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# *UNDOCUMENTED IMMIGRANTS, HEALTHCARE ACCESS AND AN ILLNESS NARRATIVE*

# INMIGRANTES INDOCUMENTADOS, ACCESO A LA SALUD Y UNA ENFERMEDAD NARRATIVA

Alberto García Gómez*
Claudia R. Sotomayor

***ABSTRACT***

*The story of a Mexican undocumented immigrant in the United States, and her use of healthcare, illustrates the vulnerability of these population. According to Art. 8 of the Universal declaration of Bioethics and Human Rights: "Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected (UNESCO, 2005)." However, when the sovereignty of each Country and their free exercise of the law regarding healthcare comes to play, the situations gets more complicated. Even though the definition of healthcare as a right is difficult to prove, it is easier to argue that it is a social responsibility.*

**Keywords:** Social Responsibility, Right, Healthcare, Vulnerability.

**RESUMEN**

La historia de un inmigrante indocumentado mexicano en los Estados Unidos, y su uso de la salud, ilustra la vulnerabilidad de esta población. De acuerdo con el art. 8 de la Declaración Universal de Bioética y Derechos Humanos: "Los individuos y grupos de vulnerabilidad especial deben ser protegidos y se debe respetar la integridad personal de tales individuos (UNESCO, 2005)". Sin embargo, cuando la soberanía de cada País y su libre ejercicio de la La ley con respecto a la asistencia sanitaria viene a jugar, las situaciones se vuelven más complicadas. A pesar de que la definición de cuidado de la salud como derecho es difícil de probar, es más fácil argumentar que es una responsabilidad social.

**Palabras clave:** Responsabilidad social, Derecho, Atención sanitaria, Vulnerabilidad.

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## 1. NARRATIVE

B. was born in Jalisco, Mexico. Her childhood was a typical Mexican lower-income childhood: deprived from many luxuries, but still happy and surrounded by a big and loving family. She attended school until middle school, and after that she helped with the household chores, and participated in the festivities and customs of her town. On a December 12, day of our Lady of Guadalupe, the town had the usual big party, full of music and good food. It was that day when she met Noé, who was visiting from the United States. Noé was an undocumented immigrant in the United States, who left his hometown in Mexico to search for a better future for his family. They fell in love and after eight months of knowing each other, they got married. Noé wanted to come back to the United States, and so they did.

The experience of crossing the border without legal documents was a shocking experience for B. "*No se lo deseo a nadie*" (I don't wish that experience to anyone)-she said- "We went through the desert in May, so it was very hot during the day and very cold at night. We ran out of food and water, and we didn't bring warm clothes for the night. We even saw a cadaver. I cried I lot." They finally got to Arizona, where a van picked them up and took them to Chicago, which was a staging area for people to be taken to various states. N. and B. were the second to last to be "delivered" to Atlanta, Georgia.

Once they were settled in their new life in a modest trailer home, N. wanted to start a family, but B. had to break the bad news that according to her doctors in Mexico, she couldn't have any kids due to severe polycystic ovaries. N. felt disappointed, but he never lost hope. Two months later, she noticed that her period was late, but she never thought she was pregnant because she was generally irregular, and she lost a lot of weight during their crossing through the desert. At the time, she weighed 80 pounds and she is about 5'6'' tall. N. immediately bought a pregnancy test, and then they found out they were expecting their first child.

