

### **Mennonite Health Journal**

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#### This issue of Mennonite Health Journal



The lead article in this issue picks up on the "Moral Dilemmas in Healthcare" theme of the 2013 Mennonite Healthcare Fellowship Annual Gathering held in June. **Peter Carney**, a neurosurgeon from Elkhart, Indiana, explores the topic of "**Reclaiming Moral Probity**" from a Christian perspective as it relates particularly to the responsibility of physicians in the current climate of healthcare reform in the United States.

**Barry Hieb**, a physician from Tucson, Arizona, working in medical informatics, informs readers of a proposed solution to another dilemma in the increasingly automated U.S. healthcare system, balancing "Identity and Privacy" concerns for each individual patient.



MHF Executive Director **Paul Leichty** follows up on a column in the last issue of MHJ on societal choices, with an article in this issue on "**Personal Choices in Community Context.**"



Turning to the international scene, the final two articles encourage us to see the world from the interface between North American affluence and the poverty and lack of resources in many developing nations. MHJ is particularly pleased to offer "Reflections on SET in Zambia," a Student Elective Term report by John Stoeckle from Philadelphia, who completed his SET term in April and graduated from medical school in May.

Finally, **Murray Nickel**, president of International Mennonite Health Association shares his thought-provoking musings from the perspective of the Congo, in a short piece entitled, **"Hanging on for Dear Life."** 

As always, the perspectives of our readers are also welcomed and we welcome additional articles for upcoming issues of *Mennonite Health Journal*. Contact us as noted below.

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# **Reclaiming Moral Probity**

# An Essential and Foundational Part of Being a Physician Peter Carney, M.D., F.A.A.NS.

"Medicine is a sensitive societal moral weathervane.

When its beneficence is blurred it is time for society to examine its own claim to moral probity." 1

#### Health Care Impacts the Viability of the U.S.

Health care costs are rising faster than the gross domestic product (GDP). This has caused many to project that by 2020 health care will consume 20% of the nation's GDP.<sup>2</sup> This has led Dr. Robert Brook to conclude that the federal "deficit cannot be reduced unless medical spending can be controlled." Elisabeth Rosenthal has noted "Americans pay more for almost every interaction with the medical system. .... A list of drug, scan, and procedure prices compiled by the International Federation of Health Plans, a global network of health insurers, found that the United States came out the most costly in all 21 categories – and often by a huge margin." Yet a recent review matching the state of health in the U.S. as compared to 34 other countries in the OECD (Organisation [sic] for Economic Co-operation and Development) showed that in the U.S. age-standardized death rate changed from being ranked 18th in 1990 to being ranked 27th in 2010 while for the Healthy Life Expectancy (HALE) the U.S. moved from being ranked 14th in 1990 to 26th in 2010. Clearly, spending more money for health care in America than the rest of the world has not resulted in outcomes that are better than other developed countries have.

Dr. Robert Brook describes three scenarios open to physicians in controlling rising health care costs. First, do nothing. Costs continue to rise *unabated* and sooner or later the solutions will be applied that neither "physicians nor their patients want." In the second scenario, health care is *rationed*, a solution that causes "all rational discussion to cease." The third scenario requires physicians to "take the lead in identifying and eliminating waste in U.S. health care." After defining wasteful medical procedures, devices, or drugs as ones whose potential harms are greater than their potential benefits, Dr. Brooks states that "Before draconian measures are enacted, the waste question needs a scientific answer that physicians agree is valid and reliable."

<sup>&</sup>lt;sup>1</sup> Edmund D. Pellegrino, "Medical Ethics Suborned by Tyranny and War." JAMA 2004: 291, pp. 1505-6.

<sup>&</sup>lt;sup>2</sup> S. P. Keehan, *et al.*, "National Health Spending Projections through 2020," *Health AFF* (Millword) 2011:30(8): 1594-1605; Shatto, JD, and Clemens, MK, *Projected Medicare Expenditure under an Illustrative Scenario with Alternative Payment Updates to Medicare Services*. Washington DC: Centers for Medicare Medicaid Services, Office of Actuary, 2011. https://www.cms.gov/ReportsTrustFund/Downloads/2011TRAlternative Scenario.pdf.

<sup>&</sup>lt;sup>3</sup> Robert H. Brook, MD, ScD, "The Role of Physicians in Controlling Medical Costs and Reducing Waste." *JAMA* 2011:306, pp. 650-51.

<sup>&</sup>lt;sup>4</sup> Elisabeth Rosenthal, "Paying Till it Hurts: The 2.7 Trillion Medical Bills," *The New York Times* (Health Section), June 2, 2013.

<sup>&</sup>lt;sup>5</sup> U.S. Burden of Disease Collaborators, "The State of U.S. Health, 1990-2010. Burden of Diseases, Injuries, and Risk Factors." *JAMA* 2013: 310, pp. 591-608.

<sup>&</sup>lt;sup>6</sup> Brook, "Role of Physicians," pp. 650-1.

<sup>&</sup>lt;sup>7</sup> Ibid.

