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The Journal is an interdisciplinary, academic, peer reviewed international publication. Its mission is to explore the full expanse of holistic and integrated health within the nature and meaning of human experience. Its scholarly and professional explorations richly convene all possible areas within the arts/humanities and the sciences, cultural and social concerns, diverse technologies, ethics, law, civil rights, social justice, and human rights. The Journal invites the reader into the fullness of our human nature, our history, and the expanding futures before us.

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Mission

The Semper Vi Foundation

“From Victim to Survivor to Victor”

Mission: The Semper Vi Foundation is a 501(c)(3) tax exempt public charity dedicated to the design, development, implementation, and promotion of social justice and human rights resources, programs, and diverse opportunities in education, publishing, research, and services that help the suffering find healing and meaning in their lives. Of particular interest for the Foundation’s mission is Wounded Warrior Care and, equally, the care of all those who suffer in our wounded world.

Vision: Semper Vi reaches out to all who have known the many forms of life’s suffering and tragedy. Semper Vi activities and opportunities seek to help all those who suffer, not only to survive, but also to become victorious so that their wounds become sources of healing for others. Semper Vi assists those who have benefited from our programs and activities to help others in need. Some of those who benefit from Semper Vi’s humanitarian and relief commitments include our Wounded Warriors and their families, as well as individuals and communities who have experienced violence and terrorism, victims of assault and destruction, those who have suffered discrimination and the loss of their human or civil rights due to religion and values systems, race, gender, sexual orientation, socio-economic status, national origin and ethnicity.

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Mission

across the globe. This Foundation designs and provides workshops, seminars, webinars, podcasts, full conferences and continuing education courses at various international locations. Depending on resources, events are filmed and posted on the website.

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Reflection: Tales of heroes abound throughout world literature. Our attention is always captured by the stories of those who accomplish great deeds that benefit others and the world. Yet what is it that we mean by the term, “hero?” When is something “heroic?” A hero is one who, despite danger and weakness, musters the courage to sacrifice herself or himself for the needs of others. Sometimes this comes at the price of the hero’s life. However, in all instances, the hero vanquishes the danger and rises above it as victor. Yet there is another nuance. The work of the hero often goes deeper. In many tales, the hero not only fights the oppressor, but also suffers grievous wounds in doing so. The hero embodies the suffering and takes it into her or him self. The hero endures and survives. Yet even more amazingly, in these stories the suffering and pain are transformed from curse to blessing. The hero matures from victim to survivor to victor! The hero becomes “semper victorius!” Always the victor!

Invitation: Join us as we build Communities of Victors, for today and tomorrow!
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Preface

Author Biosketches

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Bruce R. Boynton, MD, MPH, FAAP, is Editor of the Journal of Health and Human Experience. Dr. Boynton has had a distinguished career as a Naval Officer, pediatrician, researcher, educator, and hospital administrator. He was Executive Officer, Naval Hospital Sigonella, Italy; Commanding Officer, Naval Medical Research Unit 3, Cairo, Egypt; and Commanding Officer, Medical Treatment Facility aboard USNS Comfort, a 1,000 bed hospital ship. He is currently the Statewide Medical Director for Centurion of New Mexico.

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Preface

De Fischler Herman, RP, SD, SM, serves as a hospice chaplain in Washington, DC. She is an ordained Spiritual Director, co-president of the board of the Rabbinic Pastor Association of ALEPH -- Alliance for Jewish Renewal Seminary, facilitator for Age-ing to Sage-ing, and a Champion of the Center for Medicine After the Holocaust. Rabbinic Pastor Herman is an artist, poet, educator, gardener, environmentalist, and bicyclist.

Jan Herman, MA, holds the Master’s in History from the University of New Hampshire where he also held a Ford Foundation Teaching Fellowship. He is the retired Special Assistant to the Navy Surgeon General for Medical History and Archivist. He has produced many Navy Medicine historical documentaries including “The Lucky Few” premiered at the Smithsonian in 2010. He is the 2015 recipient of the lifetime achievement Forrest C. Pogue Award for Excellence in Oral History.

Deborah J. Kenny, PhD, RN, FAAN, is Associate Professor at Helen and Arthur E. Johnson Beth-El College of Nursing and Health Sciences at the University of Colorado Colorado Springs. She was the college’s first Carole Schoffstall Endowed Professor. Dr. Kenny is retired from the Army Nurse Corps and was the Executive Director of the TriService Nursing Research Program. She is a Fellow of the American Academy of Nursing and active on the bioethics expert panel.

Laura Mateczun, JD, PhD (Student), is a graduate of the University of Maryland Francis King Carey School of Law, and a member of the Maryland Bar. She is currently a PhD student studying public policy at the University of Maryland, Baltimore County. Her policy interests are interdisciplinary in nature and span fields from criminal justice, to health, and public management, focusing on issues of equity and efficiency.

Moni McIntyre, PhD, is Assistant Professor in the Sociology Department at Duquesne University in Pittsburgh, Pennsylvania. She is also an Episcopal priest and Assisting Priest at Calvary Episcopal Church in Pittsburgh. She is a retired Navy Captain and teaches Navy physicians and dentists in the Advanced Medical Department Officer Course at the Walter Reed National Military Medical Center in Bethesda, Maryland.

Tod Schneider, MS, is a writer, researcher and advocate currently focused on international humanitarian crises. Over the past 35 years, Mr. Schneider has served as a police department crime prevention specialist, homeless veterans’ advocate, socio-medical clinic director, grant writer and storyteller. In addition, he is an international consultant on Crime Prevention Through Environmental Design, with an emphasis on schools and public spaces, and is a founding partner in the Interprofessional Studio for Complexity Thinking.

James Shraisky, MARCH, is the founder and director of InterSCT–The Interprofessional Studio for Complexity Thinking - a research-based studio that explores systematic solutions to current and complex social issues. Prior to creating InterSCT, he was a professor and the director of the healthcare initiative at Arizona State University. Currently, InterSCT is investigating projects that address Syrian refugee issues around the world, wellness concepts in Haiti, and environmental factors to combat PTSD among wounded veterans.
Preface

Katharine L. Sparrow, MSW, graduated from the Boston College clinical social work program and has worked in the mental health field on the South Shore and Cape Cod. She has been writing poetry for eight years and was named Poet Laureate for 2015 on AllPoetry, the largest poetry-sharing forum on the internet. Her next project is to follow her passion for genealogy and obtain certification in genealogical research from Boston University.

Danielle Wofford, RN, is an emergency medicine nurse, Jonas Scholar (2016-2018), and PhD student at the College of Nursing and Health Innovation, Arizona State University. Her current research centers on addressing health equity and improving health outcomes among vulnerable populations globally. Prior to ASU, Ms. Wofford served as an educator and international aid nurse in Africa and Eastern Europe. While working for the Magdi Yacoub Heart Foundation in Egypt, she helped to create delivery models and nurse education curriculum.

Tyrell Tysheen Yorke, BS, is an Ensign in the United States Navy. Mr. Yorke graduated from Tuskegee University with a degree in Aerospace Science Engineering. In 2016, he published a first article in the Journal’s Emerging Scholars Corner. He was chosen as one of the 20 Twenties of 2016 by Penton’s Aviation Week magazine. He entered the Navy as a Nuclear Propulsion Officer but is now pursuing a career as a naval pilot.

Chloe’ Whittington Yorke, BS, recently graduated from Tuskegee University with a degree in chemical engineering. Her ultimate goals are to become an entrepreneur and teach others how to establish generational wealth; and become a medical doctor, helping people within her community and around the world heal holistically. She is also a lyricist and the creator of her self-titled YouTube channel where she shares beauty tips, video logs, and words of encouragement.

Michele Savaunah Zirkle, MA, mentors verbally abused women through her program, “Free to Speak.” She is the author of Rain No Evil, a novel based on true events. In addition to hosting a weekly radio show, “Life Speaks,” on AIR radio, she writes a weekly inspirational column for several Ohio Valley Publishing newspapers. Michele is a graduate of Concord College and Marshall Graduate School. After twenty years teaching, she follows today her passion for writing.
FROM THE
EDITOR-IN-CHIEF
Preface

From Discovering to Serving.....

Dr. Edward Gabriele
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President and Chief Executive Officer,
The Semper Vi Foundation
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In this edition of the Journal of Health and Human Experience, we continue to pursue our theme for this year, "Reform and Renewal." As such we remember any number of historical events that call us to consider the necessity of change in the human experience. We also have recalled the immense discoveries that have advanced our modern world and how in the past year or so we have lost some of the great explorers who led us into the far reaches of space as well within our human nature.

Of particular mention, this autumn we remember in a special way the 500th anniversary of the Reformation --- when Martin Luther is said to have nailed his 95 Theses to the door of his local church's leadership calling for correction and change. But how did Luther come to the propositions that he espoused in his nailed protest? And what was it that he was really calling for?

In his monastic life Luther engaged in the scholastic pursuits of his time. By virtue of his place in religious life at that period of his own life, he would have studied and read intensely. As he did, he entered the path of “Discovery.” He engaged in learning things he never previously knew. And his discovering led him to call for the church to correct practices and stances that he believed were outside the pale of the scriptures and the origins of the church's religious experience. But note carefully: Luther’s discoveries led him to correction of the past and present. His call was to return to things as he supposed they originated.

But is correction the only reason for discovery? And is it only about returning to the supposed purity of the past?

To answer these questions, we need to consider the nature of discovery itself. What is discovery? And to what does discovery really call us?

To approach these questions we could engage in researching what past scholars have told us. But the nature of discovery for me is summed up with incredible beauty in an image that recently crossed the eyelines of my daily life.

A few doors down from my home I have some neighbors who in the past few years gave birth to two wonderful children. Both of them, a boy and a girl, have begun to leave their infancies. They are delightful children whose joy is captured each day before us neighbors especially when they head outside with their father for a bit of play before dinner. That time is also a time for them to learn so much. One day, Dad went to our common mailboxes to pick up the family mail. Both of the children ran after him and stood behind him. Turning toward them,
he gently encouraged them and lifted them to see what he was doing. Each in their own turn, the little boy and girl were lifted up and peered into the empty and dark mailbox. There was no fear. Instead, something very gentle but very powerful happened. I was honored to see it closely as I was waiting to get my own mail. As each of them looked inside, they stretched their hands to explore. And their eyes glistened with “something.” Something was happening. And it brought them into a sense of delight. As I saw this quick experience, something not-so-quick happened in me. For what I saw in their eyes, their stretching little fingers, their intake of breath, and then their giggles was an experience for which all of us as human beings long --- the sense of Wonder.

Indeed, the experience of Discovery is first and foremost the call to Wonder. Each of us as human animals is born into a world from the uterine experience in which we rather passively are fed and warmed and loved. But when we emerge we are set on a lifetime pathway of reaching out to touch, to see, to taste, to hear, to know, and to be swept up into the “Something That Is More.”

Indeed, we learn in this life so as to correct and change. We even more deeply are called onto the pathway of Discovery to be swept up into a quantum leap that brings us to the Unforeseen “More.” And yet there is still a question that lurks in all this. What is the ultimate purpose of discovering and searching for the “More?” Unfortunately, there are pressures in our contemporary life that promote all this for the seemingly sole purpose of “metrics of productivity,” of “relative value units,” of profit, of gain, and even of greed. In fact, all of these are so easily placed like carrots before the hungering eyes of the pupil or professional so as to tempt us out into the experience of the groundswell of all addictions, namely the addiction to power and domination. And it is to defend ourselves against this addictive possibility that we must be constantly made aware.

The experience of Discovery ultimately leads us to the “More” so that we can become dedicated to promoting the Good for one and all. It is not about profit and gain.....unless we mean how all of us and our entire world profit and gain in meaning, in the quality life....not just in the quantity of dollars and titles. In fact, one of the greatest experiences that brings this all home and ensures that our discoveries promote the Good is the experience of service and care for those who are most in need.

But how do we capture what it means to serve? Is there an image that might move us to understand the nature of service its inevitable impact and cost upon each of us?

In these past weeks, America and our neighbor nations have been traumatized by the horrors of hurricanes, earthquakes and natural disasters. Many have lost their lives, their homes, their entire prosperity. The hurricanes forced the desolation of the island of Barbuda whose entirely populaton had to leave and will not be able to return for a long time to come. The people of Puerto Rico lost so much as did those who live on St. Thomas, Dominica, Turks, Caicos, and other islands. And our sisters and brothers in Mexico have had their lives made into utter rubble by earthquakes killing infants, the young and the old. The horrors and disasters are almost impossible to grasp fully in any act of the imagination.
These traumas have robbed so many of their dignity, safety and meaning as human beings. And, from a most intriguing perspective, the storms and earthquakes are a curious coincidence in a time when so many in our nation and world are experiencing the hurricanes and quakes of hate, discrimination, terror, and supremacy. Yet hope strikes us with all healing when we realize how many of our community members have donated funds or traveled to serve those who are in need. We see our nation’s defenders gear up for the battle against despair, and help to rebuild homes and hearts. The many discoveries of the sciences, technologies, social services, and the arts are important so as to raise up those who are bowed down. Indeed, it is in all this that we can sense what is the ultimate call of what it means to know and to learn. You see.....

.....Discovery *always* calls us to service!

In this edition of the Journal, we have academically superb and creatively imaginative works that will stoke your very selves. More than anything, it is my hope that the overall spirit of this edition will lead us together to see how someone is knocking on our own door and nailing an
From the Editor-in-Chief

invitation --- an invitation to come outside and peer into the Unknown so that we are inspired to know, to learn, and to serve those who need us most.

Do you hear the knock?

Will you answer the door?

But if so, be careful.

You just might walk outside into a quantum experience you never thought possible!
A Time for a Paradigm Shift?  
The Necessity for the Human Side of Patient Care

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The opinions of this review are those of the author alone and do not represent the views of the Helen and Arthur E. Johnson Beth El College of Nursing and Health Sciences at the University of Colorado, Colorado Springs, or other institutions or organizations the author may serve. The author has no financial conflicts of interest.

Abstract

This article discusses the need to bring caring and compassion back as the core of caring for human beings. It addresses a number of perspectives, including the explosion of knowledge in the last 50 years, the potentials and pitfalls of technology, and the role of healthcare reform in degrading a caring atmosphere. It attempts to define the human side of caring, provides a very abbreviated history of healthcare, the physiological benefit and cost of caring, and some of the ethical issues involved. It concludes with a reflection of the article’s content and a call for healthcare providers to begin to examine their own caring practice and to create an atmosphere for others to do so.

Keywords: Care, compassion, healthcare, empathy, sympathy, technology

Introduction

It would be very easy to sum up this entire article in one sentence, and that would be a statement made by Geraldo Rivera when speaking about his watershed moment while covering an exposé of the Willowbrook State School (Film Rise, n.d.). He stated “...The assembly line works for cars. It does not work for people. People need humanity. They need the spirit of compassion. They need to be loved.....” Though he was speaking of the horrific conditions he saw at Willowbrook in 1972, his comment seems to be even more relevant in today’s healthcare environment. However, to fail to delve deeper into this important topic would be dismissive of this topic as unworthy of further examination. Therefore, this article will look at this problem from a number of perspectives including: the explosion of knowledge in the last 50 years; the role technology is playing, and the contribution of healthcare reform. It will attempt to define the human side of caring, provide a very abbreviated history of healthcare, the physiological benefit and cost of caring, and ethical issues involved. It seems a very large undertaking and perhaps it is. Yet the bottom line is and always has been that there is the ultimate human experience of suffering and illness that we must recognize from the humanistic point of view.
The Human Side of Caring

Because of the profound advances in the science of healthcare, the organizational and system changes, and advances in technology, the human side of caring and healthcare seems to have taken a back seat. The following is an exemplar of the current lack of consideration of the personhood of the patient as related to this author very recently:

John had suffered some sort of spider bite that was beginning to look more and more like a brown recluse bite. Often with these bites, there is significant tissue loss, requiring intensive and early medical intervention. After a few days, the bite began to look angry, red, and was quite swollen with some tissue necrosis. The usual home remedies were not working. A call to John’s family practice provider’s office for a same day appointment was unsuccessful. The untrained medical assistant who was in charge of triage gave John the next appointment, which was 3 days away. It was suggested that John visit an urgent care clinic in the meantime. Therefore, John went off to a local urgent care. After waiting some 30 minutes (considered a short wait), he was taken to a room where vital signs were taken, then left alone. The person doing this never introduced herself, just performed her tasks with no interaction. Sometime later, another person came in, told John it was red and infected, and then gave him a prescription. As well, this person never introduced himself. John had a few questions about the bite, but was not given an opportunity to ask them; instead, he was ushered back out to the waiting room so the next person could come in.

John then went to his appointment 3 days later and was told it was indeed a spider bite, it was infected and he needed stronger antibiotics. At this point there was significant skin breakdown and it was still red. He was given a referral to a dermatologist and told to wait for a phone call. The next day, the dermatologist’s office called and explained to John the next available appointment was in 6 weeks. When he tried to tell the office scheduler (not a medical person) that this was an acute problem and he was concerned about it, the scheduler simply responded with “Well, this Dr. is very busy and I cannot get you in to see him.” John felt belittled by someone who seemed to have no empathy for his situation. So, John was left to continue the antibiotics and hope the bite healed on its own. All indications were that it would. John related to me, “I believe I would have been better treated by robots.”

Fortunately, this story had a good ending. Unfortunately, this is an all too frequent experience in healthcare today. Patients are shuttled through a system that seems to have little regard for the human condition when a person, a human being, is ill or injured. Instead, they are a “number,” even called so. The provider often spends more time staring at a computer screen than genuinely communicating with the patient. A barrage of standardized questions are asked, all in the name of collecting metrics to provide data for regulators. The numbers in the computer are thought to tell the story, yet they do not. The response by big data managers is that a small number of anecdotes simply cannot be relied upon to drive healthcare when compared to the large amount of quantitative data collected.

The following serves as a stunning example of what can happen when individuals at all levels of a hospital organization fail to attend to patient care issues in the midst of a massive reorganization of the healthcare system. This event occurred between 2005 and 2009 at two
Mid Staffordshire hospitals in Great Britain. An inquiry into patient complaints and a higher than normal death rate showed, according to a report by Robert Francis, QC,

…..failure on a scale that cannot be adequately expressed in statistics. The individual accounts of suffering are too numerous to list here, nor could they be done justice; but they spanned almost every aspect of care and painted an overall picture of a trust devoid of humanity, totally incapable of recognising patients as people. (Holmes, 2016; p. 521)

Francis concluded:

The shock that is the appropriate reaction to many of the experiences the Inquiry has been told about reflects the distance between the standard of basic care that is every patient’s legitimate expectation and what has, on too many occasions, been delivered at Stafford Hospital. (Ibid)

The conclusion of the report was that this was an immense failure of all involved, from less than adequate care by caregivers to disregard by managers and overseers. The result was injury and death to patients. In the current unknown state of healthcare in the United States, we too, risk a similar event in our system. We are at a point where definitive action must be taken to preserve the dignity of healthcare.

Recently a very small boy with a very rare genetic disorder has been headline news. Charlie Gard’s case had been considered futile and too expensive, so he was ordered off life support and experimental treatment denied, citing the statistics and unsubstantiated claims of harm as reasons for the denial. While court battles raged for several months, Charlie remained on life support and his disease went untreated. What is so interesting about this case is the fact that the doctors stated they believed he “might” be suffering, so to end life-support would be more humane, overruling even the parents’ ability to pay for an “as yet unproven” treatment. At the same time, this little boy’s parents were suffering from their own kind of battle, dealing with a devastating disease and the reduction of both them and their child to numbers and headlines. After Charlie’s case was deemed to be catastrophic and irreversible, and the European Court of Human Rights rejected the patents’ final appeal, the parents subsequently decided not to waste any more of the time they wanted and needed with their son in seeking further treatment for him. Even then, Charlie’s parent and the hospital could not agree on how Charlie was now to die. He was put into hospice, immediately taken off life support, and subsequently died the next day. This was despite the fact that Charlie’s parents had asked for a few more days to spend privately with their little boy who had valiantly fought for his life.

This case illustrates the collision of science and humanity. Charlie’s parents believed their son deserved a chance; the providers thought his case was futile and that he was likely suffering, though there was no proof. They thought he should be allowed to “die with dignity.” In the end, he was not even allowed to die with dignity in his parents’ sense of the term. The science of Charlie’s disease had advanced to the point where a treatment was available that might offer improvement. The courts sided with the providers. The case went international with President Trump and Pope Francis becoming involved, siding with the parents. The parents’ opinion never really had a chance. The window of opportunity for Charlie’s successful treatment closed with his and his parents’ humanity pushed to the background. What kind of “care” was shown to Charlie?
Caring, Compassion and Empathy

Hence, exactly what is meant by the term “caring” in the context of this article? Throughout the literature, the word “care” is used differently and in different contexts. Merriam Webster (healthcare, n.d.) defines the term health “care” as, “the maintaining and restoration of health by the treatment and prevention of disease especially by trained and licensed professionals (as in medicine, dentistry, clinical psychology, and public health)”. Nowhere in this definition can one find the words, human, care, or empathy. The same dictionary defines the term “care” in two contexts: one as a noun in the sense of things achieved to avoid harm to persons or things, the other as a verb in the sense of feeling concern or affection for another. The term “care” in the context of this article is used in the latter definition. That is, it includes the concept of empathy and compassion for another human being. The term health “care” could be called a misnomer when discussing the human side of disease treatment and prevention. One might suppose that care in the sense of the first definition of receiving a treatment or physiological care would constitute exemplary care. It would seem to be sufficient in today’s healthcare framework of product lines and emphasis on clinical competence. Still, this is not enough to alleviate the needs and suffering of the human condition. As so eloquently expressed by Mr. Rivera above, humans need compassion and to feel loved. Caring in this sense implies an act based on concern for and understanding of another’s burdens. In today’s framework, this human viewpoint is quite frequently missing and healthcare is undergoing a crisis where compassion is scarce.

Care by health professionals frequently is touted as both an art and a science. In the current knowledge explosion, the art of medicine has been largely lost to the science. Shelley (2015) provided an excellent editorial describing how medical professionals need to re-integrate spiritualism (not in the organized religion sense), dignity, and compassion. He describes an “empathy gap” in medical education, with new knowledge focused mainly on learning the treatment of underlying disease processes (pathogenesis), as opposed to the role of humanism and compassion on the healing process (salutogenesis). Clark (2016) also described the difficulty nurses and nursing students currently have with integrating transpersonal caring into their practice and offers advice to educators for helping students assimilate this aspect of patient processes.

Jean Watson, a nurse theorist, has been instrumental in beginning to bridge that gap with her Caring Theory. She began to define this in her early work in the late 1970’s and described this as central to a nursing caring relationship. She believed an integral part of nursing’s healing role was to help an individual to maintain humanity and individual wholeness. Her work had deep philosophical and international experiential roots and had at its core, a genuine caring relationship as integral to healing. Later, she further evolved her theory to develop the 10 Caritas Processes (Watson, 2008). These included such things as being completely present to the person being cared for and creating an environment that allows for healing on physical, spiritual and emotional levels. Her work was so groundbreaking in nursing that it has been adopted by numerous hospitals world-wide as the foundation for their patient care practices (Watson, 2009). Dr. Watson has led the field in defining a caring philosophy for practice for all healthcare professionals. Even with the advances in her work, genuine caring and compassion seems to continue to be lacking. Most of the literature on compassion is concerned with compassion fatigue and burnout experienced by caregivers.
Lown, McIntosh, Gaines, McGuinn, and Hatem (2016) discuss the need for compassionate care as vital to medicine and that this should be a part of the provider’s education. They state:

...compassion without collaboration may result in uncoordinated care, while collaboration without compassion may result in technically correct but depersonalized care that fails to meet the unique emotional and psychosocial needs of all involved. (p. 310).

Shelley (2015), a neurologist, believes strongly there is a physiological mechanism for healing based on humanism and spiritual wellbeing. He iterates that compassion and humanistic care is vital and necessary for creating health and that such education also should be requisite for healthcare providers. Fiering (1976) discusses a term he calls, “irresistible compassion” in which a human being is compelled to move toward relieving suffering. Also termed sympathy and humanity, it described our need to assist others. By contrast however, during the eighteenth century, if we as humans are irresistibly compelled to relieve suffering, then anyone who showed apathy was considered as less than human (Fiering, 1976). Fernando, Arroll, and Consedine (2016) differentiate compassion and empathy, stating one can feel empathy, for example with the patient who may have a broken leg, cannot walk and is in pain. However, they assert compassion is the next step on the continuum whereas one takes action toward alleviating the suffering of the patient. Empathy can occur without compassion, but compassion cannot occur without empathy.

Philosophically, compassion could be compared to caring. The two terms are often used interchangeably, yet they are different, or at least differently considered. To have compassion means to have deep empathy for an individual and to have a desire to alleviate their pain and suffering. Caring has many meanings, but can be used in the above sense with a person, but can also be used with an inanimate object as in to care for a book, or a watch. The term compassion is a much deeper representation of the concept as it is coupled with the desire to remove distress where as it is not necessarily so with the term “caring.” (caring, n.d.). Thus, when we are discussing the need for a shift to humanity in health care, we should probably use the term, “health compassion.”

Humans have the unique ability to elevate empathy to higher realms and in more complex situations, even to extend it to other species. Darwall (1997) compares sympathy to care as a synonym, but differentiates it from empathy. Whereas empathy is more a first-person experiencing something from another’s standpoint, sympathy involves a caring response. He goes further to declare that empathy is dependent on the perspective of the observer and can range from indifference to deep, visceral feelings of sharing mental turmoil. Both empathy and sympathy are conditions of, but do not necessarily lead to, the act of compassion (Von Dietz, 2000).

Goetz, Keltner, and Simon-Thomas (2010) provided an evolutionary picture of compassion, referring to three different types as a trait that “enhances the welfare of vulnerable offspring……a desirable emotion or attribute in mate selection processes and….. it enables cooperative relations with non-kin.” (p. 354) It is the third evolution that gives rise to compassion in the healthcare context. Von Dietz and Orb (2000) attempted to define compassion as conceptually different from both sympathy and empathy. They describe compassion as having both an emotional component, but also what they term, a “rational dimension and…..deliberate altruistic participation in another person’s suffering” (p. 168). The
work setting in which clinicians practice is a highly stressful and demanding environment that leaves little time for compassion (Graber & Mitcham, 2004). The literature on compassion in healthcare professions continues to be scant, except in terms of compassion fatigue. Even though different conceptually, it is a term that continues to be used synonymously with empathy, sympathy, and caring. They are all often referred to as the most valuable attribute of healthcare, yet appear to be lacking (Schantz, 2007). The very fact that it must be defined and described in some detail speaks volumes as to the search for its true meaning.

Traditionally, medicine has been thought of as both a science and an art. Bronowski (1956) discusses the truthfulness of science, but also admits that the truth cannot be extricated from meaning. He implies that meaning is simply more challenging to communicate, but is an integral part of science. The science of healthcare has expanded exponentially. We are at the point where we can identify even pieces of a gene that will affect expressions of health and behavior. This enables very targeted interventions, giving rise to the terms precision, or personalized, medicine. Use of the term “personalized” can be misleading in that it is simply a misnomer, Aspinall and Hamermesh (2007) go so far as to state that our outdated systems and even physicians create barriers that need to be surmounted, as if use of genomic medicine would constitute a new medical panacea. It does have promise, but overlooks an important factor, the human who owns the genes.

Almost 100 years ago, M. Adelaide Nutting, in a speech to students at the Vassar Training Camp on September 9, 1918 titled, “Apprenticeship to duty” stated,

We may have great and imposing buildings, the last word in hygienic and sanitary appliances, dazzling operation rooms and laboratories, but that stricken human being lying there has many needs that none of these can satisfy. We must lean also upon the soul and spirit of the place to sustain and strengthen him. Such a soul and spirit many generations of workers, nurses, doctors and others, have constantly striven to keep alive in our hospitals, (AJN, 1918, p162-163).

Though spoken years ago, this statement is as relevant today as it was then. We must continue to strive to care for the human, to keep the kindness and empathy necessary for the person to act.

Even so, there is a physiological cost to empathy and caring. Manczak, Delongis and Chen (2015) describe an increased parental inflammatory response to empathy toward adolescents in parent/adolescent dyads. Even though increased empathy was beneficial to their children, it came at a cost to the parent. Bevans and Sternberg (2012) described a case study of a caregiver in which the caregiver experienced numerous negative physiological health effects. Of course, there is a growing body of literature explicating the psychological effects of caregiving, including compassion fatigue and caregiver burn out. However, this only serves to stress the importance of care for both patient and caregiver, because the physiological effects of being genuinely cared for are enormous. Lebowitz and Ahn (2014) discuss the positive outcomes based on a therapeutic relationship between clinician and patient. Some would suggest patient adherence to a medical regimen is greater in the presence of perceived empathy by the clinician through both social and neurobiological actions. (Decety & Fotopoulou, 2015; Kelley, Kraft-Todd, Schapira, Kossowsky, & Riess, 2014).
In Examining the History of Caring

There are three principal requirements in a medical man (sic passim): first, that he be skilled in the curative arts and familiar with the resources of the body, the powers of diseases, and the treatment to use for each illness; second, that he should be sincere and not have his eye on anything except the health of the patient, for many are led on by ambition or money to the point of administering poison instead of medicine; third, that he should pay close attention and take the necessary pains.

Erasmus
(Albury, 2001; p. 36)

Caring for the sick has ostensibly been done since the beginning of humanity, but has taken on numerous forms and been performed differently by different people. Philosophically speaking, using Laudan’s Historico-Social assumption, one could surmise caring is a consistent feature of alleviating suffering (Laudan, 1977). Contextually, social scientists would say caring arose from the natural nurturing instinct of mother and child and was done by the women members of a tribe. However, despite the caring aspect carried out by women, the practice of medicine and rituals was performed by a medicine man, or shaman (Dock, 1920).

Greeks were the first to take care of the sick away from superstition and magic and into the realm of scientific and rational thought, based on nature (Longrigg, 1993). Interestingly, the Hippocratic Oath, purported to be written in the fourth century BCE, and which is used today as one of the oldest “rites of passage” into medicine, uses as its foundation, medical practice based on science rather than caring. The oath does not mention caring in the human sense of the word (Hulkower, 2010).

As humanity progressed in both knowledge and ability, there was a differentiation of duties, again according to those who healed and those who cared. Interestingly, Maggs (1996) identified a gap in historical accounts of nursing in which caring is consistently omitted in favor of political, social and demographic accounts of the progression of the profession. He asserts that throughout its history, nursing is simply an imitation of familial roles whereas the women assume the role of caregiver, thus yielding power to the more male medical roles. In his paper, he calls for a unification of theory and practice such that caring becomes part of the history of the profession.

Dock (1920) explained that the profession of nursing and of medicine closely parallels the standards of present humanity. Her lengthy History of Nursing follows the profession from ancient times to the modern day (at least in 1920). She discussed the impact of the Christian religion on the role of carrying out “God’s work” in caring for the sick and the fact that, even though they had equal status in the early church, women were primarily the ones caring for the sick. Even during the Middle Ages, women held high-ranking positions in the monasteries, where hospitals were developed for housing the sick. During the Middle Ages those caring for the sick, both men and women (Dock, 1920), were from upper class families and this was considered part of their duties to society, especially during the Crusades; and institutions enjoyed the benefit of growth from land and monetary donations. However, in the thirteenth century, church oppression overshadowed growth of charitable monastic institutions. For example, in 1212 the Council of Bishops developed strict regulations for French hospitals and, in the name of efficiency, ordered patients to be cared for by as few Sisters as possible.
This seriously affected the flourishing Hotel-Dieu in Paris, resulting in the Sisters’ becoming cloistered and the degradation of their abilities. Because of this and the necessity to close huge numbers of hospitals, leaving few options for the poor, nurses at that time were drawn primarily from lower classes and were untrained, generating a disinterest to suffering (Dock 1920). Later, during the Renaissance, physicians were educated at universities while women simply took on the role of caregiver. One of the most immortalized stereotypical characters of that period was Charles Dickens’ Sairy Gamp, a crude and untrained medical attendant who was given to drink. Some believed that women healers practiced among the commoners, yet were persecuted based on the existing political themes of the era, including religious persecution of women healers as witches (Ehrenreich & English, 1973).

Historically, war seems to hasten the proliferation of knowledge for the healthcare field. One of the most notable examples is Florence Nightingale’s contributions to the significant decline in the mortality of soldiers simply based on keeping meticulous records and instituting sanitary conditions in the hospitals (Kopf, 1916). War is where advances in specific diseases and surgical innovation are used in an effort to improve survival rates and techniques (Bennett, 1990; Clifford, et al., 2014; Salcido, 2015: Dock 1920; Schwab, 2016)

A theme that seems to appear over and over again throughout the history of caring for the sick is one in which there is division of labor and differing roles in care of the sick. The “treating” role has traditionally been reserved for men, while the “caring” or “caregiver” roles were reserved for women. The medical profession seems to be cyclical, transitioning between lay and religious influences, and having periods where suffering and humanity were important and periods where this was not focal. Additionally, in most of the historical texts, the context of “caring” is not seen, except to mention its origins and the fact that it was separated into those who treated and those who cared for the sick. What has remained constant through the historical evolution of healthcare, though not always emphasized in the same way, was the fact that humans who are sick and suffering have basic needs to be treated humanely.