She went to a clandestine clinic to start her prenatal care with a doctor who spoke Spanish. She was afraid to go to a regular clinic due to the fact that she was undocumented. Given her weight and hormonal problems, she was under a high risk pregnancy care. She got the prenatal vitamins and all the medication needed. She got an ultrasound by the 5$^{th}$ month of pregnancy, where everything looked normal. Her blood work and other tests were normal too. Everything was going smoothly until the 6th month of pregnancy, when one day she started feeling very sleepy and tired. N. invited her to a restaurant, and during dinner she felt a sharp lower abdominal pain that radiated to her back and was increasing over time. She started vomiting and feeling dizzy. They called her doctor's office, but it was closed, they were reluctant to get any medical care out of fear to get into "the system", but, the symptoms escalated so they decided to go to the Emergency Room. When they arrived, they tried to communicate their situation the best way they could in English, but there was no interpreter so another Hispanic woman that was at the ER offered her help. Due her low weight, her belly wasn't big so

they didn't believe she was pregnant. After a long period of time, she was seen in the triage area, where they decided to admit her to the 4th floor (labor and delivery). When she arrived to her room, the nurse that was in charge was an intimidating African-American woman. B.'s impression of the nurse was that she was dirty: "She *had long dirty nails, a lot of rings, smelled funny, and she kept scratching her head*". The nurse told B. that she wasn't pregnant but rather she was complaining over nothing, "just like a Mexican soap opera actress", so she asked her for a urine specimen to do a pregnancy test. B. went to the bathroom, when suddenly an even greater pain came and then the baby was born. She asked for help, and the nurse, without gloves or previous sanitation of her hands, grabbed the baby girl, cut the umbilical cord and ran with her, leaving B. unattended on the bathroom floor. No one came back to help B. for a long time. She was feeling terrified because she didn't hear the baby cry, and didn't have the chance to see her. Finally someone came to help B.. When the nurse came back, she said to her: "You really made a mess on the floor, look at that." B. felt scared, anxious, and terrified for her baby and for herself. It took a while for her to see her baby, and she was feeling desperate: *"Like if my heart was going to stop beating."* When she finally saw her baby girl, she couldn't believe how small she was*: "Her head was soft, her legs were as long as my pinky."* The doctors told her that her baby was in a bad shape, that she was blind, had a heart condition, and needed two blood transfusions. She agreed with any treatment needed to save the life of her baby.

B's health was improving, and even though she wasn't feeling very well, she managed to pump breast milk to be able to feed the baby, but her body couldn't produce enough milk and it only lasted for a month. She spent as much time as she could with her baby. When I asked her how she felt, she said: "There were times when I thought I couldn't do it any more, I wasn't sure If I was going to be able to go to the NICU because the pain of seeing my daughter under those conditions. It broke my heart. Besides, I was all alone. I needed my mom and my family to give me support, but they couldn't come because they didn't have the means to do it. I didn't know anyone but Noé, and he had to work. I cried every day, almost all day long."

The baby girl was in the NICU for two months. When she was discharged, a social worker came to B.'s house to see their living situation and to see if there was a cause for the premature birth. There was not an apparent cause.

The experience was painful for her, but at the end she feels blessed and happy because her daughter is alive and doing well. She had to go to auditory therapy, and she has her cardiac condition under control. So far, the girl is living a normal life. Although traumatic in the beginning, now she sees it as a precious moment where she learned how frail life is and how important it is to cherish it. *"Now I enjoy every minute of my life with my daughters, and I appreciate every new day. I am teaching my daughters the incredible gift life is, and I am a volunteer with the Missionaries of Charities, where I take care of dying women suffering from AIDS, and I try to offer them compassionate care and to help them to not be afraid, because at the end, here or in heaven, everything is going to be O.K."*

When I asked her: "What do you think caused the problem?" She answered: *"the poor service at the ER, the incompetence of the nurse and the lack of doctors."* She denied being a victim of domestic violence, although I know from other sources that she has suffered the unfortunate situation of being mistreated.

## 2. IMMIGRATION AND THE RIGHT TO HEALTHCARE

For many, this is a controversial topic. Studies led by researchers at Harvard Medical School (Leah Zallman, 2013) showed that immigrants in the United States of America contributed an estimated $115.2 billion more to the Medicare trust than they took out in 2002 -2009. But that doesn't seem to be known by the general population because a recent poll shows that 63 percent of people said immigrants place a burden on the economy (CBS DC, 2014), and eighty percent of Americans were opposed to including undocumented immigrants under a taxpayer-subsidized national healthcare plan, according to a June 2009 Rasmussen poll.