Among his solutions, Dr. Brook includes "teaching physicians to recognize and reduce clinical waste. Board certification examinations and tests in medical school could require physicians to separate waste from necessary care and demonstrate that they use such knowledge in day-to-day practice." To accomplish such a scientific solution, Dr. Bradley Weiner<sup>9</sup> recommends the use of evidence-based medicine, improved education for surgeons and their patients, regulations to restrain wasteful surgical practices, and a strong ethical foundation for surgical care. Where can such a foundation be discovered?

### **A Christian Perspective**

At the 27<sup>th</sup> Annual Notre Dame Medical Ethics Conference<sup>10</sup> an example of wasteful medical care was presented wherein a Worker's Compensation patient underwent a procedure that cost \$369,244 and had very little chance of being helped by the operation. Some renowned medical ethicists used this case to emphasize the need for a Christian Medical Ethic as opposed to a more secular medical ethic. In response to this assertion, the original case has been changed slightly to emphasize its relevance for those who wish to practice medicine in accordance with the teaching of Jesus Christ.

Case #4: A 33 year old teacher who works part time in the summer at his father's carpentry shop injured his back at work. His MRI showed mild to moderate degenerative changes. After three months of conservative management including medication, physical therapy and spinal injections failed to relieve his pain he was referred to a surgeon. The surgeon reviewed the patient's case, told him that he could be paralyzed within the next five years without surgery and recommended that the patient undergo a two level 360° fusion operation.

The teacher, who had already examined the medical evidence concerning his case, knew that:

- 1. The chance of his becoming "paralyzed' following an injury such as he underwent is "rare." <sup>11</sup>
- 2. 80-91% of Worker's Compensation patients with low back pain who underwent a fusion operation have significant functional impairment following their operation.<sup>12</sup>
- 3. 74% of Worker's Compensation cases with low back pain who underwent lumbar fusion operation had *not* returned to work two years after their surgery.<sup>13</sup>
- 4. This operation would generate \$369,244 in costs.

<sup>9</sup> B. K. Weiner, "Necessary and Potentially Evil." *The Spine Journal* 2011:11, pp. 715-717.

<sup>&</sup>lt;sup>8</sup> Ibid.

<sup>&</sup>lt;sup>10</sup> Case #4. "Greed and Medicine," 27<sup>th</sup> Annual Notre Dame Annual Medical Ethics Conference. March 2-4, 2012, pp. 15-19.

<sup>&</sup>lt;sup>11</sup> Eugene Carragee, et al., "Does Minor Trauma Cause Serious Low Back Illness?" Spine 2006:31, pp. 2942-49.

 $<sup>^{12}</sup>$  Leah E., Carreon  $\it et al.,$  "Clinical Outcomes after Posterolateral Lumbar Fusion in Worker's Compensation Patients,"  $\it Spine 2010:35, pp. 1812-17.$ 

<sup>&</sup>lt;sup>13</sup> Trang H. Nguyen, *et al.*, "Long-term Outcomes of Lumbar Fusion among Worker's Compensation Subjects." *Spine* 2011: 36, pp. 320-331.

Fortified with this information, the teacher stood up, turned to his left and said to the surgeon: "Get you from my presence you cursed into everlasting fire reserved for the devil and his angels." <sup>14</sup>

This patient's response may cause Christian physicians and surgeons to consider this question: "Why should we be surprised that this patient accurately described how Christ has responded to those who harm people?" Christ states very clearly that "As you have done unto these the least of my subjects so you have done unto me." <sup>15</sup>

Thus, doesn't any physician who recommends that a patient without cancer or a life threatening illness undergo a very expensive operation that has an extremely low chance of benefiting the patient violate the basic Hippocratic principle: "as to disease make a habit of two things; to help or at least do no harm"? And don't those who consider themselves Christian physicians have an obligation to support and promote the concepts taught by Christ and Hippocrates?

#### **Forgiveness and Truth in Medical Practice**

Yet even Christ himself does not immediately apply the judgment he describes in Matthew 25:41. Within twenty-four hours of pronouncing what Christian retributive justice entails, Christ discovered what the real world would do to him. One of his disciples betrayed him. The "rock" upon which he would build his church denied him three times. The authorities arrested him and prosecuted him unjustly. They marched him through the streets of Jerusalem with a crown of thorns on his head while the people mocked him and then had him nailed to a cross to be crucified and die while hanging between two criminals. Having endured all these tribulations, Christ did not return to what he taught in Matt. 25:41, but rather with his last words said: "Father, forgive them for they know not what they do." These last words represent the most profound, fundamental, and radical concept taught by Christ. Thus, as we look at how physicians sometimes do not embody the noblest aspects of their profession should "forgiveness" rather than retribution be a more effective way to ensure the integrity of the practice of medicine, since it would give offending physicians an opportunity to acknowledge and remedy their errors?

