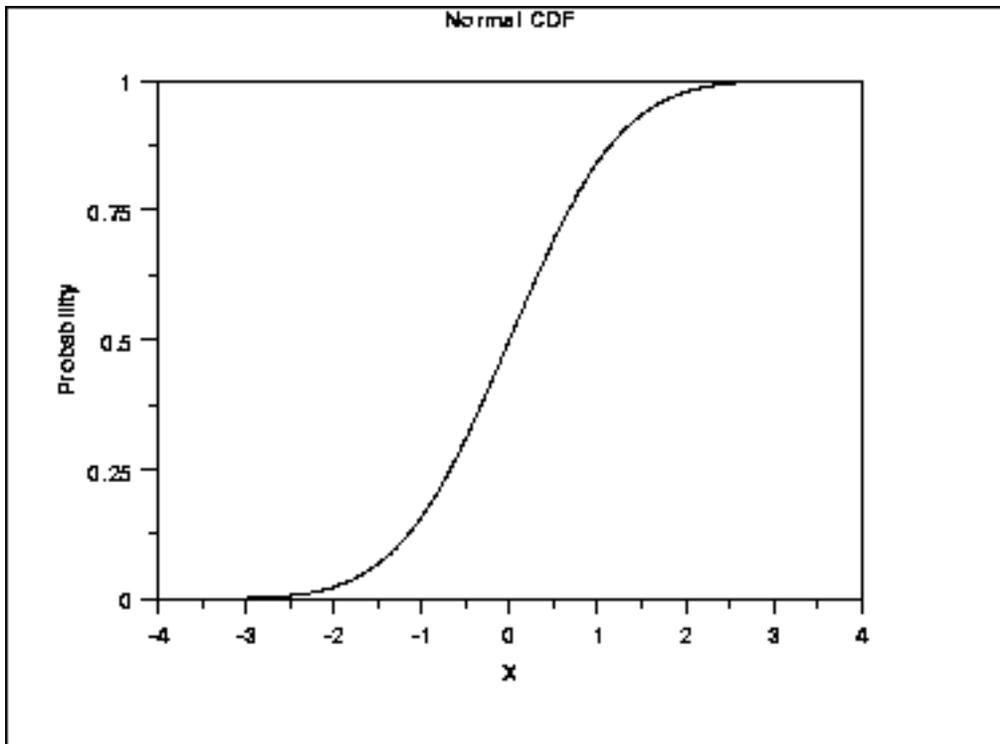
Variations in  $\mu$  and  $\sigma$  allow for different cumulative distributions to be graphed, such as indicated below. These colors correspond to the normal distributions indicated previously.



The cumulative distribution function returns a probability given a certain value of  $X$  is equal to or lower than a value of  $x$  in the distribution. In order to find certain specific values given a certain probability, essentially the reverse, we must use the inverse of the cumulative distribution function, also known as the percent point function or the quantile function. This can be shown simply as

$$H(x) = \Phi^{-1}(x)$$

Graphically, this causes the graph to invert, as indicated by the two pictures below.



With such graphs, we can find specific values based on a particular probability. We can treat patient autonomy as probability, because more patient autonomy indicates a higher possibility of

finding new information that will important for the patient to use and could provide marginal benefit above a standard medical baseline of treatment. We must also indicate that the curve must only have non-negative values, with the assumption that only when a certain level of patient autonomy is reached will the patient find additional information that will provide additional marginal benefit rather than simply what the baseline treatment is, according to the doctor. This means we must revise our quantile function in order to mathematically explain that certain probabilities will not return negative values, but rather a non-negative value of 0. This is explained as such, in Equations 4 and 5:

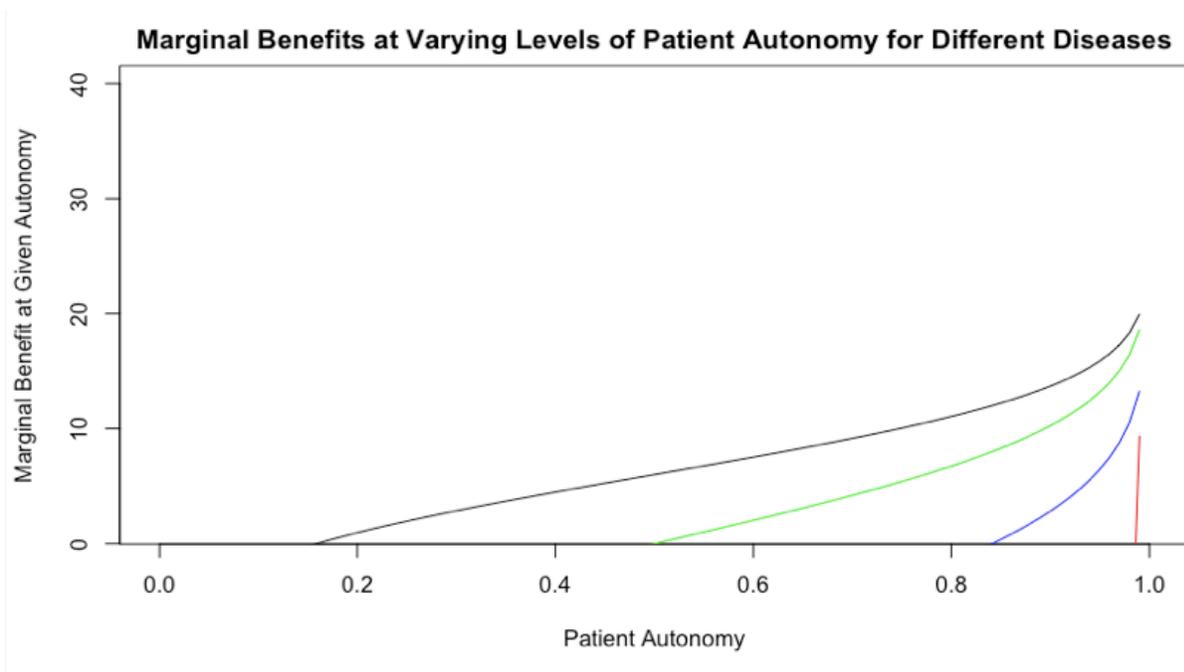
$$H(x) = \max(0, \Phi^{-1}(x)) \text{ (Eq. 4)}$$

$$MB(A_p) = H(A_p) = \max(0, \Phi^{-1}(A_p)) \text{ (Eq. 5)}$$

We can graph different quantile functions in order to visualize how the marginal benefits of additional information increase as a function of increased patient autonomy in regards to different diseases. Each different quantile function can indicate at what level of patient autonomy does the patient have the chance of finding particular information that can lead to positive marginal benefits. Each different quantile function indicates not only when the marginal benefit at a specific patient autonomy goes from zero to positive, but can also indicate how quickly or slowly the marginal benefits increase as patient autonomy increases. This is indicated as such in the following graph by using the parameters of Table 1. By changing the mean and the SD of these quantile functions, different curves can be generated for different diseases. These are simple models that can explain different marginal benefits for different diseases, and the following four diseases will serve as case samples for our simulations and paper.

Disease	Mean	SD	Colored Line	MB at $A_p \approx 1$
Cushing's	6	6	Black	19.95

Syndrome				
ACL Tear	0	8	Green	18.61
Exertional Headaches	-10	10	Blue	13.26
The Common Cold	-200	90	Red	9.37



The mean and standard deviations provided in the table above are used to generate inverse cumulative distribution functions based on the normal distribution in order to generate the values for our simulation of different diseases and their marginal benefits, as well as to visualize in the graph above. In the graph above, we have mapped the different Marginal Benefits at different levels of patient autonomy for different diseases, based on how those diseases are characterized. The black line represents Cushing's Syndrome, a particularly rare disease, and the green line represents an anterior cruciate ligament (ACL) tear, a somewhat common occurrence which has

a somewhat limited variety of treatments. The blue line represents exertional headaches, a more common affliction with a limited treatment variety, and the red line represents the common cold, a typical illness most people experience in their life. We will talk about each of these diseases as specific cases, and why these quantile functions are drawn the way they are for these diseases.

