NARRATIVE AUTHORITY: A NARRATIVE-BASED MULTICULTURAL ETHICS TO OVERCOME WESTERN BIASES IN THE CURRENT MODELS OF CARE

Fahmida Hossain

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NARRATIVE AUTHORITY: A NARRATIVE-BASED MULTICULTURAL ETHICS
TO OVERCOME WESTERN BIASES IN THE CURRENT MODELS OF CARE

A Dissertation
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McAnulty College and Graduate School of Liberal Arts

Duquesne University

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the degree of Doctor of Philosophy

By
Fahmida Hossain

May 2022
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TO OVERCOME WESTERN BIASES IN THE CURRENT MODELS OF CARE

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Approved April 8, 2022

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ABSTRACT

NARRATIVE AUTHORITY: A NARRATIVE-BASED MULTICULTURAL ETHICS TO OVERCOME WESTERN BIASES IN THE CURRENT MODELS OF CARE

By

Fahmida Hossain

May 2022

Dissertation supervised by Dr. Joris Gielen, Ph.D.

Technological advances and globalization are transforming healthcare dramatically. But unfortunately, current medical practices remain blind to their multicultural patients’ varied worldviews and norms, especially in the West. As a result, patients often find themselves isolated, anxious, and resentful.

All the humanistic models in the current literature view the individual as a unique and autonomous being and, in turn, provide practices to access and recognize the patient’s personhood. These models—Narrative Medicine, Narrative Ethics, and Ethics of Care—attempt to catch sight of the individual, the person’s situation, and some semblance of the person’s story before
diagnosing or offering prescriptions. However, all these models have been derived from predominantly White, Western, scholars and the models lack concrete directions or specific tools to respond to the patient’s humanness and the story-founded social nature of being in the service of providing good care.

The thesis presents a complementary, human-centric, narrative-driven model: Narrative Authority (NA). NA embraces components of the existing models and proposes a modified, integrated, and expanded version of the notions that ground Narrative Medicine, Narrative Ethics, and Ethics of Care. In addition, NA claims to be more attuned to the nature of human interactions, more culturally sensitive, and importantly provides specific application tools: Open Listening (not knowing), Storied Hearing (attention to), and Shared Healing (responding to). This dissertation aims to positively transform contemporary medicine via a perspective and a method that is thoroughly other-oriented, dialogue-based, culturally sensitive, nonjudgmental, and always story-dependent. The phenomenological investigation of NA presents a method to respond to the lived, experiential nature of illness, suffering, obligations, beliefs, norms, and responsibilities.

Further, the model proposed in the thesis is applied through examples ranging from the local to the global, from the interpersonal to organizational. This multifaceted applicability demonstrates the versatility of the NA. Such versatility is possible because the model is constructed on the foundational nature of human beings as relational and narrative based. The model is further applied to actual, current examples throughout the dissertation to show how components of NA can be implemented in different situations and among various populations. The dissertation intends to show how Narrative Authority offers an innovative model and complementary humanistic approach to care, and it provides an ethical justification of the importance of embracing Narrative in our care practices.
I dedicate this work to my father (Abbu), who longed to obtain a Ph.D. but could not do so because of the political climate before Bangladesh's independence in 1971. So, I chased his unfinished dream.

Also, this work is in praise and honor of my younger brother, Sabir, who died at the age of seven. The events surrounding his tragic passing revealed the ethical importance of a healthcare that is grounded in shared narratives and expressed by storytelling.
ACKNOWLEDGEMENT

I call this journey a five-year journey by train. During this journey to acquire my Ph.D., many people boarded my train at different times and at various stations to aid and guide me and keep my train on the rails.

First, I would like to thank Allah for providing me the strength and courage to begin my journey and the grace to have me arrive smoothly at the destination.

This work would not have been possible without the ongoing and patient mentorship and support of Dr. Joris Gielen, who trusted my stories, welcomed my enthusiasm, accepted my ever-energetic mood of doing at least two things at a time, and always supported and promoted my work. His wisdom and insights have been invaluable throughout this journey. And he kept me on the train, in my seat, away from the doors.

I would not be where I am today without Mr. Frank Lehner. I met him at the station. He encouraged me to pursue my dream, helped me onto the train when I became fearful of the trip, supported me with my thinking (and my English), and walked with me every step until I reached my destination station, my Ph.D. Life is smoother because of his presence.

I am very grateful to the members of my dissertation committee, Dr. Gerard Magill and Dr. Peter Osuji for their guidance and feedback in every step. I am thankful to Dr. Henk ten Have for trusting my story and vision and being an inspiration and presence, even from afar.

However, nothing has been more critical than the unwavering support and encouragement from my family, friends, and chosen others. Every time I felt I should get off the train, to quit, my mother (Ammu) held me tight. She gave me the power to keep going and kept me away from the emergency-stop chord. Ammu supported me, leaving her home in Bangladesh to stay with me for
months and months to lend an extra hand when I (or we) needed it. My father’s (Abbu) ever silent presence gave me the strength to get going. I had to keep going. I had to get it done, because I was compelled to get my Ph.D., and complete his unfinished dream as best I could.

I am indebted to my husband, Tanvir, for his continuous support, especially when unfortunate family issues broke me. He made me stay the course and supported me in chasing my dream even when his career dream seemed it might derail.

My son, Zuaib, has spent a significant part of his life on this train. I began my Ph.D. when he was two years old, and I am ending this journey just as he turns seven. I fear I have missed many beautiful moments with him. Yet, none of this would have continued without this little human being’s patience, understanding, and sacrifices.

I’d like to thank my brother (Bhaia), sister-in-law (Nima), and nieces (Zuni and Walu) for the love, support, and encouragements they gave. I also thank my in-laws and relatives in Bangladesh and the many friends back home who made themselves available to me. Each has been a blessing, providing feedback, insights, support, and joy that I sometimes had difficulty finding.

And lastly, I give my special thanks to my friends without whom I couldn’t have made this journey to its end. Eva Apu, for introducing me to Dr. ten Have and to the Ph.D. program. Shafee for pushing me to use endnote software. Adele and Yoelit, thank you for listening to my frustrations and keeping me going with your insightful thoughts and inspirational wishes. I thank every member of the Bangladeshi community in Pittsburgh who supported me through thick and thin, encouraging me along this journey with your unique contributions. Oh, yes, all the coffee shops in Pittsburgh where I visited, and those sips had me write.

I love you all; thank you for boarding my train and accompanying me on this Ph.D. journey.
As-Salaam-Alaikum, one and all.
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<th>Abbreviation</th>
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<td>NA</td>
<td>Narrative Authority</td>
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<tr>
<td>EOC</td>
<td>Ethics of Care</td>
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<tr>
<td>UDBHR</td>
<td>Universal Declaration of Bioethics and Human Rights</td>
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<td>NE</td>
<td>Narrative Ethics</td>
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<td>NM</td>
<td>Narrative Medicine</td>
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<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>DABDA</td>
<td>Denial, Anger, Bargaining, Depression, and Acceptance</td>
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<tr>
<td>NIH</td>
<td>National Institute for Health</td>
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<tr>
<td>PGP</td>
<td>Personal Genome Project</td>
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<tr>
<td>HIPPA</td>
<td>Health Insurance Portability and Accountability Act</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
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<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
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<tr>
<td>PPE</td>
<td>Personal Protective Equipment</td>
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<tr>
<td>MD</td>
<td>Moral Distress</td>
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<td>MI</td>
<td>Moral Injury</td>
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<tr>
<td>OECD</td>
<td>Organization for Economic Cooperation and Development</td>
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Chapter 01: Introduction

We live in an age where globalization, technology, and efficiency profoundly affect medicine—reshaping interpersonal relationships and questioning the nature of organizational best-care practices. However, current care practices and the present models of care have yet to respond to these influences. Most noticeably, the Western biases, influences, and assumptions widely applied to care make it difficult to respond to new and different ethical challenges providers and organizations face when encountering patients and populations from and with non-Western worldviews.

Currently, standardized “best practices” are often oblivious to the various yet specific needs, beliefs, and cultural and religious perspectives patients bring to the consulting room or the hospital when seeking care. However, in the face of these standard practices, the global healthcare landscape is experiencing unignorable seismic structural changes. Rapid technological upheavals, coupled with the international cross-pollination of economies and diverse cultures, create challenges to the status quo that lead to culturally insensitive care.

Also, there is a significant shift to recognizing and responding to patient autonomy in Western healthcare systems and increasingly globally. Yet many resource-limited, non-Western countries lag in adopting modern medical practices. This occurs for a couple of reasons. One is the collective, community- and family-based nature of identity and decision-making in many non-Western cultures. Another is the exalted status given to professionals, especially physicians. Thus, the relationship between the patient and providers, in many ways, remains excessively directive, distant, isolated, and “clinical.” However, those systems—wherever housed—that creatively and engagingly respond to the opportunities of this technological and cultural transformation will succeed and lead and shape the future of healthcare.
Therefore, the whole gamut of healthcare practices, procedures, and perspectives must be re-viewed and re-seen in a new, transformative light—a light that reveals the humanistic and interpersonal connections required for excellent care. This reformation requires healthcare to become narrative-driven, other-oriented, and culturally competent.

Various models and concepts appear in the literature that address the humanistic perspective of medicine. The two most prevalent and noted models are Narrative Medicine and Ethics of Care. However, while critical and influential, each model has notable limitations and deficiencies. Most striking is that the theories which underlie these models were developed by Western scholars, contain unconscious and implicit biases, and overlook or do not account for the perspectives, experiences, and cultural norms of non-Western populations.

This dissertation identifies these limitations and presents a model for care that acknowledges and embraces the perspectives and importance of non-Western worldviews. This dissertation aims to offer an integrated, complementary human-centric model that welcomes the available literature, combines its strengths, and stretches the current models’ boundaries. The objective is to provide a modified approach to healthcare that accounts for and responds to the differing worldviews of all who seek care in a multicultural society. In addressing and responding to these existing models’ limitations and strengths, this dissertation presents an alternative, expansive, integrative, and complementary model: Narrative Authority.

1.1 Chapter Summaries

Narrative Authority places narrative as central and fundamental to successful, ethical, patient-centric medicine in any setting. Narrative Authority and its three structural components—
Chapter 2 critiques the prevalent current models (Narrative Medicine and Ethics of Care), presents the foundational nature of narrative in bioethics, and offers Narrative Authority (NA) as an integrative, synthetic, and complementary model. Chapter 3 applies NA to the patient-provider relationship. The application of NA within a non-Western context, Bangladesh, serves as an illustration. Chapter 4 addresses NA in clinical counseling, focusing on two critical clinical areas: end-of-life care and genetics counseling. Chapter 5 applies NA to interpret an organization as a social structure and shows how narrative can reshape organizational culture and strengthen best practices. Muslim patients in a non-Muslim community serve as an illustration for this chapter. Chapter 6 applies NA to global health crises and the interdependent matrix of the modern health system through the lens of the Covid-19 pandemic and the migration of healthcare providers from resource-limited countries to developed countries.

1.2 Narrative Authority: A Complementary Model

Ethical care requires an understanding of and appreciation for the narrative dimensions of care and healing. Chapter Two addresses the importance of narrative in medicine, critiques the isolated and distanced stance of contemporary medicine, provides insight into and comprehensive appraisal of the two main narrative-based models, Narrative Medicine and Ethics of Care, then introduces an integrative, complementary, and more inclusive model called “Narrative Authority.” The goal is to offer a model to respond to and care for the biological body via significant insights and clarity of worldviews and belief systems that the stories of the illness provide. The chapter
claims that it is high time for medicine to embrace the power of narrative, become fundamentally human-centric, and serve as a genuine healing agent, specifically in diverse settings.3

1.2.1 Contribution of Narrative in Medicine and the Dominant Models of Care

Understanding and becoming attuned to a patient’s narrative are ever more vital given we live in a globalized world where diversity is prevalent, but its significance is often ignored. The focus is mainly on the abstract, universal, clinical representation of the illness rather than on providing individual, person-centric attention4. If providers do not come to the consultation room to listen to and hear the patient’s story and perspective—especially those coming from ‘different’ backgrounds—it is impossible to provide excellent patient-centered care that maintains the patient’s dignity5.

1.2.1.1 Importance of Narrative in Medicine

The importance of narrative is often unrecognized or underappreciated in current medical practices and, as a result, leaves medicine hobbled. Narrative is the touchstone for seeing, understanding, and healing patients. Narrative integrates, via story, the temporal nature of human being. Narrative reveals the past from which it creates a connection to an opening for possible futures by providing sense-making for actions in the present6. Narrative offers a human-oriented response to care. For example, illness can give rise to isolation and fear when a patient confronts the reality of a disease7. This imbalance often creates dysfunction or a chasm in the relationships the patient holds with others, leaving the patient to feel alone, unheard, and unseen8. When this occurs, she often becomes detached or distanced from ways to interpret or imagine a future, feeling sheared from the past. Thus, making actions in the present seem meaningless, terrifying, or irrelevant.
Narrative plays an integral and binding role in creating a culture of care—a culture that recognizes the patient as a storied being in need of hospitality and support. Narrative Ethics, which rose to prominence during the 1980s, but with roots that go back to the ancient Greeks, is a model that helps to recognize the practical and cognitive understanding of narrative and its contribution to medicine. This chapter unfolds via Narrative Ethics and highlights the importance of a provider being contextually responsively and reflectively attuned with the patient. Being-with-the-other-as-self is the means to find appropriate and realistic care options.

To become a healing agent, it is essential to achieve narrative competency. Narrative competency is the ability to honor and respond to the other’s story in ways that allow both parties to understand one another and to find meaning-based avenues to address a current situation. The chapter also addresses the importance of a clear transmission and reception of stories between the tellers and the receivers. Story discloses worldview, values, beliefs, fears, expectations, etc. Narrative competency ensures a provider can interpret and appreciate the other’s worldview and then respond in a way that leaves the other person feeling seen, heard, and understood. Story-sharing is a means for opening dialogue, building trust, and offering treatment options that the patient will embrace.

1.2.1.2 Comparison and Correlation with Other Primary Models

Narrative Medicine and Ethics of Care are the two dominant models called upon in healthcare. However, Narrative Medicine is another vital model that utilizes individual narratives in clinical practices, research, and education to promote healing. Narrative Medicine is not an approach to help providers reflect upon their work and identity but operates as a “treatment intervention tool.” Narrative Medicine serves to de-distance practitioners from patients by situating both practitioners and patients squarely in shared narratives.
Narrative Medicine has three components: Attention, Representation, and Affiliation. Through these, Narrative Medicine recognizes, absorbs, and interprets the stories of the illness. Narrative Medicine acknowledges the seen and unseen aspects of medical practices. It offers responses that become evident by and through the stories and context the patient presents through a lived narrative.

All three components of Narrative Medicine are highly effective in resource-rich Western settings, particularly in countries with ample resources devoted to the healthcare sector. However, the implementation of the three components of Narrative Medicine is highly problematic in non-Western populations—particularly in countries where healthcare and educational resources are scarce. Attention and Affiliation components work, but the act of Representation is challenging to adapt in a resource-limited country. For instance, the creative writing assessment component of Narrative Medicine is an excellent way of Representation, but it is not feasible in many settings. Creative writing is an undertaking that requires a prerequisite level of literacy, as well as resources and time to conduct the task. Also, a significant focus of Narrative Medicine is grounded in English-language literature. In areas where people are uneducated and do not have ample resources, it is impractical to apply such techniques as creative writing. Creative writing, poetry, literature, and crafting stories about patients’ sensory details and metaphors bump against practical and structural barriers. Even if this approach were attempted within medical school curriculums, in most poor and non-Western countries, practitioners and facilitators would struggle given resource constraints and the current rigidity of teaching and practicing methods. In a nutshell, it would not be feasible to practice medicine via poetic and artistic interventions.

From this context, this dissertation claims that Narrative Medicine carries unintentional biases. The model presumes and assumes a Western, affluent, literate worldview. This worldview
is not held globally. Tasks and approaches that seem easily doable in Western and resource-rich countries are challenging or come off as tone-deaf in countries where the populace is poor or illiterate, and the healthcare sector struggles for resources. The dissertation addresses this unintended limitation of Narrative Medicine and provides a modified, practically applicable, and more flexible version of the model through Narrative Authority (NA).

Ethics of Care (EOC) is the other prominent humanistic care model to be explored in the dissertation. It is feminist and constructed around the concepts of concernment and compassion. From the perspective of EOC, an action is interpreted by the nature of a person’s relationship with others. EOC describes human decency through the concept of care, which is closely connected with vulnerability. EOC’s grounding belief is that humans are interdependent, physically vulnerable, and face cognitive uncertainty; the means to ethically and adequately respond to this existential predicament is through care. EOC recognizes the intrinsic worth of each human being, the shared experience of vulnerability and finitude, and the obligation to and for the other through care.

While EoC is a profoundly human-centric model, and though its tenets do not explicitly mention the ontological importance of narrative, the connections and obligations to care for others are profoundly narrative-oriented. EoC does not offer concrete directions or specific tools to respond to the patient's humanness and in the service of providing good care. The feminist grounding of EoC is constructed around the concepts of concern, compassion, and a welcoming of and interdependency with the other. However, that presents EoC as a form of social theory. While important and influential, the position remains abstract, philosophical, or supplies a pedogeological grounding. Yet, tools for application are required. Narrative Authority offers such tools coupled with an approach that complements the primary tenet of EoC: to provide care.
1.2.2 Conceptualization of Narrative Authority

The dissertation presents a concept of Narrative Authority (NA) as a driving force that can transform healthcare and guide providers to create other-oriented, story-centric practices and procedures that recognize healing as the ability to-be-with-the-other-as-self. Narrative Authority is a modified, integrated, and expanded version of the notions that ground Narrative Medicine, Narrative Ethics, and Ethics of Care. NA particularly embraces Narrative Medicine and Ethics of Care, combines their strengths, and, notably, overcomes the unconscious, implicit Western biases within each. NA brings a non-Western perspective into the practices with the intent to—as best as possible—eradicate Western prejudices in the narrative practice of medicine. Narrative Authority incorporates a phenomenological investigation to reveal privilege and a method to respond to the lived, experiential nature of illness, suffering, obligations, beliefs, norms, and responsibilities.

1.2.2.1 Foundations of Narrative Authority

Emmanuel Levinas’s notion of ‘calling into question of the same’ is applied in the construction of Narrative Authority, specifically to address “The Ethical” foundation of Narrative Authority. Levinas’s way of recognizing the other—as not as same, but as someone to whom we are obligated to provide hospitality and care—supports and shapes the responsibility to and for communications and non-judgment that rest at the heart of Narrative Authority. In seeing and witnessing the “face of the other,” we recognize—without contemplation—that we are human but not reducible one to the other. In this recognition, we experience ethics, obligation, care, and love to and for the other before-and-with-and-beyond-me. And in this difference, we recognize our mutual dependency and vulnerability. Here, we respond to the human plea we each make to the other, “do not kill me.” The notion of “a calling into question of the same” helps to create
the platform for embracing the differences within the same. The ethical response to our recognition of not sameness is to tend to and offer hospitality. Narrative Authority embraces these distinctions and informs all aspects of the concept.

Narrative Authority guides practitioners to welcome and understand the differing worldviews of others in the consultation room. Structural designs and culture and philosophical presumptions confine and define our perspectives and notions of reality, whereas story and narrative, and the call to be-with-the-other, help practitioners step through these limitations and to see the other as she presents herself—another human, not an abstraction or stereotype.

1.2.2.2 Components of Narrative Authority

NA is best understood as existential-phenomenological hermeneutics of care. NA presumes: (1) humans are fundamentally relational and understand one another through the contextual power of story, and (2) the urgency, importance, and meaning of tasks and actions arise through the shared significance story provides. NA is the process of giving oneself over to the foundational nature of the narrative act and to stand in the shared space where one sees the other-as-self.

Narrative Authority is action-based and comprises of three components: Open Listening (not knowing), Storied Hearing (attention to), and Shared Healing (responding to). These three components are built upon the foundation of narrative. They also complement and enrich the properties guiding Narrative Medicine and Ethics of Care. The focus of these components is to recognize and embrace our obligation to and responsibility for the other, regardless of circumstance. By using these practical tools, Narrative Authority provides a context-sensitive way of practicing narrative in all settings, but especially in resource-limited, non-Western countries.
1.3 Narrative Authority at the Interpersonal Level

Medicine should be seen as practicing the art of humanity, with the sole purpose of revealing the intimacy of a patient’s welfare.\textsuperscript{36} The patient-provider bond is a critical component of this art and the holistic and sacred relationship it fosters. Treating the patient’s physical illness is secondary, whereas care for the patient—as other-as-self—is primary.\textsuperscript{37} The dissertation aims to ensure that medicine is viewed as a healing agent. Healing begins at the core by connecting one to the other via narrative. This approach holds that the patient-provider relationship is sacred, and if not nurtured properly, the whole healthcare system will continue to collapse into de-humanizing technique and abstraction. This chapter emphasizes the importance of the patient-provider relationship. Then, Bangladesh, a non-Western and resource-limited country, serves as an example for applying Narrative Authority in the context of a non-Western worldview.

1.3.1 Reconfiguring Patient-provider Relationship

The patient-provider relationship is very crucial in providing the best possible other-oriented care. Autonomy and paternalism play vital roles in shaping the patient-provider relationship. Paternalism was once considered as a normative and practical medical practice in the healthcare arena.\textsuperscript{38} However, from a modern medical practice perspective, care is not about biological diagnoses but involves an active moral judgment. The moral judgment reveals the provider’s responsibility to and for the patient. The patient and provider share a contemporaneous space and a being-with-one-another; in this space, the provider offers her care expertise.\textsuperscript{39}

1.3.1.1 Paternalism and Patient Advocacy in Patient-provider Relationship

Although the pendulum in the West has swung from physician paternalism to patient autonomy, paternalism remains normative in non-Western countries. In many countries, poor and
illiterate patients lack fundamental health knowledge, are unable to read, are frightened or confused by a hospital, and find it challenging to make well-informed decisions.\textsuperscript{40} Patients expect and want the provider to make decisions for them, and they voluntarily accede their authority to providers.

However, this Western shift of focus to patient autonomy has fostered a fundamental change in the nature of the patient-provider relationship and has caused a quandary. Methods to reduce paternalistic practices give rise to mistrust when there is a call for more autonomous notions of medicine in the East. From an ethical and moral standpoint, this swing of the pendulum has resulted in unintended consequences, which this chapter details.\textsuperscript{41}

\textit{1.3.1.2 A Joint Narrative-based Patient-provider Partnership}

The question remains, what constitutes good care? Merely respecting a patient’s autonomy and considering the patient as an ultimate arbitrator of choice does not represent good care.\textsuperscript{42} On the other hand, overt paternalism by the physician also does not constitute good care.\textsuperscript{43} The goal is to find a balance that constructs and maintains a responsible relationship between the patient and the physician/caregiver. A physician-patient balance must be established to ensure a power equilibrium between both parties if there is to be excellent, ethical care. Too often, balance is obtained when the provider is seen as the technical expert and the patient as the customer. In those situations, care decisions occur through an exchange of mere information.\textsuperscript{44} To provide and receive other-oriented care, it is imperative to understand the reciprocal relationship between paternalism and patient autonomy.\textsuperscript{45} Therefore, the patient-provider relationship must find an ethical intersection, a point of consensus. They must find a connection where paternalism and patient autonomy are respected, with consensus (not compromise), through shared agreement and decision-making.\textsuperscript{46} The focus of this chapter is on relational autonomy along with principle-based
ethics; placing relationship-oriented ethics on equal footing makes it easier to establish and maintain a balanced approach in delivering excellent care.  

1.3.2 Illustration: The Patient-provider Relationship in Resource-limited Countries

This section offers the example of an Eastern and resource-limited country, Bangladesh, which has an ineffective healthcare system. In Bangladesh, there is no coordinated, centralized, or reputable and respected entity to oversee and maintain an integrated or coherent healthcare system. Compounding the situation are significant ethical issues concerning equity and fairness, which go unaddressed.

1.3.2.1 Patient-provider Relationship in the Context of Bangladesh

People in Bangladesh overwhelmingly mistrusts both its healthcare institutions and care providers. There are calls from progressive healthcare agents in Bangladesh to change practices so that patient autonomy is more readily recognized. These change agents claim that for this to occur, the health system of Bangladesh needs to change from the top. This chapter, however, offers and suggests a bottom-up approach to jump-starting this immense cultural change. Change occurs from the core, from those closest to the patients, by shifting the general public’s hearts and perceptions. Simultaneously, the system needs to be reimagined to support the necessary moral and ethical structural changes occurring locally to keep them sustainable. Naturally, without the active participation of and commitment by the social and economic influencers, it is impossible to make significant changes. But this chapter demonstrates that incremental and small steps are praiseworthy too. A case study is used to demonstrate the broken nature of patient-provider relationships in Bangladesh, and suggestions are offered for repairing and reimagining these relationships.
1.3.2.2 A Reformed Relationship through Dignity-enhancing Care

This section demonstrates how NA can serve to transform, remake, and reestablish the patient-provider relationship through Gastmans’ foundational ethical framework of “Dignity-enhancing Care.”51 The root of this change is only possible through a dignity-enhancing therapeutic care model, which is ethical and restores a patient’s belief in the physician ethics and motivations. To respect a person’s dignity, it is imperative to understand the wholeness of the person, understand her personhood, and respect her vulnerability.52 And the wholeness of a person can only be understood by embracing the person’s narrative and worldview.

Narrative Authority sets the ground and offers an approach to embrace the significance and primacy of the intersecting narratives the provider is immersed within when meeting a patient. Narrative girds the concept of Dignity-enhancing Care and is foundational to becoming a skilled, ethical healer—an agent who constructs being-with-the-other healing relationships.53 This is why the word Authority is used in the Narrative Authority model. Narrative Authority is offered to provide a guiding role in this transformation.54 Relying on NA, physicians are guided ethically and responsibly to implement practices that maintain and uphold the patient’s dignity. When they do so, they reclaim the art of healing and embrace their role-fulfilling, identity-affirming gift of being-with-and-for-the-other as physicians. The art of ethics is disclosed by holding narratives as the gateway to human connection.55

This can be done through the framework of Responsiveness. Responsiveness must change—on both the interpersonal and systemic sides—if healthcare is to become genuine, adapt to, and anticipate the patient’s health expectations.56 This chapter focuses on people-side interactions while recognizing that systemic structures are equally integrated and inseparable from the construction of worldviews and everyday significance. The patient-provider relationship is not
merely dyadic; it is the byproduct of many forces within and throughout the healthcare system.\textsuperscript{57} Narrative Authority will play a significant role in providing the perspective and subsequent best-practice approaches to embrace and implement dignity-enhancing care, which is context-sensitive, responsive, and relational. Granted, broader structural changes must address graft, corruption, and favoritism so apparent and widespread in the Bangladeshi healthcare system. This change itself can be addressed through an honest, narrative assessment of intent, purpose, and the obligation of Bangladeshi healthcare to the citizens of Bangladesh.

A good portion of Chapter Three is comprised of the article, “Moral distress among healthcare providers and mistrust among patients during Covid-19 in Bangladesh,” recently published in the Developing World Bioethics. This article discusses the importance of interpersonal relationships in driving change while noting the need for complementary, systemic, and best practices change to rebuild trust in the Bangladeshi healthcare system. Even though the article focuses on the Covid-19 pandemic, the article addresses the failures of the current Bangladeshi healthcare system. This pandemic only further highlights the broken trust between Bangladeshis and the country’s healthcare system. This article recommends that by relying on the framework of Responsiveness, care providers can re-establish, improve, and strengthen patient-physician relationships while reducing moral distress and rebuilding trust within and throughout the community.\textsuperscript{58}

\textbf{1.4 Narrative Authority in Clinical Counseling}

The current care delivery process, in all parts of the world, faces numerous ethical dilemmas, even though Four Principles bind the field: autonomy, beneficence, nonmaleficence, and justice,\textsuperscript{59} which, together, serve as a systemic ethical guide for responding to the complexity and nuance of “real-life” scenarios providers face. To navigate such daily ethical challenges and
to better respond to critical situations, the concept and role of the clinical ethics consultation emerged in healthcare. While this practice of clinical ethics consultation/medical ethics consultation is gaining its voice in the Western world, unfortunately, many parts of the world are not yet attuned to the ethics consultation concept/process. This chapter explores the challenges in clinical counseling and provides a way to facilitate the consultation via the framework of Narrative Authority.

A clinical ethics consultant’s goal is to facilitate a meaningful conversation with the provider and the patient (or family) that recognizes and respects the other’s point of view and serves to guide the parties to a consensus. Thus, it is also essential that the clinical ethics consultant understand the narrative, positions, and worldviews of both parties involved in the conversation. This chapter outlines two difficult situations where clinical counseling faces immense challenges: End-of-Life counseling and Genetic Counseling. The focus of this chapter is on Western medical practices. Whereas the focus of the other chapters of this dissertation is on the non-Western world, Chapter Three and Chapter Four analyze dominant Western-world practices to demonstrate that the application of Narrative Authority is relevant globally.

1.4.1 End-of-life Care and a Narrative Approach to Difficult Conversations

Death is inevitable, and there is no escape from this tragedy in healthcare. Confronting death is a challenging time for the patient and the patient’s family. Patients and their families often view the patient’s demise as a direct failure of the provider. Yet, while death and dying are common, responding to these facts remains one of the most difficult tasks that care providers face. It is also a complex, stressful, and often an emotional experience for the care providers having to convey this heavy news to the patient’s family. To properly conduct such difficult conversations, the provider must respond to the patient/family with empathy and compassion.
1.4.1.1 End-of-life Ethical Dilemmas in Medicine

As mentioned above, death is the universal and inescapable reality and a routine occurrence of the medical professions. Medicine has limitations; the power of medicine is imperfect; not all patients recover, nor may their wellbeing be fully restored. No medical intervention is justified until it serves the wishes and wellbeing of the person dying. An effective discussion must occur for this difficult conversation to be effective, ethical, and empathetic. One must understand and recognize the other. During the conversation, the provider must find ways to solicit the patient’s beliefs and positions on living and, importantly, how she wishes to die. Therefore, active, attentive involvement, engaged presence, and demonstrations of compassion and empathy are required if such conversations are to be meaningful and get to the storied heart of the matter.

Two things must be clear while approaching an end-of-life conversation. The first is to plainly define End-of-life care (Palliative and Hospice Care), and the second is to take into account cultural and religious differences. To resolve conflicts concerning end-of-life care, systems must educate people broadly on the importance and availability of advanced care planning so that they can be prepared for this fearful and emotional situation. Due to globalization and the increased frequency of diversity, practitioners or ethicists must understand a patient’s end-of-life preferences. Due to cultural and religious values, End-of-life care is seen and embraced quite differently by different people.

1.4.1.2 A Narrative-driven End-of-life Clinical Counseling

The practice of Narrative Authority leads to an open-ended conversation where a person’s quality of life is approached by focusing on the person, their story, beliefs, fears, and hopes. The existential-phenomenological foundations and predication of Narrative Authority guide the
provider to always being-with-and-for the other, which, in turn, demands asking questions that solicit a person’s perspective—their worldview. Practicing NA is the process of developing a relationship, of seeing the other-as-self, and offering care as an expression of love.70

1.4.2 Genetic Counseling and Associated Challenges

Genomics—one of the significant breakthroughs in medical science—can decipher the mysteries of confounding and common diseases. Genomics has catapulted medicine into a new era.71 The benefits genomics offer is remarkable, and they will continue to grow and influence both medical and community perspectives.72 However, the advancement of medical genetics has also brought new responsibilities and challenges to clinical counseling. The challenges circle around Privacy, Autonomy, and Informed Consent.73

1.4.2.1 Data-sharing Consensus and the Consent Process in Genetic Counseling

Genomic data are more frequently shared than ever before. However, reaping the benefits of genomic testing requires an extensive set of sequencing data, which, given the explosion of genomic testing technology, is ever more at hand.74 Clinical counselors should remember that genomic medicine, in the best case, operates for and by the common interest; therefore, the open exchange of and access to genomic information is fundamental to the growth of this new method of healthcare. Also, understanding the common good is important because we live in an era of globalization; the healthcare system is interconnected in ways that have transformed traditional notions of local and far.75

The complexity and scope of genomics also present challenges to traditional informed consent, such as shared decision-making,76 cultural competency,77 single-episode occurrence,78 and data collection and data storage.79 Genomics requires informed consent that incorporates the
notion of being interactive, narrative-based, and coming from a not-knowing approach. Interactive Informed Consent ensures that the subject/patient maintains her autonomy and is actively involved in the decision-making. This approach also makes the patient fully aware of how her genomic profile and the specifics of her situation can and will serve broader social responsibilities and obligations individuals hold, i.e., to serve others and improve the health and welfare of the community and humanity at large.\textsuperscript{80} Even though genomic profiles are very personal, in aggregate, they serve the larger social good through better, more accurate, and innovative healthcare. The challenge is to remove the fear patients or participants carry due to their lack of knowledge about how the genomic data is and will be used.\textsuperscript{81} Genetic counseling aims to support and promote the common social good while respecting the patient’s autonomy. One of the prime reasons genetic counseling is nondirective is that it offers the patient the autonomy to avail herself of the testing. But the patient must understand that her participation can fulfill her obligation to contribute to and directly participate in the welfare of society.\textsuperscript{82}

1.4.2.2 An Open-ended, Not-knowing, Narrative-based Counseling

Narrative Authority’s being-with approach helps counselors facilitate effective dialogue with patients, illuminating a participant’s sense of social obligation to others. By coming to the conversation with a not-knowing approach and a respect for the other’s story, the counselor opens a space of trust that helps the patient understand the nature of genomic data and its bigger social purpose—doing such guides participants to make a voluntary judgment on whether to participate and have a firm grasp on the reasons for her decision.\textsuperscript{83} It is essential to convey the message to the patient that all ‘personal’ identifiers will be removed from the information. Sharing these details serves to foster narrative partnership and helps ensure that the consent the patient provides is informed and willingly and knowingly given.
This more integrated notion of informed consent seeks to find ways to respect the individual while allowing the benefits of genomics to flourish for all. Narrative Partnership reshapes the normative assumptions concerning human relationships and makes a relationship inseparable from the shared storied space, the social context in which it occurs. Narrative Partnership rests on the belief that all human relationships are radically social. Narrative Partnership serves to revise the notion of the individual as separate and autonomous. It redefines individuality as socially shared and, hence, ethical by nature. \(^{84}\)

1.5 Narrative Authority at the Organizational Level

Medicine is in the throes of disruptive change as it responds to the forces of globalization, multiculturalism, and dizzyingly rapid technological progress. In this changing landscape, contemporary healthcare requires revised practices and procedures to become culturally responsive, narrative-driven, i.e., founded on soliciting patients’ personal narratives and guided by cultural-forming, style-guiding organizational narratives. \(^{85}\) The previous two chapters focused on the personal and individual, but making changes at personal and interpersonal level is impossible without making organizational-structural and normative-practice changes; they are intertwined.

1.5.1 Culturally Responsive Organizations in a Multicultural Society

If healthcare is to succeed in this global landscape, it must also come to see and embrace its role as a healing agent in service to individuals and society. Technology, science, footprint expansions, and efficiency are means, not ends. Healthcare organizations should be redesigned to encourage physicians to see patients as individuals—as others-as-self—as the pathway to constitute an ongoing, attentive process to attain excellence, welcome the other, and create culturally attuned, sensitive, and responsive healthcare systems. \(^{86}\)
1.5.1.1 Ethical Considerations for Cultural Diversity

Cultural insensitivity can lead to significant and unexpected consequences in a diverse world. The imposition of Western colonialism and Western notions of structure are common when organizations design and implement healthcare practices and procedure.\textsuperscript{87} The excessive presence of patient autonomy arising from principlism is a prime example of the Western perspective having been imposed globally.\textsuperscript{88} The criteria for autonomy (liberty and agency) predicate that no one controls a person, is radically free, and has a free will to choose as she pleases. The way individual autonomy is practiced in the West quite often varies from how it is practiced in the other parts of the world—especially in cultures that have a collective sense of identity and practice family-based decision-making. Therefore, it is imperative to understand autonomy through the lens of cultural sensitivity.\textsuperscript{89}

For organizations to operate effectively in a global environment and to provide excellent patient-centric care, they must come to understand and embrace a different version of autonomy—relational autonomy. This is a form of autonomy as practiced normatively in many countries where people see themselves as part of a larger collective, whether family, clan, or nation.\textsuperscript{90} Open-mindedness and multidisciplinary approaches to recognize the values, beliefs, and practices of various culture is required. This is a means to assimilate the different medical practices into healthcare and loosen the tight and narrow hold the Western perspective has on most organizational cultures.\textsuperscript{91}

1.5.1.2 A Culturally Responsive-Storied Care System

In turn, the organization and associated providers must become culturally competent, globally responsive, ethical, and attuned to the other’s humanness, regardless of culture.
Contextualism and ethical relativism have been called upon to disclose cultural competency. We are immersed in a “quantitatively grounded, cost-driven, bureaucratic marketplace model” of healthcare. In the quest to measure, rate, and make processes more efficient, healthcare systems overlook or discount the narrative of care, the narrative of illness, and often their guiding, healing organizational narratives to improve the patient’s life. Narrative Authority provides the perspective from which to interact and understand each individual’s story, and in doing so, improve and strengthen best practices. Thus, an organization can operate in a culturally responsive-storied way. This section of the dissertation appears as a chapter within the book, “Dealing with Bioethical Issue in a Globalized World.”

1.5.2 Illustration: A Minority Religious Practices within a Dominant Religious Community

The norms and practices prevalent in Islam, as they apply to healthcare, have not been explored thoroughly in non-Islamic communities. Western care providers generally come to a patient with the presumptions and assumptions of autonomy, individuality, and logic. Doing so, often unknowingly, makes Muslim patients feel uncomfortable, unseen, unheard, and self-conscious or angry. It is naïve to believe that Western worldviews can continue to set the norm.

1.5.2.1 Muslim Patients and Their Experiences in Non-Muslim Communities

Findings in a recent study revealed that 63% of Muslim women in rural areas within the United States do not seek healthcare or visit a doctor because they believe the doctor does not understand them. This study indicates that many healthcare providers do not understand the traditions and mores of Muslims, especially those of Muslim women. Developing and embracing an understanding of these cultural practices—by developing cultural competence—will help non-Muslim care providers respond to Muslim patients in a culturally sensitive way.
At a minimum, practitioners must possess foundational and basic knowledge of this patient population. However, this minimum knowledge often is not sufficient to provide excellent patient-centric care. What’s needed is a more in-depth understanding of Muslims’ varied cultural and normative practices from different areas of the world and different sects of Islam. However, the interplay between culture, religion, and worldview is very critical, and yet it is essential to be attuned to potential blind spots. Gaps in knowledge and cultural biases give rise, often unintended, to stereotypes which often have the provider dismiss, discount, or diminish the uniqueness of a person, even within the same cultural group. Providers cannot be expected to be experts on the norms and practices of all the patients they serve, but these issues should be addressed during medical training. And practitioners must continue to learn and remain inquisitive and sensitive to these differences if they are to practice ethical, culturally sensitive medicine.

1.5.2.2 Respecting Muslim Patients’ Worldviews in the U.S.A

However, in highly diverse settings, the collision of worldviews between culture and religion is very common, but responses vary regarding cultural competency and sensitivity. One must remain attuned to differences and the tendency to stereotype. For instance, even members of the same family will respond differently when confronted with the same situation. Through its phenomenological investigation of lived experience, NA helps organizations recognize that diversity and difference are integral to providing excellent other-oriented care. Attention to narrative, focusing on beliefs, values, intent, meaning, and significance, provides the sense-making to change practices and encourages cultural sensitivity as a standard, ethical cause. The aesthetic quality of NA facilitates genuine encounters with everyday practices through the notion of connectedness, belonging, and being affirmed by others. The sense and power of connectedness opens one to the worldviews of others and makes evident the reasons for and importance of
identifying and modifying best-care practices. The articulation of the narrative often reveals unquestioned assumptions, which, when recognized, identify anomalies, drive innovation, and promote improvement.\textsuperscript{107}

This section highlights Muslim women as a focal point and suggests that Western practitioners must come to recognize a Muslim woman as a person in need of care; a person—not a religious or cultural abstraction—with a story that includes specific beliefs, practices, and worldview.\textsuperscript{108} As both an approach and working tool, NA can serve as a guide for healthcare providers to ensure that non-Western worldviews, expectations, perspectives, and religious and cultural norms of diverse patients are recognized, understood, respected, and incorporated into best practices for providing ethical and effective care to and for Muslim women and Muslims in general.

1.6 Narrative Authority at the Global Level

The previous chapters presented the implementation of Narrative Authority at interpersonal and organizational levels. In this final chapter, the dissertation moves from a local to a global perspective and lays out the applicability of NA in global crises. Two examples will be used: A global humanitarian crisis and the migration of health practitioners. Disasters or crises do not arise suddenly. A crisis typically unfolds over time and is often only addressed or acknowledged when the situation becomes overwhelming or undeniable.\textsuperscript{109}

1.6.1 Ethical Obligations in Global Health Crises

With rapid environmental changes and global conflicts, disasters seem to be ever more frequent, and, with this, the number of humanitarian crises is increasing. Such upheaval hampers the operation and effectiveness of health systems, stymies existing infrastructure, and disrupts and
debilitates society’s normative functioning. As a result, people, in desperate search of safety, are often displaced or become refugees.\textsuperscript{110} This final chapter describes the harmful and unintended consequences of disaster management interventions that create additional suffering during a humanitarian crisis. It then suggests ways in which Narrative Authority can be used to more efficiently, effectively, and humanely respond to such crises.

\textit{1.6.1.1 Unintended Consequence of Post-disaster Management}

A disaster causes many injuries, fatalities, illnesses, the loss of family and loved ones, the destruction of property, and the shattering of neighborhoods and communities. All these issues give rise to the immediate need for physical and mental health support.\textsuperscript{111} The four UDBHR Principles: Respect for Autonomy, Beneficence, Nonmaleficence, and Justice are used to demonstrate the challenges of post-disaster management.\textsuperscript{112} A crucial matter addressed is researching a humanitarian crisis. Frequently, in a rush for data, researchers overlook the humanity of those in need and, in turn, infringe upon or discount their dignity.\textsuperscript{113}

Culturally inappropriate behavior can also be hurtful and distancing when providing support to the victims. Regardless of the situation, it is mandatory to acknowledge and be respectful of the other’s cultural practices and beliefs by applying the broad lens of autonomy.\textsuperscript{114} The appropriate recognition and consideration of another’s culture and religious practices positively contribute to the success and accuracy of research and the support the researchers receive.\textsuperscript{115} Language also plays an essential role in post-disaster management, as disaster brings diverse groups of people together in the same compound.\textsuperscript{116}
1.6.1.2 Moral Distress and Moral Injury During the Covid-19 Pandemic

The Covid-19 pandemic is used as an illustration to demonstrate the 2019-21 global health crisis and the need to integrate NA in response to this crisis. Frontline workers, globally, face severe mental health challenges as they attempt to respond to and work through the pandemic.\textsuperscript{117} Healthcare providers, like all people, have families and loved ones in their lives. In this Covid-altered landscape, nurses confront choices that are often morally and ethically challenging: E.g., fairness and justice, duty to care, professional integrity.\textsuperscript{118} They find themselves with competing obligations to work and their duties to families and loved ones. This gives rise to a dilemma often experienced as a conflict between professional commitments and personal responsibilities. On the one hand, there are obligations to virus-sickened patients, staring at the provider, longing for help and assurance. And on the other hand, there is the embodied obligations of the care giver to those they love and depend on in so many everyday ways. Beyond the ethical challenges of properly caring for patients during this crisis, the scarcity of personal protective equipment (PPE) adds further confusion into the decision-making landscape practitioners face.\textsuperscript{119} These conflicts create extreme moral distress among front liners and, in turn, produce moral injury, manifest in long-lasting emotional, social, psychological, and spiritual effects.\textsuperscript{120}

1.6.1.3 A Narrative-based Responses to Global Health Crises

This obligation to respect disaster victims can be demonstrated by honoring the other’s personhood equally, regardless of her condition, culture, and language. It is possible to address and promote the primary obligation of being-with-the-other if researchers, care providers, and associated management practices are informed by and grounded in the principles of Narrative Authority. NA addresses this challenge through the ethics of engaged presence. Engaged presence helps care providers and support staff understand, recognize, and honor the fear and danger victims
face. And to remember moral and ethical responsibility is to be present with and for the person or persons being attended to. By practicing Narrative Authority and consistently questioning or validating operating assumptions, it is possible to limit the unintended consequences or actions assumed to be correct or normative.

To confront and overcome these traumatic situations, providers need to adopt self-care strategies for themselves. Narrative Authority helps providers embrace and respect self-care strategies, which result in building and strengthening moral resilience. Focusing on one’s personal narrative helps a practitioner re-recognize the reasons and importance her role plays in forming her identity. This attention helps to clarify why self-care is essential. If a practitioner comes to work unhealthy, there is a greater likelihood of making errors and mistakes. And there is the certainty of becoming further stressed, fatigued, and burned out. Therefore, providers need to self-care first before they attempt to help others. Moral resilience prevents frustration and makes frontline workers more buoyant and responsive to change. Thus, providers who become more mindful of everyday actions and more readily embrace this sudden new-normal.

In this time of Covid-19, the type of distress healthcare providers face should no longer be considered moral distress but rises to moral injury. The ongoing trauma and the harshness of the pandemic is creating damage which may become permanent if not addressed otherwise. There are different types of self-care strategies that need to be administered by the organization to protect providers from such psychological damage.

1.6.2 Interdependency of Healthcare in the Globalized World

One of the outcomes of globalization—given the ease and increase of mobility—is more expansive and distant health options and opportunities. Health and medicine have become a
globally shared platform, and healthcare practitioners have even greater opportunities for moving from one country to another. One of the byproducts of this migration is the shortage of skilled practitioners in the home countries from which the practitioners leave behind.\textsuperscript{125} The migration of physicians from developing countries to developed countries only fills the shortage of physicians in developed countries; the home country is often left wanting for talent.\textsuperscript{126}

\textit{1.6.2.1 Ethical Dilemmas with the Global Migration of Physicians}

The four Principles of the Universal Declaration of Bioethics and Human Rights (UDBHR) are applied to define the consequence of this migration as ethically and morally suspect. The principles are Equality, Justice and Equity, Solidarity and Cooperation, and the Sharing of Benefits.\textsuperscript{127} The UDBHR principles clarify how this type of healthcare migration is morally and ethically wrong because it creates imbalances in the health sector. This is discussed through the lens of moral imagination and moral reflection, which expands the circle of moral concern and helps to recognize and respond to our shared humanity.\textsuperscript{128}

Given the dynamics of globalization, it is impossible to restrict migration. Such restrictions stymie a person’s autonomy. But it is possible to devise alternative methods to ensure that home countries receive adequate healthcare and recompense for their initial investments in education and social infrastructure.\textsuperscript{129} To respect a person’s autonomy and to safeguard a country healthcare system, it is imperative to construct processes and regulations that protect individual autonomy—the right to migrate—but also respect and support the needs of the home country, which has often invested in training physicians who leave for opportunities in other lands.
This section of Chapter 5 was published in the Journal of Global Bioethics under the title, “Global responsibility vs. individual dreams: addressing ethical dilemmas created by the migration of healthcare practitioners.”

1.6.2.2 Turning Obligations into Responsibilities via Narrative Authority

Narrative Authority is applied to investigate the ethical perspectives involved with physician migration, guide officials to formulate regulations that are person-centric, and offers a platform to understand the shared responsibility to and for global healthcare. NA provides the sense-making, meaning, and urgency to a shared context and, in turn, guides practitioners and policymakers to understand their responsibilities and obligations to others. We do not live in a world of isolated individuals; the world is filled with people who are interconnected through story and narrative. NA reveals this interconnectedness and the narratives and stories which define, shape, and ground ethical behavior.

The practice of medicine is continuously shaped and directed by and through the advancements of science and technology. Many major medical breakthroughs occur rapidly and frequently; however, a persistent gap exists between healing and cure. Medicine, specifically via technology, shines a light on the importance and power of being a ‘curing-agent.’ Still, while focusing on curing too often, these efforts and approaches leave the need and importance for being a ‘healing-agent’ in the dark. To understand the role of a healing-agent plays in excellent medicine, it is crucial to appreciate the central role narrative plays in illuminating and creating person-to-person relationships for each party involved in the care process. Being available to the other’s story opens a shared space in which a dialogue can occur by eliminating the distance that takes place in ‘communications’ between a ‘provider and customer.’ A conversation that is narrative based ensures that the other is seen and shifts the perspective, removes the distance of abstractions,
and places two people in connection, opening each to the other’s humanity, where heartfelt dialogue occurs to heal the wound.

Various humanistic models appear in the literature that address these challenges. Most referenced are Narrative Medicine and Ethics of Care. Western scholars and practitioners developed the theories underlying these two models. Each carries implicit biases that often fail to account for the perspectives, experiences, and cultural norms of people from the non-Western world—who are generally non-White and predominately non-Christian. The two prevalent theories unknowingly presume the Western worldview is transcendent and universal.

The thesis of this dissertation fundamentally disagrees with this presumption. The thesis presents a complementary, human-centric, narrative-driven model: Narrative Authority. The intent is to positively transform contemporary medicine via a perspective and a method that is thoroughly other-oriented, dialogue-based, culturally sensitive, nonjudgmental, and always story-dependent. Narrative Authority is the route for healthcare systems to become genuine healing agents at the individual, organizational, and global levels.

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Chapter 02: Narrative Authority: A Complementary Model

Ethics arise through the moral imagination revealed through the narrative act. A narrative provides a context in which ethics make sense. Without knowing someone’s narrative, it is impossible to judge the morality of a particular behavior or act. Ethical decision-making is not a detached or abstract exercise of choosing good over evil.\textsuperscript{133} Ethical decision-making requires honoring and respecting the other’s values and beliefs and incorporating that perspective into the dialogue. Narrative determines which value or values are most suitable when responding to a particular situation. This holds because our narratives reveal how our values become integrated into our personal acts.\textsuperscript{134} Therefore, while providing care, narrative or story is inseparable and, in fact, a part of the care process.