Just as the American populace cannot come to a consensus on access to healthcare, the law likewise lacks consistency and clarity. Some would argue that access to healthcare is not a right based on the notion that there are no natural rights or moral rights. As Bentham would argue, "the notion of moral rights was 'nonsense upon stilts' because rights require social recognition and moral rights have none" (Rainbolt, 2006). The American legal system is lax in recognizing positive rights to state-funded resources, and health care is seen more like a negative right, where patients and doctors have the right to pursue a course of treatment without interference by the government (Robertson, 2006). But, these views are clashing with global views, especially those related to human rights. The Constitution of the World Health Organization (WHO, 1946), adopted by 193 countries, recognizes the fundamental right of every human being to the enjoyment of the highest attainable standard of health. The Universal Declaration of Human Rights declares in article 25 that *"Everyone has the right to a standard of living adequate for the health and well-being of himself... [Including] medical care and necessary social services*." Lango argues in favor for a right to healthcare with the thesis of indispensability, stating that sometimes enjoyment of some human rights is indispensable for enjoyment to other human rights. In this sense, the enjoyment of a good life, needs the enjoyment of access to food and healthcare (Rhodes, 2012).

Baumrin (Rhodes, 2012) argues that there is no right to healthcare because "*mere talks of rights does not create duties*." However, if the community already has a social responsibility to act, it likewise has a duty. The "talks" of rights simply give this underlying duty the necessary structure to become enforceable by the individual. Baumrin also argues that the right that establishes *an ought* is contingent on some agent to accomplish the task, and if the agent is not capable of fulfilling that task, then the duty is placed on hold. Ultimately, he says, if the duty is not fulfilled, it is not genuine, and if there is no genuine duty, there is no genuine right. But if that were the case, then many rights would cease to be recognized merely

because of difficulty of fulfillment. For example, there are federal laws in many countries[1] legislating the right to education. To fulfill that right the state has to provide schools, and yet there are many kids with no access to schools. As of 2012, 58 million children of primary school age and another 63 million children of lower secondary school age were still out of school, including in countries with federal legislation mandating compulsory education. Given these facts, the logical extension of Baumrin's argument would be to question the right to education as well.

The fact that these rights are not always fulfilled does not mean they are not genuine rights, what it means is that more efforts should be made by society to fulfill them. Lango states that the intention of fulfillment is enough to prove the existence of such right. He argues that all human beings have the duty to provide necessary health assistance, in accordance with their means (Rhodes, 2012). Lango makes reference to Shue's tripartite typology of duties in arguing for the recognition of healthcare as a right, which states that there are duties to avoid depriving, duties to protect from deprivation, and duties to aid the deprived (Shue,1988). Despite the difficulties of complying with these duties, there exists nevertheless the responsibility to fulfill them. By viewing then these duties as having corresponding rights, there now exist agents to demand their fulfillment and thus put pressure on society to find creative solutions to overcome the limitations of resources.

## 3. SOCIAL RESPONSIBILITY AND HEALTH CARE

According to the International Organization for Standardization (ISO,2008), social responsibility is defined as an ethical framework in which people and organizations must act for the benefit of social, cultural, economic and environmental issues that as a consequence would have a positive impact on development. On a global level, social responsibility in health care refers to a moral duty held by all societies to promote health, prevent and treat diseases, and to provide the highest attainable standard of health. These goals have been recognized by the international community as a central purpose of governments (UNESCO, 2005). Art. 14 of the Universal Declaration of Bioethics and Human Rights states that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition, progress in science and technology.