We begin talking about Cushing's Syndrome. For this example, there would be positive marginal benefits with a very low level of patient autonomy because such a rare disease has different diagnoses and treatments based on the diagnosis. Such a diagnosis depends on not only the doctor's knowledge of the rare disease, but also the patient's own knowledge about what may cause this disease in the first place. Cushing's Syndrome is caused either exogenously, by the patient consuming a medication that produces too much cortisol, or endogenously, where the patient has a tumor that produces too much cortisol, with numerous different tumors being potential causes of Cushing's Syndrome. The doctor may not make the correct treatment decision if the patient did not have the capacity, or autonomy, to tell the doctor that the patient was consuming that medication that caused Cushing's Syndrome. And the patient may not have told the doctor if the patient did not already know that certain medications could increase cortisol production which could lead to Cushing's Syndrome. The patient would find marginal benefit even if given a low level of autonomy because of the rarity of the condition that requires the patient to have the autonomous capacity to learn about it outside of the doctor's visit. If the doctor went with a regular baseline treatment without any communication or input from the patient, this may have led to unnecessary or incorrect treatments. As a result, it is accurate to portray that the patient will have some marginal benefit at a low level of patient autonomy because of their capacity to understand more specifically what is happening to their body, and even possibly how best to act. Here, we can say that approximately 15% of the time ( $A_p < 0.15$ ),

the patient will either not find any useful information, and therefore will receive no marginal benefit, or will find information that is useful, but does not deviate from the typical baseline treatment of the doctor. For the other 85% there is an increasing marginal benefit as a result of a continuously informed patient over the process of deciphering medical information. The highest marginal benefit is also the highest here among the four diseases, since this deals with a rare disease that has numerous side effects and could be indicative of cancer. This is simply a model for a disease, such as a rare disease like Cushing's Syndrome.

Continuing, we can examine the green line as an ACL tear, in which a ligament in the knee is torn due to excessive twisting or vertical motion in the knee. Here, the patient will only receive a certain level of marginal benefit from a higher level of autonomy because most treatments regarding ACL tears involve rehab as well as surgery, with our model saying that 50% of the time ( $A_p < 0.5$ ), there will be no marginal benefit for the patient given a level of patient autonomy and information. But once the patient has an autonomy of 0.5, there is a marginal benefit that increases as patient autonomy increases above 0.5, indicating that there is a 50% chance of some positive marginal benefit being accrued if the patient were given such choices and had such information. This may involve different treatment options based on what the patient read about treating ACL tears, and how surgery may be more in line with a more active lifestyle, rather than just rehabilitation. The maximum marginal benefit for an ACL tear is lower than that for Cushing's Syndrome, as there is significant benefit from being able to exercise again, but rarely indicates something else. For a third example, the blue graph indicates exertional headaches. Exertional headaches, which cause significant pain in the head after intense exercise, are not particularly rare, but are not common enough, and hence sometimes require MRIs in order to see if additional treatment is needed, though the likelihood of the

exertional headache indicating something else is very low. Hence, there is a much higher patient autonomy that is the threshold for where marginal benefits are experienced. In our model, in approximately 85% of cases ( $A_p < 0.85$ ), exertional headaches are treated the same way, which involves lower levels of activity for a week or two. This means that in 15%, the patient's information about what an exertional headache is and what to do about it could lead to some positive marginal benefits. The highest marginal benefit for an exertional headache is lower than that for an ACL tear, because the treatment usually involves lowering activity levels very temporarily, and almost never indicates something worse. Finally, our last case is about the common cold. The marginal benefits for this disease are only visible in approximately the top 1% of cases, where essentially the patient has complete control over their decision and knows essentially everything about the common cold, and treatment remains largely the same in 99% of cases ( $A_p < 0.99$ ). Additionally, the marginal benefit of curing the common cold is not significantly high, since the common cold is not a disease that causes much harm to the patient to begin with. We have discussed the marginal benefits of these different diseases, but now we much evaluate the expected values of these diseases. These are simply hypothetical examples for our model, and are just to demonstrate how this model may work for understanding the expected value of marginal benefits of different diseases for varying patient autonomy. There can be different levels of patient autonomy that change from zero marginal benefit to positive marginal benefit, and the slopes of these changes can also increase at different rates and have different shapes.

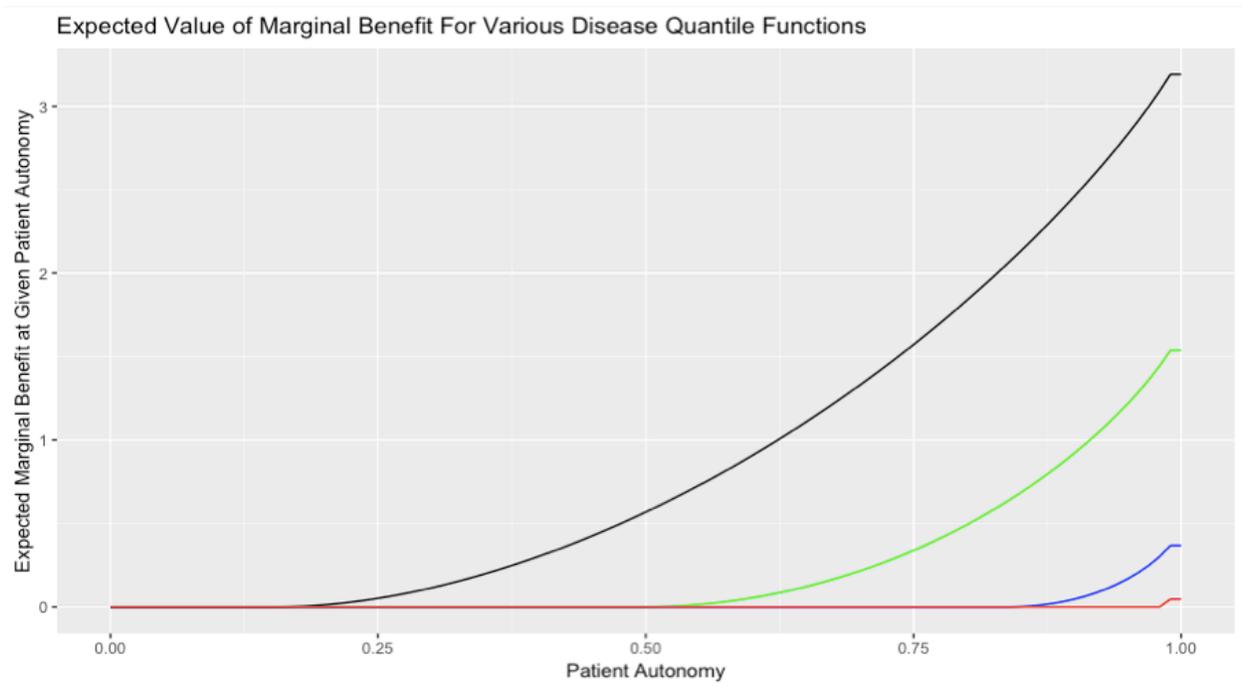
To measure the expected value of marginal benefit of attaining new information, we take the integral under the curve of our quantile function, with  $A_p$  indicating the upper limit of the

integral and 0 as the lower limit of the integral, since the patient can have a minimum of zero autonomy. This can be written out in Equation 6 as

$$E[MB(A_P)] = \int_0^{A_P} xH(x)dx \text{ (Eq. 6)}$$

This formula calculates the expected value of marginal benefits received when a patient reaches a certain level of autonomy indicated by  $A_P$ . We can graph the expected marginal benefit when the patient reaches a certain level of autonomy based on the graphs provided earlier. As indicated earlier, Cushing's Syndrome is the black line, an ACL Tear is the green line, exertional headaches are the blue line, and the common cold is the red line. These integrals were calculated using the Trapezoidal Rule, with intervals of patient autonomy having a width of 0.01.

Additionally, a correction was needed near an  $A_P$  values of 1, as this would indicate complete patient control or information about a disease, and would have a value of infinite, which would make our graph and values as undefined. Such a correction is necessary, since it would essentially be impossible for the patient to have exactly all information or autonomy when making a medical decision with a doctor.