However, we live in a time when we are overly focused on efficiency. For instance, physicians’ interactions with patients are often timed. In such time-pressured interactions with patients, care stories are often overlooked, missed, or disregarded. Sometimes the root cause of any illness is not the disease; the illness manifests the discomfort in which the person is surrounded or immersed. Illness is the interference that hinders the body from functioning in the desired manner. Healthcare professionals often can examine illness more fully by taking a phenomenological approach. This is approach holds that an individual’s connections and immersion in her world of relationships, social norms, and cultural beliefs influence behaviors and actions and directly affect her well-being. Therefore, a phenomenological and narrative approach helps the physicians to catch sight of the patients’ beliefs via their stories. Medical ethicist Dr. Eric Cassell defined a sick person as failing to achieve their purpose in life. As a result of this, an impairment or change has occurred.\textsuperscript{135} Thus, to understand the perspective of the sick person, it is crucial to understand the background and the stories of the failure. This understanding leads to
illness’ influences and determinants, often unique and personal. Hence, the benefit of approaching
the patient through a dialogue and storytelling approach helps to reveal the connections that cause
the illness. Doing such helps the care providers to understand the illness of the patients better, and
thus care providers can assess if there are gaps and blind spots in the care itself. To overcome
what might be described as the tyranny of efficiency, providers must, in many cases, understand a
patient’s story.

A few humanistic models present in the literature address the importance of story in terms
of illness and care. The two most prevalent of these models are Narrative Medicine, and Ethics of
Care. All the humanistic models see the person as a unique being and provide practices to access
and recognize the patient’s personhood. These models attempt to catch sight of the person, her
situation, and some semblance of her story before diagnosing or offering prescriptions. However,
these models have been derived from predominantly White, Western, Christian scholars. Thus,
the models have some limitations and carry implicit biases which presume the Western worldview
is transcendent and universal.

This chapter addresses those limitations and presents a more comprehensive and
complementary model called Narrative Authority, which combines the strengths and responds to
the weaknesses in the models. Narrative Authority helps to positively transform contemporary
medicine via a perspective and a method that is thoroughly other-oriented, dialogue-based,
culturally sensitive, nonjudgmental, and always story-dependent. The two words, story and
narrative, will be used interchangeably in this chapter.
2.1 Contribution of Narrative in Medicine and the Dominant Models of Care

Medicine is in the throes of remarkable technological growth and demographic change. Through improvements in diagnostic tools, treatment options, and means of care (in-person or online), care providers stand ever more confident in their abilities to eradicate fatal diseases, circumvent heart disorders, replace organs, provide gene therapy, and the list goes on. This technology-proficient care serves to overcome or dissolve the “dread of illness.” The therapeutic relationship in this mode is, however, often very one-sided. What’s missing are the humanistic and the inter-personal exchanges between patients and care providers. This lack has created a deep gap in behavioral medicine and is a threat to medicine and patient-centered care. Generally, patients are eager to have care providers who walk with them as they embark on the journey of their illnesses. In the face of growing efficiencies and consultations in which time is limited, narrative is a connection that helps medical providers and patients to bridge the pitfalls of deficient interactions with one another and, likewise, to resolve the ethical dilemmas that result when there is a human distance between provider and patient.

The clarity and intent of a narrative or story help form substantial ethics. A narrative gives sense-making, meaning, and urgency to a shared context, which then defines and shapes moral and ethical behavior. The narrative heart of ethics calls the story, the teller, the listener, and the witness into the context—the space it opens—and immerses all involved into a co-created process of being-with.

2.1.1 Importance of Narrative in Medicine

Healthcare organizations spend enormous amounts of energy and resources on becoming ever-more effective, efficient, streamlined, best-practice focused, and highly attentive to the
The intent is to provide a well-orchestrated, structured, but flexible system through which a patient arrives; doctors assess, prescribe, and treat by all means necessary; nurses and aids complement and facilitate the care prescriptions; and hospital administrators construct a system of practices and procedures to meet regulatory and legal demands and to ensure the hospital delivers and documents the quality and safe care for the patient at each touchpoint of service.

Following this integrated process flow, the patient is discharged—and the orchestra continues to play for the next and the next, not missing a beat. The goal is a “well-oiled machine,” where everyone in the system contributes, each person can fill a “well-designed role,” assessment best practices are applied, and the hospital receives a highly favorable “delivery score.”

The more effective the orchestration, the more likely the hospital’s ranking rises, its reputation grows, and, importantly, the more profitable the hospital becomes. But, in this quest for effectiveness and, more often, efficiency, one question generally remains unasked: “Did this well-orchestrated band of highly skilled professionals, conducting a proficient, ratings-rising, well-respected hospital, change, enhance, or improve, the patient’s life remarkably?”

Why is this critical and crucial question not asked routinely? This happens, in good part, because of the way the rating process is constructed and conducted. Generally, the rating assessment focuses on the system's process-oriented input/output construction: patient "admitted" into the process, patient "discharged" from the process. Each step includes a checklist of practices to be followed and met, which, in turn, can be measured and assessed and given a quantitative score. Yet, in the face of detailed quantification and high levels of abstraction, patients are desperate for a physician who will understand their problems, recognize their fears and concerns, and guide them—using plain, understandable language—through the process of healing.
Patients do not necessarily want a physician who only comes to fix the problem or defeat the dreaded illness. While certainly looking to be healed, the patient is also looking to be seen, heard, and recognized as a human in need, with a story that reveals who she is and what’s important to her. Therefore, along with the know-how to “fix” the problem in a well-oiled system, the physician should be trained to understand, solicit, and embrace the narrative of the patient. This skill, these essential human practices, will make a highly talented, technically trained physician into a physician who is a profoundly compassionate, present-with, listening partner and healer.

Thus, care providers become dulled to the necessity for humility, trustworthiness, and respect in medical practices. Pain, suffering, worry; are problematic conditions in human life, especially when confronting an illness. For all the brilliance of technology, it remains blind to the human response when facing the plights of illness.

2.1.1.1 Narrative and Storytelling in Healthcare

The focus on and belief in efficiency, quantification, measurement, and comparative ratings can make the narrative—a qualitative, integrative approach—appear airy-fairy, romantic, or from the dustbin of another era. Yet, narrative can serve as an antidote to many of the maladies afflicting health care, which have turned the person in need into a patient—a customer, a consumer of services. Healthcare must become sensitive to the narrative—the storiedness—of the patient. In doing so, a hospital can reimagine and strengthen how it understands itself and then, in turn, begin to offer care that heals, not treats. This approach is guided by a foundational question: “Have we changed or improved the patient’s life remarkably?”
By sharing and listening to the patient’s story, the provider can find a common connection with an ‘other’ and come to see meaningful ways to have her see pathways forward, even in the direst situation. Stories help to create a sense of meaning and community. Stories provide a connection with and to another. Each care provider should be a narrativist (someone who practices a narrative approach) who captures the participant's story concerning a particular dilemma or situation. A narrativist helps the other understand how she came to a specific moral decision and how her moral reasoning is connected, integrated, and integral with who she has been throughout her life in similar situations. Thus, narrative connects the past to an imagined future that, in turn, give sense-making to decisions, at hand, in the present.

Narrative and its ability to bring two people together—to be-with—open access to collaborative, shared, and ultimately creative discourse, and a means to articulate and implement possible shared outcomes. This occurs because stories help one to understand the other’s perspective from various angles. Story unfolds the depth of someone’s viewpoint through context. Stories are always cultivated, grounded, and have a sense within a particular context. Thus, a story helps the hearer see. Story also helps the listener understand the reasons, grounding, and meaning behind the other’s identity, her presence in her world. And story always serves to bring two people together through an intersection and recognition of their humanness.

Stories reveal to the patient and physician how the particulars of health are related to the wholeness of wellness and identity. A care provider can best assess an individual’s wellness by knowing and understanding her narrative and story. The story provides the vehicle through which a person can reveal herself, to show herself, to the other. The story discloses what is significant to her, her dreams, what challenges she has and does face, how she sees herself in the face of her
current predicament, and her beliefs and guiding principles. Her story reveals her worldview. Her story presents her as a person in the presence of another person who, too, has a story. Her story provides an intersection where the physician, who is listening, sees her not as patient, there, but as an-other-as-him, here. Story helps the doctor understand a patient-as-person, thus, to act as a healer, not a service provider. Story helps the doctor to understand the patient’s preferences, notably when the patient lacks or has limited decision-making capacity. Story helps the caregiver to grasp the patient’s fundamental values and guiding perspectives. Thus, narrative serves to reveal the actual meaning of medicine and its therapeutic nature of care.

Even though the two terms “Narrative” and “healthcare/medicine” seem to come from different disciplines, they are—or should be—closely tied. It is often difficult to embrace or take the importance of narrative in healthcare seriously because healthcare/medicine is commonly seen as directed by biology, science, and technology. Narrative is seen as fiction, literature, philosophy—soft science at best. What is often ignored is that biological science and the business of medicine create a moral relationship and ethical connection between the patient and the provider. These facts are best illuminated by appreciating the narrative shared between the healer and the person in need of care. In fact, medical philosophers have developed a branch of medical philosophy which integrates medical phenomenology as means to better understand the bodily illness.

2.1.1.2 Narrative Competency

To adopt, apply, and find the advantages provided by the narrative- it is necessary to develop Narrative Competency throughout medicine and in its practices. Therefore, as we embrace the importance of narrative in medicine, the first step is to establish narrative competency.
Narrative competency is the ability to absorb and respond to the other’s story in ways that allow both parties to understand one another and find meaning-based avenues to address a current situation. Narrative competency is the capacity to approach the other with reflection, empathy, and trustworthiness. Because, in medicine, we serve wounded souls, it is essential to understand and acknowledge the stories that reveal the soul's wounds before arriving at treatment prescriptions. Narrative competency helps a caregiver identify the otherwise unspoken subtext of the pain of an illness, which can be revealed in the light of the story told by the patient. Narrative competency helps the physician to understand the storied and lived context and the story-fitted consequence of the illness. Narrative competency helps to establish a personal connection between the patient and the physician, serves the physicians as a healer, and, more broadly, benefits society through the normalization of narrative-based best practices.

Whether she knows it or not, a patient seeks a physician’s or ethicist’s guidance to help repair or heal a broken or misaligned story. Most often, this task is not as easy as it may appear. The physician is merely a character in an ongoing play. Conventional health care perspectives do not generally consider the role narrative plays in the quest for effective healthcare. Often the voices that need to be heard to understand the patient’s story are missing or opaque. The objectivity of modern medicine devalues the narrative and emotions. Opening the space for a patient to tell her story requires time and focus, but because of the time-regimented nature of the ‘visit,’ patient stories often remain half-illuminated in the dark. Not having access to the full of someone’s story becomes even more critical when a patient is in her final chapter of life. The role of the care provider is to help a patient integrate the previous chapters of her life and assist her in finding meaning and stability as she confronts the known unknown of death.
The events and happenings that comprise a life-story are interdependent, reveal expectations, confront disappointments and failure, but always remain open to the possibility for choice and revealing desired futures—even in the face of one’s death. One’s life-story is temporally integrated and intertwined. The past, present, and future are simultaneously apparent. Each temporal component is like the tick-tock of a clock. Each tick creates an expectation of the return tock. The unnoticed gap between the tick and tock creates dilemmas in clinical ethics.

Narrative competency builds a therapeutic alliance that overcomes the silence between the tick and tock and helps develop more genuine relationships between patients and physicians. Narrative competency helps to disclose a broad, storied understanding of the illness considering the patient's lived experience. A physician who develops narrative competency becomes more empathetic in practice and fosters a closer, shared relationship with the patient. Narrative competency helps the physician understand and access the patient's reflective understanding of her life and identity. The patient's story reveals the who, how, and why of her lifeworld. Only by understanding the patient’s sense of the illness and its place in her lifeworld can a physician robustly diagnose a patient’s illness. Possessing narrative competency is vital because each person’s conceptualization of illness is different.

One of the critical components of narrative competency is the ability to solicit narrative knowledge, insights, footholds—the other’s story and in-context. By applying narrative knowledge, it is possible to mine each person’s story from the spoken but also symbolic and written forms. Narrative knowledge provides rich insights into a patient, which serve the physician’s aim to heal the patient. Unlike logico-scientific knowledge, which is gathered by detached observation, narrative knowledge is collected through an engaged being-with-the-other. Narrative knowledge
helps to understand an individual through the eyes of the other, which is very different from the logico-scientific way of seeing the other as an abstraction or problem to be solved. Narrative knowledge arises through the intersection of the teller and the listener, where context and meaning can be revealed, shared, and understood. Narrative knowledge is experience-rich and reveals the lifeworld of the other. Narrative knowledge is situational and individual-specific. Narrative knowledge is not monolithic, ridged, or one-size-fits-all. Each person’s decision-making is shaped and influenced differently; knowing the other’s story helps the provider serve the patient or her family to find a way to the ‘right’ decision. Therefore, it is necessary to gain narrative knowledge to understand the other’s illness and explore her assumptions, expectation, and wishes.

In almost all medical ethics dilemmas, clock time is the biggest constraint. Economic forces tend to restrict the length of time a doctor can spend with the patient. For instance, in the United States, an average of ten minutes is allocated for the family doctor; 15 minutes for a specialist’s visit. Therefore, the patient has restricted time to share her story with the physician. This time-framed process nudges the physician to perform a quick assessment and subsequent prescription without the benefit of gathering the richness or valuable diagnostic insights available within the patient’s background narrative. An illness is most likely to be diagnosed by the lab results. Yet, the patient’s goals, wishes, fear, and history are not expressed clearly in many cases. This time rush tends to separate the physician from the patient, especially when immigrants, their cultures, traditions, and normative practices are involved. Narrative competency is the skill and approach to address these obstacles; it places the physician as an active listener in the process of healing the other. Narrative competency also encourages the physician to abandon the cure-the-illness-at-any-cost perspective and privilege the patient’s quality of life by considering the patient’s wishes.
When the physician shifts his focus to the quality of life, he quickly moves away from the conventional medical practice of seeing the patient in the abstract when making his diagnoses and prognosis.\textsuperscript{171}

Also, it is necessary to understand what story or whose story the physician is looking for. Is it the teller’s story, someone else’s, or something else? One of the significant components that is often missed during a consultation is defining from whose perspective the story is being portrayed.\textsuperscript{172} For instance, whose story should be counted if multiple family members are participating in the consultation? While each member may explain the story as she sees it, a dilemma occurs on which stories to count and how to determine how much weight each should carry. In these situations, the teller often shares a story that misperceives or misrepresents or mistakes the patient's intent or conflicts with other tellers. This different storytelling can distract, overly influence, or misguide gathering the story that most closely aligns with the patients. To identify the story, in context and nuance, it is necessary to gather multiple narratives.\textsuperscript{173} Narrative competency provides the means to assess if a story/perspective is missing or if one voice plays too prominent of a role. It is essential to hear everyone’s voices—both active and passive participants of the story—to portray the real story.\textsuperscript{174}

The physician must be proficient enough to ask the necessary questions that help to reveal the answer to the how questions. How questions are those which attempt to ascertain the situation or context in which the patient sees and experiences the world in a particular way. Sometimes, a patient will share something in a way that is understood differently by the healthcare provider than the way it is meant or felt by the patient. For instance, if a patient refers to an accident as ‘unfortunate,’ this word can have different meanings based on the assumptions of the teller and
hearer. Unfortunate to whom? To the patient or the family or someone else? Or a physician may tell a patient that the assessment of the illness is unremarkable. In response, the patient can take this as notice of not being heard or her plight being diminished, when in fact, the physician is offering good news in the form of clinical jargon.

Narrative-focused listening serves to catch sight of the unarticulated meaning, hopes, desires within her word. Such language issues are more difficult when the patient and the physician have different first languages, notably in situations when a patient has limited or no English proficiency. In those cases, the physician can often grasp the meaning and context through gestures, silences, pauses, pantomime, and focused interpretation. The physician's inquisitive nature and narrative-focused eye serve as a critical therapeutic mechanism in healing. When a narrative-founded connection occurs, the patient feels that she has been heard, her expectations addressed, and her dignity respected.

In their everyday practices, apart from listening to patient stories, physicians must also revisit their own stories, addressing their narrative competency. A physician can only remain available to the patient by conducting self-reflection and self-awareness during a therapeutic engagement, always being in touch with their own stories. Given the advancements in science, increasing reliance on technology, and the time-pressures of physician’s visits, it is easy for the doctor to get lost and thus become detached from recognizing the patient as a person. Narrative competency builds the skills to remain reflective and stay with the other in the light of her story, and the physician stays attuned to his story as a healer, not a mere provider. The physician upholds his responsibility as a healer by practicing active engagement by remaining reflective.
By being in touch with her own story, a physician more easily solicits the patient’s story. Physicians should be encouraged and rewarded for capturing and documenting patients’ stories and their own stories. The physician also revisits her own story, assumptions, and beliefs by doing so. When physicians are attuned to their own stories, they often better relate to others’ stories. A physician who keeps her story to the fore remembers how and why being a physician is essential and meaningful to her. It has her remember how she became a physician, what are her value, her influences, and the meaning and significance found in the identity of practicing medicine. By holding her story near, she is more like to understand how others who stand before her are immersed in their own stories. Thus, those physicians become more attentive to their patient’s stories. By including the patient’s story within the treatment processes, physicians or nurses can often capture concerns that should be addressed to provide excellent care. Narrative competency coupled with documenting patient stories helps future caregivers to become more active participants in their encounters with the patients.178

Physicians are influential members of society; there is quite a bit of public trust awarded to a physician. Public expectations of a physician are no less than an individual patient’s expectations of the physician. Through self-reflection, physicians can meet the expectation placed upon them by the public and society.179 However, that public trust is in peril due to the complex, efficiency- and insurance company-driven healthcare model employed in the United States. Physicians can satisfy and meet the social expectation of the public through their active participation and professional knowledge. Physicians must play an essential role in the reconstruction and narrativization of the healthcare system. Only robust and sophisticated narrative competency, rooted deeply within a physician’s approach, can help reform the conventional medical system and ensure a physician best addresses the patient’s wellbeing. Through narrative
competency, the healthcare system can be reconfigured to create a place where healing, compassion, and care prevail.\textsuperscript{180}

Narrative competency helps the care provider come to an engaged and mindful care process and thus discard abstract and rote ways of conducting care delivery. Clinical practice is a binary loop where a team effort counts. Everyone within the team needs to have the same goal and story-driven values to adapt practices and drive change. Care providers need to understand the importance of narrative medicine to gain narrative competency. Theoretical knowledge lays the foundation for change, but technical expertise and practical knowledge come only from working with one another and by relying on and expanding current best practices. This change model occurs only by having a guiding organizational narrative. Those who fill roles within the process serve the organization’s vision and must know each other’s stories. Together, they create a story-based healing culture that improves the treatment process.\textsuperscript{181}

In professional life, physicians, nurses, and the medical staff rely heavily on one another. They monitor one another and support and substitute as necessary. Therefore, it is also essential for team members to understand components of one another’s stories and know the responsibility of those roles. Otherwise, it is impossible to complement or substitute for the other. Unfortunately, our individualistic and hierarchical society, coupled with organizational pressures for efficiency, often leads to disconnected and fragmented teams. In a traditional efficiency model, each person strives for their gain and is often competitively pitted against other workers. Knowing the other’s story often seems irrelevant or quaint. Without a binding and guiding narrative founded on healing, teams’ fragment, caregivers become frustrated, and the workplace becomes inhuman, driven by
rules and a tangled bureaucracy. A team that is not cohesive cannot be expected to understand the integrated needs of a patient.\textsuperscript{182}

Even in conducting clinical research, colleagues need to understand each other’s narratives. In clinical research, people often gather in a team for a short period. However, most often, they work without knowing each other’s story. Thus, the working relationships become cold and distant with no personal or professional bonding.\textsuperscript{183} However, a shared narrative can illuminate the process and make it animated, creative, and inventive. Narrative competency addresses this need and guides members of the research team to share their stories. Therefore, narrative competency calls for a team- or work-community-based practice, which supersedes a rule-based, legalistic system of medicine where processes and technology prevail over the human-centered interactions and therapeutic interventions.\textsuperscript{184}

In a nutshell, narrative competency helps fulfill the ethical duties we each must and for another. When each team member begins practicing a narrative-based approach, a wave of narrative-driven change and improvements will take hold and become normative. However, this change is not possible unless the organization itself is committed to creating an other-oriented and human-centric culture. Narrative plays an integral and binding role in creating a culture of care—a culture that recognizes the patient as a storied-being in need of hospitality and care.\textsuperscript{185}

2.1.2 Comparison and Correlation with Other Primary Models

As noted above, various models and concepts appear in the literature that addresses the humanistic perspective of medicine. The two most prevalent and noted models are Narrative Medicine and Ethics of Care. However, while critical and influential, each model has notable limitations and deficiencies. Most striking is that the theories which underlie Western scholars
developed these models contain unconscious, implicit biases and overlook or do not account for the perspectives, experiences, and cultural norms of the non-Western population.

This section will address the inherent strengths and limitations (often unintentional) of these two prevalent models. In the sections that follow, I will then offer a modified integrated, and complementary human-centric approach to healthcare, which addresses and responds to the limitations and strengths of these existing models while incorporating the necessity to account for and recognize the differing worldviews of all who seek care.

2.1.1.1 Narrative Ethics (NE)

Narrative Ethics addresses the role narrative serves in the delivery and practice of medicine. Narrative Ethics and storytelling work, as does good literature. Good literature offers access to seeing, understanding, and grasping a particular condition by providing a context that intersects with the reader’s story. A narrative often helps us see something anew, and Narrative Ethics provides the human, ethical intersection of two beings, being-with. A narrative helps to create an emotional connection; it puts one in relationship with the other. Narrative put two people, in relationship, who, in the face of the other, see themselves. Narrative Ethics thus create a pathway for ethical, robust, effective, and successful healthcare illuminated by the power of narrative. Like virtue ethics and existential ethics, Narrative Ethics serves as a moral guide for good doctoring.

Narrative Ethics plays a different role than does rational decision-making. Whereas analytical thinking focuses on analyzing, quantifying, and maximizing the value of an outcome, narrative ethics strives to uncover the background of a situation, circumstance or setting to explicate the backstory to find a way to an outcome. Narrative does not abide by hard and fast
rules and regulations as in law or certain types of philosophy. However, this does not imply that a narrative approach ignores or dismisses the fundamental bioethical principles; instead, narrative serves to validate or confirm the essential importance of their guiding insights. Narrative does so by asking different types of open-ended questions besides questions derived from the areas of moral agency, rules, and laws. Narrative helps to identify and answer how one arrives at a particular decision or has become immersed in a specific moral predicament. Understanding and knowing the answer to ‘the how’ makes it possible to explore other options that fit within or expand the storyteller’s imagination of the future, her guiding beliefs, and the reality of her experiences. Narrative reveals the notion of norms and provides insights and solutions that strict or fundamental adherence to rules, principles, and absolutes thwart.

Narrative Ethics is an approach by which to guide people to reflect upon their positions, assumptions, and unquestioned beliefs and escorts them to identify how they have come to act or respond in particular ways, and question if this is congruent and aligned with their role, the situation, and ethical or professional commitments. Rather than being prescriptive and acting in a mere problem-solving capacity, a narrative approach helps one address any situation contextually, responsively, and reflectively—being-with-the-other-as-self—to find appropriate and realistic options for moving forward. A narrative approach serves, always, to answer the fundamental question of ‘how we got here’? It’s a not-knowing approach: the practice of coming to the situation openly, without prescribed answers. Thus, this practice allows the intersecting stories to illuminate the situation correctly and, therefore, a shared diagnostic and care-plan emerges. Narrative Ethics recognizes the supreme power of the dialogical chorus by incorporating multiple voices in one platform. It’s privileging the how. This denotes privileging the intimacy, context, significance, and meaning the patient offers through her story, rather than privileging ‘what’. The
‘what’ means privileging the distant, authoritative, and diagnostic gaze of the physician who sees only the patient, there; another problem to be solved standing before him.  

However, unfortunately, healthcare, for the most part, is only intent on answering ‘what’ questions and overlooks the fundamental human brilliance that comes by asking ‘how?’ The answer to how provides a storied way for each participant to be heard, seen, find meaning, and come to an agreement for a pathway forward. By giving importance to the how, Narrative Ethics construct a joint narrative of illness and care. For instance, how does the surrogate of an incapacitated patient come to a termination decision? How do we make decisions for pediatric and end-of-life issues? How does this decision reflect upon and contextualize the patient’s actual wishes? How is the decision narratively connected to and integrated with the past? How does the story reveal the fears, misperceptions, or assumptions held by the decision-maker that might cloud the ‘right’ decision? All these answers thus construct a joint narrative developed by the patient and caregiver. A narrative-driven means—Narrative Ethics—helps to answer ‘the how’ questions and serves to ensure well-founded decision making occurs in the face of disorienting ethical dilemmas.

Ethical dilemmas are common in medicine, and Narrative Ethics can play a vital and beneficial role in decision-making by disclosing the preferred choices of the involved parties through narrative. Narrative Ethics is an emerging field for ethics consultation. Ethics is not about absolute right or wrong rather it’s about the best alternative based on individual preferences. As is generally understood, the role of the ethics consultant is to serve as facilitator. A narrative approach is a powerful, flexible “tool” to promote, facilitate, and enrich how-based dialogue. A narrative approach helps unpack the nuance of complicated human situations in ways logic-based approach overlooks or mistakes. Why is this? Because narrative solicits the person’s lived
experience. The strengths of narrative ethics have been utilized in the development of Narrative Authority. I suggest that Narrative Authority is more applicable than Narrative Ethics; it is less abstract and gives the guiding power the Narrative as both an approach and method to understand and respond.

2.1.2.2 Narrative Medicine (NM)

Narrative Medicine is not widely applied as a theory, but it is used as a “treatment intervention.” This practical and application-based approach to Narrative Medicine helps medical providers become more attuned to insights available in and through a patient’s stories and make them better and more astute practitioners. The method encourages medical practitioners to write about their experiences and their patient’s stories, illuminating the importance of interpersonal connection to effective medicine. Narrative Medicine serves to de-distance practitioners from patients by situating both practitioners and patients squarely in shared narratives.

Proponents of Narrative Medicine contend that humanities training should be a part of the medical curriculum, recognizing the importance of interpersonal connections and interactions as key to effective caregiving. Doing such will develop medical students who are more observant to the lived experience of their patients and themselves. Rather than entirely residing in a worldview that validates or accepts the rational and quantifiable as real, narrative-oriented care professionals recognize the foundational importance and ontological significance of embracing and interpreting physicians lived observational experiences. Caregivers would come to embrace what might otherwise remain unseen or unheard. Students would be trained to adopt a phenomenological approach as physicians and caregivers, standing in concrete narrative connection with the other before them. This concrete and lived approach to medicine will make
them better doctors, serving to eliminate the distance that occurs when one sees the other in the abstract—not as a human, ill in need of care, but a patient, a thing needing to be fixed.  

Narrative Medicine ascends from intersections of literature study, creative writing, narrative ethics, disability studies, nursing, social work, and medicine. From this combination of disciplines, Narrative Medicine arises, constructed of three components: Attention, Representation, and Affiliation. Through these, the approach of Narrative Medicine provides a means to recognize, absorb, and interpret the stories of the illness.

Attention indicates the mindful observation of the patient that helps to understand what might otherwise remain unseen and unsaid. The philosophy of Levinas’s “ethics of the face” grounds the first component of Narrative Medicine: Attention. A care provider is always “face-to-face” with the patient and interwoven within this connection; this connection is intersubjective. As such, the provider and patient are already connected and bound. The provider, mindful of this, thus responds to and is responsible for the human who stands before him, with a story to tell, which opens access to the particulars to which the provider will respond. The second component, Representation, indicates the expression of the feeling you received from the attention to and experience of the other. How representation takes place in Narrative Medicine is precise and essential. It takes form through writing an act that brings the two seemingly isolated being together. Writing the stories of the other provides the story a shared narrative. Stories provide a means to depict, represent, and make evident and tangible worldviews that can be shared and exchanged. These stories and their context present the patient through their lived experience. Representation encourages healthcare providers to tell, perform, write, and paint in as many ways as possible. The third component, which is the most important, is Affiliation. Affiliation encourages one to join the other through the intersections of
shared stories where patients and physicians join one another in the journey of the suffering. Narrative Medicine intends to have one see, understand, and embrace the other’s suffering as their own and to respond as such with love, humility, and grace. It is a narrative means to empathetically understand the desires and pain of another.

However, implementing the three components of Narrative Medicine is highly problematic in non-Western populations—particularly in countries where healthcare and educational resources are scarce. Attention and Affiliation components work, but the act of Representation is challenging to adapt in a resource-limited country. For instance, one critical part of representation is the application of creative writing. It intends to use writing about a patient’s stories as a tool to manifest what is present yet unseen and unheard and make those concerns seen and heard. Without applying the creative writing tool, these insights might have otherwise remained unnoticed or covered over. The application of creative writing in Narrative Medicine encourages and assists caregivers in providing meaningful and effective care. The creative writing assessment component of Narrative Medicine is an excellent way of Representation, but it is not feasible in many settings. Creative writing is an undertaking that requires a prerequisite level of literacy, and resources and time to conduct the task. Also, associated financial concerns will be an issue.

A significant focus of Narrative Medicine is grounded in English-language literature. A vital Representation component, creative writing, involves reading, literature, and poetry. Narrative Medicine teaches and trains the skills of close reading and creative writing by reading texts of literature and poetry so that the care providers are better skilled in telling and writing the patients’ stories. In areas where patients are uneducated or have, at best, minimal reading and writing competencies, the application of such narrative- and story-based creative-writing tools,
unfortunately, become impractical. Firstly, because of the literacy level of the patient and, two, a lack of hospital resources and personnel. In these situations, having patients engage in, creative writing, poetry, literature, and crafting stories to reveal their sensory details and metaphors bumps against the practical and structural barriers.

Also, when applying Narrative Medicine techniques, the physician will use creative writing to capture and express insights about the patient’s world. This approach works well with literate patients, validating that the physician has seen her and heard what she offered. The practice is far less effective with uneducated populations who lack basic literacy, let alone knowledge of creative arts. Therefore, it is crucial to have a minimum literacy among patients because the stories the physicians will write should be shared with the patient, or the physicians should take permission from the patients. That is mentioned in Narrative medicine. Again, it is vital to have a minimum literacy among patients to understand why the physicians are writing their stories. Also, when the physicians ask the patients to read the stories they wrote, the patients have the competency to read them.

Incorporating arts and humanities into medical education is a privilege of resources. Unfortunately, there are not enough resources (or will) to develop narrative-centric curricula in many parts of the world. Furthermore, in areas with a shortage or lack of physicians, even routine healthcare cannot be delivered due to resource limitations.

The notion of applying the current application of Narrative Medicine in these settings is most challenging and nearly impossible. And even should this approach be attempted in most poor and non-Western countries, practitioners and facilitators would struggle given resource constraints and the current rigidity of teaching methods within medical school curriculums. In a
nutshell, currently, it is not feasible to practice Narrative Medicine via poetic and artistic interventions in these resource-limited countries.

Given this, the current configuration of Narrative Medicine carries unintentional biases. The model presumes and assumes a Western, affluent, literate worldview. This worldview is not held or available globally. Tasks and approaches that seem easily doable in Western and resource-rich countries are challenging or come off as tone-deaf in countries where the populace is poor or illiterate, and the healthcare sector struggles for resources. This dissertation addresses this unintended limitation of Narrative Medicine and incorporates the strengths of Narrative Medicine and, thus, provides a more comprehensive, attainable, modified, practically applicable, and more flexible version of the model through Narrative Authority (NA).

2.1.2.3 Ethics of Care (EoC)

Ethics of Care, an older, feminist approach, emerged in the 1980s and is understood “as an ethic grounded in voice and relationships, in the importance of everyone having a voice, being listened to carefully (in their own right and on their terms) and heard with respect. An ethics of care directs our attention to the need for responsiveness in relationships (paying attention, listening, responding) and the costs of losing connection with oneself or others. Its logic is inductive, contextual, psychological, rather than deductive or mathematical.”

Some scholars have pointed to EoC as virtue ethics because it relies on—responsibility, care, and dependency. However, EoC is based on relationships, whereas virtue ethics is concerned about the characteristic of the individual. EoC contends that we depend upon one another because we need, require, desire care, and, thus, this dependency creates a responsibility. This responsibility makes us, in turn, obligated to care for others.
Ethics of Care values emotions' fundamental and disclosive importance and argues that they are incorporated into practices. Emotions such as sympathy, empathy, sensitivity, guilt, and even anger must be cultivated rather than ignored while considering morality. Morality is less rational and more emotional and thus, in essence, more profoundly human. From this perspective, rationality, reasoning, and mere efficiencies are deficient means of accessing the human condition. EoC firmly decries the over-reliance on universal moral theories, which are essentially abstract and create distance from the other and the concrete situation at hand. EoC discounts the application of universal and abstract rules in the realms of healthcare, family, and friendship. 217 Such relationships and applications should be responsive to the norms and worldview of individuals. A physician’s response to the patient should not be predetermined or prescriptive based on assumptions or universally prescribed beliefs.

While EoC is a profoundly human-centric model, and though its tenets do not explicitly mention the ontological importance of narrative, the connections and obligations to care for others are profoundly narrative-oriented. EoC does not offer concrete directions or specific tools to respond to the patient's humanness and in the service of providing good care. The feminist grounding of EoC is constructed around the concepts of concern, compassion, and a welcoming of and interdependency with the other.218 However, that presents EoC as a form of social theory. While important and influential, the position remains abstract, philosophical, or supplies a pedogeological grounding.219 Yet, tools for application are required. Narrative Authority offers such tools coupled with an approach that complements the primary tenet of EoC: to provide care.

EoC defines human decency through the concept of care, which is closely related to vulnerability. EoC’s grounding belief is that humans are interdependent, physically vulnerable,
and face cognitive uncertainty; the means to ethically and adequately respond to this existential predicament is through care.\textsuperscript{220} EoC recognizes and privileges the intrinsic worth of each human being, the shared experience of vulnerability and finitude, and the obligation to and for the other through care.\textsuperscript{221} However, EoC does not fully articulate the profound interwoven and interdependent human-centric nature of relationships, which gives rise to our ethical obligations to care.

2.2 Conceptualization of Narrative Authority

Conventional bioethics struggle to construct the best approaches and practices to solve ethical dilemmas. Current methods to resolve ethical dilemmas are too thin and inadequate to cover the multitude of challenges and misunderstandings in our multicultural world. Several ethical practices have emerged to respond to these conflicts, such as feminist ethics, care ethics, liberation ethics, hermeneutical ethics. Each attempt to provide a more robust and inclusive theory or approach to solve ethical dilemmas that face bioethics.

We should acknowledge that human beings are not best understood or defined through rules, theories, and regulations to resolve ethical dilemmas better. Applying rules and regulations over time can bring temporary fixes, but a sustainable solution requires something beyond the surface nature of rules and regulations. Human beings are best understood through the thick of experience, context, culture, language, and time. And most importantly, the world we live in is very diverse. In this globalized world, each person brings a different identity and a different story, and particular ways of approaching and understanding the same situation. The same situation can be perceived differently by an individual, not from the dominant or normative group. By looking at their narratives—the stories people are immersed within—it is possible to catch sight of their worldviews, beliefs, hopes, fears—their humanness. Story reveals a person’s expectations and
illuminates an identity within a lived context, a culture, a language. In many ways, narratives are inseparable from the self. Our narratives shape and disclose our views of life, our perception of illness, and our understanding of what constitutes a well-lived life. Narrative Authority embraces these beliefs and presents a modified, integrated, and expanded version of the notions that ground Narrative Medicine, Narrative Ethics, and Ethics of Care.

2.2.1 Foundations of Narrative Authority

A narrative is a guiding story configures understanding, significance, and context. As such, it serves to bring two people together, to be-with. In this space, the two (or more) find access to collaborative, shared, and ultimately creative discourse and a means to articulate and implement possible outcomes. This occurs because stories help one understand another person’s perspective from various angles. Story reveals the depth of someone’s viewpoint by offering the context which makes that viewpoint make sense and have meaning. Story serves to uncover and articulate details of the patient’s situation and worldview that help the caregiver catch sight of what might otherwise remain hidden or overlooked. Story helps the listener understand the reasons, grounding, and meaning behind the other’s identity, her presence in her world. And story always serves to bring two people together in the intersection and recognition of their shared humanness.

In healthcare settings, stories reveal how the particulars and components of health are related to the patient’s overall wellness. An understanding of an individual’s wellness can be best assessed by soliciting and understanding her narrative, story, and worldview. The story allows a person to reveal herself—to show herself—to the other. This story discloses what is significant to her, what are her dreams, what challenges she has and does face, how she sees herself in the face of her current predicament, and what are her beliefs and guiding principles. Her story reveals her worldview. Her story presents her as a person in the presence of another person who, too, has a
story. The patient’s story provides an intersection point by which the physician, if listening, “sees her not as patient, there, but as an other-as-him, here.” A story helps the caregiver understand a patient-as-person, and thus to act as healer, not provider.225

The term, narrative, carries three different notions: (1) the story only, (2) the text of the story alone, or (3) the narrative act. Narrative Authority applies the third connotation. Narrative, in Narrative Authority, means the two-fold, reciprocal act of initiating the narrative act and revealing both the story within. On the other hand, Authority means the power of and the guideline for leading a process. Here, the word authority does not represent autonomous power but the collective and shared power that emerges through the narrative act.226

![Narrative Authority](image.png)

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**Narrative Authority**

For Example, Authority is in relation to oaths providers take to their profession. Do no harm...etc.

In each of these instances, the provider turns herself over to the Authority of the belief that transcends the individual and connects with the more significant notion of humanness and the power of an ethical demand.

So, in some ways, these are demands, not mere suggestions or recommendations. These are demands for one to respond to obligations and responsibilities of being human—which need be defined no further than that because it is obvious.

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**Authority**

- **Authority** is not patriarchal in the sense of maleness, position, or common structural power as seen to subvert autonomy.
  (Those are deficient responses to Authority.)

---

**Authority**

1. The meaning and significance that come to and for you in the situation.
2. The sense-making and claim to act, respond, toward the other & world.

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**Narrative**

1. Is access to the situation, the social bonds, and the recognition of the humanness of the other and self. (both the self-as-others) & (same but otherwise)
2. Dialogical, and disclose/recognizes the space where the authority is revealed/experiences. Whooshes up.
3. Means by which one and the other recognize intent to live lives of well-being, engagement, and choice.
4. The articulation of imagined or intended identity (individual, group, organization).
The word authority (see figure 1) is used to describe the power of narrative. For instance, think of Authority in relation to oaths providers take to their profession—e.g., “Do no harm,” or the precepts and guides foundational to the other medical ethics models and international commissions. Those concepts and oaths carry authority or an ethical command to act. The encounter with the other is similar. In each of these instances, the provider turns or gives herself over to the authority present in the moment: the obligation and command to heal. Authority is the ethical command which lays ‘claim to or calls one to act and respond to others.’ Authority reveals the ethical demand of our humanness and transcends the individual.227

Thus, the word “Authority”—as it might be more commonly understood, is not used here in patriarchal in the sense of maleness, position, religious power, or typical structural power as seen to subvert autonomy. Those notions are, in fact, deficient responses to Authority.

**Narrative in the Narrative Authority:**

1) Provides access to the situation, the social bonds, and the recognition of the humanness of the other and self (both the self-as others) & (same but otherwise).

2) Is understood as the means through which one finds a coherent connection with the other—their shared human and communal connections. But practically, discourse and recognition of the other’s story is a means to understand her needs for care/inclusion/being seen and my professional and human obligation to heal in ways that are unclouded by presumptions of knowing what cannot be known but only disclosed in the moment of the discourse that ties both of us to an Authority—a debt always
unfulfilled but attended to in the revelation of the other before me in the spectacle of being.

3) Gives rise to the articulation of imagined, or intended identity (individual, group, organization)

**Authority in Narrative Authority:**

1) Authority refers to the ineffable nature to understand and articulate the call which comes to us as we stand in our humanness. The only response to the call is to act in a way that attempts to fulfill the obligation and duties of this demand coming from humanness. And this is connected, and it is fundamentally relational.

2) Authority refers to turning yourself over to the broad intimacy one experiences when recognizing one’s humanness and, in terms of physicians, also further validated by the commitments to their professions. From both, a caregiver finds the reason, meaning, significance, and claims to act, to offer care; acting is a response to the necessary.

The enigma of Narrative Authority is that it is “ethical in quality and moral in tone.”

Therefore, together, the two words, *Narrative Authority*, describe the foundational structure of human being. It denotes the interconnected and radically shared storied space where humans find sense-making between the teller, listener, and witness. Here, in this space, story reveals ethics—the context where responsibility to and obligation for the other are intertwined and inseparable. The responsibility-obligation act is twofold. On the one hand, it is an ethical duty to engage and reveal one’s own story. On the other hand, it calls for the attention and openness to incorporate, welcome, embrace, and embody the other’s story as a response. Narrative Authority is the process of giving oneself over to the narrative act's foundational nature and standing in the shared
space where one sees the other-as-self. From here, ethics arises—as the obligation to and responsibility for the other as self.\textsuperscript{231}

Narrative Authority is strongly influenced by Emmanuel Levinas’s notion of “calling into question of the same.” This has been applied in Narrative Authority’s construction. And Levinas’s concept of “The Ethical” provides Narrative Authority its ethical grounding. Levinas’s way of recognizing the other—as not as same, but as someone to whom we are obligated to provide hospitality and care—supports and shapes the responsibility to and for communications and non-judgment that rest at the heart of Narrative Authority.\textsuperscript{232} In seeing and witnessing the “face of the other,” we recognize—without contemplation—that we are human but not reducible one to the other.\textsuperscript{233} In this recognition, we experience ethics, obligation, care, love to, and for the other before-and-with-and-beyond-me. And in this difference, we recognize our mutual dependency and vulnerability. Here, we respond to the human plea we each make to the other, “do not kill me.”\textsuperscript{234} The notion of “a calling into question of the same” helps to create the platform for embracing the differences within the same. The ethical response to our recognition of not sameness is to tend to and offer hospitality.\textsuperscript{235} Narrative Authority embraces these distinctions and informs all aspects of the concept.\textsuperscript{236}
In terms of Levinas (figure 2) Narrative ‘Authority’ interpretation of Authority is analogous to Saying and ‘Narrative’ as analogous to the Said. Only by engaging the Said can the Saying be recognized and responded to. The Saying precedes the Said because Authority stands beyond description. Recognizing this is the ethics of Narrative Authority.

The difference from the other current bioethical models is that NA incorporates a phenomenological investigation to present a method to respond to the lived, experiential nature of illness, suffering, obligations, beliefs, norms, and responsibilities. This phenomenologically influenced approach becomes particularly relevant to critique; it offers a pathway to free ourselves from the tyranny of rationality. An existential-phenomenological investigation breaches the perceived boundaries between one and the other, which, as generally understood in contemporary
medical practices, is seen as measured distance or proximity.\textsuperscript{238} We are one human family, but each family member has their own way and own thoughts. From here, processes and methods of moral and ethical decision-making arise by acknowledging the differences and appreciating the blessing of globalization—a world that offers differences from different parts of the world in one place.\textsuperscript{239} We should be ready to appreciate the difference this multicultural society offers because of the globalization.

2.2.2 Components of Narrative Authority

Narrative Authority is action-based and comprises of three components (figure 2): Open Listening (not knowing), Storied Hearing (attention to), and Shared Healing (responding to). These three components help to understand the other and guide the provider to act accordingly while providing care.

2.2.2.1 Open Listening (not knowing):

The foundational tenet of Narrative Authority is to come to see something or someone from a not-knowing perspective which is open listening. This ‘not knowing’ approach is prevalent in many counseling techniques and widely used in narrative therapy. This approach was developed by Harlene Anderson and her colleagues based on the understanding that human connections are relational and collaborative and are expressed via the creative and disclosive act of narrative. Their contention is—at the moment of an encounter, one opens oneself to the possibilities and worldview of the other. Therefore, one should not approach an encounter abstractly, judgmentally, or with a diagnosis at the ready. Instead, one should arrive with a not-knowing approach as the means through which to reveal a coherent interconnection with the other—a shared human and communal connection.\textsuperscript{240} Their intent is for people to open themselves to the possibilities and presence of the other; This should be like—I do not presume to know what I have yet to be presented with. This
is an attitude that is highly encouraged to adapt. Even though, this approach has been criticized by many scholars, it emerges as one of the most potent approaches to counseling. Taking a not-knowing, listening approach opens a space where the other (e.g., patients) reveals her situation to a caregiver who has not predefined the situation or outcome. This approach honors the agency, sincerity, and lived expression the other offers to the caregiver. By responding as such, the caregiver recognizes and honors the dignity and the presence of the other. Knowing how to respond to the other's care needs (desires) enables healthcare professionals to listen and hear the lived story the other offers openly. Thus, Open Listening demands genuine curiosity by listener.

The not-knowing approach opens a connection, a dialogue, a being-with rich with new possibilities, new hopes and new relationships, and new dimensions that otherwise would not have been opened even via an amicable conversation. A not-knowing approach recognizes and embraces the uniqueness of the individual and individuals’ stories and creates a safe space for everyone to share their stories, which is the core of Narrative Authority.

2.2.2.2 Storied Hearing (attention to):

Storied Hearing is the second component of Narrative Authority which is offering ‘mindful attention’ to patients. Storied Hearing requires the care providers to mute their inner distractions (or presumptions) and focus on and attention to the patient’s story. Storied Hearing dissolves the isolated ‘I’ and constitutes the shared ‘We.’ The call of Narrative Authority is to give oneself over to others by emptying the self of distractions. Narrative Authority erases the ego and separation and fills the gap with empathy and connection. When we give full authority to the narrative, it is then possible to obtain the perspective of mindful attention that Storied Listening requires. Storied Hearing helps the physician ‘hear’ what a patient wishes, desires, hopes, and intends. A patient who is suffering cannot always express her feelings or experience clearly in the face of the
distressful condition. Storied Hearing attempts to create a space in which the other feels seen, respected, and made comfortable enough to share her story of illness.

Another component and skill of Storied Hearing is ‘close reading.’ Close reading is a type of being-with that allows the listener to recognize and interpret the words and plot, the nuance, and details of the story’s context. This practice is beneficial in surrogate decision-making situations when the patient no longer has decision-making capacity, and the caregiver must work with a surrogate in the care process. However, as a teller, a surrogate can misrepresent the position of the other, often unintentionally. In addition, a surrogate’s decision-making capacity is often questioned because of the debate concerning ‘substituted judgment’ and ‘best interest.’ Substituted judgment indicates the surrogate can make decisions based on the patient’s preferences expressed at an earlier date. If the intention is unknown, then the surrogate can make the decision based on what is believed as the patient’s best interest. However, in many cases, the authenticity of the reflection on a patient’s preference can be a challenge because the surrogate is unable to identify the patient’s preference.

But through the skillful close reading practices of Storied Hearing coupled with story-inspired follow-up questions, it is possible to capture the narrative most attuned with the patient’s wishes and values, regardless of the patient’s decision-making capacity. Close reading, in these situations, reveals the story, and the patient’s intent, even though the haziness, dryness, enigmatic nature, and the unspoken tone of the story. Close reading helps to highlight many aspects of the story that are underprivileged or overprivileged by the surrogate teller. Close reading also allows the listener to pay attention to and grasp the possible routes where the story may be plotted or expanded further.
Storied Hearing help the practitioner interprets the unspoken words, gestures, facial expressions, body postures, and even silences that are apparent in the conversation, all of which become a meaningful measure for the care provider who practices Narrative Authority. It helps a physician open herself and allow the patient to speak through her. Thus, the physician finds empathy in the patient’s sufferings, needs, and desires and applies these insights to generate a proper diagnosis. Without a Storied Hearing approach, a care provider remains filled with his concerns, pressures, and goals, and he is unable to supply proper attention to the patient.

2.2.2.3 Shared Healing (responding to)

The third component of NA is Shared Healing. Once we present ourselves to others from a not-knowing approach, we begin the process of healing. The healing is predicated on attention, empathy, and respect we offer to the other by opening a conversation, a dialogue, in which the other’s story is solicited, welcomed, and heard. Such exchanges provide connection, reveal shared concern, and engender truth through the shared we. Yet once the caregiver has heard the story, how should the caregiver respond? To this, NA offers Shared Healing, the skill grounded in reciprocal recognition and seeing oneself-in-other. Hearing the other’s narrative opens a space in which healing the other is also a means of healing the self. And such self-reflection is lifelong and constant. Hearing the other’s story is to continuously recognize and cultivate oneself via the creative and loving connection with and to the others before us. Thus, in the act of Shared Healing, patients see themselves in the gaze of the doctor; the physician’s see the other need of care as if he needed care.

While responding to the others’ stories, it is imperative to designate a ‘frame.’ A frame helps the listener and teller determine what should be left in and left out of the story. In many cases, too broad of a picture overshadows the specificity or clarity of the story. A narrower frame
helps to pinpoint important, relevant information. But of course, the frame should not be too narrowly constructed because it will affect the accuracy of information obtained. One of the significant drawbacks of medicine is that its frame is tied back to biological and a rationally constructed perspective in which there is no room (or time) for personal narratives. Shared Healing requires that care providers be skilled at creating the narrative frames that effectively solicit and clarify a patient’s story. This narrative curiosity and active engagement in the other’s story, therefore, become a treasured asset to becoming an effective medical provider by creating a space where each participant’s narrative is seen and heard.

Besides understanding and creating a framework, Shared Healing requires a better understanding of the use of time. Healthcare providers should come to understand how patients experience time. There is a profound difference between clock time and lived time. A physician must understand that a clock hour to a patient with severe pain in his stomach may seem like an eternity. Often the clock seems to stop when one is ill. Practitioners must stay aware of this fact and remain empathetic of the lived time of others. Often this is a challenge for providers who are often under-prescribed clock-time limitations in their consult with a patient and therefore become oblivious to the lived time of the patient’s experience.

2.2.2.4 Application of Narrative Authority

Narrative Authority is based on the ontological and lived nature of narrative. Narrative Authority states that the narrative structurally supersedes and makes possible other practices because narrative provides significance and meaning to the world. However, narrative is by nature troublesome. Narrative—one’s story—is not simply formulaic or rules-based. Narrative is always unpredictable and law-abiding. However, the wonderful side of narrative is that it discloses its own path and breaks its own barriers. Narrative Authority provides a perspective to see the overlaid
or buried sides of medical practices. In each chapter of this dissertation, there will be offerings on how Narrative Authority is applicable in different aspects of our lives at the individual, organizational and global level.

Narrative Authority helps providers reclaim the core of the healthcare system by reconfiguring the reason for its existence by having it return to its ethical command to care for, to heal. Narrative Authority helps the care provider to understand that the mission of health care is not to heal the wounded merely but to serve the afflicted and help them obtain a better life and well-being. Narrative Authority helps the practitioner hear the patient’s call—her voice—by reflecting on the context and meanings in the patient’s story. Thus, the application of Narrative Authority calls for a shift from conventional and overly dominant medical-scientific, rationally based practices to therapeutic-holistic medical practices founded on narrative, the command of the other in need of care, and one’s submission to and responsibility for the other. Practicing Narrative Authority in a conventional setting will be challenging because it requires practitioners to change how they approach illness. Generally, the move is from direct problem-solving to a more discourse-oriented, open-ended means of discovery and diagnosis. This change requires the caregiver to privilege the patient’s story. It also means the caregiver must build the skills to solicit perspectives, fears, and hopes apparent in every patient’s story. It should also be noted that such change requires the organization to revise its understanding of care and support structural changes to make such an approach possible. This will be addressed in chapter five.