**Medicine as Big Business**

It appears that the modern concept of healthcare is more business oriented than caring oriented. Currently, a basic motivation is to “process” as many patients through as possible to obtain the maximum reimbursement to meet the office overhead. So what has driven healthcare to this point? It is extremely complex and is not the subject of this article. However, it currently boils down to dollars and product lines. Moreover, contributing to the confusion is a lack of healthcare literacy, sometimes-unreasonable expectations by patients, and lack of insurability and healthcare access by the poor, causing them to use the emergency room for services because there, they will not be turned away (Joseph & Marrow, 2017).

Castano (2014) stated the business model should take precedent over the “oversimplifying approach to patient satisfaction with amenities and interpersonal skills....” He further posits that business models would do well to be substantially innovative. He does however, address the fact that patient-centeredness is an essential, but often overlooked component of such innovation. Angeli and Jaiswal (2016) go so far as to state that using efficient business models in underdeveloped countries can influence a decrease in poverty. Many espouse the notion that healthcare professionals also need to be educated in business practices to increase their
awareness to entrepreneurship and business acumen (Hill, 2014; Miron-Schatz, Schatz, Becker, Patel, & Eysenbach, 2014; Peterson, Adams, & Demuro, 2015; Castano, 2014)

Yamamoto (2013) distilled the cost of healthcare down to per capita spending for each age group, as if humans were simply a number on a graph. He further refined it to the type of insurance plan on which an individual was enrolled, which showed no significant differences. Devaraj, Ow & Kohli (2013) examined data from 567 hospitals and concluded that efficient flow of patients through a system positively affects performance and the quality of patient care. The question remains, however: What is meant by quality of patient care? Even more so, what is meant by the term “care.” In the business sense, it seems to mean treatment and prevention of a disease (Kahn, Maurer, Wartman & Sachs, 2014; Miron-Schatz, Schatz, Becker, Patel, & Eysenbach, 2014).

It appears in recent years, Accountable Care Organizations’ (ACO) patient care quality has been linked with lowering care costs as a method to manage healthcare. In her paper explaining the origins of the Affordable Care Act, nowhere does Quadagno (2014) mention caring, but rather government reform of the US healthcare system from an economic perspective. This is all well and good, but there is some literature where this can be found to be linked with patient perceptions. For example, Kerrissey, et al. (2017) conducted surveys of patients in structurally integrated care and found they perceived care was less integrated in patient-centered domains. By integrated, they meant a seamless organization of multiple caregivers to address the entirety of the patient’s health issues. A study by Fryer, Friedberg, Thompson, and Singer (2017) concluded that increased patient integration as reported by patients could improve efficiencies of the healthcare system. Nowhere in these studies did they include patient perceptions of the humanness of care delivered. Their surveys only included demographics and care utilization and how their care was administered across services. As well, some literature links ACOs to provider perceptions of healthcare based on utilitarian perspectives (Noble, Greenhalgh, & Casalino, 2014).

As of this writing, the United States is in the midst of a great debate on healthcare. The Affordable Care Act (ACA), was signed into law in 2010 and fully implemented in 2014. It was designed to provide greater healthcare equity to an increasing the number of insured Americans. It created healthcare exchanges and a Medicaid expansion plan, using subsidies to insure more people. However, the result for many was a decrease in services covered and rising premiums (Joseph & Marrow, 2017; Gaffney & McCormick, 2017). Disagreement in Congress led to the creation of the American Health Care Act (ACHA) that would limit Medicaid expansion, eliminate the employer mandate and lower tax credits for lower and middle income Americans. Also known as the “repeal and replace,” this bill has failed to gain support enough to pass the Senate. What is most interesting in this entire discussion of American healthcare is what is not being said. What is missing is the patient, the human, and any mention of compassion or caring. Additionally, most of the literature did not mention sustainability of the flawed system. Also known as the “repeal and replace,” this bill has failed to gain support enough to pass the Senate. What is most interesting in this entire discussion of American healthcare is what is not being said. What is missing is the patient, the human, and any mention of compassion or caring. Additionally, most of the literature did not mention sustainability of the flawed system. However, the Massachusetts Health Reform could serve as an example of longer-term effects of healthcare reform. Garabedian, Ross-Degnan, Soumerai, Choudhry, and Brown (2017) only make a passing mention of sustainability related to short-term enrollment of patients with higher costs. In all the literature, the business model seemed to be the intent of the primary discussion. There is much literature in educating healthcare professionals toward a business model of care and in improving business skills (Hill, 2014; Miron-Schatz, Schatz, Becker, Patel, & Eysenbach 2014; Kahn, Maurer, Wartman, & Sachs, 2014).
In his speech to the Waldo Symposium, Gawthrop (1997) stated,

The façade of pretense applied in the name of public service tends to project bureaucracy in its most unfavorable light. If this perception is to be changed in the years ahead, it is incumbent upon public servants, individually as professionals and collectively as a profession, to create a new reality for themselves, a new image that rings true of a service in the name of democracy. (p. 205)

This is most certainly true of healthcare, if we are to move away from the hypocrisy of product lines and profits to a profession that genuinely cares about and sympathizes with those under our care. Patient engagement in their care should revolve around goal setting with patients, monitoring and reporting. Again this literature only implies these activities constitute caring and compassion, but business models typically lack in the humanity of caring.

Additionally, as the breadth and depth of new knowledge explodes, providers are hard-pressed to keep up; technology will be used more and more in diagnosing and recommending treatment for disease (Khan, Maurer, Wartmean & Sachs, 2014). As they state, “....health care teams essentially become the human interface between patient and machine” (p. 1216). For example, the mobile health and related applications continue to grow at a deafening pace as more patients download personal applications related to tracking their health, making appointments and accessing records (Peterson, Adams, & DeMuro, 2015). Mobile health allows for patients to communicate with physicians’ offices without a personal interface. Despite widespread use, privacy concerns and safety issues continue to be worrisome to providers (Peterson, Adams, & DeMuro, 2015). There is a plethora of websites and blogs where health information is inaccurate. Yang, et al. (2017) describe robotic systems with differing levels of autonomy levels ranging from no autonomy to “full autonomy (no human needed).” Already robots are being used for telemedicine and are proposed for various tasks in hospitals and to perform transport, food delivery, information transmission (Rogatkin, 2016). Tanioka, Osaka, Locsin, Yasuhara, & Ito (2017), in a frightening article designed to assist in the theoretic development of Humanoid Nursing Robots (HNRs), discuss the need for some HNRs to have the ability to “care” and show empathy for those for whom they care. This is contextualized in the aging of the population and the need for eldercare. They speak in terms of these HNRs as replacing human-to-human interaction because of a severe shortage of human resources, as if the human capacity for caring will be exceeded. A very recent ad sent over the internet states, “Similarly, artificial intelligence will act as virtual clinical assistant, patient care bots and digital coaches which would enable mimicking one on one interaction that keeps patients disease free and happy.” (OmniMD, 2017). This is very frightening indeed.

Sim and Aida (2017) describe the attempt to synthesize molecular machines as the “Holy Grail” of future medicine. These tiny machines have promise in the specific endogenous treatment of disease and could be considered differently from their larger counterparts that might be expected to replace the human touch in medical and nursing care.

One of the most important impetuses driving the use of robotics is they are more cost effective than humans. Hamet and Tremblay (2017) suggest that avatars may be used to provide care for older adults because of more frequent conversation that is comforting and thoughtful. They do however admit that more research and evaluation needs to be done. Additionally,
ethical challenges should be scrutinized before use of robots becomes the standard. By no means
could or should a robot replace caring human interaction, but as social media and electronic
communication becomes more sophisticated and humans to interact from a distance, the
slippery slope may not be far away.

One of the latest innovations is personalized medicine, which seems to be synonymous
with precision medicine. In a 2007 article, Aspinall and Hamermesh speak of personalized
medicine, but not in the human sense of the word. Instead, they detail a more genomic
approach, using a patient’s own genetic make-up and physiology to treat disease. Even this,
though called personalized, is based on the patient’s cells, not the patient. As well, Crawford et
al (2014) outlined several institutional barriers of conducting genomic testing within academic
medical centers. They concluded that the institution and its processes precluded the human side
of caring for patients.

**Conclusion**

Caring for and nurturing other human beings is and has always been the very root of
healthcare in some fashion. At different times throughout our history, that purpose seems to
have gotten lost in the weeds of the time. Currently, there is a pervasive atmosphere where
genuine human caring is taking a back seat in health care. Additionally, our world has begun to
go in a direction where our technology allows for non-human interaction. It is only too easy to
hide behind the anonymity of a handheld device or computer to communicate with others. Our
systems seem to be enamored with numbers as a metric for quality of care rather than stories or
input from those being cared for as to how best to do that. The continued quest for the ‘holy
grail’ of replacing humans with robots in an effort to achieve more efficiency will lead down a
slippery slope from which there may be no recovery. Admittedly, as the population and lifespans
increase, this necessitates finding other ways to use scarce resources, but it is not clear that it is
better to seek to replace human-to-human interaction. To ignore the human in need of our care
is not ethical, nor is it desirable. Humanity and dignity must be preserved.

A very interesting talk, given by Dr. Robert Sapolsky to the Stanford graduating class
in 2009, stated that what makes us most unique as human beings is our ability to react to
contradictory ideas. He stated, “At the end of the day, it is really impossible for one person to
make a difference. And thus, the more clearly, absolutely, utterly, irrevocably, unchangeable clear
it is, that it is impossible for you to make a difference and make the world better, the more you
must.” (https://www.ted.com/talks/robert_sapolsky_the_uniqueness_of_humans)

Considering all that has been shared, permit me to provide some reflections from a
personal perspective. As human beings we can, at our worst, hurt and injure one another; and,
at our best, show genuine compassion and caring for each other. I, for one, as a human being, do
not want to rely on a middleman to relay information back and forth between a machine and
me. I would much rather spend more in order to be assured that I am listened to, and cared for,
by another human being. We need to find our way again, remembering the basic human needs
of those who need our help to alleviate their pain and/or suffering. Therefore, it is a moral
imperative for us as healthcare providers to move beyond the business models, the barriers of
complacency, the harsh work environments, and the incivility and begin to bring back the “care”
into caring. We need to be intentional about patient-centeredness.
In light of this discussion, I wish to call for a change to the paradigm of our healthcare system such that health “care” truly becomes health caring as opposed to the current health product lines. How much difference can a single person make? This was clearly illustrated in a movie titled “Pay It Forward” in which a young schoolboy was assigned to find a way to change the work. He decided to do good deeds to others, without expectation of repayment in response to a good deed done to him. This created a cascade of good deeds that made a difference in the town surrounding this boy. In fact, there is even a movement called “Pay It Forward Day” in which 80 countries participate.

If there is any doubt about the difference one act can make, one only needs to read the short story titled “A Sound of Thunder” by Ray Bradbury to realize how one simple act has the ability to drastically change outcomes --- something our healthcare system is very concerned about, but cannot seem to grasp in the human sense of the concept. In this story, one has the ability to go back in time and hunt dinosaurs, but must stay on a path. One individual strayed off the path and killed a single butterfly, changing time forever. In the case of caring for a human, an act of concern and kindness could actually mean the difference between resignation of an illness and motivation toward health. It could mean the difference between a provider who is tired and ready to give up and a provider who gains the energy to keep going and pay the kindness forward.

When it comes to the need for more caring in our defunct healthcare system, there are more questions than answers, and numerous points to consider. What would be the results if healthcare professionals were to take the time to listen to a single patient on any given day? How might that change the face of healthcare, or the outcomes of that patient for the better? How might we act as an example for others to emulate? Can we encourage patients to assume responsibility for their own health rather than to leave it to the hands of others who are more interested in data points than the person? How can we use the information quite literally at our fingertips and leverage our technology to create a caring system? It only takes one person, one caring act, one at a time. What would it look like if multiple people committed abundant caring acts, many at a time? I highly suspect we could change the face of healthcare from a data driven, business model with dismal outcomes to a caring, efficient model where our patients not only feel well, but also feel good.
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Zika Virus: What Can We Learn

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Abstract
Ever since ancient times humans have been “plagued” by epidemics and pandemics. From the bubonic plague of the middle ages to influenza pandemics, Ebola epidemics and Zika epidemics of more recent times, people have most often responded to these outbreaks with short-sighted, after the fact measures. There has been little pre-planning. Recently the medical community was caught off-guard again by both the Ebola and the Zika outbreaks. No doubt, with greater planning these outbreaks could have resulted in less morbidity and mortality. What can we learn from the latest outbreak of Zika and what is being done to plan for future outbreaks of some unknown infectious agent? Over the past two years there has been increasing interest and anxiety concerning the outbreak of the Zika virus in the Western Hemisphere. This previously little known mosquito-borne virus was first reported in South America in 2015. Since its first appearance in Brazil the virus has spread to many other countries in both South America and North America, including the U.S. Although the infection is usually mild or even asymptomatic in adults, the virus can cause neuropathology in both the developing fetus and in some adults. This article will discuss some of the salient issues regarding Zika virus infections including history, the virology, the course of infection and prevention. Vaccines are being tested but none have yet been approved. How can our experiences in recent epidemics help us to be better prepared for any upcoming epidemic/pandemic?

Keywords: Zika virus, epidemic, pandemic, mosquito control, microcephaly, sexual transmission, plague
Introduction

The year is 1348 and we are living in the beautiful city of Venice, Italy. This bustling city is a hub for shipping and merchant traders. Ships from Genoa and Asia are unloading spices and silks for the merchants who are planning to become very rich. Also, being unloaded are the mice and rats as well as insects from the many places the ships docked before the Venice port-of-call. But wait! Some of the sailors and passengers appear ill! They have black egg-shaped lesions under their armpits, groins and on their necks. In years to come these lesions will be called buboes. Some of the sailors are coughing and spitting up bloody sputum. Within one year the entire Italian peninsula is involved in the Black Plague epidemic. Within ten years the known world would be involved and deaths would reach one-quarter of the population.

What can we learn from history and from the recent Zika outbreak? The recent appearance in the United States of the tropical infectious agent Zika Virus (ZV) has been extensively covered by the media. The virus first came to the attention of most Americans because of an outbreak in Harris County, Texas (Glenza, 2016) and because this little-known, mosquito-borne virus has been linked to serious birth defects. While the Harris County case and several others in the U.S. have been imported from endemic areas (CDC, 2016a), the virus is usually spread to humans by various species of *Aedes* mosquitoes that appear worldwide (Hayes, 2009).

As of June 14, 2017, 5,292 total symptomatic cases of Zika (January 1, 2015 to June 14, 2017) have been diagnosed in the continental U.S. (CDC, 2017a). Of this total, 5,020 cases were in persons returning from areas of endemic Zika; 224 were presumed to have been from local mosquito inoculation and 48 were from other presumed routes including sexual transmission with one being a laboratory transmission and one person-to-person via an unknown mode of transmission (CDC, 2017b). All other cases have been imported from endemic areas outside the U.S. Sexual transmission of ZV has also been documented (CDC, 2016f, CDC, 2017b). Currently, as of June 22, 2017, there have been no local cases of Zika transmission from mosquitoes in the U.S. (CDC, 2017c). However, the mosquito season is only beginning in the U.S. Interestingly, the Zika cases, including microcephaly, have leveled off in South America and have been significantly below 2016 levels (Pan American Health Organization, 2017).

Public Health officials were concerned about when, and not if, the virus would appear in U.S mosquitoes. On Friday, July 29, 2016, Dr. Tom Frieden, the director for the Centers for Disease Control and Prevention (CDC), announced this had occurred: “As we have anticipated, Zika is now here” (CDC, 2016f). At the time, two of the suspected local disease transmissions occurred in Miami-Dade County, and two in Broward County (CDC, 2016f). By August 1, 2016, the number in affected counties in Florida had increased to 14.

Evidence had been forthcoming that linked the virus to birth defects, including microcephaly (babies with smaller-than-normal heads and decreased brain capacity), as well as other neurologic diseases (Glenza, 2016, and European Centre for Disease Prevention and Control, 2015). The link between microcephaly and the virus is now well-established and has been demonstrated by the recent epidemic of ZV in Brazil. Historically, the number of cases of microcephaly in Brazil was about 150 a year, but this past year saw a dramatic increase to about 3,500 cases (BBC, 2016).
As indicated above, there were 5,292 confirmed cases of ZV infection in the U.S. from January 1, 2015 to June 21, 2017 in 48 states and the District of Columbia (CDC, 2017b). All but 272 cases were imported. Of the 272 locally acquired cases, 224 were associated with mosquito-borne acquisition, 48 infections by other routes including one infection acquired in the laboratory, and one was acquired by unknown means. This last case of ZV acquisition is troubling. A patient with ZV infection acquired outside the U.S., who eventually died, was cared for by a relative who later acquired ZV. This person was not bitten by a mosquito, did not have sexual contact with the patient, did not receive a transplant, nor did they have blood or serum contact. They did have contact in the form of kissing (on the forehead) and routine medical care. This may be the first case of aerosol or non-sexual spread of ZV (CDC, 2016m). A recent theory is that the ZV transmission may have followed contact with tears (Beck, 2016). This patient eventually recovered.

Rapid diagnosis of severe infections is imperative, even though only supportive care is currently available. This is due to the potential for neurologic sequelae. Cases requiring hospitalization can occur but are rare. ZV infections are notifiable and should be reported to the local or state health departments (CDC, 2016h).

**Historic Perspective**

Zika virus was first isolated in 1947 from a rhesus monkey in the Zika Forest of Uganda, Africa, and was isolated for the first time from humans in 1968 in Nigeria (CDC, 2016a). From 1951-1981, clinical and retrospective evidence of human infection was reported from other African countries such as Uganda, Tanzania, Egypt, Central African Republic, Sierra Leone, and Gabon, as well as in parts of Asia, including India, Malaysia, the Philippines, Thailand, Vietnam, and Indonesia (European Centre for Disease Prevention and Control, 2016). Until the recent outbreak, little was known about the virus and there was little interest, since it was thought to cause minimal disease. The link with microcephaly in newborn children or with other neurologic diseases was not readily apparent. In May 2015, the Pan American Health Organization issued an alert regarding the first confirmed ZV infections in Brazil (Pan American Health Organization, 2015). In December 2015, Puerto Rico reported its first confirmed ZV case. Subsequent cases have been reported in the Caribbean, Central America, Mexico and several Southeast Asian countries. On January 15, 2016, a report issued by the Hawaii State Department of Health and confirmed by the CDC indicated that a baby was born in an Oahu hospital with microcephaly caused by ZV. The child's mother had lived in Brazil in May 2015 and probably was infected by a mosquito early in her pregnancy (Brumfield, 2016).

Miner et al. (2016) detected abundant viral RNA in tears, suggesting that the virus might be secreted from lacrimal glands or shed from the cornea. This is consistent with the report of potential spread of the virus in tears (Beck, 2016).
Travel Information

Domestic cases of ZV have occurred in American Samoa (14), U.S. Virgin Islands (15), and Puerto Rico (803) (CDC, 2016g) and most recently in Florida (4) (Walters, 2016). ZV cases have been reported to CDC (2016j) as follows:

a. Cape Verde

b. The Caribbean: Anguilla, Aruba, Barbados, Bonaire, Cuba, Curacao, Dominica, Dominican Republic, Grenada, Guadeloupe, Haiti, Jamaica, Martinique, the Commonwealth of Puerto Rico, St. Barthelemy, St. Lucia, St. Martin, St. Vincent and the Grenadines, Sint Eustatius, Sint Maarten, Trinidad and Tobago, U.S. Virgin Islands

c. Central America: Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama


e. South America: Argentina, Bolivia, Brazil, Colombia, Ecuador, French Guiana, Guyana, Paraguay, Peru, Suriname, Venezuela.

f. North America: United States, Mexico

Countries in Africa, Asia, and Europe have had ZV outbreaks (CDC, 2016e), as well as an outbreak of ZV in Singapore. In all cases of travel into endemic or outbreak areas, persons should check the latest CDC directives (periodically updated) at http://wwwnc.cdc.gov/travel/page/zika-travel-information.

The Virus

ZV is a member of the Flaviviridae virus family and the Flavivirus genus and is transmitted by Aedes mosquitos (European Centre for Disease Prevention and Control, 2016). ZV is related to other viruses in this family in both molecular biology and spread of the agent. ZV is enveloped and icosahedral with a non-segmented, single-stranded, positive-sense RNA genome (Faye et al., 2014). Positive-sense viral RNA is similar to mRNA and thus can be immediately translated by the host cell into viral proteins (Hunt, 2016). ZV is a relative of dengue virus and is found in tropical regions of the world, especially rain forests. ZV, dengue, and chikungunya (a togavirus) viruses are found in similar habitats and can complicate diagnoses (Fauci, and Morens, 2016). It is important to note there are two lineages of ZV, one African and one Asian, with slightly different antigens (Cugola, 2016). The virus seen in the Western Hemisphere appears to be a variant of the Asian lineage.

It is interesting to note that previously, the only other large outbreak occurred in French Polynesia (2013-2014) (Cugola, 2016), where it was estimated that nearly 20,000 persons became infected. This outbreak was caused by the Asian strain of ZV, but there was minimal evidence of microcephaly at that time (Cugola, 2016). The outbreak in South America was generally considered to be of the Asian strain of ZV as well (Adiga, 2016). However, genetic
analysis by Adiga (2016) has shown there to be changes in the C-terminus of the NS5 sequences of South and Central American isolates of ZV. These changes may be responsible for the increase in neurotropism of the so-called Latin American genotype of ZV.

Symptoms and Transplacental Transfer

The most common symptoms of ZV are fever, rash, joint pain, and conjunctivitis (red eyes). About one in five infected persons actually come down with symptoms (Brumfield, 2016), and the illness is usually mild. When symptoms do occur they will include at least two of the following: acute onset of fever with maculopapular rash, arthralgia, and/or conjunctivitis (CDC, 2016h). Myalgia and headache are occasionally reported. Severe cases involving hospitalization are rare, but cases of severe neurologic manifestations including death have occurred. Such untoward outcomes usually occur only in immune-suppressed individuals or in the very young or very old patient (CDC, 2016b). In a large outbreak in French Polynesia in 2013-2014, an unusual symptom of oral lesions occurred in a significant number of patients (Cugola, 2016). This manifestation is rarely seen in the current outbreak. Other manifestations of ZV infections can include other peripheral neurologic diseases, such as ocular lesions and Guillain-Barre syndrome in adults (Mawson, 2016).

As previously stated, transplacental transfer of the virus during pregnancy may result in microcephaly and/or death of the baby. Dr. Lyle R. Petersen, director of vector-borne diseases for the CDC, said the agency had found ZV in tissue from four Brazilian infants, two who had microcephaly and died shortly after birth and two who died in the womb (McNeil, 2016). Previously, Brazilian scientists had found the virus in tissue or amniotic fluid from three malformed fetuses. (There are several other causes of microcephaly, including genetic defects or rubella or cytomegalovirus infections of the mother during pregnancy.)

Diagnosis

Many people infected with ZV are asymptomatic. Diagnosis is often based on symptoms alone during outbreaks in endemic areas. Based on the typical clinical features, the differential diagnosis for ZV infection is broad. In addition to dengue, other diagnostic considerations include leptospirosis, malaria, rickettsia, group A Streptococcus, rubella, measles, parvovirus, enterovirus, adenovirus, and alphavirus infections such as chikungunya virus infections. During the first two weeks after the onset of symptoms, ZV can often be diagnosed by real-time, reverse transcriptase-polymerase chain reaction (rRT-PCR) on serum and urine (CDC, 2016c). Trioplex rRT-PCR is intended for the qualitative detection and differentiation of RNA from Zika virus, dengue virus, and chikungunya virus in human sera or cerebrospinal fluid (collected alongside a patient-matched serum specimen), as well as for the qualitative detection of Zika virus RNA in urine and amniotic fluid (each collected alongside a patient-matched serum specimen) (CDC, 2016 and FDA, 2016).

Virus-specific IgM tested by ELIZA and neutralizing antibodies typically develop toward the end of the first week of illness. Cross-reaction with related flaviviruses (e.g., dengue and West Nile virus) is common and may be difficult to discern. Plaque-reduction neutralization testing can be performed to measure virus-specific neutralizing antibodies and discriminate between cross-reacting antibodies in primary flavivirus infections (CDC, 2016c).
ZV testing is performed at the CDC Arbovirus Diagnostic Laboratory and at some local and state public health laboratories (CDC, 2016c). Specific testing information can be obtained from the CDC (CDC, 2016d).

**Prevention and Treatment**

No specific antiviral treatment is currently available for ZV. There is currently no FDA-approved vaccine, although several vaccines are in clinical trials, most in phase I and phase II trials (NIH, 2017). Treatment is generally supportive and can include rest, fluids, and use of analgesics and antipyretics (CDC, 2016b). Due to similar geographic distribution and symptoms, patients with suspected ZV infections should also be evaluated and managed for the infectious agents listed above. To reduce the risk of hemorrhage, aspirin and other non-steroidal anti-inflammatory drugs (NSAIDs) should be avoided until dengue can be ruled out (CDC, 2016b). People infected with ZV, chikungunya, or dengue virus should be protected from further mosquito exposure during the first few days of illness to prevent other mosquitoes from becoming infected and thereby reduce the risk of local transmission.

Protection currently rests with elimination of, or protection from, the mosquito vector (CDC, 2016d). As such, use of insect repellents containing ingredients such as DEET (CDC, 2016d), screens, and insect netting is suggested. Long-sleeve clothing and long pants should be used. Larvicides can be used to kill mosquito larva in water and standing pools. Since the mosquito vector is active during the day, daytime activities should be reduced as much as possible, although the *Aedes* mosquito can also bite late into the evening. Pregnant women and those planning to become pregnant should avoid travel to endemic areas if possible, especially if there is an outbreak of ZV.

In the U.S., many local health departments periodically spray for mosquitoes, which have apparently eliminated many of the mosquitoes infected with ZV from the Miami area. The schedule for spraying is usually posted in the local newspaper or can be obtained by calling the local health department. Care should be taken to make sure standing water is removed, such as in pools or tires.

**Transfusion and Sexual Transmission**

Generally, there is minimal risk from Zika transmission via blood transfusion. With the discovery of endemic ZV infections in two counties in Florida, transfusions from these areas, including the surrounding counties, were discontinued for the time being (CDC, 2016i). On August 26, 2016, the US Food and Drug Administration (FDA) issued revised guidance to prevent the spread of ZV through the blood supply. This new FDA guidance calls for blood collection centers in the United States to screen all donated blood for ZV (CDC, 2016i).

Although sexual transmission of ZV from males to females has been documented since early in the current epidemic, female-to-male transfer of the agent has now been documented. Barrier protection, including male and female condoms and dental dams, can reduce the chance of passing ZV through sex (CDC, 2016k). To be effective, these products should be used from start to finish each time during vaginal, anal, and oral sex. Not sharing sex toys can also reduce the risk of getting ZV through sex. Note that spermicides are not effective in protecting against
any infectious agent (CDC, 2016k). In areas without active transmission of ZV, the CDC/ 
FDA guidance for couples in whom the man or woman has had possible ZV exposure who want 
to maximally reduce their risk for sexually transmitting ZV to an uninfected partner should 
use condoms consistently and correctly or abstain from sex for at least six months for men or 
eight weeks for women after symptom onset (if symptomatic) or last possible ZV exposure (if 
asymptomatic). (CDC, 2016n).

Discussion

ZV is the latest in a number of recent outbreaks of diseases world-wide, and the response 
appears to mirror the poor effort with the Ebola outbreak in West Africa, when several months 
had passed before the WHO and other agencies responded to the very serious impact the 
Ebola virus has on human life (Health News BBC, 2015). Since then, a great deal of discussion 
occurred about more rapid responses to future outbreaks of infectious agents. The ZV epidemic 
presented another response challenge, but unfortunately, the response to this outbreak was less 
than adequate (Star Tribune, 2016). This outbreak is ongoing and spreading, and it appears an 
effective vaccine is still about a year away (Fox, 2016).

There are a number of efforts currently being undertaken to provide a more rapid response 
to infectious diseases outbreaks in the future. In April, 2015, in response to the Ebola “wake-
up call”, the United Nations Secretary-General established a high-level panel to address issue 
related to outbreaks of diseases and make recommendations to the international community 
related to new outbreaks (UN, 2016). The Panel made 21 recommendations to the world 
community to address future disease outbreaks. Unfortunately, these recommendations are only 
now being reviewed by the international community for possible implementation. Action plans 
are currently being funded and reviewed by agencies such as the HHS Biomedical Advanced 
Research and Development Authority (BARDA), other governmental agencies, the Bill and 
Melinda Gates Foundation (Gates, 2017) in cooperation with the Coalition for Epidemic 
Preparedness Interventions (CEPI, 2017). Although the emphasis by the Gates and CEPI effort 
is directed at vaccines, it may provide an effective framework for other efforts.
Articles

References


Articles


Academic Law Commentary

Function Creep: Investigating the Effects of the Subjugation of Scientific Innovation and Its Moral Applicability and Potential Consequences

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Abstract
This article will explore the innovation of familial DNA searches, including its use and misuse in the guise of human betterment and improved public safety. This exploration will include the misuse of familial DNA searches as violations of privacy and increased burdens on certain members of the population. Within this context, this article will promote the need for a new social contract. The article will begin with an explanation of DNA profiling, and then discuss the scientific analysis that supports such profiling, the development of DNA databases and the potential of such impacting and endangering the right to privacy. It will then compare and contrast familial DNA searches with that of autosomal DNA searching. In illustration, a short case study will demonstrate the limitations of such searches and the dangers posed to individual privacy. Finally the article will delve into the concern of function creep, specifically in familial DNA profiling and how such is a singular manifestation and worry of a larger and serious concern in the battle for the protection of a citizen’s right to privacy.

Keywords: DNA databases, familial DNA, familial search, function creep, privacy
Introduction

The Claim of ...[justice]... in a domestic setting has the same kind of power as the claim of “national security” in matters relating to foreign policy. Both claims are very powerful arguments for ... action. Both claims are amongst those least likely to be questioned... and therefore subject to abuse.

City of Newark v J.S
1993

History is replete with examples of scientific innovation and discovery being used off-books, or in a clandestine manner, a manner outside its original mandate or purpose. Some take the view that this itself is innovation as it harnesses the usefulness of a discovery into a yet unforeseen usage. On first blush one may take the view there is nothing wrong with such usage as it benefits society, solves mysteries and possibly stems the tide of misery and despair. However, if we dig deeper and can illustrate that the application of an innovation can directly cause or result in social and doctrinaire conflicts, what then?

In a best case scenario, or in a perfect world, these conflicts/tensions would be confronted and discussed prior to the widespread use, or more importantly, potential or real misuse of such scientific tools. However in most real world scenarios this does not occur. Often time the public through attrition retroactively discovers that rights imbued by an overarching statutory document have been curtailed or significantly eroded.

This article will explore the use and misuse of the scientific tool/innovation of Familial DNA searches. This is but one of a myriad of ancillary topics that confront the broader overarching issue of the erosion of privacy rights amongst the collective. We as the collective human society must be sharply aware of erosions that might be occurring in real-time with little fanfare or discussion. We must be ever vigilant to ensconce and fortify our constitutionally derived rights lest they become a footnote of history. We can never allow the Greater Good to be eroded.

DNA and Its Applicability to Profile Individuals

DNA profiling, sometimes coined as DNA fingerprinting, is a biological/scientific tool retrofitted for a forensic application. In crime scene analysis or, in broader terms, law enforcement investigations, it is a technique used to identify individuals via variations in their individual genetic composition. A DNA profile utilizes a small set of differences encountered in the human genetic code that separates and more importantly identifies individuals with a high degree of certainty. It allows for the differentiation of individuals with the same applicability as a fingerprint. Another application for DNA profiling includes paternity testing.

By way of background, 99% of human sequences are identical. However there is enough variation in the other 1% of the human genomic sequence to enable science to distinguish individuals. The one caveat is monozygotic individuals, more commonly referred to as identical twins. Through germination such twins share identical genomic sequences. DNA fingerprinting targets highly variable sections called variable number tandem repeats (VNTRs) and, more specifically, short tandem repeats (STRs) in application for law enforcement investigations and in paternity testing.
VNTRs are expected to be, and in most circumstances are, very similar between closely related people (i.e. families). Note the term similar, meaning they are not identical. It is the variation in these regions that allows the pinpointing and accuracy of the application to profile individuals notwithstanding identical twins. In all individuals DNA is maternally and paternally derived; half is obtained from the mother and the other half from the father. As DNA is stored in all of the cells within the body, the collection of this genetic information can be performed through non-invasive techniques, such as the swabbing of the inner cheek with a Q-tip or other similar devices.

The collected cells then undergo a scientific process or analysis enabling the scientist to extract the needed genetic material through a series of manipulations and extractions thereby targeting certain locations in the human genome found to be useful in determining distinctive identity and biological parentage and other familial relationships. Each location (referred to as a locus) contains DNA markers scientists use in “unmasking” an individual. These markers are also labeled STRs and are inherited from both mother and father. As such they differ in length and sometimes sequence. The combination of markers and sizes comprise each individual’s unique genetic fingerprint.