Disease	Mean	SD	Colored Line	MB at $A_p \approx 1$	$A_p > X$ at which $E[MB A_p] > 0$	$E[MB]$ at $A_p \approx 1$
Cushing's Syndrome	6	6	Black	19.95	0.15	3.190
ACL Tear	0	8	Green	18.61	0.5	1.537
Exertional Headaches	-10	10	Blue	13.26	0.85	0.368
The Common Cold	-200	90	Red	9.37	0.99	0.047

Table 2 above provides the parameters of the inverse cumulative distribution function, indicates the level of patient autonomy where the expected marginal benefit is greater than 0, and the expected marginal benefit of having complete or near complete information about a disease and complete or near complete autonomy to make a decision about treatments for this disease.

To make our model more comprehensive, we can apply a similar multiplier here as we did to the cost function. Different people have different hassle cost multipliers, where each unit of time spent finding information can be particularly taxing for someone, or not as taxing for someone else. The reasoning behind the addition of an Expected Marginal Benefit multiplier to our model is that different people also have different multipliers in regards to how much they value their utility as a result of medical care. Someone can very highly value the additional treatments or they value their health very highly, indicating that health is very important to that person. Another patient may also value health, just not as much as another person. As a result, we can add a multiplier to which we can capture how much someone values their health. This is shown in modified Equation 7 below, with the addition of the Greek symbol kappa ( $\kappa$ ).

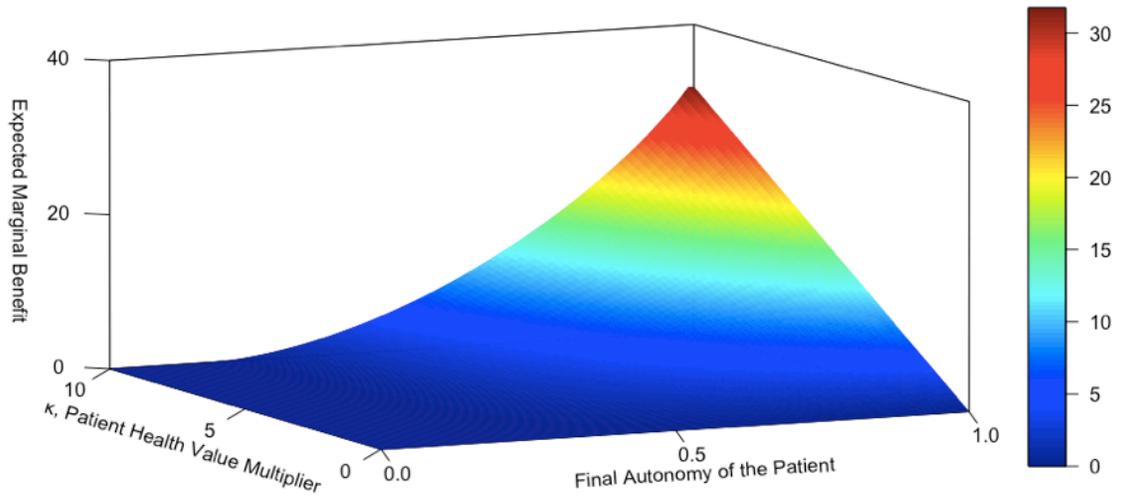
$$E[MB(A_p)] = \kappa \int_0^{A_p} xH(x)dx \text{ (Eq. 7)}$$

We also must clarify that the value of patient autonomy should be of final patient autonomy, implying that if there is a change in a patient's autonomy from some initial value  $A_p^{Initial,Disease}$  to a final value  $A_p^{Final,Disease}$ , then the expected marginal benefits will be analyzed from the final patient autonomy, as the patient has now a new amount of information and capacity for using that information than before. We also have to specify our function  $H(x)$  for a specific disease.

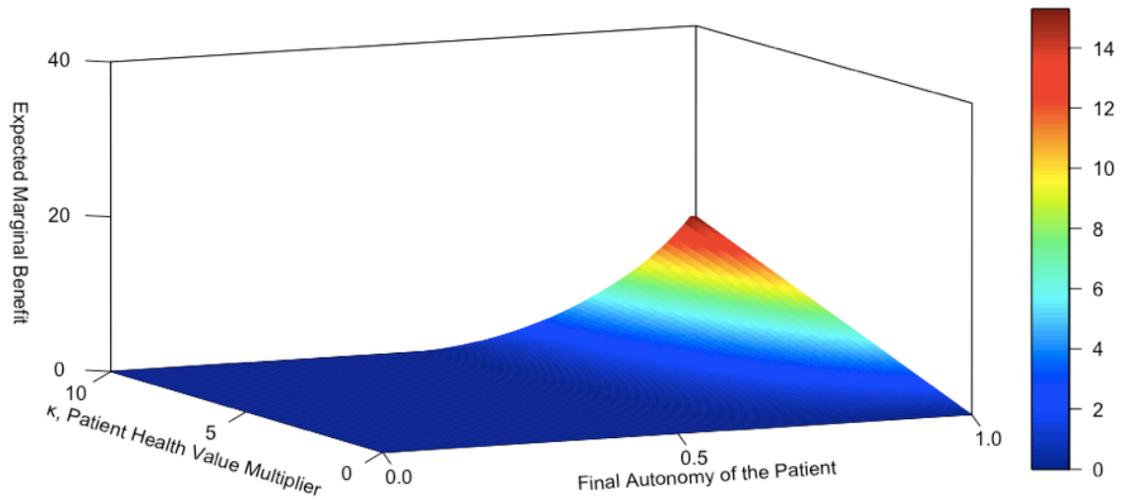
$$E[MB(A_p^{Final,Disease})] = \kappa \int_0^{A_p^{Final,Disease}} xH(x)^{Disease} dx \text{ (Eq. 8)}$$

We can create visualizations to see how different kappa values as well as different values of final patient autonomy can lead to different expected marginal benefits in regards to different diseases.

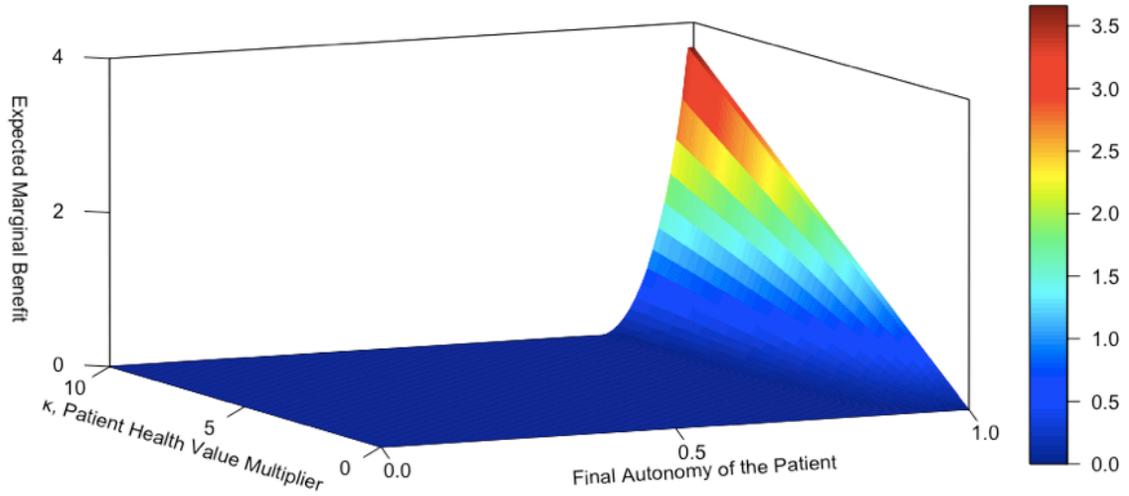
**Expected Marginal Benefits Due to Variations in Kappa and Autonomy for Cushing's Syndrome**