Ingmar Bergman, in his famous movie, *Wild Strawberries*, teaches that the first act of any physician who deals with a patient is "to ask forgiveness." I first heard this concept in my first year of medical school. In the last fifty-four years since then I have dealt with over 15,000 patients many of whom have had some of the most challenging and difficult neurosurgical problems one could imagine. Over 90-95% of these patients have, in one way or another, benefited from what I have done. But some have not, in part because of the complexity of their problem and in part because I did not help them as well as I should have. Thus today, each time I encounter another patient I continue to marvel at the wisdom contained in Bergman's concept. But of course many will dismiss the need for and the very act of forgiveness as weak and destructive. As Auden states, "Every crook will argue 'I like committing crimes. God likes

<sup>&</sup>lt;sup>14</sup> Matt. 25:41.

<sup>&</sup>lt;sup>15</sup> Matt. 25:40. The word "subjects" is author's word choice.

<sup>&</sup>lt;sup>16</sup> Hippocrates, Vol.1 (Cambridge, MA: Harvard University Press, 1962), p.165

<sup>17</sup> Luke 23:34

<sup>&</sup>lt;sup>18</sup> Ingmar Bergman, Wild Strawberries, 1957.

forgiving them. Truly the world is admirably arranged."<sup>19</sup> That analysis misses the basic point of forgiveness. Having been forgiven, one can either accept or reject the gift. Those who accept the gift must acknowledge the harm their actions have created and take steps to rectify that harm. On the other hand, those who reject the gift must be willing to accept the judgment that awaits them. For Christians who reject the gift of forgiveness, it means realizing that they may hear Matthew 25:41 read to them on their final day of judgment. For Buddhists it means creating more bad Karma which will follow them into their future lifetimes. For those who deny the existence of either heaven or hell or Karma and claim that "we live, we die and that is all there is to that" the words of Gandhi still apply; "the future depends on what we do in the present."<sup>20</sup> What type of future do we create when our children grow up believing that "it doesn't matter what the truth is?"<sup>21</sup>

#### **Goodness and Virtue in Health Care**

Since I first reviewed the first case I have subsequently seen three additional Worker's Compensation patients treated by three other spine surgeons, all of whom recommended that his or her patient undergo a similar spinal operation, even though all three of these patients had the same chance of doing as poorly as the first patient. The four surgeons involved in the care of these patients are well trained to perform an exceedingly difficult and demanding operation. All have helped hundreds of patients, all are well regarded by their peers, all generate millions of dollars for the institutions at which they work, and all also make a few million dollars a year for themselves.

Accordingly, a more profitable analysis of these cases comes from understanding how the goodness inherent in all physicians can help to correct the harm these good and decent surgeons wish to inflict on some of their patients. These four surgeons represent approximately 20% of spine surgeons<sup>22</sup> in the two areas where they work and receive widespread support from both their surgical colleagues and their medical communities. The fact that they function as they do demonstrates the ease with which the current culture of medical practice allows physicians to accept wasteful and harmful medical practices which undermine the very foundation of the art of medicine and the economic viability of this country.

Looking at how Iraqi physicians functioned under the Saddam Hussein regime, Dr. Edmund Pellegrino suggested the environment within which these physicians functioned acted "like perverse retroviruses....[that transformed] moral DNA.<sup>23</sup> Pellegrino discussed the dangers inherent in actions that subvert the "moral center of medicine." He goes on to state that

<sup>&</sup>lt;sup>19</sup> W.H. Auden. For the Time Being: A Christmas Oratorio, 1942: Herod's speech.

<sup>&</sup>lt;sup>20</sup> Memorable quote from M. Gandhi.

<sup>&</sup>lt;sup>21</sup> On Sept. 11, 2003 the Chairman of the Department of Anesthesiology at a hospital said under oath. "It does not matter what the Assistant Professor of Anesthesiology from our State University School of Medicine says. It will not change my mind." That very same day the Chairman's hometown newspaper had a front page story describing how his schizophrenic son had been sentenced to life in prison for brutally murdering and decapitating a young woman. For rational and thoughtful people these two facts validate Bateson's Double Bind Theory of Schizophrenia. Bateson described the "double bind" as "a situation in which no matter what a person does, he 'can't win.' It is hypothesized that a person caught in the double bind may develop schizophrenic symptoms." (Bateson, Gregory, et al. "Toward a Theory of Schizophrenia" *Behavioral Science* [1956} 1 [4]: 251-4.)

<sup>&</sup>lt;sup>22</sup> There are 21 spine surgeons in the two metropolitan areas where these four spine surgeons work.

<sup>&</sup>lt;sup>23</sup> Edmund D Pellegrino, "Medical Ethics Suborned by Tyranny and War" JAMA, 2004: 291, pp.1505-6.

"More than education is needed. Character formation is in the end the surest way to inculcate the virtues. This cannot occur unless the profession is itself ethically rigorous. Even the most virtuous physicians need a supportive culture to remain virtuous. Heroes can stand alone, but they are few and often castigated."<sup>24</sup>

In June of 2013 the Indiana Department of Insurance announced that \$63 million dollars will be paid out of its Patient's Compensation Fund (PCF) to cover settlements reached in nearly 350 malpractice cases brought against a single defendant. Gordon Hughes, M.D. and ISMA (Indiana State Medical Association) President has said: "These settlements are an important reminder to all of us that it is our legal and moral duty to police our profession. When we don't, we hurt our patients, ourselves and our profession." The effectiveness of his statement depends on the vigor with which he and ISMA will implement his words. Those physicians who believe that they have a legal and moral duty to speak out against their friends, partners, colleagues and competitors may face great difficulty and potential harm. Yet as Martin Luther King Jr. taught "Like a boil that can never be cured so long as it is covered up but must be opened with all its ugliness to the natural medicine of air and light, injustice must be exposed, with all its tensions its exposure creates, to the light of human conscience and the air of national opinion before it can be cured." So with all its uglines to the light of human conscience and the air of national opinion before it can be cured."