Narrative Authority reshapes the normative assumptions concerning human relationships. It makes a relationship inseparable from the shared space the story reveals and the social and referential context in which it occurs. Within this space, meaning, coherence, and intelligibility of the everyday occur. Narrative Authority rests on the belief that all human relationships are
radically social. Narrative Authority serves to revise the notion of the individual as separate and autonomous. Narrative Authority redefines individuality as socially shared and hence ethical by nature. The embrace of the narrative act is both the revelatory command of the obligation to self and the responsibility for the other. Narrative Authority helps individuals’ sense and understand that they are always and primordially socially connected.260 There is no escape: this is the fabric of human being. Narrative Authority helps all participants re-cognize that being-in-conversation is to co-create a dialogue. Narrative Authority allows participants to embrace the normal motion of the everyday as a collection of ethical practices and beliefs which implicitly and explicitly honor the context of shared being.261

Narrative Authority guides practitioners to welcome, embrace, and honor the differing worldviews others bring to the consultation room. Structural designs, as do culture and philosophical presumptions, confine and define a caregiver’s perspectives and assumptions of reality. Whereas, story and narrative, when applied via Narrative Authority, guide the provider and patient towards recognizing that there are two humans in connection and discourse with one another. Narrative Authority serves to abolish the distance between care provider and patient. What occurs is an intimacy described as being-with-the-other. In doing such, practitioners step through these limitations and see the other as she presents herself—another human, not an abstraction or stereotype.262

By exercising Narrative Authority, it becomes possible to illuminate the context and purpose of healthcare: a shared obligation to and responsibility for the patient and society. Narrative Authority, in its most broad application, can help individuals and communities form an engaged presence through the ubiquitous context of shared story, i.e., shared being.263
Narrative Authority always serves to reveal the ethics of engaged presence. Of course, sometimes, the patient’s narrative can misguide the listener. This occurs when the listener is deaf to or dismisses the patient’s story and misses the nuances. The patient’s narrative, in this case, can then misguide the “listener” to a wrong outcome or a presumed conclusion. Often, providers over-hear or under-hear the patient’s story.\(^{264}\) For instance, a patient may want to share something, but the provider hears something else by missing the context or her story's nuances. Also, the provider sometimes manipulates the narrative to fit a preconceived notion they hold. Understanding the narrative of another without manipulating it is the art of active and engaged listening. Therefore, Narrative Authority itself calls for a broader spectrum of individuality that is by nature social and ethical.\(^{265}\)

Narrative Authority requires continuous practice if the approach is to make consistent and ongoing contributions to the effectiveness of clinical and administrative practices. For the provider to comprehend the secret that occurs between the body and the tongue, it is necessary to develop the art of listening throughout the system. Telling and listening to a narrative help to solve the troublesome aspects of the patient-physician relationship.\(^{266}\) Narrative Authority develops a reflective and shared mode of listening and reading stories told or written by the patient or colleagues. With consistent application of the approach and accompanying methods, the skill of reading and hearing stories eventually gets into the practitioner’s bones. Thus hearing, interpreting, and understanding a story comes naturally and easily. Such skill development is required if there is to be genuine intertextuality between a listener and the teller.\(^{267}\)

Again, Narrative Authority is a radically ethical concept. Narrative Authority rests on the belief that we are radically social. Being radically social defines humans. We find ourselves within a narrative context and disclosive space through which we find everyday significance and meaning.
Within this space, we are immersed in an “organized set of practices for dealing with oneself, other people, and things that produce a relatively self-contained web of meanings.” The sense-making of the world is pre-reflective and reflexive because of this. Our identity and sense of belonging rely on this radical socialness very concretely. There is no stepping outside this configuration; we cannot be alone. Even in the absence of others, they are present in their absence. So, it is in and through this recognition that I am identifiable and rooted in an understanding and identity that is only possible because of our social sharedness—made immediately and particularly apparent in the sharing of stories—that am beholding, responsible, obligated to you.

Contemporary healthcare is undergoing rapid change and struggles to develop practices that consistently address and solve ever-more-complex ethical issues. Given the effects of globalism and the intersection of divergent cultures, healthcare professionals often do not understand or presume the patient’s experience. As a result, patients find themselves isolated by fear and anxiety. In turn, professionals become isolated by their lack of knowledge of the illness as presented by the patient. However, when a healthcare provider understands and discloses the patient’s narrative, it can bridge this divide. Narrative—story sharing—reveals meanings, beliefs, assumptions held, and imaginations of the future, which serve—by connecting people’s stories—to stave off isolation and help a willing decision to arise “in-connection-with” someone else. Thus, narrative helps to reveal the meaningful integrated relationship between past, present, and future events and choices.

Illness is the nightside of life; thus, it is inseparable from the dayside. To heal the night, providers should embrace the light apparent in the narratives with which they intersect. A narrative provides the context and meaning of events in the patient’s experiences. Narrative helps to reveal
the patient’s lived experience of her illness. In doing so, the practitioner comprehends the
intersubjective nature of the relationship—a place where ethics arise. By understanding the
intersubjective nature of the patient-provider relationship, healthcare providers find the reasoning,
meaning, and urgency to change existing practices and strive to become healers rather than mere
service providers. Though not yet prevalent, we must come to realize that highly effective medicine
is driven by and inclusive of the narratives of all involved.

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Chapter 03: Narrative Authority at the Interpersonal Level

Autonomy and paternalism play a crucial role in shaping the patient-physician relationship. Paternalism was once considered a normative and practical medical practice in healthcare. However, perceptions have changed over the past few decades, and the pendulum has swung from physician paternalism to patient autonomy. This swing to patient autonomy has fostered a fundamental change in the nature of the patient-physician relationship. From an ethical and moral standpoint, this shift from paternalism to patient autonomy has resulted in unintended consequences.

In our current normative healthcare practices, we strive to give greater autonomy to the patient. Yet, in doing so, we sometimes harm the patient. For instance, a physician who is too focused on honoring a patient’s autonomy or acquiesces to a patient’s demand may hesitate or refrain from providing appropriate care. When this occurs, the physician’s professional integrity is challenged. A single-minded or absolute focus on a patient’s autonomy can create more harm than benefit. Each of the four principles of principlism is equally important. The principle of autonomy cannot supersede the principle of beneficence, justice, or non-maleficence.269

Rather than fully espousing this current radical swing from Paternalism to Patient-centrism, it is better to let the pendulum come to rest at the intersection, where both parties have a say in constructing the relationship. Narrative Authority provides a perspective and approach to make sense of the balance and guides in creating a human-to-human partnership between patient and provider. This chapter uses Bangladesh as an example to review the patient-provider relationship and details how practitioners can apply Narrative Authority to establish trust and faith through the frameworks of dignity enhancing care and responsiveness and creating a healthy partnership between patient and physician.
3.1 Reconfiguring the Patient-provider Relationship

Paternalism was once considered a normative, effective, and common-sense medical practice within healthcare. However, the notion of paternalism has fallen from favor, and healthcare now embraces a more patient-centered model to avoid what is now seen as the adverse effects of paternalism. It is now understood that the patient's well-being extends beyond medical health, including the patient’s worldview, beliefs, and social norms. To overcome the harmful effects of paternalism, the role patient plays must be reimagined in ways that build trust, promote communication, and foster consensus between the patient and physician.

When patient autonomy is given prominence in a patient-centered model, the physician may excessively focus on, or demure to, the patient’s voice or preferences. On the other hand, when the physician’s role is dominant in a paternalistic model, the physician may be insufficiently attentive to the patient’s needs, preferences, or worldview. From the perspective of ethics, to provide effective treatment and care, both the physician’s and the patient’s voices need to be heard, valued, and respected.

The chapter offers a model for healthcare founded on a shared decision-making platform. In this model, the patient and physician co-create optimal communication for combined decision making. This model provides the opportunity to positively transform the patient-physician relationship into one which is other-oriented, empathy-focused, dialogue-based, culturally sensitive, mindful of value judgments, and always story-dependent: Narrative Authority. Narrative Authority reflects the dialogic engagement of the physician and patient in partnership together in the quest for effective patient treatment and care.
3.1.1 Paternalism and Patient Advocacy in Patient-provider Relationship

Paternalism refers to the physician's perspective and stance to the physician-patient relationship. Paternalism involves the practice by the physician (or institution) of applying and exercising power, knowledge, and position over a patient to reach what is considered or believed to be in the patient’s best interest. Paternalism often overrides the patient’s preference or desired action, leading or leaving the patient to believe or be told that the physicians know best. However, paternalism also sometimes serves as an appropriate, necessary, and proper approach when assessing the well-being of the patient when considering the physician’s ethical obligations to the patient and society.

Thus, promoting patient advocacy is a means to solve or counteract the dilemmas raised by paternalism by protecting individual choice and individual dignity, without ignoring or disregarding the physician's knowledge, insights, expertise, and suggestions and prescriptions. Patient advocacy is a check on rampant paternalism. It provides a perspective that believes that physicians cannot solely determine the patient's best interest. The physician must acknowledge and affirm the patient’s position and concerns, then offer thoughtful and empathetic feedback and perspective concerning a proposed care plan. Patient advocacy is a means through which the patient and physician can more effectively form a just partnership. Narrative Authority promotes patient advocacy. Physicians and providers come to engage and solicit the patients’ stories and narratives as a way to learn not only what ails them but what are their beliefs, fears, and expectation of the care process. By soliciting stories and worldviews, patient advocacy becomes a natural and primary mode for care. Doing so opens a shared space where the patient and physician construct and configure the relationship. The relationship emerges as a response based upon the authority and ethical responsibility each party provides, based on the intersecting narratives.
3.1.1.1 Patient’s Autonomy in Today’s Healthcare

Autonomy is “self-governance,” which indicates the freedom of choice making. The two underlining criteria of autonomy—liberty and agency—reveal that an autonomous person is not under the control of someone else; she can clearly and freely present the choices she wants. Autonomy reflects the conception of individual agency. Autonomy is respected when one is allowed to articulate this agency into voluntary actions without interference. Autonomy is a form of independence that enables a person to make the decision she chooses. Autonomy is understood as a part of the human condition, and people express their independence through decision-making and choice-making. However, it is complicated to exercise autonomy, for instance, when we are struggling for survival or when society willfully imposes its values, which dictate behavior and limit choices. American medicine now places a high priority on patient autonomy. This belief shapes how we approach care, and it has become the most dominant principle in the contemporary bioethics.

According to Kant, we are autonomous beings, and we try to respond to the criteria that we set for ourselves without another’s influence. As autonomous beings, we use our rationality to make moral judgments freely and independently. Autonomy allows us to live intentionally. In doing so, rather than serve as a follower of universal rules, we embrace our standing as a “universal rule giver.” Kant considered autonomy as a form of self-rule. However, this autonomy does not guarantee that every person’s preference or choice must be accepted. To respect the autonomy of another, one’s choices or decisions must also be morally sufficient.

For instance, euthanasia can be morally justified in Kantian notions of autonomy by considering the principle of self-determination. In terms of self-determination, individuals are free to make their own choices based on their values and individual judgments. From this perspective,
an individual should be allowed to make her own choices based on how she defines the scope and meaning of her life. If she finds, while in a competent state, that there is a diminished or unacceptable quality of her life, she is free to choose euthanasia as an end-of-life choice. Now, if we view the concept of euthanasia through the lens of autonomy, we find there is no moral or ethical inhibition to euthanasia and thus no barriers to legalizing this choice-making. However, does that indicate that we should encourage euthanasia because it is an autonomous choice and forgo our social and professional obligations? What would be the consequences if we legalize euthanasia?

For practitioners and patients, medicine is full of uncertainties and surprises. Within and in response to the uncertainties, systems attempt to erect rules to guide decision-making and behavior when the unexpected or unknown occurs. For instance, new clinical practices are founded on the belief that the patient should be the “ultimate arbiter” in determining her fate. Allowing individuals to make their own decisions, even if it goes against the physician’s advice, gives her power over herself, regardless of the harm or benefit. The assumption is as individuals, each of us knows what is best for us even if “what is best for me” might seem wrong or misguided by someone else. This belief in individual choice often leaves providers and others in an odd situation, by not thwarting another’s decisions or imposing our judgments on someone else. This is a means to respect another’s autonomy, even when they are extraordinarily vulnerable or seemingly misguided. In terms of this current era of patient autonomy, this means we must respect the patient’s autonomy, almost without question. However, a patient can have compromised decision-making capability, for instance, due to fear and anxiety. So, the question is, to what extent should we uphold autonomy and compromise beneficence?
Haliburton, in his book, “Autonomy and the Situated Self,” argues for terming patients as “clients.” He believes that referring to patients as clients will change our assumption about and understanding of the patient. Even though the word client is also problematic, Haliburton uses the term client to make a point. He emphasizes the duty to recognize seeing the patient as a human who is not vulnerable because of the disease but is as strong, aware, and making choices of their own volition. Generally, we see patients as individuals with specific goals within a particular medical condition. By calling them “clients,” he contends we will shift our focus and see them as individuals with unique expectations that the healthcare organization can alleviate. This would allow individuals to make their own choices based on their perceptions, even though that may be harmful to that person. Like other organizations, physicians and caregivers must see the patient as clients—specific individuals—whose choices must be respected, at any cost.284

Beauchamp & Childress contend that we should respect an individual’s autonomy by appreciating the situational context in which we encounter them and being attentive to the other’s perspectives. To honor the principle of autonomy, the patient and physician must appreciate and respect the autonomy of the other. To preserve and promote individual identity, each party must understand how the other’s perspective influences the choices she makes.285 However, it cannot be overlooked that each individual is simultaneously and contextually “embodied, social, and historical.” This implies a fundamental, shared, and intimate social connection. Therefore, ethics obligates each individual to respect the social intimacy of our interwoven relationship with another. Patient autonomy, as an essential domain in medicine, should be seen through this relational lens.286

Patient-centered care emerged in the 1970s as a response to the dominant culture of paternalism—the era of doctors knows best. During this transformation, society marginalized the
well-being of the physician. Integral within this shift in perspective comes the viewpoint that the illness is no longer seen as a treatment but an experience. Thus, doctors should respect the patient's understanding of illness as hers and treat her experience accordingly. However, this focuses on honoring the patient's experience places doctors in a position of withholding or providing care that can compromise or weigh on their professional integrity. The doctor loses her voice and is distanced or removed from the "relationship." To receive the patient's care, the patient should respond to the physician respectfully, understanding that the physician intends to heal and guide the patient through her illness. Physicians are not technocrats. Physicians have the obligation (and liability) to provide appropriate and situational recommendations to support clinical decision-making, even in the face of the patient who holds the final decision-making autonomy.\footnote{287}

\textit{3.1.1.2 Physician’s Paternalism in the Past and Present}

The effects of paternalism depend on how we understand the role it plays in the patient-physician relationship and the subsequent extent to which paternalism is exercised to shape this relationship. The principle of beneficence is often overly applied to support and justify the physician’s paternalistic attitude, perspective, or actions. A physician aims to provide care to the patient. However, there is no proof of evidence that determines that the physician, alone, can best judge or guide the patient's well-being. The medical or physical determinants do not solely measure a patient’s well-being; well-being is also significantly influenced by a combination of social, mental, and physical beliefs and norms the patient holds and practices.\footnote{288} A physician who enters the relationship with the client, believing he already has the answer or knows best, does a disservice to the physicians’ creed and acts in ways that overshadow the patient’s autonomy, leading to forced or uninformed medical decisions practices. In short, in such cases, the physician serves the patient through a limited and self-serving viewpoint.\footnote{289}
Besides applying the principle of beneficence, paternalism relies on nonmaleficence to justify its grounding. Paternalism often takes charge when minor harm is associated with a patient’s autonomous decision. In this instance, the physician applies the principle of nonmaleficence to override the patient’s choice. Thus, paternalism often provides unacceptable freedom to the physician to influence and derail the decision-making and consent process. Given the shift in care thought and practices, the patient has the right to deny treatment suggestions and choose a medical decision that, from the physician’s perspective, could cause harm to the patient. The physician cannot determine or be the final arbiter of what is the “actual harm” associated with the patient’s decision. When paternalism prevails, the physician notes and gives preference to the medical-harm evident but fails to consider the importance of the normative and social influences guiding the patient to make her choices.

Paternalism, thus, conflicts with autonomy. An increase in paternalism inversely reduces a patient’s autonomy. This is how we currently understand medical practices. When a strong sense of paternalism prevails, the likelihood of overriding or ignoring the patient's autonomy increases because the physician follows beliefs and patterns that supersede the patient's desires. Modern science is founded on authoritarianism and the belief that the physician's knowledge extends to him the authority to make the final decision. From the perspective of new medicine, the patient's experiences, beliefs, and choices "overrule" the scientific and experiential judgments of the physician. Our new medicine does not deny scientific conclusions; instead, the fresh perspective denies that the physician always knows and speaks to the patient's best interest. It is no longer "permissible" for the physician to impose his judgment in place of the patient's wishes or cultural perspectives. Strong paternalism warps the physician’s obligation to care for the patient or to
gather informed consent at any level. Therefore, from the skewed vision of paternalism, the choices of the patient are disregarded and violates the patients’ rights.

However, sometimes the patient can also misunderstand or mistake paternalism. A common form of such confusion occurs when the patient demands a treatment that is inappropriate given the diagnosis or situation, leading the physician to deny the request. When this happens, the patient responds believing her autonomy has been ignored or overlooked. In reality, denying such treatment is medically justified and ethically sound because it is not an issue of abridging her autonomy or the tyranny of paternalism. Respect for autonomy has its limit, and that needs to be understood.

For example, when a patient intends to do self-harm, the physician must override the patient’s autonomy for ethical reasons that serve the greater common good. For example, the architecture of in-patient facilities for patients with mental disorders traditionally has involved physicians in the designing process. Physicians provide their perspectives and inputs in designing the asylums and allocate space for each patient based on the severity of the illness while fully considering the safety of others. This can be seen as paternalism apparent in the architectural design but is understood as ethically appropriate because it is deemed to serve both the best interests of the patient and society. Therefore, it is often too strict to always consider paternalism as the bad practice medicine.

Paternalism also plays a vital role in life-sustaining treatment. When a competent patient refuses life-sustaining treatment, the physician’s obligation to benefit the patient holds sway. To serve the patient, a physician, in the best case, attempts to gather knowledge about the patient by collecting and understanding the patient’s story. Doing so leads to better communication. And through effective communication, the physician tries to build a relationship with the patient
through which she can come to understand the reasons for the denial of treatment. The intent of this communication—especially through shared stories—is to ensure that the patient’s voice is heard and respected.\textsuperscript{298} Often, in cases involving depression, anger, or fear, a patient delays or foregoes life-sustaining treatment. Knowing this, the physician cannot simply accept the patient’s claim of autonomy because the patient’s decision or viewpoint may change when the physician helps the patient review the underlying causes mentioned above. A conversation directs the patient towards better care. This is not paternalism; it, instead, is a form of mentoring.\textsuperscript{299} Each of us benefits from the guidance of a mentor for specialized tasks or conditions. Mentorship never removes our autonomy; instead, it helps us make the right choice and fill in potential gaps in knowledge or perspective. Physicians gain their knowledge and expertise from a rigorous process to serve as a mentor in our medical decisions.

By helping a patient imagine the next chapter of life and by being empathetic and understanding the patient’s beliefs and perspectives, a physician can help the patient embrace a fulfilling and meaningful future, which the patient has yet to see or believe is obtainable.\textsuperscript{300} For example, a vibrant person injured in a significant accident became despondent because he did not want to live bedridden and be dependent upon and a burden to family members. In this situation, only weeks following the accident, the patient was not prepared to anticipate or accept a future that could be rich with meaning despite his long-term maladies. In this situation, by talking with him and providing counseling for his anxiety, fears, and depression, it was possible to reshape what presently appears as intolerable and disclose a future that the patient is willing to embrace. Here, the physician’s intervention and insights served to open a dialogue with the patient, which avoided hasty or rash decision-making. The continuation of the life-sustaining treatment serves in the patient’s best interest and helps him continue to live a life of meaning and purpose.\textsuperscript{301} This is
also an example of how Narrative Authority opens a space for dialogue and honors the other’s dignity thus promoting consent and serving society.

It is imperative to understand the reciprocal relationship between paternalism and patient autonomy. Therefore, the patient-physician relationship needs to find an intersection point where paternalism and patient autonomy are respected, without compromise or concession, but through shared agreement, decision-making, and consciousness. It is possible to come to that point through other-oriented, empathy-focused, dialogue-based, and story-dependent care practices. Listening and telling stories helps providers (and patients) to recognize our obligations and responsibilities towards others. When providers do such, the patient and physician can act to co-create a healing partnership.302

3.1.1.3 Patient Advocacy and Co-creating the Clinical Relationship

The physician’s mission is to provide care, regardless of situation or circumstance. However, care is best delivered through a reciprocal relationship, when both the patient and physician find consensus by being involved, attuned, and obligated to the medical care.303 Therefore, to provide optimal care, both the patient and physician must be in dialogue, share stories, and jointly participate in the decision-making process. By practicing professional integrity and exercising patient advocacy in the decision-making process, it is possible to incorporate the strengths and opportunities offered through paternalism and set aside its weaknesses to best support and promote the patient’s autonomy. The act of exercising Narrative Authority diminishes the effects of paternalism and the physician’s skewed authority, thus, respecting the autonomy of both the patient and physician via a partnership of shared intent.304
The physician’s professional integrity obligates him to act in the patient’s best interest. In the best case, this professional integrity is shaped by the physician’s knowledge and experience gained by a history of examining patients from different backgrounds who hold different worldviews. These practices and the physician’s broad expertise contribute to the vitality of a shared platform in the healthcare system. This knowledge and insight should not be ignored or overlooked to merely prioritize patients’ preferences. Likewise, the physician cannot simply ignore the patient’s need while executing his professional expertise and beliefs.\textsuperscript{305}

Physicians should never brag or boast about their medical and technical competency but should communicate their expertise to the patients by asking open-ended, reflective questions, to ensure the patient does not feel humiliated, embarrassed, or lesser-than. The physician should draw a standard line between beneficence and autonomy and exercise their knowledge in ways to protect the patient from any known or perceived harm.\textsuperscript{306}

An essential goal of the physician is to educate the patient about the medical practices and strive to avoid any misunderstandings or confusion. Patients often struggle to understand the difference between good medical practice and paternalism. Therefore, the physician’s decision should always be followed by proper clarification to avoid the patient’s misconceptions or assumptive thinking. A well-informed consent process can serve as a guide for making the patient welcome the physician’s knowledge expertise and embrace her participatory role in the care process.\textsuperscript{307} Such activities like well-written informed consent low literacy study materials provided by the organization empower the patient and help the patient better understand the physician’s diagnosis or recommendation, regardless of the patient’s literacy level. This is how an organization, and the providers can practice patient advocacy. Often, a direct, science-fact way of
sharing information with the patient may be counterproductive to someone who is accustomed to hearing good or bad news in a narrative or story-based form.\textsuperscript{308}

The embrace of patient advocacy respects and exercises the patient’s autonomy. Even though in some situations, a physician is morally obligated to exercise her autonomy for professional and ethical reasons, the physician still must follow the route of patient advocacy sets forth to support and guide the patient’s decision-making.\textsuperscript{309} The root meaning of the word patient means to suffer or bear. The root meaning of the word patient means to suffer or bear, which the caregiver often interprets can as passivity. Thus, the caregiver responds in ways that further amplify this belief. The term patient with its call to act and care for the other can often have the caregiver see the other’s need for help as a form of passivity. When this occurs, the practitioner may intercede and amplify their rationale for exerting their authority and overlook the opportunity to allow the other in need to display or articulate their autonomy. The practitioner must not get lost in the notion of the patient as only needy, weak, helpless. The word ‘patient’ itself indicates a burden imposed upon a person. Practitioners would do better to resee the patient as a patient-other to keep to the fore the full humanity of the person in need before them. In this way, it becomes more likely that practitioners remain attuned to the freedom and agency to exercise individual authority and dignity when making or offering medical decisions.\textsuperscript{310}

Regardless of how we term the other seeking care, knowing the patient’s story and intent is a necessity for the practice of advocacy. Knowing the patient’s background, preferences, and culture helps guide the provider to respect and promote the patient’s autonomy. Asking the patient questions about how they perceive a particular medical intervention helps the physician to assess and understand the patient’s acceptance level.\textsuperscript{311} Even when there is a disagreement, the physician can approach an alternative path with the patient. This is only possible when the physician has a
clearer understanding of the patient’s perspectives and intent. As each patient is distinct, the ethical decisions made in similar circumstances can have different outcomes for different patients. Therefore, the physician must be situationally attuned with each patient before offering a diagnosis or suggested interventions. Sometimes the physician must apply creative ways of treating a patient that fit the physician’s understanding of the patient’s point of view.

Another way of exercising patient advocacy is to communicate alternatives and options to help the patient consider or reconsider a decision. Exploring different opportunities can help patients step out of their comfort or safety zone and see the decision in a new light. Advocacy is often under threat because some patients feel reluctant or fearful to provide accurate information to the physician. A patient’s self-determination may hold him back, and he fails to communicate fully or honestly, which, in turn, overrides his autonomy and decreases self-empowerment. However, the physician must overcome such obstacles by facilitating a dialogue that allows the physician to see the illness from the patient’s perspective. Good doctoring requires listening, asking the right questions, and meeting the patient where they are.

Also, each patient’s view of care and pain is unique, so the physician must communicate effectively with the patient to avoid stereotyping or assumptive thinking. Veatch clarifies how difficult it is to create a particular framework for making medical decisions that consider and account for different worldviews and religious and philosophical beliefs. Veatch contends that it is simply inappropriate to define a correct set of beliefs and values to practice medicine. Every patient’s conception of an illness is based on their own explanatory model of illness. Knowing a patient’s explanatory model of illness, exploring patient’s agendas, and rationalizing illness helps physicians act in a more appreciative, assistive manner. Therefore, to gain a proper diagnosis and determine a patient’s acceptance level, it is highly recommended that the physician
communicates in ways the patient understands and then offers options and choices that lead to consensus. This process is often complicated when the patient is incompetent. For an incompetent patient, the physician should communicate with the family and understand the patient’s history to meet the needs of the patient.\textsuperscript{320}

3.1.2 A Joint Narrative-based Patient-provider Partnership

To overcome the paternalism debate, both patient and physician have to view each other with trust and thus co-create their partnership. The physician only hears the patient’s voice and demands by practicing patient autonomy. On the other hand, based solely on his knowledge and expertise, the physician cannot always make the right decision for the patient. Therefore, to co-provide effective care to the patient, both the physician’s and the patient’s voices need to be heard, valued, and respected.\textsuperscript{321} Therefore, considering the ultimate goal of care, both the physician and the patient should act as a partner in a place where Narrative Authority prevails.

3.1.2.1 Autonomy as Shared Obligation

Autonomy is “self-governance,”\textsuperscript{322} which discloses the freedom of choice making. The two underlining criteria of autonomy—liberty and agency—reveal that an autonomous person is not under the control of someone else; she can clearly and freely present the choice she prefers. Based on this, Beauchamp & Childress suggest ideas to protect and promote the autonomy of both the patient and physician. Beauchamp & Childress contend that practitioners respect autonomy by recognizing and appreciating the situational context and, in turn, the other’s perspective. To honor the role autonomy plays in a story-based relationship, the patient and physician must each appreciate and respect how autonomy can promote, support, and champion the individual dignity of the other. To preserve individual dignity, each party must understand how the other’s
perspective influences and shapes the choices they choose to make. This interplay of understanding and recognition is possible because each individual is simultaneously embodied, social, and historical. This implies a fundamental, shared social connection. Therefore, ethics demand an obligation to recognize, respect, and respond to the social intimacy apparent in the bound of this relationship with the other. Through this intimacy, we uphold the dignity of others, particularly those who are suffering. Thus, individuals’ stories prevail in shared meaning.

Individual dignity is closely connected to and influenced through autonomy. This is a crucial concept in healthcare, especially when addressing the elderly, end-of-life, and incompetent patients. Often, medical care procedures override the ethics of preserving individual dignity and the autonomy of the patient. For instance, a patient with dementia often has her dignity compromised by the care procedure imposed upon her by the caregivers and caregiving or legal processes. However, individual dignity should not be compromised regardless of the degree or severity of cognitive impairment. Individual dignity must be equated with humanness. If caregivers believe that a brain-dead person no longer has dignity, then this position converts the person into a thing, other-than-human, which possesses only material or commercial value. Therefore, for any level of patient’s competency, dignity should be preserved by recognizing, embracing, and respecting the patient’s autonomy. In doing so, physicians then serve their obligations towards the shared, every day, story-disclosed society.

To understand the relationship between individual dignity and autonomy, the physician should clearly understand and respect cultural differences in decision- and choice-making. Cultural sensitivity, at heart, respects the other’s individual autonomy and allows the other to be seen as fully human. Respecting another’s autonomy affirms the fact that an ethical decision can have different outcomes given the various perspectives of dignity constructed through other societies.
By recognizing, accepting, and respecting cultural differences, the patient and physician have the opportunity to respond appropriately to the other’s view of autonomy. For example, an Asian patient’s autonomy is most often seen as collective autonomy. While for a Western physician, autonomy mostly means individual autonomy. In this situation, the physician must understand that the cultural perspective of autonomy may, for example, be collective and respond accordingly. Regardless of the situation, the physician must recognize and be attuned to the patient’s cultural perspective and, consequently, respond to the patient based on her view of autonomy, and, in turn, respect that patient’s dignity. If physicians or caregivers are not sensitive or attuned to the cultural norms of the patient, it is virtually impossible to preserve the dignity of the patient.

Both the patient and the physician have the freedom to assess their own foundational beliefs of their autonomy, clarifying and solidifying each individual dignity. Doing so serves to create a partnership between patient and physician. Yet, the physician must understand the position and perspective of her patient. For example, a Jehovah’s Witness may decline a blood transfusion based on her religious belief. This presents a challenge for the physician who understands both the importance of the blood transfusion and the patient’s choice to reject the treatment. The culture of a Jehovah’s Witness shapes the notion of her independence, dignity, and this cultural/religious norm which serve to supersede what the physician sees as common sense.

However, the patient or physician may often understand autonomy as a person’s independence but fail to understand the obligations connected to that independence. In a patient-centric culture, a patient may exercise his autonomy over the doctor’s directive. Yet it is the physician’s obligation and ethical duty to intervene for the well-being of the patient and attempt to make the patient understand or reconsider her choice. At the same time, the physician should also check back to make sure the patient’s dignity is not compromised to protect his social
obligation further. That is, the medical and the care objective should not be the heart of the care; rather, the physician should see the patient first as a human with dignity in a shared social narrative, and both the patient and the physician have an ethical obligation to society.\textsuperscript{333}

Naturally, the patient and the physician are concerned about their rights but often disregard their obligation to the other. Ego and arrogance play an essential role in the disregard of obligation.\textsuperscript{334} However, a focus on obligation provides the ethical context to see and respect the other as an individual. Therefore, to respect the culture and to preserve individual dignity in a multicultural society, it is critical to view and embraces autonomy through the lens of shared obligation.\textsuperscript{335}

As noted above, effective communication is an important pathway for preserving individual dignity. Two people may speak the same language, but this fact alone does not guarantee effective communication, where both parties understand one another’s positions and points of view. Effective communication connects understanding, meaning, and context between the patient and physician and thus encourages dialogue and creates a platform from which to tell each other’s stories.\textsuperscript{336}

For example, consider a situation when a surgeon attempts to inform a Navajo patient of the details of proposed bypass surgery. Navajo often do not take well to direct facts or news perceived as unfavorable. While what to the physician appears as a best-case diagnosis, coupled with standard and routine prescriptive procedures, may well be heard by a Navajo patient as a death sentence, who then responds by refusing treatment.\textsuperscript{337} In this instance, the surgeon unwittingly undermined the patient’s autonomy. He assumed the patient was operating from the same communication perspective and worldview as his when, in fact, the patient needed to hear
the doctor’s diagnosis in another way. The direct, science-fact way of sharing his information with the patient was ineffective and proved counter-productive.\(^ {338} \)

Had the surgeon offered his assessment in a positive, ritually oriented, or story-bound language, he could have more effectively communicated his diagnosis and fulfilled his obligation to the patient. Given this scenario, it is crucial to understand the broader context: language does not merely describe reality, language shapes reality.\(^ {339} \) In many ways, the Navajo patient did not understand the worldview of the physician: it was something foreign and incomprehensible. The Navajo world is configured otherwise. It is a world in which sense-making is constructed on myth and story, rather than rationality and logic.

3.1.2.2 A Responsible Relationship for Good Care

Principle-based reasoning often compromises the professional’s integrity to uphold the first principle: respecting the patient’s autonomy. However, all the principles are equally important, and they are not rank ordered.\(^ {340} \)

Relationship-oriented ethics understand autonomy as relational autonomy, opposed to individualistic autonomy. We focus on a rational individual’s free will and agency when exercising moral responsibility in individualistic autonomy. Interestingly, one driving reason for the emergence of and emphasis on individualistic autonomy is the requirement to satisfy informed consent. To meet the demands for informed consent, the patient must fully understand what she is giving consent to and freely sign the consent form without intervention or coercion. If we follow an ideal healthcare system that rests on the belief that the patient and physician are equally crucial in the decision-making process, then the professional’s role is to give information, and patients are free to accept and reject the information.\(^ {341} \)
However, if we follow the route of relational autonomy, we provide the physician with a bit more authority. From this perspective, the physician offers more than information. Relational autonomy understands that one person is always in relation with and connected to the other. It provides the freedom to make a moral judgment while at the same time accepting the other’s opinion founded on the belief that one is always deeply rooted with the other. When a physician arrives at a solution, and there has been a dialogue and an open and respectful sharing between the physician and the patient, the patient is more likely to value and respect the opinion and suggestion of the physician, believing that they both are connected deeply at the human level.\textsuperscript{342}

Generally, in our medical practices, vulnerability and autonomy are separated. It is a given belief that you abdicate (often willingly) your autonomy when you become vulnerable. Vulnerability is seen as neediness, helplessness, and a diminished state of autonomy. Whereas relational autonomy sees vulnerability as a necessary criterion for interdependency, we are interdependent and caring because we are vulnerable. This view says that some people are more vulnerable than others, and we each have a moral responsibility to take care of those who are vulnerable. A physician’s professional integrity plays a role in treating highly vulnerable people. Some may term this physician’s paternalism, but in many instances, it is not. It is a benign, mentoring form of intervention that will adequately serve vulnerable people because their vulnerability stands in the way of their decision-making-capacity.\textsuperscript{343}

Many feminist philosophers also contend that individualistic autonomy is a masculine, rationalistic concept, which leads us to believe that we are separate and isolated beings. These thinkers also argue that this concept of individualistic autonomy is deficient because it overlooks the fact that we are fundamentally social beings. This individualistic autonomy leaves no room for interdependency and devalues the feminine nature of care, which is deeply interdependent.\textsuperscript{344} On
the other hand, relationship-based autonomy provides an alternative approach. It supplies a perspective from which we catch sight that we are individuals who are always embodied in the shared narrative understanding of the everyday. We are interrelated and interdependent by nature. We are radically social.345

For instance, patients often reject interventions because they are fearful and distressed. Their fears stand in the way of their better judgment. Thus, their decision-making capacity is compromised within this circumstance.346 Adhering to the professional integrity guides and obligations, a physician cannot leave the patient hanging in such a state; she must respond to guide the care. She can best accomplish this through effective, other-based communication.347 If the physician fails at first sway the patient, then she has the professional obligation to continue to ask open-ended questions that serve to nudge the patient towards a better decision and to ensure the patient receives good care.348

Physicians should call a timeout from their evidence- and scientific-based practices and embrace a value- and meaning-loaded, story-founded perspective to approach the patient. However, this doesn’t mean that the physician sacrifices her knowledge- and skills-based judgments to treat the patient.349

Similarly, the patient’s autonomy should welcome the physician’s input to satisfy the other two essential bioethics principles: nonmaleficence and beneficence. We must let go of the unquestioned assumption that we are fully autonomous individuals and catch sight of the fact that we are connected to and with one another. For instance, considering the legalization of euthanasia, the only thing that needs to be revealed to confirm that it is a moral act is to show that the choice is a willfully made, autonomous choice. However, the legalization of euthanasia raises other queries. For example, is it morally suspect that by legalizing euthanasia, the law also strides upon
values and beliefs of others? What is at issue is the ability to see the same situation differently. This insight arises only if we have constructed a reciprocal relationship between the patient and physician.

3.1.2.3 A Power Balance for Maintaining Trust

The Patient-physician relationship rests on trust. The trust is seen through the actions taken by the physician. However, this relationship cannot be maintained by only the physician’s respectful behavior towards the patients. As we privilege the patient’s autonomy in Western healthcare practices, we often discount or overlook the wisdom healthcare professionals bring to the table. However, we often forget that if professionals are not of sound mind and heart, they cannot provide sound and heartfelt care to the patient. Like respecting a patient’s autonomy, a physician’s self-care should be explicitly noted, addressed, and appreciated equally. Only then can we find our way to healthcare that is trustworthy and compassionate.

Physicians need authority to exercise their professional integrity. Patients need authority to defend their preferences, values, and quality of life. Both parties can exercise their authority equitably in most situations. Authority is not mutually exclusive; it isn’t a given that if one exerts her authority, the other’s authority will be deprived. However, there are certain situations where empowering and respecting the authority of both parties is not possible. Depending on the situation, one’s authority may supersede the others. But this does not imply that one holds absolute ruling authority over the other. Nor should it be seen as a submission to the other’s power. Instead, in a relational setting, it is a mutual understanding of a ‘person-to-person relationship,’ with the belief that authority is an inescapable aspect of an interpersonal relationship.
When there is a healthy patient-provider relationship, the authority is seen as an exchange of knowledge. The provider holds the medical knowledge that can heal the patient; the patient possesses an understanding of the self that seeks to be healed. But, unfortunately, we often place these ‘powers’ at opposite poles. Not long ago, the pendulum began to swing from providers’ paternalism, and it now rests in the position of full patient autonomy. On one end of the spectrum, the patient is the sole decision-maker, and the providers are mere informers. On the other extreme, the provider makes decisions, regardless of the patient’s input—as if ‘Physicians are God.’

Rather than viewing the two parties as adversaries, we should see the two parties as one—two interrelate beings—with authority to complement one another. Balancing power is power well shared. It is, in fact, a mixture of ‘balance-owned power,’ ‘shared power,’ and ‘aimed power.’ Balance-owned power addresses the benefit and harm associated with a decision. Shared power brings the two players into the boat to row together. Aimed power assumes in appropriate interventions whenever needed. Where shared power can be seen as compassion, aimed power can be seen as mere facilitation. In some instances, aimed power overrules shared power when ‘double agents’ occur. A dual agent is a public health and social responsibility issue where the care provider’s moral responsibilities conflict with the need to safeguard the public or someone other than the patient. In this situation, a physician can break the confidentiality of a patient who has an intention to harm herself or another.

Therefore, we must understand that it is not always possible to exercise or empower both the patient and caregiver, even with the best intentions simultaneously. One sometimes must trump the other, depending on the situation. If we believe in this trustworthy relationship, the patient should be ready to accept paternalism in exceptional cases, believing that the physician is serving her best interest. As professionals, as relational beings, and healthcare providers, we should be
ready to delegate the authority to others to give or receive the best care. If each party openly considers or acknowledges the other’s best intentions, the solution to a problem will be much easier and more transparent. Thus, we can let the pendulum rest in a middle position—where both paternalism and autonomy find consensus and harmony.

The disputes concerning autonomy and paternalism cannot be resolved instantaneously. By imposing parameters and imposing controlling agents, we can calm the debate, but only temporarily. The ethical resolution, consensus, or compromise on these matters is only possible through the exercise of a story-based, dialogue-orientated, other-welcoming approach: Narrative Authority. Narrative Authority opens the space and provides the sense-making to see the other person as a human being. From this perspective, the physician considers the patient as a person in need of care, and the patient sees the physician as a caregiver. When this occurs, a shared space opens in which dialogue and consensus-building can occur. Narrative Authority reflects and honors the dialogic engagement of the physician and patient in a person-to-person partnership. This is a partnership to disclose effective and ethical patient treatment; it is a concerted means to overcome biases, misconceptions, and unquestioned assumptions that blind one to the other, a darkness where no true healing can occur.

3.2 Illustration: The Patient-provider Relationship in Resource-limited Countries

The patient-provider relationship in Bangladesh is used as an illustration for this Chapter. Bangladesh has a complex healthcare system. There is no coordinated, centralized, or regulated manner to establish or maintain an integrated or coherent healthcare system. The public overwhelmingly mistrusts its healthcare institutions and care providers, which compounds the ethical challenges of equity and fairness in Bangladeshi healthcare. Currently, people do not trust their care providers, and this situation continues to spiral downward.
It will not be easy to solve the associated policy-level issues facing the Bangladeshi healthcare system, which are tremendously complicated and multi-layered. However, change can be made at the local level by building and sharing best practices. It is possible to systematically re-establish trust in the provider-to-patient relationship, which, in turn, reinforces trust in the healthcare system. What is required is a bottom-up approach, focused on repairing individual-level, person-to-person relationships as the means to rebuild the trust between the patient and physician and uphold the dignity of the patient.

This chapter discloses the already disrupted patient-physician relationship in Bangladesh and suggests a way to respect the patient’s dignity to maintain a healthy relationship. As mentioned in the first section of this chapter, upholding dignity is a way of acknowledging autonomy and seeing others as individuals. This section further discusses dignity through the lens of the dignity-enhancing care model. This model is context-sensitive and relational. The model rest in the belief that responsiveness is a way to be engaged with the patient and, in turn, respect the patient’s dignity.

3.2.1 Patient-provider Relationship in the Context of Bangladesh

Bangladesh, about two times smaller than Germany, is a densely populated and emerging country. Bangladesh is ranked as the tenth most populated country. The population, as of July 2020, is estimated to be 168,108,246 people.\(^{359}\) The 2019 per capita income of the country is $1909 (USD).\(^{360}\) As a result, the efficacy of the healthcare system is severely challenged by the lack of resources, mismanagement, and corruption. There also is virtually no health insurance structure or social safety net. Currently, the population exceeds available resources and infrastructure capacity. Without a visionary plan, the situation will only get worse.\(^{361}\)
Presently, Bangladesh has no strategic plan to prioritize healthcare over other vital national concerns such as education, public safety, and commerce. Also, due to the rapid growth of Bangladesh’s urban centers, healthcare in the most significant cities is strained even further. Dhaka, the capital of Bangladesh, is ranked (and has been for the past three years) as the world’s most densely populated city. As of 2018, Dhaka city has 47,400 people per square kilometer. The poor find access to healthcare services nearly nonexistent. The poor often die without treatment for easily treatable ailments. Currently, Bangladesh is unable to provide the minimum healthcare facilities to its people.

The health system in Bangladesh has multiple actors, with the government being the primary one. Private-sector hospitals provide significantly better service than government hospitals. However, the aim of private providers is profit, and they lack a clear functional or mandated mechanism to serve those without the means to pay for individual care. Furthermore, there is no coordination between the government and private sector; each act in its own perceived best interest. The government and the private sector exacerbate the problem by competing. As a result of this competition, a type of business war, the most vulnerable and most needy patient population is left without access to healthcare, both in routine and emergency care.

The obvious culprit for this broken system is systematic inefficiencies and mismanagement. However, beyond the system-level inefficiency, and perhaps more insidious, are the incidents of physician’s malpractices, the exploitation of the uneducated population, and the predatory practices of the pharmaceutical industry. In short, Bangladesh’s healthcare system is in crisis, ethically and structurally.

Given the chaos, corruption, the lack of regulation and oversight, mismanagement and incompetence, and blatant profiteering, patients, even those with resources, no longer trust
physicians' competence, honesty, or ethics. The title of doctor, which Bangladeshis once most revered, is now tarnished. Being a physician, which was perhaps the most respected profession in Bangladesh, has become highly criticized and often openly reviled. This tension only further weakens the healthcare system. To tame this turmoil and construct a trustworthy healthcare system that equitably serves the people of Bangladesh, cooperation and a healthy relationship between patients and physicians are required. Moreover, the vision of and will make changes are perquisites. All is not lost. Bangladesh remains, at heart, a proud country. The reconstruction and stewarding of the Bangladeshi healthcare system can be achieved through visionary governance, firm oversight and accountability, and the commitment to reform by all leading actors.

In general, the mistrust of the Bangladeshi health system occurs at three levels: societal, institutional, and interpersonal. Societal uncertainties, faulty institutional practices, and inconsistent interpersonal communications adversely affect the efficiency and effectiveness of the healthcare system. Reliable, honest, and ethical policymakers must step in if general governance is to improve and exert a positive influence. Policymakers must lay the foundation upon which societal and institutional level best practices can be built or reconstructed. However, system-level changes alone cannot create a better healthcare system in Bangladesh. Change also will be required at the interpersonal level. Doctors and caregivers must lead and own the charge to foster improvement, one interaction at a time, one patient at a time, one situation at a time. Individuals, the populace, rightfully wary and mistrustful of all parties involved in healthcare, should follow their lead, give the benefit of the doubt, and participate in remaking and re-narrating the story of the healthcare system in Bangladesh.

In the context of Bangladesh, the nature of the patient-physician relationship falls within the two broad categories: relationship with educated patients (school graduates) and patients with
some or no formal education. Educated patients want, and expect, to be active players in the
treatment, whereas the illiterate and less uneducated patients depend upon, and give autonomy
over to, a physician’s expertise. However, the role of physicians as God no longer holds among
any group. Patients in all groups throughout Bangladesh have lost faith and trust in both physicians
and the healthcare institutions over time.

To re-establish trust in physicians and the medical system, it is essential that physicians
focus on seeing the patient as a human in need and respond ethically, morally, professionally, and
legally from that standpoint. Doctors must find their ways to compassion, regardless of the
structural obstacles in their paths. Physicians must find ways to stop seeing the ill abstractly, as
things with problems to fix. Ethical medicine cannot be practiced under the current circumstances. The future of the Bangladeshi healthcare system is dependent on the revised actions
of its physicians. A physician must come to understand and accept the claim of compassion and
take responsibility for providing care as he or she was caring for herself. Trust cannot be built or
reestablished when there is no interpersonal connection or compassion.

Even in situations where the physician is directive, it is essential to build trust that will
have the patient understand why the doctor is prescribing a particular treatment option. It must be
kept in mind that the doctor-patient relationship is a mutual investment where both the patient and
the doctor become intimately, humanly, connected to one another, irrespective of the patient’s
education, contribution, or outcome of the treatment.

Even though many physicians are overcome by the number of patients they must see, it is
imperative that they revise their common practices. To build a relationship and to evoke trust,
physicians should begin a conversation by asking non-medical questions, opening the opportunity
to break the ice and create an interpersonal bond. Showing interest in non-medical issues in the
patient’s life helps the patient to realize that the doctor sees the patient as an individual. This relationship-building process tills the ground from which trust can grow.\textsuperscript{374} When this occurs, communication improves, the patient relaxes and speaks more honestly; in turn, the physician becomes a more knowing and responsive participant in the healing process. Trust is built on one question, one response, at a time. Through such best practices, the relationship becomes a healthy and trustworthy patient-physician partnership.

Currently, in Bangladesh, mistrust occurs when the patient becomes anxious or pessimistic about the intention of the physician. Patients, to some extent, do have confidence in the physician’s abilities, but they lack trust. There is a difference between trust and confidence. Confidence comes from recognizing the skill and abilities of the physician. Trust, on the other hand, is a function of integrity, compassion, and communication. Trust and confidence are both requisites to a strong patient-physician relationship.\textsuperscript{375} Another way of seeing this is that confidence is the expectation of the partner’s competence, and trust is the partner’s benign motivations. For instance, a patient is told by the surgeon that she needs surgery. The patient has no doubt of the surgeon’s technical skills, but that patient is doubtful about the surgeon’s motives. The patient may, for instance, believe that the surgeon is pushing the surgery for his own personal or financial benefit.\textsuperscript{376}

3.2.1.1 Case Illustration: A Six-month-old Boy

What follows are the details of a case. The facts were gathered by the author through personal conversations with the family.

A boy born in September 2018 was taken to the pediatrician multiple times, beginning two weeks after his birth. The reason for the initial and subsequent visits was that the baby cried non-stop. The only way the family could quiet the infant was by feeding him. In conjunction with the
crying, the boy was docile, lethargic, and not very animated, which the parents explained to the physician. The parents also informed the doctor that the baby consistently pulled his ears and rubbed his eyes and nose. The infant also had an inordinate number of bowel movements, up to 10 per day, which was also shared with the doctor each time the family spoke to him. On each occasion when the baby was taken to the same pediatrician. The immediate and consistent response from the provider was that the child was experiencing stomach gas. The child, on each occasion, was prescribed medications to counter the effects of stomach gas.

It also turned out that the baby’s right supra clavicle was fractured during NVD. This injury went unnoticed by the pediatrician during his 2-week wellness visit. The fracture was only identified when the parents recognized that the baby had stopped moving his right arm twenty-one days after birth. At that point, the parents took him to the emergency room. An x-ray revealed the fracture.

Following the fifth visit, when the boy was two-months-old, the pediatrician increased his medication for gas and diagnosed the boy to be colic. However, his symptoms remained unchanged. He continued to cry non-stop.

On February 3rd, five months after birth, during another visit to the pediatrician, the doctor noticed that the boy’s left supra clavicle lymph node was swollen and had grown into a ball (3-4 mm diameter). Tests were administered, and given the results, the doctor suspected tuberculosis. He then prescribed tuberculosis drugs. Tuberculosis drugs are very powerful, and they should not be administered to an infant without being sure about the infection. The child had not had any direct contact with any tuberculosis patients. Usually, to become infected with tuberculosis requires direct contact with an active pulmonary tuberculosis patient. This was not the case with
this infant because the family didn’t take the baby into public places. Regardless, the drugs were prescribed for suspected tuberculosis.

It is of note that the family has a history of Chronic Granulomatous Disease CGD. CGD is an inherited disorder in which the white blood cell struggle to fight infections. The family did inform the physician of this fact, but the physician discounted this fact and instead labeled the mother as anxious. Even in the face of this details, doctors began the child on a regiment of tuberculous drugs beginning on February 18, 2019.