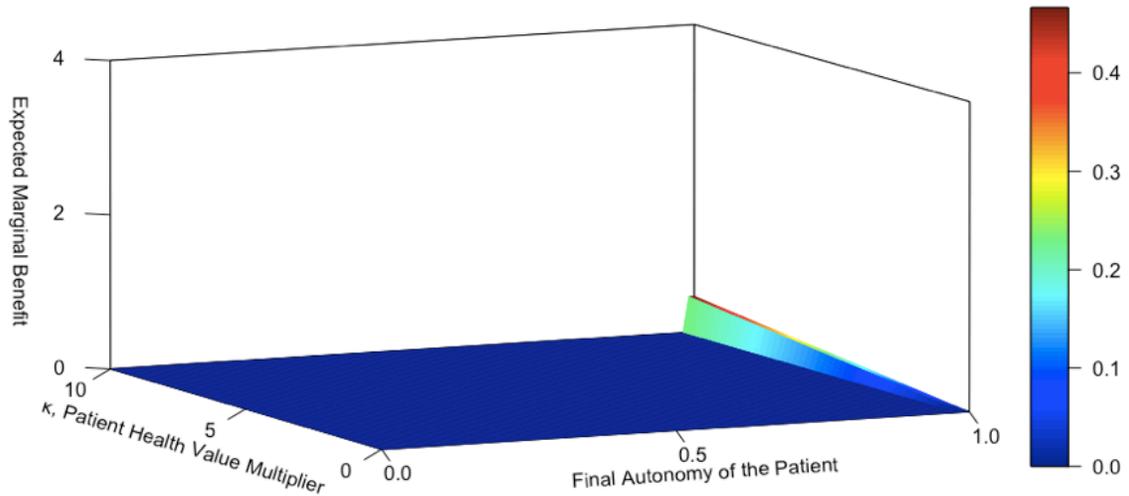
**Expected Marginal Benefits Due to Variations in Kappa and Autonomy for an ACL Tear**



**Expected Marginal Benefits Due to Variations in Kappa and Autonomy for Exertional Headaches**



**Expected Marginal Benefits Due to Variations in Kappa and Autonomy for the Common Cold**



On the x-axis of these graphs, we indicate final autonomy of the patient in regards to a specific disease, with values that increase by steps of 0.01 from 0 to 1. For the y-axis, we have a range of values for  $\kappa$ , our Patient Health Value Multiplier that increase from 0 to 10 by steps of 0.5. On the z-axis, we have Expected Marginal Benefit as a result of the specific final autonomy of the

patient and the Patient Health Value Multiplier. For Cushing’s Syndrome and ACL Tears, the z-axis has a range of 0 to 40, while for Exertional Headaches and the Common Cold, the z-axis has a range of 0 to 4. This change in range was needed due to the significant differences in values for the z-axis between our different disease case studies. Here we can see that how much someone values their health would see significant increases in utility from having expected marginal benefits of care that are above the standard baseline of what the doctor ordered.

#### **D. Combining the Model for Cost of Information and Expected Marginal Benefits**

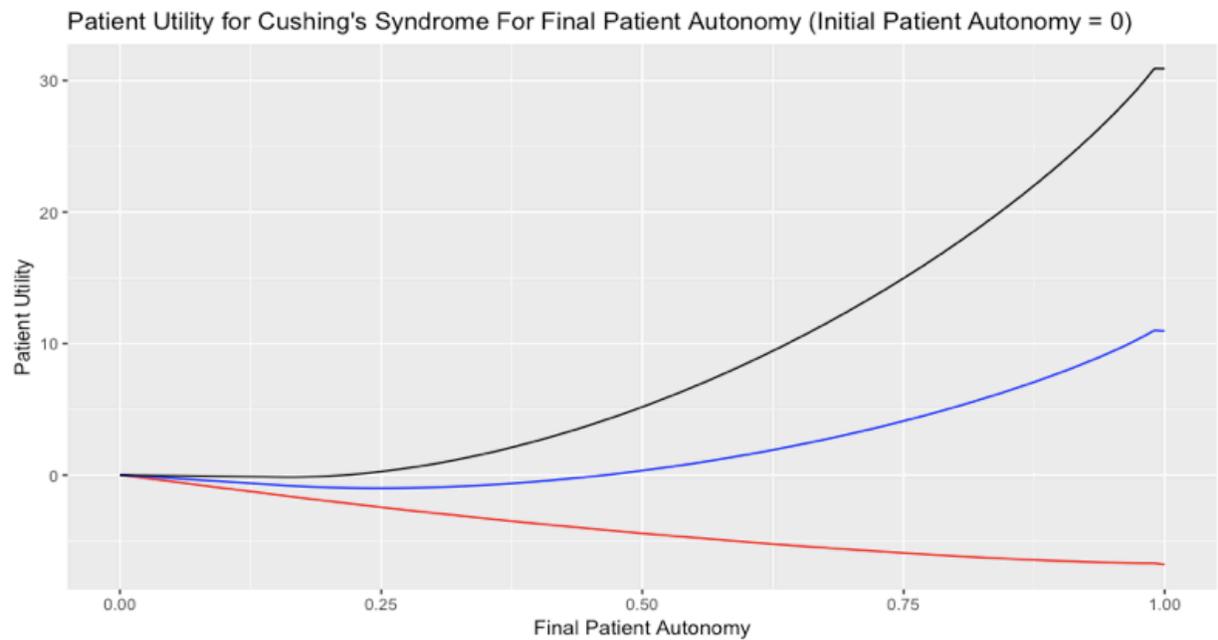
By combining our models for examining the cost of information and the expected marginal benefits of health, we can write a comprehensive model that describes how a patient’s utility is impacted by expected marginal benefits and costs of information.

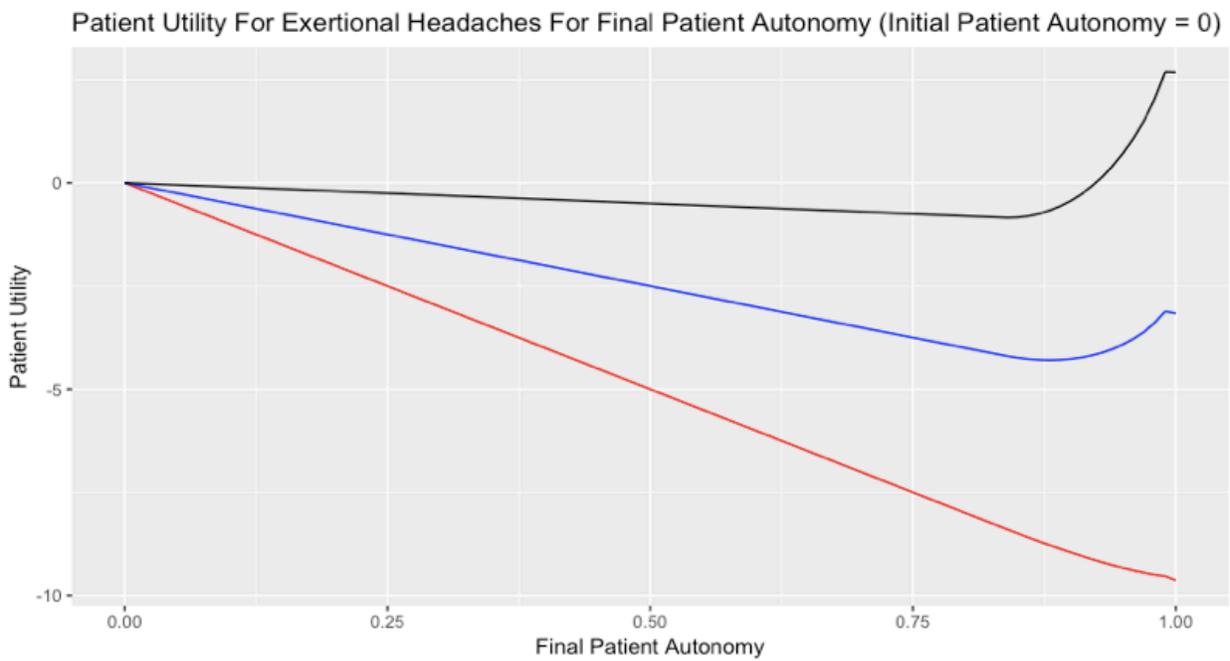
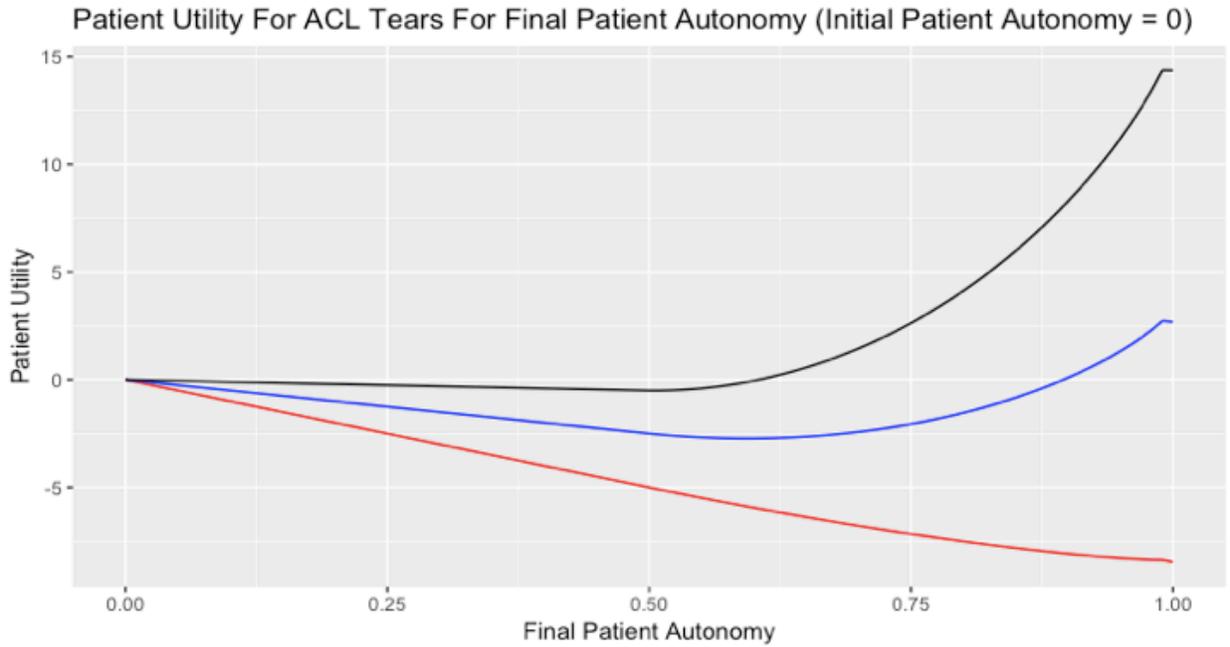
$$U_p = E(MB|A_p^{Final,Disease}) - \Delta C(A_p^{Disease}) \text{ (Eq. 9)}$$