When determining parentage or any type of familial relationship, individual DNA fingerprints are compared for shared characteristics or patterns that are considered to be statistically significant. As the markers emanate from highly variable regions (statistically speaking) it has been determined that anywhere from 13 loci (original number used back in 1985) to 23 loci are needed (including the sex determining loci) to provide a unique genomic profile of identification.

**Y-chromosome Analysis**

Recently science has targeted the variable regions on the male chromosome (Y-chromosome). This has many applications such as differentiating a mixed sample from a male and a female, such as would be needed for the analysis of a crime scene (e.g., rape or assault). As the Y-chromosome is paternally inherited, it can also help in the identification of paternally related males. This type of analysis likewise aids in the identification of siblings for paternity or familial testing and is relatedly used (albeit not universally so) by police to identify family members in the investigation of cold-case crimes.

However caution must be taken in Y-chromosome analysis. The Molecular and Cultural Evolution Laboratory at University College London reports that this type of analysis yields statistically weaker results than non-sex determining chromosome analysis (autosomal analysis). As the Y-chromosome is only paternally received, it calls for greater speculative conclusions, increasing its potential for less precise analysis when compared to autosomal testing.

**DNA Databases**

After individual profiles are generated they are then stored in a database along with other profiles. This storing of genetic material has proved to be problematic, not due to the science or analysis of the genetic material, but instead due to the policies and lack of consistency involving the collection and storage of the genetic samples. Some jurisdictions collect and analyze samples from every person arrested irrespective of the offense. Other jurisdictions collect after the
individual has been charged with a crime. And yet in other jurisdictions the decision to collect and store is subject to and dependent on the type of charge.

However, regardless of jurisdiction, once the authorities decide to collect a sample, all profiles are subsequently placed in a DNA database, of which several are in existence, around the world. Some are private (e.g. Ancestry.com). Nevertheless the majority of these databases are under government control. When any database is searched and a match is found it links the profile found on the database to the one found at the crime scene or however the profile was involved in the commission of an offense. This is of obvious importance to any law enforcement agency as it provides specificity. It allows law enforcement to consolidate its resources and focus on a singular lead, individual or a group of individuals while abandoning others.

As it currently stands, the United States maintains the largest DNA database with the Combined DNA Index System (CODIS) holding over 5 million records as of 2007. In illustration of the initial paragraph under this heading it is noteworthy to state that the FBI cannot legally store DNA of a person not convicted of a crime, and it must be disposed of if already entered into a database. In contrast, individual state agencies are not subject to this stringent federal mandate and are left to their own policies and devices in deciding when to store a profile. Typically, innocence is not a consideration of the policy.

The United Kingdom (UK) maintains a DNA database labeled The National DNA Database (NDNAD) that is of comparable size to CODIS, the US national DNA database. This is despite the disparate sizes in populations. Perhaps this specific point belies and reflects the perspective of the UK when it comes to policing and prevention of crimes. Moreover it may denote their view of potential privacy violations and the issue of privacy in general. Coincidentally, the UK was the first government, whether state or federal, to utilize familial DNA as a tool.

**DNA Databases Misuse and the Potential for Additional Abuse of Privacy**

Some pundits take no issue with the decision to collect and profile any and all people arrested irrespective of whether they are charged and/or convicted. However these commentators either fail or perhaps ignore the issue of privacy. Note carefully the following when considering the privacy versus public safety dichotomy. It has been documented that an arrest can occur due to extremely arbitrary conditions. Equally, arrest does not automatically indicate the individual will be charged let alone convicted of an offense. How far does the right to public safety allow the law to impinge on personal freedoms and liberties? Is being arbitrarily stopped and potentially arrested for something as benign as a broken taillight or failure to perform a turn signal enough of a breach to signify a relinquishing of a person's fundamental right to privacy? Genewatch UK, a UK advocacy group, has been raising these questions since 2005.

This leads into another ancillary issue, the handling of profiles depending on the outcome of the arrest and subsequently the charge and conviction. Some jurisdictions upon acquittal remove the profile from the database while other jurisdictions retain it. The specific purpose of such retention however remains unclear, indeed critically unclear as it applies to constitutionally derived rights such as privacy.
Familial DNA Testing

A familial DNA search can be described as the search through DNA databases by law enforcement for genetic profiles. This search is not to find the actual suspect, as previous searches have provided no database hits in that respect. This search is performed with the hope of finding a partial match, thereby indicating that the identified individual from the database could be a relative of a person they seek to identify. This occurs when a “regular” search for an exact match to a DNA sample is unresolved.

Consider the following. A familial DNA search may bring back a partial match, thereby indicating a male relation, be it a child, parent or other relative with close familial ties. In illustration, if DNA from an investigation cannot be matched through any database, a familial DNA search can be done. If that individual’s male relative is in the database for whatever reason, be it arrest, charge, conviction or coincidence, a familial DNA search could lead the authorities to the relative and, with luck, to the suspect.

Familial vs. Autosomal DNA Searches

As explained above autosomal searches will provide an exact match to a DNA sample. This can be defined as a traditional DNA search which will only bear fruit if the profile has been previously stored in the DNA database. Contrast this with Familial DNA searches. As familial DNA searches do not identify exact relatives of a female DNA sample or female relatives of a male DNA sample, these searches allow law enforcement agencies to expand a traditional search to include male relatives of those within the searchable databases.

Let us unpack this use of scientific analysis. Autosomal DNA searches use between 16 - 23 loci including the sex-determining chromosome. This number of loci has been determined to be statistically relevant, meaning a match is unlikely to have occurred by chance, and has been validated via peer review and consensus within the DNA community. Therefore, a match enables discrimination between individuals within a global population, depending on the quality of the match and sample. This includes brothers and sisters, mothers and children, cousins, etc. Put another way, autosomal DNA searches can distinguish between close relatives, notwithstanding identical twins. This is a tool with potent discriminating power. And in certain circumstances and applications such a discerning tool is warranted even when considering concomitant civil liberties concerns and the like.

Familial DNA searches do not and cannot harness the above-mentioned discriminating power as it focuses on the Y-chromosome, primarily, to identify closely related relatives. In application, other relatives are introduced and impacted. These other relatives are those that have no connection to the particular offense, other than potentially being related to a potential suspect. Some have argued this concern is a tempest in a teacup, as it only impinges on those that are in the database, meaning those that have been arrested, charged or convicted of a crime.

However, this is ostensibly inaccurate. An arrest does not indicate culpability; neither does being charged with a crime. This perspective also flies in the face of a tenet anchored in common law that “a person is innocent until proven guilty.” As previously stated, the UK takes a concentrated approach in the utilization of this type of analysis and does not appear to view its use as a concern of the erosion of individual liberties, namely privacy. In contrast the US takes
a more disparate approach as not all agencies use or condone the use of familial DNA searches. Many states have yet to adopt procedures either to allow or ban familial searches.

There are a limited number of states that allow such searches, of which even fewer have alerted the public to their use. For them, the policies regarding familial searches have been relegated to internal laboratory manuals or remain unwritten. At least one state has statutorily banned its use and practice, namely Maryland. There is no systematically and all-encompassing approach to the application of familial searches amongst the states that allow their use. This is a fundamental issue. For example, California officially allows their use in investigations of major violent crimes in which the public faces safety risks, and only after all other avenues have been exhausted. Colorado allows familiar searches on more routine investigations and does not relegate them to the most high profile violent crimes.

Continuing on with the issue of lack of consistency in application and approach to familial searching, it is broadly akin to the reporting of partial results in autosomal testing. This is an important distinction as many governmental agencies do not use or condone the reporting of partial results. Therefore it is ironic that some entities will allow the use of familial searching, thereby effectively increasing statistically the likelihood of error into the equation, notwithstanding the privacy issues.

**Limitations of Familial DNA Searches: A Case Study**

A young filmmaker was suspected (wrongly) by local authorities of committing a murder in Idaho, in large part because of a familial DNA search, compounded by his penchant for making gory films. Michael Usry, a young filmmaker from New Orleans who has made award-winning films with macabre subject matter, was thought to have committed this 1996 murder. In 2015 a local investigator used a familial DNA search that yielded a partial match from a semen sample that was evidence in the latent case with the genetic profile of Mr. Usry's father.

This finding instantly “breathed life” into a decades old case in which the local authorities had been criticized both locally and nationally. The older Mr. Usry, who lived in 2015 close to Jackson, Mississippi, had his DNA entered into the database through a project sponsored by the Mormon Church. Members gave DNA samples to a molecular genealogy foundation, a nonprofit organization whose database was acquired by Ancestry.com, currently the world's largest for-profit genealogy company.

Ancestry.com received a court order requiring it to reveal Usry’s name to the Idaho Police Department even though it was listed as “protected” in the original DNA database. This was confirmed by court records. Following this “new lead,” the Idaho authorities mapped out a family tree thereby narrowing their search and focus to three men. Only one of the men, Mr. Usry the filmmaker, could have been a plausible suspect as stated on a search warrant from the Idaho authorities. He was 36 and had ties to Idaho, meaning he had two sisters who had attended university 25 miles from the crime scene. Additionally he had Facebook friends that lived in Idaho.

The Idaho authorities also listed his profession and genre of films as a reason justifying the warrant, as according to the authorities the works generally “...dealt with some sort of homicide or...
“killings.” Idaho officials even commented: “All the circumstantial evidence was right... he seemed like a really good candidate. But we have had that happen before.”

Detectives then travelled to New Orleans and persuaded a judge to sign a search warrant compelling Mr. Usry to provide a comparison DNA sample. For approximately a month while waiting for the result, Mr. Usry was racked with fear that regardless of the results he would be taken into custody. On 13 January 2016, he received an email informing his profile was not a match to the semen sample found on the victim.

Was there enough probable cause to warrant a DNA sample? That is debatable; however what is not debatable are the concomitant issues of the public safety/interest and Mr. Usry’s right to privacy. Questions were asked of Ancestry.com about the number of requests it receives regarding profiles on its database and if it tries to resist such requests. Those questions and the request for answers have remained unanswered.

In full disclosure, familial DNA searches have also yielded positive results. The most widely known case is from California, labeled the Grim Sleeper. In that case a serial rapist was roaming the streets of Sacramento accosting and raping women as they walked to work or headed home from parties. The rapist was exceptionally violent as he smashed the heads of his victims with rocks and he wrapped his hands around their necks, also occasionally threatening them with a gun. Local authorities performed a partial search on a DNA database and received a hit – a man in custody, which led authorities to the assailant.

However, regardless of the acknowledged success, privacy as well as wider civil liberty concerns and burdens are unequally yoked to certain communities. This should cause the wider community as well as various law enforcement authorities to have reason to pause. Sadly, as has been the historical precedent, the focus of law enforcement has been myopic in approach and perspective namely: only those who commit crimes and/or harbor criminals should be concerned as the use of the new technology is needed for what are termed as various “wars” such as: war on drugs, wars on crime in general, and wars on terror. As such, the danger of function creep looms slowly and subtly; creeping from a threat lurking on some distant horizon to an ever-present danger. Therefore, let us turn our attention now to the subject area of function creep and how it is critical to this discussion.

**Function Creep: Privacy Concerns & Inequitable Burdens**

*When politicians use bad science to justify themselves rather than good science to make up their minds... we can safely assume that wrongheaded and even disastrous decisions lie ahead.*

The Republican War on Science

C. Mooney

2006

As we have seen there seems to be emergent patterns regarding the use of genetic materials for law enforcement. These are appropriately named as function creep and mission creep. A definition of each is first needed. The Collins English Dictionary defines function creep as:

*The gradual widening of the use of a technology or system beyond the purpose for which it was originally intended, esp. when this leads to potential invasion of privacy.*
The Oxford Dictionary defines mission creep as:

_A gradual shift in objectives during the course of a campaign, often resulting in an unplanned long-term commitment._

Suffice it to say that the two terms are related by applicability and ultimately via the result. Both fight the same battle but on different fronts. However both pervasively erode fundamental rights of the collective and individual respectively. In the aftermath of 9/11, counter-terrorism measures sought to limit the advance of terrorism. Yet it can be argued in that process, and similarly in the process of familial searches, that the endeavors have created enormous challenges for constitutionalism. This has been coined as “The 9/11 Effect.”

This effect causes tensions with long-held principles that are the cornerstones of democracy, namely the rule of law and the protection of human rights, of which one is privacy. Though not to such an all-encompassing extent, the same holds true for the application of familial DNA searches. Further these tensions pose an unfettered and inconsistent approach to both issues undermining the rule of law and personal freedoms, and leading to unfair discrimination thereby sweeping away the right to privacy.

**The Privacy Challenge**

The applications of both function and mission creep operate subtly but their effects ripple through the community at large through the erosion of core aspects of individual privacy. What is more sinister is that most, though not all, community members remain personally unaffected and thereby accept, albeit through a tacit belief, that the measures are for societal benefit as they only impact the guilty or the wrongdoers. These challenges to privacy can fundamentally alter the nature of human behaviour and interaction, our sense of personal freedom and the ethos of democratic societies.

The primary question is not when should these practices be performed. Rather it is the age-old question of whether they should be performed at all, and what are their short-term and long-term effects. These new practices are challenging the fundamental concept of privacy, evoking the question: How can privacy still be sensibly safeguarded in this new environment of constant surveillance and use of data which has been in a number of cases arbitrarily obtained and kept?

International human rights law explains that privacy enjoys significant but not unlimited protection. Article 12 of the _Universal Declaration of Human Rights_ informs “…no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attack upon his honour and reputation…”

Equally the _European Convention on Human Rights_ (ECHR) and the _American Convention on Human Rights_ (ACHR) recognize respect for private life as a human right. However, it is recognized that privacy is not an absolute right as there is a palpable tension between the rights of the individual, the public interest and the rights held by other individuals.
Additionally the burdens of a challenge to privacy in the community are not fully shared or, more importantly, equally shared. Certain communities will be targeted to a greater extent than other communities. Earlier we discussed the application of this tool; however we did not directly inform which communities will be most affected. Communities of colour have been more affected by the applicability of this technology as data has shown, on balance, that these communities are more likely to be arrested, charged and convicted than other groups. This group comprises Latinos, Blacks and Muslim/southeast Asian communities. In the current climate, this seems to be true in most western countries, and would be historically true for Latinos and African-Americans in North America.

The GeneWatch UK article cited in the bibliography of this article chronicles the advent and potential of DNA profiling to reinforce racial prejudices. The authors chronicle the plans of the National Research Institute of Police Science in Tsukuba, Japan to set up a database “...that will allow police to predict a suspect’s ethnic origin and physical appearance.” The justification is cited as being caused by the increase in crimes perpetrated by ‘foreigners.’ This initiative, even if it does not come into fruition, aptly illustrates the hazard of function creep.

Notably, another journal article, The Challenge to Privacy, posits the following:

\[\text{While there is a shared discourse on the framework or privacy protection at an international level, international rights instruments tend to give states a 'margin of appreciation' as to how privacy is to be effected and how it is to be balanced against conflicting public interests. This has resulted in significant differences concerning the nature and precise extent of privacy protection between jurisdictions. Even among liberal Western democracies, there is no consensus regarding the status that privacy should enjoy at a constitutional level.}\]

In addition, ...

\[\text{The debate on privacy has always been shaped by new technological developments... Cultural concepts of privacy have always varied between different states and societies in the world but the contemporary and emerging techniques of intrusion into privacy create a new global standard of possibilities. Privacy protections no longer keep up with these developments...}\]

Finally, in its conclusion the authors of the same article state the following:

\[\text{... Safeguarding privacy in times of terrorism requires the reaffirmation of the rule of law nationally and in intercultural dialogue on privacy internationally.}\]

The use of familial DNA searches has the potential to intrude deeply into the personal lives of millions of citizens globally; and for circumstances outside of their control, any person can become a potential target of law enforcement initially and often without personal knowledge. At this time, as in California, the application of familial DNA is reserved for the most violent and high profile cases whose investigation has been stalled. However function creep has already surfaced in Colorado, as it is now being used in non-violent offenses. Therefore it will only be a matter of time and circumstance before the primary and political reason for introducing this measure is effected. It has already been given a broader field of application in Colorado.
When discussing increased surveillance of the public at large, the authors of *The Challenge to Privacy*, make the following telling point:

...intrusion is also more encompassing because of modern technologies allow monitoring of the whole or significant sections of society. Surveillance is no longer dependent on suspicion of criminal (or terrorist) behaviour. Societies under surveillance lose freedom.

If the term “surveillance” is substituted with the term “familial DNA searches” the sentiment aptly still applies. The article goes further and makes this salient point:

A[nother]... dimension of the new intrusion is its permanence. There is no prospect that the current level... will be scaled back... the move seems irreversible. Technological advances...add a further dimension of permanence.

The article also informs us that:

...the spectre... no longer appears impossible..... Data processors can be public or private, and the state increasingly coopts private business into its... agenda.

Lastly the article warns:

... there is no universally shared understanding of privacy. Different legal cultures and jurisdictions have adopted different approaches to privacy... each reflecting their unique historical, political and legal development..... and that Simon Chesterman proposes in his book 'One Nation under Surveillance' that the establishment of a new social contract has become necessary... in society.

With the specter of function creep becoming an all too present reality, there is clearly a need for a revised social contract. As technologies advance and potentially can assail privacy norms, new agreements must rise up to the fore. There is growing recognition that privacy can no longer be effectively guaranteed in the absence of scientifically accepted and agreed upon standards and policies. However, agreement on privacy standards for familial DNA searches and other scientific endeavors must be secured for they can too easily be subjugated and subjected to function and mission creep.

**Conclusion**

Clearly, the areas reviewed and explored in this academic law commentary have great importance for the scientific and legal issues involved. As discussed, there is an undeniable tension between the manner in which familial DNA searches is utilized and the impacted civil liberties of the community at large. Concomitant with tension is a juxtaposition concerning the public interest/safety and the erosion of the rights of the individual. As technology becomes more sophisticated, discriminating and invasive, there is a greater need for the revision of a social contract on a global and parochial hierarchy to secure primary human rights. Not to do so is ill advised as potentially it leads to an increase in an ever-fragmenting society that today is seeing the re-discovery of extremely problematic areas that endanger the rights of citizens.

Yet there is something more.
By way of personal reflection, it occurs to me that the topics I have presented have particular importance in this calendar year of 2017. This year marks the 70th anniversary of the Doctors’ Trials at Nuremberg. As we all will recall, those trials exposed to the world the horror of health and medical scientific knowledge being used to abuse, torture, maim, and kill those that the research so-called experts involved deemed, within Nazi beliefs, as less than human. In their failed eugenics experiments they were attempting to create a master race. And in that obsession their actions destroyed the rights of equal human persons to equality of human rights. This horror, however, was not something confined just to the middle of the 20th century in Europe. Nor has it ended in our world today as we know. Various historical ages give expansive testimony to the ever-horrific presence of extremism and discrimination that some use to declare others as “less than human” and therefore capable of being enslaved, used, abused, and killed. Those who perpetuate these horrors promote their actions as ways of securing the perfection of the human race. And in doing so, they violate the absolute right of all human beings of every race, nation and culture to the right to life. This pattern in human behavior and its visibility amid the various tensions, as cited in this article, move me to ask myself what we need to do to ensure that we are defended against these violations of the very beings that we are.

As a Barrister and a forensic scientist, my years of experience have enabled me to value both law and science and their intersection from an uncommon perspective. However, one poignant challenge has struck me in my career and continues to mature within me. Beneath the common law and its contemporaneous statutory framework there is something far deeper that humans must honor, that is ethics. No, not ethics as in regulations or regulatory compliance. No, something far deeper. The term ethics has its origins in the ancient world meaning the bedrock character of individuals and communities. In this regard, it is a moral imperative that the law must move us to protect the fundamental nature of what it means to be human and to secure our humanity within The Greatest Good. This is the apt ontology of law and ethics. And it is likewise the overarching skyline under which all discoveries and innovations in our lives must be made. When we discover or innovate, we must look to be sure that what we develop and come to know truly advances The Greatest Good of life itself. In this way of living, we then know that we can, in the words of another academic colleague, prevent the worst by promoting the best.

This article has explored the confluence of the powerful nature of our biological basis, human DNA and the indomitable authority of our sociological interactions, the rule of law. It is my hope that what I have shared with you can move us all on a much wider scale to explore, defend and promote even more deeply the powerful basis of who we are as persons, our human dignity and being, and the policing and protection of our individual rights under the rule of law.
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Abstract

This article examines the phenomenon of structural violence as well as, to varying degrees, cultural violence, in the lives of refugees. In addition to the overt physical violence of war, as well as nationalistic violence faced in subsequent host countries, Syrian refugees have faced cultural biases reinforced by rules, regulations and other restrictions that undermine their ability to rebuild most aspects of their lives, including their health, their livelihoods and their spirits. This is intentional violence to some degree, but to perhaps an equal measure it is violence by neglect, or by default, collateral damage that occurs while succumbing to a combination of pragmatic, socioeconomic realities and irrational nationalistic pressures.

Keywords: Syrian refugees, structural violence, cultural violence, indirect violence, invisible violence, descriptive, humanitarian

Introduction

As of March 2017, at least 11 million Syrians were “on the run,” with 6.3 million internally displaced and another 4.8 million escaping to other countries, all uprooted by a violent civil war (Mercy Corps, 2016). Since 2011, refugees have been pouring into neighboring countries by the hundreds of thousands, and as those nations have become less receptive, the Syrian refugees have headed north to Europe (Migration Policy Centre, 2016), still hoping to find some semblance of the normal lives they once lived, with their families and communities reunited (Sovcik, 2016). But their lives have continued to prove extraordinarily harsh throughout their journeys. Initially, competing military forces were the primary concern in-country, where they raped, kidnapped, and killed on a massive scale (European Commission, 2017). But both within and beyond Syria, unethical smugglers and opportunistic criminals often proved dangerous as well, robbing their clients, taking many captive, raping, torturing and killing (Di Giovanni, 2017).

Yet even beyond these atrocities, having escaped barrel bombs, Sarin gas attacks, snipers, robbery, and in many cases near-drownings at sea (Al Jazeera, 2016), and having found means’ of entry into host countries, refugees continued to face violence at the hands of governments, separatist groups, criminal gangs and others throughout the displacement journey and the resettlement process (Di Giovanni, 2017).

Such horrors, while widespread, have not been universal. Many host-country citizens have been extremely generous and even heroic in their efforts, but others have responded with hostility, and the same range of responses can be seen on the national level. Some countries welcomed the refugees with open arms initially, but as the immensity of the challenge overwhelmed them they changed their tune, rolling out barbed wire and turning their backs on those pleading to be let in (Baczynska & Ledwith, 2016). Compassion fatigue, inadequate funding, political considerations and social tensions, along with a lack of management, shelter and service capacities wore many nations down. Even some cities that had willingly taken in thousands are now pleading for help. In May, 2017, the Mayor of Athens made this abundantly clear, saying the problem is “spiraling out of control,” and that more efforts should be made to distribute refugees to other parts of the country (ANSAmed, 2017). As hostile citizens have become emboldened, and as government responses have fallen short, more and more refugees have found themselves increasingly vulnerable, fearful, and in too many cases the victims of violence.
In some cases, this has occurred in official refugee camps. Theoretically, camps should be safe havens for people fleeing from war and disasters, but they often fail in this respect. Many official camps have been sites for attacks on refugees, not only by the recognized warring parties but by other players, including conflicting refugee groups (such as rival tribes or incompatible cultures living together), or anti-refugee groups in host nations.

Yet despite official refugee camp shortcomings, unofficial camps, squats, shelters, streets and sidewalks proved no safer. As refugees became increasingly visible and active in the public realm, encounters and conflicts with locals became more common. In Turkey, for example, this led to “several lynching attempts, stereotypes, prejudices, communal conflicts and other forms of harassment against Syrians” (Gokay, 2015; Kaya, 2016), and an erroneous presumption that “Syrian refugees are associated with criminality, violence, and corruption” (Kaya, 2016). Overt violent attacks on refugees, migrants or other foreigners by followers outside camps in Greece increased as well.

Unfortunately, such blatant, acute, direct violence is only the tip of the iceberg. There are other, often insidious, chronic manifestations of violence woven into the day-to-day reality of many refugees, causing them grave harm in ways not always recognized as forms of violence, but very much worth examining. Researchers refer to these types of violence as invisible, indirect, cultural or structural violence (Burtle, 2013).

Overt physical violence is blatant and clear-cut when it occurs. While there may be controversy about who is to blame, there is little debate that it is indeed violence and that it has caused grave harm to human beings. But other manifestations of violence are often subtler and less direct, and a particular focus for this research. While many studies emphasize direct violence, and many tackle aspects of indirect violence, a much smaller number specifically tackle the various manifestations of indirect violence in the lives of refugees, experienced throughout their displacement and resettlement journeys. The purpose of this descriptive study is to answer the following questions: (a) To what extent is indirect violence present in the lives of Syrian refugees, as narrated by refugees and aid workers; and (b) Within that broad category, what common themes are apparent?

Background

General

The Syrian civil war is widely recognized as the greatest international humanitarian crisis since World War II (United Nations [U.N.], 2015). It was triggered largely by the Arab Spring pro-democracy uprisings in 2011, and the subsequent violent official response, that within the following five years devastated the country, causing hundreds of billions of dollars of damage, wounding 1.9 million individuals, and torturing, murdering or otherwise indirectly causing the deaths of at least another 470,000 citizens (Erlich, 2016). In the midst of the chaos, a complex mix of idealistic and opportunistic militarized forces, with ever-shifting loyalties, emerged, adding to the fragmentation of social, economic, political, and cultural structures throughout the country (Syrian Center for Policy Research, 2016).
Millions of Syrians still in-country are in dire need of assistance. Over five million others have fled to Turkey, Lebanon, Jordan, Iraq, Greece and points north, where they have frequently encountered severe neglect and abuse, exacerbated by a shortfall in U.N. funds due to unfulfilled pledges from member nations (United Nations High Commissioner for Refugees [UNHCR], 2017). Forced to choose between miserable, under-resourced camps and arduous lives in the streets, refugees have been heading further north ever since.

What initially was seen, and to some degree dismissed as a manageable migration crisis, rapidly escalated into an alarming flood of refugees. Hundreds of thousands trudged through the Balkans, with their eyes set on resource-rich Western Europe. Macedonia, Hungary and Serbia responded with everything from barbed wire fences to courteous safe passage and everything in between, but it made little difference: regardless of their efforts, the refugees continued to come. In 2010, approximately 2,400 refugees made it into Hungary; by mid-2015 that number had already jumped fifty-fold. Farther south, by late 2015 as many as 9,000 people were landing on Greek islands daily (Kingsley, 2017).

Europe has struggled to accept refugees. At least a couple of countries earnestly rose to meet the challenge in the earliest years, but they were the exception rather than the rule; as the trickle turned into a flood it became clear that most countries were feeling overwhelmed. One major attempt at crafting a solution took the form of a March 18, 2016 agreement between Turkey and the European Union which required that refugees who arrived in Greece from Turkey (clearly intending to head north into Western Europe) be sent back, and accepted by Turkey (European Commission, 2016). In return, the EU would accept one Syrian refugee from Turkey for each refugee returned from Greece. It would also pay Turkey six billion Euros along with additional political benefits. But strict adherence to the agreement ran contrary to the EU’s commitment to existing international law, both in letter and in spirit (Collett, 2016). This has led to a state of confusion and semi-paralysis, a kind of purgatory for refugees lacking a place to go (Holehouse & Weise, 2016).

For example, in Greece, as of late May, 2017, the Vial and Souda camps were occupied at almost twice their stated capacity, hosting over 1,000 people each, including many who were obliged to sleep on the open ground or out on the streets, despite the fact that ministry of migration inspectors reportedly told aid workers the camp was now empty (Are You Syrious, 2017). Chios island volunteers advised that conditions are “deteriorating rapidly” with at least 3,000 refugees on the island, and dozens of new refugees arriving daily (Are You Syrious, 2017).

Furthermore, those who fled during the early days of the war (especially if they could support themselves) were met with a much greater degree of civility, including many acts of human kindness, on a broad scale, and on the human, one-to-one level, such kindness continues. The nations closest to Syria have taken on by far the heaviest load, making efforts to support millions of refugees despite a severe shortage of funding (Sobelman, 2015). But in most cases, as the years have dragged on, prejudice, real-world costs and compassion fatigue have set in, leading to a shift in attitudes by national governments as well as sub-populations (Holden, 2016) and as services deteriorate refugees appear further motivated to move on, heading for Europe, where more conflict awaits them (Erlanger & Freytas-Tamura, 2015). Political philosopher Slavoj Žižek sees Europe as trapped between two major forces, one being an inclusive, liberal-left model unprepared for a flood of immigrants, the other being an anti-immigrant populist/fascist...
model unwilling to recognize that large migrations are inevitable harbingers of what the future holds (Žižek, 2017). Increasingly, this angst has led to a number of seriously overwhelmed national governments implementing largely improvisational responses, intended to discourage further migrations, but often with remarkably inept as well as inhumane consequences. Increasingly, host countries have taken in refugees begrudgingly, sometimes even with open hostility, while many have stopped accepting refugees entirely. Austria, for example, is building more fencing and has declared a state of emergency in order to justify restricting the right of asylum otherwise guaranteed under international law (Hume, Shubert, & Veselinovic, 2016).

**Background of Structural Violence**

Indirect Violence is a term for formal or informal social arrangements that hurt particular groups of people, (Farmer, Nizeye, Stulac, & Keshavjee, 2006) such as the poor, women, or refugees. These obstacles make most aspects of daily living much harder, ranging from keeping your hut in a shantytown to receiving adequate medical care (Burtle, 2013). Overt violence can range from blatant individual abuse to outright war, but indirect violence manifests in other ways, by informally (through cultural beliefs, behaviors and attitudes) or formally (through rules or laws) causing harm to human life.

Furthermore, indirect violence can take many forms, such as harming people by impeding access to living wage jobs, healthcare, education, training, housing, healthy food, potable water, clean air, self-agency (control over one’s life), or self-identity (religion, sexuality, gender, marriage or citizenship) (Farmer, 2009). Some manifestations of indirect violence can be fairly clear-cut, and hard to defend, when the damage is pointed out. With other manifestations, challenging indirect violence can be both uncomfortable and controversial. For example, cultural beliefs can permit behaviors in one location that in others would be considered unconscionable, such as genital mutilation, spouse abuse, child abuse, prostitution, slavery, drug use or polygamy. Widespread cultural violence is often invisible from within a culture, even while it may be a glaring injustice when observed from the outside. Nevertheless, red flags might be raised by such behaviors if they are selectively inflicted upon only certain subsets of society.

On a closer look, other iterations can require equally careful attention. Neglect, or denial of services, under some circumstances, can do as much harm as may be caused by other more direct actions. For example, withholding medication, food or water can easily be fatal, but such actions can also contribute to a slow deterioration that is not as dramatic. In a similar vein, restricting access to income, shelter or even human contact can destroy people’s lives without being clearly recognized or acknowledged as doing harm. Both direct and indirect violence can be culturally rationalized (by demonizing or dehumanizing particular castes, races, religions or sexual orientations), and can then be reinforced structurally (formalized by regulations and the rule of law). They can also be parsed as to whether they are conscious, hostile acts (such as slavery) or something less obvious (such as paying less than a living wage, or even failing to deliver adequate care out of ignorance, lack of resources, or religious beliefs).

Once such behaviors become integrated into laws or social mores, instigators may find themselves in positions of rationalizing their acts simply because “that’s what we do, or what we believe,” or “I was only doing my job, following orders or obeying the law.” Questioning these behaviors can draw defensive or antagonistic responses. Nevertheless, as people have become
increasingly aware of harm associated with these practices, a growing number of researchers have zeroed in as well, attempting to shine a light on the many manifestations of violence, raise awareness about their findings, and determine what interventions appear promising (Farmer, 2009; Sørensen, 2014).

To muddy the waters further, the study of indirect violence can easily fracture into a variety of nuanced subcategories. For example, a distinction might be made between structural violence and structural deficiency—the former actively, and usually intentionally, handicaps a particular subset of the population, while the latter simply fails to deliver—it may even handicap a wide swath of the population. If structural obstacles impede refugees, women, children or seniors from accessing healthcare, jobs, shelter or food, that would be structural violence. If the rules and regulations of a society allow the top 1% of the population to prosper at the expense of the bottom 99%, that is structural violence as well. For example, police services may be fully accessible to upstanding citizens and power brokers, but may be at least perceived as far less available to minority groups, people living in poverty, or homeless individuals, and indeed refugees in Europe express considerable anxiety about turning to police for assistance, and in some cases report being victimized by the police directly (Strickland, 2015). Structural deficiency can put all of this in a different light -- if a country is bankrupt, it truly cannot provide more services. The difference here, once again, is whether or not the deficiency harms everyone equally, or selects only certain subpopulations for inequity.

In addition, one curious aspect of the indirect violence phenomenon is the striking difference in perceptions, or even rationalizations. Structural violence usually reflects cultural violence, which means that cultural judgments contribute directly to the creation of laws formalizing and enforcing that judgment. The violent impact, even if acknowledged, is rarely recognized as a problem by those in power, who may declare themselves innocent of wrongdoing since they are only doing their jobs, regardless of whether such declarations are sincere or not; whereas it is starkly apparent to those who are suffering the consequences. In other words, they may have conflicting paradigms or beliefs regarding what is real or valid.