On February 20, the parents noticed that another lump had grown in the lymph node, now on the right side. When the child was taken, this time, to his pulmonologist, the symptom was disregarded as uneventful. The doctor agreed with the possibility that the CGD could be a cause of the crying and the appearance of the lumps. Seemingly the doctor continually disregarded the input from the family, especially the family history. In fact, the pediatrician didn’t delve into details about the family history of CGD. The pediatrician may have known that the child had a poor prognosis and was hesitant to inform the parents about this to avoid a difficult conversation. However, hiding the truth and avoiding the difficult conversation is not a good medical practice.

On March 18, 2019, the baby was admitted to a local hospital with a respiratory condition. His situation continued to worsen, and the parents, frustrated and fearful, lost all confidence in the system and the doctors attending to their son. The baby’s pediatrician did not visit the child at the hospital, even when the child’s vitals were failing and he was in distress. Though in severe respiratory distress, the baby was not given oxygen during his stay in the hospital. Finally, convinced the doctors had abandoned their son, the parents transferred the baby, by ambulance plane, to a facility in Singapore.
The doctors in Singapore offered all the available treatments and diagnosed CGD. The medical team expressed its frustration about the misdiagnosis in Bangladesh. The doctors in Singapore assessed his condition and concluded there was nothing to be done. It was too late. Within four days, the baby died from the effects of CGD. Given the nature of CGD, the child, in all likelihood, wouldn’t have lived. But the suffering he experienced and was subject to in Bangladesh was unconscionable, cruel, and unprofessional, to say the least.

The above case is not atypical in Bangladesh and depicts how and why mistrust frequently occurs in the patient-physician relationship. First, given the above case, a physician should not judge or discount the parents’ concerns, nor should he belittle the parents. The pediatrician should have listened to and noted the family history. Had the pediatrician paid more attention to the details of parents’ concerns and insights from the early stage, the physician might have understood the unusual response of the baby. The baby was unhealthy from birth as he was carrying a genetic disease. The mother has other children and thus has experience with the nuances of a young baby’s behavior. The physician should have listened to the patient’s story. He should have paid more attention to the details and the circumstances. Had the physician considered the baby as an individual in need, he might not have overlooked the important indications provided by the parents and the baby’s behavior. Courtesy and consideration should be the first things offered when working with the parents.377

Secondly, the physician should have come to the hospital when the child was failing; even though, at this point, he probably understood he had misdiagnosed the patient by ignoring the family history. He should have acknowledged his mistakes, explained how and why he had come to his conclusion, and held himself accountable for his action. Unfortunately, the physician didn’t do anything, not even provide a few words to console the hearts of the parents. Taking
accountability and showing compassion would help to re-establish trust and lessen the pain the family was feeling. Avoiding and denying mistakes fractures a relationship.\textsuperscript{378}

3.2.1.2 A Theoretical Analysis

A patient-physician bond is holistic and sacred. Treating the patient’s physical illness is secondary, whereas care for the patient comes first.\textsuperscript{379} Those who choose this noble profession take an oath before they begin serving the vulnerable and those in need. Embracing the oath, physicians find the moral ground upon which is build the patient-physician relationship.\textsuperscript{380} Since the relationship between patient and physician is founded on moral grounds, it is important to explore the patient-physician relationship from a theoretical perspective within the context of Bangladesh. Offered below are the ethical theories that underlie and ground the moral obligations of physicians and providers. These descriptions offer a direct connection to the situation in Bangladesh.

Consequentialism

Current medical practices can be best understood by the catchword autonomy. In the West, maintaining a patient’s autonomy is the norm of medical practice.\textsuperscript{381} However, in the context of Bangladesh, autonomy is applied much differently. Whereas paternalism is seen as a deficient or antiquated practice in the West, from the Bangladeshi perspective, patients, particularly uneducated ones, accept paternalism, and the paternalism is excepted by the system and organizational practices.

From the perspective of consequentialism, the moral permissibility of an act is based on its consequence. If telling a lie helps to save a life, consequentialism says to tell a lie is morally permissible in that particular situation.\textsuperscript{382} From this moral perspective, the practices of physician
authority in decision-making in Bangladesh can be understood, given the noble intention of the physician. Often poor and illiterate patients lack fundamental health knowledge, are unable to read, are frightened or confused by a hospital, and therefore find it challenging to make well-informed decisions. In such situations, physicians act in the best interest of the patients.³⁸³ That is why, in many cases, Bangladeshi patients largely depend on and accept the doctors’ decisions. Thus, if an action by the physician seems paternalistic, that is acceptable, if that decision is to bring good for the patient.

Besides, many Bangladeshi people of all ilk tend to submit to the physician’s authority because of cultural norms that highly elevate the stature of the learned doctor. Submissiveness to authority is not uncommon in Bangladeshi culture. In both cases, the decision the physician takes about a treatment goal is accepted as long as the consequences of those actions are good.³⁸⁴

**Deontology**

From a deontological perspective, autonomy is critical. Deontology contends that moral values can be independent and are dependent on the particular action itself.³⁸⁵ As deontology suggests, one must treat every person as an end and never as a means only. Therefore, it is essential to respect a person’s autonomy, even at the expense of the greater good.³⁸⁶ However, in the context of Bangladesh, this is not practically feasible due to vulnerability and dependability. The vast portion of the population of Bangladesh is not highly educated or medically literate. Also, Bangladeshi culture is much more family-oriented and much less individualist than is prevalent in the West.³⁸⁷ People in Bangladesh tend to make decisions collectively, as opposed to individually. Decisions are generally made by discussing the options with family members and others. Even if they are free to exert their individual autonomy, a person chooses to accept and practice collective autonomy because it is dominant and normative within the culture.
Those who do not comprehend their medical situation struggle to express their wishes—as understood in the West—in terms of medical decision-making. Culturally, for the most part, they accept the physician’s influence in medical decisions, willingly or unwillingly. And it is critical to remember that most decisions in Bangladesh, including medical, are made collectively as a family. In most cases, at all levels of society, families make decisions together, or an individual delegate her decision-making authority to a senior family member or to a male. In these instances, upholding individual autonomy makes no sense.  

Therefore, considering scarcity, illiteracy, and cultural differences, it is not always possible to prove a moral theory correct for every context, even though these precepts may be universally accepted. Moral dilemmas or moral decisions are context-sensitive and situational and must be responded to accordingly. Therefore, from a theoretical moral perspective, in the context of Bangladesh, the practice of authoritative power given to the physician is accepted. Physicians in Bangladesh are given this power, and patients accept to follow the physician’s directive, so why there is such overwhelming mistrust?

3.2.1.3 A Practical Version

In the context of Bangladesh, there are a couple of things going on- 1) well-intended doctors who do not explicitly obtain informed consent. 2) Rampant and unquestioned paternalism throughout healthcare. As a result, patients are treated unethically. 3) Patients that willingly concede their autonomy to the physician. Even though the profession of physicians holds esteem and power in Bangladesh, they have failed to protect the honor and status afforded to them and have thus fallen and lost the trust of the populace. Maintaining trust is not easy, and it is fleeting; trust must be earned, and it needs constant attention and validation. Once trust is broken, it is challenging to reestablish and sometimes impossible to regain, especially if the cause of the breach.
is not addressed early on. Below are some ways in which the Bangladeshi patients view Bangladeshi physicians.

**Doctors as Curators**

Patients view doctors as curators who try to cure the disease without paying attention to the patient. Even though taking a patient’s history plays an essential role in understanding the patient, too often in Bangladesh, it is done matter-of-factly. It must be understood and embraced that when a patient has the opportunity to share her story, she provides context, meaning, and subtleties that allow the doctor to see the patient, offer a more accurate diagnosis, and keep the relationship between two people which is the foundation of trust-building. However, due to efficiency-focused time constraints and physician arrogance, consult appointments are extremely compartmentalized or technology-driven, with the physician looking at his device and following form-driven processes to take a history. The physician captures the physiological history but is given no time to obtain valuable insights offered through the socioeconomic or contextualized history. Thus, rationality and ridged processes supersede the humanness that comes through with the sharing of stories. The separation of the doctor from the other drive the doctor from being a healer to a deliverer of services to clients.

**Doctors as Covetous**

The most common complaint is that Bangladeshi doctors are greedy professionals who use patients to earn money. They exhibit no real care, empathy, or compassion. The consultation fees, laboratory tests, and the prevalent over-prescription of medication indicate how greedy physicians and the system have become. Physicians seem to show little concern for the social and economic condition of the patient. When they do prescribe medication or care plans, physicians should
identify if and how the patient might pay for possible services. Commission-taking is a common practice by Bangladeshi physicians. Such practices are unethical and immoral; but such is the outcome when the system has lax regulation, is money-driven, founded on profit-making, and graft-taking is normative.393

This market-focused healthcare model is the engine that generates the mistrust of physicians and the medical profession in Bangladesh. For instance, doctors take a commission from diagnostic centers, which promotes and prompts unnecessary testing, which worries inconveniences, and dupes their patients. Physicians also earn commissions from pharmaceutical companies. As a result, physicians then prescribe the medicines that garner commissions instead of other, less expensive, or alternative drugs that may be equally or more effective. In other cases, the physician finds a reason to prescribe the drug for which he will be compensated. In tandem with the pharmaceutical company, physicians also prescribe experimental or new drugs without proper precautions or verification of their efficacy or their side effects. These and similar practices serve the grey income of the service provider and the bottom line of the associated vendors.394

**Doctors as Defenders**

This mistrust grows and multiplies when physicians attempt to defend themselves against these controversial practices and allegations of corruption. They work diligently to protect themselves, as well as their fellow doctors. The self-protection and obfuscation by the doctors only serve to increase the level of distrust and cynicism among the patients and the population in general.395

Physicians contend that they are being victimized by angry, disgruntled, and unreasonable patients and their families.396 But for the vast majority of the cases, patients are justifiably angry,
given the unsatisfactory nature of their encounters with physicians, testing facilities, and the tiered structure of the healthcare system. The defensive posture taken by physicians is understood for what it is, a cover-up for corrupt practices, and merely fuels the tensions between physicians and patients. Physicians contend this is a hoax created by the media to discredit them. From their perspective, there are no missing pieces in the healthcare puzzle; it is effective and efficient. The practice of defending their misdeeds worsens, and the already strained and fractured relationship between patients and the physicians. 397

**Doctors as Autocrats**

Information helps to promote understanding, communication, and consent. But whether the information is accurate, incomplete, or occasionally wrong, it allows patients to believe that their doctors are tending to the importance of their needs; subsequently, the patient feels a sense of shared decision-making in the treatment plan. Unfortunately, the doctors in Bangladesh are reluctant to and rarely share any information with their patients. This is due to strict paternalism, tight time-constraints, and, in the worst cases, sheer negligence and corruption. Thus, doctors have become autocrats in the eyes of patients; patients believe little that the doctors say, even as they are eager to accept what they have to say even when it is not understood. The behavior and actions of physicians, generally, are abusive, unethical, and immoral. 398

There is a vicious circle of patient-physician mistrust apparent in Bangladesh. Due to institutional distortion and the lack of regulation, patient satisfaction scores for physicians and the healthcare system are abysmally low. While it is known that physicians act in unethical manners, not all the blame falls on their shoulders. The situation is a consequence of a variety of factors present in the broader infrastructure of Bangladesh. But the facts remain: due to systemic inefficiencies, patients are discontented and blame the doctor. Negative media coverage keeps the
issue to the fore, and doctors respond to the attacks by further and more strenuously defending themselves. Once they begin shielding themselves from the criticism, it exacerbates the perception. The posture of self-protection rubs against the grain of what the patients perceive as real and promotes further fear and distrust of the healthcare system. Thus, all forms of communication between doctors and patients become more complicated. It is difficult, even for the best and most honest of doctors, to breach the discord. As a result of the downward spiral of trust, patients receive less effective healthcare and remain discontented. And physicians continue to defend themselves again criticisms. Thus, the cycles of negativity and futility continue.

It will be difficult to break these loops without long-term, systemic changes. It is, however, possible to prime the system for improvement if individuals commit to change and implement change through their actions and behaviors. Doctors who understand the causes of the broken trust must consistently demonstrate integrity, honesty, and compassion and reshape Bangladeshi healthcare, one patient at a time. It is daunting, but it is a moral, ethical, and patriotic task to rebuild a culture rife with broken patient-physician relationships. Other entities must, of course, address the complicated nature of top-down structural change; however, it is possible to make change through a bottom-up approach: one doctor at a time, one patient at a time. The bottom-up approach is grounded on doctors and caregivers taking their oaths seriously and standing the high ground against greed and petty self-interests.

3.2.2 A Reformed Relationship Through Dignity-enhancing Care

Particularly in Bangladesh, doctors once were universally viewed in stature as second only to God. The standing given is an honor, but it also comes with the immense pressure and responsibility to live up to the expectations of the position. Given the fractured state of Bangladeshi healthcare, physicians can shift the narrative and reclaim the hearts of patients and the populace.
But there is much work to do: the noblest profession, medical practitioner, is now the most condemned due to a lack of devotion and commitment by the doctors themselves. If left unattended, or if the paths of greed, apathy, and self-interest continue, this once sacred relationship is in danger of being broken beyond repair.\textsuperscript{400}

Of course, the patient-physician relationship doesn’t exist in a vacuum. And given its intimate nature, this relationship requires extra attention to ensure its vibrancy and health. Western literature reviews reveal several models that seem could be applied to improve the above-described patient-physician problems. However, in the context of Bangladesh, these models will not suffice. Western-dominated or Western-directed models do not transfer to or fit within the Bangladeshi culture and social order. In fact, the prevalent Western world bias in medicine creates confusion and, in fact, overlooks the possibility of a broader, more inclusive ethics.\textsuperscript{401}

The restoration of trust in patient-physician relationships in Bangladesh will require a combination and tailoring of different models that respond to the cultural context. However, when the response model is constructed, the most critical domains it must address are effective communication, a respectful partnership, and joint decision-making—each of which is critical to developing a strong patient-physician relationship. Therefore, Bangladesh must implement a comprehensive, context-sensitive, and operationally viable model to restore faith and trust in physicians and the overall healthcare system. The first step, regardless of model, is for physicians to recommit themselves to their oaths, to reclaim empathy, and to heal with compassion.

Physicians must lead the charge of change; otherwise, the Bangladeshi healthcare system will continue to spiral downward into oblivion. Reestablishing trust in the patient-physician relationship depends on the thoughtful, respectful, empathic, compassion-driven, and dignity-affirming nature of physicians’ interactions with patients.\textsuperscript{402}
3.2.2.1 What Does it Mean to Be a Doctor?

The patient-physician relationship lies at the heart of good medicine. Without a strong relationship, trust fades, and the practice of healing disintegrates.\textsuperscript{403} The reliance on technology, specialization, and for-profit business models have transformed healthcare practices: healers have become service providers, and those in need of healing, customers. The ever-tightening grip of efficiency and profit-making diminishes strong patient-physician relationships. Patients are shuffled through the system; doctors respond to charts and test results, create a care plan, and head quickly off to their next patient.\textsuperscript{404} If physicians remember their oaths and that they are healers who have duties to their patients, they, even in the face of technological upheaval and business pressures, will be able to maintain trustworthy patient-physician relationships.\textsuperscript{405} Jonathan Wrinkle termed this patient-physician relationship “a sacred trust between seeker and healer.”\textsuperscript{406}

Trust is a transparent dependency on someone for something. Trust always occurs in an interdependent condition, where one party relies upon the other. The action of the other has an impact on the trust-holder, but the trust-holder still holds the right for autonomous choice-making, and those choices, like all choices, hold uncertainties. In this condition, the trust-holder can allow the other to choose to act on her behalf, believing that the other party is acting in her (and their) best interests.\textsuperscript{407} Trust also assumes and requires the expectation of honesty, fairness, lack of opportunism, and consistency. These qualities are considered (1) a ‘lubricant’ that allows the relationship to function smoothly, (2) a ‘glue’ that helps to bind people in a mutually beneficial condition, and (3) a ‘stimulant’ that allows people in relation to co-create opportunities for innovation, creativity, and long-lasting performance.\textsuperscript{408}

Trust is also a multidimensional event. The various dimensions through which trust can appear are, as in all relationships, complicated concerning a patient and her physician. Trust
between a patient and a physician is different than social trust or interpersonal trust. In fact, both social and interpersonal trust intersect to construct the trust between a patient and her physician. Interpersonal trust rests on the expectations of and belief in one person that has developed over time. Social trust is a belief in the honesty, integrity, and reliability of others; it is a faith in people.409

Concerning patient-physician trust, a patient, concurrently, (1) develops trust in the physician, which is interpersonal trust, and (2) establishes a mutual trust that extends to and includes the institution, a hospital, which is social trust. The social trust component of the patient-physician relationship rests on and is predicated by disclosure of interpersonal trust. In the context of Bangladesh, the possibilities for social trust are undermined and in peril because of the dissolution of interpersonal trust between patients and physicians. The general loss of this interpersonal trust undermines social trust and vice versa; thus, the situation in Bangladesh becomes ever worse.410

A patient’s trust in the physician depends on the following categories: competence, compassion, empathy, reliability, dependability, integrity, privacy and confidentiality, and communication. If physicians can exhibit these competencies in their interactions with patients, they are more likely to develop strong, cocreated bonds with patients. These bonds build and reinforce the trust the patient has in both the physician and the hospital and serve to create a healthy patient-physician partnership. Physicians who have solid, caring interpersonal skills also increase the probability of the patient’s satisfaction with the care she has received from both the physician and the institution.411

The open expression of empathy is often a challenge for medical professionals, who are trained to be detached, cool-minded, practical, logical, problem-solvers. Yes, some degree of
detachment is necessary to treat the patient effectively but seeing the others as a mere patient or problem distances the physician from the patient’s story and worldview and inhibits the development of trust. Interpersonal distancing from the patient can cause harm to both the patient and physician. The ability of the physician to consistently step into the shoes of her patients requires practice, discipline, and self-reflection. It is imperative that the caregiver sees the patient, not in the abstract, but as a particular human being with a past, present, and future who requires care. In the best case, it is possible for one person to become engaged in his relatedness to another in such a way that the other’s most subtle characteristics are illuminated for him.

When the physician does so, he is more likely to remain self-reflective, in the moment, and be-with-the-patient-as-other-as-self. It is in this space that empathy is possible. Empathy, in turn, opens the door for effective communications and allows the patient to reveal herself and have the physician receive the patient’s predicament in a shared context of meaning and significance. From this point, the physician can step into compassion, which is empathy in action, a notion that will be covered in the next section. But, for now, it is essential to recognize that empathy is a gateway to trust-building. Seeing the patient in this human manner allows the doctor to serve as a healer. And a by-product of trust-building is the development of strong relationships, which, in turn, promote improved patient satisfaction, fewer medical errors, and reduced incidences of malpractice.

As mentioned above, compassion is another essential element apparent in a trustworthy relationship. Compassion is the action taken on the claim of empathy. Compassion is the profound response to the condition of the other. In its earliest use, compassion meant “to suffer together with.” Compassion rises beyond empathy; it is a steppingstone into, an embrace of, and taking responsibility to assist the other in need, distress, danger; it is the art of healing wounds; it is the
creative, pre-reflective response to the illuminated face of the other. Compassion is a claim by and a call to the other. Compassion itself is a summons to action: to provide safety, solace, healing, community.\textsuperscript{418} When a person is moved by another person’s feelings, emotions, and comportment, compassion embraces the feelings and fears of the other person as share, common, and universal.\textsuperscript{419} By finding compassion, the physician can understand, respect, and step into the patient’s worldview, hear her story, and find intersections with her humanness, a place where healing and comfort can be given. Compassion requires a deep, active, and reciprocal interaction. Patients and physicians must keep front and center that before them stands another human. When this is done, they are more likely to recognize and preserve the genuine relationship that compassion reveals. A physician who can make herself vulnerable, open to, and attuned to the other as self, opens a space where trust can find roots and thrive.\textsuperscript{420}

Currently, we are in an era where the nature of the patient-physician relationship is one of mutual participation, where the patient and physician act as complementary players. Patients have tremendous access to information and often come to the examination room prepared and knowledgeable about their conditions. Patients now can actively participate in decision-making, depending on their level of knowledge.\textsuperscript{421} Furthermore, healthcare itself has become more customer-focused, and there are significant efforts to include diverse and pluralistic perspectives into everyday practices, which necessitate the physician being in dialogue with the patient and consistently checking for understanding that what’s been said has been heard and understood by all parties. So, patients who lack the knowledge and understanding of their conditions are given, and expect, detailed insights into their health before a treatment decision is put into motion. Yet, regardless of how the doctoring is done, the patient’s trust in the physician remains the key factor in the stability of the relationship.
Being a physician is perhaps the noblest profession on Earth, and it is a privilege. Physicians are called to respond to the hopes, fears, love, and joy of another human being; to help people in need of healing, and the seeker’s problem becomes the healer’s problem. A doctor should always remember the depth of the oath to which she has made a commitment and come to each situation with empathy and compassion. Furthermore, a physician must remember that medicine is not a blind science. Practicing medicine is much more than the knowledge that rests on empirical evidence and data. Medicine is beyond science; it is an act of compassion. Science reveals the facts of the disease. However, curing illness and tending to the well-being of the other in need always depends on the physician’s ability and commitment to respond to the human standing before her. Remaining distant to the patient, to the other-as-self, is the abdication of a physician’s ethical and professional oaths. Respecting and acknowledging the patient’s spiritual, social, and psychological dimensions are equally important to the physical dimensions.

3.2.2.2 Dignity-enhancing Care

It is essential to realize that care arises through vulnerability. Not only are patients vulnerable, but so too are physicians. This relationship is co-constituted and rests upon and requires mutual vulnerability if it is to be genuine and authentic. The vulnerability is not only physical. Illness is more than a physical event; it is a spiritual event, which, in turn, connects it to the soul. Physicians, as healers, are responsible for treating and tending to the soul as much as they are for attending to the body. The way to the spirit and soul is to stand with the other-as-self. Two people, each is opening themselves, in their vulnerabilities as human, to the other. This journey requires the physician to step away from seeing the patient in the abstract—as patient-as-a-thing—and then open himself to the other as an individual, with a story, with a life, with concerns, fears, aspirations, and hopes. It’s to see the patient not as statistics or data but as another
with a story constructed within the context of a life. From this position, a physician is open to empathy and the claims of compassion. In compassion, the physician tends to both the body and the spirit. The soul is touched when the physician opens a space in which their shared humanness is affirmed by the balm of what is essentially the expression of the physician’s love for and to the other in need of tending and healing.\textsuperscript{426}

By paying close attention to the humanness of the patient, the physician further tends to the soul by respecting the dignity of the other standing before her. In those moments, it’s two people sharing the event of the illness. This attentiveness helps to alleviate the sheer terror the illness provokes and breaks the loneliness and isolation the patient may feel when she senses she has lost control of her life. When this occurs, the physician shows ultimate respect for the other by affirming her dignity and humanness.\textsuperscript{427}

People require care when they are vulnerable. The meaning of the other’s vulnerability is best is understood by focusing on her wholeness and personhood.\textsuperscript{428} This includes having a strong sense of her physical wellbeing, her integration within society, her integrity, and her values: fundamentally knowing her story. Focusing only on the physical aspects of an illness is one-sided and a deficient means of assessment and care.\textsuperscript{429} As humans, we live within a shared context. We are embedded in the collective narrative and meaning-giving context of society and culture; it is foolish to believe that it is possible to separate an individual from the social context in which she finds herself. Therefore, to understand a person properly, we must grasp the person as a whole, in her situation, in her story; this approach is called Holistic Care. A foundational component of holistic care is to recognize and respect human dignity. Respecting dignity opens the physician to the full of the other’s world, which then opens the space in which to heal the body, mind, spirit,
and soul of the person, not as an abstract patient but as a human being with a specific sense of integrity, and with a particular story.\textsuperscript{430}

Gastmans’ foundational ethical framework of ‘Dignity-enhancing Care’ for nursing gives privilege dignity in the giving of care. This model is highly applicable for physicians, as well. Like nurses, physicians have to take into account the dignity of the patient while making medical decisions. Physicians generally treat patients as lesser and often only see the patient through the defining the terminology of a condition. Thus, their humanness is diminished with and through the ascension and complexity of the diagnostics terminology. It is possible to overcome the person-blinding power of diagnostic language and rigid time-based medicine by understanding and to embrace dignity-enhancing care.\textsuperscript{431}

Dignity-enhancing care uses lived experience as a starting point with any patient. It employs interpretative dialogue as a normative standard to access and catch sight of the other’s worldview. To respect a person’s dignity, it is imperative that a caregiver understand the wholeness of the person; this is had through effective communication, based upon Gastmans’ normative standard. The conversation aims to see and understand the patient as a person, then, in response, design the specific care plan. The purpose of this approach is to heal, not only to fix the wound.\textsuperscript{432}

To provide dignity-enhancing care, the provider must also develop, embrace, and practice the ethical attitude of attentiveness. It must become ingrained in the organizational culture, training methodologies, and serve as the foundation for understanding best practices. Through a shared dialogical process of communication, it is possible to catch sight of the person as a whole and thus make possible dignity-enhancing care. Through the tenets of dignity-enhancing care, providers and caregivers take responsibility to respect the other-as-self; this is a human-based means to deliver a competent care.\textsuperscript{433}
Often, it is difficult to care for the patient, especially in the perspective of Bangladesh. In Bangladesh, care providing is challenging because of what appears to be thankless, disgruntled, and frustrated patients. Due to the long and deep mistrust in the health system, patients nowadays express their frustration and disrespect to the physicians even though they accept their decisions due to knowledge power. Some patients tend not to embrace the doctor’s help even when the doctor genuinely wants to help. As a physician, even those who take their roles seriously, honestly, and with the patient’s best interest at heart, it can be difficult to professionally respond to a patient’s distrust, pessimism, and anger. But a physician must find a way to bridge the gap between them, open a space where one can see the other as self, and make headway, no matter how small, to build trust. The physician must recognize the patient’s pessimism is warranted given the fractured state of the Bangladeshi healthcare system, and her dismissal of his expertise may be a defensive response to the disruptive, world-altering nature of the illness. By being attuned to the physiological condition and the worldview of a patient, a physician can respond in a way that upholds the patient’s dignity.434

Generalization is a common practice among Bangladeshi healthcare practitioners. Focusing on dignity will help the physicians to understand that person’s identity, which is very important for excellent care. The same disease affects people differently. Each person’s explanatory model of illness is different than another’s. Each patient acts because it affects her worldview differently, in a specific way in response to an illness.435 The explanatory model of illness reveals how the patient defines the illness and the expectations, fears, desires, and hopes that accompany her encounter with the experience. Knowing this helps the caregiver understand how the patient is responding and will respond to the illness. Response to and acceptance of illness goes beyond the rational and mere factual.436 Knowing a patient’s explanatory model of illness,
exploring a patient’s agenda, and contextualizing illness help physicians act in a more appreciative, assistive manner. The way an individual respond to her illness is often story-based, affecting her imagination of the future and her hopes for living the life to which she aspires. However, if a physician is open to the patient’s explanatory model of illness, then the patient has the opportunity to tell her story and to have it be heard, which serves to build trust in and respect for the physician’s expertise and motives.

Focusing on dignity helps the caregiver to respect that each person has a different explanatory model of explaining their illness. By understanding the explanatory model of each patient, the physician can gain negotiation power. With the use of negotiation power, physicians can address a patient’s conflicting views and beliefs and build a genuine therapeutic connection that respects and honors a person’s identity, her story. Explanatory models also help to distinguish the difference between illness and diseases. Two people can have the same illness but respond very differently. One person might feel more ill than another with the same illness because each view and perceives the illness differently. Explanatory models help to integrate the biomedical, psychiatric, and social factors, which eventually shapes the illness.

3.2.2.3 Responsiveness in Delivering Care

Responsiveness is an objective criterion that helps to legitimize the patient’s expectations of the providers. While a vital element of excellent, patient-driven healthcare, responsiveness is the least addressed factor in the literature. Responsiveness must come from both the people side and from the system side if it is to legitimate, adapt to, and anticipate the health expectation of the patient. This chapter is confined to people-side interactions, even though the system is equally connected to the people, and it is inseparable. The patient-physician relationship is not merely dyadic; it is the byproduct of many forces within and throughout the healthcare system.
However, the quality of patient-physician relationships has a remarkable impact on the overall healthcare system, the impression people hold of the healthcare system, and, ultimately, on the health of the community at large. Also, responsiveness is one of the critical indicators determining if a physician’s approach to the patient constructs a dignity-enhancing, trustworthy relationship. In the context of Bangladesh, if a patient-centered health system is to be built and the negative perceptions of healthcare revised, it is urgent that healthcare providers embrace and include responsiveness within everyday best practices. The conceptual framework of responsiveness constitutes friendliness, respect, informing and guiding, trust-building, and optimizing benefit.

**Friendliness**

Friendliness is encompassed in the manner by which the provider interacts with the patient; this includes such things as warm greetings and asking casual, open-ended questions before starting the consultation. Friendliness reveals respect and expresses regard, explicitly demonstrated by soliciting the patient’s active participation and presence in the process. Ensuring active participation opens a dialogue of mutual influence, which fosters truth-telling and trust-building. This congruence guides and supports effective communication and person-to-person discourse. The system must be designed in ways that promote and are founded on friendliness; this is the relational gateway to the other components of Responsiveness. In the current health system in Bangladesh, physicians are limited by time constraints and patient loads, inhibiting their abilities to exercise friendliness in their encounters with patients. Physicians can promote change by shifting their mindsets to lessen the effects of these limitations. Physicians must recognize the moral importance of friendliness and that by allowing themselves increased time with patients, they will improve the wellbeing of both patient and provider. Physicians’ obligations go beyond...
being present to cure disease; they are ethically bound to heal the soul. And the soul can be healed by the friendliness, empathy, and compassion shown to the patient.445

**Informing and Guiding**

Informing and guiding is another vital component of responsiveness, which should be undertaken with sensitivity and aplomb. This is an absolutely important component for patients in all levels of education and vulnerability. Informing every patient of all the details and options associated with a medical intervention serves as a guiding means to empowering patients so they can make autonomous decisions. Poor and uneducated patients often struggle to understand how, why, and when to take their prescribed medication. These patients not only need respectful guidance in their treatment plan but also need assistance to carry out the treatment plan. Also, they should be educated in such a manner that they are empowered to take part in the decision-making process. Navigation is most often required to guide and support the patient along a directed, and often time-sensitive, care path.446 Attention to detail and consistent follow-up by healthcare providers is a necessity in the context of Bangladesh to navigate patients through the journey of the treatment. However, informing also must find its role in support of autonomous decisions, individually or collectively. Generally, cultural norms and values still privilege the physician’s knowledge, power, and authority over those of the patient. Thus, informing and guiding will reduce the knowledge gap and help to create a partnership between the patient and physician.447

**Respect**

In Bangladesh, there is no custom of greeting or welcoming the patient. The assumed reason is that physicians are overburdened by the number of patients they must see and by limited appointment windows. A doctor often sees more than 100 patients a day. Thus, the quantity of
consults overrides quality. However, from the patient’s point of view, there is the expectation and want for personal interaction with the physician. Patients look to the physician to help make them feel comfortable in a situation in which most feel uneasy. It must be remembered that even within the fractured nature of the Bangladeshi healthcare system, physicians, for all the tarnish on their reputations, still hold a high social status, and many see them as having God-like powers to heal. From this perspective, when the physician seemingly ignores their pleas for help and aid or does not recognize them with some form of reassurance, patients become distant, disappointed, fearful, angry, or feel they are not worthy of the physician’s time, skills, expertise, or healing touch.

The physician’s reassurance reduces patient anxiety, improves and shapes patient satisfaction, and helps build trust. Simply asking a patient what she understands or thinks about her illness can promote a meaningful change in the patient’s perception of the disease and the physician. Reassurance helps the patient face the reality of her condition in concert with the physician and helps her participate and share her concerns and hope about the treatment plan. Offering the patient reassurance helps her to express her concerns and fears; thus, the physician can, in return, acknowledge and respond with empathy and compassion and, in turn, catch sight of and share in the patient’s worldview. Encouragement and reassurance are sound and important ways to promote and strengthen the patient-physician relationship.

Given the expectations of patients and the proven benefits, physicians should dedicate at least 30-seconds to greet a patient before talking about the illness. To Western readers, this may seem like a small allotment of time. But in a culture where there is almost no time spent on greetings, welcoming, or recognizing the patient, this change of practice will go a long way in reshaping the perception of and the power of the patient-physician relationship. The practice of
greeting and speaking with a patient will help pull the physician from his abstract, distant gaze into a relationship with another human being, where he can see he is not treating an illness but tending to a person in need of healing. The time spent to make the patient feel comfortable and welcomed will improve the accuracy of their diagnoses and the patient’s confidence in the care plan.452

**Trust-building**

Trust Building is already crucial but given the current relationship between physicians and the community, it is difficult, but not impossible. Physicians rarely engage in or maintain eye contact with the patient; this leads to the patient feeling unimportant and unseen. Also, while answering questions posed by the patient, physicians should avoid brief answers or the use of technical jargon, both of which put off the patient or have the patient sense shame because she does not understand the meaning of the words the physician is using.453 The physician should, as frequently as possible, carefully listen to the patient’s story, regardless of the level of education or technical sophistication, understand her worldview, and answer in a concise but detailed way, using language and terminology the patient can understand. The more engaged a physician becomes with the patient, the better the physician can treat the patient. The art of communication is critical in building respect, trust, patient satisfaction, and positive, healing outcomes.454

When a physician makes the patient comfortable, he opens a space in which the patient feels seen, respected, and her dignity honored. Providing positive, non-verbal clues when listening to her story and history-taking has a positive impact and promotes relationship building. When the physician leans forward toward the patient, makes eye contact, and asks questions that invite a personal response, the ground is prepared for openness, sharing, honesty, and human-to-human interaction.455 These actions of respect demonstrate to the patient that she is seen, her concerns
taken seriously, and that she has the full attention of the physician with whom she looks for care, support, guidance, and comfort. These actions gain further benefit when conducted in a setting that is calm, quiet, and free from distractions or interruptions.456

The identity and individuality of a patient are gained through keen person-to-person engagement and effective communication. Separate from excellent verbal communication, it is also essential to be attuned to the patient’s emotional cues. The physician must adroitly read these cues then respond in ways that validate the patient by expressing empathy, understanding, support, and reassurance.457 By being attuned to the emotional responses a patient exhibits, the caregiver puts himself in touch with the patient, closes the gap between provider and customer, and becomes a healer. Each of these person-to-person actions, practices, and behaviors improves the therapeutic efficacy of the patient-physician relationship.458 Soliciting active patient participation helps promote physician partnership building, which is a critical component of the patient-physician relationship. When the physician shows respect to the patient and constructs a partnership with the patient, the act of controlling the patient gives way to shared engagement and mutual trust-building.459

Optimizing Benefit

Also, by Optimizing Benefit of the patients, care providers can gain trust. Optimizing benefit, in the context of Bangladesh, is directly linked with financial assistance. Physicians need to pay attention to the lifestyles and common practices of the patients if they are to treat the patient as a whole. It is not only about the disease. As Hippocrates wrote, “where there is love for a human being, there is love for the art of healing.”460 Before treating the disease, the physician must love the patient as another as self, and she must come to understand the patient’s worldview. Understanding the patient’s social, socio-economic, emotional, and physical condition helps the
physician to know better the patient and how best to offer a care plan. Knowing the patient will help him make the best decisions for treatment. For instance, prescribing low-cost antibiotics, avoiding unnecessary tests, directing the patient to an affordable diagnostic center, etc.\textsuperscript{461}

As there is no insurance industry in Bangladesh, individuals must pay for their healthcare out of pocket. The state does provide healthcare centers that offer low-cost care, but this network is overwhelmed with patients and mismanagement. Private sector care is costly and out of reach of most Bangladeshis.\textsuperscript{462} What physicians can do in this situation is to offer better ways of treatment by attending more closely to the patient’s story, to slow down enough to treat the fellow human being. Doing so will foster improved outcomes, even in a strained and fractured system. Small practice changes by physicians will help rebuild the broken trust in the healthcare system and help reestablish the honor physician have lost within Bangladeshi society.\textsuperscript{463}

Physicians should keep in mind that they are dependent upon the patient for their immediate and future incomes.\textsuperscript{464} Without patients, physicians have no one to serve. This scenario may seem absurd in Bangladesh with its enormous population, but given the current state of affairs, as mentioned above, many people simply do not go to a doctor or hospital for lack of resources and a lack of trust. If this continues, physician income will fall, and doctors, especially the best, will leave the system, emigrate, or work solely in private care facilities. If this happens, Bangladeshi healthcare will only worsen.\textsuperscript{465} A shift in perspective is necessary if the doctor and patient care to work together to form a therapeutic relationship that has essentially gone missing in Bangladesh. By being responsive to and welcoming of the patient’s input, her story, the physician embraces care as a partnership and, in doing so, recognizes and maintains the patient’s dignity.
A renewed focus on the therapeutic relationship is required to re-establish a trustworthy patient-physician relationship in Bangladesh. The perspective and ethical behavior of the physicians must change in order to re-establish this broken trust. Physicians must work on their responsiveness to maintain and uphold the patient’s dignity. They must also set greed and self-service aside. Physicians must respect the dignity of the patient if they are to serve with compassion. Physicians in Bangladesh must regain their human touch and hold their oaths dear.

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Bioethics is an independent field of knowledge and expertise. Clinical ethics is a sub-discipline of bioethics, and it is proliferating in North America, Europe, and elsewhere. A clinical ethics consultant’s goal is to analyze and resolve ethical dilemmas and conflicts in health care settings, facilitate a meaningful conversation with the provider and the patient (or family) that recognizes and respects the other’s point of view, and serves to guide the parties to a consensus in the goals of care. Thus, the clinical ethics consultant must understand the narrative, positions, and worldviews of the parties—patients, families, and providers—involved in the conversation. The goal of clinical ethics is to find mutual ground for every stakeholder involved in a case.

The professional conducting clinical ethics counseling is called Medical Ethicist or Clinical Ethicists. They usually perform the four primary functions of clinical ethics:

- Providing ethics education in the clinical settings
- Developing ethics guidelines and policies
- Conducting theoretical and empirical research
- Facilitating clinical ethics consultation

Clinical Ethics Consultation is considered one of the essential aspects of inpatient care, and this requires practice and education. The American Society for Bioethics and Humanities (ASBH) has developed a certification process that requires consultants to sit for and pass their exam. The test is designed to ensure that clinical ethicists are well-trained to impact patient care significantly and positively. The quality of an ethics consultation is assessed against a set of established standards, including the consultant’s ability to solve ethical dilemmas and identify the ethical uncertainties among different stakeholders involved in the case.
Clinical ethics consultation covers a broad but significant role in medicine. Clinical ethical consultants serve at every step of medicine from pediatric ethics counseling to end-of-life ethics counseling. However, there are two areas where clinical ethics faces immense challenges. One is at the end-of-life scenarios, and the other is at genetic counseling. Each of these has specific concerns that need to be addressed and practices that require change. Furthermore, both matters relate to the patient and affect others who are actively involved in the decision-making processes. This chapter is divided into two sections. The first section of this chapter addresses the ethics consultation at the end-of-life. The later section of this chapter outlines the ethical issues related to genetic counseling. The challenges are unique in each case. For example, the challenge in Genetic counseling mostly concern privacy, autonomy, individual good, and the common good. And the challenges in End-of-Life care revolve around autonomy, patient wishes/regrets, overwhelming emotion, and initiating and conducting difficult conversations.

The first section of the chapter addresses the clinical Ethics Consultant’s role in end-of-life care, addresses the challenges they face, and suggests a narrative-based counseling method that will create positive and effective outcomes for all stakeholders involved.

4.1 End-of-Life Care and a Narrative Approach to Difficult Conversations

Death is an integral part of human existence; there is no exception. There, of course, is the urge to postpone death, delete death, and reconcile with death, but we cannot skip our death. Death is the inescapable tragedy of life. Thus, we must learn to accept death and embrace it in the best possible manner. But due to excessive fear about death, we often ignore the living part of death, which allows us to embrace the journey of dying. We cannot control death, but we can manage the dying process. End-of-life care intends to address the dying process, make this experience as comfortable as possible, and tailor the care to support each patient's journey. But to do, it is crucial
to have a conversation that reveals and captures the patients' wishes. Having done this, care providers can honor the wishes of a dying person.\textsuperscript{469}

Medicine has limitations; its power is imperfect; not all patients recover, nor may their well-being be fully restored. Therefore, no medical intervention is justified until it serves the wishes and well-being of the person dying. But death is also not a failure; instead, it is the natural order. However, it is often difficult for the patient to express her wishes and how she wants to approach this final journey. It is the job of the ethics consultants, who are counseling on end-of-life cases, to help the patient articulate her desires and wishes so they can properly be honored.\textsuperscript{470}

This end-of-life conversation is complicated, and this counseling needs extra strengths and attention. There will be tremendous challenges the ethics consultant will face to initiate the conversation and to go through the exchange. A narrative-driven approach to these end-of-life conversations is suggested. A narrative-driven approach guides the ethics consultant to solicit and verify the wishes and hope of the patient. Thus, an ethics consultant can confidently serve the patient through the end-of-life journey. This section of this chapter addresses the challenges of ethics consultants, who are consulting on end-of-life cases, while handling difficult conversations. The section continues by recommending a narrative-based method for facilitating end-of-life conversation. A narrative-based approach helps consultants open a safe space where the patient feels comfortable and is then guided to embrace and participate in these most difficult conversations. Narrative-driven counseling relies on open-ended questions. This approach is designed to have the patient reflect on her experiences, thoughts, and wishes and find the meaning and context behind these expressions. This approach helps the patient tell her story, which, in turn, reveals her worldview. All of this creates a relationship between the ethics consultants and the patients. The consultant helps the patient acknowledge her feelings and desires, engage in the
choice-making necessary to fulfill these wishes, respond to regrets and missed opportunities, confront fears, and keep the patient apprised of available options. In cases where the patient may no longer have decision-making capacity, the consultant involves family, making them aware of end-of-life options and helping to align those with the patient’s wishes. A narrative-based approach is critical for the ethics consultants to serve their role effectively.  

4.1.1 End-of-life Ethical Dilemmas in Medicine

End-of-life is overwhelming for patients, physicians, families, and stakeholders. Death is usually a devastatingly powerfully emotional moment for loved ones. Care providers, too, are often profoundly affected by these experiences. The emotional part of death often overrides the logical thinking processes. End-of-life is an inescapable reality and a powerless moment. But care providers must overcome the challenges present in these moments and, with compassion and care, help the patient embrace this inevitable last journey.

The quotes below come from At the End-of-life: True Stories About How We Die, a collection of stories and interviews conducted with healthcare workers, patients, family members, which presents the views of those tending to patients and those experiencing the end-of-life journey. I offer these quotes because they capture aspects of the emotional and practical challenges apparent during the end-of-life:

In terms of contextualizing the journey and helping overcome the confusion and fears of facing death, a provider helps a patient understand that “there are aspects of healing and death, some we can control and those we cannot.” This quote highlights the uncertainty of death and the limited ability of healthcare providers to control death. This quote, also, reveals the vulnerability of human capacity and submissiveness towards the natural act of death.
Patients and their loved ones also come to grasp their situation more fully when they “know the living will be all right, and the living need to come to terms with letting a loved one go.”

This quotation summarizes the mental state of the patient and patients’ families. The dying patient knows he is dying but is afraid to leave the living. But knowing that friends and loved ones will continue to live is reassuring. On the other hand, loved ones should understand that it is time for the dying patient to pass on; the living must recognize this and, as painful as it may be, not impede or disrupt the process. So often, the living is afraid of a loved one’s death. As a result, they strive to keep the loved one alive by any means, which may be not beneficial, or maybe not respect the dying patient's wishes. Amid the fear and pain of the patients, loved ones become blind to the patient's best interest.

And, as one provider commented, in terms of the power of trusting the patient-provider relationship, the focus should be on the Quality of Life through the end-of-life. “For many patients and physicians their tie, is everything, not the number of our days (remaining) that matters, but the quality.”

This quotation indicates the patient often has a fear of death and wants desperately to live. In these situations, the patient’s tie to the world, to the family, to the physician become more important than wanting to live longer at any cost. During these low points, the physician and the ethics consultant should help the patient embrace the fear of death and help them understand what it means to prolong life in that situation. An ethics consultant can facilitate the conversation of analyzing what Quality of Life means for that patient and help them embrace a death that meets their wishes and is free of suffering and torment. Even in the end, our lives are precious, and the Quality of Life (QOL) matters. The thought here is that it is not how many more days I can survive, or I can keep my loved one alive, but what will be the Quality of Life for myself or my loved one’s life during the time they have left. Knowing the patient’s story, beliefs, and wishes is so important.
Such a story-founded understanding of Quality of Life significantly impacts the decision-making process towards the end-of-life choice makings.

Over the past few decades, views on death have shifted. In some instances, people can choose how and where to die. More commonly, because of the emergence of advanced palliative care, hospice care, and long-term care, patients are increasingly involved in decision-making and choice-making aspects of end-of-life care. As a result, patients are guided by their wishes and supported by care professionals through this last journey, all to enhance and recognize the patient's autonomy and dignity.\textsuperscript{476} Death was once a dark line that always was present, which each waited to cross. While that remains true in many aspects, the advance in end-of-life care now permits patients to more fully participate in the choices and decisions that make the final journey as personal, dignified, and meaningful as possible. Also, more generally, in efforts to extend our time on the living side of the line, the medical advancement of care and the contribution of public health towards continuing to prolong life was unimaginable only a few decades past. Furthermore, with the progress of vaccines, many diseases have been or are nearly eradicated. \textsuperscript{477}

In the 21st century, death is viewed less as an abstract and fearful thing than a subject to avoid altogether. \textsuperscript{478} As a result, contemporary medical practices now routinely offer many care options at the end-of-life. However, neither the patient nor care providers can fully address the end-of-life challenges unless the patient expresses her desires and wishes concerning her passing to the healthcare professional.

4.1.1.1 Death and Dying

Death is evitable but universal. All of us in the universe will die, which will be comprehended differently by different individuals and social constructs. Though death is an
integral part of human existence, a natural fact of life, the attitude towards death doesn’t remain constant. The attitude towards death is changing depending upon the advancement of technology and social changes with centuries.\textsuperscript{479}

Death, though most often out of mind, is with us consistently. We all know we will die but pay little heed to its constant presence. We each are living-towards-death, in the face of death. It is essential to understand death via the lens of history, society, and culture to understand how humans’ approach and accept death.\textsuperscript{480}

German sociologist Norbert Elias noted: “Death is the problem of the living. Dead people have no problems. Of the many creatures on this earth that die, it is human beings alone for whom dying is a problem. They alone of all living beings know that they shall die; they alone can anticipate their own end. It is not actually death, but the knowledge of death, that creates problems for human beings.”\textsuperscript{481}

In early primitive societies, rudimentary medical practices and inadequate structural support made people view death as a natural process. Death was seen as a transition from one state of life to another. Thus, during those times, pre-death rituals and funeral practices were designed in ways that integrated with their notion of death—as a journey to another world.\textsuperscript{482} Nowadays, some religions and schools of thought continue to believe that death is a transition from one life to another. Yet, unlike earlier eras which believed the dead could linger and influence the living, the current burial and funeral process are generally free of the supernatural and remnant spirit dimensions—though what remains is the general belief of transition to another life. Therefore, until the most recent times, most people were terrified of death and constructed funeral rituals to honor the dead, overcome these trepidations, and ensure a safe passage to the next world so the dead would not come back to haunt the living.\textsuperscript{483}
Gradually with time and social change, the meaning of death shifted. An abrupt change occurred in the 18th Century in how death was viewed, especially in Western culture. Up until then, the notion of death was focused on the dying person. The genuine concern circled the dying person. Family and loved ones were often invited to witness the death, the dying episode. During the 18th century, the attitude towards death shifted, and a term arose, capturing these beliefs, "thy death." It was understood as the period of the "beautiful death," as noted by French historian Philippe Ariès. Death became seen as an act of art, love, and emotion. In the 18th Century, death became a time of reconnection, full of overwhelming emotions. Friends, neighbors, family members, and near-and-dear ones began to gather around the dying person not to witness the dying process but to mourn it. Moreover, particularly in the West, the 18th century was considered a century of mourning. One example of this is that more families begin to bury their loved ones on their property or in community graveyards, a tradition that continues widely in the West. The intent was to live with the dead and revisit the journey with those gone. This practice opened the pathway of reconnecting the dead and the living—a different type reverent bonding.

By the late 19th century, the attitude towards death began to shift again with the social constructs. And by the 20th and 21st centuries, Western attitudes toward death were influenced by medical advancement, new technologies, and science. In the 21st century, death is no longer a shadow event; it has become more scientific and more predictable. Death is currently considered a “Spectacular Death”—a period in which death, dying, and mourning have increasingly become spectacles among the living. Spectacular death is viewed as an experience, constructed, and conducted as a lived experience. This time allows the living to observe the death from a safe distance with allure and detestation. It is a time in which society developed an obsessive interest in death and the dying process. This spectacular death allows people to witness death at a safe
distance with equal parts of fascination and abhorrence. Palliative care is a result of this period of spectacular death. People became aware of the context of dying, how they want to die by keeping their families informed and making their own choices.485

During the late 20th century, a “death awareness movement” or “death with dignity movement” began. People, in general, began to believe that greater emphasis should be given to death and dying, embracing that this was the end-of-life for a person, an individual. It became essential to serve the dying person in the best possible manner in their desired way.486 Although medicine managed to bring a positive attitude towards death and to die in this century, the care providers still face multiple challenges in end-of-life care. The challenges are multi-dimensional and multi-layered. Some arise from the provider’s side; some from the patient’s, some from the patient’s family’s side. The situation’s complexity and/or ambiguity arise because there are often multiple participants, inputs, and guidelines involved, thus, making the case a multi-layered challenge. Adroitly balancing and responding to these challenges make the end-of-life care conversation most challenging and delicate.