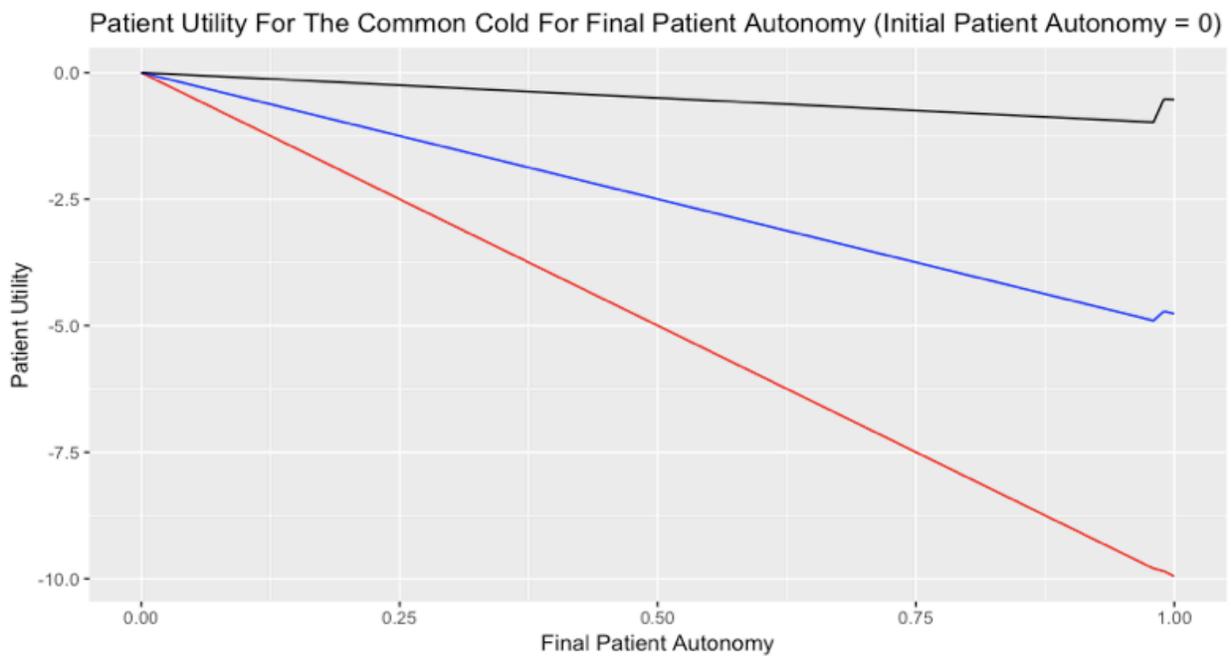
$$U_p = \kappa \int_0^{A_p^{Final,Disease}} xH(x)^{Disease} dx - \gamma(A_p^{Final,Disease} - A_p^{Initial,Disease}) \text{ (Eq. 10)}$$

This would be very difficult to graph if we attempted to graph all of the different values for  $\kappa$ ,  $\gamma$ ,  $A_p^{Final,Disease}$  and  $A_p^{Initial,Disease}$ , for each different disease. However, we can look at specific examples for a select few values to indicate different patients and how they may interact based on different disease profiles. We profile different patients with different hassle cost and health value multipliers. Different colored lines on the following graphs indicate these different patient profiles, and each graph will examine a different disease to examine patient utility at different levels of final patient autonomy. The different patient types will remain consistent between the graphs for different afflictions. The patient descriptions are explained in Table 3 below. We then use the parameters in Table 3 for different patients in our Equation 10 to generate graphs for our four disease case studies.

Different Patient Profiles				
Patient	Patient Description	$\kappa$ , Health Value Multiplier	$\gamma$ , Hassle Cost Multiplier	Colored Line
Patient 1	Patient values their health significantly, willing to dedicate hours to find research outside of the doctor's appointment.	10	1	Black
Patient 2	Typical patient, cares about health, but unlikely to spend too much time researching other information	5	5	Blue
Patient 3	Nonchalant patient, cares about their health somewhat, finding information is significantly taxing	1	10	Red