It should also be noted that in terms of the Syrian refugee crisis, Greeks in particular face a paradox—they are acutely aware of the structural violence imposed upon them by austerity measures, and commonly express a belief that they are being held hostage by the IMF (BlogActiv, 2017). So it is ironic that they increasingly find themselves, as a nation, backed into an economic corner, and as a result treating refugees with even greater levels of austerity than they consider palatable for themselves. How long this can go on is a matter of open debate (Debating Europe, 2017).

The Pervasiveness of Indirect Violence

Refugees and front-line workers consistently reported experiences with indirect violence throughout the resettlement journey, to a point where it can be reasonably recognized as pervasive – it is the rule, rather than an exception, that refugees will experience cultural or structural violence as part of the phenomenon of the diaspora, with only the specifics varying to some degree from person to person.

Solutions can be looked at from at least two perspectives: (a) fixing the system, or (b) mitigation by working around the system. If a nation wants to move in a more compassionate
direction, then fixing the system makes sense. If the powers-that-be are hostile toward such changes, then work-around options may be the only realistic options, at least in the short run.

Most (but not all), government refugee camps throughout the region have been criticized harshly by the press, refugees and volunteers alike, and those criticisms should be taken to heart (Banning-Lover, 2017). But at the same time it should be acknowledged that, despite their flawed performances, a handful of countries have taken on the lion's share of refugees for years now: Egypt—127,681; Iraq—244,527; Jordan—632,762; Lebanon—1,075,673; Turkey—2,181,293 (Ali & Ritzen, 2015). Lebanon’s case is even more astounding when it is recognized that for roughly every five citizens they also officially shelter one refugee (Refugee Compacts, 2017). Unofficially, it is even more extreme: one official estimates one out three residents of the country are refugees (Malkawi, 2015). Another 1.2 million refugees are scattered throughout Europe, (International Rescue Committee [IRC], 2017a), of whom 62,000 are currently stuck in Greece, seeking permission to move on (IRC, 2017b). On top of all that, there is reasonable suspicion that the official numbers are far from accurate. In at least one case, Jordan believes the actual number is at least double the figure listed above, with 80% of Syrian refugees living in “host communities” outside of official camps (Malkawi, 2015). By way of contrast, a mere 18,000 Syrian refugees have gained entry into the United States (Zong & Batalova, 2017).

**Gap in Research**

An extensive literature review reveals that there is a large gap in the current body of research on indirect violence as it pertains to the lives of Syrian refugees, and particularly in terms of what can be done about it. Therefore this study will target this particular population’s experiences, using a theory as a foundation to outline indirect cultural and structural violence as well as a lens for guiding principles for data collection and analysis purposes, and a conclusion with evidence of promising interventions that can be emulated.

**Theoretical Research Framework**

The theoretical framework for this study is based on Galtung’s Theory of Violence Triangle. Galtung created a model that divides violence into two categories; visible, which includes direct violence, and invisible, which includes cultural violence and structural violence (Galtung, 2015). In recent years, Galtung’s theory has been used to understand contemporary violence issues facing refugees as narrated by refugees. This theory provides a solid foundation to build upon in parsing the complexities and typologies of indirect violence. The following concept definitions clarify the differences and similarities, and help to specifically distinguish cultural and structural violence.

**Direct violence.** Direct violence is when one person directly commits an act of violence toward another individual such as torture, rape, or withholding life giving items such as food and water (Ho, 2007).

**Cultural violence.** Cultural violence, like structural violence, is considered unseen or non-direct and involves the division of cultures, religion, or differences in ideology, and that leads to unequal access or opportunity for individuals to reach their full potential (Galtung, 1990).
Structural violence. Unlike direct violence, where there is a person that commits a direct act of violence upon another that is easily recognized as such, structural violence is considered unseen or indirect. Structural violence can further be defined as any system or structure that prevents a person from achieving their full potential (Galtung, 2015).

For the purposes of this article, we will utilize the term “indirect violence” as synonymous with Galtung’s term “invisible,” which in turn includes both cultural and structural subcategories. The latter two subcategories will be specified as well when it’s productive to make the distinction.

Method

Design

The gap in research regarding indirect violence makes a compelling argument for the need to study where and how violence occurs from the perspective of refugees and those who deliver services. This study is a qualitative descriptive design. Creswell (2013), suggests that a qualitative inquiry is suitable for complex topics with little known about the subject. A descriptive approach helps to identify where the phenomenon occurs and its various manifestations (Elliot & Timulak, 2005). Descriptive studies also reveal “patterns and connections that might otherwise go unnoticed” (NEDARC, 2010) and provide information for further research.

Guiding philosophical assumptions for this descriptive study are rooted in a postmodern perspective. Creswell (2013) claims that the basic concept of the postmodern perspective is that the knowledge asserted must be set within the context of the world today and seen from multiple perspectives. To that end, this study focuses on the views of Syrian refugees with supporting views from community leaders, and non-governmental organization (NGO) workers.

Sample and Setting

Data was collected in refugee squats in Athens, Greece and displacement zones on the Greek Island of Chios. A typical case sample was utilized to recruit participants based on the NGO’s contacts with refugees and aid workers. A flyer was posted in service centers and refugees volunteered to participate. A typical case sample will allow for average or typical participants for this case study as recommended by gatekeepers or aid workers (Creswell, 2013). Inclusion and exclusion criteria included men and women over 18 years of age, who fled Syria through Turkey and who have resided in refugee camps (either authorized, formal camps or unauthorized camps, including “squats”). Aid workers and gatekeepers will need to have delivered services for at least six months.

Data Collection

Refugees (n=56), and staff of NGO’s (n=18), were invited to participate in (12) semi-structured interviews and (8) focus groups. Focus groups of six to ten people were led through an open discussion to allow a large enough group to generate a rich discussion (Polit & Beck, 2012). Focus groups and interviews began with a review of the IRB’s paperwork and establishing consent to the interview. Interview questions focused on the overall displacement experience, continued with questions on difficulties and challenges throughout the resettlement process, and concluded with specific inquiries on structural violence. Examples
of questions include: “How did you get here?” “What difficulties have you faced throughout the displacement process?” and “What are the current challenges you face in the resettlement process?” More specific follow up questions focused on policies, health care, safety, and security in Greece. In focus groups, refugees were encouraged to build on each other’s responses. As recommended by Lincoln and Guba (1985 in Creswell, 2013), several modes of documentation and data collection methods were used to enhance the trustworthiness of this study.

Data Analysis

Authors transcribed interviews verbatim. All identifying data was removed from the transcripts. Numbers and pseudonyms replaced all stakeholders identities. Transcripts were individually analyzed and open-coded by authors. Keywords, lexicons, sentences, and paragraphs generated new codes. Researchers’ individual codes were discussed, refined, and redefined through continuous comparison and reviews of data sources. Following Miles and Huberman’s (1994) guidelines for building confirmability and trustworthiness in data analysis, authors spent substantial time referencing assumptions with transcripts as well as results from the literature review.

Ethical Concerns

Special care and consideration was implemented in the creation of interview questions to reduce the triggering of traumatic experiences. Also, privacy for focus groups can be an issue in overcrowded areas, as well as gender sensitivity. Participants may also be fearful to share stories due to fear of being stereotyped or due to lack of trust in other individuals or agencies. Furthermore, from the participant perspective boundaries between the roles of researcher, learner, and friend may be unclear.

Biases

Research team biases were addressed by constant reflection, consultation, and debriefing after focus groups and throughout the study. Specifically, the research team managed biases by noting their own feelings and thoughts during data collection in a dedicated space, and openly discussed them during analysis. The research team conducted daily briefing sessions to assure checks and balance in terms of biases and assumptions.

Findings

Indirect violence was apparent in each participant’s interviews and focus groups. Furthermore, by using the concepts from Galtung’s Theory of Violence, indirect violence variables (cultural and structural) were clearly illuminated. Under structural violence, sub-themes have emerged as well, including inadequate nutrition, shelter, security, healthcare, work opportunities, and access to education. Though these themes are obvious in literature from an outside view, viewing these themes through a theoretical lens of indirect violence offers new insight for intervention and change. In addition, a substantial amount of refugee input illustrated cultural violence manifesting in the form of dehumanization and alienation. Within the structural violence variable, refugees identified specific, inadequately met physiological and safety needs for food, shelter, safety, health care, work and education, exacerbated by dysfunctional policies and procedures, with details as follows:
Inadequate Food and Nutrition

This subset includes not only inadequate quantities of food and water to meet minimum caloric needs, but inadequate food quality in terms of nutritional standards, sanitation and palatability. Many refugees were already severely malnourished before fleeing Syria, as a result of months or years barely staying alive in war zones. “Bulgur, we only ate bulgur,” one mother explained. “No bread. For two months, that is all we lived on. We could not afford food.” But things only improved relatively in host countries. Another woman told us, “The kids’ questions are constant, why we don’t have house, why we don’t have food, why you must wait, why dad doesn’t have job, why, why, why?” Typically, refugees characterized the food they did receive at official refugee camps as “very, very bad,” and usually distributed only once daily. One refugee showed us a photo on his phone of a piece of meat that he’d been served that had a live worm in it; an NGO representative advised us that camp residents frequently threw away food rather than eat it, because the quality was “so bad.”

Inadequate Shelter

This subset within the basic needs category involves sufficient protection from the elements as well as from human or animal threats. More specifically, this includes the need for protection against inclement weather, vehicle or industrial exhaust, noise, mud, flooding, insects, vermin, military attack and individual human intruders. None of the refugees and NGO representatives we interviewed for this study felt that the camps were succeeding, based on those standards or expectations. One refugee reported, “The camp is so bad, there are no toilets and the bathrooms are dirty, the place is dirty. Trash is everywhere.” Another shared his experience with a particular camp, which he describes as, “The worst refugee camp in the world. It has worms and snakes. It was previously a pig farm. They took pigs out, but they put people in...the food was awful...we didn’t take a shower for a month and a half.” A third refugee confided, “I feel that life in the refugee camp took me back to the Stone Age.” “They put us in a camp but I didn’t expect the camp to be like that,” one woman told us. “You hear how bad they are but I was shocked.” Shelters that fall short in terms of any of the above undermine residents’ abilities to gather, sleep, rest or rejuvenate--indirect violence that causes harm on many levels.

In some cases, the consequences can be deadly. One female refugee told us, “Last November, a whole Iraqi family burned to death in the refugee camp. It was cold, they had a small fire heater, blankets caught fire and burned the whole family. The camp management told us that it was the family’s fault for starting the heater in the tent.” She found this absurd in that, “Anyone with children must provide heat for them in the midst of freezing weather, and this was the only source for heat.”

In at least some camps, corruption and poor management are allegedly blatant. Unprofessional crisis and camp management can not only undermine health and safety, but demoralize residents as well. “The level and quality of treatment depends on the refugee camp director’s liking and mood,” one refugee told us. “We lived in prisons, not camps. We spent weeks restrained in the camp. They closed the camp doors and camp directors didn’t allow us to leave. The Greek government controlled the camp, the Greek Army and Police managed the camp...The Greek government also sent secret service to spy on us in camps.” A refugee woman shared her impressions from her camp experience as well: “There was fighting between African people and Pakistani people, because they put all the families in [crowded] compounds and locked us in. When the fighting started all the organizations ran away, and all the police. And
then the fighting started, for 2 or 3 hours and then they started a fire and by then it was night. For us, we were by the trees and the fire was on the trees and coming toward us. The children were screaming and crying. I felt like at that moment I was in Syria, when fire was all around and they were still fighting with rocks so we were stuck inside. Some people from the other side broke [through the fence] to make a way for all people to get out of the camp. It felt like the last day on earth when everyone runs, no one cares if you fall down, everyone just tries to save themselves. After that, when they made a way to run, everyone just run, run, run. You feel like you are in Syria, So, we are still outside after the fire had damaged everything and only when the fighting ended did the police come... As we ran, the police just stood and watched us. That was the worst thing, when people were with their children running and the police just watched everything and did not help. After that, the fireman comes, we stayed outside the camp. After that we came back to the camp with that smell, that smell... but where could we go? So we had to go back to the camp. It was so dirty and smelled like smoke. Of course, everyone got sick because so many were living in one room.”

Many desperate refugees leave official camps and find shelter in illegal squats, but these are far from perfect environments as well. One mother lamented, “...it is my right to stay in a safe place. Not like the squat that is subjected to attacks from gangs, mafia. When you live in a place with a lot of people of diverse groups for an extended amount of time you are going to face conflict.” Another woman told us, “I don't care about my health here, I don't want to see anyone, I just want to get out of here. [I need] a house, comfort for my children (loud voice), I would love to wear nothing (unzips shirt). I cannot take my hijab off at all, I need privacy.”

Unfortunately, when refugees do manage to arrange housing it’s usually off-the-books, overcrowded and substandard. One refugee told us, “I got a house finally... it was very bad, very bad, very bad. All fighting happened while I was inside. I took pictures. It was 30-40 people in one room with children, with all, we just made a wall with blankets...”

Inadequate Security

Effective security arrangements would provide refugees with sufficient protection against threats to allow them to live their lives free of fear, allowing them to move beyond a fight or flight mentality and at least attempt to rebuild their lives. Unfortunately, no refugee gave us any indication that they felt safe, or confident that they could turn to authorities if they were in danger.

Almost all refugees had frightening experiences with military, paramilitary or police officers at some point in their journeys, including being assaulted or arrested for no clear reason, to the point where anyone in uniform made them nervous. One camp resident provided insight into his perspective: “There were a lot of soldiers. We were already escaping from war and soldiers, and they put us in a camp that is monitored by the army. It was overwhelming and scary. I didn’t want to see any semblance of war, I didn’t want to see soldiers. So much so that, even today, if any one of us walks in the street and sees Greek soldiers, we run and hide from fear.”

Refugees reported police failing to protect them on numerous occasions. One refugee who had lived in an official camp reported, “The Afghans bullied us, caused problems and kept picking fights with Arabs. In the midst of the fights, the Greek police would stand, watch and do nothing. They didn’t protect us...The police didn’t care. They accused us of being angry people who can’t control our emotions and because of that, they decided not to protect us.”
more than one case, officers reportedly refused to intervene when refugees were being attacked by other groups of refugees, including one incident when Molotov cocktails were being thrown into an occupied squat. “I have fear here,” one woman explained. “I am afraid there will be a problem with [my husband] and police, that he will be arrested.” In fact, one of her elementary-aged children was arrested by host country police while enroute to participate in a school play, carrying a prop that made the police suspicious.

Another refugee relayed her understanding of a recent incident in which unscrupulous smugglers and a refugee had a dispute. “The police arrested the refugee for stealing the phone that the smuggler gave him. The smuggler spoke Greek, but the refugee didn’t… the refugee had no idea what was happening to him. This is a new economy, people are pretending to be smugglers, taking money from refugees and then fleeing. The refugee is now in prison. It is hard to trust people here.”

With all of these reports from refugees it was not surprising, when we asked, “If you feel unsafe, who would you turn to?” that a refugee replied, “This is secretive…we would not turn to officials. People will be really scared…we have our own network to resort to.”

Inadequate Health Care

This subset focuses on inadequate access to medical personnel, facilities, treatment and medication, without which refugees can suffer serious, sometimes fatal, harm, undermining their ability to move forward in their lives. Even before leaving Syria, many struggled with inadequate care. One woman explained, “Because I am Palestinian, I was born in Syria, my parents were born in Syria, but my grandparents are from Palestine, I have to pay for any treatment in Syria. Even in Syria there is a distinction made regarding descendants of immigrants, I am less than a refugee.”

In Greece, the health care system has been on a crisis footing for many years, thanks to the economic crisis; but as poor as it is for the Greeks themselves, it appears even worse, at least in some cases, for refugees. Access to health care varies considerably in refugee settings, where the demand is usually quite high. Even commonplace ailments are not always treated. For example, “There are no dentists for refugees,” one man told us. “You will just get a painkiller pill.” Refugees stated that access to free public health service was theoretically an option, but even in those cases the wait time and quality of service was often sub-par for refugees. One woman told us, “everything just takes forever, that is the biggest problem. If you go to the doctor they say to fast and so I go at 7 a.m. but do not get a test until 4 p.m.”

One female Syrian refugee told us of her experience taking her husband to a hospital: “So his gall bladder was so big, 4 centimeters, he was in so much pain. They took him to a Greek hospital, they told him we had no spaces, so they had him sleep in the corridor for two days. And then they did testing, they did IV, he said what is going on? They gave him painkillers. He was the only one sleeping outside in the corridor on a mattress. Second day I was visiting him with a Spanish volunteer, when a woman comes out starts berating me, you need to leave. The volunteer starts to sob, why are you mistreating this woman? I was the only visitor not allowed to visit their husband. The woman yelling was just another visitor, she didn’t even work at the hospital. And so I was asking her, why are you telling me to leave, who the heck are you? And then the lady called the police on me, and the police told me to leave, but I stood my ground.
and said, “if I’m going to leave, everybody should leave here. That is so unfair. Because I’m veiled. And it was within visitation hours. So I stood my ground, and the police went and kicked everybody out, all the guests. After five days in the hospital...oh guess what, the physician was Syrian but he tried to speak to my husband in English, when he could have spoken in Arabic but didn’t. I asked him why were we treated like that—because they are overcrowded, or because we are refugees? And he said predominantly because my husband was a refugee, although it may have also been because I was veiled and because I’m a woman... in the end there was no resolution for his gall bladder, and so he pulled out the IV and he left.”

For refugees, after the horrors of war and the subsequent demoralization that comes with unwelcoming host countries, latent medical needs may be of minor consequence in contrast to the underlying traumatic physical and emotional injuries that most refugees carry with them, including the stresses of living in camps as well as the stresses of surviving bombardments and other horrors.

For example, when asked about her emotional state, one woman replied, “It is so bad. Sometimes I felt it was better to be dead in Moria. It was so hard when you suddenly are so far from your mother, brothers and sisters, and it is so hard. Especially now, my mother is still in Syria and still in danger. Sometimes I hear that bombs come, so...so hard.” When asked about her health, one refugee retorted in exasperation, “How do you think it is? I live here in a box, there is no health here.”

**Inadequate Work Opportunities**

Inadequate work opportunities raised refugees’ concerns at many stages along their journeys from Syria to the north. Contributing factors included clear-cut manifestations of structural violence, such as legal restrictions on refugees’ rights to work, less direct manifestations such as broad economic conditions in the host countries and manifestations of cultural violence, including anti-refugee biases and related political tensions. Even where work could be found, structural violence was apparent. One man told us, “In Turkey, locals take advantage of Syrians. They, employ them [illegally] but pay them half. It felt like they were sucking our blood.” He found circumstances in Greece to be no better. “The Greeks themselves can’t find work. There is no work for Syrians, we can’t speak the language, and the locals always state, “our people are more important than Syrians.” Another refugee reported, “There are a lot of Egyptians that work here who are not even refugees and they only make 200 euro a month. We can’t make even that here. We can’t work, we don’t speak Greek.”

The right to work is guaranteed to refugees by the United Nation’s (1948) Universal Declaration of Human Rights, but for the vast majority of refugees, opportunities to actually find legitimate employment remain highly elusive. Unfortunately, this puts refugees in a terrible bind — whether to rely entirely on charity, or work illegally at sub-poverty wages, or engage in more lucrative criminal activity. Working illegally generally means working for substandard pay, working in the black market or engaging directly in crime. One refugee stated, “I had to work illegally in Turkey to save money with which to pay smugglers to transport me to Greece...I had to sleep under my sewing machine, in a textile factory for 6 months, as I was paid very little and couldn’t afford housing.”
Inadequate Access to Education

Beyond basic survival, refugees yearn for at least a hint of forward motion in their lives. Education for themselves and for their children is one of the only opportunities that potentially could allow this to happen. One refugee, a mother of four small boys, stated, “my three year old boy has never been to a classroom. I was pregnant when I left Syria and he doesn’t have opportunity to go to school. I just want him to learn in any classroom.” When access is denied, refugees suffer further, losing hope for the future. She continued, “We are still waiting for our paperwork. I am afraid it might be too late for him for school.”

Refugees widely recognize education as a potential means of self-improvement that can empower them to qualify for higher-paying jobs or to live more fulfilling lives. Unfortunately, even when host nations welcome refugee children to attend school they often fall short in making the experience functional or productive. This is not an unusual occurrence with structural violence—there may be no malice involved, but the outcome remains disappointing. For example, refugees in Athens consistently reported that while schools technically accepted their children, they made no special accommodations to help them learn the Greek language or behavioral expectations; but the refugees we interviewed did not perceive this shortcoming as malicious — just a reflection of the fact that the Greek schools are poorly funded. “There is no infrastructure or support for Syrian students,” one refugee explained. “It was all in Greek, so the kids couldn’t understand and left the classes.”

Cultural Violence

Structural and cultural violence usually go hand in hand, with structural rules and procedures developing that reinforce cultural beliefs and prejudices. The distinctions blur largely in terms of the degree to which they are spelled out. Initially, cultural beliefs and prejudices tend to evolve organically, on a psychological and emotional level. (Although they can be provoked or reinforced through various media.) They may be based on historical conflicts, but frequently are manufactured or provoked to political ends, such as to divide diverse populations and disempower them -- an approach commonly used in Colonial conquests and civil wars (Hallinan 2004). Those beliefs and prejudices may then be leveraged and formalized as rules and regulations which reinforce or weaponize those biases. The end result is that particular subsets of the population suffer efficient, systematic disempowerment and harm.

The harm done may be blatant (i.e. the outright banning of one group from voting) but it can also be obscured (requiring unreasonable types of identification, ostensibly with innocent intentions, such as to improve the voting system). The root of the structural violence may be cultural biases or prejudices, but it is also conceivable that it emerges from thoughtlessness, inefficiencies, incompetence, or greed. However, for purposes of this discussion, within the cultural violence variable, one broad subset became apparent through this research—dehumanization and alienation.

Dehumanization and Alienation

In general, all of the deficiencies experienced under “structural violence” have invalidating impacts on individuals, reinforcing a sense of dehumanization and hopelessness that can swamp the more practical concerns on an emotional level. For example, while the lack of employment opportunities has a clear structurally violent impact, obstructing purchasing power for essential
belongings, it is also extremely discouraging for many. One refugee woman explained that the cumulative effect of all they had been through, surviving Syria and ISIS, crossing the Mediterranean and barely surviving for the past year in Greece, only to see no light at the end of the tunnel, was overwhelming and demoralizing. “I don’t want my kids to see me crying. My husband and I go on walks to cry. He tells me ‘Cry, don’t hold anything in your chest, you have to release these feelings, if you suppress your feelings and keep them inside you, this will affect your health, if you have a chance, leave and cry to comfort yourself.’ My husband sits and cries with me. Then I feel sad for his tears. My husband’s response is ‘I am unable to provide normal lives for you and for my family, I feel very sad, I am the man and must provide a better life, but I can’t. What can I do?’” Another woman reported, “I just miss my children and cry every day.”

One Greek citizen believes mistakes were made when the government reined in the provision of services by humanitarian groups and volunteers in the heart of communities, and instead tried to isolate refugees in controlled camps, away from humanizing contact with the locals. “When we had the first arrivals we [local volunteers] organized everything just by ourselves. The food, the place to stay in the center of the city, our garden, all of society was next to the problem. And then they organized the camps, they organized [their own] clothes center and from that time big, big problems came, because they had the refugees in prison...From that time...society started changing, and started looking at the refugees like troubles, not like human beings who are suffering and are here. So this built up a totally new situation.”

Stories of dehumanizing experiences were unfortunately fairly easy to come by, often from the very first point of contact with the host country. In one such case, a boatload of terrified refugees was rescued from stormy seas in the middle of the night. Grateful, but frozen, they were shocked to find their rescuers, the Greek Coast Guard, abruptly shifting from serving as rescuers to serving as prison guards. “They treated us like animals,” one refugee told us. “We thought we were finally safe, but instead they treated us like animals. We had to squat on the floor, with every man behind every man, and we could not talk, we could not say anything, and we were freezing. Drenched. Everyone was panicking, they’re shouting, ‘Shut up, you’re not allowed to say anything!’ Now the swamp of Europe started. It’s filthy and sinks you down.”

One family in Athens has been waiting over a year for Germany to approve their request for reunification with their 11 year old son who is living in foster care. The foster mother rarely lets him talk to them on the phone, “because he cries so much afterwards.” A sympathetic Greek bar owner describes the refugee perspective as follows: “In Turkey I get in a boat...the boat stops here, I say OK, now I did it. Then suddenly they put me in prison. I am a woman with my child without my husband, and I don’t have milk for my baby, you know? Of course, this makes the refugees think ‘what’s going on here?’” One woman explained her initial experience in Greece as follows: “They just took us and put us in a camp and locked it. My husband asked to go outside. We felt like criminals in jail. Men, women and children, all. So for 40 days we didn’t know what was going on, we couldn’t leave. Not only that, they started saying, ‘We will get you back to Turkey’ – That was so hard on me. I did all of this and we crossed the border and the sea and now you will get us back to Turkey? It was so hard, we were locked in, it was so hard.”

One refugee we interviewed was so demoralized that he was willing to consider drastic measures. “I applied to go back to Syria. I went back to asylum organizations and requested being sent back to Syria. I was dying here anyway, at least I can die in dignity in Syria. But we don’t even have the funds we would need to be smuggled back to Syria...at least a quick death
in Syria would be better than a slow death here. Life here is torture, it’s like being slowly burned by a candle… a slow miserable death.” Demoralizing, dehumanizing treatment overall, whether intentional or as a by-product of bureaucratic intransigence, is just as damaging as any of the other areas of concern described above.

**Inadequate Policies and Procedures**

Dysfunctional bureaucratic policies and procedures play integral roles in structural violence, sometimes overtly, (i.e. “do not hire refugees”) but just as likely entirely through less tangible factors, such as indifference, inefficiency, incompetence, lack of resources or just general unresponsiveness. This is a fairly common problem reported in a number of countries refugees visited throughout their journeys. As an example, one refugee explained, “The Turkish side wanted a passport. Where am I going to get a passport? We didn’t have any. We barely escaped our homes, barely escaping Syrian government shelling. We fled in the midst of the night to the suburbs, dodging the crossfire between the Free Syrian Army and the Syrian government army. All of our paperwork and personal items had to be left behind, in the war-zone. We couldn’t go back for them.” Further frustrations with red tape were common once refugees made it to Greece. One refugee lamented, “…there are no benefits to receiving residency in Greece, nothing. We had to go back to zero here in Greece. In fact, we are below zero, the situation here is worse compared to Syria. Other European countries support your living somehow when you arrive, but not here. We lost everything and continue to lose everything. I have nothing to lose anymore.” Yet another man told us, “Even though we applied before March 20th, the paperwork is long, rules, regulations and processes are very, very slow. I have residency, I have a Greek ID, but I am not allowed to work or live a normal life here, there is no help to even exist here. The locals tell us, “We don’t even have work or funds for our own people let alone for refugees.” When asked how long it would take to get paperwork approved, he replied, “No one knows, there is no set rule.”

One refugee woman reported, “There has been nothing good or helpful. It is hard being someone like me who is in danger. A lot of people keep getting refused permission to be resettled in Athens with no reason. No one can leave the island. There is a paper that if you get a stamp you can leave the island, you have to have the right color of stamp…some people have been here over a year and not getting the stamp.” Even turning to NGOs led to some frustrations. A woman informed us that, “Every time I ask for help, they say we can’t help you because you have “Lam Shamel” [permission for family reunification]. If your status was “resettlement” we would have been able to give you housing. With “Lam Shamel, it is difficult. Unless you have a dangerous health issue. I tell them we are refugees, we are similar to resettlers… we all came as refugees.” One refugee told us, “They are all liars here….If I go talk to a Greek employee and tell them what I need they just say, “go away.” Similar sentiments were widespread, as was reflected by an incident that occurred the day before our arrival on Chios, when a man self-immolated out of frustration and despair, after waiting in vain for processing for most of the past year. A female refugee told us, “What happened yesterday, I saw a man burned to death because he didn’t get the stamp. I had nightmares, I cannot forget it. He was going back and forth and ran right in front of me, on fire…”

NGO’s have to maneuver through a web of bureaucracy as well. One refugee told us, “One of the local aid organizations secured a home for me and my wife because we are classified as vulnerable. However, the moment we get our Greek residency, the organization will kick us out
of the house. They told me, “you are on your own when you obtain your residency here.” So if I ever get residency I will immediately become homeless... we are learning here that when safety and security is granted from one angle, it is taken away from another angle.” Ironically, as it turns out, it is reportedly just as difficult for NGOs to register their organizations with the Greek government as it is for the refugees themselves, with long waits and frequently lost paperwork.

Discussion

The current refugee dilemma has forced the world to wrestle with remarkable moral, social and pragmatic challenges, challenges that remain largely unresolved. Refugees continue to experience violence in a variety of manifestations, from direct obvious violence, to indirect structural violence. As is understandable, the blatant direct violence is more noticeable, and more likely to draw media attention. Unfortunately, the less dramatic and indirect violence is often subsequently overlooked, either intentionally or simply by default. As a result, structural violence can slip under the radar of public outrage or media coverage, failing to draw attention, and at least from a research perspective making it more difficult to pinpoint or document.

Nonetheless, refugees experience structural violence throughout their journeys. This type of violence shows up, for example, in restricted access to resources necessary in order to meet basic food, shelter, healthcare and educational needs. Structural violence against refugees begins to take shape when hosting countries fall short in offering the same basic rights and resources as are available to mainstream citizens, regardless of the official reasoning or justification.

Furthermore, a discussion of structural violence as it pertains to refugees would not be complete without at least touching on unintended consequences. Repressive measures invariably drive people toward alternative means of self-fulfillment, such as finding ways of earning an income on the black market or through crime, or simply off the books. Bare-subsistence camps, regardless of good or bad intentions, invariably inspire desperate residents to look for ways to improve their lot, in order to increase food rations, find ways to earn an income or just plain survive. In all of the above, criminal behavior is fostered, and the state loses an opportunity to generate tax revenue. Structural violence can also undermine trust in authorities—refugees, or other repressed groups, don’t feel safe turning to the system for justice and, in some cases, will choose to resolve conflicts on their own, through vigilante action. Even if they were merely witnesses to crimes, they might not come forward to offer evidence for fear of retribution from a system that has already made their ability to stay in-country tenuous.

Ultimately, there is value in teasing out the distinctions between intentional (malicious), and unintentional, thoughtless structural violence. Either approach can lead to similar results, but understanding the underlying motivators may still be helpful when crafting improvements and interventions. Some rules may be based on xenophobia, while others may be based on economic limitations or political perceptions. Many nations that drew criticism cited in this report may be driven by a little of both; the same nations that have compassionately taken in the most refugees are now struggling with economic crises, conflicting world views, and increasingly xenophobic attitudes. An inadequate level of international financial support undoubtedly hampers their ability to provide higher quality service to more refugees, but resentment, prejudice and nationalism also have to be factored into any political equations. These particulars can have a powerful influence in selecting which paths to pursue, especially in the political
realm. Boosting funding, building in checks and balances, or nurturing pro-social grassroots efforts each hold promise, but still have to be mindful of political resistance to meeting the actual needs of the refugees, as prioritized by refugees and anti-refugee sentiments.

Limitations

Limitations in terms of both time and permissions on our preliminary tour precluded any visits to government-run refugee camps. As a result, we were limited to gathering second or third hand feedback or discussions outside of camps, on the refugee camp experience. A more in-depth examination of camps could be productive, especially if unfettered access could be arranged. Addition limitations include language barriers; more participants may have participated if able to speak English.

Conclusion

The purpose of this study was to explore indirect violence through the lens of refugee and aid worker perspectives. In addition, this study sought common indirect violence themes. Accordingly, this new perspective helps lay out a basic understanding of indirect violence, in order to help craft solutions, with the ultimate goal of helping refugees reach their full potential. This particularly makes sense when it is recognized that letting refugees into the local economy benefits the host nation in the long run, while keeping refugees in limbo does not (Legrain, 2016).

But for all the considerable good many countries and groups may do, and their excellent intentions, there is a fair chance that they lack the perspective or understanding of how their choices work in the real world, at the ground level, for actual refugees—a group not often invited to the bargaining table when plans are made. Access to school, for example, is a lofty goal, but unless planning incorporates evaluation and feedback tools to determine what actually works, with input from actual front-line workers and refugees, it is only going to look good on paper. One report determined that only 1 out of 3 host countries include refugees in national poverty surveys, and even in those cases they exclude camp residents (Forced displacement, 2016). Planning has to look at such details as: how safely to get to school, obtain shoes, pencils and notebooks, receive adequate support for special needs, be fitted for eyeglasses, receive medication, etc. It is only by sitting down with refugees and asking them how programs are working that the flaws become glaringly apparent, but it is precisely those details that get lost when answers are aggregated into quantitative reports. As one example, food is provided to camps under catering contracts, which may look fine on paper, but the refugees we interviewed consistently reported the food was inedible—a success at the political level, but ultimately an expensive, ongoing failure.