4.1.1.2 The Difficult Conversation

People are hesitant to have end-of-life conversations about care goals because it makes them nervous and uncomfortable. Some people also think that talking about death will bring death closer to them, so they try to avoid this tough conversation and want to live long. The denial of this complex conversation is more frequent among patients with chronic illness or life-threatening conditions. Also, the barrier to having this difficult conversation is not always incurred on the patient’s side. Sometimes, the care providers are hesitant to bring up this difficult conversation with a severely ill patient. Doing so makes the care providers feel like they might remind the patients that they are approaching death soon. More particularly, from the care providers' side,
they face two sets of barriers (1) patients are not sick enough that the care providers can bring up the conversation about the end-of-life care goals, and (2) the care provider’s impression is that the patient is not ready to discuss end-of-life goals of care.\textsuperscript{487}

The hesitance of having end-of-life goals of care conversation is even more restricted among the non-white and minority patients than white patients. A study conducted among white and non-white AIDS patients concluded that the non-white, minority group of patients are more hesitant to have a death-and-dying conversation.\textsuperscript{488} The primary reason for such hesitancy among this population rests on cultural and normative practices. Many non-white minorities come from countries, cultures, and traditions that do not have advanced in end-of-life care. Often, they are not familiar with the ideas and terms presented and used by end-of care providers. They think that by initiating a conversation about death and dying, they embrace death and welcome it earlier than it is supposed to come. This hesitancy generally occurs because of a lack of knowledge about end-of-life care and little or no exposure to such care. In addition, due to cultural and religious values, end-of-life care is seen and embraced quite differently by different people.\textsuperscript{489}

Death and dying are complex biological facts. One of the main reasons for this dilemma is the lack of understanding that biomedical knowledge—the physical body—has a lot to do with cultural phenomena. What must be embraced, or perhaps reembraced, are the cultural and personal beliefs and wishes surrounding death and dying. Too often, the focus is on maintaining life, healing the physical wound, and reducing the physical pain.\textsuperscript{490} Thus, the personal and social components become ancillary. A critical point to understand while giving care is that relying on only the physical body, or the medical facts is insufficient. Care must also include the patient's cultural and personal components into the process—holistic care. Our physical body is very
closely related to the mental state of mind and our surroundings, which is shaped by our culture and norms. 491

We live in the era of patient autonomy. And if we want to make sure that we are honoring a patient's autonomy, one way to do this is by understanding and respecting their end-of-life wishes and concerns. But this is very challenging. Patients experiencing an end-of-life situation are very sacred, and each person approaches death differently. Those giving care should be strongly encouraged and adequately trained to respond to and respect the dying patient's wishes. Yet fully addressing autonomy remains a challenge for end-of-life care.

Thus, in providing end-of-life care, the providers face immense challenges to initiate this difficult conversation because of the current emphasis on patient autonomy. To mitigate this challenge and to facilitate the difficult conversation, we need the presence of ethics consultants. Ethics consultants come from a neutral perspective and try to understand the patient and open the space for the care provider to jump into the difficult conversation. Ethics consultants' job is to create rapport, build trust, and generate a dialogue that fully considers the patient's wishes and the physician's responsibility towards the patient.

4.1.2 A Narrative-driven End-of-life Clinical Counseling

Each experience is different at the end-of-life. Some patients remain strong; some cannot. Some are emotionally unstable; some have cognitive impairments. Nevertheless, the goal of end-of-life care is to satisfy the patient's wishes in the best possible way that aligns with the medical code of conduct. End-of-life care makes sure the patient is physically comfortable, their mental needs are fulfilled, the spiritual needs are taken care of, and, finally, the practical tasks are done correctly and according to the patient and family wishes. 492
It must be kept in mind that a life-limiting illness is not a single event. Illness is often a process, a series of events. For example, patients can move from the initial stage, become increasingly ill, and die. Or other pathways are the patient regains health or the illness becomes chronic. In each of these scenarios, but most especially in terminal situations, practitioners undertake life-prolonging interventions which keep the patient alive but do not necessarily consider the patient's quality of life. So, there is a need for ongoing and effective communication with the patient. Such communication is the cornerstone of end-of-life care. These are challenging conversations, especially the initial ones because they revolve around addressing emotional concerns for the patient and patient’s family; bad news is not easy to deliver or to hear. However, there is no reasonable alternative to having the initial or ongoing conversation if we want to make sure the patient’s wishes are respected and follow through. There is nothing more human to help a person take her last breath, knowing her wishes would have been followed and respected. We all have a desire for a good death, and a good death is the one that occurs according to the expectation and wishes of the dying. However, to have an effective and less stressful conversation, clinical counselors need to have a better approach to the dying process, appreciating that dying is unique for each patient. And once they have embraced this notion, the application of Narrative Authority can assist them with both the approach and tools to have, hold, and follow through on the wishes these difficult conversations reveal.

4.1.2.1 Experience of the Dying Process

Death is a difficult transition for anyone to undergo. To provide an individual transition, the interprofessional team of care providers needs to know the individual nature of each death or dying process. Understanding a person's perspective on the experience of dying allows the care provider to handle the patient better. Dr. Elizabeth Kubler-Ross, in her book, *Death and Dying*,
introduced five stages of responding to the death of a loved one: Denial, Anger, Bargaining, Depression, and Acceptance (DABDA).\textsuperscript{494} It is helpful to understand these stages. Each depicts a representative, recognizable step in the death and dying is a process. These steps can provide a guide that assists the provider, patient, and family in confronting and responding to the emotional and personal challenges that occur with the terminal illness. Of course, not all patients experience these stages precisely, as outlined by Kubler-Ross. Each death is unique.\textsuperscript{495} However, knowing the progression and commonality of these stages serve as important demarcation points for the caregiver tending to an end-of-life patient.

Denial is a defensive mechanism that helps oneself protect from facing, confronting, and accepting the reality of the hardship at hand. Patients usually start with denial when they sense that bad news is coming. They try to deny the prognosis that will lead to death. The terminally ill often struggle to accept this difficult new reality.\textsuperscript{496} When denial occurs, it is essential to be empathetic and understand the patient's inability to confront the news at this point entirely. But the goal is to find the care that best aligns with the patient's wishes, even if those have yet to be articulated by the patient. The clinical counselor needs to continue re-educating the patient and facilitating a deeper conversation concerning the pathways emerging for the patient. Of course, the prominent reason for denial is that it is a very effective coping mechanism. This is a temporary defense mechanism which is usually replaced by a partial acceptance of the circumstances.\textsuperscript{497} However, one way to shorten this phase and support the patient is to ensure there is adequate knowledge about end-of-life care. With access to end-of-life care, the patient will find a partner, the ethics consultant, when addressing the travails at hand. While this may not eliminate the denial, access to or knowledge of end-of-life options can serve as a balm for the sense of fear and rejection at
hand. Ideally, there should be institutional education widely available to educate the general population about end-of-life care and the importance for one to participate in the process. Anger is the death and dying process stage that terminally ill patients often confront. First, a patient becomes angry at the providers for their limitations and inability to fight and cure the disease. Next, a patient can become angry with the family for not protecting the patient or allowing the illness to occur. Finally, the patient may get angry at higher powers, angry with God, for doing this to him or her. This stage is more difficult than the denial stage because during this stage it is often very difficult to control the patient’s emotions. When patients begin to question why this is happening, they reveal that grief plays a more active role in their anger. At this stage, the frustration the patient experiences with her plight can manifest as general anger, being short-tempered, or lashing out at others. Anger is a natural process, and a care provider must understand this and carefully and empathetically guide the patient through this stage of death and dying. At this stage, when the patient is expressing anger in any of its forms, the care provider should slow down and approach the patient, and perhaps be more welcoming to engaging in a difficult conversation.

Bargaining is the stage when the patient tries to establish their authority over their body. They try to deny the care providers' and others' contributions and suggestions. And as a result, they try to impose their understanding of the medical prognosis based on their social, cultural, and religious norms and practices. Patients try to undo the reality in this stage. This is kind of a situation we encounter when we deal with little children. In this stage, the patient might reject others, but they will also have second thoughts about the reality of the situation. Therefore, it is crucial to correct the bargaining behaviors. This is when it is essential to understand that care is not to cure but to heal, and it is a holistic process linked to multiple dimensions and components of life. First,
however, the caregiver must recognize that the patient still needs space. Too much pressure will only stimy the progression the patient must face. So the most thoughtful way to handle this is to go slow and try to rebuild the connection not by focusing on the illness but on the wishes, beliefs, fears, and hopes—the story—of the individual.

**Depression** is the stage that generally occurs after the three earlier stages have passed. The time spent in the first three stages is a constant attempt to protect oneself from emotional pain and the reality of the situation. In this Depression stage, patients are in a morass; they are frustrated and lost in the condition they find themselves in. The earlier attempts to stave off the reality of their plight have failed. In the usual sense, care providers try to offer encouragement and reassurances to the patients in this stage. But often, this proves to be more devastating. The patients should not be encouraged or pushed to embrace life's bright side in this challenging period. The patients should be allowed to express their deep wounds, scars, and sorrow, and thus they will move on the phrase of acceptance.

In this stage, the care provider’s goal is to offer compassion. Now, the care provider’s goal is to offer compassion. But in addition, the provider must help the patient establish a stable state of mind from which she is in a better position to hear and process the information necessary to address the end-of-life decisions that need to be made. Compassion is the way of building trust. Trust-building by the care provider at this stage is essential. Compassion also leads the way to the care path because it recognizes and upholds patients’ dignity at a critical time. Thus, the patient comes to realize that their words are valued and respected. Clinical ethics consultants can facilitate the conversations that lead towards compassion. And they also need to show this compassion in their words and actions. The patient must see that the ethics consultants understand the patient's concerns and predicament. The consultant must help the patient understand it is
acceptable and healthy to embrace their feelings, fears, and sense of lostness. This compassion demonstrated by the caregiver will reshape how the patient views her world. These actions will re-establish trust in the providers and ease the heavy sense of depression.

Acceptance is the final stage when the patient ceases struggling and fighting against the situation. At this stage, patients begin to reflect upon and prepare themselves for death. In this stage, the patient understands the frustration is not fruitful, and it is time to accept that life is coming to an end, embracing the end in terms that provide comfort, peace, and dignity. Acceptance is a necessary stage. With acceptance comes a renewed sense of identity and control. During this stage, healing occurs. And the healing is advanced as the end-of-life counselor helps the patient by articulating her end-of-life wishes, then acts, as best as she might, to ensure those are met.

Understanding these stage-by-stage steps is vital as the end-of-life care providers begin to care for terminally ill patients. Each stage has its unique set of challenges. It is essential to display compassion and empathy to and for the patient during each process stage. Not every patient will fully experience the steps described above. But the goal of the end-of-life counselor is to understand the stages and be able to adroitly respond to the present situation, knowing what's next to come.

4.1.2.2 A Narrative driven Approach to the Difficult Conversation

There are different ways to address the end-of-life challenges, but one of the best ways to approach this difficult conversation is to understand the stakeholder’s narrative. The narrative approach moves from direct problem-solving to discourse-oriented, open-ended means of communication as a pathway to initiate a difficult end-of-life conversation. The goal is to have the
patient feel comfortable, express her concerns and beliefs, and in so doing, avoid being directive. It means ethics consultants must build the skills to solicit perspectives, fears, and hopes apparent in every patient’s story. Ethics Consultants who deal will end-of-life cases, in this approach, create a connection to the ongoing patient narrative, which arises from the past and is applied to shape the future. By being attuned to the patient’s story, the clinical ethics counselors can create a mutual promise, a covenant. A covenant is when we embrace and make a promise or deep commitment to someone; to share in their plight. Thus, the ethics consultant’s obligation is to step into the moment, take on the difficulty of the end-of-life conversation, and support the patient as she come to terms with the meaning and significance of such a discussion. To facilitate the execution of this covenant and to insert the power of open-ended conversation in the patient-provider relationship, the recommendation encourages caregivers to embrace Narrative Authority, and, in terms of end-of-life counseling, particularly the second component of Narrative Authority—Storied Hearing (attention to).

**Storied Hearing** is the act of giving 'mindful attention' to patients. Storied Hearing requires a care provider to mute the temptation to assess or prejudge a patient by concentrating on the patient's story. It is listening to understand what the patient is attempting to convey and catch sight of what more is to be heard or is unspoken in the patient's telling. Storied Hearing attempts to create a space in which the other feels seen, respected, and made comfortable enough to share her story, her wishes, and desires. One of the most challenging parts of an end-of-life conversation is opening the conversation. To open the conversation, you need to know where the patient is. Asking a direct question about death and dying can have the patient feel uncomfortable or self-conscious. As a result, the patient might become more resistant or hesitant to answer
honestly or with detail. Storied Hearing helps the clinical ethics counselors to solicit and ‘hear’ what a patient wishes, desires, hopes, and intends.  513

A suffering patient often cannot express her feelings or experience clearly in the face of the distressful condition. Similarly, a physician under time constraints or care mandates, which can conflict with a patient's wishes, tends to push a patient to discuss topics she is not yet ready to discuss. It is a patient's wishes vs. medical priorities situation, and the caregiver is pressed to offer the patient the proper support and direction. Yet, an ethics consultant must gather as much information possible from both parties. Storied Hearing helps to bring out the unspoken information, the discomforts, the anxieties, and the fears. The foremost concern of this narrative-driven approach is to ensure that the provider and patient are comfortable and trusting enough both to speak without fear of judgment or rejection.

Storied Hearing encourages ‘close reading.’  514 Through skillful, close reading practices, it is possible to capture the patient’s narrative which reveals the patient’s wishes and values, regardless of the patient’s decision-making capacity.  515 Close reading, in these situations, reveals the story, and the patient’s intent, even though the haziness, dryness, enigmatic nature, and the unspoken tone of the story.  516 The goal is to create a safe space where a patients can feel that she exists beyond the illness, that she is a human who is being seen as such, not as a disease or condition. The ethics consultant must make certain a patient can see a ‘non-medical’ part of their existence, which is less connected with the illness and more connected with their lives: family, friends, and loved ones. The safe space Storied Hearing supports a genuine bond between the care providers and the patient. This counseling strategy during end-of-life helps avoid conflict between parties and facilitates something like a partnership working towards a common goal. such
conversations will include discussion about uncomfortable topics, but the discussion works not to make anyone uncomfortable because of the trust and respect built through in the relationship.\textsuperscript{517}

Although the Storied Hearing component is a vital tool in this end-of-life discussion, all the features of Narrative Authority are useful and fully integrated in strategic and practical ways. And the full breadth of Narrative Authority applies to Narrative Clinical counseling. Therefore, the applications detailed in Chapter 2 of this dissertation about Narrative Authority are widely applicable during Narrative Counseling. Narrative Authority will guide ethics consultants to welcome, embrace, and honor the differing worldviews of the patients and patients' families at the end-of-life care.

Below are some essential components for Narrative end-of-life counseling—

- Interpreting the unspoken words, gestures, facial expressions, body postures, and even silences that are apparent in the conversation.\textsuperscript{518} Thus, the ethics consultant can earn the trust of the patient and can dig deep into the end-of-life goals of care. During the conversation, specific rules should be followed and revised. Every word used during the discussion should show compassion and should be non-judgmental. It is highly encouraged to practice the word before you say or use them—“eyes on the prize”.\textsuperscript{519}

- Knowing when to call for a time-out can prove to be a positive game-changer for ethics consultants who deal with end-of-life issues. Frustration, anger, and bargaining are common during an end-of-life conversation. While patients go through these stages, consultants or care providers sometimes need to initiate a break in the conversation to maintain to ensure the situation does not entirely derail.\textsuperscript{520} Calling a time-out provides the opportunity to stop, relax, and think through the issues. Rather than escalating a

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stressful situation, it is prudent to pause then come back later with more positive energy to restart the difficult conversation.

- It is critical to display professional, not personal disagreement, in tense situations. The patient may show disappointment. Ethics consultants must not take this personally and understand this conflict that is at the professional level. That disappointment might be the only outcome for the day, but that needs to be counted because dissatisfaction by the patients matters even if that is not logically right. In these situations, compassion is the key to ongoing and future success.

- Even though no mistake has been made, saying "I'm Sorry" is also a critical practice. Clinical counselors should be ready to say "I'm sorry" even though the tense situation is not their fault. The counselor should never forget the intent is to guide the patient to come to a consensus about the care goals. Saying "I'm sorry" or taking the blame is an expression of empathy. Such admissions go a long way to defusing an explosive situation, building trust, and getting a discussion back in working order. Again, even though no mistake was made from the ethics consultant’s end, the consultant should recognize the impasse and acknowledge the patient's frustration. The goal is to keep the patient feeling comfortable. Often, a simple "I'm sorry" accomplishes this task. Owning the disappointment often has the patients feel heard and loved. When we share sorrow, we earn the right to hold the joy and sense it as an act of love.

- Redesigning the traditional mindset is another tool to be called upon. This might also be termed “Say much, do much” as a practical approach to follow amid a difficult conversation. This attitude runs counter to an often familiar “say little, do much” approach. The ethics consultant should “say much” because words matter at that time.
This time is often the most emotional moment in anyone’s life. Words can change the moment; words can heal. The power of words supersedes many other acts for dying patients. Words help to calm down the fear of dying or the fear of the unknown.523

- Asking a miracle question to the dying patient. The miracle question helps a patient articulate feelings and beliefs and, as a result, engage in a meaningful discussion. The miracle questions come from addressing hope. No matter what it is, there is always a place to discuss hope. The hope offers the most tremendous confidence. 524 Asking a patient to articulate what a miracle or hope may be, can positively change a patient’s engagement in the care process. In addition, the answer offered provides the opportunity to define a clearer direction for the care goal. For example, the question could be as simple as, “If a miracle happened during the night and XYZ (freedom from discomfort/open communications/conflict resolution) were to resolve, what would that look like? What would be different?” 525

Below are recommendations to help to facilitate further a meaningful and effective conversation between all those involved in the end-of-life discussion.

- Begin the conversation as early in the process as possible. A delay in starting a difficult conversation will bring more complexity. It is better to start the conversation when the patient is healthy. 526 This is often difficult to implement because the patient does not want to confront the situation, often even when death is very near. However, there are different advance care recourses, such as living will and durable power of attorney, which prompt these discussions long before the time of need.527.

- Identify the patient’s goal and the physician’s concern before meeting the patient. The patient’s goals can be identified from her social history or the medical chart.528 Doing so
will better prepare the counselor to know what or what not to ask the patient; the
counselor will have a much better understanding of the patient's worldview. The more
we know about the patient, the more we can catch sight of her story without prejudging
the situation, the more likely it is that the end-of-life conversation will unfold in
meaningful ways. Ways that have the patient feel seen, appreciated, and understood.

Each of us wishes for a good death—a death, given the choice, that happens as I expected.
In the 21st century, even though we can better predict or control death than ever before, death as
of yet cannot be avoided. Yet we can often control the means of engagement with our end. We
often can choose how to die and where to die. These wishes can be well managed and facilitated
when the patient clearly conveys and shares them with the care provider. However, often collecting
this information requires a difficult conversation because the issue of death has been avoided until
the point of need. It is the ethics consultants duty who deals with end-of-life cases to engage in
this conversation, solicit these details, and do so in a manner as compassionate as possible. End-
of-life care is heavily dependent on honest and trustworthy communication. Such communication
most often determines the achieving of end-of-life wishes. Furthermore, these difficult
conversations are crucial throughout the treatment trajectory. These conversations help ensure the
care goals are consistently and primarily based on the patient's preferences. The purpose of the
ethics consultant is to facilitate discussions of the most challenging type, to generate patient’s
active participation in the care process, and involve the family, as warranted, to facilitate decisions
that minimize end-of-life distress for all parties. By following the pathway of narrative and
storytelling, it becomes easier and effective to engage in such difficult conversations while having
the patient feel a seen, understood, respected, and trustworthy partner in the care plan.
4.2 Genetic Counseling and Associated Challenges

One of the significant historical breakthroughs in medical science, Genomics, can decipher the mysteries of both confounding and common diseases. Genomics has catapulted medicine into a new era. The benefits genomics provides are remarkable, and they will continue to grow and influence both medical and community perspectives. Genomics will soon become mainstream within most medical practices. The ready availability and the growing effects of genetic data have created confusion and tension among the patient, physician, and at-large community. The genetic counselors now should explain the broader social benefit genomics provides. Doing so presents participation in the data collection process as a social obligation. Adding this component by nature demands the current notion of informed consent to be re-narrated. This section of this chapter addresses the challenges associated with genetic counseling and prescribes a narrative-based, open-ended, not-knowing approach to ethical issues related to genetic counseling genetics counseling: Narrative Partnership. A narrative partnership is required for the patients to understand the genetic treatments.

Also, it is crucial to understand that the blessings of genetic treatments depend on ongoing genetic research, which is contingent on individual participation in the treatment and research. Genes are complex and have a tremendous influence on health and wellbeing; therefore, in-depth research is required to identify new therapies. However, people are often hesitant to share their genetic data because they don't understand the issues or feel that giving their samples is an invasion or sharing what they consider private. If patients do not understand the near and long-term importance of genetic research, including the necessity for and safety of data sharing, the advance of future treatments will be significantly retarded. The application of Narrative Authority serves
to engage patients to identify their connection to community health and the ethical responsibilities when a patient participates in such research.

4.2.1. Data-sharing Consensus and the Consent Process in Genetic Counseling

The advancement of genomics and biomedical research has changed the face of medicine. In many ways, genomics offers astounding insights and remedies that can still seem like science fiction. Innovations in genome sequencing open many doors to a transformative genetic revolution in healthcare. Genetics, ever more frequently, expands the field towards the reality of human cloning. Following the success of *Dolly the Sheep*, Chinese scientists have recently applied the technology to primates and have produced two monkeys clones: *Hua Hua* and *Zhong Zhong*. We now enter an uncharted and unknown future; can the first human cloning be next?^^530^.

In fact, it is now possible to treat many genetic disorders by sequencing the entire genome. Genetics offers new and revolutionary ways to treat cancer, infectious diseases, and many common, complex diseases like prostate and breast cancers. Genomics further offers methods that more accurately identify and predict the risk of common diseases—diseases individuals might face or diseases that might “run in their families.” Knowing this information, in many cases, helps an individual confront the anxiety associated with the unknown and, in turn, plan and make informed life choices.^^531^.

Yet this success remains predicated on the willingness of donors from different backgrounds to provide tissues and blood samples for biomedical analysis. Genetic counselors play a vital role in helping people understand the importance of genomics; genetic counselors can educate patients so that they come to see the benefits of genomics and provide insights as to how these benefits intersect with a patient’s narrative.^^532^.
4.2.1.1 Challenges of Genomics on Individual, Organizational, and Social Context

Genomics has helped increase the life expectancy, and it serves to ensure a healthier society. Thus, genomics opens opportunities to improve society at large. However, genomics has also created concerns and stirred controversy. For instance, people who do not understand genomics or the benefits of the revolution at hand exacerbate the confusion around these concerns. These concerns are seen in three primary areas: Individuals and families, healthcare professionals, and society and social institutions.

The individual and family concerns are related to confidentiality and autonomy. For healthcare professionals, the challenge revolves around informed consent and ensuring that adequate information is provided to patients and their relatives. It is also a challenge for a healthcare professional who must decide whether to share a patient’s genetic data, which could influence the welfare of relatives who share like genes. Beyond patient confidentiality, professionals also have an obligation to society, guided by the “do no harm principle.” Social concerns center mainly on the security of big data and the accessibility of this data to researchers.

Apart from that, genomics has also created concerns about allocating resources. It has raised a critical question: at what level or for whom should genetic testing be made available? Should it only be for the privileged, or should the resource become available to everyone? How should public and private dollars be allocated for genomic research? What are the guides for such allocations? For instance, a proper and unbiased risk-benefit analysis could identify where and how to allocate funds. And in a social context, the development and advance of genetics provide each of us the opportunity to embrace the collective role and obligation to contribute to improving healthcare which in turn supports healthier citizens, healthier communities and enhances, equity, liberty, and justice of all.
The possibility of genetic enhancements, for instance, the selection of traits ranging from eye color to height and body build to disease protection, reveals many social challenges that arise from genomics. However, one of the criticisms and worriers of biomedical enhancement is that clinicians who perform these acts as God. However, biomedical enhancement is merely trying to improve life and well-being by biomedical means. The efforts are targeted to enhance a particular capacity or prevent incapacity. A solid argument against genetic enhancement arises because genetic changes are irreversible. What matters are the health benefits had by helping some live better or avoid the pitfalls of congenital anomalies. The genetic intervention serves to prevent ‘irrevocable, self-replicating mistakes.’ Yet these challenges and concerns can be turned into strengths by ensuring that society readily understands the importance of genetic enhancements. We should embrace the challenges and proceed in ethical and constructive ways. Improving a patient’s condition by genetic enhancement does not necessarily represent injustice, nor should it have been imagined as such. The critics’ false assumptions and faulty metaphors clutter pathways forward and retard actual scientific advancement. There is nothing wrong with pursuing perfection if it is possible without willfully or strategically harming others.

Therefore, clinical genetic counseling must provide genetic information and honestly answer any questions patients may have about genetic enhancements. An essential aspect of the counseling is highlighting the social, communal, participatory benefits that genomics offers. If we consistently alter the environment to suit our culture, practices, and surroundings, why not human biology for the good of all? We have already crossed the threshold of genetic enhancement in minor and significant ways—from altering one gene to cloning: there is no turning back.
4.2.1.2 The Tradeoffs Between Utility and Data-sharing in Genetic Research

Most private and public healthcare and research organizations clearly understand the importance of securely sharing data and are, in turn, building and refining processes and procedures to ensure the free flow of data. For instance, the National Institute for Health (NIH) specified in 2015 that genomic data generated through NIH funding are required to be shared publicly for the promotion and translation of genomic research. The Personal Genome Project (PGP)—a coalition of projects across the world dedicated to creating public genome, health, and trait data—encourages volunteers to share genomic information for the greater good.540

Besides data sharing, all these organizations ensure that data holders' rights are preserved and respected, and their privacy is maintained. Each follow approved and required methods for compliance, data transfer agreement, nonidentification, information hiding, partial information sharing, and other similar criteria. Yet, even with these solid and determined efforts to ensure anonymity, privacy advocates often question and challenge the sharing of genetic data. That said, gene sequencing is very private and fundamentally intimate; it carries genetic markers that identify a specific individual unless, of course, one happens to be an identical twin.541 Countering strict privacy advocates are others who contend the advancement of genomics has reshaped the idea of and definition of privacy itself. From that perspective, it is essential to understand privacy to include a social and communal aspect. Of course, society has a broader duty to protect the privacy of the individuals, but the individuals simultaneously should understand their responsibility to the society.542

A primary reason patients and the public do not participate in the sharing of genomic data is twofold: (1) the lack of knowledge that genomics even exists and (2) not clearly understanding the fundamental purpose of genomics research and how it is used in healthcare and public
A defined means and consistent approach that provides clear explanations of the benefits of data donation would go a long way to dispel people’s fears and help the public more readily understand the purpose and reasons for collecting and sharing genomic data. Therefore, the field would benefit broadly from prominent and influential organizations collectively signaling the importance of genetic data sharing. This messaging to the public should emphasize the significance of social engagement and how everyone can help the field grow and, in turn, support and serve those in need. This educational and collective social message aims to clarify misconceptions about genomic testing and research. This effort should seek to bring genomics into the mainstream and, thus, have the public become comfortable with and committed to data donation and data sharing. One further goal is to have a donor see how the benefit of genomics intersects and complements her beliefs and concerns which reveal themselves in her story.

However, reciprocity remains a concern for data sharing. Addressing this concern is a must. Individuals who allow their data to be in public most often expect something in return for their sacrifice that could benefit them. For instance, when a donor shares her data, she then, in return, might call for reciprocity. But, since she is sharing her personal information, what should she receive in return? However, a donor should never forget that data sharing is not a one-way street that serves only society broadly. The collection of data may help the donor with her near and long-term health and well-being because it will be her genetic information which may be used for her future diseases. Therefore, when a patient consents to share her data, she should do so, understanding the reciprocal benefits of this sharing, including the fact that genomics data sharing serves the greater global good and benefits all, patient included. If the field of genomics is to flourish, a revised and expanded social contract must be articulated, which reinforces and extends the principle of the common good and solidarity.
This understanding of the common good is essential because we live in an era of globalization; the healthcare system interconnects in ways that have transformed traditional notions of local and far. Thus, no single country or region can ethically or practically practice, implement, or control the benefits of the gnomonic by and for itself. Genomics and its subsequent social benefits require and depend upon the combined contributions and the open and ethical exchange of data. Genetic research intends to improve human health and well-being. Without broad databases of genomic information and the free and ethical sharing data instantiation, this intent will be thwarted.\textsuperscript{548}

\subsection*{4.2.1.3 Challenges of Traditional Informed Consent in Clinical Practices}

The complexity of genetic information has challenged the concepts of adequate information and well-informed consent. Currently, there is no universal consensus on what determines or what suffices for insufficient information or sufficient information.\textsuperscript{549} The very complex nature of genomics is a sophisticated and sequential process. Consequently, it is often difficult for a layperson to understand the whole process sufficiently. For example, environmental factors introduce confusion or uncertainty in the expressions of genetic diseases. Also, it is difficult for a patient to comprehend the scope and nuances of the choices offered in the consent.\textsuperscript{550}

The first challenge to traditional informed consent is “shared information.” The primary concern of treatment procedures is the patient’s health, welfare, and best interest. This perspective gave rise to the informed consent process, which serves to make sure that the autonomy of the patient is protected.\textsuperscript{551} Genetic information is not solely confined to the patient, unlike other diseases or treatment procedures. A genetic diagnosis process is gene-based and, thus, reveals insights into the individual and all those who share her genes. Therefore, a diagnosis to the patient also may directly affect others related to the patient. Genetics challenges the “I Inform/You
Inform” consent standard. In this new arena, informed consent in terms of a collective “We.” Genomic medicine introduces the obligation to inform others, especially when the disease can pass one generation to the next.552

Secondly, genetics challenge the perceived flaws of the traditional informed consent that revolve around cultural sensitivity. There were calls to abandon informed consent even before the genetics era, contending it does not protect the patient because the notion of informed consent is generated by authorities in power (physician or researchers) and is assumed to be universal. Furthermore, in many instances, informed consent fails to consider a patient as a social being whose identity and values are constructed by social relationships. These social values shape the fears, concerns, and questions associated with a disease.553 When considering genetics, these issues often become more complicated because genetics correlate with ethnicity and race. Often the social and cultural context of the individual is overlooked or assumed in gaining informed consent.554

“The subjective substantial disclosure rule” used in the United States is an excellent example to overcome the two primary reasons for the failure of the traditional informed consent. This rule indicates, “adequate information is information that would be material or important to the decision of this particular patient in this circumstance.” Therefore, the question remains, what if the patient’s situation changes? Does the rule change according to the person’s need?555

Thirdly, another drawback of traditional informed consent is that it is mainly considered a single-episode occurrence. However, the diagnosis and treatment are not a particular episode in genetics. As such, the physician must provide information concerning the long-term nature of the process and gain consent from that basis of understanding. The patient must know consent is not a one-time, ask-and-answer process.556 Genetic testing requires multiple settings in many cases because the first test results determine the way forward.557
Therefore, in an era of genomics, a new informed consent procedure must be devised that contains renewal and re-consultation. Standard informed consent is not well suited for genetic treatment for numerous reasons. Therefore, ethically we must re-see and re-design traditional informed consent.\textsuperscript{558}

In a nutshell, traditional informed consent faces multiple challenges when applied to genetic treatment. To ensure that informed consent reflects the complexity and nuance of the intricate dynamics of genomics, genetic counselors must rework and strengthen the consent method and process. The most important part is communication, in which the genetic counselor must play an active role. It is clear changes need to be made to informed consent forms; however, the primary responsibility rests on the ability and commitment of counselors to communicate the process to patients. Therefore, sharpening the precision of communication is an essential ethical concern in genetics, which is the duty of the genetic counselor.

4.2.2 An Open-ended and Not knowing and Narrative-based Counseling

We live in a time Genomics Era. As required, genomic data are shared more than ever before. However, to reap the benefits of genomic testing requires an extensive set of sequencing data, which, given the explosion of genomic testing technology, is evermore at hand.\textsuperscript{559} Practitioners and educators should remember that genomic medicine, in the best case, operates for and by the common interest; therefore, the open exchange of and access to genomic information is fundamental to the growth of this new method of healthcare.\textsuperscript{560} However, while sharing information, we should remember that genetic information ties to a particular individual and that individuals’ privacy must be vigorously protected. As people are asked to embrace the promises of genomics, similarly, they have the expectation of their privacy.\textsuperscript{561} It will be the duty of the
genetic counselors to facilitate conversations to make the general people or patients understand the norms, benefits, and blessings of genomics.

This section overviews solutions to safeguard the sharing of genomic data. Genetic counselors must make patients and participants appreciate that none of us are isolated and radically autonomous; instead, we are beings who live in reciprocal relationships with one another, bound by narrative, norms, and shared meaning. Narrative Authority will help genetic counselors facilitate a conversation with patients to help them (1) understand the importance of genetic treatments, (2) our human nature of connectedness, and (3) provide tools to respond to the responsibility of giving care to the other.

4.2.2.1 Privacy by Anonymity in Clinical Treatment

Genetics is the most personal and intimate depiction of an individual’s identity. What could be more unique than the sequencing, long-term storage, and ongoing use of an individual’s genome? Therefore, if the anonymity of the data is not protected, the promise of collective and individual privacy is violated, and the social contract is, in turn, broken. The challenge of multiple databases and many points of access—the interconnected public domain data repositories and numerous and ever-growing social media databases—is to ensure privacy and anonymity.562

Because of these numerous and diverse databases, it can be straightforward to identify or cross-reference an individual. Even with improvements in and focus upon security, the advancement of biotechnology requires and depends upon data sharing through mobile apps, fitness trackers, and social media. Unfortunately, these apps and devices remain non-secure and easily hacked because of flaws in the devices and faulty software design. Since genomic data are
traded and exchanged on the Internet, we should assume that once the data are accessed by one, it is shared by all.

Therefore, an essential concern of patients is anonymity. The focus must be on safeguarding patient anonymity and guaranteeing shared data is unidentifiable in genetic treatments. However, protecting the anonymity and privacy of this data provides significant challenges. For instance, one area of concern is the wide variety of personal genetic kit tests that have flooded the market. Unfortunately, not all these vendors maintain strict protocols that ensure or protect privacy. Thus, without safeguards, genomic data reveals the individual behind the data. Therefore, it is necessary to draw, respect, and perhaps redefine the fine line between genetic data privacy and open data access.\textsuperscript{563}

A recent report from Heidelber cites some key concerns on genomics data privacy: anonymity, trust, and protection of generated data; the commercial value of generated data; and international legal harmonization. Therefore, it is time to consider alternative options and methods to protect genetic privacy by making sure it remains anonymously secured and shared.\textsuperscript{564}

No one wants to be a part of a data-sharing system where others can take advantage of him. Therefore, it is essential to build data access upon a trustworthy platform if healthcare expects patients to volunteer to participate in genomics.\textsuperscript{565} By imposing controlled access to the available data, it is possible to answer privacy concerns. This requires a model that allows users to download the data only after vetting and approval. It is called the “trust-but-verify” approach. In trust-but-verify, users can access data but cannot download the contents. Therefore, the user cannot, for instance, combine health data with any other available data sources, which would open the possibility for a violation of anonymity.\textsuperscript{566}
Another access control model is to hold the original participant strictly responsible for data control and access permission rights. This is called a “participant-based access control setting.” With this model, to ensure anonymity, a private and trusted agent, controls and oversees the access and communication between the researcher and the participants. This method requires log verification and auditing time and procedures and protects the donor’s anonymity. A combination of these two approaches can guard the data from unauthorized access and serve as a best practice to protect the donor’s identity.567

In conjunction with the above, current privacy rules should be aligned with the demands of genomics. The privacy rules established by Health Insurance Portability and Accountability Act (HIPAA) covers healthcare providers, insurers, data cleaning houses, and affiliated business partners. However, the health and medical information generated by other private companies: home test kits, fitness trackers, or health information collected and shared through social media sources are not always covered under HIPAA. Some companies store and sell these data. For example, Google has tremendous amounts of health data stored on its servers that are not covered under HIPAA. Just because Google does not provide health care services, they are not under HIPAA.568

As this has become clear, with the explosion of genetic sequencing and biomedical advancement, many private companies now hold vast amounts of sensitive and identifiable data. But currently, these data are not regulated by HIPAA. The scope of HIPAA should be expanded to incorporate additional privacy rules for “consumer-generated health information” by home tests, fitness trackers, mobile apps, social media, and the like. And beyond that, additional attention should be given to the security of metadata—age, race, geography, etc. These steps will help strengthen accesses points and better secure and protect the identifiability genetic data.569
Moreover, the problem is not always with access, but how the data are used. The purpose of use can be a threat. Until and unless researchers can guarantee that genetic information is secure and inaccessible to those who might use it to exploit someone, then any access becomes a threat. However, at this point, the burden to determine intent is not placed on the data-sharing source. Drawbacks and unintended consequences always follow historically technological advancements. Indeed, we should not cease data sharing until we sort this issue, but we should make concerted, determined, and coordinated efforts to address the issues of intent and nefarious use, which run counter to the ethical and social good which rest at the heart of genomics.570

During genetic counseling, counselors must ensure that patients are comfortable about their privacy and goodwill of contributing to the common good. They must feel confident in actively engaging in the treatment without fear and uncertainty. Therefore, it is necessary for there to be a revised understanding of the notion of patient autonomy571 The rapid growth of genomics has opened a new concern on individual autonomy and community benefit. However, this rapid change also raises several ethical considerations to address and evaluate. It is clear there is a need to integrate and balance social benefit with the importance of autonomy and privacy.572

Autonomy is the rational choice that one can make based on the available information. The advancement of genomics has helped people be autonomous in their reproductive decisions. One of the breakthroughs in genomics is the rise of noninvasive and early prenatal genetic testing. These tests offer a substantial benefit to and for the parents.573 Prenatal genomic testing provides information from which parents make informed choices concerning the mother and child's health and well-being. Prenatal screening benefits individuals or families because the screening results help lead to better and more well-informed family planning and reproductive choices. Genomics
broadly promotes the welfare of society, and in the instance of prenatal testing, helps to ensure the welfare of parents and the unborn child.\textsuperscript{574}

The purpose of prenatal testing and screening is to help the parents and healthcare providers know more about the fetus. These insights help the parent to understand potential health risks or identified problems the child may face.\textsuperscript{575} There are those who oppose abortion, contending that prenatal genetic testing should be regulated, curtailed, or eliminated because it serves as merely another avenue for the termination of pregnancy,\textsuperscript{576} and the testing itself is as an essential aspect of pregnancy decision-making. The goal is not to target terminating the pregnancy but to offer parents information to make informed personal decisions. Moreover, the information obtained from the testing also influences future pregnancy decision making by the women.\textsuperscript{577} Again, the primary purpose of prenatal testing is to help the patient know more about the health and well-being of her fetus. Prenatal genetic testing is no different than any other diagnostic medical test. Genomic tests provide more comprehensive, relevant clinical information from which to make well-founded, autonomous choices.\textsuperscript{578}

Sometimes a patient may seem reluctant to know more about the results of the test, but regardless, the genetics consultant’s task is to ensure the information is conveyed and understood by the patient.\textsuperscript{579} After receiving adequate knowledge and a clear understanding of the fetus's health, if the patient wants to terminate the pregnancy, within the legal limitations set for by law, it is her autonomous decision; it is her body. Therefore, the opposition to abortion has nothing substantial to do with the availability of or benefits provided by prenatal genetic testing.\textsuperscript{580} These tests serve to provide non-directive insights. Based on principle of autonomy, a mother has the right to decide what she wants to do with her body.\textsuperscript{581} It is the mother's autonomy to choose whatever she wants, considering the concept of liberal personhood, again within the scope of the
law. Providing necessary technology to help the woman decide her reproductive choice is not a social norm violation. Therefore, genomics has given more autonomy to pregnant women in the society. 582

Besides the social concerns, genomics faces challenges because of the availability of commercial genetic tests. These privately owned publicly available testing services are not regulated, which gives rise to the questions of test accuracy and the validity of the data. The primary concerns of the direct-to-consumer genetic testing services are the reliability of the tests, the condition of the labs where the test occurs, and the strength and validity of the results. 583 As we know, genetics is a very complex matter; society cannot accept lay people handling or distributing genetic information without a clinician’s involvement. 584

Even though we sense ourselves as autonomous beings, we are embodied in society. Genomics helps us realize that our autonomy has a strong tie with the common social good. Attitudes, beliefs, and values are ineradicably entwined in genetic counseling. Genetics aims to work for the common social good in respecting patients’ autonomy. One of the prime reasons that genetic counseling is nondirective is that it serves to respect the patient’s autonomy to choose but also note the patient’s social obligations. 585

4.2.2.2 Solidarity and Common Good

Solidarity gives us the framework to work together. Genomic solidarity encourages both the donor and benefactors to create a trustworthy relationship. The main goal is to create a healthier and happier life for all. Solidarity also means sharing the cost and expenses mutually. All should share the cost of sharing personal data for the benefit had for the greater good. 586 The advancement of genetics has taken us to a place where we must admit that all generations are connected. Each
of us passes on a genetic code to others, passed on generation by generation. Therefore, we are more like each other than different from each other.\textsuperscript{587}

Genomics is seen as a global public good. Interests are considered a global public good once it produces benefits for all. There are two main criteria to become a global public good, one is nonrivalrous, and the other is nonexcludable. Likewise, the benefit of genomics does not preclude another person’s use of genomic information. Also, even though genomics intends to solve problems afflicting an individual, its nature is to create a sustainable solution for all in the same family. That means genomics is helping the other family members who benefit from the genomic information.\textsuperscript{588}

The explosion of newly developed technologies and the falling costs of genetic sequencing has provided opportunities for different entities to create vast repositories of genome-set data. This has, rightfully, given rise to an ethical tension between the right of individual autonomy and privacy and the social good. What has become evident is that parameters of traditional informed consent have become too limited and are insufficient to adequately respond to the scope and breadth of the privacy concerns at hand.\textsuperscript{589}

Besides protecting individual autonomy, genomics requires solidarity—a shared commitment to the whole. Even though we act as autonomous beings, we live in a society comprised of shared values and meaning. The power of genomics helps us realize that our autonomy has strong and inseparable ties with and for the common social good. The socially constructed attitudes, beliefs, and values are ineradicably embodied in genetic counseling.\textsuperscript{590} Ideally, genetics aims to support and promote the common social good by respecting patients’ autonomy. One of the prime reasons that genetic counseling is nondirective is that it gives the
patient the autonomy to avail herself of the testing, but the patient should understand that her results can fulfill her obligation to contribute to the social welfare.\textsuperscript{591}

Within a few decades, it will be possible to develop customized drugs for an individual patient with the help of genomics. This pharma-genomics will not only benefit an individual and society at large. However, there are concerns as how to control or regulate the cost of these treatments. Currently pharmaceutical companies charge, often exorbitantly, what they see fit for these drugs. The main concern is how to control the cost to society of whatever these companies see fit to charge.\textsuperscript{592} The drugs targeted to a specific person, or a specific part of the body, have fewer risk factors than a standard drug. These comprehensive benefits can be had if people are willing to relax their autonomy for the sake of the social good. These are acts of solidarity for the common public interest. In many ways, it is no different than vaccinations. Like the vaccination debate, genomics calls for solidarity centered on social values.\textsuperscript{593}

Genomics demands a new social contract be created, founded on solidarity. A platform must be designed to include the public as part of the conversation and education about genomics. It is true that, currently, many people seem not to want to change their positions or do not want to know more about the future that genomics reveals. However, it should be made clear this is not only the individual’s choice; we have a social obligation to improve the health and welfare of all.

Offering a narrative-based context, a story that depicts the social, ethical, moral, or religious connections to genomics can serve to remove uncertainties, stigma, or misnomers revolving around choosing to participate or not.

For instance, some people conduct and disclose the genetic test results only to their families, but if genomics were depicted within the context of the broader narrative to which they abide,
these folks might see the benefits of contributing their details to the more extensive genome database. In instances where there are questions or concerns about the genomics collection, the genetic counselor’s ability to solicit the patient’s story offers opportunities to tie the value, beliefs, and concerns to the greater good of the data sharing. Engaging in story-based conversations with the patient is also a means to ensure consent is fully informed.

The personal nature of genomics has reinforced the importance of privacy and confidentiality. However, as genomics becomes more common and mainstream, perspectives of and acceptance of the technology will change. The collective nature of genomics will help people understand that genomic intends to promote public well-being. This perspective-changing and trust-building will come through transparency and accountability; when this occurs, genomics will become readily accepted as the social good it can and should be. The boundaries between public and private ownership then will be removed, and genomics will supply its benefits to transform healthcare, globally.

Ethics supplies the obligation we each should recognize, respect, and respond to—because each of us participates in a collective “we”; we are simultaneously ‘embodied, social, and historical.’ Ego, arrogance, selfishness, and greed often play a central role in blinding many to this collective obligation. Therefore, to respect social duties, it is critical to view and embrace autonomy through the lens of shared obligation.

Genomics as a public good should be managed and regulated by public entities, so maximum benefits are had from shared resources. For that to occur, a clear public policy focused on the aggregate social benefit of genomics must be developed if the field is to shape and change healthcare and global well-being entirely. Beyond creating and implementing public policies,
genomics must also gain public trust. Public trust is only garnered if individuals come to understand the communal underpinnings of genomics.\textsuperscript{601}

However, it should again be made clear that human rights require a benefit-sharing between developed and developing countries of the bounty that genomics research provides. Therefore, genomic researchers must be mindful and committed to the equal distribution strategy.\textsuperscript{602} Some genetic tests are still so costly that they are available to a small portion of society. However, this gap must be closed to build solidarity with and for genomics. Genetic disease diagnostics can have a dramatic effect on a family. If the public policy and information campaigns can persuade the population that genetics can drastically change their lives, then individuals will understand their participation in providing genetic data for the greater good will have a significant impact, help lower the costs of genetic testing and provide broad, and long-term benefits.\textsuperscript{603}

4.2.2.3 An Integrated Informed Consent

Genomics demands informed consent that incorporates the notion of being interactive. Interactive Informed Consent ensures that the patient maintains her autonomy, is actively involved in the decision making, and, at the same time, is fully aware of how her genomic profile and specifics of her situation can and will serve others and improve the health and welfare of the community and humanity at large.

Interactive Informed Consent will require significant financial and time commitments to acquire each person’s individualized consent. For instance, most patients are unfamiliar with how genomics treatments occur and the nature of its multiple occurrences. Sharing this information and tying it to patients’ stories and beliefs will increase consent and have patients understand the social importance of participation. Of course, as expected, some patients will refuse based on their
perspective and beliefs, which they believe supersede social obligation and social benefit. One way to approach refusal decisions is to allow the patient to Opt-Out of further participation. A good amount of data is generated while patients are undergoing treatment. Those data are, subsequently, used for research purposes with the permission of the patients who are undergoing those treatments. Allowing the patients to opt-out from those further data generation can help them to exercise their autonomy and privacy concerns. Considering the social benefits genomics offers, a consent process can be designed with an opt-out option. Doing so will protect the patient's right to autonomy while, at the same time, overcoming the frequent refusal by the patients in the treatment. The opt-out approach has proven successful, for instance, in organ donation. It is an approach that recognizes the communal benefit of participation while respecting an individual's autonomy. Doing so will help these patients make better-informed choices.\textsuperscript{604}

However, genomics has proven its long-run benefits. The benefit should not be sacrificed due to poor communication that gives rise to fear, anxiety, or cynicism. Many want to improve informed consent measures in genetic treatment because of the firm belief that each patient has a social obligation to promote scientific advancement.\textsuperscript{605}

If we fall back on the four principles in these situations, it is difficult to determine what is meant by do no harm.\textsuperscript{606} We recognize the ethical obligation to do no harm to others, yet, conversely, there is the obligation to heal and promote well-being. A person who supplies a sample for a particular test may be able to help improve the life of someone else, even unknowingly. Yet even though her information is being stored for future research, it is unclear if doing so might prove a violation of her dignity.\textsuperscript{607}

We all are social beings, and we cannot think of ourselves as totally autonomous. Therefore, genomics demands an integrated model of informed consent, which provides robust
moral guidance and full appreciation of the dynamics of the current scientific revolution. What will arise will be a Partnership Model that comprises a long-term relationship with the participants-researcher and the patient-physician. This partnership model will serve to foster trust in genetics and promote patient and participant engagement. This more integrated notion of informed consent seeks to find ways to respect the individual while allowing the benefits of genomics to flourish for all. The strict adherence to autonomy should be reviewed considering the social benefit provided by genomics. Genetic counselor must ensure the patient understand the social benefit genomics provide and the patient’s obligation to the society.

4.2.2.4 A Narrative Partnership: Open-ended and Not-knowing Approach

There is no plan to violate or circumvent autonomous rights; just the opposite, the field is striving to find ways to promote participation in genomics and genetics. The imagined goal is to cure a patient’s disease and, generally, to find ways to heal as many conditions as possible.

Thus, the recommendation is the establishment of a Narrative Partnership Model. This model is narrative based, embracing the entire perspective provided by Narrative Authority. The Narrative Partnership model calls upon two primary components of Narrative Authority to reshape genetic counseling: open-ended listening and a not-knowing approach to construct a dialogue and relationship with the patient. The in-depth applications explained in chapter 2 about Narrative Authority can be widely used to create the Narrative Partnership. Clinical counselors can use the three elements of Narrative Authority to establish a truth worthy relationship with the patients.

At the same time, paying attention to the narrative partnership model will help the patients understand their role as human beings with shared social connections and the importance of contributing to the research, genetic research.
The Narrative Partnership Model reshapes the normative assumptions concerning human relationships. It views all human interaction as social, communal, and narrative/story driven. Therefore, human relationships are inseparable from the shared storied space, the social context in which they occur. Narrative Partnership rests on a more accurate and experiential interpretation of human experience. From this perspective, all human relationships are radically social, meaning there is no way to understand them outside the shared context and meaning of normative practices and narrative/culture in which they take place. Narrative Partnership revises and rejects the notion of the individual as separate, isolated, and fully autonomous. It redefines individuality as socially shared and hence ethical by nature.611

The result of the Narrative Partnership approach is the consistent establishment of long-term relationships with the clinical counselor and patient.612 The goal of the counseling is to engage in a dialogue with the other party. Standing in the not-knowing position will help the genetic counselors better hear the patients/participants. Thus, the counselors’ actions will be guided by listening to the stories of the others. Listening is a means to answers the problem stated by the other person. The goal is to ask ourselves the following questions:

“Am I understanding what it feels like to be this person in this situation, or am I beginning to fill in the gaps in her story with unwanted assumptions? What more do I need to know in order to step into this person’s shoes?”613 Thus, in a Narrative Partnership Model, patients and counselors will view and experience one another as partners, working and participating together to advance research and serve the greater good.614

Genetic treatments require informed consent, which is an ongoing process in which the physician re-contacts the patient to inform the patient of the status and use of her sample. The patient may continue to grant, modify, or withdraw consent at such time. Therefore, consent is not
a one-time blanket giving of use but an ongoing, integrated, and dialogue-based relationship.\textsuperscript{615} This means the patient may need to provide consent again, even for the same treatment given at a different time. However, once the patient dies, the consenting process ends.