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[1] Some examples of countries with compulsory education
USA: No child left behind act 2002.
India: The Right of Children to Free and Compulsory Education Act or Right to Education Act (RTE) 2009
Mexico: General education Law (art. 31 of the constitution, fraction I.4)
China: Law on Nine-Year Compulsory Education 1986.
Republic of South Africa: The Basic Education Laws Amendment Act, No. 15 of 2011
U.K: Education and Skills Act 2008

For some, this view on social responsibility places a large burden on states. For example, Libertarians assert that the individual should be free to decide how to use his/her personal means to meet his/her various needs (Kelleher, 2014). Resnik argues that individuals should care for their own health and help pay for their own healthcare (Resnik, 2007). But these views do not assure equal opportunity. By arguing for individual responsibility, people on the bottom of the economic ladder (Sachs, 2005) are marginalized because they do not have the necessary means to pay for their healthcare. Romer argues that to assure equality of opportunity in health, social intervention is necessary because *"health is a prerequisite for successful achievement, illness or injury in any person is unpredictable, and obtaining medical care and a healthful environment is beyond the resources of the individual and requires collective action"(Ruth, 1988).* This argument goes with the line of what Menzel (2009) has called a *"Just Sharing Principle."* In Menzel's version of this principle, the financial burdens of "*medical misfortunes*" should be shared equally between healthy and unhealthy people, unless individuals can or have control over these misfortunes (Kelehher, 2014).

Another reason for social intervention is the fact that nowadays there are many individuals and communities that are especially vulnerable (e.g. immigrants) (Farmer, 2003). In the report of the International Bioethics Committee of UNESCO on the Principle of Respect for Human Vulnerability and Personal Integrity (IBC, 2013), it is stated that social vulnerability is caused or exacerbated by a lack of means and of the capacity to protect oneself. In many developing countries, the lack of means and access to proper healthcare affects millions of people, making them vulnerable. The lack of capacity to protect oneself is a cause for the community, agencies and the governments to step up and provide the necessary means to help people thrive and be healthy. The provision of health care is a social responsibility because humans are not isolated from each other, but rather live immersed in a web of relations that creates a duty towards one another to build a successful community.

## 4. FINAL REMARKS

Coming to an agreement of whether there is a right or not is only the first problem. If we let our imagination go, and we place ourselves in a world where everybody thinks that there is a right to healthcare, then we would face the second problem: Who is responsible for fulfilling that right? We know that there is a reciprocity between rights and obligations, and there is an understanding that in the case of health care, each nation is responsible for their citizens, but what happens then with undocumented immigrants? Should their nation be responsible for the usage of healthcare in another country? Or should the host country provide healthcare to any individual in their territory?

From a Bioethics perspective, it seems like immigration status can be a social determinant of health (Rath, 2013), and there is a lot of political and economic interest around it, leaving the basic human needs and dignity on the side.

It is true that providing healthcare is expensive and complicated, but it is also true that we are all humans in need of each other to survive and thrive. Article 8 of the Universal Declaration on Bioethics and Human Rights (2005) enshrines the principle of respect for human vulnerability and personal integrity as a bioethical value of universal concern. We must understand than undocumented immigrants come from difficult situations that forced them to look for a "better" life, but most of them find themselves marginalized, and sometimes scared of the consequences of looking for healthcare. That was the case of B., who faced the consequences of cultural incompetence and barriers that resulted in a series of events that endangered her and her child's life.

Human rights and responsibilities are born from a human need to address injustice and to protect human dignity, especially of those who need that protection the most. Those persons in vulnerable positions, victims of the poverty trap,[8] desperately need aid and protection from deprivation. The duty of providing healthcare rests with society, government, international agencies, religious groups, and others. In short, it is the responsibility of everyone who is in a position to help. If duties are correlated with a right, and the provision of health care is a duty, then it is fair to say that the receipt of health care is a right. The access to health care and the highest attainable standard of health keeps not only an individual healthy and happy, but a community active, functioning and thriving. Recognizing the right to health care is just a first step to a real improvement in resource allocation. By focusing on the duty to provide healthcare, and in turn on the right to receive healthcare, both the providers and the consumers of healthcare will have a voice in the conversation and help to realize a more equitable distribution of healthcare.

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