Indirect violence is widely prevalent for refugees and their journeys. By addressing the themes found in this study, nations and NGOs may be able to make improvements to their service delivery models, so as to serve better and even empower refugees. Broad issues worth examining might include: (a) The quantity versus quality dilemma—is it justifiable to pack more people in, in exchange for a diminished quality of support—in other words, structural deficiency? (b) The corruption quandary—how can researchers determine the level of corruption, or make recommendations for restoring honest operations, and how can countries become motivated to clean-up corruption? (c) What innovations have been introduced at
camps, and which hold promise? (d) The empowerment question—to what degree is self-
actualization for refugees an option? and (e) How can transparency in operations and budgeting
be promoted, whether for funders or for visiting researchers? Robust, sincere support for major
innovations to address indirect violence will prove critical in addressing the Syrian Diaspora and
helping refugees rebuild their lives.

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Reform and Renewal in a Post-Luther World

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Editor’s Note
This calendar year of 2017 marks the 500th anniversary of the beginning of the Reformation under the initial leadership of Martin Luther. This academic article is designed to honor this historical anniversary. It examines the history of the Reformation and its impact upon society. Of great importance, this article poses for readers an invitation to explore the significance of the Reformation for the ongoing development of culture and the human experience.

Author Note
The opinions expressed in this article are those of the author alone. They do not reflect the official positions of Duquesne University or any of the institutions that the author serves. The author has no financial conflicts of interest.

Abstract
On October 31, 1517, Martin Luther posted a document that would soon change the world of his time and lead to significant changes in ours. Luther’s Ninety-Five Theses called for significant reform in the Roman Catholic Church and led to a renewal that the Christian world has neither fully understood nor realized. Indeed, the Protestant Reformation has inspired theologians and humanists to identify a need for changes in church and society all down the centuries. Academics in disciplines as disparate as political science, theology, and sociology may find themselves celebrating the achievements of Luther, whose reforms pointed to the way humans could live better together in a hierarchical world. The purpose of this article is to explore some of the reasons for Luther’s attempt to reform the church of his day and to appreciate the renewal that it spawned. The article has great importance for furthering social justice and human rights in our contemporary era as well as for the ongoing and never-ending reform and renewal of our world experience.

Keywords: Luther, Reformation, renewal, Vatican II
Introduction:
The Luther Experience as Paradigm

When one thinks of the world’s great reformers, Martin Luther often comes to mind. His story, however, is not just one of what the world was like then. Perhaps even more importantly, his story tells us about who we are now. In other words, the story of Martin Luther is a paradigm for our time.

Five hundred years ago, on October 31, 1517, this courageous man acted to make his church a better place by proffering a theological interpretation of the role of indulgences. Theologian Karl Rahner (1975) provides the definition of an indulgence and refers to canon (church) law:

the remission before God of a temporal punishment for sins of which the guilt has been forgiven (at least by the end of the work to which the indulgence is attached: can. 925), granted by ecclesiastical authority out of the Treasury of the Church, to the living by way of absolution, to the dead by way of suffrage. (pp. 702-03)

Luther confronted ecclesiastical authorities with their errors and pleaded with them to change their ways for the sake of God and the people of God. His zeal for a purified Christianity, however, eventually led him to an intense anti-Semitism that, some claim, influenced Hitler and his Final Solution. The seeds of some of Luther’s greatest failings were contained in his ardent and steady claims for truth. Within each of us, as Luther’s life demonstrates, lies the promise for great good as well as the possibility of great evil. Even so, we must study the life and contributions of this great man for his singular gifts to the world.

More than 450 years after what became recognized as Luther’s debut on the world stage, many of the reformer’s ideas had seeped into the consciousness of some of the greatest Christian scholars and denominations of the day. For example, Luther maintained that there were two sacraments, i.e., the Lord’s Supper and baptism. The “low” end of the Episcopal Church embraced this concept. Luther was also a prolific hymnodist, and some of his compositions remain Protestant favorites, including “A Mighty Fortress Is Our God.”

Luther was discovered and made a hero of the Enlightenment during the eighteenth century. Scholars at that time valued him for his freedom of conscience and use of reason. By the time Pope John XXIII was ready to call the Second Vatican Council to order, the world was ripe to embrace the inclusive ideals that Luther had promoted so long ago. His insistence on the importance of the Bible and the laity, for example, finally found fertile ground in the Roman Catholic Church. In time, the renewal begun by John XXIII embraced many of the concepts that Luther held dear, including the reception by the faithful of communion in both species, i.e., bread and wine, and the priesthood of all believers.

People are constantly tinkering with the world as they find it. They want to make it better according to their own lights. The danger, of course, is that in seeking to reform a flawed situation, one can get carried away and bring more heat than light. The story of Martin Luther the reformer has profound implications for individuals, families, communities, nations, society, and cultures seeking to renew their lives and choose a preferred future. Five hundred years after he burst onto the world scene, it is once again time to look at what Martin Luther offers for our human experience.
Articles

Martin Luther and His World

Martin Luther was born in Eisleben, Germany, in 1483 and followed a long line of church reformers, including such notable figures as Origen of Alexandria (ca. 185-254), Augustine of Hippo (354-430), and Catherine of Siena (1347-1380). He entered the world between the last of the Middle Ages and the beginning of the Early Modern period when Christendom was ripe for disruption. Serious thinkers were questioning the self-proclaimed divine right of the Roman Catholic Church to be the established religion of the state. As the church leadership of Luther’s day declared their right to supreme geopolitical power, they were doing battle against “pagans” and the Muslim world. Christendom as Luther knew it was ready to come apart at the seams.

Luther spent his early years as a relatively obscure Catholic Augustinian monk and scholar until, as the story goes, in 1517 he pounded his “Disputation on the Power and Efficacy of Indulgences,” also known as the Ninety-Five Theses, onto the Wittenburg Castle church door. The document codified Luther’s objections to Rome’s decision to fund the construction of St. Peter’s Basilica through the sale of indulgences. Morimichi Watanabe (2000) confirms that the practice of selling indulgences had been observed for more than one hundred before Luther was born. Watanabe discusses a church in Wilsnack, Germany:

By 1384 Pope Urban VI (1378-1389) had granted the right to issue indulgences to those who visited Wilsnack . . . . The enormous amount of money that was needed for the reconstruction of the church was raised through the sale of indulgences. (p. 215)

Rahner (1975) traces the use of indulgences in the Catholic Church to “France in the 11th century” (p. 705) and points out that they “have grown historically from various factors” (p. 704). According to the Catholic teaching of Luther’s day, persons could purchase indulgences in order to mitigate or obliterate their sentence in purgatory. Those who died in the state of grace, but who were not entirely justified, would go to a temporary state, i.e., purgatory, to be purged of the punishment deserved for faults and venial sins committed after baptism. Once this process was completed, the soul would then be admitted to heaven. A kind of short cut was offered to those whose friends and relatives would gain indulgences for them. These indulgences could be applied to the sentence of loved ones after they had died and hasten their admission to the beatific vision encountered in heaven.

Luther’s humble and academic tone displayed in his Ninety-Five Theses invited questions and discussions rather than accusations. For example, he asked: “Why does not the pope, whose wealth today is greater than the wealth of the richest Crassus, build the basilica of St. Peter with his own money rather than with the money of poor believers?” (Thesis #86). Luther challenged not only the pope’s claim to have a right to charge for indulgences, but he also objected to the church’s presumed control over people’s eternal salvation. The notion that indulgences could remit the punishment for sin, whether they were paid for or not, put God under the thumb of the pope. Luther could not countenance this assertion, and he felt compelled to challenge it. As Christopher M. Bellitto (2001) makes clear, “With the 95 Theses, Luther had intended to fight the mathematical approach to faith that placed the purchase of indulgences before true and inner contrition, but he also criticized papal greed, bureaucracy, and worldliness” (p. 120). The pope would not respond favorably.
In addition to his objection to the buying and selling of indulgences, Luther argued in favor of three essential beliefs: (1) the Bible is the major religious authority; (2) people attain salvation only by their faith and not by their actions, in other words, justification by faith alone; and (3) the priesthood of all believers. The Catholic Church refused to put the Bible into the hands of the laity for fear of private interpretations that would contradict the magisterium, i.e., the teaching authority of the church. This was unacceptable to Luther, who was intolerant of human beings claiming the right to deny the Word of God to God’s people and to control its interpretation. He argued for the authority of sola scriptura, i.e., the Christian scriptures alone are the infallible rule of faith and life. Therefore, individual Christians have the right to read the sacred texts.

Luther’s action of 1517 resonated with many others who also objected to a pope’s seemingly unbridled claim to manage people’s spiritual lives. Among those who followed him were such notable reformers as Ulrich Zwingli (1484-1531, Switzerland) and John Calvin (1509-1564, France). Luther’s courageous move led to the fracturing of the Church as it was known. Much of what he counted on to be true evolved into the Protestant Reformation and subsequent renewal of the Roman Catholic Church. The Ninety-Five Theses were quickly distributed throughout Germany and then found their way to Rome.

The Catholic Church has always been about reforming itself. As is true of any human institution, it has always had serious flaws despite great leaders and dedicated followers. The fact that Luther objected to several claims of the Roman church of his day was not particularly upsetting to the church at first, because they had always been able to remain in charge. His writings were scrutinized and found wanting in some places, scandalous in others, and heretical in still others. In 1518, he was summoned to Augsburg, a city in southern Germany, to defend his opinions before Cardinal Thomas Cajetan. Luther refused to recant. On November 9, 1518, the pope condemned Luther’s writings as contrary to the teachings of the Church. Again, Luther refused to recant. In July 1520, Pope Leo X issued a papal bull (public decree) that declared that Luther’s propositions were heretical. He gave Luther 120 days to recant in Rome. Luther refused. On January 3, 1521, Leo X excommunicated Martin Luther from the Catholic Church. William C. McFadden (2004) defines excommunication as “a penalty imposed by the Catholic Church for grave reasons on baptized persons which separates those persons from the communion of the faithful and deprives them of membership in the Church” (p. 286). Luther had been put out of the Catholic Church.

On April 17, 1521 Luther appeared before the Diet (Assembly) of Worms in Germany. Once again, he refused to recant. Luther concluded his testimony with the defiant statement: “Here I stand. God help me. I can do no other.” In response, on May 25, the Holy Roman Emperor Charles V signed an edict against Luther. The emperor ordered Luther’s writings to be burned. During the next ten years, Luther translated the New Testament into German. By 1521, Luther’s attempt at reform had taken hold in political circles as well. Indeed, the Peasant’s War would soon be spreading across Germany. Eventually, Luther married a former nun and they subsequently had five children. He died on February 18, 1546. Immediately following Luther, the Catholic Church was ever after divided. Luther’s ideas largely shaped the Protestantism that soon emerged. Additionally, his writings helped to change the course of religious and cultural history in the West.
What became known as the Counter-Reformation of the Catholic Church (variously known as the Catholic Reform, Catholic Reaction, or Catholic Restoration) began with the Council of Trent (1545-1563) and lasted for approximately 100 years. Joseph F. Eagan (1995) notes that “since the office of pope and bishop were attacked by Luther, Calvin, and other reformers, the Catholic Church emphasized structure, authority, the power of the pope and of bishops and clergy. The church became defensive and focused on hierarchical and institutional aspects” (pp. 28-29). Trent stated clearly what it meant to be Catholic. During twenty-five sessions, those assembled defined Catholic doctrines that had been denied by Protestants. The world of art reflected this period of Catholic revitalization in the Baroque style of the time. Missionaries set out to discover the world and bring the Catholic Church to those in distant lands who had never heard of it. During this time the great sixteenth century Spanish mystics, notably Carmelites Teresa of Avila and John of the Cross as well as Ignatius Loyola, founder of the Society of Jesus, i.e., the Jesuits, expressed their devotion in profound spiritual writings that are still vital today.

As the centuries passed, loyalty to Rome remained a premium virtue. Catholics and Protestants became isolated from one another. For example, otherwise Christian marriages were considered “mixed” if they were contracted between a Catholic and a Protestant. Neighborhoods as well as countries formed based on Catholic and Protestant identities. With no Supreme Pontiff (pope) to attempt to hold things together, leaders in various Protestant churches occasionally broke from one another and splintered into different denominations. The age of reform meant separation, imperialism, and suspicion in addition to the freedom to form one’s own church and its ecclesiastical polity.

Preparing the Ground for Renewal

A significant development occurred during the nineteenth century. In 1868, Pope Pius IX wrote to the Orthodox and Reformed Churches inviting them to participate in the twentieth ecumenical council (Vatican I) to be held the next year. The purpose of the invitation was to invite the churches to return to the true fold. The invited guests largely ignored the invitation. The significant development at that meeting in 1870 was the definition of papal infallibility in Pastor aeternus (1870):

We teach and define that it is a divinely-revealed dogma: that the Roman Pontiff, when he speaks ex Cathedra, that is, when in discharge of the office of Pastor and Teacher of all Christians, by virtue of his supreme Apostolic authority, he defines a doctrine regarding faith or morals to be held by the Universal Church, by the divine assistance promised to him in blessed Peter, is possessed of that infallibility with which the divine Redeemer willed that His Church should be endowed for defining doctrine regarding faith or morals: and that therefore such definitions of the Roman Pontiff are irreformable of themselves, and not from the consent of the Church.

This was perhaps the apex of the assertion of Roman authority. It would be nearly ninety years before the Vatican issued a successful call for Christian unity. During those years, the triumphalism of the Catholic Church was much in evidence, although there were signs of chinks in that armor. Triumphalism (1995) is
the tendency to exaggerate the achievements and good points of the Church and to minimize or deny its mistakes and weaknesses. The term was popularized by Bishop Emile de Smedt of Bruges, Belgium, in a highly publicized speech, critical also of the clericalism and legalism of the pre-conciliar Church, given during the first session of the Second Vatican Council (1962). (p. 1272)

The claims of the Roman Catholic Church led to isolationism and kept Christians apart for several hundred years. The margins leaked from time to time in families, territories, and academia. For example, with the rise of historical consciousness, Catholic and Protestant biblical scholars developed critical methods of biblical studies. Those scholars also began to share their conclusions based on common archeological findings, especially as the tools for their excavations became more sophisticated. In France and Germany, the academy united Protestants and Catholics in their common quest for the truth, spurred on by the humanistic claims of major Renaissance figures. Much work conducted jointly developed despite and sometimes because of Rome’s objections.

Reform Gives Way to Renewal

In 1958, the cardinals in Rome elected Angelo Giuseppe Roncalli, to be known as John XXIII, to succeed Pope Pius XII. In 1959, Pope John XXIII announced his intention to call an ecumenical council not only to build up the Christian people but also to invite the separated communions to seek unity, his main goal. The gesture was not lost on believers. He was perceived by many as an interim pope. Indeed, Peter Hebblethwaite (1995) notes that “he was not expected to do much more than keep the papal chair warm for Giovanni Battista Montini, then archbishop of Milan and later Pope Paul VI” (p. 709). The tone of John’s invitation was markedly different from that issued by Pope Pius IX in the previous century. John’s invitation was neither anticipated nor expected to make much of a difference in the life of the Catholic Church. Still, much preparation ensued. The agenda was constructed based on the input of bishops and archbishops, superiors of male religious orders, and faculties of theology in universities and seminaries. A significant preparatory group that John established was the Secretariat on Christian Unity. This sent a signal to the heads of various churches and denominations that the pope was serious about moving toward the inclusive vision of Jesus (“that they all may be one,” John 17:21). A good deal of the triumphalist language of previous papacies was gone.

By the time the Second Vatican Council opened in 1962, the ground between Protestants and Catholics had softened, and the road between them was being trod gingerly and with enthusiasm. At each of the four sessions of the council, representatives from other major Christian Churches were welcomed as observers, although they were granted neither voice nor vote. The tone of the pope and the majority of the leaders in the Roman Church was one of openness and affirmation rather than the condemnation that had prevailed during previous councils. Clearly, the Christian world was moving into renewing itself. “Aggiornamento,” an Italian word that meant “bringing up to date,” was the theme of John XXIII. The church was being born anew.

By the close of the Council in 1965, Catholics had taken another look at Luther’s writings and drawn some conclusions contrary to Trent. As the council fathers looked to Christian unity as their goal, Protestants and Catholics were laying down their shields. There was growth
in ecumenical dialogue as well as shared liturgies and faith statements. Interfaith dialogue flourished. Seemingly overnight, Catholics were meeting with Jews and Buddhists on equal footing. Scholars, pastors, and lay persons were reexamining the role of the laity vis-à-vis clergy and the notion of the sacraments. Rome reaffirmed the centrality of scripture and Mass in the vernacular was now “celebrated” and not “said.” Catholic religious women and men experienced a complete renewal of their mission, ministry, and communal life. The majority of religious congregations modified their rather off-putting garb and often stowed it, preferring to be considered equal and approachable instead of superior and feared. The church’s recognition of the “universal call to holiness” (Lumen Gentium 5, para. 39) and the rise of lay ministry reflected Luther’s belief in the “priesthood of all believers” (Augsburg Confession, Article 4). Ecumenism became an honorable theme. Because Pope John XXIII had called for a look back to Jesus and not just a renewal of the Council of Trent, the natural bonds between Protestants and Catholics as well as other peoples of faith could be explored, fostered, and appreciated. After John’s death, Pope Paul VI continued many of the themes and much of the openness begun by his predecessor, particularly in the areas of liturgy, ecumenism, and social issues. The Church of Rome in the mid-1960s was exuberant and hopeful as it anticipated the future.

As the writings of Luther and other reformers were rediscovered, illuminated, and incorporated in innovative ways, practices once held to be sacrosanct lost their power, e.g., buying and selling indulgences with their subsequent promise of remission of sin. One more time, Luther’s writings influenced the course of religious and cultural history around the world. As it was nearly five hundred years in the past, the Church of Vatican II moved into a preferred future that included the renewal of the churches as they moved into an era of social justice. Indeed, Rome renewed its proclamation that salvation could be obtained through faith and by divine grace only. While indulgences were never fully abandoned, they were deemphasized and could be obtained only through prayer and no longer by money. Catholics abandoned the overbearing attitudes of a medieval papacy in favor of the consequences of the Spirit living and moving and having its being in a renewed church. Reason and experience ascended as authoritarianism and control stepped back.

**Luther’s Influence in a Post-Luther World**

Luther intended to *reform* the Catholic Church of his day, i.e., to “improve by alteration, correction of error, or removal of defects; put into a better form or condition” (http://www.thefreedictionary.com/reform). Luther did not intend to *renew*, i.e., “reestablish, start over, or replace” (http://www.thefreedictionary.com/renew) the church as he knew it. As we have seen, aspects of renewal would come later, even as late as the 1960s and beyond, beginning with the calling of Vatican II by Pope John XXIII.

Between the Reformation and Vatican II, however, was the Age of the Enlightenment, during which time Luther’s writings and spirit influenced the world far beyond his theological contributions. Albrecht Beutel (2017) assesses the impact of Luther during this time: “Luther quickly became the archetype of the enlightened identity itself” (p. 4). Indeed, Beutel notes that Martin Luther was received as a central, historical, legitimating authority. However, this situation applies only to German-speaking countries. By contrast, the English and French Enlightenment and other non-German Enlightenments barely (or not at all) included the reformer Luther in the process of their own search for identity.” (p. 1)
Beutel hastens to mention that this eighteenth century group of scholars realized that “the Reformation was first recognized and appreciated in the Enlightenment not only as a key era for the church, but also as a key era for the history of thought” (p. 3). The scope of Luther’s influence outflanked his initial intention to reform certain practices in the church. Instead, Luther “was an innovator for freedom of conscience and belief; a more sincere, more inquisitive, more rational friend of truth; a valiant fighter against religious heteronomy and for a declericalized Christianity” (p. 4). In short, during the Age of Reason scholars regarded Luther as the paragon of a kind of reason that passes any need for theological and ecclesiastical supreme authority. His use of reason served as an illustration for those who believed that religion and state interests needed to be separated.

The founders of the United States, for example, shared the belief that reason needs to prevail over state approved religion. This nation was formed upon the planks of the separation of church and state as well as notions of natural law and the social contract. These Enlightenment ideas, which one could easily trace to the flowering of Luther’s thought and person, have led us to value our inalienable rights and democratic ideals. Who Americans are as a nation stands in a direct line that links Luther and the Enlightenment to us here and now.

Not everyone gave up religion in favor of free thought, however. Notably, Catholics continued to treasure papal authority, sometimes ahead of any other. By the time the Second Vatican Council closed in 1965, some of the reforms that Luther had called for were recognizable in the changes enacted, including Mass in the vernacular and a greater emphasis on the centrality of scripture. The tensions spawned by the Enlightenment were also present. No papal decision made this clearer than the promulgation of *Humanae Vitae* in 1968 by Pope Paul VI, the encyclical that reaffirmed the condemnation of birth control for Catholics. Many people concluded that the Church had no right to meddle in their decisions concerning birth control. As Charles Skok (2004) notes, “on a practical level, the acceptance or ‘reception’ of the moral position of *Humanae Vitae* by Catholic people has at best been problematic” (p. 387). Much of the euphoria surrounding Vatican II was lost, and many otherwise hopeful Catholics left the church. It seems that reason carried the day for them.

It took Vatican II to put the Bible into the hands of lay people and to make communion in both species a regular part of Catholic liturgical life and devotion. What was remarkable about this, however, was that these isolated points of reform led to a total package of renewal as bishops, theologians, and biblical scholars scrutinized the entire Church in the modern (or post-modern) world. What transpired during and after those three years of Vatican II was nothing short of a renewal, a reestablishment, of the Catholic Church as it was known. Everything was available for examination, including scripture, religious life, missiology, church authority, lay ministry, the liturgy, and the nature of the church itself. Several of Luther’s reforms, including an emphasis on social justice, also came along the way.

Not only did the Roman Catholic Church undergo a renewal, but also the majority of the mainline churches, notably the various Lutheran, Methodist, and Episcopal churches underwent liturgical renewal, including greater roles for women. Prayer book and music revisions in various denominations soon followed Rome’s lead. These were not merely changes of form; rather, these were changes in the very self-understanding of the nature of church and one’s relationship to Ultimate Reality. Reform gave way to renewal. The understanding of the very nature of the church underwent a conversion.
Discoveries and developments in such fields as psychology, sociology, and political science accompanied some of the new self-understandings. Democracy became a model for some of the churches to consider and reject, but not without its having influenced the role of the laity vis-à-vis the clergy. As Christians in North America and Europe began to redefine their roles within churches, the value of the person began to be put forward in the political sphere as well. For example, Martin Luther King, Jr., a Baptist pastor, integrated the themes of his religion into his demands for equality as the civil rights movement took shape. Women, Native peoples, and LGBTQ citizens began to claim their baptismal dignity and demanded to be recognized as full persons and children of God with rights to celebrate and exercise.

Conclusion

Martin Luther is one of the key figures in Western history. His writings instigated the fractionalizing of the Catholic Church and sparked the Protestant Reformation. His central teachings, i.e., that the Bible is the central source of religious authority and that salvation is reached through faith and not deeds, shaped the core of Protestantism. Although Luther was critical of the Catholic Church, he distanced himself from the radical successors who took up his mantle.

Yet, while recognizing that Luther was himself a product of an age with its own injustices and discriminations, his major contributions are important to realize today and in the future. Some of Luther’s significant contributions to theological history and Christian life, such as his insistence that the Bible, which he claimed as the sole source of religious authority, be translated and made available to everyone, were truly revolutionary in his time.

But what of today? Just as Luther challenged the corruption and overreach of the major authority figures of his age, his legacy serves as a reminder of all that could be done to foster better Catholic-Protestant relations. Hans Kung (2017) suggests the following for the Roman Catholic Church:

• Martin Luther’s rehabilitation,
• Lifting all the excommunications that were pronounced in the Reformation era,
• Recognizing Protestant and Anglican ministries,
• Mutual Eucharistic hospitality. (p. 23)

Beyond the Protestant-Catholic arena, however, is the incalculable merit that a serious study of Luther can bring to those in any walk of life. Rebuffed and condemned by those who had the power to turn his life upside down, this man refused to compromise his inclusive values. From Luther, we can learn courage. Five hundred years ago, Luther’s issues concerned indulgences as they represented the misuse of power. The majority of people today are not concerned about indulgences, but they are caught up in the misuse of power in nearly every phase of their lives. We can learn to wield personal and corporate power justly. As we ponder Luther’s legacy, we would do well to reflect upon his willingness to reject the greed of his ecclesiastical culture. We can learn simplicity and how to exercise our fidelity to the poor. Martin Luther allowed his ideals to take him into anti-Semitism. We can learn to curb our excesses as we welcome the stranger.
Luther is a reminder that no one has “clean hands and a pure heart” (Psalm 24:4). Still, we may not give up trying to become the best persons and peoples that we can be. The example of Martin Luther offers a window into our own souls.

References


Academic Commentary

Palliation:
A Parabolic Pathway

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Author Note
This article is a revised and updated version of an academic position paper made by the author in 2009 in his previous executive role as Ethicist to the Surgeon General of the United States Navy. The opinions reflected in this article are those of the author and do not reflect the official policy of any institutions the author has served or currently assists. The author has no conflicts of interest.

Abstract
Sickness and healing are central to the human experience. From the dawn of time, individuals and communities have struggled with the stark realities of our human finitude and how we best can cope with the same. Over the course of centuries in an unending myriad of ways from culture to culture, the human genius has developed an unending series of approaches that we have come to call “healthcare.” In our modern era, social criticism has advanced concerning the inroads of the business model that seems to lead at times to the depersonalization of the healthcare experience. Critics point out that this depersonalization is inherently contradictory to the very nature of healthcare as the experience of healing that the human person needs and which is being appreciated today more and more as an ultimate right. Into this important boiling reality, there is a need for a pathway that can move the human imagination to understand, appreciate, reform, and renew systems of healthcare precisely as human care. Such a pathway, like parabolic images and stories of old, must have a deep and penetrating effect to change not just surface behaviors but also interior and subconscious beliefs, values and life stances. This article will explore palliation as that needed parabolic reality as a type of nova-paradigm. In the modality of a reflective academic commentary, the article will discuss a number of important historical background points, the fundamental foundations of healthcare as palliative, the establishment of palliation as a parabolic paradigm, and some practical pathways. The article will conclude with a series of reflective points to be considered for the future potential of this parabolic pathway for the continuing enrichment of health as a human experience, and healthcare as a human right.

Keywords: Palliative care, palliation, healthcare, systems of care, patient-centered, paradigm, medicalization, quality of life
Introduction: Historical Reflections

The human tribe has long obliged the care of the indigent, poor, sick, and dying. Time honored codes in various and very diverse cultures give clear evidence that the care of the sick is a firm ethical obligation for preserving human dignity and personal value. This ethos is more fundamental than any agenda, civic obligation, precept, or sentiment. It arises from the essential nature and core experience of human life, human community, and good social order.

In the West at the end of the Roman Empire and the beginning of the medieval period, the care of the sick often was taken up within the charism of hospitality of monasteries and abbeys. As an extension of the monastic infirmary for sick members of the religious community, the civilian sick would be offered comfort, care and health as part of the mission of the religious body to the wider world. This mission also included welcome for the stranger and the pilgrim in an age of political fluidity and potential violence toward travelers, serfs and all those outside the ruling class, and vulnerable others. The hospitality of medieval religious houses was the context out of which the later concept of the hospital institution eventually developed.

Resulting from educational and intellectual shifts arising from scientific thought and discovery, the provision of healthcare over the centuries took on a particular identifying character that might be termed “medicalization,” namely the provision of scientific cure by a licensed and certified profession with an assigned or recognized social status. With the coming of the Industrial and Nuclear Ages, the Information and Knowledge Management Explosion and skyrocketing costs, the need for efficient business modeling, and the advent of the hospital as a civic institution, the experience of healthcare has been modeled beyond medicalization even further into an organizational system of effective service delivery.

While respecting the need for increasing efficiencies and reducing unnecessary costs, industrial or business modeling has changed slowly and dramatically what might be termed the original “fundamentum in re” and experience of healthcare as an act of human solidarity. While understandable, this shift has also had unforeseen and undesirable consequences. In some cases, the provision of healthcare has been used for politicization. Examples of this include acts of violence against healers and healthcare professionals such as violence against Doctors Without Borders.

Complicated by discriminatory issues of class, race, gender, sexual orientation, and other forms of social injustice, community leaders in diverse cultures have, in various historical periods, reacted to such paradigm shifts or modeling changes in healthcare. In various decades, social critics and studied commentators have sought to promote a corrective re-balancing of effective institutional medical delivery with the core character of healthcare as a personalized and humanistic service. Such has been the case beginning in the 17th century in Europe to the present in the United States with the rise of new associations providing patients with the human comfort and care reminiscent of medieval hospitality toward the sick and dying.

One historical example of this was the work of Catherine Macauley, Frances Xavier Warde and company who left the traditional place of women in the home to venture into the alleys and streets of 19th century Dublin to care for cholera victims and those left to die alone and
abandoned. Frances Warde brought this culturally stretching experience to the United States in a series of founding-ventures that eventually developed into what would become one of the larger hospital systems in America. The fundamentum in re of the Macauley/Warde system was the retrieval and re-imagining of the medieval experience of hospitality --- however no longer at society's peripheral vision but directly within the eyesight of the urban experience. This was a powerful phenomenon in a time of unbending and calcified class distinctions. The reaction against Macauley, Warde and company was strong, yet did not thwart their work.

In this same spirit, in 1967 Dame Cicely Saunders gave new expression to patient-centered healthcare at St. Christopher’s Hospice in London. Notably for this discussion, this was care for the dying. There followed the founding of similar institutions in Canada and the United States. The founding of St. Christopher’s is looked upon as the modern origins of palliative care, though underscoring here again that this was focused at that time as care for the dying. Under the rubric of this seminal hospice concept and in a time when living with long-term conditions was only beginning to become more widely understood, palliative care was a means of providing a holistic approach to care for the total human person in a time when death seemed near. Such care included pain management, alternative therapies, human spirituality, counseling, pastoral care etc. However, the concept of palliative care itself has been rapidly evolving over the last 50 years beyond its original singular focus upon end-of-life issues and care for those nearing death.

**Palliative Care**

Though the popular imagination in some corners still, whether consciously or subconsciously, relegates palliative care to hospice care for the dying, palliative care has mutated over time into a beneficial approach for patients in any long term condition of need. Under this aegis, palliative care as a concept has acquired a more universal definition that is not necessarily tied only to the care for those in proximate danger of death. Its principles of holistic and interdisciplinary/inter-service provision for the total healthcare needs of the sick quickly have come to be seen as an extraordinary benefit for those who have long-term care health requirements.

Today, palliative care includes a wide and diverse pallet of services, concepts, and perspectives: medical practice, nursing care, medical and healthcare research, pastoral care, counseling and psychological services, social welfare and advocacy, family service, healthcare mediation, law, the role of the medical arts and humanities etc. These and other related areas have become enfolded into palliative care as a result of what is a long and evolving definition that is still in process. The multidimensional expanse of palliative services in society can be observed within the WHO definition retrieved in 2009 that follows. It is to be noted, however, that the underlying approach in the text still focuses largely on end-of-life issues.

*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement;*
uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Within the United States specifically, the Third Edition of the National Consensus Project (NCP) in its *Guidelines for Quality Palliative Care* incorporates and expands many of the same aspects of the WHO definition. The document is a comprehensive discussion of the nature of palliative care, its interdisciplinary emphases, the synergistic approach that must be taken to palliative care, and the ability of the concept to be applied to a wide variety of patient conditions and circumstances. As would be expected, the document discusses palliative care and its applicability to the dying or those with life long or life threatening conditions.

However, when the document discusses palliative care as a general approach to healthcare even in the primary care setting, one can sense the beginning of an applicability of palliative care to the fundamental nature of healthcare itself. When read from a more studied and objective perspective, the eight domains of palliative care that NCP addresses may well be applied to all forms of healthcare not previously thought of as applicable under the rubric of palliative care. For the sake of completeness here, the NCP eight domains are:

- Structure and Processes
- Physical Aspects of Care
- Psychosocial and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Patient at the End of Life
- Ethical and Legal Aspects of Care

There is yet another social or cultural perspective influencing the developmental nature of palliative care today. While accepting the real benefits of efficiency models, a cultural reaction is occurring within the healthcare community across the globe. To understand this reaction, the following reflection may be helpful.

Linguistics teaches us that “language talks.” In other words, the terms humans use reveal deep patterns of internal systems of valuation and meaning. This is true for individuals as it is for groups, including individual societies and cultures. Those who traditionally have been “patients” have become known in modern parlance successively as “clients, customers, consumers, and generators of metrics of productivity for electronic medical records.” Though these alternative terms have their utility, there are prudent commentators who see in this system of nomenclature a progression that, unless balanced, promotes depersonalization and obscures, if not entirely contradicts, the core experience of healthcare as human care.
These contemporary and thoughtful commentators seek a qualitative balance to quantitative methods of outcome assessment and performance measurement. In addition, an increasing over-medicalization and hyper-professionalization of healthcare has, consistent with the characteristics of all institutions, inadvertently allowed the creation of silo-effects between diverse departments and services within hospitals and care centers. These silo-effects create compartmentalization and can erode the full effectiveness of even the most robust programs of existing patient-centered services such as social services, pastoral care, counseling etc. Greater impact is lost when departments are not connected and providers do not work as actual team members for holistic treatment of persons who are ill.