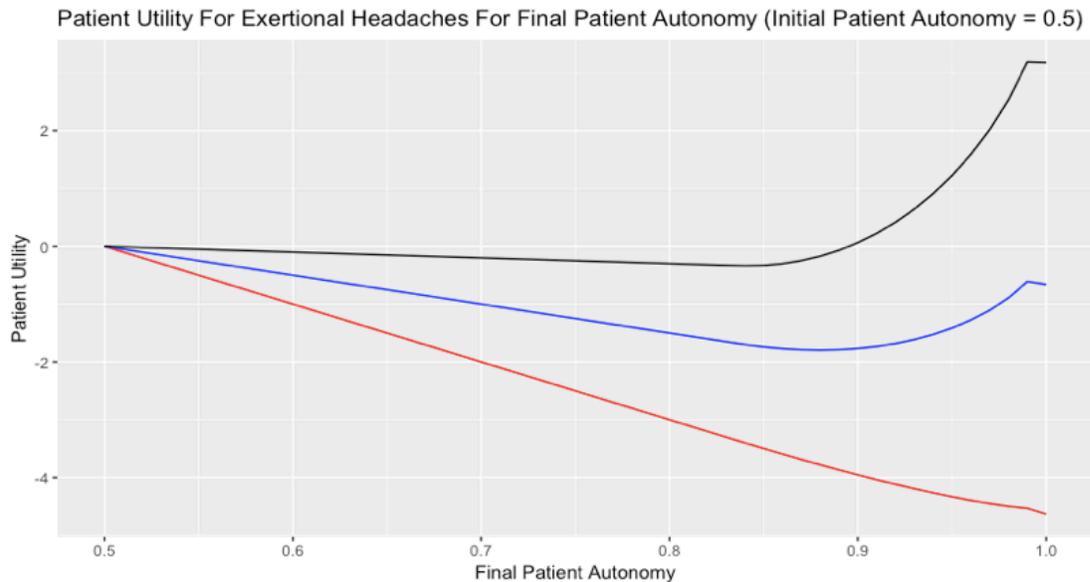
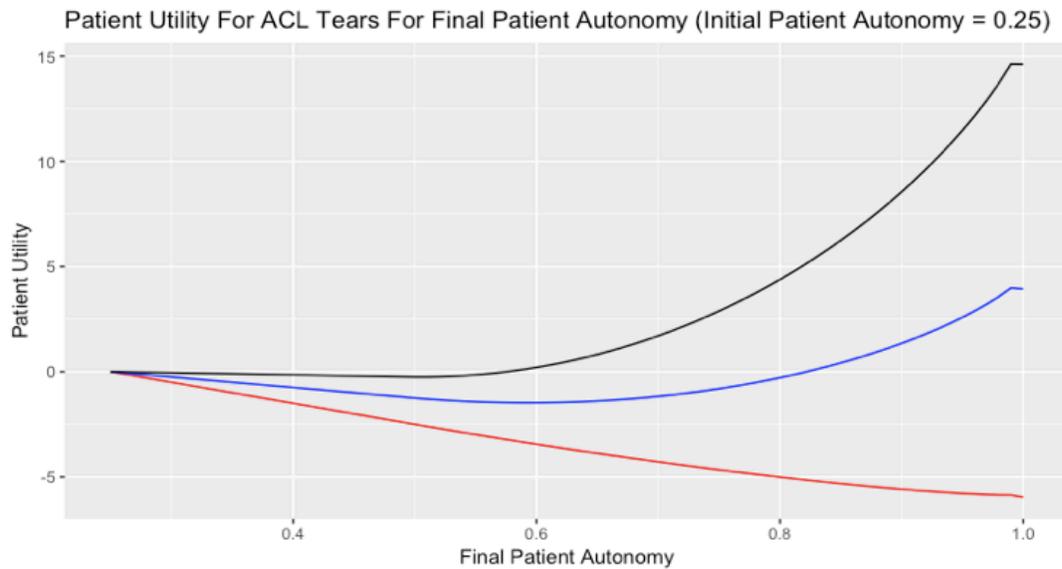


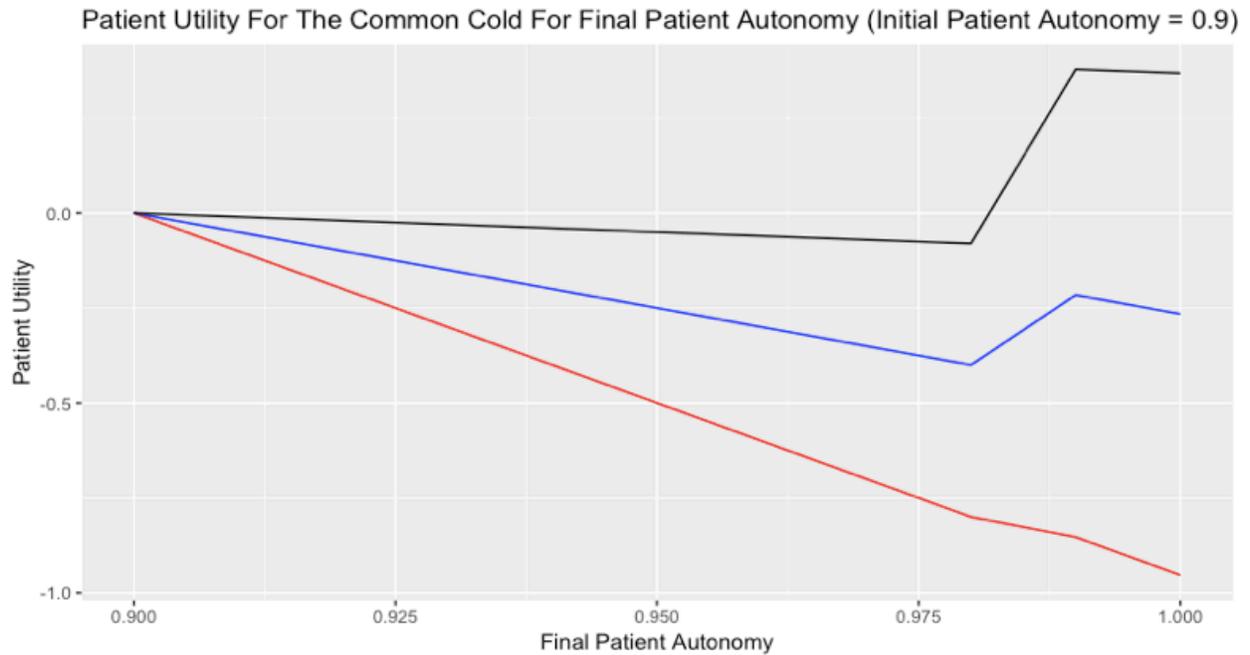




These graphs are all for patients that initially have zero patient autonomy, implying that these patients knew nothing about their disease or affliction, or that they did not have the capacity to make their own decision on how best to act. This zero patient autonomy assumption would imply a paternalistic model where the doctor would essentially tell the person what to do, and assuming there would be no change in patient autonomy, the patient would still just listen to what the doctor ordered, without experiencing any expected marginal benefits or costs associated with decision-making. However, a more realistic scenario would be that patients would initially know a certain amount of information about a particular disease, and have the autonomy to act upon it. For rare diseases such as Cushing's Syndrome, they would most likely not know anything and not have the capacity to do anything without certain feedback from the physician. For somewhat more common accidents such as ACL tears, these aren't necessarily rare, but are not as frequent as an exertional headache or the common cold, so these patients would have an autonomous value of 0.25, for example. Continuing on, patients who experience exertional headaches due to physical activity would have a certain capacity of what to do in this situation, but not all the

information, so these patients could have an initial autonomous value of 0.5. And in regards to the common cold, due to its prevalence, we can assume that most patients would have an idea of how to treat themselves without additional information or the doctor's input, implying an initial autonomous value of 0.9. If we make these corrections to our graphs above, we can illustrate some more realistic results. The graph for Cushing's Syndrome remains the same, and the scales are different for each of the graph, in order to establish new starting points for patient autonomy, and different values for patient utility.





In regards to the graph of Cushing’s Syndrome, there are high costs, due to the initial lack of patient information, but also high expected marginal benefits because marginal benefits are expected at a much lower level of  $A_p$ . Regarding the graph for ACL tears, there is still a significant expected marginal benefit without too much additional hassle costs, indicating that additional autonomy or information held by the patient could lead to significant increases in patient utility. For exertional headaches, a significant amount of information is needed in order to attain any benefits, requiring patient autonomy increase from a value of 0.5 to see any possibility of marginal benefits. Finally, regarding the common cold, the hassle costs are not significantly highly, but the marginal benefits are so meager that it is not worth the additional time or effort to research about the common cold at home. We can put these diseases in a descriptive matrix in order to place these diseases in a more organized way, describing the expected marginal benefits and the hassle costs as either Low or High. This just serves as a series of case studies for a typical patient, and as a possible guide to how diseases can be characterized.