The opportunity to treat patients less than ethically creates a major challenge to physicians who wish to maintain "the art of medicine" as the greatest endeavor ever created by the mind of human beings. Webster defines "moral" as a standard of right behavior and "probity" as adherence to the highest principles and ideals, or as uprightness. To restore "moral probity" to its place as one of the most important foundation stones of the art of medicine requires patience and courage to develop a definition of moral probity that all can understand and to which all can adhere. That definition has four parts, each of which depends on the others and cannot be used separately. These parts are (1) Integrity, (2) Compassion, (3) Honesty, and (4) Wisdom.

- 1. **Integrity** means being able to speak up for what is correct and beneficial behavior when many disregard such behavior. It also means speaking out against behavior that harms patients.
- 2. **Compassion** means not only giving compassionate care to our patients but also being compassionate to our colleagues and ourselves. Because, as we trod "the narrow and stony path" between trying to help and avoiding harm we sometimes become blind to our fundamental obligation to our patients.
- 3. **Honesty** means being able to understand how good and decent people like ourselves and our colleagues can let harmful actions occur.
- 4. **Wisdom** requires physicians to use the goodness that lies within ourselves and our colleagues to combat the dangers that the perverse retroviruses of greed, anger, and ignorance pose to our moral DNA.

<sup>25</sup> PCF settles all Weinberger cases, significantly dropping fund balance; surcharges increases likely. *ISMA Reports*, July 8, 2013.

<sup>&</sup>lt;sup>24</sup> Ibid.

<sup>&</sup>lt;sup>26</sup> Martin Luther King Jr. "Letter from Birmingham Jail" (http://www.africa.upenn.edu/Articles\_Gen/Letter\_Birmingham.html)

<sup>&</sup>lt;sup>27</sup> Richard Selzer, M.D. "The Soul of a Surgeon" U.S. News & World Report, July, 12, 2004, pp. 80-81.

By making moral probity a central part of serving the art of medicine, physicians will continue to uphold the highest values of our profession. Institutions such as medical schools, teaching hospitals, specialty boards, and medical societies must take the lead in **establishing the concept** of moral probity as the essential foundation of the art of medicine.



Peter Carney, M.D., F.A.A.NS., is from Elkhart, Indiana. After graduating from Western Reserve Medical School in 1962, he completed his training in neurosurgery and then taught and practiced in New England and in Saudi Arabia. Since 1985, Dr. Carney has practiced neurosurgery in Elkhart, Indiana while developing a special interest in medical ethics and treating patients in pain. After 51 years of medical practice, he still sees 50-60 patients a week, teaching them how to effectively deal with the ravages of chronic pain.

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# Identity and Privacy: Healthcare Automation Essentials by Barry R. Hieb, M.D.

#### Introduction

Each of us takes our identity for granted. Virtually every minute of our waking life we are aware of who we are and what our current context is. When it comes to healthcare information processing, however, things are not so clear. Healthcare information represents some of the most personal and private data concerning each one of us. As more and more of that information is captured and processed by automation systems, the ability to accurately identify the person the data is about and to honor that person's privacy wishes have become more and more problematic.

When someone asks "Who are you?" our usual response is to give our name and perhaps where we are from. That's a start, but for a healthcare automation system it is not nearly enough. The automation system might have a dozen persons named "Tim Smith" in its database. In order to be sure it has the right one the computer will want your birthday, your address, your Social Security Number, your mother's maiden name; everything it can possibly learn about you to make certain it knows who you are. This is a good thing. You don't want the computer to confuse your medical information with someone else's! There are just two problems.

#### 1. Inaccurate identification

Despite all the data they collect about you, computers still make identity mistakes: a lot of them. It is difficult to obtain accurate quantification but the literature indicates error rates of at least 5% and there are many reports of 10% or much higher. This is not good. If the computer doesn't know the right person then some of your data might be lost. Even worse, someone else's information might be mixed in with yours. Needless to say, both of these circumstances are problematic and can lead to serious consequences.

Medicine is well aware of how dangerous the situation is. There have been ongoing concerted efforts to reduce the rate of medical misidentification errors for over a decade but it has proven to be a remarkably intractable problem--and it is getting worse. As healthcare evolves to exchange clinical information across larger and larger domains--cities, states, and eventually the entire nation--identity errors become ever more frequent. An increasingly large number of healthcare organizations are involved. There are more systems to interface--with dissimilar policies, different sets of identifying data, different technologies, etc. Furthermore, identification needs to occur across larger and larger patient populations. The chance that someone else has identifying information similar to yours, what is called your "biographic profile," increases the more people there are in the system.