This Narrative Partnership model will serve to keep ethical considerations to the fore, foster trust in genetics, and welcome and promote patients to participate into the research.\textsuperscript{616} Moreover, for genomics to be widely successful, it demands the integration of diverse data, which can be ethically generated only through active patient participation. Narrative partnership opens up the space to understand our obligation towards society. Thus, patients agree to participate actively in the data sharing process and consent to participate in the research. This is an excellent way for the physician/researcher can establish a long-term relationship with the patient, as well.\textsuperscript{617}

This more integrated notion of informed consent seeks to find ways to respect and protect the individual while supporting and furthering the broad benefits of genomics for all. The idea of patient autonomy should be reviewed or redefined considering the social benefit provided by genomics. Genetics demands an ongoing interactive, informed consent that will persuade the patient to sacrifice her autonomy for the greater social good willingly.\textsuperscript{618} Thus, Interactive Informed Consent in the Narrative Partnership Model incorporates the belief that genomic participation ethically requires a long-term, dialogical relationship between the subject/patient and researcher/physician.\textsuperscript{619} Therefore, Narrative Partnership is the bedrock upon which interactive informed consent is built.

The embrace of the narrative intersection of the human experience is at one time both the revelatory command of the obligation to self and the responsibility for the other. Narrative Partnership helps individuals’ sense and understand that they are always and primordially socially connected to one another, there is no escape; this is the fabric of human being. Narrative
Partnership helps all patients to recognize that being-in-conversation is to co-create a dialogue, which ground the meaning and significance of relationship. It, more broadly, allows patients to embrace the normal motion of everyday life as ethical practices which implicitly and explicitly honor the context of shared being.\textsuperscript{620}

Often it is challenging to see and understand the other’s perspective, especially given the changing and shifting demographic and the acceleration of technology within healthcare. By embracing and practicing Narrative Partnership, it is possible to approach the practice of medicine, and the nuance required for ethical genomics practices, through an introspective and other-oriented viewpoint that serves to keep to the fore a range of contextual features: social norms and cultural and religious practices. The partnership Model serves to encourage patients to embrace genetic treatments and support the smooth data flow of genomic research, which occurs when patients are willing to share their data.\textsuperscript{621}

The advancement of medical genomics is in its infancy; the future ubiquity of genomics practices in medicine is a given. Genomics is advancing at a dizzying pace. Genomics has much to offer, but we must rethink and redesign some of the shared rules and guidelines of medical science. The challenge is to ensure that innovations and developments in genomics protect the privacy and autonomy of individuals by developing an informed consent model that is ongoing, interactive, and narrative-based.

Furthermore, another significant challenge facing the field of genomics is to have patients understand and embrace the social, moral, and ethical obligations to the community and future generations that the embrace of genomics serves. Current medical practices and social norms concerning genomic counseling must be revised or reimagined to overcome this significant challenge. Therefore, to improve and strengthen the effectiveness of genomic treatments and to
ensure that patients see the more significant and communal benefits of genomic research, genetics counseling should embrace the concept of Narrative Partnership.

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Chapter 05: Narrative Authority at the Organizational Level

Excellent contemporary healthcare requires a revision and the transformation of practices that have been based, almost exclusively, on privileged Western notions of individuality and autonomy. The time for this revision is at hand, given that globalism has “flattened” the world and brought countries and cultures—including healthcare—into economic exchange. Global healthcare delivery now requires practices and procedures that embrace the multicultural nuance patients carry to the consultation room. This means that cultural competency is a fundamental requirement for all involved in contemporary healthcare. The first important step to achieving this is recognizing, acknowledging, accepting, and appreciating the distinctions and narratives different cultures offer as they enter the healthcare system. A complementary narrative-driven and narrative-attuned organizational ethos are necessary for culturally competent, other-oriented perspectives and practices to arise. This revisioning can be best approached and achieved by embracing and applying the concept of *Narrative Authority*.

This chapter uses the terms ‘cultural competency’ and ‘cultural sensitivity’ interchangeably. Muslim patients in a non-Muslim community serve as an illustration in the latter part of this chapter.

5.1 Culturally Responsive Organization in a Multicultural Society

To be a successful healthcare system in the global marketplace, an organization must fully acknowledge and embrace the imperative to become culturally competent and culturally responsive. Globalization and multiculturalism have forced fundamental and, indeed, paradigmatic changes across healthcare practices. However, these alterations are particularly evident in the changing shape of Western healthcare practices. They can be seen in emerging new operating
agendas and business models, the internationalization of research protocols and clinical trials, and revised organizational values, practices, and norms. Healthcare must become more sensitive and attuned to the nuances and particularities of the many and varied cultures and diverse perspectives that increasingly intersect and make their way to the healthcare system.

5.1.1 Ethical Considerations for Cultural Diversity

Healthcare can no longer operate effectively, efficiently, or ethically if it does not foundationally recognize and respond to the opportunities present by cross-cultural intersections. Therefore, cultural competency is now a requisite for any reputable healthcare system. Thus, a revised orthodoxy—a re-visioned and shared narrative—is required that articulates and discloses the meaning and reasons why cultural competency rests at the heart and spirit of healthcare itself.

The current guiding narrative is deficient. It is mired in a misperception of humans as rational, isolated, autonomous decision-makers and, likewise, organizations as calculative, efficient machines. Narrative Authority aims to reclaim the disappearing human element of healthcare as an antidote to cultural blindness and paternalistic, but still Western, biases. Narrative Authority questions these assumptions and contends that humans are always in relation to and with one another as radically social beings. This approach helps us understand the patient’s point of view and solicit the narrative of illness. By understanding the narrative of illness, it becomes possible to provide medical care that recognizes the patient as situated within a story and, as a result, offers care with humility, trustworthiness, and respect.623

5.1.1.1 Globalization and its Impact

Globalization blurs the local and global distinctions and cultures mix as never before. The force of these changes necessitate that healthcare providers re-imagine the ethical landscape before
them, not merely in terms of geographical distances, but rather as a world comprised of one human family.\textsuperscript{624} Healthcare must become attuned to various cultures, beliefs, perspectives that arrive for treatment and, in turn, develop and revise processes and protocols to ensure that the “other’s” perspective, i.e., her story, is taken into account. To this end, healthcare organizations must become more diverse and reflect the changing nature of our ever-intersecting cultures, perspectives, and stories.\textsuperscript{625}

Narrative Authority will guide healthcare systems to drive this change by defining illness from multiple perspectives and by recognizing culturally and socially determined views on illness and disease.

Globalization creates business and wellness opportunities in healthcare through the exchange of medical products and shared services. However, the complexity in the financing, regulation and the types and availability of devices used in different countries often hinders the flow of and opportunities for these services. Given the increased ease of travel and the enhanced speed of communication. The health system should focus on innovation, transformation, and collaboration that satisfy the global need for care. The world has essentially become a single place where different practices intersect and intermix.\textsuperscript{626} In addition to the call for resource mobilization, healthcare also has seen a significant expansion of knowledge sharing. Even though there remain considerable knowledge and development divides in medicine between the East and West, globalization is a force that serves to bridge these gaps.

For example, Cornell and Harvard Universities have developed satellite medical practices in the Middle East. Similarly, John Hopkins University has expanded its operations into Singapore and Abu Dhabi. Such initiatives are direct responses to new global knowledge-sharing and market opportunities. Despite the geographical distance, people can now receive the same or very similar
high-quality healthcare services globally. Knowledge-sharing and medical practice exchanges create a healthcare system that must embrace and incorporate diversity and inclusion into its normative practices to succeed.

“Medical tourism” is also a direct byproduct of globalization. Patients can travel abroad from their home countries to find less expensive and often better services. For instance, European countries attract American couples for fertility services, offering these services at significantly reduced costs compared to the fees charged in the US. On the other hand, physicians from emerging countries migrate to developed countries to take advantage of higher wages and improved lifestyles. As a result, there are increasing numbers of healthcare systems that are, by necessity, becoming more diverse. Healthcare is not confined to medical practices only. Another impetus to change is that healthcare organizations compete with other systems for market share and prestige within and outside their counties. Insurance companies, non-governmental organizations (NGOs), and political influence have significant impacts on the care delivery processes. These groups are usually staffed with people from different cultural and ethnic backgrounds and often better attuned to various cultural norms. Therefore, healthcare providers are further pressured to bridge cultural gaps and revise practices if they are to be relevant and successful in these new cultural markets and offer the best possible care to their patients.

It is predicted that by 2050, the majority of the population will be people of color in the USA. Current “minorities and the people of color” will grow to 54% of the total US population. By 2050 the US population is expected to be 439 million, of which 235.7 million will be “minorities.” This is, in good part, an effect of globalization, and it indicates how important it is for a healthcare system to become culturally competent and responsive. It is imperative that US
healthcare providers become culturally sensitive if they are to adequately address the large and
diverse groups of people who will need and expect their services.\textsuperscript{630}

Healthcare systems that do not embrace this change will become isolated, less relevant,
and less patient centric. A global-serving healthcare organization that embraces healthcare ethics
needs an integrated portfolio of offerings and services that will remove boundaries and untangle
the complexity to care for people of all cultures and religious persuasions. Also, part and parcel
with these activities is the need to understand and address the moral and ethical implications of
resource integration. There is a cultural and economic sea change occurring: for a healthcare
system to succeed, it must now focus on the interdependent nature of shared medical practices and
resource integration. This new age of healthcare demands pluralism as adherence to guiding
principle.\textsuperscript{631}

Since health is a global public good and a fundamental human right, the healthcare system
must, therefore, be culturally competent before it can act in a culturally responsive manner.\textsuperscript{632} It is
now time to understand that embracing pluralism is critical if a healthcare organization intends to
provide ethical and excellent healthcare. The growing diversity within almost every country
requires an embedded, interactive system where theoretical knowledge and normative, other-
oriented sense-making prevail. The transformative power of Narrative Authority well serves any
organization in its quest to become culturally competent and positioned to embrace the demands
of the future. Narrative Authority provides an approach that guides organizational culture change
and, if followed, will, in turn, disclose normative practices through which individual providers act
in culturally sensitive ways.
5.1.1.2 Cultural Insensitivity

A successful healthcare system must be culturally sensitive and responsive to varied social norms. Otherwise, the system gives rise to a form of cultural imperialism. A common criticism of the current healthcare system in the Western world is that it ignores the social and cultural aspects of minorities. In these cases, the healthcare systems are often involved in poor and unethical practices driven by the dominant community, which often ignores minority perspectives of the community.

The concept of culture generally refers to any community's social practices and dominant values. However, this understanding of culture frequently invokes stereotyping. Cultural sensitivity occurs when one understands the nuances of subgroups within the community, which in turn, opens the possibility to be sensitive to and see another, not through the gaze of an assumed stereotype, as an other, but as human, and as-self.  

Ignoring or remaining insensitive to cultural differences indicates a disregard of the new global normativity emerging in healthcare. Cultural insensitivity blinds leaders, administrators, and professional caregivers to the ethical necessity for change. Thus, emerging normative practices are discounted, and the system acts as a status-quo social institution rather than a genuine, forward-thinking—and practical—care provider. An example of cultural sensitivity of how stereotypes can influence decision-making can be seen in diversified decision-making for white patients vs. nonwhite patients. For instance, nonwhite patients are generally prescribed less pain medication because of stereotyping, because it is assumed that they, as nonwhite, are likely to misuse the drug. Such experience instills, for minorities, a fundamental distrust in the healthcare system. As a result, the healthcare system fails in its obligation to provide equitable care.
Therefore, for a healthcare system to change, it should focus on becoming familiar with and soliciting narratives of the various culture with which it interacts and commit to revising organizational practices to accommodate these different voices and perspectives.\textsuperscript{637}

Normative ethical practices that are attuned to the other’s story and recognize the importance of embracing difference are often not adopted in healthcare systems because intolerance, bias, and bigotry remain deeply entrenched, even though communities are becoming multiethnic and pluralistic. Another limiting factor is that different practices of medical ethics, rooted in or coming from other multicultural communities, are merely discounted, ignored, or understood as deficient.\textsuperscript{638} Therefore, a system and its stakeholders must find ways to become comfortable with and accept cross-cultural differences through an integrative narrative approach that opens the space to see others as guided by specific beliefs and perspectives. A culturally sensitive, narrative-driven healthcare system serves to improve the health outcomes of patients, increases the effectiveness of practitioners, promotes patient satisfaction, and makes for an excellent healthcare system where ethical medical and business practices prevail.\textsuperscript{639}

However, the notion of multiculturalism often hinders cultural sensitivity. Multiculturalism is frequently interpreted in negative ways and missing the inclusive components by focusing only on differences. In this way, people are characterized by group, race, and ethnicity. This view of multiculturalism reveals a form of blindness, which inhibits the ability to recognize individuals and, as a result, promotes stereotypical, paternalistic responses.\textsuperscript{640} A healthcare system can counter this phenomenon and promote cultural sensitivity by tempering the notion of group identities. The system must develop practices based on the belief that each person has a unique cultural component and also has a complementary individual identity— an individual’s story—that deserves and demands respect.\textsuperscript{641} Narrative Authority offers a means to reveal each individual’s
distinctive perspective by engaging in and requiring a story-based, dialogue-oriented form of communication.

Every human is a narrative being. We understand and respond to the world by the continuity- and sense-making that our shared narrative provides. Shared narrative is the story that gives the everyday its meaning and significance. It pre-reflectively provides an understanding of how things matter. The shared narrative makes things intelligible and opens a space, and, within this space, the story conveys values and norms. Empathy and obligation are valued through the story’s tenets. The shared narrative—the common understanding of the everyday—helps to make things and practices intelligible and gives them significance. A shared narrative configures a society or community’s tools, practices, and values into an inseparable ‘weave of references’ and meaning. “Weave of references” is a term that refers to how we generally find things meaningful or significant. It is the condition that makes it possible for any phenomenon to be the kind of thing it is. The intersecting, interconnected, inter-reliant set of references configure human practices and concerns. The meaning of one thing is related to the meaning of all other things. Thus, while immersed within this larger narrative, we each find ways to embrace our imaginations of whom we want to be and how we would desire to live, given the possibilities provided by that referential context.

We now find overlapping narratives regarding healthcare and wellness, and within these narratives, we each see and interpret the definition of illness and well-being. Thus, a practitioner’s understanding of illness may differ from the patients. This is likely when the patient and the doctor come from different cultures. Given the growing intercultural makeup of healthcare, the practitioner and the patient’s understanding and expectations of medical practices are more complicated than ever before. Again, this is why the effects of medical technology, the current
medical model, and its accompanying practices must be reviewed, revised, and understood through a guiding narrative that provides the perspective and accompanying norms that welcome and embrace the ethical nature of cultural sensitivity. Narrative Authority guides practitioners in a multicultural society to understand the patient’s often complex and different story through the power of narrative clinical imagination.\textsuperscript{645}

Therefore, systems must emerge, guided by a narrative of inclusion and the recognition of the other-as-self to create, and refine operational practices, procedures, and norms where individual providers fundamental and firstly solicit each patient’s story. Doing so serves to prevent stereotyping and assumptive thinking that retard access to the other.

Also, it should be recognized that a person can belong to, or identify with, more than one cultural group, depending on the situation or context. For instance, an individual can possess multiple identifiers that are revealed through her story.\textsuperscript{646} Narrative Authority guides providers to recognize that it is difficult to construct a universal approach that effectively categorizes or assesses people by group. And similarly, is misleading, presumptive, and paternalistic to believe and expect that people from the same group will all necessarily act alike.\textsuperscript{647}

Understanding the importance of individual identity demands recognizing the identity and behavioral nuances a person embraces and acts upon at the personal, group, and global levels. There is little doubt that people from similar backgrounds act, generally, in similar ways because they share similar narratives. However, it is essential not to be blinded by this broad generality. A patient may well act differently than another from the same group in very similar situations. Each person, by nature of her humanness, strives to construct, define, and articulate an individual self-identity that must be recognized and respected.\textsuperscript{648} True cultural sensitivity implies providers conduct focused attention on and commitment to the personal level while, at the same time,
understanding the role the group and universal levels play. However, access to the interconnected levels becomes apparent by focusing attention on the individual and her storied autonomy. Developing practices that direct the practitioner to concentrate first on the individual help to ensure that the system acts as a trustworthy other-oriented caregiver rather than a mere client-provider healthcare facility.\textsuperscript{649}

\textit{5.1.1.3 Imposition of Western Colonialism}

Globalization and multiculturalism present a fundamental challenge for Western medical practices. Principlism is often criticized because of its Western world biases, resulting in cultural insensitivity. The Western viewpoint is founded on the belief that the objective healthcare ethics principles or their interpretation cannot and must not vary from country to country. This belief is grounded on the foundational tenet that modern medicine is scientifically descriptive and unchangeable within a given period.\textsuperscript{650} Based on this Western worldview—this guiding belief—scientists have developed bioethics theories, which are unquestioningly assumed to apply to and be appropriate for any culture or situation.

For example, one of the four principles of bioethics is patient autonomy. The two underlining criteria of autonomy—\textit{liberty and agency}—reveal that an autonomous person is not under the control of someone else: she can openly and freely present the choices she prefers.\textsuperscript{651} This principle stirs debate because autonomy is an essential and overtly debatable component of the Western worldview, whereas, in the East or many non-Western communities, the majority of people fundamentally understand themselves through a more social, collective narrative that privileges communal decision-making and interdependence. Similarly, the understanding of and the demand for informed consent takes center stage in Western medical ethics, while, ironically, developing countries fight for access to healthcare in any form, where the concept of informed
consent is less dominant, while important, seems trivial. People are more worried about access to healthcare, safety issues, and efficacy. This discrepancy exemplifies that the belief in universalism prioritizes Western healthcare ethics and overlooks or mistakes the possibility that there may be a more broadly defined, globally inclusive form of healthcare ethics. Thus, it is time to investigate the robust sway that Western-based assumptions exerts on ‘biopolitics’ and conscientiously shape a global, inclusive, and diverse ‘biodemocracy.’  

For instance, a widespread practice in Pakistan is to defer to the physician’s knowledge and authority to make a medical decision. In many cases, families and patients routinely relinquish medical decisions to the doctor’s authority and rely on the doctor’s expertise and status to guide or even make the decision. This would seem counter to acceptable Western medical decision-making practices and patient autonomy. Yet, in Pakistan, an unquestioned social trust is integrated into the community narrative, which makes this practice generally expected and acceptable. Physicians, culturally, are considered as healing agents. Research indicates that many patients normatively abdicate decision-making authority to the physician. This would likely be interpreted as mere physician paternalism concerning Western medical ethics. However, in Pakistan and many other resources-limited non-Western countries, such actions are understood as respecting the individual’s autonomy and are therefore ethically justified and valued within this cultural context and this particular sense-making narrative. In this situation, it is not paternalism but patient centrism.

While this is generally true, it must be noted that there is a systemic change that must occur in Pakistan and other countries because too often, physicians routinely make decisions as a matter-of-fact and ignore the patient and family. In these incidents, physicians act outside the boundaries
of cultural understanding and behave unethically. This behavior can only be seen as paternalism, even in a society that gives much decision-making authority to the physician.

It is hard to apply Western individualism in Pakistan because people there believe, normatively and pre-reflectively, in interdependency. One need not be in Pakistan or outside the United States to experience this. In Michigan, a similar situation occurred concerning an Arab family and the decision to remove a loved one from life support. The Arab family deferred the decision-making authority to the doctor. It took some time and a bit of persuasion for the Western doctor to understand that the family was not abdicating or avoiding choice-making. This was how the family chose to make the decision within their cultural norms. Generally, Arabs are as communal as Pakistanis. They also tend to believe in the positional authority of the physician. These examples highlight that it is a mistake to presume and assume the global prevalence of the Western norm of autonomy in an ever-diverse, intercultural world. In fact, in such increasingly diverse and pluralistic settings, it is culturally insensitive and merely unethical to privilege a Western perspective and assume its universality.654

The prevalent Western world bias in medicine creates confusion and overlooks the possibility of a broader, more inclusive ethics. The Western notion of autonomy can strip a patient of her personhood or self-identity in many cultures. Therefore, Western world conceptions of autonomy and identity must be revised and modified. Respecting the normative understandings of personhood in different societies and cultures, and, in fact, among other individuals within similar contexts, should be championed as the universal standard in a cross-cultural healthcare system.655

Since Western beliefs and business models continue to skew bioethics models, providers must recognize that it is no longer wise or good business to impose these conceptions onto the rest of the world. The understanding of ethics has grown. Proper ethics demands respecting each
individual’s identity, regardless of setting or cultural background. Knowing patients’ stories helps us do so. The notion of bioethics must expand by adding nuance and by showing that it is only possible to universalize common moralities by recognizing the specific situation and the social context. This can be accomplished by embracing the local moralities and values of different cultures—by understanding the shaping forces of the local narrative. Doing such also requires a re-visioning of the unquestioned privilege given to the Western view in the normative and narrative practices shaping the healthcare system.

Many non-Western medical practices worldwide are more normatively holistic than the process- and efficiency-oriented model of Western medicine. They arise from a different narrative understanding of the world. Examples of such holistic practices can be found in Japan, Tibet, Korea, and Ayurveda and Unani healing techniques. These approaches to medicine rely on an integrated notion of health and well-being that extends beyond responding to a symptom or wound. These medicine practices fundamentally narratively embrace and respect the other dimensions of life beyond the physical, which collectively encompasses well-being. These practices address and respond to well-being as a balance and an intersection of the body, mind, and spirit conceptually and narratively. Western medicine reveals its insensitivity to other worldviews and other guiding narratives by disregarding or ignoring these Eastern narrative-based medical practices and perspectives. Western medical biases will only change when organizations shift their mindset and revise their narratives to embrace and value different medical procedures and philosophies. Open-mindedness and multidisciplinary approaches will integrate or assimilate the various medical practices and loosen the Western perspective's tight and narrow hold on bioethics. The time is now to understand the foundational role narrative plays in shaping healthcare organizations. Understanding and welcoming the narratives that give rise to holistic and integrated care practices
are pivotal if healthcare hopes to provide global-based care. Global-based care embraces healthcare as a human right. Thus, the standard care involved addresses, embraces, and responds to individual and cultural differences and integrates the preferences of each individual and their culture in the care delivery process.\textsuperscript{658} 

Developing cultural sensitivity and global perspective to bioethics provides solid direction and firm grounding from where to address the many ethical dilemmas apparent in our ever-flattening, global society.\textsuperscript{659} As a result, I suggest, Narrative Authority is the key guiding principle to guide any organization to offer excellent and ethical health care in this new cross-cultural world.

5.1.2 A Culturally Responsive-Storied Care System

To become culturally competent, a healthcare system must design systems and procedures that reveal each patient’s story. For this to occur, an organization must revisit or re-narrate its organizational story, which serves to guide the necessary structural changes that, in turn, open a cultural space where each provider can be more attentive to and respectful of the patient’s story. Likewise, each patient’s story/profile reveals the person’s race, gender, ethnicity, economic status, educational level, social status, fundamental beliefs, and likely her future aspirations and hopes. Knowing the person’s profile—her story—provides insight into the individual’s conceptualization of illness and her explanatory model of illness.\textsuperscript{660} To become a culturally competent, patient-centric, and globally competitive healthcare provider, the system must develop a straightforward organizational narrative that articulates the importance of and belief in other-oriented, storied-driven bioethics. Narrative Authority offers the perspective and tools to articulate this narrative and to identify and implement subsequent and necessary structural and best-practice changes.
5.1.2.1 Understanding the Patient-level Disparities

When a healthcare system provides services for a patient, the patient must be seen as a person with a socially based, story-informed identity. This is an identity replete with experiences of, and beliefs and fears about specific diseases. It is essential to see the patient in an as-individual manner. Doing so acknowledges a patient’s hopes, fears, and concerns and offers other-centric healthcare that fosters partnerships with the patients.\textsuperscript{661} When practitioners work in conjunction with and through a patient’s story, they can understand her perspective and, in turn, enhance the quality healthcare provides. This narrative-driven, other-centric approach, by nature, serves to promote cultural sensitivity and build cultural competence systemically.\textsuperscript{662}

However, the need to embrace and shape other-oriented healthcare systems is urgent. The diversity and disparities among patients grow at an increasing rate. More and more frequently, majorities encounter minorities. As a result, individuals often face inequities and feel alienated, isolated, and alone. This, in turn, affects their assimilation or participation in the broader narrative. Often, they are left to feel like spectators, outsiders, rather than welcome participants. The sources of such inequalities are revealed via historically ingrained norms and are generally supported and enabled by status-quo bureaucratic processes.\textsuperscript{663} The healthcare system, coupled with the standard, unquestioned, and status-quo narrative, drives and perpetuates such disparities.\textsuperscript{664} For instance, ethnic minorities receive less treatment for diagnoses of depression and anxiety than do the white majorities because of the underlying and culturally ingrained belief that minorities—\textit{they}—are less sophisticated and tend to misuse drugs.\textsuperscript{665} Furthermore, due to socioeconomic disparities, there are significant access barriers to health care among marginalized groups.\textsuperscript{666}
Ethnic disparities are pervasive in healthcare, even when adjusting for socioeconomic status. There are two consequences of the disparities. One, the performance of the hospitals, and two, differential treatment patients receive within the hospital.

Hospitals strive to garner high-performance ratings. In this quest to measure, rate, and make the process ever more quantitatively efficient, a healthcare system often overlooks the qualitative components that give rise to excellent, other-oriented, ethical healthcare. Hospitals often neglect the narrative of care—the narrative of illness—and often its guiding, healing organizational narrative to improve patients' lives. And in the second instance, the hospital supplies different treatment to different ethnicities because of stereotypes, unquestioned assumptions, and lack of cultural competence. This raises the chicken-or-the-egg question: do ethnic minorities receive inadequate care because of their ethnicity or because of the setting in which they are receiving care?667

These patient-level disparities occur in many segments of the system. For instance, a common form of disparity occurs when a hospital discharges a patient. Hospitals that have more resources tend to spend more time counseling and preparing patients for discharge. However, hospitals with limited resources usually have less staff designated to counsel patients who are to be discharged. In many cases, minorities are served by a lesser-quality hospital with fewer resources. Beyond limitations of financial and staff resources, language also plays a critical role in creating patient-level disparities. Often staff and nurses feel less comfortable or confident interacting with a non-English-speaking patient. Because of this, miscommunications and misunderstandings can occur, and patients leave the hospital with incomplete knowledge and mistaken assumptions about care. Cultural and linguistic training coupled with sufficient organizational resources must be provided to ensure cultural competence and ethical care. Patients
who are properly discharged from the hospital is one indicator of an organization that builds trusting partnerships with patients and the community.668

Besides discharging patients, disparities are also widespread in preventive care. For instance, studies reveal that African American and Hispanic patients are less likely to receive influenza or pneumococcal vaccines than are White patients. Surprisingly, more than one-third of all minorities remain unvaccinated compared to White patients. Lack of access to primary care and an incomplete understanding or mistrust of vaccinations are causes for such disparities in preventive care.669

All these disparities can be overcome through a commitment to the transformative power of Narrative Authority. Narrative Authority offers the power to uncover the social-economic background of the patient and provide an approach by which to comprehend, respect, and value a patient’s worldview. This worldview guides the provider to walk in the patient’s shoes. This occurs by listening to the other’s story, through which the practitioner sees, understands, and is-with-the-other-as-a-person, not as a patient or customer—but as a caregiver, not as an institutional agent.670

The road to change is different for every healthcare system. Each has its own story. Articulating this story opens the space for cultural changes and process improvements necessary to supply progressive and revolutionary healthcare. Regardless of the particular situation, Narrative Authority serves as the vehicle that helps make this journey easier. Narrative Authority serves as a magnet to bridge the gap between what is expected and what is actual. Narrative Authority unifies diverse fields of thought to help understand the diverse cultural practices within the organization.671
However, we live in a time when the healthcare system is designed within a performance-based structure and thus serves two opposing masters: profitability and patient care. Over the past 20 years, healthcare systems in the USA have changed dramatically in the direction of profitability, which generates bureaucracy and system rigidity that foments mistrust and uncertainty for patients. Healthcare providers have established roles as profit-making systems rather than human healing agents. The system has become a cost-conscious bureaucratic marketplace that can appear as indifferent to the patient’s sufferings.\footnote{672} In such settings, practitioners often have little time, and often less impetus, to see the patient as a person—the setting is designed to assess the patient only as a \textit{customer}. In the face of his rush to meet organizational dictates, a physician is not allotted enough time to take a patient’s oral history or investigate her story. Efficiency drowns out the illuminative power of narratives.\footnote{673} Not knowing the patient’s history retards optimal, ethical, other-oriented care. Optimal care rests on understanding the patient’s storied history, which provides the physician with a sense of the narrative coherence that shapes the patient’s life.\footnote{674} Therefore, understanding a patient’s perspective—her story—helps to avoid patient-level disparities. Story gives the provider access to her culture and normative surroundings, which commonly determine a patient’s sense of wellbeing. Therefore, if the healthcare system wants to provide excellent and ethical care, it must design and structure its systems and practices in ways that offer physicians the appropriate time and flexibility to get to know the patient’s background—hear her story.\footnote{675}

As in every other aspect of society, there are gender disparities in healthcare. Gender discrimination and gender inequality in healthcare are not always immediately evident. Gender-related obstacles to creating patient-centric healthcare are often blurred by or hidden within other aspects of the organization’s culture and normative practices.\footnote{676} Females are generally just not
considered as important as males because they typically produce less income and are seen as less central to the everyday workings of society. This predisposed and stereotypical position proves to be disadvantageous for women. They have less bargaining power in the roles they can assume in the workplace, family, or community. For instance, in countries like India, where poverty, hierarchy, and patriarchy are the prevailing norms, women are generally confined to household duties and have less connection with or access to the broader society. Even in Canada, a developed country, research reveals that women receive less treatment than men for chronic diseases.

Therefore, gender plays direct, indirect, and often unrecognized roles in the patient-physician relationship in healthcare. These inequalities and disparities can be addressed and overcome by creating an environment and practices that serve all actors involved in healthcare as a human being—an other-as-self with equal rights and reciprocal obligations. The adverse effects of gender discrimination on the patient-physician relationship can be overcome through a commitment to the transformative power of Narrative Authority. This transformation occurs by embracing the other’s story. Through her story, one sees, understands, and is with the other as a person, not as patient, as a caregiver, not as an institutional agent. Therefore, if the system recognizes the patient-level and the system-level disparities within society, it can respond by developing practices that value and capture patients’ stories and worldviews.

As has been stated above, the field of healthcare is in flux and is confronted with enormous opportunities to embrace change, expand, and enhance its quality and reach. Consistent inhibitors are bias, stereotyping, and unquestioned assumptions, often not well addressed, and thus change is retarded. With the advancement of technology and medical science, the stories and narratives that ground our beliefs must change to promote and demand inclusion, diversity, and commonality
as ethical and business imperatives. Healthcare practice can and will only change when guided by a narrative that offers no place for disparities to lurk.

The means to undo common bias and stereotyping is to shift the perspective on how patients and physicians understand, see, and embrace diversity. The goal is to become more individually and organizationally self-reflective. Imagining and articulating a guiding narrative that discloses a space where vulnerable population and diverse individuals of all types are seen not as others, but as people; not as things, but humans.680

5.1.2.2 Explanatory Model of Illness and Conceptualization of Illness

Contemporary healthcare has spread beyond what was previously considered traditional medical practices. Due to globalization and multiculturalism, health practitioners must now be skilled, trained, and attuned to a patient’s perspectives, perception of illness, and the narrative roots shaping her understanding of illness. Care is no longer only about diagnosing and treating disease but also finding the related contextual features that can affect an individual’s or a family’s wellbeing. Healthcare providers must understand the patient’s beliefs about health to understand the patient and respond in an other-oriented, culturally sensitive, ethical manner. Also, providers should note, acknowledge, and respect the interplay between an individual’s social and cultural influences to accurately understand the story-driven context of the illness. Care in a multicultural society must redefine the status quo by welcoming others’ perspectives. Doing so eliminate many current biases and makes its possible orientation that respects the patient, communicates well and checks for understanding, is rich with active listening, acknowledges and embraces cultural differences, and regards the patient as human other in need of care.681
Comfort and mental wellbeing are known to affect and transform physical wellbeing positively. Especially in healthcare, it is necessary to have a therapeutic model of care to ensure that the patient actively participates in and contributes to the healing process. A therapeutic model of care driven by open-ended questions, reflective responses, and silences and pauses builds a dialogue-based partnership between the care provider and patient. Since we live in a multicultural society, not every therapy or procedure will work for all. Care providers should keep this in mind when practicing a therapeutic model of care. For instance, a therapeutic model of care might face challenges in a particular culture. E.g., Indian patients generally believe that a care provider has knowledge power and expect the provider to be prescriptive. In this instance, the care provider should use a narrative approach to resolve the power distance and guide the patient to speak and share her thoughts and concerns.682

Sustainable healthcare should always be conscious of satisfying both mental and physical wellbeing by ensuring a therapeutic model of care. However, that may only be possible when the care providers know how the patient perceives the illness: a provider has to know the patients’ story. The perception of disease and the explanatory model of illness are the way to understand how the patient and the patient’s family see, understand, and are influenced by the illness.683 For instance, consider a patient in the emergency room. The patient and the patient’s family commonly experience high levels of and require gentle and assuring care. It is not possible to provide such care without understanding the patient’s view of illness. Pain, suffering, and distress are conditions that are very difficult to measure. Only through engaging with the narrative of the patient it is possible to understand the illness.684

Each patient’s explanatory model of illness and her conceptualization of illness is unique and differs even from those from the “same” background. A patient’s story that includes
immigration history, culture, social network, socio-economical background, and educational level shapes the perspective of illness. Therefore, a healthcare system must develop creative and adaptable narrative-based protocols to determine the patient’s sense of illness. A patient’s socioeconomic background and education also determine her conceptualization of illness. Even healthcare literacy defines a person’s conceptualization of illness. All these are pieces of her story—they tell the provider who she is and what she believes; she reveals herself and can be seen.

It is vital to state again that those directing global healthcare growth must recognize that Western worldviews are not universal. The population of the Western world is only a portion of the global population. Almost one-third of the world’s population lives in emerging countries. People in these countries often rely on traditional healing or self-care. The views and the perceptions of those patients from cultures accustomed to traditional medicine will not change their viewpoints easily or quickly when they migrate to a Western country. For instance, some groups believe in guardian angels and believe that illness is sent from God and must be healed by God. These people believe in the power of the supernatural and that the supernatural intervenes in the natural world. Their beliefs are not easily modified by the rationality of traditional Western medical practices. Such patients will look for therapeutic communication that satisfies and aligns with their indigenous understanding of healing. Unfortunately, healthcare institutions often ignore or overlook the centrality of indigenous beliefs that powerfully shape the explanatory model of the patient’s illness. For instance, the Muslim patient’s practices in the non-Muslim community, which has been used elaborately in the second part of the chapter.

Therefore, healthcare organizations must value indigenous medical practices and the narratives that give rise to those beliefs to properly understand the illness of the patient in a multicultural setting. A means to see or gain access to a person is through her story. Narrative
Authority guides caregivers to solicit those stories as a pathway to provide culturally competent care. Cultural competency, therefore, helps the provider find her way to the patient’s values, expectations, fears, and beliefs as a part of the treatment process.

However, the economic pressure to be efficient can often lead to time-limited visits, further pushing practitioners to compartmentalize, categorize, and stereotype “patients” of the same culture or group. The practitioner often assumes that every person of a particular group falls into “that category” and thus acts and believes similarly. Generalization assumes a common ground for each culture. By understanding cultural variance, the system’s processes, and, as a consequence, the individual provider can embrace the importance of implementing specific and well-designed best practices for each scenario. Therefore, the system cannot ethically generalize or prescribe a single way to address a group of people. Doing so creates stereotypes and bias. In such situations, the practitioner stops listening and misses the nuance and the insights the patient offers through her story. These are instances where the organization abandons its commitment to care.

The organization should design and develop individual practices and procedures that root out biases and blind spots. Regardless of the situation, a physician must be placed in a position to consistently recognize and account for the story-based understanding of the patient’s explanatory model of illness. To gain a proper diagnosis, it is highly recommended that the practitioner collects details about the patient’s explanatory model of illness, and remains aware of the fact that each individual sees the world through her own storied eyes: we see through the culture and narrative we inherit. Each patient’s view of care and pain is particular and nuanced, which is why it is imperative that a physician understands her story and communicates effectively with the patient to avoid stereotyping or assumptive thinking.
Veatch clarifies the difficulty of creating a universal framework for medical decisions, given different religious worldviews and philosophical beliefs. It is simply inappropriate to define one correct set of beliefs and values as the guide to the practice of medicine. Knowing a patient’s explanatory model of illness, exploring a patient’s agenda, and contextualizing illness help physicians act in a more appreciative, assistive manner.

Each person’s manner of conceptualizing illness is specific because it is influenced and grounded by her explanatory and story-based model of illness. It is routine to diagnose the biological understanding of an illness, but it is challenging and more nuanced to access the psychological and story-based components that shape a patient’s conceptualization of the illness. The ideal way to see the patient’s illness or beliefs is to have the “physician enter the patient’s world, to see the illness through the patient’s eye—to know her story.” Because each person holds different normative beliefs, which affect their conception of the illness, the physician’s autonomy and his perception of the patient can result in a different outcome for the same illness.

A physician’s knowledge and position power often inhibit the practitioner from accurately diagnosing an illness. A physician possesses technical insight and expertise that the patient does not have. This gives her power over the patient. Therefore, the physician must be attuned to the cultural perspectives offered by the patient. A physician should never initiate treatment from an assumed understanding or “knowing position” because the patient’s conceptualization of illness determines and shapes the type of care needed. Understanding and being open to the patient’s conception of illness is vital if the physician is to provide a proper diagnosis. Therefore, making assumptions about educational levels or other categorizations erects obstacles to achieving an effective and ethical other-oriented healthcare system. By being empathetic and attuned to the other’s story, it is possible for a physician to help a patient imagine the “next chapter” of her life.
and thus envision a fulfilling and meaningful future, which the patient has yet to see or believe.\textsuperscript{699} Again, knowing or helping to articulate the patient’s story is key.

No evidence shows that the physician alone can best judge or guide the patient’s well-being. Because a patient’s well-being is not only defined by medical or physical elements. Well-being is also greatly influenced by the combination of social, psychological, and religious beliefs and norms that the patient holds and practices.\textsuperscript{700} A physician who enters a professional relationship with the client, believing that they already have the answer or know best, does a disservice to the individual and acts in ways that overshadow the patient’s autonomy, which leads to forced or uninformed medical practices. In short, in such cases, the physician serves the patient’s benefit from a limited and self-serving viewpoint.\textsuperscript{701} The organization’s narrative, if genuine and grounded in healing, provides the sense-making and the urgency to design practices that give the practitioner the flexibility to spend the appropriate amount of time to understand the patient’s story and worldview.

Therefore, to gain a proper diagnosis and determine a patient’s acceptance level, it is highly recommended that the physician communicates in ways the patient understands and then offers culturally clear options and choices that lead to consensus. This process is often complex when the patient is incompetent. For an incompetent patient, the physician should communicate with the family and understand the patient’s history to meet the needs of the patient.\textsuperscript{702}

\textit{5.1.2.3 Prioritize the Patient}

Narrative Authority is a means to solve ethical dilemmas raised by changes brought forth by globalism and multiculturalism in cross-cultural healthcare. Relying on the power of Narrative Authority, an organization can ensure that processes, procedures, and practices guide stakeholders
to see a patient as a person with individual identity. Every ethical encounter should be approached person-to-person, where human rights prevail. To be culturally competent and to act responsively, an organization should rely on practices that exercise Narrative Authority normatively. Trusting and applying narrative methods provide an accurate picture of what is going on in the patient’s lifeworld. Because humans are fundamentally social, we are connected through and are constituted by and through narratives. By following Narrative Authority, caregivers can become more fully and meaningfully engaged with patients and more meaningfully engaged in their own stories.

Illness is often experienced as isolation. Patients can feel isolated and alone when they confront the reality of disease. In systematic healthcare, there are many instances when the nuance and clarity of a patient’s story are incompatible with a standardized, computerized checklist workflow process. Human interactions turn to abstraction, a faux reality in such cases, leading to patient isolation and poor “doctoring.” This is particularly common in cases of dementia, patients confined to their homes, and elderly patients.

Structured “appointment windows” and length-of-service measurements hinder the practitioner’s ability to delve into a patient’s worldview. The practitioner is forced into a time-efficient, mechanic process that undermines his obligations to the patient-as-human and causes the practitioner to forgo normative ethics. The patient-physician relationship becomes a patient-institution relationship rather than a person-person relationship. Therefore, to overcome this barrier, an organization must change or revise its narrative and, thus, its understanding of its fundamental model. An organization must transform from a machine model to a humanistic, communal model. Narrative Authority serves as a mediator to stimulate a dialogue between patient and physician with the intent to form a partnership. Narrative Authority provides the foundation
from which to revise and create practices and protocols that ensure the patient and physician build and maintain a partnership based on shared and intersecting stories.

Therefore, the structure of a healthcare organization should allow more face time with the patient to decrease the patient’s stress, improve the patient’s experience, and allow for the person-to-person bond to form between provider and patient. A longer appointment window can help a physician capture the patient's history and thus avoid or overcome biases and stereotyping. Time pressures force quick judgments, increase cognitive load, and result in more decisions founded on unquestioned assumptions. Therefore, rather than working toward pure efficiency, the system should strive for effective care. The healthcare system should not operate like a machine. It should act as an integrated social body with a narrative conscience.

The organization should develop and maintain a database to house patients’ information and stories. The system can, in turn, assess the data and create a reference for the physician. If a physician encounters a person from a culture unfamiliar to the provider, having the cultural information available in the database can help the care provider stay aware of their perspectives and unquestioned assumptions while administering care. For Instance, the practice of the Navajo patient and their expectations could be in the database as knowledge for care providers who often do not attend to Navajo patients. Documenting a particular culture’s norms and practices will help providers treat another patient from the same or similar culture. Also, having available specific information about the patient would allow the providers because not all patients from one culture behave in identical manners. This would help to avoid stereotypes and biases and reduce the occurrence of disparities.

Despite the numerous benefits of technology in the medical field, organizational structures and procedures dedicated to efficiency and profit distort the physician’s gaze, and he or she comes
to see a customer, not a patient. For example, a physician keeps jotting case notes into a networked computer during a consultation. Indirectly, both the patient and the physician communicate to the computer, to the calculative efficiency process. The relationship is mediated. In collecting “information,” the physician is procedurally detached from making an emotional connection with the individual identity of the patient. Thus, they, in turn, lose the scope of normative ethics, narrative practices, and human connection. Exercising Narrative Authority is fundamentally a moral response to the existential appeal of the patient, where the physician not only hears the patient’s story but also tells her story to others involved in the decision-making at hand. To become a culturally competent and responsive healthcare system, the voices of both the physician and patient must be heard, valued, and respected. By exercising Narrative Authority, both the patient and the physician can experience the actual meaning of autonomy, which can be dependent, independent, and interdependent depending on the perspective and mood of a particular patient or setting. Narrative Authority helps identify the fundamental values of a person and thus helps to protect the person’s identity. Therefore, considering the goal of care, both the physician and the patient should act as partners—where Narrative Authority prevails.

Narrative Authority should, therefore, also guide the informed consent process. Patients are not adequately guided through the consent because of time constraints. The predetermined structures make healthcare providers rush through the process. In many cases, patients give consent without understanding the treatment process. Time-restricted processes often thwart autonomy by not providing proper attention to the patient to gain appropriate informed consent. This can be overcome by fostering a culturally sensitive, culturally responsive narrative practice that promotes ethical engagement and builds client-provider partnerships. Through culturally sensitive, dialogue-based, and story-bound partnerships, the system allows the individual caregiver to understand and
embrace autonomy as an obligation and, subsequently, view consent as consensus. Thus, the care providers can understand the importance of adequately guiding a patient through the consent process without rushing. Narrative Authority grounds this partnership. Narrative Authority guides the patient and physician to see the other-as-same and to find common connection through a story-based, dialogue-oriented, mutually shared relationship.\textsuperscript{712} A dialogical and story-based interaction solicits sincere viewpoints and connects each stakeholder engaged in the conversation.\textsuperscript{713}

5.1.2.4 Practice Effective Communication

Communication enhances patient satisfaction, provides coherence, and promotes healthy outcomes.\textsuperscript{714} Effective communication connects understanding, meaning, and context between the patient and physician and thus encourages cultural responsiveness and preserves cultural competency. Even though language and communication may appear to be “the same,” they can be interpreted in remarkably different ways in what may seem to be similar contexts. Two people may speak the same language, but this fact alone does not guarantee effective communication—where both parties understand one another’s positions and points of view. Even in a case where there is an English-speaking patient and an English-speaking physician, there may be misunderstandings and miscommunications, which, in turn, create mistrust, a poor diagnosis, a wrong prescription, or an inappropriate follow up.\textsuperscript{715}

A significant and crucial challenge facing the organization is to ensure effective communication. In many ways, ineffective communication diminishes individual identity the validity of the consent and overlooks obligations the providers should afford the patient. For example, there is often less distinction between treatment and research in the case of a terminal disease. The information or explanation often comes across to the patient as abstract or merely incomprehensible, which, in turn, leads a patient, for a variety of reasons, to give uninformed
Therefore, proper communication is necessary to provide optimum care throughout the system.

Even direct scientific ways of communication often create confusion. This happens, for instance, when the language of science is used to explain treatment procedures or when the communication is written in language that the reader struggles to understand. For example, pregnant women face a decision in labor to choose a water birth or an epidural, yet often they remain confused as to which choice to make because the consent forms are not written in ways or with language the patient can understand.

The solution to this language challenge is to consciously, systematically, and operationally strive to ensure that all verbal and written language is simple, short, and direct. For complicated and complex cases, such language must not stand alone. Often in such instances, multimedia serves to facilitate a clearer understanding of the situation, which, in turn, leads to consensus. Practicing Narrative Authority helps to reveal the gap between the perceived and actual services provided. Therefore, the organization should be committed to presenting material to the patient that is understandable and culturally sensitive.

An excellent example of an effective communication practice is the attempt to find consensus. Working toward consensus diminishes the harmful effects of power and helps to ensure that each person’s autonomy is respected. Even though the physician is expertly trained to diagnose disease, he should still consider that an illness is understood differently by each patient. Hence, the system should ensure practices are in place that allows the physician and patient to see the other to reach a consensus of understanding and consent to treatment. By exercising Narrative Authority, the system will enable physicians to respond to a patient in creative ways that rely heavily on understanding the patient’s cultural worldview, her story. For instance, a direct,
science-fact way of sharing information with the patient may be counterproductive to someone accustomed to hearing good or bad news in a narrative or story-based form. The straightforward, logic-based approach, in this case, would be ineffective and inhibit the development of a prosperous patient-based therapeutic relationship.\textsuperscript{721}

For example, consider a situation when a surgeon attempts to inform a Navajo patient of the details of proposed bypass surgery. Navajo often do not respond well to direct facts or news perceived as unfavorable. While what to the physician appears as a best-case diagnosis, coupled with standard and routine procedures, may well be heard by a Navajo patient as a death sentence, and the patient then responds by refusing treatment.\textsuperscript{722} In this instance, the surgeon unwittingly undermined the patient’s autonomy. He assumed the patient was operating from the same communication perspective and worldview as his when, in fact, the patient needed to hear the doctor’s diagnosis in another way. The direct, science-fact way of sharing his information with the patient may be efficient and logical but was not effective.\textsuperscript{723}

Had the surgeon offered his assessment in a culturally sensitive language, he could have more effectively communicated his diagnosis and fulfilled his obligation to the patient. Given this scenario, it is crucial to understand a broader context: “language does not merely describe reality, language shapes reality.”\textsuperscript{724} The provider, procedurally, didn’t communicate well with the patient; thus, the power of story was diminished via assumptive thinking. Narrative Authority serves to keep both the organization’s and the patient’s stories to the fore, through which person-to-person consensus becomes possible.

Communication becomes more problematic when the patient and the provider speak different languages. To address this concern and improve the clarity and efficacy of communication, healthcare organizations should make an interpreter available. An interpreter can
help ensure that both the provider and the patient understand one another and that the patient's autonomy is acknowledged and respected. An interpreter helps to ensure both the patient and physician understand the nature and the purpose of the treatment process. An interpreter does more than convey the meaning of the words. He also provides the cultural nuances hidden within the language. Of course, it is impossible to provide all medical materials in every language. Doing so will incur a high cost and loss of resources because no one can predict how many different languages the system will encounter. Therefore, it is cost-effective for the system to situationally hire an interpreter and train them to support better care. However, the interpreter should make sure they participate by relying on the principles of Narrative Authority to ensure that the patient’s story emerges and fosters a partnership between the patient and physician. The interpreter can serve this process by ensuring that both parties understand one another. A skilled interpreter can sense when the communication is out of synch. She can help continue the conversation until she feels the translation has been properly achieved. Narrative Authority guides the interpreter by reminding her that she acts as an intermediary, illuminating details and nuance of the teller to ensure the provider can adequately direct the care delivery process. Narrative Authority also offers guidance to ensure that the interpreter does not manipulate or embellish the patient’s narrative. When hearing the patient’s story or the provider’s feedback, the interpreter must ensure that they maintain and genuinely expresses the authority of the teller—her role is that of narrative-translator.

When there is no interpreter, family members tend to speak on behalf of the patient, which sometimes causes bias and, thus, compromises the patient’s autonomy. Therefore, having access to an interpreter also reduces the risk of biased decision-making. The interpreter most often is trained in and knowledgeable of medical terminology and facilitates patient-physician communication.
Apart from interpreter service, there are times when negotiation plays a crucial role in effective communication. Negotiation is an essential component of communication. This skill helps an individual express her opinions and points of view without dishonoring the other involved in the negotiation. For instance, negotiation is essential when a patient and physician disagree about a particular medical treatment. In such cases, Narrative Authority drives the negotiation by employing open and respectful listening practices. A negotiation that Narrative Authority drives helps the physician ensure that the patient’s preferences are heard and allows the patient to understand the importance of the physician’s recommendation. Thus, mutual agreement occurs. Consensus is a byproduct of a well-rendered negotiation. Undoubtedly, negotiation is the starting point for understanding and respecting the position of the other parties involved and engaged in conversation.\(^{729}\)

Beyond treatment-option negotiation, negotiation also occurs between care providers. Confusion between providers can directly affect the care delivery. Confusion and miscommunication often cause providers to become demotivated and, in turn, provide poor or lackadaisical patient care. Skilled negotiation is a means to solve such problems. This skill can be obtained by applying Narrative Authority. By respecting others and understanding their narratives, it is possible to avoid or clear up confusion. The art of negotiation is a vital skill in the exercise of effective, other-centered communication.\(^{730}\)

Without the other-oriented approach that Narrative Authority provides, it is challenging to see and understand the other’s perspective and find the meaning to change existing practices. The competency of “being reflective” is critical of the skills required of all those in healthcare. By practicing Narrative Authority, it is possible to maintain an introspective and other-oriented viewpoint that serves to keep to the fore a range of contextual features: social norms, cultural
practices, and the nuance of language. Narrative Authority supplies a framework for creating practices that ensure introspection and reflection and serve to have each person see the other as someone with autonomy. Narrative Authority delivers an approach to see the other person, understand her story and concerns, and respond with hospitality, empathy, and respect.