Against this backdrop and consistent with the overarching NCP approach above, an appreciation of palliative care as a human-centered paradigm for healthcare as a whole can be observed in the 2008 report of Wolfgang Wodard to the Parliamentary Assembly of the Council of Europe. Several passages of the opening summary follow:

The importance of palliative care as a comprehensive approach, with the potential to complete and improve existing care programmes, is now recognised in many of the Council of Europe’s member states. Palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where subjective wellbeing of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side-effects. The report endeavours to highlight the central problem of the highly sophisticated and costly healthcare provided particularly in Western Europe, which, at ever shorter intervals, produces new medical techniques and medicines, raising high public expectations of curative success. At the same time, however, this type of healthcare is increasingly - and obviously - failing to meet the basic needs of people suffering from chronic or rare diseases. The rapporteur considers palliative care as a model for innovative health and social policies. Palliative care does not simply meet a cultural and humanitarian need of the most pressing kind. It also provides an innovative structure which, if intelligently developed, will not only produce sustainable change in the health sector, but may also serve as a recipe for success in other policy areas with serious, systemic and recurrent problems (eg drug prevention). The rapporteur therefore regards palliative care as an essential component of appropriate health care based on a humane concept of human dignity, autonomy, human rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.

Palliation as a Parabolic Paradigm

From all of the above, it can be posited that underneath palliative care there exists a paradigm that can be termed, “palliation.” Phenomenologically, palliation operates as the essential foundation for healthcare itself. It serves as a type of universal against which are best understood the subsets of specific clinical services. Without the universal of a paradigmatic concept such as palliation, individual clinical acts can be easily misperceived or caricatured in the contemporary mindset as assembly line activities. Palliation is a holistic and synergistic paradigm. In fact, it serves powerfully as a type of parabolic entity. Like parables and parabolas, the word and image indirectly but powerfully can lead us to understanding something that is far deeper than initially imagined. Palliation requires that the care of the sick and suffering integrate both scientific/medical cure and humane/humanistic care, medicine and human services, to create an ever-developmental, interdisciplinary, patient-centered approach to individuals, to their families, and the cultural communities in which they live.
To coin a new phrase, effective palliative healthcare is a *de novo* intentional approach to treatment team design and operations. It requires that sickness and health not be viewed as isolated phenomena in individual patients inhabiting individual beds. Palliative healthcare is a relational construct that touches the relational dimension of any sickness and disease as these are experienced within the condition of human beings who are themselves relational by nature. Academics and social scientists clearly attest that, underneath symptoms and diseases, patients suffer a more fundamental illness, namely alienation. Disease creates in patients both psychosomatic or somatic pain, as well as existential angst. Palliation/palliative healthcare might be the best underlying parabolic paradigm for contemporary healthcare delivery. It challenges providers and institutions to bring together and integrate medical/scientific cure and full humanistic care in the most robust fashion possible but in new and unprecedented ways.

The impact and importance of palliation is highlighted when we reflect upon the dimensions of the human experience itself. Traditionally, we are often taught that the human person is a creative combination of body, mind and spirit. While an easy vehicle for beginning to teach our young about what it means to be human, this tripartite image needs expansion and even deeper wording. This author suggests that we as human persons are constituted by matter, mind, motion and meaning. These “4Ms” lead us to understand that while we are made up of the physical and mental, we are deeply joined within ourselves and with others through those inner realities we call emotion and movement. And ultimately, our entire being is both joined together but also quantum leapt by one’s moral meaning as a unique human person or as a unique human community and culture. Our experiences, including those of sickness, woundedness, and death, touch us deeply in all four substantial modes. Thus even new health and illness understandings such as “moral injury” need to be reimagined on these deeper levels as realities that can be experienced by any of us in this life. Ultimately, this 4M image or metaphor is a critically important horizon that calls us to understand the immediate need for healthcare as human care, for healthcare as palliation --- something far deeper than what modern society seems to embrace.

Of immediate historical importance is the contemporary drive in the United States to some form of nationalized healthcare such as is found in other democratic nations. Reactions to this national drive are plentiful and broadly diverse. Often, they are also divisive. One set of critiques questions whether any form of nationalized healthcare will be responsive to the total human needs of patients, their families, and communities. Models and approaches are needed to give flesh to the palliation paradigm. In this way, the existential disease of “alienation” can be met by a cure/care dynamic of “integration” bringing together in a unified way diverse services, approaches, analyses, resources, and outcomes. Such an approach will require careful delineation of new institutional doctrine as well as education/training to assist providers with new critical thinking skills and worldviews so that they might act more as healers and as team members serving the needs of patients who themselves are not isolated persons but relational beings.

Parenthetically, this author is reminded at this juncture of his experience as a hospital chaplain in the early 1980’s assisting patients in a burn unit. There was no touch, no ability to express care through simple human contact. A plastic sheet separated the patient so there could be no contamination. There also was no means of conveying the simplest form of human communion via touch. While the medical need was clear that physical separation was needed, the existential disconnection was powerful and endures to this day as a profound memory of stinging wonderment.
In current discussions regarding potential national programs of healthcare, the Military Health System and Veterans Administration System (MHS-VA) is critically central. MHS-VA are themselves the original “socialized medicine” in the American experience. Despite surges and gaps over time, they remain as a context in which key elements of palliation/palliative healthcare are experienced and emergent. It is in the MHS-VA context that palliative healthcare can lead the nation’s progress.

**Potential Practical Pathways**

- Based upon the previous reflections, it would be strongly recommended that executive healthcare leaders establish in their institutions Executive Task Forces (ETF) on Palliation and Palliative Healthcare Initiatives.

- These ETFs should explore the full nature of palliation as a cultural-metaphor, and palliative healthcare as the basic strategic doctrine for all healthcare delivery within the system and institution. ETF should explore tactical implementation of the doctrine especially for the education of healer/providers to “think and act palliatively.” These ETFs should explore methods by which the institution/system effectively can integrate departments, resources, and capacities for patient-centered, holistic, and community-contextualized healthcare delivery.

- The ETFs should undertake a comprehensive review of contemporary literature and specifically analyze the NCP definition of quality palliative care for incorporation into the self-understanding of the community’s mission. The ETFs should analyze and determine the best applicability in the institution’s overall healthcare delivery systems and operations of the eight domains of palliative care as found in the NCP Clinical Practice Guidelines for Quality Palliative Care.

- ETF results should be used to augment long-term development for strategic planning and mission for the next decade. This aspect of the institution’s mission should be used to address wider, emerging needs of national programs of healthcare.

- ETF membership should include a wider representation of leaders and healing providers whose diverse services are part of the expanse of palliative healthcare in contemporary society. Of particular importance will be those who have a strong background in the medical humanities. Of equal importance would be those who lead the local Healthcare Ethics Committees.

**Concluding Reflections**

Within the metaphor of “palliation” and the development of palliative healthcare there is nuclear cultural power for the advancement of model healthcare systems for the nation’s future. Yet, how might one understand this power? A creative reflection upon the linguistic/etymological origins of the term “palliative care” will prove intriguing, challenging, and fruitful.

The word “palliative” has its origins in the Latin “palliare,” meaning to cover or cloak. Using this as a rich metaphor, the monastic practice of hospitality toward the sick was an act of
extending the monastic habit or cloak to wrap up and enfold the suffering from the doorway or porter’s guard gate into the care of the religious community in fulfillment of the mandate of compassion central to the Western spiritual tradition. The care of the sick and suffering, not just the dying or long-term ill, is captured powerfully within this metaphor. While religious communities were the *loqui* of pharmacology and medicinal care during the Middle Ages, they contextualized the offering of curative therapy as part of and within the healing event of human welcome. For them, the former made no sense without the latter. This is a powerful metaphor. However, all metaphors are symbols, and therefore are tensive or polyvalent. They are many meaning-ed. They can conjoin disparate even contradictory meanings. The following exemplifies this point.

“To enfold” is only one of the functions of a cloak. It also can conceal, hide or disguise. In children’s stories and mythology, cloaks can be magical pieces of clothing allowing the wearer to disappear completely. Early medieval monasteries and abbeys often were located at the fringe of villages prior to the rise of the cities in the 13th century. They were relegated outside the normal civic population, partly to meet the theory of the time that a vowed celibate life was to be a “flight from the world” (*fuga mundi*). In a certain respect, they were a “hidden life” cloaked from regular daily view. Even after the 13th century when it became more common for monasteries, canonries, friaries, and convents to be located within city walls, religious houses were ordinarily still separated from the streets by a strict cloistered life. Religious life struggled then, as it does now, with being something “hidden” despite its powerful social witness in every century.

Within this context, the care of the infirm, the poor and the sick became cloaked, compartmentalized, even hidden, from the sight of society. Sickness and human dying were realities that could be forgotten, or treated as the unmentionables. They could be and many times were gladly ignored. Infection control, popular misconceptions, ignorance, and superstition contributed to a gradual, historical pushing of sickness to the fringes of perception. In other words, what developed in culture was a “denial” of sickness and dying.

In our own time, the analytic work of Ernest Becker and Elizabeth Kubler-Ross powerfully has underscored much of this tendency, namely a fear and denigration of aging and the human experience of finitude as experienced in a society where humans live longer and where we are commercially bombarded to take every measure to counter the aging process and the inevitability of death. In other words, building upon the poetry of Dylan Thomas, while we may never wish to go gently in that good night, it is another matter entirely to deny that the night exists in the first place.

Yet into this discussion it must also be recalled that from the Latin “*palliare*,” another term evolved, namely pallium. The *pallium* is an ecclesiastical vestment in the Western church that has its origins in Greco-Roman garb. In the Western liturgy, it is a decorative stole worn around the neck given by the Roman pontiff to archbishops under his jurisdiction. The pallium signifies the induction of the individual archbishop into a close-knit circle of the highest-ranking leaders. It is a symbol of the highest form of cultural visibility. Interesting; in fact, very interesting. What might this curiously pose for understanding the power of palliation in culture today?

As Charles Gusmer discusses, the experience of human illness is revelatory of a deeper experience of alienation and identity-disintegration. The human animal in sickness experiences
a crisis of communication and relationship with the other that is the physical world, the others with whom we share the world, the other that is the self, and the utterly other that is our ideal self or the self within us that gives us meaning. It is an experience of disruption and loss of control. One's time is no longer one's own. Space and the freedom to utilize it are ruptured. One's sense of being an active “agent” gives rise to a diffuse ambiguity between bodily or psychological pain and existential anxiety or meaninglessness. Perhaps it is precisely this internal chaos that makes sickness/death denial attractive. Much like the caricature of young adults in the 1970’s film “Logan’s Run,” society seeks to terminate from its visual field anything that reminds us of our finitude, our inability to extinguish death. From a philosophical perspective, it is possible to consider that this fear of death and finitude is the ultimate disease that exacerbates our fear.

Into this volatile mix, the symbol of the pallium reminds us of some classical academic perspectives in the medical humanities arguing for an honored role of the sick and the suffering in society: that the sick and the suffering have as much a mission or service to society and community, as do society and community to them. With this as a reflective backdrop, it is then an interesting invitation to consider that palliation and palliative healthcare are systemic means by which we make acutely --- even uncomfortably --- visible within our worldview the sobering experiences of sickness and death.

While covering the ill and the suffering with care and compassion, palliative healthcare challenges us not to disguise or deny them, and how they carry in their bodies the universal human realities of disease and our inevitable finitude. Palliative healthcare may be itself the cure in this age for our blinding fear, urging us to face squarely, accept, and finally integrate within the individual and social psyche the age old problem of suffering that Western philosophy sees as part of what it calls “theodicy.”

We humans are truly courageous. We have explored the expanse of the cosmos and plunge into the limits of the seas. We delve deeply into concept and configuration. But perhaps the journey that is most needed is the one we resist with the greatest energy and fear: the journey into the deepest shadow of our human existence --- a shadow that envelops the shades of sickness, but also is the necessary prelude to the glint that is our hoping.

I wonder, are we ready for such a journey?
Articles

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PROFILES IN COURAGE: 
THE NEXT CHAPTER
Suddenly I heard a roar like I had never heard before. We couldn’t hear anybody else because the noise was right outside at the helicopter pad. We put on our helmets and flak jackets. Then all four of us “newbies” followed everybody else to triage. High-velocity dirt and small rocks were being hurled through the narrow entrance so everyone turned their back to the direction of the helo pad. It wasn’t a rocket attack, as I first thought, but downwash from the helicopters bringing in the casualties. I did what everybody else was doing. You couldn’t talk to anybody. The guys bringing casualties in were using hand signals. We had sawhorses, three corpsmen, and me. I had never met these corpsmen. I’m not very religious but I whispered to myself, “God, please give me something I can handle.”
The casualty I was assigned had most of his face blown off. A corpsmen rapidly placed a dressing over his face, another placed a large bore intravenous line into his ankle vein, and another, oblivious of my presence, deftly placed a tracheostomy tube into his neck to ensure his breathing. With more hand signals, he and other casualties were reloaded with other wounded Marines on new choppers that had just offloaded a second wave of casualties. These choppers took the first wave to the hospital ship 30 kilometers away in the South China Sea.

The casualty was gone, the blood was washed into several drains in the floor of the triage bay. The corpsmen turned their backs and went off to other tasks. I was alone in this now empty triage station. It was suddenly quiet. I now realized that I don’t belong here. I can’t do this. I’m useless. It was a shock to whatever remaining ego I had.

This was Dr. Frederick Burkle’s initiation as a combat surgeon almost 50 years ago at Delta Med, a forward casualty field hospital at Dong Ha, located in Quang-tri Province of the beleaguered Republic of Vietnam. His medical theater of operation was a mere five miles from the so-called Demilitarized Zone. Although his observations were real enough, the 28-year-old physician’s agonizing self-evaluation was far off the mark. Frederick “Skip” Burkle would go on to add many skills and titles to his résumé.

Nothing in Skip Burkle’s early life would have hinted at the direction his life would take. Born on April 29, 1940, he grew up in what he calls a typical lower middle class New England family outside New Haven, Connecticut. To say his upbringing was restrained would be an understatement.

My father never allowed me to go across the street. I was restricted to sitting on the grassy curb. Every year the town would re-tar the street, and I would pass my dull day puncturing holes in the tar when it bubbled up on a hot day. My physical world was dictated by many strict and seemingly ridiculous physical boundaries.

Indeed, his relationship with his father was more than strained; it was repressive bordering on abusive. As World War II drew to a close, Skip recalled his first liberating moment.

I was playing on my side of the dead-end street. My older sister and her friends were close by. Suddenly we heard the roar of engines overhead. The sky was filled with bombers. They were coming back from Europe and flying in the direction of Long Island.

He then added,

Everyone came out of their homes to look up at hundreds of planes. The best place to view them was in the middle of the street. I was left behind so I went across to the other side of the street and stopped in front of a home that looked bigger and bigger as I approached it. After all those years, I was now on the forbidden side. I looked back across the street to see an opposite view of my house for the first time. I realized this was a new frontier.

Although dyslexia had not yet entered the vocabulary in the 1940s, Skip’s inability to effectively express himself verbally hindered his feeling of self-worth. A Yale University specialist conducted a battery of tests, and he tersely summed up the results to Skip’s parents by reporting that the boy was “bright but lazy.”
Skip reflected on his father’s disregard for his son.

I was pretty much written off by my father at that time and often heard my parents arguing about my laziness, blaming it all on my mother who was a teacher. My father took great pride in my sister’s high school honors, but I obviously disappointed him. So even though I was the first male and I was named after him, I failed him. I was a disappointment in his eyes.

Skip did not begin to read until fifth grade and was a chronic stutterer. “I was a dreamer, just as the specialist described. But dyslexia, as we call it today, wasn’t a condition that was known, tested for, or accepted by educators.” The youth realized that he had a good memory and good retention, but the horrible grades continued and he convinced himself he was an academic failure. His poor scholastic record further isolated him, even though he admits he was fun-loving and rarely took his schooling seriously.

Despite all the personal and social turmoil, Skip’s seemingly quiet and detached demeanor hid an unbounded curiosity and thirst for knowledge. He loved geography and found heroes in faraway places, many of whom he read about in Life and Look, which always had photos of far-off exotic settings. Some were of physicians treating Africans in jungle hospitals. One idol was the famed Dr. Tom Dooley (1927-1961), a Navy physician, who made his reputation as a humanitarian following the Indochina War (1946-1954).

I had an inkling that I wanted to be a doctor. But I also had enough sense not to say anything to anybody at the time because they would have laughed. They all thought I would be the last person who would ever be a physician.

Skip knew he would not get any support and encouragement from his father who did not see him as college material, and who steadfastly refused to hear any talk of him attending college.

Burkle attended nearby Notre Dame High School over his father’s objection. Spiritual yes, but not particularly religious, he was a thorn in the side of his teachers.

I questioned abstract concepts and took offense that there was some hidden message from God to explain wars and the killings of children and other vulnerable populations. I was in the frame of mind to say, ‘Tell me, show me, and prove it.’

In his late teens in the 1950s, Skip worked afternoons and weekends in a food store. But his first job in a health-related environment was as an orderly at Saint Raphael’s Hospital, today part of the Yale-New Haven hospital campus. He advanced each summer where his duties included drawing blood from patients for the laboratory, working in the blood bank, and serving as the autopsy room attendant.

But now, at least, I was in the medical scene. It was an amazing world for me. It’s close to what I saw in Life and Look magazines. I kept imagining what it would be like to be a doctor, which was increasingly my secret dream.

At age 14, Skip met Phyllis Dinnean. His future wife was just 13 at the time but that relationship would change the course of his life. Her family not only welcomed him into their
home but provided the nurturing environment so absent within his own family. To apply to Saint Michael’s College in Colchester, Vermont, Skip had to borrow the $25 application fee from a Catholic brother at Notre Dame High School. Phyllis’s encouraging parents gladly drove him to the college campus for an interview. He was accepted and when he told his father about being admitted, the elder Burkle predictably flew into a rage and did not talk to his son for the next two weeks.

Saint Michael’s would be anything but a cakewalk for a student with so many personal and academic challenges. Skip wanted to major in biology, pre-med. The admissions officer was not encouraging, telling him that with hard work at best he might someday qualify as a high school biology teacher.

Despite this discouraging forecast, Skip disciplined himself for this collegiate undertaking, and, as a result, during the next four years, he received several scholarships. Once away from his family, he thrived in a college where European-style academics were still cherished—sciences, languages, history and the humanities, philosophy, art, music, comparative religion, and literature. In fact, Skip far surpassed his past academic achievement, going so far as to join “every academic club to learn social skills.” In his junior year, he formed the college’s Pre-Medical Honor Society. He found that an isolated campus in Vermont was the best place for someone with his learning disability. He worked hard, was proud of his grades, and for the first time he began to believe he could actually become a doctor. That positive attitude changed his outlook on life. He was accepted into medical school after three years of college. Becoming a physician was within reach—if only he could find a way to pay for it.

A Navy scholarship was one way to make medical school happen. Unfortunately, a prior history of asthma disqualified him from this military approach. Nevertheless, he enrolled at the University of Vermont Medical School, and obtained several expensive loans to finance his degree program.

Skip graduated from medical school and did his internship and residency at Yale-New Haven Medical Center. By this time he had married Phyllis and they had two children.

I loved coming into the hospital and inhaling all its smells and the frenetic nature of the work. Diseases fascinated me and Tom Dooley remained my secret hero. I wanted to specialize in pediatric surgery and do cleft lip plastic surgery on children in other countries.

Little did he know at that point that part of that dream would soon come true.

**Combat Surgeon**

Skip’s medical career began with a letter from his local draft board—every young man’s nightmare during the mid-to-late 1960s at the height of the Vietnam War. It began: “Greetings: You are hereby ordered to report for induction into the Armed Forces of the United States. . . .”

Although Skip Burkle had earlier tried to fulfill his military obligation by obtaining a Navy scholarship, he felt the asthma was still an issue, and because of that medical condition, he would be exempted from service. Nevertheless, he reported for his military physical as ordered.
and, much to his surprise, was deemed fit to be drafted. He immediately applied for the Navy’s so-called “Berry Plan,” a program that deferred physicians who were taking their residencies. He was to report for duty in July 1968.

When his residency ended, he learned he was assigned to the 3rd Medical Battalion attached to the Marines and headquartered at Dong Ha, Republic of Vietnam. Reporting to a war zone was a reality check for every man or woman who stepped off a plane on the other side of the world. But Skip was confident that his residency prepared him well to perform his duties.

Physicians are taught to be independent. We were trained to make critical decisions. We were in charge. I knew a lot of medical techniques because we did so many procedures and were seemingly well trained.

His naiveté showed through. Nothing he experienced at Yale-New Haven Medical Center could have prepared him for what awaited at the 3rd Medical Battalion hospital—Delta Med. He would witness combat carnage on an unimaginable scale. “Expectations were different in Vietnam, and the training became an unforgiving and demanding crash course that not all draftees could tolerate.”

But Skip passed his “crash course” in combat medicine, even if surviving his year-long deployment was never assured. Rocket and mortar attacks were frequent in Dong Ha, a very small town in the embattled Quang-tri Province. During one such strike, he did not make it to the triage shelter in time.

I heard something coming in so I dived outside the triage entrance. I did not have my helmet on or it fell off when I dived, but I never hit the ground. The impact was like being hit by Muhammad Ali.

Burkle suffered serious injuries to his inner ear. The blast even dislodged several fillings in his teeth. Blood accumulated behind his eardrum and in the opposite eye. Deafness in one ear and issues with vertigo remain to this day.

Skip Burkle had become a combat surgeon by necessity. Yet his desire to provide healthcare to those in need was as strong as ever. His idol, Tom Dooley, was never far from his mind, nor were the civilians who were in dire attention of medical care. These provincial villagers were living all around the base. Skip and his colleagues had treated only those wounded civilians brought into their hospital. “We were so encased, even by the structure behind the massive blast wall we were housed in, that we didn’t know what was going on outside with the civilian population.”

Skip and his medical team decided to open up the Dong Ha medical compound to treat children because of their desperate medical needs related or unrelated to wartime conditions. The surrounding villages and refugee camps, which housed thousands, witnessed grinding poverty and chronic disease. The American doctors, normally up all night treating Marine casualties brought in by helicopters after dark, somehow found the strength to treat the many villagers’ children during the day. “We saw more than 300 children a day, and no diagnosis or lifesaving procedure was simple.”
Once the hospital opened, patients flooded in with a host of bizarre diseases and injuries—shrapnel wounds, traumatic amputations, scurvy, bubonic plague, blackwater fever, meningitis and a type of tuberculosis that eroded the children’s spines. One of the most dramatic cases Skip treated involved a 5-day-old infant with a raging fever and near death. When large doses of antibiotics proved ineffective, he attempted, as a last-ditch effort, an age-old procedure for desperate cases used long before antibiotics were developed: an exchange transfusion. Exchanging the baby’s blood for someone else’s healthy blood, which contained lifesaving globulins and healthy white cells, might fight the infection.

Using blood donated by two Marines, Skip twice replaced the infant’s blood, also using antibiotics. Throughout the night, the infant began to improve. When the mother arrived at the hospital the following morning, she brought a tiny wooden coffin, expecting that her infant had died. “She ran over to me, dropped down on her knees, put her arms around my legs, and cried,” he vividly remembers.

Word of such a dramatic outcome spread quickly. Lines of waiting patients soon became even longer, sometimes numbering 300 patients a day. “I’d look over at the lines and realized we were going to be seeing patients until the gate was shut at 5 p.m. Everyone was exhausted.”

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Profiles in Courage

Dr. Skip Burkle performs an exchange transfusion on a 5-day-old Vietnamese infant, a procedure that had miraculous results.
Practicing medicine in Vietnam provided Skip more than a glimpse into medical traditions and customs in a Third World country. “What I learned that year would have taken me a century to learn anywhere else.”

When his one-year tour ended in July 1969, Skip left with mixed emotions. It was a great relief to finally be out of a war zone, but he adds,

There was a real urge to go back to Vietnam. There I was the kind of physician I always wanted to be. And the diseases and diagnostic challenges were fascinating. I realized that I loved that kind of medicine.

Skip’s Vietnam experience would put him in good stead for the rest of his medical career.

Following his Navy stint, Skip entered private practice to make ends meet and support his family, even though he still dreamed of doing “Tom Dooley humanitarian work.” Rather than simply fantasizing about it, he entered the University of California, Berkeley for a master’s degree in public health with the intention of working for the World Health Organization, the Red Cross, or a non-governmental organization [NGO]. While taking graduate courses at UC Berkeley, he soon discovered that he had not seen the last of Vietnam.

**Operation Babylift**

It was 1975 and the Vietnam War was reaching its tragic climax. The North Vietnamese Army was pushing south. With American military support no longer forthcoming, by the first week of April, it was evident to Washington that Saigon itself was doomed. President Gerald Ford announced that U.S. Air Force aircraft would begin evacuating orphans in a series of 30 scheduled flights. Several NGOs also expressed their intention to sponsor these evacuations and to help resettle the orphans with American families. The military flights were abruptly canceled after a C-5A transport crashed outside Saigon on April 4th, killing 138 passengers, including 78 children. Skip Burkle was about to embark on his first and most dangerous humanitarian mission--to date.

While earning his degree in public health at UC Berkeley, an NGO agent contacted Skip and asked if he would serve as medical director for an orphan evacuation mission to Saigon. His previous experience treating children in Vietnam was already known. Skip readily agreed. His medical team, consisting of 13 nurses, 13 physicians, and 26 flight attendants, most of whom were nurses, departed from San Francisco aboard a World Airways 747, with the first class section reserved as an intensive care unit for the sickest children.

When the plane arrived in Vietnamese airspace, Skip’s medical team was not granted permission to land because then-President Thieu put a stop to any more evacuations. With added fear of drawing enemy ground fire, the 747 flew to Clark Air Force Base in the Philippines to reassess the situation. While on the tarmac, a DC-8 aircraft landed with 30 infants and toddlers, having just arrived from Vietnam. Skip learned that the pilots of this aircraft were willing to go back to Vietnam on their way to Cambodia, and they could drop him off at their Flying Tigers’ Airline offices at Tan Son Nhut Airport. He agreed. The possibility existed that military aircraft could still get documented orphans out of the beleaguered city. Before he departed for Saigon, Skip ordered all the seats in the first class area of the World
Airways 747 to be removed while he was away, readying it as a treatment center in case he was able to return to Clark AFB with very sick children needing intensive care.

When the DC-8 arrived over Saigon, the passengers found themselves in range of surface-to-air missiles (SAMS).

The pilots were scared. I thought after all those close calls I experienced in Vietnam that this was going to be an odd way to die. The co-pilot stood up to look outside his side window, assuring us by announcing he could not see any surface-to-air missile trails in our direction.

When the DC-8 finally touched down, Skip peered through the window to see the debris of war—hundreds of aircraft bulldozed onto the grassy areas between the runways of Tan Son Nhut Airport.

The haphazardly stacked aircraft, one on top of the other, looked totally artificial, almost like piled up Mattel toys. These planes and choppers—worth millions—were on their sides and upside-down. The massive pile-up extended for hundreds of yards.

With an airlines office manager acting as guide, Skip and a CBS cameraman went into Saigon in search of infants to rescue. Chaos reigned in the capital’s streets with an estimated 100,000 refugees roaming the city in search of safety, shelter, and food.

The several orphanages that the guide showed him left Skip with indelible images. Those facilities for children...

...were absolutely black holes of Calcutta, decrepit old structures in poverty-ridden areas. The buildings didn’t look appropriate for orphanages. I entered these orphanages which had no lighting. In one, I tripped almost immediately over an infant who was stuck to the floor in his own feces. I looked at all these babies in disbelief. About 15 or 20 kids were in some scattered bassinets, some two to three in one bassinet. They were, of course, just orphans with no names.

Arranging transportation back to the airport for these infants was no small task. “By that time, I was thinking that this state of affairs is insane. Here we were in the heart of madness—a world gone crazy.”

After several more misadventures, including an encounter with an armed North Vietnamese soldier, Skip and the cameraman made it back to the airport. The departure the next day aboard an Air Force C-141 transport, which was loaded with even more refugees, was as chaotic as the arrival. Before takeoff, Skip witnessed a chilling incident. A Viet Cong bus driver, who had taken the orphans out onto the tarmac, sneaked aboard the plane only to be apprehended in the act of planting a satchel charge in one of the transport’s lavatories.

After landing at Clark AFB, Skip and the medical crew he had left behind began loading children on the World Airways 747. He immediately informed them that they “had a lot of sick kids to attend to.” One child died during the flight, ironically the child he had tripped over in the orphanage.
As they approached the West Coast, authorities in San Francisco refused the landing of the World Airways plane. San Francisco agreed to accept only orphans registered with designated families. The plane requested immediate landing instructions for Los Angeles where medical authorities in Los Angeles made plans to quarantine the flight even before it arrived. When Skip and his colleagues attempted to deplane with some of the children, they were all ordered back aboard for fear of infectious diseases. But the children were finally allowed off the aircraft before the crew and medical staff flew on to San Francisco.

Skip summed up this most dramatic humanitarian operation in which he participated.

As medical director of the last orphan lift out of Saigon in 1975, I was secretly slipped into Saigon, which was already surrounded by the North Vietnamese Army. The city was dangerous and packed with more than 100,000 frantic refugees. During the city’s death throes, I had to find abandoned and ill infants, many who were alone and starving in dank and dirty orphanages. We airlifted out 327 nameless infants and small children in file boxes.

Twenty years later, by chance, that 1975 signature event in his life returned in a very memorable and poignant way. At that time, Skip was a professor at the University of Hawaii School of Medicine in Honolulu. He was dining with a colleague and her son and the man’s young female companion. Skip recalls,

She was a most beautiful, ebullient Asian woman who looked Vietnamese but she spoke perfect English. She told me she was a graduate student in international affairs and had been valedictorian of her university graduating class. I asked if she was Vietnamese and she said she was. ‘How long has your family been here?’ She responded, ‘I was part of the orphan lift that landed in L.A.’ She was one of the infants I had rescued and was just a toddler at the time. Life had come full circle. It was a really good day.

In the years following his Operation Babylift experience, Skip expanded his qualifications by earning additional degrees from many academic institutions including Harvard Medical School, a residency in psychiatry at the Dartmouth-Hitchcock Medical Center, a Diploma in Emergencies in Large Populations at the University of Geneva, and a Diploma in Tropical Medicine at the Royal College of Surgeons in Ireland. And by then, he was himself a professor at the University of Hawaii School of Medicine.

**Persian Gulf War**

In 1990, Skip Burkle again went to war, this time to serve at a new medical base in Saudi Arabia. When Iraq invaded Kuwait on August 2, 1990, initiating the Persian Gulf War, Skip, as a Navy reservist, was recalled to active duty and deployed to Saudi Arabia. Because of his Vietnam combat medical experience, he became senior medical officer of a desert hospital in northern Saudi Arabia, just a few miles from the Kuwait border and where the assault into Kuwait was launched.
Al Khanjar Navy-Marine Corps Trauma Center was the largest field medical treatment facility in Marine Corps history since World War II with approximately 500 medical personnel on the staff. The hospital contained 12 operating rooms and 270 beds, including a 36-bed intensive care unit. During the so-called “100-Hour Ground War,” which ended the conflict, that hospital treated 80 percent of the casualties, including many Iraqi prisoners of war. When the war ended on February 28, 1991, Skip recalls,

Everybody was proud of their accomplishments. And I was glad they felt this way about themselves and the teamwork. At every opportunity, I told them, ‘You did a damn good job.’ I had brought these people together to do a job and they excelled at doing it.

Skip Burkle as Senior Medical Officer of the al Khanjar Navy-Marine Corps Trauma Center during the Persian Gulf War of 1990-1991.

The Kurdish Crisis

Skip then went home to Hawaii, but that interlude lasted only ten days before he was on another plane headed back to the region he had just left. Another humanitarian crisis needed his expertise. Saddam Hussein, still in power in Iraq, was again on the rampage, unleashing his surviving military on the Kurdish population in northern Iraq, many of whom had fled to the mountains along the Turkish border.
Living in squalid camps quickly set up by the United Nations, an estimated 200,000 Kurds were in urgent need of assistance, 1,500 having already died of exposure. As part of a contingent made up of the International Federation of Red Cross and Red Crescent Societies, he first went to Jordan to inspect Iraqi refugee camps, and then he made a special trip to Baghdad to negotiate with Saddam Hussein's government. The talks centered on allowing the Kurds to return to their homes in northern Iraq. Skip recalls continued stalemate after many meetings. Saddam was not present at these meetings but the negotiators knew he was close by. Skip realized that without the dictator's input and approval nothing would be accomplished.

As the talk was winding down, I finally felt it was time to speak up. I blurted out, 'It seems to me that after all that has happened,' meaning the war without mentioning the war, 'Saddam would want to be seen by the world as a humanitarian. These are his people.' I was aware of the psychological profile on Saddam and his narcissistic pathology. I was playing into his need to be seen as someone great.

An Iraqi negotiator left the room and when she returned 20 minutes later, Skip remembers that... it seemed Saddam had decided to invite us to stay for the next week, and he would consider our proposal on the Kurds. We stayed for several days and his military took us all around Iraq by helicopter. If I hadn't spoken, we would have been on our way back to Jordan.
Finally, Saddam agreed and the contingent then drove east up into the hills on the Turkey-Iraqi border. During this operation, working under the aegis of the International Committee of the Red Cross, Skip and other team members acted as liaison among the United Nations, the International Committee of the Red Cross, other NGOs, and the U.S. military, which provided food, tents, and medical supplies.