### 2. Privacy is diminished

Despite the fact that there are good reasons for information health systems to collect all that data about you, the process can put a major dent in your ability to manage your privacy. First, the information indicates who you are and second, it is subsequently attached to your medical information, some of the most private information about you that exists. When the medical system wants to order a test about you, they use part of your biographic profile. When they want to report a result, they use part of your biographic profile. When they want to submit a bill--you guessed it-- they use part of your biographic profile.

Remember, all of this use of your private data is with the best of intent. You wouldn't want your lab result to end up in someone else's medical chart. Nor would you want to be billed for someone else's medical procedure. Yet, all of that information sharing puts your privacy at risk. Large parts of your biographic profile are being attached to parts of your sensitive medical information and being transmitted electronically to a variety of locations that are outside of your control. "You," or at least enough about you to identify you, are being sent to various medical facilities, being seen by their personnel, and being stored in their databases. Is it any surprise that medical identity theft is one of the fastest growing crimes in America?

#### The VUHID solution



Fortunately there is a simple and straightforward way to "solve" both the identity and privacy problems for healthcare. The VUHID system creates and manages unique identifiers that can be used by healthcare organizations to manage personal identities. A healthcare organization can obtain a VUHID identifier, store it as part of your biographic profile, and hand it to you on a personal identification card.

From that point on you can hand the ID card to every new caregiver who treats you and asked them to add the identifier to your biographic profile--or the network of automation systems may be able to do this for you. Over time, all of your clinicians will be able to identify you using your VUHID identifier.

A few notes here about VUHID identifiers. They are globally unique, they are never reused, and they are issued to only one person. They are permanent and they cannot be counterfeited. Once you get your VUHID identifier card you should be able to use it for the rest of your life. VUHID identifiers remove any ambiguity about your identity. If you are Peter Smith, it doesn't matter if there are none, one, or one hundred other persons named "Peter Smith" in your town. Each of them can have their own unique identifier and their records should never be confused with anyone else's. It doesn't matter how many patients a large healthcare organization treats, the use of VUHID identifiers will help ensure that they never confuse one person with another.

### **VUHID** privacy support

But what about privacy? Let's look at just a few aspects of how the use of VUHID identifiers makes your privacy better. Note that once your caregiver begins to use your VUHID identifier to identify you, they can stop using most of the other data in your biographic profile. They might want to send your initials along with your VUHID identifier but they won't need to use your name and they certainly should not send your Social Security Number. This means that your privacy can make a comeback. Your VUHID identifier is at risk as it is sent back and forth between medical facilities but your private biographic profile can stay safe at home.

It turns out that VUHID identifiers actually come in two varieties, "open" and "private." You will want to use an open VUHID identifier (OVID) for all of the medical information that you want to be freely available to all of your caregivers, e.g. the time you had a broken arm, your immunizations, the fact that you had appendicitis, etc. However, you may also have some medical information that you want to keep private. Perhaps you are concerned that the history of your treatment for depression should not be widely known. This is when you want to use a private VUHID identifier (PVID). You can have your psychiatrist obtain a PVID, give you a PVID card, and use it to identify your psychiatric records. With a PVID as its primary link, your

psychiatric data can be kept separate from the rest of your medical information. Because you control your PVID card you can decide who has access to that information. If you provide your PVID to your primary care provider then they can view your psychiatric information, otherwise not. Later, if you have some genetics testing and need to keep your genetics information separate you can get a different PVID for that. So, in the general case, you will have one open identifier and as many private identifiers as are needed for your particular medical circumstances and privacy preferences.

#### What about errors?

Getting privacy right can be tricky, especially since we haven't managed it very well in the past. In addition, what one person needs for privacy of their healthcare data is likely to change over time. So we have to make provisions to correct errors when they occur and to make changes when they are needed. If you change your mind about what data you want to keep private, if you develop a new disease, if you get divorced, or any of dozens of other events; you may need to make a change in your privacy specifications.

Fortunately, with VUHID you are in control. You can acquire new private IDs as you have need. If you determine that an existing PVID can no longer meet your needs you can decide to have it terminated and/or replaced with a new one. It is important to note that you cannot turn back the clock. Although data that was previously public can be made private at any point in time, this new privacy status cannot hide this data from someone you gave it to previously. With this one major caveat, the VUHID system can support virtually any set of privacy requirements that you and your caregivers are willing and able to support. VUHID represents an example of full patient empowerment. As the user of one or more VUHID identifiers, you are in control and are able to configure them to fully meet your privacy needs.

#### **Summary**

The VUHID system represents a simple and cost-effective way to achieve accurate identification and it also enables a fundamentally different approach to patient privacy. Through the deployment of unique identifiers that are under the direct control of each patient both identification and privacy functions are easy to accomplish. By making privacy simple, VUHID gives users the best chance to get their privacy right. And by making it easy to make changes, VUHID lets patients readily correct the infrequent errors that will occur.