		Expected Marginal Benefits	
		Low	High
Hassle Costs	High	Exertional Headaches	Cushing's Syndrome
	Low	Common Cold	ACL Tears

When examining this table, we can make some suggestions as to what a patient should do when faced with a specific affliction, and how a doctor could respond. When expected marginal benefits are low, such as exertional headaches or the common cold, the benefits are very low, and the costs no matter how low they may be, are not worth the expected marginal benefits. However, for the common cold, since the patient already most likely knows how to treat the illness, they could simply treat themselves without significant hassle costs, while for exertional headaches, it is much better for the patient to visit the doctor. The doctor would most likely provide only the baseline treatment, but that is all the patient would need, as the expected marginal benefits would be less than the costs. When expected marginal benefits are high, this leads to a more interesting discussion. For an ACL tear, because hassle costs are low, the patient will find it valuable to have a discussion with the doctor about what they hope to gain from treatment and what treatment options they should consider based on their conversation. This would make sense for an ACL tear, as depending on how active the patient may want to be, they may choose one option over another. This can lead to either a weak recommendation from the doctor, with the patient evaluating their options on what to do, or a strong recommendation from the physician based on how the patient articulated their needs. These scenarios could imply more patient autonomy, and value what the patient values, and hence the doctor would more likely provide a series of suggestions rather than a strong recommendation. For Cushing's Syndrome,

there are high expected marginal benefits, but the hassle costs are also high, because of the rarity of the disease. This would mean that the doctor would need to involve the patient, and therefore make an active effort to inform the patient about the specific disease, but also require the patient to have a certain level of autonomy to make the correct decision that is best for his or her own health as well. Additionally, this could require strong or weak recommendations from the doctor, depending on the necessity of patient interaction and how the doctor best believes treatment should go. This is where patient preferences matter. How much the patient values their health (through a variable Health Value Multiplier  $\kappa$ ), and how much of a hassle it is for the patient to be informed (through a variable Hassle Cost Multiplier  $\gamma$ ), could potentially lead to significant variation in patient utility, as examined by different patients in the graphs above, and could significantly alter the strength of the doctor's recommendation. In regards to the ACL tear, for patient 1, a patient that very highly values their health and does not induce significant hassle costs, having an active role in their medical decision could have significant benefits, and would more likely have a weak recommendation from the physician, or a series of suggestive treatments with their downsides and upsides. In contrast, patient 3, a patient that does not value their health as much and induces significant hassle costs, would more likely just listen to a strong recommendation from the doctor, because assuming any level of patient autonomy would induce more costs than benefits. What is essential is that depending on the patient, and their Health Value  $\kappa$  and Hassle Cost Multipliers  $\gamma$ , there will be different final patient autonomy levels that dictate when the patient would like either a weak recommendation/series of suggestions from the doctor, or a strong recommendation about what treatment is necessary.

What if a patient induces significant hassle costs for researching one disease, but it is not the correct disease they were diagnosed with. For example, assume a patient has a Health Value

Multiplier  $\kappa$  of 5, a Hassle Cost Multiplier  $\gamma$  of 5, and an initial patient autonomy of 0 regarding the common cold. If this patient spends time doing research on the common cold, and their final patient autonomy is 0.5, they induce a hassle cost of 2.5. However, if this patient is diagnosed with Cushing's Syndrome, then their final patient autonomy for Cushing's Syndrome will remain at 0 (assuming an initial patient autonomy of 0), because the patient did not find information relevant to Cushing's Syndrome, and as a result, will not receive the potential expected marginal benefits. In mathematical terms,

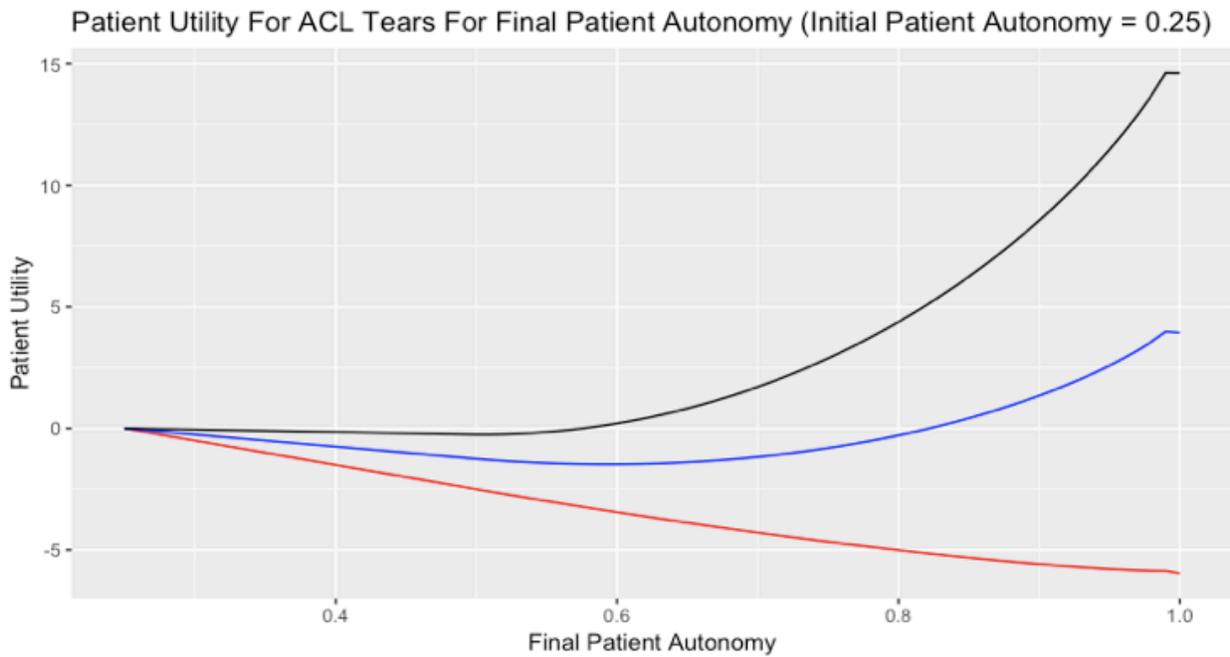
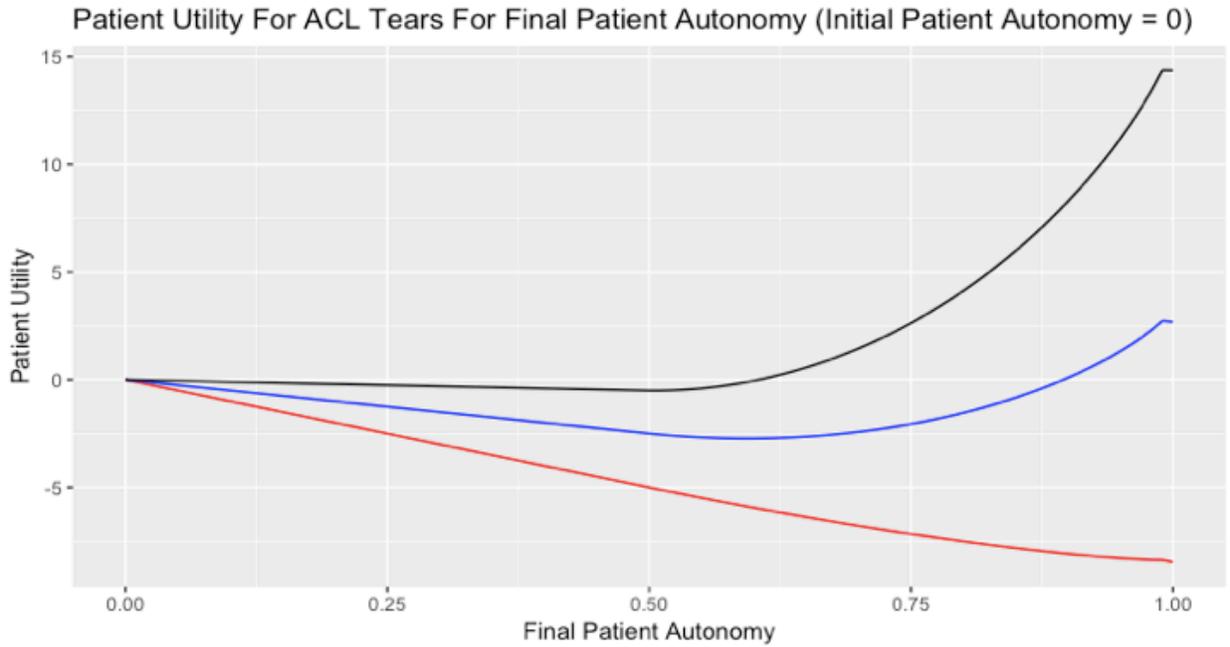
$$U_P^{Disease} = \kappa \int_0^{A_P^{Final,Disease}} xH(x)^{Disease} dx - \gamma(A_P^{Final,Disease} - A_P^{Initial,Disease})$$

$$U_P = \kappa \int_0^{A_P^{Final,Cushing'sSyndrome}} xH(x)^{Cushing'sSyndrome} dx - \gamma(A_P^{Final,CommonCold} - A_P^{Initial,CommonCold})$$

$$U_P^{Cushing'sSyndrome} = 5 \int_0^0 xH(x)^{Cushing'sSyndrome} dx - 5(0.5 - 0) = -2.5$$

This implies that if the patient does not find the adequate information necessary for their disease, then they will have wasted energy and time into unnecessary hassle costs without receiving the benefits of doing such research or assuming such autonomy.