**Interim Health Minister**

Iraq seemed to be a recurring theme in Skip Burkle’s career. The 2003 invasion and conquest of Iraq left that nation in a shambles with its medical infrastructure almost totally destroyed. Skip points out that

...within two weeks of the war’s conclusion, more people, primarily women, children, and the elderly died from indirect preventable public health causes rather than by violence, even though the direct violent deaths were all Americans saw in the newspapers and on TV. The latest statistics show that at least 1 million Iraqis died, not just from violence but primarily from public health issues related to water, sanitation, medicines, and access to healthcare.

The George W. Bush administration offered Skip a White House appointment and he became a deputy assistant administrator for Global Health and the U.S. Agency for International Development. But the main reason the Bush people wanted Skip was for his knowledge about complex humanitarian emergencies. His real title would be “Interim Minister of Health” under the U.S. occupation, and his job would be to rebuild Iraq’s health infrastructure.

Immediately after the fall of Baghdad in early April 2003, Skip was on one of the first planes to land at Saddam International Airport in Baghdad. He needed to assess the situation and get to work immediately. Returning to the airport following a meeting with officials from the International Committee of the Red Cross, his convoy was ambushed in the streets of Baghdad, an attack which he still believes was an attempted assassination. “It was evident that a Shia cleric, Muqtada al-Sadr, wanted to be Minister of Health and placed a fatwa [a death sentence in Islam] against me.”

After a protracted firefight with the attackers shooting from rooftops and overpasses with small arms, machine guns, and rocket-propelled grenades, Skip and his Marine bodyguards reached the safety of the airport. Miraculously, there were no American casualties. Faulty intelligence and an incorrect assessment of the city’s security nearly cost Skip his life.

Burkle had also declared Baghdad a “public health emergency,” but the U.S., claiming to be a liberating power and not an occupying one, denied responsibility under the Geneva Conventions to restore the public health infrastructure. Skip resigned in protest. Shortly thereafter, Secretary of Defense Donald Rumsfeld, who was now running the occupation, needed that ministry position for a friend, a conservative Republican who headed an adoption service. A man with no international experience would take over as Iraq’s Interim Minister of Health—and with disastrous results.
Interspersed in the years between often intense humanitarian work, Skip became an educator. He acted as chairman of emergency medicine, pediatrics, and surgery departments at the University of Hawaii, with teaching appointments at Uniformed Services University in Bethesda, Maryland, Monash Medical University in Australia, African Center for Strategic Studies in Washington, D.C., Tulane University School of Public Health in New Orleans, and the Harvard Humanitarian Initiative at Harvard University, and the Center for Global Health at Johns Hopkins University. He has served for more than 10 years on the Board of the International Rescue Committee, the world’s largest refugee NGO, and on the Scientific Advisory Committee of the American Red Cross.

In 2007, Burkle was elected by his peers to the prestigious National Academy of Medicine, part of the National Academy of Sciences. His esteemed reputation also put him in high demand as a consultant in international crises. In Somalia, he offered advice to the U.S. military and the American chief of mission in Mogadishu.

I dealt with the chief of mission because we no longer had an ambassador to Somalia. I gave advice on ways to negotiate and not negotiate with sociopathic leaders, such as Somalia’s Mohamed Farrah Aidid and in Iraq in 1991, when we were face-to-face with Saddam Hussein’s persistent and malignant narcissism.

In his role as a psychiatrist, Skip has studied pathological narcissism among world leaders since the Cold War. He has written numerous articles in an effort to educate the public about a behavioral disorder not uncommon among many current undisciplined and dangerous international heads of state.

He has published more than 200 medical studies, one recently instructing today’s physicians on the forgotten nuances of triage that he learned 50 years ago in Vietnam. His published studies have been a mainstay of practice for new physicians and nurses who are serving in resource-poor conflicts around the world.

In “retirement” at his home in Hawaii, Burkle continues to write about another subject he finds critical with conflicts raging in so many parts of the world—the 1949 Geneva Conventions and international humanitarian law, as they relate to global health. “To some degree, war in past centuries was much more ‘civilized’ than it is today, if that can legitimately be said about any war,” he points out. “We had explicit obligations as healthcare providers who were allowed specific protections others did not enjoy.”

Skip points to the status of military and/or medical personnel who, more frequently, fall into the hands of belligerent national forces or insurgents.

As detainees, we were allowed to practice our art of medicine. We were supposed to be given supplies to do our jobs. . . . Even though the Geneva Conventions define the rules of war, those rules are now being disregarded more and more.
He points out that wars are no longer interstate cross-border wars, but intrastate non-international wars where medical personnel are afforded little protection. The killing of more than 700 medical personnel in Syria is the most recent example.

Never far from his thinking is the ongoing Syrian civil war. That long, drawn-out conflict has taken a terrible toll on physicians and other medical personnel who have been injured or who have paid with their lives caring for the conflict’s hundreds of thousands of casualties. Skip was much gratified when, under his guidance as a member of the Harvard Humanitarian Initiative, 46 eminent health professionals and institutions signed the Health Neutrality Declaration, which was submitted to the United Nations. In the document, these highly regarded signatories reiterated the inherent protections provided to patients, healthcare workers, and hospitals, and other medical facilities under international humanitarian law, including the Geneva Conventions of 1949.

Since his days as a Navy physician in Vietnam, Skip Burkle has served in at least five wars and 40 complex humanitarian emergencies in various countries. He has become known and respected worldwide. He found each mission and experience to be different and informative. With other colleagues, he recognized that humanitarian crises change every 10 to 15 years, both in the reason for the crises and how the world responds to them. Bringing those lessons to governments and the international humanitarian community has been and continues to be the subject of his articles and speaking engagements.
In a career spanning at least a half century, Skip Burkle has been a combat surgeon, emergency medicine physician, pediatrician, rescuer, psychiatrist, diplomat, peacemaker, public health and tropical medicine expert, professor, and mentor. But beyond all those labels, he might very well prefer the title of “international humanitarian.”

In 2016, Skip Burkle was the commencement speaker at Saint Michael’s College, the institution that unselfishly gave him his academic foundation. Quite an achievement for a neglected and dyslexic youth who, at the very least, seemed destined for very modest accomplishment or at best, becoming a high school biology teacher, according to his teachers in his formative years. Even his childhood hero, Dr. Tom Dooley, might have been surprised how Skip Burkle’s life turned out.
**Waking the Mermaid**

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Do you believe in mermaids? Thanks to a client I had many years ago, I definitely do.

Maria was just a name on a referral sheet that had been assigned to me through the mental health clinic where I worked. I was doing a lot of outreach in those days, driving around to see clients who couldn’t make it to the office for sessions, for one reason or another. Turned out, Maria had a pretty good reason.

As I walked up to the door of her ground-floor apartment, I saw an attractive dark-haired woman, about middle age, sitting on a small wooden bench just outside her door in the spring sunshine. I held out a hand to her shepherd-mix dog sitting on the grass beside her.

“That’s Starlight,” Maria said, “she’s friendly”.

I joined Maria on the bench and our first session began. It was one that she would often recall during the next several years of her therapy, a turning point for her, she said, and she knew it by the end of that first meeting.

Maria described her large Italian family of origin, growing up in the North End of Boston, her strong Catholic faith, her love of animals, her passion for the ocean, Then she told me of a fiancé, David, she’d had in her early 20’s, how the wedding had been planned and how her sister was to be maid of honor. Then the unthinkable happened. Her fiancé was killed in a freak accident at work.

After that trauma, she gradually became less and less willing to leave her home, despite pleas from her concerned family. Devastating panic attacks began to grip her several times almost every day. Eventually she moved to an apartment in the elderly/disabled complex where she still lived. Her agoraphobia became more and more pronounced, until the only time she was able to leave the apartment was to sit on her bench outside the door or carry her laundry down a short pathway to the complex’s laundry room. She had not been away from her apartment in twenty-seven years.

Maria had neighbors whom she paid to walk Starlight twice a day. Another friend took her grocery list with her own when she went to the store. She had found a nurse practitioner who was willing to make house calls for annual physicals, medication management, and occasional illnesses. A priest from her church came out every Sunday evening to hear her confession, pray with her, offer her communion.

Sitting on that bench, at the end of our first session she looked at me with steady brown eyes and said “All right now, before you go I have something to ask you. I’ve had dozens of therapists over the years and I always ask, and please don’t say you don’t know.” I nodded and waited for her question.
Vignettes

“Do you think, after what I’ve told you, that I can ever be normal again? Please,” she begged, “tell me the honest truth.”

Therapists and most behavioral professionals hate that word “normal,” because in terms of a human being’s psychological wellness, it is so imprecise and can have such a wide range. I was about to say something about “normal”, but decided against it. Instead, I held her gaze and paused, thinking carefully about how to respond. I wanted to be honest, but didn’t want to promise something I could not deliver. Yet, this bright, articulate, resourceful woman in front of me had already made an impression. Looking directly into her eyes I said “Yes, Maria. I know that you can be normal again. I know it.”

She cocked her head and gave me a skeptical look. “You KNOW it?”

“Of course,” I said. “That doesn’t mean it’s going to happen easily or overnight. It will take hard work and commitment and perseverance. But I know that it’s possible for you.” She regarded me thoughtfully for a long moment.

“Thank-you for that” she said. So ended session #1.

As spring turned to summer and then to fall and winter, Maria and I met every Tuesday afternoon and worked through the tangle of fears that had crippled her life. One technique we frequently used was a “worst case scenario” model that I’d invented. (This was years prior to the best-selling book of the same name. Now why didn’t I think of writing that?) I would ask her “What would happen if you were to take a walk down to the pizza place on the corner?”

“Oh, I could never do that!” she said.

“What would happen, though? What’s the worst that could happen?”

“Well, I could have a massive panic attack. I could lose my balance and fall on the sidewalk and everyone would be staring at me.”

“Then what would happen?”

“I guess someone would probably call 9-1-1.”

“And then what?”

“An ambulance would come.”

And so on. We would work our scenario through to a logical conclusion, pushing through every dreaded event that might come up. One time she decided, during the course of a “worst case scenario” exercise, that she might die. “Okay,” I said, “what would happen then?” She looked at me like I was out of my mind. I waited. After a moment she said “I think David would meet me and take me with him to heaven.” I watched as the anxiety drained from her face, replaced by a quiet smile.
We worked together for two more years. She continually reminded me of what I’d said out on her bench that first session. I never backed down from it. I knew that I was holding that truth for her until she could believe it herself. I was facing her demons with her until she could face them herself. I was modeling the “me” that she so desperately wanted to be until she could claim that person for herself. Though we used many cognitive behavioral methods in addition to insight therapy, I came to understand that the power of our therapeutic relationship was in the relationship itself. I gave her a new perspective on herself. She “borrowed” strength and confidence from me, tried it on like a new outfit, looked at herself in the mirror. And, gradually, she saw a change in her reflection.

She began to go out with me on drives. We went to the DMV to renew her ID card. We went to an appointment at a doctor’s office. We went to that pizza place. We went to the grocery store. Each trip was a struggle, but each a step closer to her “normal.” We worked through the pain of losing her dog, Starlight. We shared the joy of her favorite niece’s graduation from high school, which she attended with her sister. It was the first time she’d been out with someone other than me. It was about that time that I knew she was ready to launch herself into her new life.

Coincidentally, I’d decided to leave that clinic just then, due to the hour long commute from my home. With young kids at home, it was just taking up too much of my time. I didn’t look forward to telling Maria.

As it happened, after three years of working with this courageous woman, I hadn’t given her enough credit. She took the news calmly, though she did say she hoped she would not slip back into old patterns. She asked if she could keep in touch. I told her that wasn’t a good idea, as she would need to focus on getting to know a new therapist, forming a new working relationship, and talking to me would interfere with that. But I promised to let her know the new clinic I was working at so that, when some time had passed, she could contact me for an update.

After an emotional good-bye and lots of reassurances that she would continue to improve, my therapy with Maria was over. I felt a sense of satisfaction as I exited the parking lot of her apartment complex for the last time. So often with clients who have severe issues, progress is made in baby steps, there are frequent back-slides, and even after years of effort there can be little to actually point to as progress. With Maria I’d been privileged to see the unfolding of a remarkable woman who had been curled up against the world for twenty-seven years. I was content, and grateful for having known her.

I didn’t hear from Maria that year, as I’d thought I would. This pleased me, though I’d have liked to have known how she was doing. It likely meant that she was secure and continuing to do well. Just after the one year mark after we’d said our good-byes I did get a message in my box at work that she had called and wanted me to call her back when I could. It was summer and I was about to leave the office and enjoy the balmy evening on my deck at home, so I put the message in my bag and headed out.

I called her from home. When she answered, her voice sounded different in a way that’s hard to explain. She sounded more mature, somehow, her voice even and cool. Yet she was glad to hear from me and she was obviously bursting with news. She told me that she’d met a man at a potluck at her sister’s about six months ago. His name was Anthony and he was everything
Vignettes

she’d ever dreamed of, very much devoted to her, and the two of them were looking for an apartment together. But that wasn’t really what she had wanted to tell me, not all of it.

She described how, before she’d met Anthony and not long after we’d parted, she’d gone to stay at the shore, about twenty miles from her home, where her family owned a cottage on the beach. She had stayed there a week, all by herself. She described what a wonder it was to see the ocean again, after so many years, how she felt like a child, digging her toes in the sand and letting the waves rush up around her ankles.

“Then I went into the water,” she said. “I wasn’t sure I’d remember how to swim, but I needed to be in that water. No one was around, just me and the seagulls and the waves. I began to float, lifted and cradled in the rolling sea. I lay on my back and closed my eyes and let the waves take me. And I knew, I just knew in that moment that I was a real mermaid. And that I was free.”

Personal Post Script

Sadly, I learned three years later that Maria had died of a brain tumor. I cried all that day. I knew that in her final years, she’d been loved and freed from the terrors that had so paralyzed her, but her death truly pulled at my soul. And yet, I was still grateful to have been a part of her life, still uplifted by her courageous spirit and so very glad that I had been the one to hold her hand as she struggled back to “normal.” Even if she were the only person I had ever touched, I knew that my life had meaning. I had witnessed the awakening of a mermaid.
Sleep Eating Syndrome: My Recovery

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How many sheep does one need to count before falling asleep or, in my case, how many spoons of peanut butter does one need to consume?

Anywhere from two percent to twenty-seven percent of Americans experience intense hunger in conjunction with insomnia. Sleep Eating Syndrome (SES), also referred to by researchers as “binge eating syndrome” and “night eating syndrome,” is linked to obesity. The condition is promulgated by inadequate neuroendocrine function and has been effectively treated by enhancing serotonin function.

According to the Centers for Disease Control and Prevention, insomnia is a public health problem that plagues up to 70 million people in the United States. Of the five main types: acute, chronic, comorbid, onset and maintenance, my nemesis is the latter, meaning one falls asleep, but wakens often throughout the night. Within these main types exists eleven subtypes, the psychophysiological option being the one that describes my inability to turn off my sympathetic nervous system.

My maintenance insomnia is also chronic since I have struggled with the condition for over one year. Popcorn bags, half-eaten protein bars and crackers are a few of the snacks I’ve woken to find scattered in bed with me. I’ve even woken with a yogurt-stained spoon in my hand, but none contributed more to the fifteen pounds I’d gained than the peanut butter—jars of it.

The taste, the texture, called to me in my sleep and lured me to the kitchen. I’d head toward the pantry and straight for the magic jar of Jiffy. Even when I avoided the nut butter aisle at the market, I couldn’t escape the signal it sent out like a beacon from the kitchen of every friend and family member with whom I’d spend the night.

Nocturnal eating hadn’t always been a part of my nighttime routine, but for over a year it controlled me. The unhealthy regimen began when my husband and I started growing apart emotionally, often going to bed at different hours to avoid each other.

Every evening I’d set my intention to not get out of bed, not even to relieve my bladder, but inevitably find myself pouring walnuts into the jar of creamy peanut butter and indulging my palette. I’d often get creative and add vanilla extract or cinnamon.

As the scales got heavier, I got more determined, but the more I fought the feeling of hunger, the more I ate. Many nights I was up and eating seven and eight times. The cycle was exasperating.

I refused prescription medications and diagnosed myself with chronic maintenance insomnia. Consults with doctors failed to lead to a solution. This was, in part, because of my
desire to treat my disorder naturally with melatonin and Cannabidiol (CBD) spray, both of which lent relief for a few nights, but the effectiveness was short-lived.

I knew there had to be something in the peanut butter that I was craving. Upon researching the topic, I was surprised to find numerous support groups for people who were addicted to peanut butter—people who spread the creamy goodness onto everything from eggs to cookies—even people who substituted peanut butter for salsa on their corn chips.

With approximately two percent of the population having a sleep eating disorder, I was relieved to know I wasn’t alone. I tackled my disorder with a psychological approach. Perhaps, I was filling up with food to compensate for the lack of connection with my husband. So, I set a protocol for determining whether I should eat in the night. First, I’d say to myself, “I am awake and do not need to eat just because I am awake.” I’d then place my right hand on my belly and ask myself if I truly felt hungry.

Regardless whether the answer was yes or no, I took a deep breath, checked the time and made myself lie in bed for three minutes breathing and repeating, “I am full of love and creativity.”

The frequency of my waking remained constant, but the amount of times I would eat decreased to an average of two or three times a night. Moderate success, but I wanted full recovery.

I scoured medical sites looking for the missing link. There had to be something in the peanut butter that my body needed or I wouldn’t be so hooked on it. When I found out the amino acid L-tryptophan was a key nutrient, I began taking an L-tryptophan supplement and, not only did my cravings subside, but I felt more positive in general and started sleeping through the night for the first time in two years.

Seems the benefits to L-tryptophan are trifold. It increases serotonin and melatonin while decreasing cortisol, all of which are conducive to a restful sleep. Although, my experience is contradictory to a recent study of the American Academy of Sleep Medicine, which does not support L-tryptophan supplementation as a treatment for insomnia, Stunkard contends that treatment for NES should include increasing serotonin levels. Other researchers report a decrease in nighttime eating after treated with serotonin reuptake inhibitors.

I am still in the recovery phase and about once a month indulge in a 2 a.m. popcorn feeding, but I am not elbow-deep in a peanut butter jar. A key component of my success involved accepting my perceived weakness for nighttime eating and allowing myself a healthy snack of celery dipped in humus should I still be hungry after adhering to my pre-set guidelines and meditation.

Due to a multi-faceted approach to my night-time eating disorder, I’ve reclaimed my unconscious hours and have dropped ten pounds I’d gained. The sleep-eat-sleep cycle taught me there is more than one remedy for much of what ails us, and when we tap into our intuition and implement mindful practices, we cure much more than the symptom. We heal our mental, spiritual and physical bodies from the inside, growing wiser, rather than rounder. Now that’s something to sleep on.
**For Further Reading**


“It happened right here.” My guide pointed to a stone column in the old Coptic Church. “Everyone saw it,” he continued, “There were tears of blood oozing out of the stone.” I looked at the column but saw nothing unusual and turned away. The guide peered at me inquisitively. “Do you believe in miracles?” he asked.

“I work in the neonatal intensive care unit,” I replied. “I see miracles every day.”

Many years before, I had been the attending pediatrician at a Catholic maternity hospital outside of Boston. A little girl was born prematurely at only 26 weeks gestation. As expected, she had severe respiratory problems. Her lungs were underdeveloped and the tiny air sacs tended to collapse with every exhalation. I placed the baby on a ventilator with 100% oxygen and waited to see how she would do. She got worse and I had to increase the ventilator pressure to keep her lungs expanded. This was an ominous sign and I considered whether she might have additional problems. She did. The cardiologist called to inform me that the baby had Tetralogy of Fallot, a complex congenital heart disease of unknown etiology. This explained why we could not improve her oxygenation – she was a blue baby. Tetralogy of Fallot can be surgically repaired, but no surgeon would attempt a repair in an infant this tiny. And there was more bad news. An ultrasound of the child’s head showed that she had bled into the ventricles of her brain.

The child’s respiratory problems became more complicated. The 100% oxygen and high ventilator pressures were destroying her lungs. Another neonatologist asked me to try a new ventilator that delivered twenty puff-like breaths a second. This high frequency ventilator is now part of the standard therapeutic armamentarium, but in the eighties it was still regarded as experimental. The new ventilator helped a little, but now a new problem arose. The baby could not take milk and had to be fed intravenously. A solution of proteins, fats, sugar and minerals was prepared each morning and dripped into the child’s veins to meet her daily nutritional needs. However, the baby stopped growing and became jaundiced. The protein supplement had caused liver failure.

There was nothing more we could do; despite our best efforts the child would die. I met with the mother to explain the situation. As I went over the baby’s problems one by one she listened impassively. Finally I said, “Sometimes we do all we can and it is still not enough.”

The mother looked at me and answered with a seeming non-sequitur, “We haven’t finished painting her room.” I was surprised at her reply; it made no sense. Clearly she was not yet ready to deal with her daughter’s impending death.
To my surprise the baby did not die. Although she received no additional treatments her liver healed and she began to grow. She weaned from the ventilator and went home on supplemental oxygen. After further weight gain she returned to the hospital and the cardiac surgeons repaired her heart. She no longer needed supplemental oxygen. At three months of age she was given a battery of developmental tests. She passed with flying colors; she was completely normal.

Some months later, mother and child returned to the hospital for a checkup. After congratulating her on her daughter’s progress I asked the question that had perplexed me: “Do you remember when we spoke that day your baby was so sick? Did you understand what I was saying?”

The mother looked at me calmly. “I knew what you were saying,” she replied, “But I wasn’t giving up!” And thank goodness she didn’t; that desperately ill baby is now a young woman of thirty.

Some recoveries defy scientific explanation; this one certainly did.
CARRY ON

A Story of Resilience, Redemption, and an Unlikely Family

LISA FENN
Book Review

Carry On
A Story of Resilience, Redemption and an Unlikely Family

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Author Note

The opinions in this review are those of the authors alone and do not represent the views of the Department of the Navy, the Department of Defense, other agencies of the United States Government, or any of the institutions with which the authors are associated or which they serve. The authors have no financial conflicts of interest.

Introduction

Carry On emerged onto the literary scene promoted as a story of friendship between two young men that surpassed barriers of physical capability, a disparaging environment, and ghosts of pain’s past. However, what began as a story of friendship flourished into a beautiful testimony of how love pulls us out of our dearest comforts and draws us into an inconvenient and selfless expanse of social service. This page-turning book provokes its readers to challenge their traditions, beliefs, and perspectives in the most poignant ways, especially regarding social injustice, prejudice, and privilege. Overall, it leaves readers in a stupor, soul-searching and introspectively pondering, “To what extent am I willing to go to help my neighbor carry on?”

This very special book captures the story of the growing family-style friendship between Leroy Sutton and Dartanyon Crockett with Lisa Fenn of ESPN and her family. The story is not just a story of simple history. More deeply, it represents the evolution of what it means to care for others, especially those to whom a shorthand was dealt. The book itself describes the events leading up to and following the initial screening of the “Outside the Lines: Carry On” segment.
on ESPN. It is highly encouraged that the reader view the story at the links provided. The first link (https://www.youtube.com/watch?v=GIKjRdTCKwc) is the original story released to the public in 2009. The second is “Carry On: Why I Stayed” (http://www.espn.com/espn/otl/story/_/id/9454322/why-stayed), published in 2013 as a follow-up story in which we learn why Lisa just could not walk out of the lives of Leroy and Dartanyon.

Summary

One February morning while reading the newspaper over coffee, Lisa Fenn’s father came across a front-page article of two uniquely-abled young athletes who were making waves at their high school. Seeing an opportunity, he gave Lisa, an off-of-the-court feature producer with ESPN, that fateful call to share. After getting a closer look at the story for herself, Lisa was moved by the narrative and pitched the idea to her supervisor. Although he was not entirely convinced at first, he trusted Lisa’s gut, took a gamble, and gave her the approval to start producing the feature.

The two young athletes were students at Lincoln-West High School in Cleveland. Lincoln-West’s student body was one plagued by poverty and a dropout rate far exceeding the graduation rate. Many athletes there lacked the experience and at-home care usually required for peak athletic performance. The wrestling team at Lincoln-West was as awkward as it was comical; an unlikely group that gained in heart what it lacked in talent. The star of the team was a legally blind powerhouse with a name as formidable as he appeared - Dartanyon. The member who kept everyone laughing and pumped up throughout the meets was Leroy, a double amputee who did not seem to let his unique ability get the best of him. Lisa and her ESPN crew showed up to the gym at Lincoln-West on a very important day for the wrestling team- the sectional meet. The heat Dartanyon felt with the presence of the lights and cameras was apparent, crumbling under the pressure and faking an injury to account for his eventual loss of the match. On the other hand, his friend and the other star of the feature, Leroy, seemed nonchalant and shut out the unfamiliar faces with his attitude and his headphones. Lisa could already see this story would be a battle for trust.

Bringing the story together was a struggle at times for Lisa, having to prove time and time again through small acts of kindness that she was worth trusting, just to get the two young men to open up. Whether it was rides home, buying meals, or just being around without her camera crew, Lisa was steadfast in proving her genuineness. Dartanyon was the first to yield, and as he did we come to experience the motif of loss in his life. He was accustomed to the feeling, starting with the loss of his dear mother, Juanita, the glue between her seven children and the neighborhood in which they lived. She was a hardworking woman who had her vices but made a habit of praying and was devoted to keeping her full house a home. When she passed, Dartanyon became motivated by two words - “She’s watching.” Since then, he never let his low vision keep him from excelling in athleticism.

Leroy was much harder to crack; his wounds deeper. It took much more than a few favors to get him to part his lips. He wanted someone to listen to him and be understanding. Lisa came to his grandmother’s house where he lived, and sat with him in the basement for hours. It was a silent protest of sorts, sending a message that she was not going anywhere. And it was on the sticky carpet of that basement floor that Leroy finally opened up to her.
As we learn more about Leroy’s background, we glimpse a raw image of the harsh realities faced by so many. Remote parenting, older siblings assuming adult responsibilities, drug dealing, strung-out mothers, unsanitary living conditions, and hopelessness were just some of the ingredients of Leroy’s childhood environment, no matter where he and his family seemed to move. Despite this setting, Leroy maintained a joyful countenance and always made other students laugh, appreciative of everything he had. One ominous morning, he endured a terrible trauma when a train stole his legs from underneath him on his way to school. That train took Leroy’s chance at a normal life, but the scars of the accident cut deeper still. He spent many nights in the hospital writhing in pain, surgery after surgery, unable to sleep under post-traumatic stress, losing his desire to continue living. When his mother’s finances grew thin, he was unable to continue physical therapy and attend doctor’s appointments. Furthermore, we learn that Leroy had a history with the media, one that made him initially resistant to Lisa and her ESPN crew from the beginning. After Leroy’s tragic accident, the media granted him the attention he lacked at home, but left him feeling empty when it came to dealing with the root cause of his lingering pain. Leroy could fool the media and the public that he was coping with his trauma well, and even convinced them in a follow-up story years later that his life was even better after the accident. The previous reporters documented what happened, but failed to see the ‘why.’ And this was true of almost everyone interviewed for Leroy’s story. Leroy had to find his own ways to cope, some more harmful than others. No one cared to consider the reasons why he was in his position or why his mother made some seemingly neglectful decisions. No one, that is, until Lisa. Lisa was single-minded in the effort to open more opportunities for Leroy and Dartanyon to have better lives, despite their past ones.

As filming for the feature ended in an interview with Leroy and Dartanyon, we can already see the impact that Lisa’s love had on each of them and that their brotherhood had on one another. After the filming for the ESPN feature was over, Lisa just could not turn a blind eye to what she had learned of generational poverty, compassion, family and sacrificial love. She wanted to know how she could do more, and she went above and beyond the call of duty to help Leroy and Dartanyon have a brighter future. Possibly the most touching part of the feature was Leroy and Dartanyon’s high school graduation. Not simply because they were among the few students who graduated, but because these brothers who once carried one another physically and spiritually were now walking side-by-side. Leroy had finally gotten properly fitted for his prosthetic legs and walked across the stage to receive his diploma with Dartanyon’s assistance, tears welling in their eyes. The feature ended with the simple, yet profound question, “What would you do for a friend?” After Leroy and Dartanyon’s story aired on ESPN, thousands and thousands of supporters wrote in asking how they could help and how they could give. It was no small feat, but Lisa set up a small trust for the boys and prepared them for attending college after graduation. She was even able to set up Dartanyon with a trip to the Olympics training facility in Colorado. Everything seemed to be looking up for these two young men.

However, as we continue to discover in this work, it was not too long before the long-term mental effects of poverty made themselves evident. Lisa had done an excellent job setting up a monthly allowance for Leroy and Dartanyon so that they could have all that they needed and still save, but she ran into a problem when Leroy over drafted his bank account by almost $300 in a matter of days. Financial literacy was not something Leroy had access to and this is evident as he explained that he did not know that there was a limit on a bankcard and that he was not keeping up with his spending from day to day. Meanwhile, Lisa checked in with Dartanyon
and discovered that he had 13 cavities and 2 cracked teeth. His response? He had gotten used
to the pain --- not to mention that his stick-to-itiveness was faltering in his Olympic training,
having yet another episode where he used a false injury to justify his loss. Surmounting all, Lisa
discovered that Leroy and his girlfriend were now expecting. Regardless of these circumstances,
however, Leroy was able to rise above and graduate from Collins College in Arizona with a
degree in video game design. And Dartanyon won the bronze medal in judo his first time at the
2012 Paralympics.

These were just a few of the many moments that Lisa had to encounter in addition to
keeping her own marriage and family life together. Her will to continue loving these young men
despite themselves is a true ode to what agape love is. It is self-sacrificing, it is uncomfortable,
and it is life changing. Despite the many warnings from family members not to get too close
and the many frustrations of setbacks that came with the task at hand, Lisa fought for what
she believed. In the book Lisa goes on to say that, “In two years’ time, I essentially became a
mother to four children of different races, ages, and abilities.” Now they are one big family that
supports one another. Lisa and her husband have two children of their own, which is an amazing
testimony of itself, along with Leroy and Dartanyon.

**Reflections**

*Your money, your family, your security, your will, your future. Poverty takes a percentage
of everything, indefinitely, until the cycle is broken.*

-Dartanyon

When you hear the word *poverty* what mental image is painted? What is the imagery
of poverty to you? If you think of dilapidated homes, barely making ends meet, crime rates
off the charts, and entire neighborhoods forsaken by oversight, then you are only seeing half
of the reality. On the personal level, the human experience is on the verge of destitution. For
Dartanyon and Leroy, they were fortunate to have enough assistance and the dedication of Lisa
to transition out of that state. But for many who want to create change, the simple thought of
alleviating each poverty-stricken individual worldwide is an overwhelming task. Many of us in
this life have events that move us to act. However, the great question is “How?”

Are we willing to sacrifice a portion of our day, week, month, year or ultimately our lives to
help another succeed? Are we willing to reach down from the social class pyramid and delve into
root causes of poverty? Just the idea of temporarily leaving our comfort zone causes adrenaline
to pump through the bloodstream. However, how can “peace of mind” exist knowing that
someone is going to bed hungry or that they do not have a permanent place to call home?

Pushing past boundaries of culture and class, Lisa Fenn stepped in to bridge the gap simply
because it was the morally right thing to do. She challenged the ethics of professional journalism
by getting involved in the lives of Dartanyon and Leroy. She went beyond the television screens
and praise to sit with people very different from herself. She broke the chains of generational
prejudice by loving unconditionally. Initially, some readers of this work and viewers of the ESPN
documentary well could ask themselves: “What is this privileged white woman from middle
class America going to do for these young black men from the ghettos of Cleveland, Ohio?”
But when the story first aired on ESPN one sees a paradigm shift. She assimilated many new
experiences on her trip into the mind of the impoverished. The wall of ignorance was broken down brick by brick. Life lessons were reinforced with love, patience, and education. Leroy and Dartanyon’s lives were forever transformed. So, yes, it may be too daunting for us individually to end poverty on a worldwide scale, but what if we could impact the life of one or two? To change one is to change indirectly the world itself. And if we start there as a community, there are no limits to what we can do.

Final Thoughts

_Carry On_ is a book that takes you through every human emotion: joy, deep sadness, compassion, frustration, humor, and contentment. The most profound experience it gives you, though, is the call to rise to the challenge, to rise above your comforts and selfish ambition, to reach beyond your small scope of the world and outside your realm of privilege to touch your neighbor and meet their need. Not because they can do anything for you in return, but simply because it is our duty to love deeply, give of ourselves freely, and to help one another “carry on.” This book is a must-read for anyone who has a burning desire to give back and make a difference in one’s world but needs inspiration or personal motivation. This narrative is the perfect model of how to do so with just the smallest first step; and it also gives a real view into the sacrifice that may be required to continue down the path.
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Book Review

The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures

By Anne Fadiman

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Introduction

In The Spirit Catches You and You Fall Down, journalist Anne Fadiman interweaves the story of the treatment of young Lia Lees seizure disorder in the United States, with the social and political history of the Hmong people and their immigration to the US. The Lees are a family of Hmong refugees who have little if any understanding of English or the American medical system. The doctors in charge of Lia’s medical treatment have little if any understanding of the Hmong culture and values. Both the Lees and medical staff are indeed overwhelmed by frustration with the others’ inability to cooperate with their personal belief systems.