5.1.2.5 Ensure Education, Ongoing Training and Development

Organizations should devote extra time, money, and effort to training and development. Cultural competence training should be provided for existing and incoming physicians, nurses, and caregivers. Ideally, the training should be offered early in a caregiver’s career before they are enveloped in the professional world. However, that reveals another systemic deficiency within medical school curricula. Healthcare organizations alone cannot shape a landscape of cultural sensitivity and diversity. The educational system must integrate such development and training into their curricula and work hand-in-hand with healthcare organizations to make cultural sensitivity normative.

The educational system is a natural place to introduce this training and development. Such education and skill-building provide self-reflection opportunities and promote the belief of equity and welcoming the other. Otherwise, the disparities inherent in the system are passed on to the next generation of caregivers. However, these efforts often neglect to address the importance of diversifying the makeup of the student body, those who will enter the profession. Having a diverse body of students will help the students and educators become accustomed to various narratives. They will learn to share their narratives and create a shared platform where diverse perspectives intersect. The educational system should bring changes in its vision to engender a diverse student body in school.
However, disparities begin before schooling. Minorities and less privileged populations often cannot find access to a good school. The underprivileged have fewer educational opportunities. Thus, fewer minorities are employed in the healthcare workforce in skilled positions. To make the healthcare system diverse, medical schools should encourage more diverse student bodies in their schools. The system needs to include health professionals from marginalized backgrounds to create a culturally responsive healthcare.\textsuperscript{734}

Skills that promote diversity cannot be attained without necessary training and development. Role-playing, diverse educational resources, and group work help students think critically and respond to change self-reflectively and in ways that are respectful and empathic to the other. Moral insights and moral questioning arise through experience. Thus, heterogeneous group interaction can help develop future practitioners who see and respect the values of different people, of different stories.\textsuperscript{735} Early classroom teaching and intervention help to promote the skills and abilities healthcare providers need to skillfully, respectfully, and confidently handle the nuances of cultural discourse.\textsuperscript{736}

Besides providing professional skills on conflict resolution, therapeutic communication, or dress codes/norms, the school should arrange hands-on clinical training sessions. Culturally sensitive clinical training is a worthwhile investment for health professionals because it offers the learner a perspective and “tool” that she can implement and apply in all situations. Clinical training should include first-hand experience working with a diverse patient body. Clinical training helps professionals to think critically and analyze themselves and others in the throes of this dynamic global arena.\textsuperscript{737}

Diversifying the workforce is another way to change the existing system positively to become culturally competitive and responsive. Appointing practitioners, staff, management, and
nurses from diverse backgrounds helps create a healthcare system's knowledge- and value-sharing platform. A minority patient will often feel more comfortable and engaged when she sees a physician from the same or similar ethnic background. On the other hand, an African American patient may feel uncomfortable when her first interaction in a healthcare system is with staff and care providers who are overwhelmingly white. Having diverse management teams also will change the perspectives throughout the entirety of the system. These leaders can promote and encourage diversity, demonstrate leadership, and hold others responsible for practicing inclusion.

Narrative Authority and the practices it evoke help to create a personal connection with each other-as-same, which, in turn, engenders a culture that feels like one integration community of practices. To be culturally competent and to encourage diversity, organizations should integrate the power of Narrative Authority into the mainstream of the decision-making process and practices.

However, training and development efforts must be seen as ongoing, founded on the credo that “there is no sufficient level” of cultural competence. The system should reassess its development needs and reflect upon the policies necessary to respond to the growing needs and priorities of a healthcare system operating in a global world. It is now possible—via technology—for more people to collaborate in real-time more frequently than ever before. Therefore, there should be yearly reviews and assessments of these trainings and educational practices to keep them up to date. Management should also hold itself responsible for remaining current on best practices. The organization's staff cannot fully exhibit culturally competent if upper management lacks or discounts the importance of or fails to practice cultural competency in everyday practices. Trust building activities within the community should also be integrated into the healthcare system.
Narrative Authority should sit as the heart of any the healthcare system, at all levels, as a means to build and maintain the trust and promises made to society.

Narrative Authority is a foundational approach and a powerful means to shift and develop practices, processes, and procedures that create an organizational culture where other-oriented caregiving can blossom. Narrative Authority is an approach founded on the belief that humans are radically social and we understand one another only through the intersections of our stories and the coherence and meaning-making that arise through these narrative acts. Embracing this perspective provides a narrative sensitivity that places the caregiver and the other-in-need-of-care in an intimate and ultimately loving relationship founded on the significance that emerges through shared stories. Narrative Authority makes possible the opportunity to construct an ethical healthcare system where practices emerge that are culturally sensitive. Such practices strive to open the space for the other to be seen in and through her story, stripped of stereotype, bias, or prejudice. An exemplary healthcare system is founded on partnerships that promote effective and ethical patient treatment. Narrative Authority further reveals how the organization itself arises from a narrative. This narrative articulates the organization’s intent, aspirations, and purpose for its existence. This narrative also shows core values, normative behavior, and best practices. It provides an aspirational goal that calls for like-minded people who bring their skills, experiences, and passions to fill required roles to make the intent real and, in doing so, create an organization that is a narrative-based community. To become an other-oriented organization, this narrative must be embedded in the fabric of the organizational culture in ways that overcome biases, misconceptions, and unquestioned assumptions that blind one to the other and create darkness where no true healing can occur.
5.2 Illustration: A Minority Religious Practices within a Dominant Religious Community

Healthcare systems, in general, are increasingly receiving patients who are ‘diverse.’ Patients from different cultures and backgrounds have different expectations and comfort zones, depending on religious practices and cultural norms. Therefore, it is critical that healthcare organizations better understand, and give a note to, the cultural and religious norms and expectations of patients who hail from ‘other’ cultures, religions, or lands.

This section addresses the normative and faith-oriented challenges Muslims face in Western healthcare settings and uses the USA as an example of the West. It also offers a practical pathway to protect the rights and dignity of Muslim patients through Narrative Authority. Narrative Authority is an approach that guides healthcare providers and patients to see and be with one another through the shared power of their stories. It is a human-to-human approach to change and reform best practices on sharing personal narratives.

5.2.1 Muslim Patients and Their Experiences in the non-Muslim communities

Islam is the second-largest religion in the world, with 1.57 billion followers. This number represents 23% of the global population. Islam requires giving one’s self over to the book of God “Allah,” The Quran (the holy book of Islam), and the words of the Prophet and the Sunnah (the prophet’s words and actions). The people who practice Islam are called Muslims. Like other religious adherents, Muslims have particular religious and cultural ways of viewing illness.

5.2.1.1 Who are Muslims?

Muslims are the people who follow Islam and the rules and guides of Islam. However, not every Muslim abides by all the same rules and regulations of Islam. The spectrum is broad, running
from devout to secular. The majority of the practicing Muslims eat meat that is termed Halal. Halal means the animal must be slaughtered following guidelines detailed in the Quran. Seafood and vegetables are by nature Halal. Pork and alcohol are forbidden. Practicing, devout Muslims remain strictly halal (not unlike remaining Kosher). Other Muslims avoid alcohol and pork, but they are less strict about how the meat was slaughtered. Also, preferences and beliefs vary depending on how an individual, or group, interprets the guidelines of the Quran and the Sunnah. Practicing Muslims, from the strictest to the secular, follow a nine-month lunar calendar. One month—Ramadan—is designated as a time of spiritual devotion. Ramadan is considered a month of supplication and solidarity. During Ramadan, healthy adult Muslims fast from sunrise to sunset. Fast is not mandated or expected if someone is ill or if the fast will cause physical or mental harm.

According to Islam, humans are the most remarkable creation of the Almighty. Humans are given responsibilities and the ability to choose to uphold the honor bestowed upon them from the Creator. Islamic tenets direct Muslims to act in moderate and balanced ways in their everyday encounters. Islam encourages each person to act in a manner that resembles the humility and modesty demonstrated by Prophet Muhammed. Practicing Muslims strive to follow the rules and words of the Quran to shape their everyday practices. However, Islamic practices vary from person to person, culture to culture, and within the two primary Muslim groups: Shia and Sunni.

For Muslims, life is considered sacred, and each moment holds high value. The majority of practicing Muslims believe that everything happens for a God-given purpose. Muslims do not always view illness as a negative. Many Muslims view illness as a blessing because when one is ill, she (1) tends to remember God’s blessing and (2) is compelled to provide charity and good work to and for others. When a Muslim becomes ill, it is viewed as a test of patience; this test
brings her closer to God. Conversely, some Muslims view illness as a punishment for impiety. They believe bodies are a gift from God, and a Muslim has to maintain a healthy physical and spiritual lifestyle to protect the God-given gift of humanness.  

Islam is a monotheistic religion, but Muslims are far from monolithic. Muslims come from various backgrounds and practice Islam differently, even though all follow the same the Quran. Besides Shia and Sunni Muslims—the two primary sects of Islam—Muslims from different cultures practice Islam differently. There are also Sufis who practice a mystical form of Islam. There is a mix of Islamic practices in the USA, given that there are American Muslims, Arab Muslims, Indonesian Muslims, and African Muslims who have come to the USA seeking a better life. Many Muslims called by the beckoning, welcoming light shining from the Statue of Liberty arrived in the USA as refugees, fleeing war or some form of discrimination. With the intersection of these populations, it is apparent that there is no ‘one Muslim’. Muslims are a dynamic mix of cultures, customs, particularities, and differences. Therefore, it isn't straightforward to know the various Islamic practices in detail, but it is helpful to understand the practices and beliefs common to almost all Muslims.

Many Muslim practitioners in the USA and worldwide read and conduct research on biomedical ethics and remain up to date with its rules and norms. They read and embrace Western medical ethics literature and apply those in their practices. However, whereas Western secular bioethics is rights-based, Muslim’s view ethics as obligation-based. The majority of Muslims believe they have an obligation to the other and right comes later after obligation; they believe in community-based practices. Unfortunately, Islamic ethics is not well-studied globally. Therefore, medical ethics, as practiced worldwide, is primarily Western. Muslims in the West—or Western-influenced systems—who arrive for care fall under the gaze of Western medical
ethics. However, it is supremely naïve and arrogant to think that these underlying Western beliefs and values best support those with different worldviews.

### 5.2.1.2 Illness Through the Lens of Muslims

According to PEW Research Center, in 2017, 3.45 million Muslims lived in the USA. This is 1.1% of the total USA population. However, this number is rising due to immigration and the arrival of refugees. According to Pew researchers, by 2050, there will be more Muslims than Jews in the USA. Islam will then become the second-most-practiced religion in the USA. Estimates predict that Muslims will account for 2.1% of the total population of the USA in 2050. Given the rise in the Muslim population, the likelihood increases that healthcare providers will encounter more Muslim patients. Therefore, Western healthcare providers must possess a general understanding of varied Muslim cultural practices and how they may shape the perceptions Muslims bring to the consultation room. To be culturally sensitive, this is a requirement to understand others' cultures and incorporate the different practices into existing practices.

To understand basic Muslim practices, it is also essential to broadly understand the psychology, thoughts, values, and perspectives of Muslims. Unfortunately, there is no significant research on Muslim populations and their psychological perspectives. However, this section explores the views of various available Muslim scholars. Analyzing the opinions of Muslim psychologists will help Western practitioners and decision-makers further understand the values, practices, and concerns of Muslim patients. The reason behind emphasizing Muslim psychologists is that they exclusively deal with this population and thus have more experience and exposure than general psychologists. Bringing them into practice would offer a more inclusive understanding of this population. Also, Muslim psychologists offer non-Islamic practitioners’ valuable insights into how Muslim’s view health and illness. In Islam, the spirit, body, and the soul have equal
importance; they are interconnected and inseparable. Most generally, Muslims believe that to be healthy. It is vital to maintain a healthy soul, body, and spirit like other religious.\textsuperscript{759}

There is a strong interplay between religion and health in Islam. According to Avicenna, an 11th Century Muslim polymath, the body is closely related to the self. He classified the body into two categories: the natural body (not man-made) and the artificial body (man-made). Human bodies are, of course, natural bodies; the body exists without human intervention. And the artificial bodies are those created by men, such as tables, chairs, eating utensils. However, the human body, again, according to Avicenna, has two levels of perfection. The first is the human form, considered as being human. The second perfection is the functions and practices a human maintains to satisfy their existence. The first perfection leads the way to the second.\textsuperscript{760}

Avicenna’s first perfection is the self; the second perfection is the biological body. If the self is not balanced, the biological body cannot function properly. The self and the physical/biological body are tightly interconnected. The self requires the body to express itself, and the biological body cannot function without the self. Avicenna argued that the ‘I’ is the representation of this ‘self.’ Our body changes over time, but the ‘I’—the self—remains the constant.\textsuperscript{761} Therefore, to treat the biological/physical body, it is essential to understand the self. A proven way to understand the self is by exploring a person’s narrative.

The Quran also explicitly mentions the importance of the patient-physician relationship. Healthcare providers are referred to as ‘Hakim’ in Quran. Hakim means a person who is wise and who is a healer.\textsuperscript{762} The Quran refers to physicians as healers, indicating the importance and sacredness of the relationship between the patient and the provider. Practicing Muslims believe that healthcare providers who are well-connected to their religion and have a solid knowledge of the Quran can treat a patient more personally and interpersonally than those who do not.\textsuperscript{763}
Islam firmly holds that illness is tied to the faithful practice of religion and that illness is given to an individual from the Almighty. Some Muslims believe that by practicing religion correctly, they can avoid or prevent some diseases. For instance, fasting helps the digestive system; it leads to weight loss, maintains a proper weight, and moderates stomach and intestinal functions. Praying—especially honoring the practice of praying five times per day—reduces psychological stress and serves as physical exercise. The postures taken during Islamic prayers are seen to be very beneficial to the body and the mind. 764

Muslims believe life is a gift or a loan from the Almighty Allah, and only Allah can heal illness. Even those who do not often pray do so when they fall ill. They want to become a practicing Muslim to fight the illness. Many Muslims ask for assistance from a scholar—an Imam—to serve as a guide when they become ill. 765 Muslims who live in a non-Muslim community sometimes struggle to find an Imam while in the hospital. Most hospitals have visiting Christian Clergy, Jewish Rabbis, or non-denominal ministers and advisors; few have Muslim spiritual counselors. Thus, unfortunately, the Muslim patient often has no one of her faith in which to find support beyond family and friends. Sometimes, the presence of a Christian spiritual counselor, at the end-of-life cases, create more stress than comfort. 766

However, Muslims, like all patients, have particular needs. Suffering and pain are existential commonalities. While Muslim patients have the exact requirements as most non-Muslim patients, there are some dissimilarities. Therefore, caregivers must recognize that they may be tending to a Muslim patient and, in turn, be sensitive to her needs. Doing so will help ensure that healthcare providers deliver culturally competent care, build trust with the patient, and provide better healthcare. Healthcare providers must embrace and welcome the differences this particular group brings to the Western healthcare system.
5.2.2 Respecting Muslim Patients’ Worldviews in the U.S.A.

It is absurd to expect healthcare organizations to have all their providers become anthropologists. It requires time, experience, and training to become proficient in recognizing cultural cues and behaviors and knowing the values, habits, and customs of different religious and cultural groups. However, it is realistic to expect practitioners to come to the examination room with an approach that welcomes the other, solicits her story, avoids judgment and stereotyping, and creates a safe space where the patient feels seen, heard, and respected. Healthcare organizations need to provide the ground and culture that acknowledges and respects the patients’ cultural and religious beliefs and social norms on which she bases their identity. Organizations should consistently encourage providers to attempt to understand a patient by listening to what her verbal and nonverbal cues reveal about her worldview. Western healthcare culture should develop an approach that helps them see the other as she presents herself, not as he assumes her to be.\textsuperscript{767}

Medicine is about healing (not fixing) the whole person. To do so, understanding the patient and knowing her story is critical. Medicine is about altering a currently displaced mood and reshaping the claim that a past trauma exerts on the present and future. According to Frohock, medicine treats the mind and the body in an integrated manner. He believes medicine is a ‘narrative form of reasoning.’ Medicine requires intuition and a bit of mystical thinking beyond scientific and logical reasoning if it is to recognize and respond to the human spirit.

Therefore, health and illness are shaped, influenced, and guided by the historical condition through which they arose; health and illness cannot stand alone. To catch sight of a patient’s historical condition, no approach is more effective than having her tell her story. Storytelling—having a patient share her context, values, expectations, beliefs about illness—allows the patient to feel heard and seen.\textsuperscript{768}
A common tendency of Western medicine is to physicalize illness. Doing so is a rational activity and seems to be the logical approach to treating a physical ailment, even mental illness. Through an overemphasis on the body and the physical manifestations of the disease, physicians are quite often blinded to the spiritual or lived existential roots of the illness and therefore miss seeing the person as a whole.

5.2.2.1 Barriers for Muslim Women in Western Healthcare

As Muslim practices are not standard, well understood, and often carry negative connotations in the West, it is challenging for Muslim women patients to feel comfortable entering the healthcare system. Considering these religious and normative concerns, it is particularly difficult for practicing Muslim women to comfortably engage in Western medical practices while maintaining their faith practices. A recent study revealed that 63% of Muslim women in rural areas in the USA do not seek healthcare or visit a doctor because they believe that doctors do not understand them. These women forgo healthcare because they believe physicians are not knowledgeable enough about Islam or their particular cultural practices and their norms. Also, Islam has strictly defined guides concerning the propriety of gender relationships, which Westerners often never consider, know exist, or consider irrelevant. This is of concern for Muslim women, especially in the matter-of-fact settings of a hospital or physician’s office.

Among many religious practices within Islam, modesty is a central tenet. Modesty can be demonstrated through both verbal and nonverbal communications and serves to preserve a person’s privacy. Modesty can be expressed through speech, dress, and behavior. Modesty is also tightly tied to gender relationships. There are many verses in the Quran that address women’s modesty. For example, “Hence, let them draw their head-coverings over their bosoms. And let them not display more of their charms to anyone but their husbands, or their fathers, or their
husband’s fathers, or their sons, or their husband’s son, or their brothers, or their brother’s sons, or their sister’s sons.” The Quran also guides men to lower their gaze when in the company of women, not of the family. It reads, “Say to the believing men that they cast down their looks and guard their private parts; that is purer for them; surely Allah is aware of what they do.”

5.2.2.2 Modesty in Gesture

Certain gestures and postures are viewed as being polite and customary in the West. For example, shaking hands, direct eye contact, touching, and hugging. For Westerners, such nonverbal communications are normative and essential to opening a shared space for a conversation, doing business, or welcoming the other. However, these same gestures from the Islamic perspective are limited to the same gender—except with a spouse or close relation, as mentioned above. For instance, a handshake with someone of the opposite gender is seen as ‘Haram’—which means prohibited. Therefore, some practicing Muslim women would be very uncomfortable if greeted with a handshake by a male physician. If Western physicians understand this boundary, they can dispense with the handshake and find an alternative means to open the space for communication. For example, simply saying “hello,” addressing the patient by name, and offering a smile would suffice.

Eye contact is another friendly and respectful gesture in Western culture. It can also signal confidence and serve to establish trust. In the West, direct eye contact sets the tone before further interpersonal communication occurs. For Muslims, eye contact—even with someone of the same sex—demonstrates a lack of respect for the other and the absence of individual humbleness. In interactions with the opposite sex, it is suggested that each lower his or her gaze; for Muslims making eye contact with the opposite sex might induce unacceptable conversation, which is haram. Proper interactions with the opposite gender are essential in Islam. In many ways, for a Muslim,
maintaining direct eye contact is a breach of intimacy that is only permitted with a spouse or immediate family members. Given this, it is easy to see how the practice of direct eye contact from a male doctor might, and probably do, make a female patient feel uncomfortable. From a Western perspective, not making eye contact can be interpreted as a demonstration of disrespect or a sign that that patient lacks self-confidence or social acumen. But, for a Muslim, not making eye contact is merely following her religious guides and social norms.\textsuperscript{778}

Touching is considered a sign of empathy in the West. Physicians tend to and are often taught to touch the patient to make the patient feel safe and grounded, strengthen the bond of the relationship, and engender trust. Touching the patient is seen as a gesture of support and kindness. Likewise, sometimes hugging a patient seems warranted because it can make a patient feel seen, welcomed, comfortable, or is a means to console an upset or fearful patient.\textsuperscript{779} However, touching or hugging someone of the opposite gender is not permissible for Muslims. Again, if a physician is unaware of this boundary and demonstrates typical Western behaviors, he is likely to make the patient uncomfortable, and she will be wary of their relationship from the outset. This knowledge gap weakens the bond between the patient and the physician and often hampers the delivery of care.\textsuperscript{780}

For instance, a Muslim woman who requires dental attention is most likely to prefer a female provider because dental hygiene and repair need the dentist to touch the face and neck. However, if a woman practitioner is not an option, the physician should attempt to minimize physical contact while examining the patient or cleaning or repairing her teeth. And generally—regardless of the kind of medical service required—a physician should not schedule an appointment during a period of fasting. Often because the non-Western Muslim patient will defer to the physician, he or she may be hesitant to mention a conflict, keep the appointment, and, in
turn, break her fast. A fast is ‘broken’ when water, paste, or other liquid or food passes into the throat. It is impossible to satisfy these criteria during a dental examination or cleaning. Knowing this would help the provider make appropriate scheduling appointments with the patient. As a note: for a medical emergency, one is permitted to break the fast.\textsuperscript{781}

\textit{5.2.2.3 Modesty in Clothing}

Wearing culturally and religiously appropriate dress is a necessity for a practicing Muslim. It is recommended that Muslim women cover themselves in a particular way, as mentioned above. Many practicing Muslim women wear a ‘Hijab’ that covers their hair; some women cover their face with a ‘Niqab,’ also called a veil.\textsuperscript{782} Also, other practicing Muslims wear neither a Hijab nor Niqab. However, many Muslim women are very conscientious about modesty, some express this by choosing to cover their faces, yet in most Western healthcare settings, these same women are asked to wear a typical hospital gown in examination and the hospital rooms. Wearing a standard open-back gown is highly uncomfortable for the Muslim women.\textsuperscript{783}

Often Westerners find themselves uncomfortable or flummoxed when speaking with or addressing a person whose face is covered. Westerners often find a hijab (head covering) or niqab (veil) establishes an unfamiliar boundary and disrupts normative interpersonal practices. However, it should be understood that such attire for the woman is culturally appropriate, religiously attuned, comfortable, and normative. Of course, judging a person because of her attire is not rational or proper, but it happens frequently. However, without an understanding of Islamic norms and given the negative perceptions of Muslims perpetuated in the mainstream media, such reactions commonly occur.\textsuperscript{784} Also, one should not interpret that a woman whose head or face is covered is a sign that she is oppressed or submitting to patriarchy. A growing number of Muslim women see wearing a hijab as empowering. They wear a hijab of their accords, not due to any male
intervention or demand. Doing so is seen as a statement rejecting the common conclusion that women can be reduced to their sexual allure. Also, many Muslim women wear a hijab as a stand and statement against societal stereotypes that a head covering is a symbol of oppression. These concepts can be challenging for Westerners to digest. In terms of Islamic woman’s religious practices. It should be understood as her choice to wear attire that makes her feel comfortable, safe, and in step with her beliefs.

The Western worldview is pluralistic—culturally, religiously, and sexually. Privileging the Western perspective in healthcare is unfair and dangerous. Healthcare professionals must expand their cultural understandings and find ways to catch sight of another’s preceptive. Healthcare providers must set aside presumptive beliefs and come to better know the patients before them in the consulting room. Understandably, cultural unfamiliarity can shake both parties. However, if appropriately understood, from the physician’s point of view, this unfamiliarly can be applied to recognize the other’s differences, query her expectations, and use these inquiries to open a dialogue, develop a relationship, foment trust, demonstrate to the person that she is being seen, and, ultimately, improve care.

For instance, facial expression is a significant component of a psychiatric assessment. It is critical to examine facial expressions, eye contact, gaze, and mannerism to diagnose a patient. In fact, for a non-cooperative patient, facial expression is a vital way to conduct an assessment because the physician understands the patient is not telling or obfuscating the truth. Interpreting nonverbal facial expression is very important in all psychiatric evaluations. In fact, in most psychiatric assessments, the assessment components can be broken down as follows: verbal, 7%; tone of voice, 38%; body language, 55%.
A Muslim woman who wears a “veil” (covering the head and face, with only the eyes visible) creates a clinical dilemma when conducting a psychiatric assessment in a Western healthcare setting. For the woman, the veil is an expression of faith, modesty, privacy, and protection from the opposite gender. How then should a male psychiatrist react to this situation? How can he conduct a proper assessment? Should the psychiatrist ask the patient to remove her veil? Will this likely make her uncomfortable and disrupt or challenge an accurate evaluation? Or should the psychiatrist accept and respect the patient as she presents herself? The latter is the better choice. However, if the psychiatrist does not understand what the veil signifies for the patient and what it reveals about her worldview, how can he or she respond in a culturally sensitive manner that promotes a proper assessment?790

Of course, there are limitations on cultural accommodation. However, approaching a patient from a not-knowing perspective will make it easier for providers to engage the patient and build trust and open a dialogue with someone whose culture with which she is not entirely familiar.

5.2.2.4 Modesty in the Physical Examination

Muslim women prefer to be examined by female providers. In particular, in reproductive, vaginal, or breast examinations, they are incredibly uncomfortable being attended to by a male physician. However, these same concerns extend to any examination, particularly those that include physical contact. A Muslim woman generally becomes uncomfortable when asked to expose her body to be physically examined, including arms and legs. She also, as noted above, prefers not to be alone with a member of the opposite sex.791

For instance, getting a Pap test done before marriage can be problematic for a Muslim woman. It is normative in Islamic cultures that a woman remains a virgin until marriage.
Culturally, it is taboo for any man for any reason to touch a woman’s genitalia. An unmarried Muslim female facing a Pap test conducted by a male doctor would find the situation extremely stressful (and, in some senses, cruel). She would prefer a female provider as a means to hold on to her norms and, often, self-worth. From the perspective of a Western provider, this problem may be invisible, given the general ignorance of Islamic values and practices and the importance it places on sexual abstinence before marriage. Also, in many situations, providers may not only be unaware of the importance of sexual abstinence in Islamic practices but may also be unaware that the process of receiving a Pap could, in other cultures, be linked to the question of sexual abstinence. This can lead to further confusion in communication because even if a woman states that she is uncomfortable with a male physician performing her Pap because of her beliefs about sexual abstinence, the doctor may still not understand that/how the Pap test could be related to sexual abstinence. It is crucial to understand the religion-specific and culture-specific needs of the patient to provide patient-centered care. Otherwise, the patient will be embarrassed in the consultation room and would not be able to express what she wanted to say.

As exemplified above, Muslim patients will often avoid care if situations regularly arise because they do not feel confident and comfortable enough to participate in a Western healthcare system. Cultural insensitivity promotes misconceptions within Muslim communities concerning the value and propriety of receiving care in the US healthcare system. When this happens, patients become frustrated and disillusioned with the healthcare system or opt-out. Muslims in these situations are left feeling as if their cultural and religious practices are not understood or respected. This viewpoint—and common belief—eventually dissuades many Muslims from seeking help even for routine issues. As a result, Muslims “stay home” and attempt to find alternative methods to heal themselves, either through their knowledge or consulting others. The
practice of self-administered medical “treatments” is dangerous and can compound what initially may have been an easy-to-fix medical concern.\textsuperscript{795}

Healthcare providers should further remember that Muslim women’s beliefs and practices vary from very devout to very secular. Muslim women do not demand that providers know all Islamic practices and norms. They expect providers to be empathetic, sensitive to their needs and respect their practices. Unfortunately, Western culture, generally, and healthcare specifically, have yet to understand the need for or importance of changing their best practices. Therefore, most hospitals and physicians do not adequately accommodate standard Islamic practices. Knowing about Islamic bioethics and attracting scholars from diverse backgrounds also add value in stemming the challenges of not knowing the other’s perspective.\textsuperscript{796} Muslim women (and men) seek a simple acknowledgment of Muslim traditions and norms are what Muslim women (and men) seek. Therefore, physicians must understand the cultural and religious worldviews of Muslim patients if they are to be treated effectively.\textsuperscript{797}

5.2.2.5 Implications of Narrative Authority

To make Muslim patients comfortable in a predominantly non-Muslim setting, healthcare organizations should place narrative and storytelling at the heart of all interactions. Narrative Authority guides the physician to ask questions that recognize the other. For instance, “How can I make you feel comfortable?” “Tell me how I can help.” By opening the conversation as such, the physician opens a space for the patient to tell her story, her personal narrative. In doing so, the patient will share information and provide insights that go beyond her physical suffering—all of which the physician can use to heal the whole patient.\textsuperscript{798} These simple and open-ended questions lead to similar follow-up queries that would not have occurred otherwise. However, such
approaches and practices must be supported by accompanying systems and complementary directives.

In terms of understanding the other, when worldviews clash, we tend to privilege our views and reject or discount the other’s perspective—we tend to close our ears and thus cannot hear. When this occurs, we close the space where connections can happen. And therefore, separation and distancing occur. At best, it becomes two people talking at one another rather than two people in discourse. Hearing, respecting, and receiving the other’s narrative discloses a space in which the physician can be self-reflective, responsive, and “in touch” with the other. Narrative Authority guides the organization and its providers to stand in a space of receptivity, nonjudgment, and compassion. It is vital to know thyself before it is possible to understand and respond to others appropriately. Without having a clear and confident sense of identity and purpose, it is often hard to engage another in an authentic and open matter. Knowing oneself involves knowing one’s personal story. Narrative Authority helps providers to see the ‘I’ as in ‘parity with,’ but not ‘superseding the other thus, this simple perspective helps to reshape and refine the culture of the organization.

Narrative Authority and its accompanying practices help us see the patient (or coworker) as a self that has an identity and is immersed in a shared world with others. For instance, it is often challenging for a claustrophobic patient to submit to a Magnetic resonance imaging (MRI). If the physician only focuses on bodily issues and ignores or is ignorant of the patient’s story and, in this case, her aversion to closed spaces, he will not recognize her fear and panic. Placing a claustrophobic patient into the MRI can have a devastating effect on and for the patient. Physicians must be sensitive to bodily ailments but also be robustly self-construal.
Similarly, a Muslim woman who is very bodily conscious will feel uncomfortable, embarrassed, uneasy, and possibly irreligious if asked to wear a ‘hospital’ gown that is open in the back and reveals her legs and arms. In turn, this will likely affect her willingness to “reveal more of herself.” The guide of Narrative Authority: know the patient first, then treat the disease. In Portland, Oregon, Main Center has set a great example by changing its revealing gown into a modest gown in terms of modesty. They increased the length of the gown and closed the back.  

Caring is a moral and ethical act that requires the physician to step into the story and worldview of the other, and remove the blinders of judgment, stereotyping, and already knowing the answer. Reciprocity and inter-presence—being-with-the-other—are required to be a proper caregiver. Generally, and for the most part, we see things effortlessly through the familiarity of our subjective lens and worldview. We believe our worldviews are valid, and we often apply rationality, logic, and certainty to prove this.

Narrative Authority dismisses this practice as deficient, contending that it misses the fundamental and ontological nature of a shared world. Narrative Authority relies on a phenomenological investigation and strives to privilege lived experience, which becomes available and apparent when stories are shared. Empathy and compassion are not within logic or rationality; they arise in the storied space we share, which connects us. Narrative Authority asks the physician to step out of the rational gaze and de-distance himself from the patient, ‘the other-as-self.’ The physician finds the patient revealed in and through her story (and himself as caregiver). Receiving her story, he finds himself and can reciprocate in kind, sharing himself with her in quest of wellbeing and healing.

A Muslim patient may seem overly quiet and reticent to speak and share from the physician’s perspective. The physician must recognize the possible cultural and normative
backstory for such behavior if he is to avoid judgment, stereotyping, or labeling. By giving authority to the revelatory nature of narrative, a physician finds an entrance into the patient’s worldview and gains access to the history required to provide patient-centric care. Narrative Authority provides an approach to ensure the patient feels comfortable and less wary of the situation. The physician asks questions that allow the patient to sense she is being seen, respected, and taken seriously. Given this approach, the physician speaks less, listens more, and responds with open-ended follow-up questions that solicit the history and the patient’s understanding of the illness. Such narrative-driven discourses reveal details and nuance—such as her take on pain, her sleeping habits, her sense of morality, and the roles she undertakes in her lifeworld—that might be overlooked through more direct and one-sided queries.

By applying a Narrative Authority, organizations can create a practice and a culture that solicits the other to reveal herself and share the meaningfulness and significance of her beliefs, concerns, passions, fears, imaginations of and for the future; in short, her worldview. Such sharing establishes the bedrock of a strong patient-physician relationship. It is a creative act that fosters trust, honesty, security. Thus, a story-driven approach can help bridge the chasm that separates Muslim and non-Muslim worldviews. Doing so is vital because Muslim patients in a non-Muslim community generally feel uncomfortable and out-of-place because of cultural (and social) barriers, misunderstanding, and stereotyping (which can occur from both sides).

Another challenge can be language; English is not their primary tongue for many Muslims in the USA. This can impede clear and accurate expression by the patient and may inhibit how she understands what the physician is saying. In this situation, it is vital to have the patient become comfortable, feel seen, and believe the physician is with her to establish clarity and understanding between them. When this occurs, defenses and suppositions dissipate, and two people share
“lived space”—two people connected and transformed through the disclosive power of story, and a therapeutic relationship form.

The practice of Narrative Authority solicits genuine encounters and promotes authenticity. Narrative Authority recognizes that, fundamentally, we are beings who face towards and share with the other. This ontological notion of connectedness can help Western physicians recognize that Muslims bring a different world-shaping narrative to the consulting room, but this worldview is not so disparate that both parties cannot find shared meaning in their essential humanness. Also, both step into the uncanny revelation of the other-as-self in doing so. From here, the physician (and the patient) finds he must serve, protect, and defend the other’s life and wellbeing. The ethical obligation to the other supersedes superficial differences in worldviews. Soliciting the patient’s story further provides the physician the context and specificity to catch sight of her world and find the experiential nature of her behavior and her reactions to and roots of the ailment. Separation is replaced by solidarity. The derogatory and supererogatory merge, and trustworthy-patient physicians relationship blossoms.

To make healthcare organizations culturally competent and culturally responsive, the organization must lead the way and understand its role, intent, and obligation as healing agents to and for individuals, the community, and society. A healthcare organization should be designed to encourage physicians to see the patients as individuals, as others-as self, and for patients to see and experience physicians as caregivers. This humanistic, narrative-driven connection opens a space for dialogue and consensus-building. The solutions proposed through the lens of Narrative Authority are intended to create practices to overcome or mitigate uncomfortable, insensitive, or embarrassing situations people from different cultures face when entering or participating in the system. A culturally competent organization encourages its providers—and places practices in
place—to solicit and understand the perspective the individual brings to the consultation room. These practices succeed when the conversation is founded on story-sharing. Within this, the nuance, detail, and specificity of the other, her beliefs, her take on illness, and, in reality, her dreams are revealed, and care can occur between two people. Narrative Authority serves as a foundational, organizational guiding principle for confronting the challenges contemporary healthcare faces in the face of globalization and multiculturalism.

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Chapter 06: Narrative Authority at the Global Level

The dissertation has explored Narrative Authority at the individual-interpersonal and organizational levels in the previous chapters. The dissertation moves from an individual to a global perspective in this final chapter. This chapter lays out two critical global issues: a global humanitarian crisis and the migration of health practitioners. The reason behind addressing these two topics is that they have created global health crises. A crisis typically unfolds over time and is often only addressed or acknowledged when the situation becomes overwhelming or undeniable. With the overwhelming situation, often we are too focused on resolving the immediate fixes of the crisis that we overlook the ethical obligation towards the sufferers, beyond safety and security. A narrative-based approach helps care professionals to understand the broader picture and helps care professionals to act in ways that honor our ethical obligations and shared responsibilities to the sufferers or victims.

6.1 Ethical Obligations in Global Health Crises

With rapid environmental changes and global conflicts, man-made disasters seem to be ever more frequent, and, with this, the number of humanitarian crises is increasing. Such upheaval hampers the operation and effectiveness of health systems, stymies existing infrastructure, and disrupts and debilitates society’s normative functioning. As a result, people, in desperate search of safety, are often displaced or become refugees. The first segment of this section addresses both the Rohingya Refugees Crisis that happened in Myanmar-Bangladesh in Southeast Asia and the Covid-19 Crisis among Nurses, in particular. The third part of this first section offers a narrative-based solution to address the challenges of both the crisis and suggests how to respond to such crises more efficiently, effectively, and humanely.
6.1.1 Unintended Consequence of Post-disaster Management

A disaster causes many injuries, fatalities, illnesses, the loss of family and loved ones, the destruction of property, and the shattering of neighborhoods and communities. These issues give rise to the immediate need for physical and mental health support. However, the first responders often get so deeply engaged in ensuring safety and security that mental health needs are neglected. Frequently, intervention efforts overlook the humanity of those in need and, in turn, infringe upon or discount their dignity. Culture helps a person and often when people face disaster, they tend to forgo the impact of culture that shapes a person. Culturally inappropriate behavior can also be hurtful and distancing when providing support to the victims, which is often neglected because of the urgency of safety and security. Regardless of the situation, it is mandatory to acknowledge and be respectful of the other’s cultural practices and beliefs.

The appropriate recognition and consideration of another’s culture and religious practices positively contribute to the success and accuracy of care. In fact, language plays an essential role in post-disaster management, as disaster brings diverse groups of people together in the same compound. So when caring for the people in need, it is important to keep in mind that it is not about the physical health of those people but also the mental health, which is in separable from the physical health. ‘Rohingya Refugee Crisis’ is used as an example in this chapter to demonstrate the humanitarian crisis and how we often time think about the action to fix the immediate need and forgo the long-term consequence.

Rohingya refugees are victims of ethnic cleansing. Myanmar has forced the Rohingya to flee or face death. One of the preferred destinations for this displaced population is in Bangladesh. Based on ethical sensitivity and social obligation, Bangladesh opened its borders to this needy, exiled population. Acts of non-consequentialism, focus on the noble act but not the
consequence, by Bangladesh set an example, sending a clear message recognizing the communal nature of humanity, and the obligation not to isolate or shun a particular ethnic group.

However, in making its noble decision to welcome the Rohingya, Bangladesh failed to fully judge and prepare for the actual consequence of receiving the refugees. Bangladesh’s act served to remedy the short-term need of this displaced population—making sure that the Rohingya found safety and comfort—but the unplanned situation has caused complications and unforeseen and unintended consequences. This is evident in the discrimination they face in Bangladesh and the high number of post-traumatic stress diagnoses among the Rohingya; the effects of these psychological wounds will prove to be a long-term concern for this population and Bangladesh.

The first section addresses the noble, ethical act Bangladesh performed in welcoming the Rohingya and raises questions about the unintended, long-term ethical consequences for this displaced, fragile population.

6.1.1.1 Rohingya Refugee Crisis

A real-life example illustrates the severity of Rohingya refugee crisis. Mubari, a 10-year-old child, is forced to flee on a boat, leaving his parents behind in Myanmar. The boat travels on rough waters for 20 days; there is not enough food. Because the boat is overcrowded and unsteady, the boat keepers beat the frightened passengers with belts and iron rods should they dare move or change their assigned positions. The boat’s seaworthiness is so fragile they are prohibited even to stretch their legs; this they must endure. The purpose of this treacherous journey for Mubari and the others is to make way to an unknown land and undefined security, abandoning a life which each may never see again.\textsuperscript{812}
There are thousands and thousands of stories like Mubari’s; children and women separated from their family and homeland with no guarantee of safe landing or a secured life elsewhere. However, the story of their suffering does not end with the migration phase. Instead, the story expands after the Rohingya arrive in Bangladesh, where, in many cases, they face another form of social discrimination in the host country. The physical and psychological trauma these refugees faced during the migration phase is nearly incomprehensible to those who have not witnessed it. In most cases, the immediate concern for the host country is to attend to the health care needs of the needy—short-term intervention. However, the nature and urgency of the situation ignores the long-term impact of the mental health crisis among this population.

The Rohingya are an ethnic group in Myanmar, which is primarily Muslim. They are not considered one of Myanmar’s 135 official ethnic groups; thus, they face persecution. Due to ongoing violence, discrimination, and deadly intimidation, hundreds of thousands of Rohingya have been forced to flee to neighboring countries. As of February 2021, at least 980,000 refugees had sought asylum and shelter in neighboring countries. Bangladesh is one of the host countries among the others. Nearly 890,000 Rohingya refugees reside in the Cox’s Bazar region of Bangladesh in “Kutupalong” and “Nayapara” refugee camps. These are the most densely populated camps in the world as of the year 2021.

The camps are overcrowded, and the living conditions are deplorable. Malaria and diphtheria spread quickly, causing significant problems for the refugees and the overtaxed aid workers. The refugees also struggle to gain access to clean water and hygienic food, further exacerbating the problem for these stateless people. Beyond the unhealthy living conditions, most Rohingya can find no work or employment. This only fosters and compounds the symptoms of post-traumatic stress and negatively affects their identities and agency. Their stories are complex
in every dimension: personal, social, physical, and psychological. All these dimensions collectively create a complicated situation and create significant ethical concerns for Bangladesh.817

6.1.1.2 The Concerns of Bangladesh

The Bangladeshi government followed the noble path in welcoming the Rohingya refugees into the country. It is considered a deontological action. Deontology contends that if the action is morally right, then the action must be taken because the value depends on the nature of the action.818 The Bangladeshi government acted morally and ethically from a human rights perspective and welcomed this vulnerable population. The government realized that this was the right thing to do, and they did it. Bangladesh is a resource-limited country, and it is already overcrowded. Bangladesh—which is about half the size of Germany—is a densely populated and emerging country. Bangladesh is ranked as the eighth-most populated country in the world. As of June 4, 2020, the population of Bangladesh was 164,564,713.819 Therefore, welcoming the extra group of population created a negative impact in many ways.

What Bangladesh has missed is the consequence of the act. In many ways, the country’s leaders failed to consider the more significant implications of this noble and necessary action. Consequentialism addresses and relies on the importance of the outcome from a particular action.820 The authorities in Bangladesh did not address this well. They followed the deontological route rather than consequentialism. However, and unexpectedly, a single action can have many different dimensions. Therefore, before taking the ethical and morally founded action in welcoming the Rohingya, the full scope of the consequences of the initial decisions should have been considered.821 In not doing so, Bangladesh now faces many unintended consequences, resulting from their ethical decision.
Even before this current crisis, Bangladesh suffered the ills of overpopulation and overextended infrastructure. The enormous influx of refugees has proven to be an extremely social and fiscal burden on an already resource-taxied country. In many ways, the citizens of Bangladesh see the crisis and the Rohingya as a threat to their own and the country’s well-being. The citizens of Bangladesh have started to suffer; they are feeling threatened because of the presence of the Rohingya population in their already stretched resources. Thus, the citizens have become less welcoming and are expressing a more self-protective nature. As a result, the refugees often face discrimination within the host country for merely attempting to gain access to health care, food and water, and work.822

Bangladesh acted ethically in welcoming the refugees but now struggles to maintain its ethical intent with ongoing ethical actions and policies. To promote integration, Bangladesh has allowed many Rohingya to become citizens. In doing so, ethics demands that Bangladesh provide the Rohingya-Bangladeshis equal access to all available services and resources.823 Unfortunately, the government, for all its good intent, has proven incapable of delivering equality due to scarce resources; therefore, the refugees continue to find themselves as outsiders, facing discrimination, prejudice, and isolation.824

Beyond the perils and horrors of their original journey, this vulnerable population now finds themselves further wounded by the citizens of their new country. The traumatic conditions in their migration process resulted in severe mental health concerns and a range of psychiatric disorders, which often go unrecognized.825 No one should place blame upon the shoulder of the Bangladeshi citizens. Even before the arrival of the Rohingya, Bangladeshi citizens faced immense suffering within the confines of their own country. The Rohingya find themselves fighting for the same scarce resources with Bangladeshi citizens. Now, Bangladeshi citizens are seeing the refugees
as outsiders. This conflict between Bangladeshi citizens and the Rohingya is one of the significant unintended consequences of the act to accept the Rohingya.\textsuperscript{826}

This is not uncommon. Not only Bangladesh faces the unintended consequences of noble acts of welcoming refugees. But, resource-rich countries like Germany also face immense challenges after receiving millions of refugees from Syria. Until 2017, Germany was able to manage the refugees, but after 2017, their resources have become over-stretched, thus facing increasing challenges on many fronts. Covid-19 has only exacerbated the problems.\textsuperscript{827} So, the unpreparedness of crisis management in a humanitarian crisis has global importance. This requires individual and international attention. Of course, it is a moral duty to stand up and positively respond to a humanitarian crisis, but embracing these ethical actions will incur challenges, often unanticipated by the host country, which must be considered. To properly stand beside others during a crisis, governments must plan for the management and allocation of existing resources.

6.1.1.3 A Humanitarian Concern

The Rohingya refugee crisis is a Humanitarian concern, which, by definition, requires every possible effort to mitigate the refugees’ sufferings. Even though it is an immediate and large-scale emergency, focusing only on the current and short-term issues will not generate the conditions for the refugees to build new and positive lives.\textsuperscript{828} Focusing on relocation, smooth journey, and safe arrival does not end the ethical obligation of Bangladesh to the Rohingya. Humanitarian action demands a longer-term commitment to reduce the Rohingya's suffering and continues to create the conditions by which the refugees can become integrated and accepted into the larger community. However, as of now, these follow-through actions are not being taken, and the Rohingya continue to find themselves subjected to discrimination, with limited access to food, clean water, healthcare, education, and most importantly, respect and dignity.\textsuperscript{829}
Humanitarian actions are understood to fall within three different categories: the well-being of humanity, the alleviation of suffering, and the humanitarian crisis. The ‘well-being of humanity’ considers the physical and mental well-being of a person. It is not about what is absent and what is present. But, the overall lived experience is considered under the well-being of humanity. That accounts for the norms, values, preferences, and overall lifestyle. On the other hand, ‘alleviation of suffering’ includes the missing pieces in one’s life, which often reveals an individual’s vulnerability. The vulnerability could be the access to food, safety, security, medicine, etc. When attempting to alleviate suffering, people in need will clarify what is required to provide them security. And during ‘the humanitarian crisis’, it becomes quickly evident that inhuman situations are occurring, and those affected require attention and care. The decisions to intervene usually focus on how to rescue the victims most efficiently. But through the lens of efficiency, the overall wellbeing of those in need may, as a result, be overlooked. For instance, the goal may be to rescue 200 refugees in a week, keep them safe, and give them food and shelter. However, how these people will operate in confined to small spaces for months or perhaps years must be considered. How will such conditions affect their mental health and physical wellbeing? These possibilities must be taken into consideration responding to a refugee crisis. In the case of Rohingya refugees, the issue is only dealt with through the lens of alleviation of suffering and the humanitarian crisis. But the part of the well-being of humanity is not well understood or well taken care of. There was lack of dignity and respect. The lack of attention to the well-being of the Rohingya gives rise to the question of human rights.

Tension arises when considering whether the human rights framework fits within the scope of humanitarian actions. Human rights are broadly concerned with improving the human condition, not specifically responding to the immediate suffering a crisis produces. However, by looking
more closely at human rights, we can reimagine those human rights are inseparable from ethical responsibilities. Human rights and humanitarian actions are thus embodied and intertwined: one demands the other. The perspective of human rights, arising first in the Enlightenment era, gave rise to beliefs that assume humanitarian actions and human rights are inseparable. The notion of rights intertwined with action constructs the platform for humanitarianism. Therefore, focusing only on the short-term needs of the Rohingya violates the human rights of the Rohingya refugees.

Countries and NGOs must develop an expanded vision of humanitarian relief, which, from the start, produces short- and long-term intervention strategies. Relief efforts should be structured to support refugees whose lives continue, albeit somewhere other than home. Everyday needs will arise, and their wellbeing should not be overlooked or compromised. The short-term support does not encompass the full range of responses required. Recognizing the agency—the humanness—of those affected by crises and understanding and appropriately responding to their needs to be an integral component of strategy, planning, and implementation of relief action, both near- and long-term. The ethical responsibility of all stepping in to assist and support those affected by a humanitarian crisis is to plan and pledge long-term subsidies to the countries and communities in need. Those implementing and supporting these actions must also always remember that those in need are people in need of care. Policymakers and all managing or funding these efforts must not come to see them in the abstract and overlook their humanness.

6.1.1.4 A Global Crisis

Many emergencies result from a crisis generated by an unpredictable event requiring immediate intervention. However, many emergencies do not rise suddenly; the crisis unfolds over time and is only addressed or acknowledged when it becomes “immediate.” The refugee crisis of Rohingyas in Bangladesh falls into the latter category—it was many years in the making. The
truth is the crisis has numerous causes with multiple actors. The magnitude of the situation demands a response and intervention that is regional and international in scope.\textsuperscript{836}

Because of globalization, it becomes easy to imagine the broader and collaborative role other countries can take in responding to this crisis. Responding to a humanitarian crisis, the Rohingya should no longer be viewed as distant and without local concern. Instead, given the ever-interconnected nature of the world, the humanitarian crisis should be seen as a collective, human obligation to the rest of the world.\textsuperscript{837} In the case of the Rohingya crisis, this indicates, in part, that the response should not be merely to provide immediate care and a short-term solution but be embraced in ways founded on the long-term enlightenment of human kindness and care. The humanitarian response should be shared and focused on the long-term needs of the Rohingya and Bangladeshis, which, in turn, is in the best interest of all, globally.\textsuperscript{838}

Tying the moral and ethical considerations to a crisis like the Rohingya is a recent historical phenomenon. We recognize the ethical obligation to do no harm to others, yet, conversely, the obligation to help those in distress is often overlooked.\textsuperscript{839} We harm one another by allowing the other—in this case, both the Rohingya and the Bangladeshi citizens—to fall below the standard of living that they held before this crisis. The goal of the intervention, regardless of the nature of the original decision to act, must be structured to create healthy, safe, meaningful, and culturally sensitive conditions that lift all groups to higher standards of well-being.\textsuperscript{840} Therefore, if distressed people are suffering, society must act ethically on their behalf. To do otherwise violates the ethical principles, abdicates moral obligations, and allows harm to come to others.\textsuperscript{841}

There is a debate between the egalitarian and efficiency-grounded models for treating suffering. The egalitarian model favors treating those most severely affected by the crisis. The efficiency model believes the response should be based on ensuring the maximum impact given
the scarcity of resources. But because contemporary disasters affect people immediately and disrupt their everyday lives and well-being, it is near impossible to abandon the egalitarian perspective.\textsuperscript{842} It is best not to ascribe to only one of these models but apply both as required. The goal of planning, in this case, is to lift the refugees to a common and improved standard of living as well as give a sense of security to the Bangladeshi population. But the question is—can this be done within the capacity of the Bangladeshi Government?