One final contention is regarding the differences in values of initial patient autonomy. We will show again the graphs for different values of initial patient autonomy for ACL tears.



When comparing patient utility for different patients, the initial patient autonomy causes differences in patient utility for all three patient types. For patients beginning with an initial autonomy of 0, essentially not having any role in their decision or not knowing anything about ACL tears, at a final autonomy of 0.99, there are patient utility values of approximately 15, 2.5,

and -7.8 for patients 1, 2 and 3, respectively. For patients beginning with an initial autonomy of 0.25, having some role in their decision or knowing something about ACL tears, at a final autonomy of 0.99, there are patient utility values of approximately 15, 4, and -6.5 for patients 1, 2 and 3, respectively. This means that as patients have more initial information about certain diseases, then they will experience less of the costs associated with trying to find additional information, and experience the expected marginal benefits earlier. This makes sense, because if the patient had a significant amount of information about a disease and the capacity to make a decision about the disease, then they would not need to go to the doctor to make the decision about what is best for them. This model also implies that if patients have more accurate medical information available to them, then over their lives they can attain information to make better decisions, essentially implying that a more medically literate patient and therefore society could lead to potentially significant expected marginal benefits, and decreased hassle costs, since the patient would already know what to do when dealing with a particular disease. These are assumptions about patients being completely rational, but provide a framework for a model that can be modified and adapted in the future.

## IV. Conclusion

This paper develops a comprehensive model through Equation 10 that can describe patients and their interaction with doctors through different values of patient autonomy, and the associated expected marginal benefits and hassle costs with assuming different values of patient autonomy. This model also describes how different patients have different parameters in how they deal with hassle costs and how they value health. This model was used to examine four different diseases as examples, and hopefully as a template for future models to be developed.

Whether the patient receives positive patient utility depends on if expected marginal benefits exceed hassle costs, and these are determined by the quantitative profile of the disease, as well as the necessary amount of hassle costs to increase patient autonomy. The different factors can determine in which scenarios the physician can dictate a strong or weak recommendation for treatment, and whether the patient should accept the advice or not. If the patient makes an inaccurate judgment about what disease is affecting their health, then by our model, they assume additional hassle costs without experiencing expected marginal benefits. Additionally, these also have implications that the more widespread medically accurate information is, in general there is improvement for the patient due to reduced hassle costs.

A limit of this study involves the lack of granular data that can be used to accurately describe different patients in regards to how much information they know about particular diseases, and data to describe different Health Value and Hassle Cost multipliers for a particular patient. This is the primary reason why a theoretical model with simulated values and scenarios was drawn up, and can serve as a foundation for additional models to be built upon. Hopefully data can be used in the future to generate more accurate simulations in order to see if the model is correct, or can lead to necessary adjustments in the model for improved accuracy.

## V. Citations

- Agarwal, Aakash K., and Beth B. Murinson. “New Dimensions in Patient–Physician Interaction: Values, Autonomy, and Medical Information in the Patient-Centered Clinical Encounter.” *Rambam Maimonides Medical Journal*, vol. 3, no. 3, 2012, doi:10.5041/rmmj.10085.
- Ahmad, Farah, et al. “Are Physicians Ready for Patients With Internet-Based Health Information?” *Journal of Medical Internet Research*, vol. 8, no. 3, 2006, doi:10.2196/jmir.8.3.e22.
- Brédart, Anne, et al. “Doctor-Patient Communication and Satisfaction with Care in Oncology.” *Current Opinion in Oncology*, vol. 17, no. 4, 2005, pp. 351–354., doi:10.1097/01.cco.0000167734.26454.30.
- Canalse, S. Terry. “How the Orthopaedist Believes He Is Perceived by the Public and How the Public Actually Perceives the Orthopaedist.” Annual Meeting of the American Association of Orthopaedic Surgeons. AAOS Symposium, Patient-Physician Communication, 15 Mar. 2000, Orlando, FL.
- Charles, Cathy, et al. “SHARED DECISION-MAKING IN THE MEDICAL ENCOUNTER: WHAT DOES IT MEAN? (OR IT TAKES AT LEAST TWO TO TANGO).” *Social Science and Medicine*, vol. 44, no. 5, 1997, pp. 681–692.
- “Cushing's Syndrome/Disease.” *American Association of Neurological Surgeons*, American Association of Neurological Surgeons, [www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Cushings-Disease](http://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Cushings-Disease).
- Dilliway, Greg, and Gillian Maudsley. “Patients Bringing Information to Primary Care Consultations: a Cross-Sectional (Questionnaire) Study of Doctors' and Nurses' Views of

- Its Impact.” *Journal of Evaluation in Clinical Practice*, vol. 14, no. 4, 2008, pp. 545–547., doi:10.1111/j.1365-2753.2007.00911.x.
- Emanuel, Ezekiel J., and Linda L. Emanuel. “Four Models of the Physician-Patient Relationship.” *JAMA: The Journal of the American Medical Association*, vol. 267, no. 16, 1992, p. 2221., doi:10.1001/jama.1992.03480160079038.
- Gerber, Ben S, and Arnold R Eiser. “The Patient-Physician Relationship in the Internet Age: Future Prospects and the Research Agenda.” *Journal of Medical Internet Research*, vol. 3, no. 2, 2001, doi:10.2196/jmir.3.2.e15.
- Goold, Susan Dorr, and Mack Lipkin. “The Doctor-Patient Relationship.” *Journal of General Internal Medicine*, vol. 14, no. S1, 1999, doi:10.1046/j.1525-1497.1999.00267.x.
- Hamm, Robert M, and Stuart L Smith. “The Accuracy of Patients' Judgments of Disease Probability and Test Sensitivity and Specificity.” *Journal of Family Practice*, 1998.
- Haug, Marie, and Bebe Lavin. *Consumerism in Medicine: Challenging Physician Authority*. Sage Publications, 1983.
- Herrle, Scott R., et al. “Bayes’ Theorem and the Physical Examination: Probability Assessment and Diagnostic Decision Making.” *Academic Medicine*, vol. 86, no. 5, 26 Aug. 2011, pp. 618–627., doi:10.1097/acm.0b013e318212eb00.
- Lim, Jae-Young, and Changik Jo. “The Effect of Patient's Asymmetric Information Problem on Medical Care Utilization with Consideration of a Patient's Ex-Ante Health Status.” *Hitotsubashi Journal of Economics*, vol. 50, no. 2, Dec. 2009, pp. 37–58., doi:10.15057/18050.
- Lopez, German. “The Opioid Epidemic, Explained.” *Vox.com*, Vox Media, 21 Dec. 2017, www.vox.com/science-and-health/2017/8/3/16079772/opioid-epidemic-drug-overdoses.

- Sechrest, Randale C. "The Internet and the Physician-Patient Relationship." *Clinical Orthopaedics and Related Research*, vol. 468, no. 10, 2010, pp. 2566–2571., doi:10.1007/s11999-010-1440-3.
- Tan, Sharon Swee-Lin, and Nadee Goonawardene. "Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review." *Journal of Medical Internet Research*, vol. 19, no. 1, 2017, doi:10.2196/jmir.5729.
- Tongue, John R, et al. "Communication Skills for Patient-Centered Care." *The Journal of Bone and Joint Surgery*, 87-A, no. 3, Mar. 2005, pp. 652–658.
- Topol, Eric. "Can Too Much Information Harm Patients? [Excerpt]." *Scientific American*, Scientific American, 27 Jan. 2012, [www.scientificamerican.com/article/can-too-much-information/](http://www.scientificamerican.com/article/can-too-much-information/).
- Weaver, Jane. "More People Search for Health Online." *NBCNews.com*, NBCUniversal News Group, 16 July 2013, [www.nbcnews.com/id/3077086/t/more-people-search-health-online/#.XBIVic9Kiu5](http://www.nbcnews.com/id/3077086/t/more-people-search-health-online/#.XBIVic9Kiu5).
- Zeckhauser, Richard, and Benjamin Sommers. "Virtual Mentor." *American Medical Association Journal of Ethics*, vol. 15, no. 11, Nov. 2013, pp. 988–992.