The twin requirements of accurate identification and improved privacy continue to increase in importance within healthcare. The VUHID approach represents a straightforward way to achieve these important goals. Hopefully VUHID will be able to play a central role as healthcare moves more deeply into the era of automation. I hope that it will not be long before you have an opportunity to use the VUHID system to improve the medical care that you receive.



Barry Hieb, M.D. is a physician with a master's degree in computer science. He has enjoyed a career of over 35 years working in medical informatics. For the past five years he has been the Chief Scientist for Global Patient Identifiers Inc., the healthcare non-profit sponsor of the VUHID project.

# **Personal Choices in Community Context**

# Editorial by Paul D. Leichty, M.Div. Executive Director of Mennonite Healthcare Fellowship

In the last issue of *Mennonite Health Journal*, I reflected on the choices that we as a society make as we attempt to resolve the moral dilemmas that are before us. I suggested that as we ask the question, "Who actually benefits by our choices?" we move toward a broader circle of persons who merit consideration in our choices, especially those who are most needy.

I also hear the language of personal choice used in a variety of healthcare-related decisions that many of us face as individual persons. How do we make those choices?

- I was recently involved in a loved one's choice of living and caregiving arrangements. The choices were not easy between a comfortable home-like atmosphere and providing for long-term medical care, safety, and well-being.
- Some of us are confronted with an array of choices as we consider a new healthcare insurance plan. We are told that we have a choice as we weigh low monthly premium costs vs. having costs more fully covered for a major medical event and thus paying higher premiums.
- I attended a workshop recently on end-of-life issues. Repeatedly, the presenter emphasized that the use of advance directives gives each of us choices on how we live our remaining days and how we die.

In the complex world in which we live, we have so many choices that it is easy to get paralyzed by the desire to make the right decision. Here are some ideas that have helped me to make choices that are consistent with the values of my Christian faith.

#### **Information**

I am a person who likes to have all of the information I can get in order to make a decision. I generally get my information from two main sources: (1) Asking people who have some experience or expertise on the subject, and (2) Searching the Internet. In both cases, I want to have some assurance that the information I am receiving is accurate and reliable. The ideal situation for a healthcare decision is that the key person with the experience and expertise is my doctor or other healthcare professional whom I see regularly. Yet, for major issues, I like to have a second opinion. When I find controversy or disagreement on an issue, I also want to know why that is the case. What are the underlying assumptions that lead to conflicting information?

A number of years ago, my physician wanted to put me on a statin drug to help prevent further heart disease. I complied, but I also started reading. I eventually came to think that for me, the risk of a heart attack was roughly equal to the risk of health-damaging side effects of statins. I proposed an alternative to my physician and was pleased to hear in reply, "You are smart and informed; you can make that decision." As I continued reading, I realized I could do even more through healthier eating. As a result of having good information, my cholesterol is considerably lower, well into the acceptable range. My physician is pleased, and I am monitored yearly instead of quarterly.

#### **Individualism and Community**

Most of the language of choice that bombards me emphasizes that we are all individuals. I'm told I have to make my own choice, what is "right for me." All of that is valid—up to a point.

Our Anabaptist Christian faith informs us on both the importance and the limitations of individual choice. We believe that choosing to follow Jesus is a personal choice, one that each person should make freely and not be subject to coercion. Yet, making that big personal choice to be baptized as a Christian is ultimately a choice about what community I belong to. Do I find my grounding in being a member of a particular nation, race, or culture? No, belonging to the people of God in Christ subsequently affects, and indeed, provides a foundation for all my other identities as well as all of the other choices that I make.

My congregation encourages small groups, and my wife and I belong to one. Some members of our group are in the process of considering end-of-life issues. They have heard the messages around them encouraging them to choose their advance directives, their healthcare representative, and how they want their body disposed. Yet their questions are, "What does our faith say about these matters? What does the Bible say? How are my brothers and sisters in the faith coming to terms with these issues?" So, as hard as it is, our group is starting to talk together, as well as to seek counsel from other churches in our area who have studied end-of-life issues. That is the value of a faith community.

#### Who is in control?

Finally, I realize that despite the many choices that I do have, and despite a supportive family and faith community around me, there are many factors affecting my life over which I do *not* have a choice. I am *not* in control.

Thus, I can select a healthcare insurance plan with a low premium and high deductible based on the fact that I think I am living a healthy lifestyle and will not need many medical services. However, I don't know that I won't get a serious illness and need to pay thousands of dollars for diagnosis and treatment. I don't know that I won't be involved in a serious accident and be hospitalized for many weeks. I am not in control of all of the factors.

Instead, ultimately, my life is in God's hands. This is where my faith and future ultimately rest.

Living by faith is not a form of fatalism which says, "My choices don't make a difference anyway; I don't need to be concerned about them." Living by faith does not absolve us of the responsibility of discerning the information available and deciding between what is life-giving and what is harmful. Living by faith certainly does not kick us back to an individualistic "God and me" approach that says, "I'll do what's best for me, regardless of the consequences for anyone else."

Rather, our Christian faith gives us a solid rock foundation from which to make our choices, in consultation with our brothers and sisters to whom we can be accountable. Faith gives us the courage to wade through and make the choices that we can make under the guidance of the Holy Spirit, and then rest in God who is ultimately in control of the overall picture.