The book is an honest account of the unfortunate results of clashing worldviews of health professionals influenced by a culture of modern medicine with those of an age-old indigenous group. The dynamics of power in the doctor–patient relationship are clearly exposed in this inspiring account of one family’s devotion to a chronically ill child. Misperceptions were compounded daily until they became colossal misunderstandings with tragic results. Fadiman allows her readers to share the full range of emotions of all those involved, including fear and grief in the face of change, parental love, and the doctors’ sense of duty and misgiving.
Brief Summary

According to her parents, when Lia was around three months old, her older sister, Yer, slammed a door and Lia had her first seizure. Her parents, Foua and Nao Kao Lee, believed that the noise of the door had caused her soul to flee. They diagnosed her illness as ‘qaug dab peg,’ ‘the spirit catches you and you fall down.’ This is an illness of particular distinction in Hmong culture because Hmong with epilepsy often grow up to become shamans.

A Hmong shaman, or ‘txiv neeb,’ is a person who has a healing spirit. One does not choose to become a shaman the way one chooses to go to medical school. The healing spirit makes the choice. The seizures are often taken as evidence that the person with epilepsy has the power to perceive things that other people cannot see. This power facilitates the entry into a trance-like state, which is a prerequisite for the journey into the land of the unseen made by all Hmong shamans where they try to intercede with the malevolent dab spirit in order to retrieve their patients’ souls. Because shamans have been ill themselves, they are thought to have an intuitive empathy for those who are ill. The family’s attitude toward Lia’s seizures reflected a mixture of concern and pride. They were distressed to think that something might compromise the health of their child, yet believed the illness was an honor.

During the months following the initial episode, Lia had more than twenty seizures. In at least two of those occasions, her parents were worried enough to carry her to the emergency room at Merced Community Center (MCMC). At that time MCMC did not have a Hmong interpreter, hence the resident on call practiced what he referred to as “veterinary medicine” (pg. 25). During those visits, Lia’s seizures had stopped by the time she arrived at the emergency room and, with the results of a chest x-ray finding, she was misdiagnosed with early bronchopneumonia or tracheobronchitis, not knowing that her bronchial congestion was probably caused by aspiration of vomit or saliva. It was not until the third emergency room visit when Lia was eight months old and she was still seizing that the diagnosis of epilepsy became clear. Epilepsy, one of the most common of all neurological disorders, is a result of sporadic malfunction of the brain. Lia was discharged with an anticonvulsant to suppress any further seizures.

Lia’s primary physicians, Neil Ernst and Peggy Phlip, tried to provide the highest standard of medical care possible. Neil and Peggy, a married couple, were both the children of physicians, both high school valedictorians, and both Phi Beta Kappa graduates of Berkeley. However, although Neil and Peggy were “excellent physicians ... they were imperfect healers” (pg. 265). They were very deeply imbued with the culture of medicine and following a path that the culture dictated. They failed to understand that in Hmong culture epilepsy is considered a highly distinguished condition. The reality is that the Lees never wished for Lia to be completely cured of the very condition that might allow her to become a shaman, and which would thus confer on her a prestige impossible to obtain otherwise.

Unfortunately, Lia continued to have frequent tonic-colonic seizures sometimes resulting in status epilepticus. Between the ages of eight months and four and a half years, Lia Lee was admitted to MCMC seventeen times and made more than a hundred outpatient visits to the emergency room and to the pediatric clinic at the Family Practice Center. Her prescriptions were changed twenty-three times in less than four years and were constantly being fine-tuned.
The regimen often required the Lees to give their daughter several different pills at different times of the day. Sometimes they had to cut the tablets; sometimes the tablets had to be mixed with food, because Lia would otherwise spit them out. Sometimes they were supposed to measure liquids in syringes, a process that would have worked better if they had been able to decipher the markings. The instructions were, of course, written in English that they could not read. Not surprisingly, the Lees were not always able to adhere to the medication regimen.

The doctors did not have any understanding of the parents’ motivation or concerns as communication was so limited. Neil and Peggy were frustrated by the inattention to the necessary medication regime and wrote the phrase “noncompliance” hundreds of times in Lia’s chart. When Lia was two years old, it was finally decided by Neil to involve Child Protective Services because he was worried that if Lia was not given her medications properly, she would either become severely brain damaged or would die. He felt morally and professionally obliged to report the Lees. Neil practiced the same standard of care that he provided to all his patients, Hmong or American. For a year Lia was placed in a foster home where no one spoke Hmong. Although her foster parents were loving and caring people, Lia was miserable and at times she would smear the walls of the foster home with feces and went on 24-hour crying fits. Even though Lia’s foster parents strictly followed the medication regimen Lia continued to have seizures.

In the interim, her parents were overwhelmed with grief over the removal of their beloved daughter. Eventually, her parents were allowed to visit. Finally, after almost a year away from her family, Lia was returned home, after her parents, assisted by a very sensitive social worker, demonstrated a greater willingness and ability to give their daughter her medications as prescribed. It was a time of optimism. Unfortunately, at the age of four, Lia experienced an unusually severe and prolonged episode of status epilepticus in association with septic shock from a pseudomonas infection, which was initially undetected. She became comatose, and ultimately was left in a persistent vegetative state. The doctors held out no hope for her survival and assumed she would die within the next few days. Her parents wanted to take her home to care for her. Only after a great deal of unnecessary drama, Lia was released into her parents’ custody and care where she remained for two decades more.

**General Reflections**

When reading the title of the book, ‘*The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*’, one might initially assume the two opposing cultures are Hmong versus American. However, it becomes clear that the cultures clashing are the Hmong culture versus the ‘culture of biomedicine.’ The book demonstrates how medicine is its own culture, and has its own set of guiding rules and principles that may clash with those who partake in the medical system. As powerful an influence as the culture of Hmong is in this story, the culture of biomedicine is equally powerful.

One does not need to read far into the book to see evidence of the first clash. The book begins with a descriptive contrast of one of the most important events of the human life cycle, birth. In Hmong culture, the birthing process is a far cry from our Western medically optimized sterile event. In their culture, the main goal of birth was to protect the child from a malevolent, soul-stealing, spirit called a ‘dab’ and every small detail of the circumstances surrounding a birth can have cosmic ramifications. Ritualistic Hmong animal sacrifices are the order of the day to
prepare the way for a safe arrival into this world. From the moment of birth onward, each of these very different cultures has its own specific focus: one is on the body and the other is on the soul.

As the story unfolds, we are told that the Hmong people have a saying, “bais cuaj txub kaum txub,” which means, ‘to speak of all kinds of things.’ These simple words edify the intricate and complex worldview of the Hmong. To them, everything in the world is connected, no event occurs in isolation from others, and you can miss a great deal by focusing on events in isolation. Perhaps this is why Fadiman spent so much of the book on the Hmong people’s history, trying ‘to speak of all kinds of things,’ and facilitating our deeper understanding of the Lees. To understand fully the Lees, one needs to understand the Hmong people.

The Hmong viewpoint seems to be diametrically opposed to our western biomedical view of examining things on a microscopic level, where it is common to separate every problem into each of its smallest fundamental units and then to study that factor in isolation, so as to avoid specifically contiguous influences that might alter the surroundings in which it functions. In essence, a disease involves the microscopically or chemically demonstrable indicators of a pathological process so familiar in all those afflicted with it that it can be easily recognized from a comprehensive description in a medical textbook. The evidence of its presence is objective and verifiable.

To better understand the inevitable yet calamitous results of the collision of cultures, Fadiman encountered Arthur Kleinman. In his 2008 work “The Illness Narratives: Suffering, Healing, and the Human Condition,” Kleinman defines disease as the problem as seen from the point of view of the doctor; and illness as the problem as seen from the point of view of the person who is sick. An illness is the total of the psychological, social and cultural ways in which the patient experiences the bodily symptoms caused by a disease. By its very nature every illness is subjective and distinct to the individual in whom it exists. According to Fadiman, while to a physician a stomach-ache might be seen as nothing more than firing of visceral fibers triggering a pain response, to a Hmong, a stomach-ache was an indication that the “entire universe was out of balance” (pg. 61). Even today, many doctors pay more attention to the report of a pathologist or a radiologist rather than to the words of the patient, whose very life it is that they are responsible to safeguard. Instead a doctor should take into account the complete patient, including their culture and the worldviews of their families’ history, rather than be seen as merely a combination of pathologies.

While the original book was written in the 1980’s, the current edition was published in 2012 with an afterword by Fadiman. A great deal of progress in multiculturalism and cross-cultural communication has transpired since then. However, in Fadiman’s afterword, it is evident that there is still a ways to go, as the current training in many medical schools of ‘cultural competency’ is insufficient. She believes that one cannot truly be competent in another culture, but rather schools should espouse the concept of ‘cultural humility’ that says that each culture brings its own baggage, including that of our own biomedical culture. Enabling medical professionals to be aware of their own biases and overcoming them in relation to their patients would lead to a major improvement in the care of patients of differing cultures.

Neil and Peggy continued to fine-tune Lia’s prescription in a way that might have been appropriate, but they were unwilling to change their standard of care — by prescribing, for
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example, a single “pretty-good” anticonvulsant that would have been easier to administer and would have merely controlled some of the seizures while not completely suppressing them. They wanted to treat Lia the way they would want their own child to be treated if she were the patient. While this was admirable in theory, it became catastrophic in practice. As well, it is significant to acknowledge that the Lees did not want to remove completely the seizures. With this in mind, it is important to make sure that the doctor and patient are on the same page as to what exactly the end goal really is that they are targeting. A doctor should not merely assume that there is only one way to treat a patient’s disease, but rather accommodate the patient’s needs and wishes. In the Lees’ case, it should have been what the Lees wished all along … “a little medicine and a little neeb” (pg. 110).

First Author’s Personal Reflection

As I am about to embark on the next step towards my medical career, after reading this book, I am forced to confront my personal cultural biases in relation to the practice of medicine. Most people who initially meet me assume that I am a typical American-born and American-trained medical student, which to a larger extent than I care to admit, is true. However, I, like most people, have a little more narrative to my cultural background than being a New York native. Both of my parents were born and raised in Afghanistan and immigrated to the United States before I was born. I was lucky to grow up in a home that was a multifaceted mixture of the cultures consisting of Afghani, American and Jewish. This taught me a great deal of tolerance for divergent worldviews and opinions.

When I attended college to obtain a Bachelor in Science, I decided to obtain a concurrent degree in Talmudic Law from a Rabbinical Seminary. This degree involved the in-depth study of the Talmud, a comprehensive written version (c. 500 CE) of the Jewish law, comprised of sixty-three tractates, and in standard print over 6,200 pages long. Besides dealing with Jewish Law, Talmud discusses a variety of subjects including Jewish ethics, philosophy, customs, history, and many other topics.

One of the most enigmatic statements in the Talmud is “The Best of Doctors Go to Hell” (Kiddushin 82b). Clearly this statement begs for explanation as some of the greatest Jewish leaders were physicians (e.g. Maimonides), and seems to be a rather harsh condemnation for wanting to help people. As is expected in Talmudic analysis, there are various interpretations of this statement. One novel statement interpretation came to mind as I read this book. Perhaps the Talmud means “Even the Best of Doctors Go to Hell.” Essentially, even the most knowledgeable and accomplished doctors can fail to see the illness and aim just to treat merely the disease, perhaps causing unnecessary pain in the process.

As a medical practitioner, it may occasionally be enough to treat a disease, but to care truly for a patient’s wellbeing much more is needed. I am in no way criticizing anyone in this book. It is quite evident that as there are no heroes in this book, yet there are no villains either. Rather, Lia’s story is a sad example of a unique set of circumstances in which what can go wrong does go wrong.
Conclusion

Today there are still enormous challenges in cross-cultural communication between the health professional and the patient. In an effort to alleviate the possibility of unfortunate miscommunications and misunderstandings, health professionals must be continuously encouraged to look at their own cultural biases, challenge these assumptions, and learn to see people beyond simple stereotyping. Culture is not something that can be taught in a classroom; rather we must strive for cultural humility. While cultural competency implies that one can manage with a thorough knowledge of the customs and beliefs of another culture, cultural humility acknowledges that it might be more difficult to be completely understanding and accepting of other cultures that are contrary to our own. It is essential for good medical treatment that all health professionals be encouraged to develop a far greater capacity for compassion and respect for other cultures. Cultural humility includes a lifelong commitment to introspection and self-assessment in order to equalize the imbalance of power in the doctor-patient relationship. The book leaves the reader with a clear understanding of just how much self-awareness and sincere commitment are truly necessary to understand another culture’s perspective and to transform that understanding into a mutually beneficial practice of medicine.
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Film Review

Hidden Figures

A Film by Theodore Melfi
(2016)

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Author Note

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Introduction and Background

Hidden Figures is one of the most powerful films of our time as it brings together an enormity of issues that have long needed our attention for true social justice and human rights in American society. However, before addressing the specifics of the film itself, it is important to consider the socio-cultural issues that stand behind this inspiring piece of contemporary cinema. These issues are critically important for the fullest possible appreciation of this work of art.

It is well known that, throughout history, the evolution and development of the sciences has centered largely on the work of white men. Although this is true for both “hard” and “soft” sciences, “hard” sciences, such as mathematics, engineering, and computer programing, have experienced a much smaller influx of the work of women, let alone women of color. This severe underrepresentation of women of color in science, technology, engineering, and mathematics, or STEM, majors and careers has been called the “double bind,” due to the double oppression incurred by sex and race, as well as the third oppression of a chosen career in the sciences (American Association for the Advancement of Scientists, 1976).

Although there has been some improvement in this area since it was first discussed in 1976, there has been little sustained effort to increase the population of minority women in the field, outside of efforts targeted specifically towards women, and minorities (Ong, Wright, Espinosa, & Orfield, 2011). Ong, Wright, Espinosa, and Orfield’s extensive research, and synthesis of research in this area, on which this film review heavily relies, is presented in full in their article in the 2011 Harvard Educational Review issue reviewing the history and progress of the “double bind.” As is discussed in the article, such outreach efforts generally have a disproportionate influence on white women, as the “double bind” of being both a woman, and of color, creates a distinct experience from that of white women. This distinct perspective has the potential to provide novel answers to questions long puzzled by those historically dominant within these fields, especially to questions long left un-posed. Such an influence can comparably be seen in
the changes to law and policies that affect women disproportionately, such as those related to domestic violence, sexual assault, and employment discrimination, upon an influx of women into the legal field. In the STEM fields this potential extends to addressing issues of disparities among populations, and other equity concerns, related to the environment, health, and structural limitations towards access, which might otherwise go unexamined.

The underrepresentation of women of color in STEM fields has typically been dismissed as an issue of lack of interest or desire to pursue careers within them. For 9.9 percent of all science and engineering doctorates in 2006 to be awarded to women of color, when they comprise 16.4 percent of the population, due to a lack of interest, belies issues of structural access and support within institutions throughout an individual’s academic career (Ong, et. al., 2011). Although there is great interest amongst women of color to pursue STEM degrees, there remains a large underrepresentation in terms of completion. The imbedded structure of academic and research institutions does little to assist the very real, daily experiences of facing two forms of oppression. Not only do women experience gender bias as STEM majors, as at least 61 percent of participants in one study did within the past year (Robnett, 2015), but women of color also undergo racialized treatment from their peers and faculty, which can reinforce the perception of STEM professionals as white and male, and therefore reduce their STEM self-concept, or ability to feel as a legitimate member of the field (Carlone & Johnson, 2007). The lack of supportive networks and mentors for women of color within said institutions is significant, as they can typically fall through the cracks of the STEM major-career pipeline, especially when they must engage in extra, unseen, work in order to gain acceptance from their male peers in the first place (Ong, 2002). The difficult nature of finding a sense of self, and worth, as a woman of color within fields where one’s presence is not expected, let alone heavily supported, can indeed help explain the lack of women of color in STEM.

This should be an issue of major concern, not only for the sciences themselves, but also for the country at large. The success and growth of STEM fields are correlated with issues related to economic growth and national security (Ong, et. al., 2011). The greater the investment in STEM, especially with a long-term perspective, the greater the opportunity for societal changing advancements, as was seen during the Space Race, and highlighted in the film Hidden Figures. In today’s United States there are two important demographic shifts that must be taken into account. First, as the majority of the national population growth is from non-whites, whites make up a declining share of the population. Second, within this non-white population, women attend college at a much higher rate. Considering the facts that women of color are the most underrepresented recipients of STEM degrees by share of the population, which is steadily increasing, and that lower shares of the population receive degrees in said fields compared to other developed countries, the United States is risking both its economic competitiveness and national security by not addressing this disparity.

Summary

Hidden Figures was released in theaters in late 2016, and nominated for three Academy Awards: motion picture of the year, best performance by an actress in a supporting role, and best adapted screenplay (IMDb, 2017). It is based off of Margot Lee Shetterly’s book Hidden Figures: The American Dream and the Untold Story of the Black Women Mathematicians Who Helped Win the Space Race, published earlier the same year. The purpose of both is to present
the invaluable efforts of three black women, Katherine Johnson, Dorothy Vaughan, and Mary Jackson, who helped win the United States the Space Race, and therefore a significant edge up in the Cold War. Yet their effect is to shine a light onto the, until now, unseen, yet inordinate, influence of women of color in STEM fields on the trajectory of growth, success, and power of the United States. Most significantly, the film presents history in a way that makes it visceral to the viewer, in ways that simply knowing the facts cannot. It portrays the story of three incredible role models for all young women and people of color, in a highly accessible and easily approachable fashion.

The film begins in 1926 with a young Katherine, the story’s main protagonist, in White Sulphur Springs, West Virginia. An incredibly bright and gifted child, she is offered the opportunity to attend the most advanced school in the state for “colored” children, which would require her family to move and for her to skip numerous grades ahead of her age. This sets the foundation for the first of three major themes throughout *Hidden Figures*, that of systems of support. Without the strong encouragement of her parents, Katherine would not have been able to receive the best education possible for her at the time, and for her to reach her greatest potential. These support systems extend beyond our immediate families, to those of our peers and mentors. For Katherine, that includes her friends and colleagues Dorothy and Mary.

Fast forward to 1961 in rural Virginia, the three women are on their way to work at the National Aeronautics and Space Administration, but their car has broken down, and they are stranded on the side of the road. Here, the second major theme arises, of living with and overcoming discrimination, as a racist cop pulls over to investigate the problem. When he learns of their jobs, human “computers” at NASA Langley’s Research Center, who help astronauts in the Space Race against the Russians, he immediately shifts gears to help them get to work. It is clear that their job requirements go beyond his understanding, as he is surprised such a significant agency would even employ black women. These human “computers,” all women throughout NASA’s history, perform complex mathematical calculations by hand; prior to the advent of machine computers capable perform these tasks at incredibly fast speeds. Not only were these women computers separated in terms of hierarchy from the men of the organization, in that they performed calculations for the male engineers and scientists, the computing groups were themselves segregated by race.

Dorothy, the de facto supervisor of the West Area Computing Group, or black computing group, experiences discrimination from multiple sources throughout the film, from the hierarchy of NASA, as well as society at large. Octavia Spencer was nominated for an Academy Award for her role as Dorothy. Her manager, a white woman who calls Dorothy by her first name, but is addressed as Mrs. Mitchell in return, insists it is the powers at be who will not promote Dorothy and provide her the pay for the supervisor position she has effectively been working without the additional income. It is through a combination of the film’s three themes, systems of support, overcoming discrimination, and unstoppable determination that Dorothy fights to reach her fullest potential and continue to maintain the highest level of achievement possible. From her relative position of power, Dorothy assigns Katherine, Mary, and all members of the West Computing Group, to the positions most fitting for them and the greatest potential for success.

Katherine, who is stunningly portrayed by Taraji P. Henson, is chosen to go to the Space Task Group to do analytic geometry computations, assist and check the numbers of the engineers in the group, and ultimately calculate the trajectories and landing coordinates for John
Glenn’s Friendship 7 mission to orbit the Earth. She is the first person of color assigned to the Space Task Group, and immediately senses the amount of pressure this entails. She is told not to embarrass Mrs. Mitchell, is mistaken for a janitor, and is told “your bathroom” is not within the building, let alone the East side of the Langley campus. Katherine must run a half mile back to the West Computing Group, wearing heals and a skirt below her knees, which translates to 45 minute long breaks to use the restroom. The lead engineer does not trust her with sensitive information, and requires that she check his calculations with a large portion of relevant information censored from the page. After using the communal coffee pot for the first time, the next day her white co-workers have “conveniently” provided her with her own pot, labeled “colored,” which they have not plugged in or brewed. It is Katherine’s brilliance, determination, and perseverance that ensured her success within the position, as well as that of the overall Space Task Group’s mission of determining landing coordinates and proper trajectories. She holds the paper to the light and is able to make out some of the censored numbers, and is therefore able to solve the puzzle evading the top engineers of the group. Katherine repeatedly insists that her name should be on the byline of the written reports, even though it is not standard practice for computers to author reports, and makes known that her presence is necessary in the top secret meetings in order for John Glenn’s landing coordinates to be as accurate and up to date as possible, despite there being no protocol for women attending such meetings with the Joint Chiefs of Staff. She was successful in achieving both feats of being the first woman, to receive credit as an author, and to attend such a meeting.

Mary, who is played by Janelle Monáe in her second role of the year to receive high praise, the first being Moonlight, which won the Academy Award for Best Film of the Year, is assigned to assist the engineering department. The department is struggling to determine how best to build the capsule for the Friendship 7 mission so that it can withstand massive wind and heat upon reentry. Rather than build a new shield, Mary suggests that they use different fasteners for the same panels, to which her new “boss” responds that she should also be an engineer. However, Mary muses that this is not a realistic possibility, as she is a black woman, and therefore not allowed to attend most engineering programs. Her “boss,” a white Jewish man, responds that if it is possible for him, a Holocaust survivor, it is possible for her, as well. Not only does society believe that she as a woman, and a person of color, is unable to be an engineer, her husband initially also believes it is beyond what she should attempt. Despite these obstacles, the support of her friends and encouragement from her “boss” motivates her to bring suit in order to attend evening engineering classes at the local, all white, high school. She inspires the Judge hearing her case to think towards history, how he will be remembered, and what will make him the first, like Alan Shepard to reach space, or her to attend classes at an all white school in Virginia, and ultimately wins the support of the Judge and her husband.

Understanding what was to come, Dorothy realized the lack of job security she and her fellow human computers would have when a new IBM 7090 electronic computer arrives and is assembled at Langley. In order to secure her position, and that of the West Computing Group, she decides to learn the computing language FORTRAN. To do so, she takes her children to the library to find a book on the language, which happens to be located in the white section. Dorothy is redirected to the “colored” section by a librarian, and ultimately escorted out of the premises by security. She later reveals to her sons that she stole the book from the library, since it was not in that section, as is her “right” as a taxpayer. Ultimately, Dorothy not only learns FORTRAN, but also teaches the language to the entire computing group, who are later reassigned as data center staff. An incredibly revealing scene takes place between Dorothy and
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Mrs. Mitchell, where in the desegregated bathrooms Mrs. Mitchell apologizes to Dorothy for not making her a supervisor and says she does not hold anything against “y’all,” to which Dorothy responds, “I know. I know you probably believe that.” Later, Mrs. Mitchell makes Dorothy a supervisor in the Analysis and Computation Division, and addresses her as Mrs. Vaughan.

As the dramatic arc of the film follows the ultimate success of John Glenn’s orbit around the Earth, so it parallels the audience’s growth in understanding of the skills and contributions of Black women in STEM, in terms of the progress of both STEM, and the nation itself. This increase in appreciation for the contributions of Katherine, Mary, and Dorothy is elevated by the straightforward nature which the distinct experiences of being a woman of color, during the height of the civil rights movement, is portrayed in this film. Watching this film is truly an immersive experience, allowing the viewer to honestly attempt to empathize with the struggle of experiencing the double bind of being a woman of color, and the triple bind of being a physicist and mathematician, like Katherine, a mathematician and aerospace engineer, like Mary, or a mathematician and NASA’s first Black manager, like Dorothy.

Reflections

It is of the utmost importance to appreciate and recognize the ability of women of color to address issues in a unique and profound way, and to search for ways to ensure their continued contribution to, and leadership in, society at large, and the STEM fields. We must encourage implementation of programs to address concerns about the environment of academic and research institutions to encourage the retention of women of color, whether it be mentorship programs, peer support groups, or scholarships. Pipeline networks from K-12 through graduate school and job placement would likely be the most effective. Creating a positive STEM self-concept is easier at a younger age, and could likely be helped by watching Hidden Figures in the classroom. Despite any institutional or governmental policies that could be enacted to increase the proportion of women of color completing STEM degrees, it is within the ability of those currently in positions of privilege and power in STEM fields and programs to assist in placing women, and people, of color into leadership positions, and encourage their growth within the field. It is within each of our ability to listen to and raise the voices of women in color in each of our fields.

As is shown in Hidden Figures, the contributions of women of color in STEM to the success of the United States, both in terms of national security and economic growth, are invaluable. This film is a true accolade to their brilliance and fortitude in the face of multiple levels of oppression.
References


UNDER CITY LIGHTS
The Flood and the Rainbow
A Poem and Reflection

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Author Note
The insights or views expressed in this creative reflection are those of the author. They do not reflect official policy or the position of any of the institutions the author serves. The author has no financial conflicts of interest. A note about the poem: Italicized words are Hebrew transliterated into English, followed or preceded by English translation.

Reflection
It seems most fitting to share a poem about Noah and the Ark at this moment in North America in Autumn 2017, fresh on the heels of Hurricanes Harvey and Irma that devastated Texas, Louisiana, the Southeast, and the Caribbean. Harvey dumped 51 inches of rain on the city of Houston alone. Irma packed sustained record-breaking winds of 185 miles per hour over the Atlantic Ocean before battering the Caribbean islands and Florida. As of this writing, the two tropical cyclones have caused 82 deaths. Estimated damages: $300 billion and counting. And this is only in our corner of the globe.

Elsewhere, particularly in the African countries of South Sudan, Niger, Chad, Nigeria, Somalia, and Ethiopia, recurring drought and political instability have brought on severe food shortages and famine-like conditions and a full-blown famine in Yemen.

As ocean temperatures continue to rise, so do the frequency and intensity of catastrophic storms. Drought prone areas become even more susceptible to food insecurity, diseases and death to crops, livestock and people. Melting glaciers and collapsing polar ice sheets further threaten coastal populations around the globe. How do we cope with such devastation? What, if anything, can we do to mitigate, or even better, prevent, natural disasters like these? Do we humans have the power to counteract the increasing chaos of the earth’s changing climate?

Eighteen American scientific societies have signed the following statement on climate change: “Observations throughout the world make it clear that climate change is occurring, and rigorous scientific research demonstrates that the greenhouses gases emitted by human activities are the primary driver.” (2009). The statement can be found on the NASA website at: https://climate.nasa.gov/scientific-consensus/.
Under City Lights

Eleven international science academies issued this joint statement in 2005 as found at the website of the National Academies of Science, Engineering and Medicine: http://www.nationalacademies.org/onpi/06072005.pdf.

Climate change is real. There will always be uncertainty in understanding a system as complex as the world’s climate. However there is now strong evidence that significant global warming is occurring. The evidence comes from direct measurements of rising surface air temperatures and subsurface ocean temperatures and from phenomena such as increases in average global sea levels, retreating glaciers, and changes to many physical and biological systems. It is likely that most of the warming in recent decades can be attributed to human activities. (Original from Intergovernmental Panel on Climate Change 2001)

I am led to ask, if human activities [through the burning of fossil fuels] have brought about such radical shifts in the earth’s climate, then should not it also be possible for humans to design, develop and implement activities to reverse the catastrophic trend? I am only one person. These are my choices: I could stick my head in the sand and live in denial for the rest of my earthly time in this body; I could sink into despair and depression or I could heed my teachers and attend to my divine call.

What led to the writing of this poem began in childhood, when I learned from Depression Era parents the values of “reducing, reusing, and recycling” well before this phrase became a household (word?) motto. My father composted our food scraps, kept the thermostat low in winter (how I disliked getting dressed on those chilly mornings!), and used the single window air conditioner only on sweltering summer afternoons to keep my couch-bound mother comfortable. Dad was health conscious and taught me to read food labels, shun processed food and sugary soft drinks, and be mindful of what I put in my body. I bicycle commuted to my high school in Elizabeth, New Jersey, a city already infamous for toxic waste sites, and became an environmental activist during the inaugural Earth Day, April 22, 1970.

Once in college, my passion for healing the Earth overtook a strong interest in math, and I became an “aggie.” I earned a bachelor’s degree in Natural Resources and Conservation with a concentration in nutrition. It was the beginning of the vegetarian movement in the U.S. and Frances Lappe’s groundbreaking book Diet for a Small Planet became my bible. I took my first internship after college graduation as a nutrition activist at the Center for Science in the Public Interest, a spin-off from consumer activist Ralph Nader’s Public Citizen. Putting my passion to a test, I bicycled coast-to-coast across America to celebrate this nation’s bicentennial and demonstrate how it is possible simultaneously to empower oneself, conserve resources and have fun.

Fast forward several decades, my life’s trajectory has propelled me on a spiritual journey. I am ever the outdoors type, finding inspiration, solace and prayerful moments among the trees. I have been blessed to have studied with a most gifted teacher, Rabbi Zalman Schachter-Shalomi (1924-2014). Reb Zalman, as we called him, grandfathered the movement known as Jewish Renewal and founded the Aleph Ordination Program, the seminary from which I received smicha—ordination—as Rabbinic Pastor in 2009. Since then I have served as a hospice chaplain while I have continued to pursue my spiritual life.
In his eldering years, Reb Zalman wanted to be known as Zeyde—Grandpa. A decade ago I sought out his grandfatherly guidance after viewing Al Gore’s documentary *An Inconvenient Truth* (2006). The film’s urgent message had provoked me to host screenings and discussions in local congregations and libraries. One point in particular haunted me: scientists’ best models predicted that we had about 10 years before reaching the tipping point to reverse the course of human induced climate change. “Reb Zalman,” I pleaded, “I’ve been an environmentalist my whole life. I’ve started activist groups, run programs, tried to walk my talk, and after seeing this film, I don’t know what else I can do!” My eyes well up with tears and my revered teacher looked right in my eyes and said, “My dear, you’re going at this from a place of despair. You need to do this from the place of joy.” The moment was an epiphany. It was as if he had thrown a light switch in my heart.

The poem came through my pen in 2010 and speaks of my theology: Each of us is here for a divine purpose. It is up to us individually and collectively to deeply listen and discern what we are gifted to do to help heal the world’s broken places. We have suffered from traumas and our wounds can bring us down. If we acknowledge our wounds, feel our feelings and resolve them, we can affect positive change. We cannot do this work alone. We were not born to be rugged individualists, pulling ourselves up by our bootstraps. It takes a village.

I am inspired by the words of Rabbi Tarfon who wrote, “It is not up to you to complete the work. Neither are you free to give up” and by the words of my friend and hero Ruth Messinger, former director of American Jewish World Service, who says, “Listening is a prerequisite for action. Listening is a principle for living Jewishly in a globalized world.”

**The Flood and the Rainbow**

It doesn’t take much  
To make a flood  
Blow in the clouds  
Load them with moisture  
Temper the wind  
And open the spigot

Leave your home if you must  
Take only what’s precious  
LIFE in all its forms  
All creatures great and small  
All living things winged and finned  
All beings that walk or crawl on the earth

Follow on Papa Noah’s heels  
Build an ark  
A safe haven,  
A shelter, a womb  
To ride out the time  
Of the raging waters
Watch, awestruck, through the portholes
And wonder at nature's power
What are we to learn from this?
Where is God as we toss about the ceaseless waves?
How will we survive the onslaught and, if we do,
What will life be afterwards?

What will be our service?
How will we fix our broken world?
Will the flood wash it clean
For us to begin again?
Or will it leave debris in its retreat
That can never be restored to shlaymut --wholeness?

God, after all I’ve done
To heal my corner of our earthly home,
You used to leave me, feeling despair,
Sunk in my own flood of tears at my insufficiency
But despair only bred more despair
It served only Death, not Life

I needed guidance and turned to my teacher
Not unlike Zeyde--Grandpa Noah did with You
I learned, above all, to turn towards the rainbow
The beautiful arc of colors
At the end of the storm
And reach for joy

For joy is our inheritance
And our legacy to pass on
So our children and our children's children
Can listen, sh'ma, to your divine call
From a heart of love
And their own place of joy

Aleynu!--It is up to us
To heal from past traumas
To free ourselves from the shackles
That have kept us down
And become the sacred vessel
Like an ark

A cocoon for transformation
Safely holding the coming generations
As a bulwark against the stormy tides
That they may take on
The hard, yet holy, healing work
Only You can gift them to do.
Elder Floyd Blackbear
Social Justice and Civil Rights Leader

SSGT (ret) George Brummell
Blinded Veterans Association

NASA Women

Elie Wiesel
Professor and Holocaust Survivor

Dr. Fergus and Ruth Pope
International Human Rights & Healthcare Leaders

John Glenn
Astronaut, Senator, Veteran

Vera Rubin
Astronomer

Gwen Ifill
Newscaster

Jim Vance
Newscaster

Edith Windsor
Social Justice Leader

Sisters of Selma
1965 Civil Rights Activists

Edith Eva Eger
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