The Rohingya refugee crisis requires both internal (Bangladesh) and external (international) intervention and assistance. The disruption of hundreds of thousands of lives demands an expanded perspective and a broad, coordinated response.\textsuperscript{843} Humanitarian actions are signs of the virtues of civil society. Situations such as the Rohingya’s create tension between ‘value rational action’ and ‘instrumental version of liberal ethics.’ Value rational focuses on justifying the self-perceived value in reducing suffering. On the other hand, instrumental orientation requires responsibility, productivity, and situational engagement.\textsuperscript{844} Both approaches are required to help the displaced people in this humanitarian crisis. Because one complements the others, and it is necessary to secure human rights for the vulnerable population.

The Rohingya refugee crisis demands humanitarian aid. It is high time to think politically and act accordingly. The international organizations and partner countries should act upon the ethical, normative obligation to help others. It is a moral, social, and ethical obligation to distribute relief, especially when the host country, Bangladesh, is overwhelmed and crippled by the disaster event.\textsuperscript{845} It is not about merely providing money and short-term resources but developing strategies, processes, and networks to raise the living standards and well-being of both the Rohingya and Bangladeshis. In making their initial and nonconsequential ethical decision, the Bangladeshi government hoped strong international support would follow. This has yet to happen.
And the light of hope has dimmed with time. Bangladesh’s lack of long-term planning and resources continues the crisis and the unintended consequences of their ethical goodwill mount.\textsuperscript{846}

In the face of ethnic cleansing, the Rohingya have been forcefully displaced from Myanmar, and hundreds of thousands have found a haven in Bangladesh. However, this displaced and fragile population finds itself without food, health care, and work in Bangladesh. They also face discrimination by the Bangladeshi people, who believe they are fighting for access to the same limited economic resources as the refugees. This is a significant unintended consequence of a non-consequential, noble act made by Bangladesh’s leaders. Ethics and action have helped create a place for the Rohingya in Bangladesh. However, their migration is far from complete. The successful completion of the migration will not happen until conditions permit the Rohingya to live lives of meaning in which they participate and contribute to the welfare and benefit of their new country—living lives that are prosperous for all. At the same time, the citizens of Bangladesh need to feel safe and not threatened by the presence of the Rohingyas. Yet this will not happen without global support and a long-term humanitarian vision to this crisis management.

6.1.2 Moral Distress and Moral Injury During the Covid-19 Pandemic

This section used the Covid-19 pandemic as an illustration to demonstrate the 2019-21 global health crisis and how a narrative-based approach can help in response to this crisis. Frontline workers, globally, face severe mental health challenges as they attempt to respond to and work through the pandemic.\textsuperscript{847} Healthcare providers, like all people, have families and loved ones in their lives. In this Covid-altered landscape, nurses confront choices that are often morally and ethically challenging: E.g., fairness and justice, duty to care, professional integrity.\textsuperscript{848} They find themselves with competing obligations to work and their duties to families and loved ones. This
gives rise to a dilemma that is often experienced as a conflict between professional duties and personal responsibilities.

COVID-19 has disrupted our medical systems, society, and healthcare practices. The fear that it will happen in our hospital, fear that it will overwhelm the system, fear that it will return in second and third waves murmurs in the heads of every healthcare worker. This fear has immense impacts on medical staff's mental and emotional well-being, especially nurses. As a result of the pandemic, the practice of nursing could be significantly changed. This section explains the ethical dilemmas nursing faces during this pandemic and the moral distress that arises when caring for critically ill patients with COVID-19. The dissertation argues that it is high time to consider this moral distress as moral injury and suggests a narrative-driven approach to overcome the challenges.

6.1.2.1 COVID-19 and its Impact on Nursing

Nurses are an integral part of the health system. With the uncertainty of COVID-19, nurses face new, daunting, and extreme challenges. During the pandemic, nurses work long, arduous shifts for extended periods. As a result, many are experiencing severe emotional trauma. Many nurses feel overwhelmed by the massive number of patients needing care while being immersed in settings full of contagion. As the number of confirmed cases continues to rise, nurses face high-stakes, decision-making challenges that affect both their professional and personal lives. 849

Given the severity of the crisis, a significant shift occurred in terms of ethics. The quick change from patient-centered ethics to public health ethics presents a substantial challenge for nurses. Whereas public health ethics focuses on equity, the common good, and the risk and benefit to society, patient-centered ethics focuses on the duty to care for a particular patient. The focus of public health ethics is the greater good for society, while patient-centered ethics focuses on the
Within a few short weeks, the nursing profession was directed to apply public health as the guiding dictate when caring for patients. This transition is challenging, cumbersome, and rubs against many basics of nurse training. In the USA, nurses are trained to provide patient-centered care or an autonomy-driven approach. During the pandemic and given the scarcity of resources, nurses often have no other choice but to be paternalistic in their practices. Nurses become directive in allocating resources and their time. Even though a patient may want more comforting care, a nurse must leave this patient unattended to serve another more vulnerable patient. Situationally, and in short order, nurses have become directive decision-makers, which runs counter to their ethical directives, and the values instilled by modern patient-centered medicine.

Nurses who routinely face difficult situations now confront conditions that most have never experienced before. Nurses are called on to provide end-of-life care to Covid-19 patients without the patient’s family and loved one’s present. Closure for family and friends is delayed or does not occur. Patients are relegated to FaceTime, and other video means as ways to communicate, often to say goodbye, sometimes not even that. Nurses are placed in the position to tell families they cannot visit. Nurses are called on to enforce new protocols and policies. More so, nurses find themselves anxious about carrying the weight of being “family” to the patients, many of whom will not survive the virus. These changes, and particularly taking on the role of surrogate “family” give rise to distress that can become injurious to the caregiver. In the maelstrom, it becomes more difficult for nurses to separate what needs to be done and what ought to be done. Nurses thus experience moral injury, which is a long-lasting psychological and emotional effect that arises from actions taken that run in opposition to one’s personal moral values or beliefs.
Moral injury occurs when the people failed to uphold their moral values or beliefs. Nurses are morally and ethically obligated to provide patients with the best treatment.\textsuperscript{853}

\textit{6.1.2.2 Ethical Dilemmas in Nursing}

In this altered landscape, nurses confront choices that are often morally and ethically challenging, such as:

- \textbf{Fairness & Justice}

  During the COVID-19 pandemic, even the wealthiest countries have relied on triaging as patient demand overwhelmed available resources. However, the practice of triage and prioritization gives rise to ethical questions. During this chaos, nurses must decide whom to provide care and resources and how long to tend to this patient. These are perplexing ethical and moral dilemmas.\textsuperscript{854} In parts of the world, the number of patients hospitalized due to COVID-19 has depleted the available ventilators supply. Despite the lack of resources, every nurse continues to have an obligation and duty to treat the patient at hand. Nurses find themselves forced to make moment-to-moment ethical decisions on who should receive treatment. Who should be seen first, who should be seen later? How much time to allocate at the bedside? How to address the grief? All these choices confront core ethical questions which revolve around preserving the life and dignity of the individual patient. This situation is highly stressful. Such choice-making often falls outside the realm of nurses’ training and expertise.\textsuperscript{855}

- \textbf{Duty to Care}

  Nurses are trained to care for patients with empathy and expertise. However, patient-centered care is not always possible due to a lack of resources. Nurses are asked to make tough ethical decisions contrary to their training and the core human concern for the other’s well-being. With
the debilitating nature of COVID-19 and its deadly intensity, nurses are forced to follow the guides of public health ethics, some of which are significantly different than those of patient-centered ethics of care. Public health ethics holds the community’s welfare as a greater good than the well-being of an individual patient. Whereas in care ethics, a nurse must care for the patient at hand and serve through the ‘actual giving of care’ while respecting the dignity and worth of each patient. Moral distress occurs when nurses cannot follow their moral convictions; COVID-19 places nurses in situations where they are forced to choose one patient’s well-being over that of another. As a result, the nurse is unable to provide due care to all equally.856

Being forced to make a clinical decision in the face of limited resources is a heavy burden for nurses. It is emotionally challenging to force a nurse to pick between what is morally right and what is viable or affordable in each situation. The tension arises when deciding between individual needs vs. community need.857 Also, a nurse is obligated to provide compassionate care to each patient. However, during this pandemic, nurses cannot provide this level of care due to time, resources, and facility constraints. As a result, many nurses are taken by a sense of helplessness, question their abilities, and are forlorn and frustrated at the bedside of a patient who is cut off from family and friends, dying alone.858 “That’s a tough thing to watch every single day, to watch somebody die without their family there,” said Jennifer Mueller, RN, in recent media news report.859 Nurse Mueller spoke about her experiences as the pandemic was unfolding and the heavy toll it was taking on her and others as they witnessed patients dying every day, many of them dying frightened and alone. Facing death is daunting; doing so without loved ones near makes the process even more challenging and cruel. Mueller's statement clearly and succinctly reveals the trauma she and many nurses faced in the throes of the pandemic.
The inability to provide care to all presents near-insurmountable ethical dilemmas. Nurses struggle mightily to adapt to this “new normal.” Many have difficulty responding to the excessive traumatic stress they face and, as a result, may develop post-traumatic stress as a byproduct of making untenable ethical decisions. Nurses need support, coaching, and reassurance that “the less than the adequate care” given in the name of social welfare is not unethical or done to harm individual patients intentionally.\textsuperscript{860}

- **Personal Safety vs. Professional Integrity**

Nurses, like all people, have families and loved ones in their lives. Nurses find themselves with competing obligations to work, family, and loved ones. This dilemma is a conflict between professional obligations and personal responsibilities. How can nurses balance or make peace with this predicament? On the one hand, there are obligations to virus-sickened patients staring at them for help and assurance. And on the other, the embodied duties to those they love and depend on in so many common ways.

Beyond these ethical challenges, the scarcity of personal protective equipment (PPE) adds further confusion into nurses' decision-making landscape. The United States, as do many other western countries, struggles to provide adequate protection to frontline workers. This gives rise to another ethical dilemma nurses confront. Nurses face the obligation to care for patients, but they also have the right and responsibility to care and protect themselves and their families.\textsuperscript{861}

- **Re-narrated Job description**

Most nurses in the United States and other wealthy countries have little experience practicing medicine in a compromised, overwhelming situation like the one COVID-19 has created. During their education and clinical training, nurses generally have ample resources and support. Nurses
are not trained for situations like the one they are now immersed in. Many nurses find themselves overwhelmed, uneasy, confused, scared, angry, yet committed to their nursing roles—often while compromising their health and that of those they love. Furthermore, nurses (and all staff) find themselves as innovators, problem-solvers, and sometimes mechanics, finding creative ways to stretch or re-allocate scarce resources or re-purposing one thing to do another.

Nurses applied insight from handling Ebola patients, and they used their knowledge, expertise, and creativity to construct a lightweight, protective shield. Eighty-one thousands of these shields have been distributed. Another group of creative nurses implemented virtual rounds for the families of patients who cannot visit in person due to Covid-19 restrictions. They called their virtual visits “Real Talk Real Time” in the best possible way to bring the family and patient together. Another nurse invented a “code card” to help the care team provide important messages quickly and effectively in a patient room, saving others from entering and risking infection. The idea for the code card came to her after she experienced her first code blue incident at the ICU. These are only a few of the numerous examples of nurses as active innovators, problem-solvers, and leaders. In the face of the COVID-19-related challenges, nurses have naturally taken on the role of just-in-time innovators. Some nurses have also found ways to use digital technologies to ensure social distancing in the hospitals.

The crisis came with no playbook that accounts for the intensity of the illness or the lack of resources. Thus, nurses are creating new practices or adapting current practices to tend to those they find in need of care. Nurse are learning, creating, and applying new skills and processes on the fly within the middle of the crisis. Even though, the innovations the new roles are adding more to their plates, these are giving them a sense of accomplishment. The added role creates ongoing ethical challenges to their professional integrity and gives rise to moral distress.
6.1.2.3 Moral Distress (MD) and Moral Injury (MI)

Many nurses and healthcare professionals are likely to experience post-traumatic stress because of serving during the COVID-19 crisis. The ethical dilemmas mentioned above, alone or in combination, can lead to severe moral distress. Moral distress occurs when a person acts in a way that goes against an established ethical and moral response to a situation. Institutional and structural limitations have placed nurses in positions where they must make a series of decisions, shift after shift, minute by minute, which run counter to their training, responsibilities, and personal beliefs. Repeatedly these decisions are made knowing they do not best serve a particular patient.\textsuperscript{865} As a consequence of COVID-19, various mental health problems are surfacing, leading many healthcare professionals to seek counseling and support services. Tragically, there has also been a spike in suicides among healthcare professionals during this pandemic.\textsuperscript{866}

Nurses are critical to the administration of excellent care. They are even more focal during this crisis because they play expanded and multiple roles simultaneously: conducting screening processes, attending to the critically ill, deciding triage protocols, contacting and updating families, and informing the family of the death of a loved one. In many ways, moral distress in this situation might be better seen as moral injury. These moral injuries may be long-lasting due to the intensity of the crisis. Post-traumatic responses are highly likely as a result. During this crisis, many nurses struggle to share with others the effect of seeing someone die, knowing the reality of the situation did not permit them to provide the care that was needed or necessary. Here is where the seeds of moral injury are sown.\textsuperscript{867}

Moral injury is the term that is used in the military. Moral injury is a long-lasting emotional, psychological, social, and spiritual effect from actions taken that run contrary to one’s moral values.\textsuperscript{868} The stress nurses experience will not only create moral distress but will have a lasting
impact. Therefore, the term moral injury is best used in the context of COVID-19. However, some scholars argue that the term moral injury is inappropriate for medical professionals. The argument is the scenarios in war and the scenarios in medical practice are significantly different.\textsuperscript{869} However, the gravity and the complexity of COVID-19 have erased many of the distinct differences between military and medical workers' experiences. As experienced, in chaotic hospital settings, caregivers frequently depicted their situations using battlefield and war analogies.\textsuperscript{870} The volume of deaths and the high number of critical patients give rise to the battlefield and war metaphors to describe the clinical scene. The results seem to be the same or eerily similar regardless of terminology. Given the duty nurses take on during this crisis, there are clear and abundant signs of psychological distress that must be recognized and addressed.

Nurses may find difficulties translating their moral decisions into moral action due to the lack of sufficient healthcare ethical training and education. Ethical training is necessary to educate student nurses and new nurses on ethical concepts and methodologies to recognize and respond knowingly and appropriately when encountering ethically challenging situations.\textsuperscript{871}

6.1.3 A Narrative-based Responses to Global Health Crises

Both crises mentioned above—the Rohingya refugee crisis and the Covid-19 pandemic—have shown the advantages of a narrative-based response to overcome the challenges. First, the obligation of those providing relief is to respect disaster victims. This can be demonstrated by honoring the other’s personhood equally, regardless of her condition, culture, and language. When someone is in danger, protecting their physical needs are essential, but the intervention will not be sustainable or effective without incorporating a human-centric approach. Each victim must be seen as a person, an individual who has a story. The stories the refugees tell reveal their hopes, beliefs, and their physical and psychological desires for wellbeing. The call of the provider in these
situations is to be-with and attuned to the victims’ stories. This primary obligation of being-with-the-other can be met and experienced if providers understand the importance of narrative. Thus, establishing such practices can be informed by and grounded within the principles of Narrative Authority (NA). NA addresses this challenge by calling on and extending the ethics of engaged presence. NA encourages the rescues teams, the care providers, and the authorities of Bangladesh to embrace and apply its three components (described in Chapter Two) to ensure a humanistic, story-honoring approach to care (figure 2): Open Listening (not knowing), Storied Hearing (attention to), and Shared Healing (responding to). These three components of NA provide the means to understand the other’s situation and offer practical tools to be-with, or more, broadly provide an engaged presence in relationship with others.

Secondly, moral injury can be more fully comprehended and addressed through the lens of Narrative Authority. The components can also be used for self-assessment. Through the embrace and practice of the three components of NA, nurses can better comprehend the severity of the situation, appreciate their own needs, and more confidently express them to others, and be in a more stable position from which to support, comfort, and to console and be-with their colleagues. And once nurses catch sight of their predicaments and articulate how they have been and are being affected by the loads they are being asked to carry, they can better choose which forms of self-care and relief work for them.

Narrative Authority helps expand the notion of engaged presence by offering three interrelated practical concepts and tools. Engaged presence helps care providers and support staff understand, recognize, and honor the fear and danger victims face. And to recognize moral and ethical responsibility is to be present with and for the person or people being attended to. Narrative Authority provides a narrative-based and human-centric approach through which the
provider falls into relationship with the other, sees themself in the face of the other, and recognizes their obligate to care for the one standing before and with them.

Narrative Authority also serves a means to ensure best practices are being attended to an improved. At the heart of NA is the call to consistently question or validate operating assumptions. The benefit of such question is to limit the unintended consequences or actions assumed to be correct or normative. For instance, in both of the examples cited above, NA helps us understand, for instance, that while safety and security are essential, but a person cannot live well if other needs and desires are not met. A victim of a disaster has the right to lead a dignified life, and that life needs to be addressed. A nurse has the right to have the severity of her situation recognized and addressed. Knowing their stories and engaging with the victim in good conversations will help to understand the mental and spiritual needs of a victim and that needs to be well taken care of.

In Chapter 02, the dissertation ‘Dignity Enhancing Care’ is mentioned. That care model is highly applicable in terms of the Rohingya Refugees. Dignity-enhancing care uses lived experience as a starting point. It employs interpretative dialogue as a normative standard to access and catch sight of the other’s worldview. To respect a person’s dignity, it is imperative to understand the wholeness of the person; this is had through effective communication, based upon Gastmans’ normative standard. So, it is essential to protect the dignity of these refugees. Only offering shelter is not sufficient; this approach will create adverse effects, which are already apparent. Gastmans’ framework needs to be incorporated in the policymakers planning. And that cannot be implemented without the change of mindset that understand the importance of narrative and consider the benefit of narrative-based conversation. And it is here that Narrative Authority provides the means and tools to ensure dignity enhancing care.
To provide dignity-enhancing care, the ethical attitude of attentiveness must also be developed, embraced, and practiced. Attentiveness is engrained in NA via its three interrelated components of Open Listening, Storied Hearing, and Shared Healing. These concepts must become ingrained in Bangladesh or any the country’s, in general, administrative affairs and training methodologies and serve as the foundation for understanding best practices. Through the tenets of dignity-enhancing care as supplemented by NA, the Bangladesh Government can take responsibility to respect the refugees-as-self. This is a human-based means to help support those in need. As a story-sharing approach, NA by nature serves to build relationships.

For nurses, the experience of the Covid-19 pandemic has inflicted severe and unprecedented trauma. The practice of Narrative Authority offers a practical pathway upon which they can interpret and respond to these extraordinary encounters in ways that promote self-care, healing, and well-being. Narrative Authority, as both an approach and a tool, helps nurses recognize their situation in terms of their stories, beliefs, concerns, and the significance of those people who have a place in their lives. As a result, the necessity to embrace self-care strategies becomes apparent, activities through which moral resilience is built and strengthened. Moral resilience buffers frustration, helps nurses remain buoyant, and generally become more responsive to and confident to initiate change. Thus, through the embrace of NA, nurses become more story-driven and better attuned to what they need to do to remain healthy given the sudden onset of this new-normal.

It is important to restate that focusing on personal narrative helps nurses recognize the reasons and importance her role plays in the formation of her identity. This attention helps to clarify for the nurse why self-care is essential. If a nurse comes to work unhealthy, there is a greater likelihood of making errors and mistakes. And there is the certainty of becoming further stressed,
fatigued, and burned out. Therefore, providers need to self-care first before they attempt to help others.\(^875\)

During a global health crisis, it is also essential to acknowledge the successes achieved by nurses, no matter how small they may be. Recognizing successes will boost morale, and nurses will know their hard work is noticed and appreciated. By practicing the components of NA, organizational leaders are better attuned to see the excellent work the nurses are performing, realize how it serves the mission of care, and become open to making necessary process changes to alleviate the stress facing nurses. Furthermore, when nurses understand and use their stories to guide them, they become more present to themselves and others. They know it is vital to give and accept praise as a component of self-care. All providers must help nurses acknowledge what went well, no matter how small the act may seem to a nurse. Such acknowledgments help bring light into the darkness that seems to cloak everyone and everything the chaos brought on by the crisis. And beyond mere acknowledgment of successes, administrators must also cultivate a sense of hope, support, and work community. Instilling hope—and a belief that conditions and processes will improve—into the fabric of the organizational culture can bring a remarkable change in mood, safety, mental health, and performance.

**6.2 Interdependency of Healthcare in the Globalized World**

One of the outcomes of globalization—given the ease and increase of mobility—is more expansive and distant health options and opportunities. Health and medicine have become a globally shared platform, and healthcare practitioners have even greater opportunities for moving from one country to another. One of the byproducts of this migration is the shortage of skilled practitioners in the home countries which the practitioners leave behind.\(^876\) The migration of physicians from developing countries to developed countries only fills the shortage of physicians.
in developed countries; the home country is often left wanting for talent. This creates an ethical dilemma. This section of this chapter addresses the ethical dilemmas present due to the migration of the physicians and gives a narrative-based approach to turn the obligations into responsibility.

6.2.1 Ethical Dilemmas with the Global Migration of Physicians

The four Principles of the Universal Declaration of Bioethics and Human Rights (UDBHR) are applied to define the consequence of this migration as ethically and morally suspect. The principles are Equality, Justice and Equity, Solidarity and Cooperation, and the Sharing of Benefits. The UDBHR principles clarify how this type of healthcare migration is morally and ethically wrong because it creates imbalances in the health sector. This is discussed through the lens of moral imagination and moral reflection, which expands the circle of moral concern and helps to recognize and respond to our shared humanity.

Given the dynamics of globalization, it is impossible to restrict migration. Such restrictions stymie a person’s autonomy. But it is possible to devise alternative methods to ensure that home countries receive adequate healthcare and compensation for their initial investments in education and social infrastructure. To respect a person’s autonomy and to safeguard a country’s healthcare system, it is imperative to construct processes and regulations that protect individual autonomy—the right to migrate—but also respect and support the needs of the home country, which has often invested in training physicians who leave for opportunities in other lands.

6.2.1.1 Migration of Physicians

Mobility is a hallmark of Globalization. Globalization—given the ease and opportunity for mobility—has made possible more expansive and sophisticated healthcare career options and opportunities worldwide. Health and medicine have become a globally shared platform, and health
care practitioners now have expanded opportunities to move from one country to another. The majority of this migration is from developing countries to developed countries.\textsuperscript{881} One of the byproducts of this movement is an ample supply of diverse practitioners in developed countries, which would otherwise run a shortage of skilled practitioners.

Furthermore, the intersection of different cultures improves the diversity mix within the workforce. These diverse workers bring with them cultural knowledge, which, in turn, enhances the efficacy and cultural sensitivity of the receiving system. Migrating practitioners also bring the best practices from their homelands, which are assimilated into the host healthcare systems. The practitioners who migrate are generally graduates of the finest schools in their home countries. The best, brightest, and most talented depart for foreign lands; this migration, in turn, dilutes the talent in their home countries. For example, the majority of all practitioners who migrated from Bangladesh to the USA are graduates from Bangladeshi Medical Schools, and, in particular, from Dhaka Medical College, which is the best medical school in Bangladesh.\textsuperscript{882}

This one example indicates how the finest talent migrates abroad, brings best practices, and the desire to succeed to the receiving system. Most often, the benefit of migration is one way: from developing to developed countries. Little of the new knowledge or knowledge from the established receiving systems finds its way back to the developing countries. Thus, given current economic and social incentives for a talented practitioner to leave their homelands, there are direct and negative consequences in terms of global health equality.\textsuperscript{883}

The voluntary migrating of practitioners is termed the ‘pull-up’ approach. Pull-up migration is the quest to secure an improved personal lifestyle and economic well-being in a new country. This is also more broadly termed ‘consumption abroad.’ This occurs when a patient, practitioner, or student from one country travels to another for superior treatment, an enhanced
lifestyle, better education, or expanded professional opportunities. These forms of migration create a talent vacuum, and, thus, the home country is without sufficient numbers of skilled practitioners. However, the migration of practitioners from developing countries to developed countries conveniently serves the growing demand for practitioners in developed countries. Also, the healthcare systems in developed countries not only gain practitioners who are “technically” talented and highly skilled; these incoming practitioners also add cultural and linguistic diversity to the receiving systems. Ninety-eight percent of all migrating practitioners are fluent in two or more languages. Having such knowledgeable resources at hand is invaluable to help patients overcome what otherwise would be significant linguistic and cultural barriers to excellent care.

Even though the General Agreement on Trade and Services (GATS) permits or has no deterrents to the practice of consumption abroad, pull-up migration fosters global healthcare inequalities. During the practitioners’ permanent migration to host countries, the home countries are deprived of their best practitioners—the lifeblood talent of their systems. Thus, the health systems in the home countries struggle to provide high-quality, “developed-world” healthcare due to the absence of a highly skilled workforce. Often this talent drain is so significant and severe that the “home” country cannot routinely satisfy essential levels of care. As of 2005, 11,000 licensed physicians were working in the USA. 22.7% are international graduates, 27% of which have come from India. Also, many practitioners arrive from Nigeria, Syria, Pakistan, and Lebanon. This migration creates a deficiency of skilled practitioners in these poor “home” countries, all of which already have dangerously low doctor-patient ratios.

According to the World Health Organization (WHO), the appropriate doctor-patient ratio should be 1:1000. The oil-rich country Qatar has the highest doctor-patient percentage, 77.4
practitioners per 1000 patients. Monaco (71.7) and Cuba (67.2) are the next two leaders. However, in contrast, the doctor-patient ratio in Bangladesh is 5.26:10,000: there are only five doctors for every 10,000 patients. Nevertheless, many highly talented Bangladeshi physicians migrate to developed countries for a better and more secure future even with such shortages.

There is reliable data—mainly out of Africa—which reveals that restrictions placed on free, outward practitioner migration improve the quality of the healthcare services in the home countries. Also, almost all migrating practitioners are the country’s best and the brightest. This is due, in good part, to the strict and high standards that practitioners must meet in the receiving country. For example, to become a licensed physician in the United States, a practitioner must pass a detailed and highly rigorous comprehensive examination. Moreover, to be a licensed practitioner in the United States requires above-average English language proficiency.

The migration of practitioners benefits the wealthy, privileged, and niche groups. The migration, on one level, preserves financial resources and infrastructure for the developed countries because they do not have to invest as much in educational services or training and development processes. The developed countries received a ready-made workforce in which the developing countries invested limited and precious resources. Thus, these migration benefits strengthen the rich and developed countries that already hold privileged positions in the healthcare hierarchy.

This disparity is even more remarkable when considering sub-Saharan Africa. “Eleven percent of the world’s population live in sub-Saharan Africa and bear 24% of the global disease.” However, they only have 3% of the healthcare practitioners. In contrast, the United States, which has a significantly lower percentage of the global population and accounts for about 10% of all global illness, has 7% of all healthcare practitioners.
Migration directs resources away from the poor and underprivileged. From a pragmatic perceptive, this migration of healthcare practitioners retards the quest for universal, high-quality health care. It also has the consequence of overburdening national health systems. Thus, this practice makes the rich more powerful and destabilizes the public health infrastructure of poorer countries. The underprivileged continue to suffer due to the lack of readily available primary and essential treatment. Therefore, migration undermines public health systems and leaves the home countries struggling to provide consistent, readily available, quality care.

The wealthy actors in the global healthcare system exploit the weaker players. This practice compromises the health of the poor in service to the broad and niche needs of the privileged. The developed countries do not “see” these inequities and seem baffled as to why the developing countries cannot provide world-class healthcare, oblivious to the fact that the best “local” talent has migrated to their countries.

6.2.1.2 The Lens of Universal Declaration of Bioethics and Human rights (UDBHR)

This physician migration trend will be analyzed through the lens of the Principles within the Universal Declaration of Bioethics and Human rights (UDBHR). There are four Principles of the Universal Declaration of Bioethics and Human rights (UDBHR) applied to define the consequence of this migration as ethically and morally suspect. The principles are equality, justice and equity, solidarity and cooperation, and the sharing of benefits.

The Universal Declaration on Human Rights refers to all humans as one family (Article 1), and individuals have duties to the community (Article 29). Article 1 states that each individual has rights, but simultaneously all have an obligation to the community as ‘one human family.’ Also, the notion of shared responsibility affirmed in the “United National Millennium Declaration”
(2000) states there is a collective responsibility to maintain equality at a global level. Whereas the Principle of Human Rights focuses on the obligations collectively held to secure and ensure human rights and honor the belief that each person is entitled to receive the ‘shared responsibility’ of the collective.\textsuperscript{899} Regarding migration, health practitioners have the ‘right’ to move freely, searching for a preferred life. However, the right to emigrate must be qualified by and balanced with corresponding and corollary social obligations—especially regarding healthcare. The ethical and social obligations of healthcare professionals are rightfully held to a higher standard than many other professions.\textsuperscript{900}

Healthcare professionals have collective ethical responsibilities to be global citizens. Balancing such rights and obligations is a dilemma, to be sure. Therefore, practitioners should first consider community obligations before deciding to migrate permanently. According to the UDBHR principle of solidarity and cooperation, the migration of practitioners can be viewed as morally and ethically unjustified. The principle of solidarity dictates that all human beings act ‘as one family.’ This requires each practitioner to view the self and others as global citizens. The principle of solidarity highlights the inalienable relationship between equals, which fosters cooperation and shared commonalities.\textsuperscript{901} Such international solidarity founds the concept of a universal, moral community through which to critique the consequence of the migration of practitioners. According to this Principle, health is understood as a common good; thus, the health of all citizens—globally—is, by consequence, a common, shared concern. Healthcare equality is impossible if one’s actions cause others harm, no matter how seemingly benign. Therefore, practitioner migration must be seen as a direct violation of this Principle because it does not foster health as a global common good.\textsuperscript{902}
According to the Principles of equality, and justice and equity, health benefits are human rights that should be available to all. The current and ever-increasing migration of practitioners creates an abundance of medical staff in developing countries. In contrast, the citizens in the home countries face a dearth of skilled practitioners. This resultant inequity reveals that developed countries undermine social justice in developing countries and thus bring the issue of international justice and responsibility to the fore. The Maximum Principle and the principle of equality of opportunity address that priority should be given to those most in need to meet the obligation that others live a healthy life. This ethical issue remains in the background concerning the effects of healthcare migration. Few institutions or practitioners take global responsibility for this fact. This injustice is experienced both at a global level and individual level. Those within the healthcare profession—and beyond—should agree on the concept of justice to ensure an equitable, peaceful, healthy world. As global citizens, healthcare practitioners (and administrators) are bound to respect the principle of Justice.

Coupled with the principle of justice and responsibility is the complementary principle of sharing benefits. Benefit-sharing is founded on the notion that the benefits of service should be equally available to all. In the case of the migration of healthcare professionals, we see that the privileged increasingly benefit but are seemingly ever-less concerned about sharing these benefits with others. Pull-up migration is morally problematic because the resources emerging countries invest in education do not bear local fruit because practitioners depart to practice elsewhere. An argument can be made that the nation that nurtures the physician holds limited claim to the practitioner’s skills and services. Likewise, citizens of the “home” countries overlook their obligations. To improve living standards for themselves and their families, they leave behind fallow fields. No one expects medical practitioners to be saints or be indentured servants, but each
practitioner has a moral and ethical obligation to their country of origin. Furthermore, developed countries are not compensating the home countries for the abundance of this found talent.

The UDBHR principles make clear how healthcare migration is morally and ethically wrong. This migration trend is responsible for an uneven, unequal global healthcare system.

6.2.2 Turning Obligations into Responsibilities via Narrative Authority

Migration is, of course, a human right, and any individual should be free to relocate in search of a better life. However, this right should also carry a corollary: an obligation to the community. Pull-up migration reveals how healthcare is increasingly a service or commodity available to those who can afford it, which, in turn, offers economic benefits (profits) to the practitioners and the systems which benefit from the practitioners’ skills. However, ethically, healthcare should not be seen in an economic light. Health and wellbeing are fundamental human rights; the underprivileged have a right to equal access to healthcare. Given current and growing healthcare inequities, disadvantaged populations should be given greater healthcare attention and resources—the purpose of healthcare is to heal. Therefore, in many ways, the radical acceptance of pull-up migration is extraordinarily self-centered and ethically and morally dubious because it ultimately benefits the privileged and causes increased hardships for those already underprivileged and struggling.

To understand the nature of this self-centeredness, practitioners need to understand the self. It is in this area that Narrative Authority can be of use. It is challenging to convince someone that they should not seek a better life. However, efforts should be made to contextualize the effects of physician migration on the home country. NA should be integrated into the national or educational messaging to highlight the social and identity connection between the physician and
country/society. NA offers methods to have physicians articulate their beliefs and goals that include the benefits and opportunities provided to them, which open pathways for their education and possibilities for success. These avenues were certainly opened by those who had gone before them, including the social infrastructure—tenuous as it might be—that educated, protected, and provided stability. So, the narrative, social component of Narrative Authority can be applied to present human beings as a shared connection. From this perspective, educators and leaders can argue for an ethical and moral responsibility to continue supporting the home country after migration or recompense or as an ongoing component of migrating. As for NA and understanding oneself, the contention is that by reflecting upon one’s aspiration and goal, one finds that their goals, dreams, hopes, and values were influenced by family, friends, cultural norms, country, etc. And from this, one most often experiences gratitude and the want to repay and honor those past privileges and gifts. And to best understand the self is to recognize and embrace our shared responsibilities, in the same that we come to realize that being is communal and shared. Narrative Authority helps discover the fine line between our growth and our responsibility towards society.

6.2.2.1 Narrative Authority—Obligation Turns to Responsibility

Narrative Authority is applied to investigate the ethical perspectives involved, guide officials to formulate regulations that are person-centric and offers a platform to understand the shared responsibility to and for global healthcare. NA provides the sense-making, meaning, and urgency to a shared context and, in turn, guides practitioners and policymakers to understand their responsibilities and obligations to others. We do not live in a world of isolated individuals; the world is filled with people who are interconnected through story and narrative. NA reveals this interconnectedness and the narratives and stories which define, shape, and ground ethical behavior.
The practice of medicine is continuously shaped and directed by and through the advancements of science and technology. Many major medical breakthroughs occur rapidly and frequently; however, a persistent gap exists between healing and cure. Medicine, specifically via technology, shines a light on the importance and power of being a “curing agent.” Still, while focusing on “curing” too often, these efforts and approaches leave the need for and importance of being a “healing agent” in the dark. To understand the role of a healing agent in excellent medicine, it is crucial to appreciate the central role narrative plays in illuminating and creating person-to-person relationships for each party involved in the care process. Being available to the other’s story opens a shared space in which a conversation can occur by eliminating the distance in “communications” between a “provider and customer.” When the physicians can see themselves as human instead of provider, they will understand their obligation to benefit and give back to society. It is not about the physician; rather, the physician realizes the resources and time allocated to train them. It is essential to look for those details that can only be revealed through the stories we share or told. The more we share our narrative the better we understand how we become a shared we.

A narrative-based conversation ensures that the other is seen and shifts the perspective, removes the distance of abstractions, and places two people in connection, opening each to the other’s humanity, where heartfelt dialogue occurs to heal the wound. Narrative Authority also guides towards ‘moral imagination.’ Moral Imagination addresses the critical thinking necessary for individuals to understand and embrace his or her obligation to society. Moral Imagination serves to sensitize an individual to the lives of all others, especially those less privileged or in crisis. Moral Imagination expands the circle of principled concerns and helps practitioners recognize and respond to shared obligations to the human community. Based on the concept of
Moral Imagination, it is the duty of all to step forward and take responsibility for developing a better migration plan, which includes the subsequent actions to improve the lives of the underprivileged and those most affected by practitioner migration.

Narrative Authority also help us to understand Moral reflection. Moral reflection appeals for common responsibilities, which extend to all, globally.

6.2.2.2 Practical Interventions

Healthcare has become a form of global business. However, healthcare systems should remain distanced from the realm of “mere” business because the primary purpose of medicine is to heal—which goes ethically and morally beyond the monetary value of service. Even though on the surface, migrations appear to be a national issue for the home country, they should be seen and understood in broader terms as a global ethical concern. Also, health is a universal human right, and the health and well-being of all should be addressed equally, everywhere, and for everyone—without compromising the rights of individuals or the responsibilities to the global community.913

Given the scope and force of globalization, we cannot directly restrict the migration of health professionals. However, it is possible to devise alternative methods to ensure that the home countries receive adequate healthcare and compensation for their initial investments in education and social infrastructure. It is impossible to stop the ‘brain drain’ of talent completely, but it can replace the loss with ‘Brain Circulation.’ Brain Circulation is an innovative approach that the Chinese government has taken to entice the lost talent to come home, even for a short or scheduled period of time.914

Establishing international agreements for benefit-sharing would promote the ethical migration of health practitioners. Such benefit-sharing could take monetary and non-monetary
forms. Monetary benefit-sharing should entail that receiving organizations in the developed and privileged countries supply financial assets to the developing countries to support healthcare and ensure enough medical practitioners are trained for their country’s needs. A joint research fund, access fees, or any other modes of monetary assistance could be given to the home country to reduce healthcare inequality.

Nonmonetary benefits (teaching and training) could also be offered to the home country to support and compensation for accepting migrated practitioners. Furthermore, healthcare practitioners and organizations should share textbooks, professional journals, and other educational materials as a means of support and ensure the most up-to-date references are at hand. Holding seminars, workshops, and training in the home countries is another way to mitigate the effects of the talent drain; this would be an effective means to develop home country practitioners without the need for students to travel abroad. Implementing telemedicine projects could also be a highly effective means of training and skill-building. By applying web-based technologies, it is possible to schedule sophisticated consultations almost anywhere. Such consultations would provide at-need expertise not available in the home country. China set an example by becoming the first developing country to participate in the Human Genome project to collaborate with the developed countries. Targeted educational opportunities like this are practical and valuable ways to mitigate or counteract the effects of brain-drain.

A Healthcare Ethics Curriculum also should be implemented in all medical schools. The incorporation of ethical education that highlights the global responsibilities of practitioners must be included in medical curriculums internationally. Embedding the belief in global citizenship within the teaching curriculum will help practitioners embrace their social and international obligations when making "personal" choices. Whether providing benefits or sharing best practices,
policymakers must be keenly aware of a particular country’s social and cultural context. Developing countries should organize ethics-oriented training and workshops to manage or moderate the migration process.917

To mitigate the negative consequence of pull-up migration, policies and practices should be established to offer practitioners temporary or limited migration opportunities. One option is to provide a short-term visa that would require medical practitioners, after a specific period, to return to their home countries to provide health care services—much in line with the notion of country service. Another way might be specified periods of “service time” required by the home country following the completion of medical education and training. Such practices would ensure that medical tourism and pull-up migration do not solely benefit the privileged but also help local systems.918

A practice of note is the international agreements between the Organization for Economic Cooperation and Development (OECD) countries. Health practitioners must fulfill specific and prescribed requirements to migrate to another country through this agreement. Doing so will ensure the home country continues to reap benefits from its investment in training physicians.919 Of course, it is understood that if these policies and rules become too restrictive, they could interfere with the human right of self-determination, but it is possible to frame this debate by addressing the responsibilities established by the human rights principles that highlight the universal obligation to the other.

However, home countries can take one of the soundest approaches to build infrastructure attractive enough to ensure local gems stay “home.” Reverse brain-drain programs that offer attractive financial packages and high-quality work environments should be implemented to lure
or keep talent “home”.920 “Brain Circulation” programs should also become a great source of the triangular flow of knowledge and expertise.921

Effective non-financial reward systems should be developed to retain skilled talent, which ensures that practitioners work in dignified and motivating settings.922 However, this is problematic for developing or emerging countries because they have limited resources to construct attractive strategies and facilities to retain skilled professionals. In these instances, others—receiving-country systems and successfully migrated practitioners—must embrace the role of global citizenship and ‘payback’ to the home countries. Developed countries that benefit from migration should likewise payback to the countries of origin in associated forms of political or trade support. When this occurs, countries can route these new resources to develop policies to retain their most skilled workers. Thailand and Ireland are good examples of countries that have successfully found policy ways to avoid migratory brain drain of medical talent.923

The debate on the migration of health practitioners is a dominant issue for global bioethics. Few would argue to deny the right of an individual to seek a better standard of living. However, this right does not free those leaving their homelands from the moral and ethical obligation ‘to the other’—especially to those negatively affected by the practitioner’s decision to migrate. Furthermore, healthcare practitioners must adhere to the highest, guiding ethical and moral standards. Migration has direct and profound ethical and moral ramifications for the migrant, the receiving country, and the country left behind. Fair and socially based policies must be developed that counter the radical argument that individuals have an unfettered right to live their life as she sees fit. Practitioners and policymakers must consider themselves global citizens and embrace and respond to the stated and agreed upon moral and ethical obligations required to global healthcare equity. To construct, implement, and safeguard equitable healthcare, practitioners and
policymakers—at a worldwide scale—must maintain a firm balanced approach between individual rights and social obligation.

Practitioners have the right to build lives that meet life- and career goals, wherever this may be; however, this freedom comes with an important caveat: as human beings, we coexist on this Earth—global citizens who have moral and ethical obligations to the other.

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Chapter 07: Conclusion

Every patient comes to the consultation room or hospital with a story to tell. Frequently, the nuance, clarity, and connections that a patient’s story provides are structurally incompatible with—have no place within—a standardized, computerized, time-restricted, checklist, work-flow process endemic within current healthcare. In this setting and these instances, human interaction is converted to an abstraction, a faux reality. As a result, healthcare practices often suffer from a cold overemphasis on pure efficiency. For instance, physicians’ interactions with patients are often timed and based on asking rote diagnostic questions. Given such practices, a physician can overlook significant details that the patient might offer. If these heard pieces of the patient’s story were known, the physician might have better understood the client and her situation. And, in terms of illness, not knowing these details adds inefficiencies and ineffectiveness to the process. It leads to a distancing and separating of the provider from the patient, which is a deficient form of doctoring.

The art of medicine is to heal; the technique of medicine is to cure. The art of medicine guides the wounded soul along the care journey, whatever its twists and turns may be. It is impossible to navigate this journey as a healing agent without embracing and standing in the intersection a shared narrative provides. Sharing narratives—understanding and catching sight of the other through her story—is the most straightforward way to learn about, connect with, and effectively engage with patients, and teams, in the healthcare sector. Also, narrative helps one see the invisible, the unseen, the overlooked, and the otherwise unspoken, which, when known, often reframes how healthcare professions—and organizational best practices—approach, promote, and welcome the other. By embracing the power of narrative and story, providers find or reclaim significance and meaning in their specific roles and identities as healing agents.
Key Findings of the Research and its Contributions

This dissertation contends that now is the time for medicine to construct humanistic, narrative-driven cultures and associated best practices that open spaces where the disclosive power of narrative ‘runs the show’ by configuring meaning and significance while providing the sense-making and urgency to implement substantial and transformative change.

To deeply explore the centrality of narrative in reshaping healthcare, this dissertation offers an integrative, complementary, and inclusive model—Narrative Authority (NA). Narrative Authority relies on the disclosive power of narrative as an approach/method/means/tool to redefine, reshape, reclaim—re-narrate—medicine from its deficient current model founded on abstraction and isolation.

Narrative Authority provides a perspective and method to reveal and construct narrative-driven organizational cultures and other-oriented best practices. A narrative-centric interpretation of individuals and workplaces rests at the heart of changing global healthcare and medicine. NA combines and expands the foundations of Narrative Ethics, Ethics of Care, and another influential model, Narrative Medicine.

Narrative Authority relies on the disclosive power of narrative as an approach/method/means/style to redefine, reshape, reclaim—re-narrate—medicine from its deficient current models of care, which can foster cultural insensitivity and patient (and practitioner) isolation. Cultural insensitivity and patient (and practitioner) isolation are due to the underlying and unquestioned beliefs in rationality, quantification, and abstraction. If seen at all, this distancing and insensitivity are viewed as isolated mechanical problems and overlook or discount the integrated worldview and experiences of the patient. Narrative Authority also
provides both a perspective and a method to reveal and construct narrative-driven organizational cultures and complementary other-oriented best practices. A narrative-centric interpretation of individuals and workplaces rests at the heart of the changing, global healthcare, and medicine.

The research indicates that the reconfiguring power of narrative provides pathways for positive, responsive change. NA’s applied approach and method promote human-centric care practices and interventions, deep-rooted, other-oriented communication, and opportunities for systemic transformations. The Narrative Authority care model is an other-oriented response to overcome Western biases and assumptions and it will guide and influence the other current models of care. More so, Narrative Authority offers an approach to rehumanize the art of medicine and to reframe the negative structural influences of globalization, technology, and efficiency on best practices and organizational intent.

Narrative Authority, unlike the three models mentioned above, is specifically constructed to include, and account for, the perspectives and understandings of non-Western worldviews in providing excellent healthcare. The dissertation offers some practical tools and specific recommendations for applying Narrative Authority. The dissertation uses a narrow-to-wide approach—first applying the model at the local, then expanding to the global level, including individual and organizational levels. To demonstrate the inclusive, cultural scope of Narrative Authority, the dissertation presents examples and scenarios from non-Western countries, minority groups, and religious faiths whose norms and worldviews fall outside common and unquestioned Western values, practices, and assumption of individuality and autonomy.

Narrative Authority is helpful as a response to the ethical challenges arising in genomic research and palliative medicine. Finally, the dissertation shows how Narrative Authority can investigate and reshape best practices in the field, for instance, how genomics affects patient-
provider relationships, end-of-life counseling, palliative care, the ethical impact of technology, and patient privacy and autonomy in the era of precision medicine.

This dissertation aims to adapt, combine, and redefine the current models of healthcare ethics and normalizes diversity within healthcare. It applies methods and tools that recognize and overcome unquestioned assumptions and practices that embed and perpetuate biases (race, gender, ethnicity, class, and personhood) throughout contemporary healthcare.

The dissertation presents the belief that the pathways to ethical and excellent healthcare, and, more broadly, normalizing diversity and difference, run through understanding the other’s narrative and embracing the differences and commonalities therein. The ethical claim to care for others is founded on hospitality and love.

Limitations of the Dissertation

The proposed model of Narrative Authority is an emerging model. While promising and finding initial acceptance, the model is based on normative research. The model’s limitations are that it has yet to be rigorously applied and requires implementation and development with healthcare (or other) settings.

This dissertation emerged after catching sight of the apparent gaps and deficiencies in the current models of care. Narrative Authority is a response to overcome these concerns. While the model is constructed on theoretical and normative research, it requires application and validation within the domains it proposes to improve. The model, as built, is a product of the timeframe, scope, and requirements of the academic program and will be applied and tested with ongoing future research. I am highly confident that this evidence-based research will validate the model.
and move narrative and humanistic perspectives of care further into the normative mainstream of US and global healthcare.

Also, there is a limitation because of the available current literature. Frankly, there is little literature present that focuses on narrative and healthcare. There is also a dearth of research on the importance of narrative in care. These limitations are an opportunity for this dissertation to supplement and deepen current literature and to highlight the need for additional development in these areas of research.

**Scope of Future Research**

The future reach of this dissertation is to make healthcare more equitable, reshape the nature of physician-patient relationships, strengthen and revise organizational best practices, improve community relations, and significantly expand the breadth, effectiveness, and quality of care. Therefore, redefining healthcare models and reshaping the quality and effectiveness of everyday practices will drive my research.

Future research will focus on practical approaches that reshape the beliefs, perspectives, and practices that currently retard effective care. This research and its application will reshape how healthcare professionals understand themselves as caregivers and policymakers and better present themselves as they care for the patients.

Indeed, other researchers are working to make healthcare more diverse and human centric. However, this dissertation’s uniqueness brings a proposed model embracing non-Western and non-Christian perspectives, integrated with narrative and storytelling methods. Narrative Authority thus offers an assimilated, complementary, human-centric model that adapts the available
The originality of this dissertation is also enhanced by the integration of significant non-US/European researchers in this field. It offers a needed global perspective and insights to strengthen and expand the field in the USA and then abroad. These practices developed and improved via Narrative Authority also will be transferable internationally and to the open markets within healthcare.

This research’s future goal is to explore further the influence and relevancy of Narrative Authority, ranging from the individual to organization level and from the local to the global context, by conducting qualitative research in categories and areas mentioned in the chapters. This normative research will become supported and furthered by significant empirical research. The goal is to normalize diversity, integrate narrative and storytelling into care practices, and reduce mental health issues among care providers, patients, and all associated stakeholders.

To that end, the dissertation has taken steps to make its mark in the field by publishing four peer reviewed papers and a book chapter and there is one further book chapter forthcoming. 926 927

This acceptance of the concept and its application open future opportunities for research, furthering the goal of the dissertation and, and my intentions, to normalize diversity within healthcare, improve the mental health and wellbeing of providers and patients, integrate narrative and storytelling into best practices, and strengthen physician-patient relationships.

Moreover, the 2020 statistics in diversity index in the US shows that if two people are selected randomly, there is a significant likelihood that they will be from different races and ethnic
groups. This highlights the reality of the shift toward a more diverse country, which is expected to continue through 2060. And the most significant change will be among individuals who identify as two or more races. These projections show that the population of the USA will become more diverse than ever. These changing demographics further support the need for Narrative Authority.

And unfortunately, US healthcare lacks diversity among its practitioners and administrators. This dissertation provides both immediate and long-term direction and solutions to the challenges diversity present to the US healthcare system. Conducting and expanding empirical research among these growing populations will help shape the future of healthcare nationally and globally. The goal is to prove there is a practical alternative model and method, Narrative Authority, to respond to diversity and reshape best practices.

Another goal of this research is to continue to explore the model’s impact on mental health and wellbeing. Focusing on the mental health of caregivers and patients is critical and should be given the same attention the physical body receives. However, this is rarely the case. The impact of the Covid-19 crisis demonstrates the need and urgency for mental health care. And using 2020 statistics, in the US, 21% (52.9 million people) of adults experience mental health issues, representing 1 in 5 adults. In addition, 5.6% of adults in the US have gone through severe mental health issues, representing 14.2 million people. This means 1 in 20 adults have mental health crises. Given the lag in the data, it is highly likely these numbers will prove to be higher and the situation worse than before the Covid-19 pandemic.

The future goal of this dissertation is to explore the impact of Narrative Authority via evidence-based research methods, applying its imagined strength and versatility to reshape the model of care in the USA and beyond.
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