**Paul Leichty**, M.Div., is an ordained minister in Mennonite Church USA and Executive Director of MHF. He has also served in past and present roles as pastor, music minister, disabilities advocate, and computer support specialist.

# Reflections on SET in Zambia Student Elective Term Report by John Stoeckle, MD



It had been six years since I had been outside of the United States. Now I was bumping along in Zambia on the six-hour bus ride from the airport, observing the plains separated by small mountain ranges in this very rural country. Everything was very green, except for the rock and dust, which were red. Innumerable trees were twisting at unexpected angles like Van Gogh creations, popping on the backdrop of a hyper-real blue sky with big white clouds. The Zambians I met were easygoing and friendly, ready to help a sojourner trying to find his

way for the first time.

As I seek to live out Christ's call in my life, I have been guided to a career in family medicine and public health. I want to be a partner with underserved populations, sharing the love of God, and to be a part of a multi-pronged solution to inequity both locally and globally. I recently started as a family medicine resident at Thomas Jefferson University in Philadelphia. My medical school trip to Zambia gave me an invaluable look into the possibilities of global health research.

**Since I was young**, I have been drawn to the larger world. I would sit and spin a globe and dream about going to the places where my finger would land. My parents raised me to believe that I could do whatever I put my mind to, and those dreams slowly evolved into plans. Stories of the Democratic Republic of Congo, where my uncle and his family lived as missionaries, stayed with me. The idea of someday being a missionary seemed to me a viable career path.

In 2004, I traveled to Cambodia to teach children who were looking for a chance to escape poverty and again in 2006 to complete research on the history of healthcare in Cambodia through a foundation grant. As I came to appreciate the complex nature of affirming equality and dignity in cross-cultural partnerships, I looked for people who were innovative in modeling these qualities.

After my wife Sarah, a physician assistant, worked for one month at Macha Mission Hospital in Zambia in 2010, we both thought that Macha was a place where this careful balance was being pursued. As I heard about the successful ongoing malaria research, my heart jumped inside me.

**So I found myself in Zambia**, enabled by a Mennonite Healthcare Fellowship SET grant, for a month-long rotation with the Macha Research Institute, eager to learn from a robust academic-international partnership, and to connect with a novel culture.

At the Malaria Research Institute, I worked on a project troubleshooting issues in reading old, stored malaria DNA samples which are used to identify malaria species and predict drug resistance. I worked in an impressive laboratory with about eight other Zambian lab scientists. Most were around my age, in their twenties and thirties. I found their mentorship, friendship, and company over my time there very meaningful.



Dr. Thuma, who founded the malaria institute, has a self-admitted glass-half-full outlook. "You have to, to be able to work here," he said. His optimism is a blessing as he looks to eliminate preventable sources of disease, and emphasizes the one child saved instead of the one child lost. Yet he is also realistic, not blind to the limits of what can be accomplished. He has shifted his focus from individual treatment to broader goals of fighting malaria, TB, and HIV, while realizing there are many clinical



challenges that they have not yet been able to address with limited resources.

Malaria has in large part been successfully suppressed in the immediate region around the hospital through appropriate medical management and robust community empowerment and education. Studies are underway in Northern Zambia and Zimbabwe to see if this success can be replicated in other parts of the world. Dr. Sungano Mharakurwa, the research institute director, has direct oversight of these studies and others, and is hopeful of what they might find.

I was also able to spend some time seeing patients in the hospital. There were cases I had read in textbooks, and now here they were, in front of us: malaria, advanced stage malignancies, and other maladies which are preventable in America. I had forgotten, seven years removed from Cambodia, the human faces of suffering from these preventable illnesses.

It is human nature to live and think locally. In today's global community, we tolerate enormous disparities among God's family. The average Zambian lives 48 years. The average American lives 77 years. As a physician, this is compelling. The vast majority of preventable years lost in Zambia are from communicable diseases. We have the tools and resources as a world society to address HIV, TB, malaria, malnutrition, primary education, clean water, and internet for all. We must build partnerships to narrow these divides; we must not widen them.

In Zambia, I was reminded that I have to be intentional every day to allow a generous spirit to be cultivated within me, toward my neighbors in Philadelphia and my neighbors in Zambia. Will I use my material and economic resources in a way that will honor God's love for all his children? Do I love all of God's children?

I have lately been reflecting on Matthew 25. I realized that while I was in Macha, when I was hungry, I was invited in to eat nshima, the local corn-based staple. I was thirsty from the blazing sun on a community health visit, and I was given a seat, a cup, and something to drink in the shade. I was a stranger, and yet I was invited in again and again. My new Zambian acquaintances were walking in love and solidarity with me, and I was brought out of helplessness and into kinship. I hope I, and we, continue to do likewise, and complete the appeal: "I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me...Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me."



John Stoeckle received his MD degree from Temple University School of Medicine in Philadelphia in May 2013. He and his wife, Sarah, live in Philadelphia and are active at the Oxford Circle Mennonite Church. John has also been a key organizer of MHF Regional Meetings in Philadelphia.

## Hanging on for Dear Life

#### by Murray Nickel, President, International Mennonite Health Association

While waiting for the plane in Kikwit to take me off to Kinshasa, my friend Dr. Emery Bewa mused, "You know, I feel like I'm in a boat in a lake of drowning people. But I'm tired of diving in trying to save people who have their hands folded across their chests refusing to be saved. I'm sticking to the people struggling on the surface. The people who grip my hand tight when I reach out to them."

As a follower of Christ, I have little difficulty justifying his statement. An alcoholic can't recover from his disease without wanting to. He has to take the first steps. Didn't Jesus say that his disciples should dust off their sandals and go onto the next town when their message was poorly received? Why waste time with those who don't want to help themselves?

Last time in Kinshasa I spent a good deal of time with my management consultant friend Toss Mukwa. He was leading a conference we had sponsored on "asset-based community development." During a break he said, "Murray, the problem here in Congo is deeper than people just being poor. People are mentally traumatized by war, violence and poverty. They fold their hands and refuse to come out of hiding, distrustful and afraid. We need to gently help people think differently about themselves."

Suddenly, Emery's metaphor evolved in my head. Instead of a lake of drowning people, I pictured a person hanging off the edge of a cliff, clinging for dear life to a tiny branch, a branch that is slowly breaking. I reach out to him from a solid ledge but I notice that the only way he'll be able to grip my hand is by letting go of the branch he's hanging on to.

I spent the last day of my trip to Congo with Dr. Delphin Kapasa who runs a clinic in Camp Luka, a poor neighborhood of Kinshasa. He told me that things have gotten more violent lately. People are afraid to go out at night lest they get killed by one of the roving gangs. In general, the gangs respect the clinic knowing the care they get there.

The staff feels safe most of the time, until last week when a higher ranking military man was brought in. He had sustained a fatal machete wound to the head. The staff was more than a little anxious that this might bring the fighting to their doorstep. It didn't. In fact, the police moved in and cracked down on the violence as a result. Presently, there is a small sigh of relief in the neighborhood.

But Delphin says that this is only temporary. People have been traumatized repeatedly in this area. Physical and sexual abuse run rampant. People are powerless. Justice is only available to the highest bidder. Unemployment is over 90%. There is no work in a ghetto where the average age is under eighteen.

"We need to provide alternatives. Teach young people marketable skills. Spend time counseling the family unit which is dysfunctional. We need to stop the cycle of poverty," he says. For him, dusting off his sandals and moving to the next town is farthest from his thoughts.

**I don't know if there is a right answer.** Do you stick with those who want to help themselves or do you plunge into a potentially fruitless endeavor of trying to convince people that they need help? There are no simple solutions on the front lines of poverty but it's an honor for me to have been embedded with frontline strikers like Emery, Delphin and Toss.



Murray Nickel, M.D. is President of International Mennonite Health Association (IMHA) and an emergency physician living in Abbotsford, British Columbia, just outside of Vancouver. He spent six years in Congo in association with Mennonite Brethren Mission and now travels back and forth between Congo and Canada two or three times a year. He has a special interest in human development and transformation in the context of the poverty.

## **News and Announcements**

#### **Important Dates!**



MHF Michiana Regional Meeting, November 7, 2013, 7:00 p.m. at the Greencroft Goshen Community Center, 1820 Greencroft Blvd, Goshen, Indiana. Physician Glen Miller and former seminary dean, Willard Swartley, will team up for a presentation entitled "End of Life: Values to Keep & Decisions to Make." Discussion and refreshments follow the presentation. The public is invited.

November 16, 2013. A Lancaster Area Regional Meeting will be held on Saturday, November 16 at 7:00 p.m. at Rossmere Mennonite Church, 741 Janet Ave., Lancaster, Pennsylvania 17601. Come and greet MHF Board and Staff members, learn more about the activities and ministry of MHF, enjoy refreshments, and help foster fellowship and networking with your Anabaptist healthcare colleagues.

March 6-8, 2014. **Mennonite Health Assembly**, in Kansas City Missouri. MHF plans to be present with a display. More information at www.mhsonline.org.

June 13-15, 2014. Mennonite Healthcare Fellowship **2014 Annual Gathering** at Laurelville Mennonite Retreat Center, Mt. Pleasant, Pennsylvania. This year's theme will focus on the role of personal faith in our health ministries. More information coming at <a href="http://mennohealth.org/events/gathering/">http://mennohealth.org/events/gathering/</a>

#### **Other Opportunities**

The 3rd Annual **Conference on Medicine and Religion** will be held March 7-9, 2014, at the Hyatt Chicago Magnificent Mile. The theme is "Responding to the Limits and Possibilities of the Body." A "Call for Abstracts" has been issued for 60-minute panel sessions, 20-minute paper presentations, and posters that address issues at the intersection of medicine and religion. Proposals are due by 4:00 pm CST, Thursday, November 7, 2013. For details, please visit <a href="https://www.MedicineandReligion.com">www.MedicineandReligion.com</a>.