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## Case 1—Does the Nearness of Death Diminish the Value of a Life?

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I had been standing just behind Dr. C, a head and neck surgeon, watching him perform a laryngectomy when he got a call from his chief resident at City General Hospital about a seriously ill patient who had recently been admitted. When he had concluded his brief conversation on speaker phone, Dr. C suggested I would find CS a “very interesting case” and that I should go to City General and visit her. But upon hearing the summary of her medical and social history, I said, “Well, she’s never going to talk to me about those things!” “Yeah, she will,” Dr. C countered. “She’s very open about her life. Go see her.” I did the next afternoon.

I knocked gently on her door and got back a barely audible response. I peeked in to find a huddled form curled into a fetal position. When I apologized at disturbing an obvious nap and said I’d come back later, the patient raised her head to object that she wasn’t really asleep, and asked who I was. I identified myself as Dr. X, the bioethicist with the head and neck program, a colleague of her surgeon’s, that I had merely come to look in on her to see how she was doing, but that I didn’t wish to disturb her and could certainly come back another time. She insisted that she would like some company, but asked if I could get her nurse to give her some Lidocaine rinse to numb the pain in her tongue first so that she would be able to talk more comfortably. With that quickly accomplished she became quite chatty, and I soon discovered what Dr. C had meant. CS was a very interesting person indeed.

She was 37 years old and had presented with a large mass in the right oral tongue and enlarged nodes in the right neck. She was extremely uncomfortable, requiring high doses of pain medication. A biopsy had come back as positive for squamous cell carcinoma. She identified herself as a prostitute with a 20-year history of drug use. She had recently been released from a one-year jail term for possession of cocaine. She denied use of alcohol. She had a 20-year history of tobacco use. She was 17 weeks pregnant at the time I visited her in the hospital.

CS had three living children, none by the same father: a girl of 12 living with her (CS’s) mother; a 9-year-old son living with her sister; and a 3-year-old daughter living in foster care. CS stated that her mother had recently lost both her own job and house, so that her mother and 12-year-old daughter were now living

temporarily in the sister's house. The sister, however, had said that her mother and niece would have to leave, that she'd had enough of "this dysfunctional family." She had said, nonetheless, that she would continue to care for CS's son. From what I could glean from CS's tale, she had never taken full responsibility for any of her three living children and must have lived alone or at someone else's expense her entire adult life.

Despite her past and present difficulties, CS was excited about her pregnancy, and she was eagerly collecting new baby clothes, all neatly laid out on a table beside her bed. The baby's father had paid her no visits since her admission to the hospital, yet CS seemed positive about the future. She told me about how she had most recently been living in a crack house, of her considerable anxiety over this, and of her eagerness to move elsewhere. She said she had another male friend who was a "good man," not the baby's father, and that he had said he would provide a home for the three of them once the baby arrived. This seemed to give her hope.

But nothing quite seemed to fit into the picture I was developing here. CS probably had no more than a high school education, if that, yet she appeared very intelligent, was highly articulate and well-spoken, and bore absolutely no traces of the coarseness or street language one might have expected of someone with her background and who had been largely left to her own devices as a latch-key child whose mother worked, whose father had abandoned the family, and who had witnessed other men beat her mother. "I don't blame anyone but myself," she told me, "I brought this all on myself by making bad choices." Still, she was convinced that "God was going to heal her" of her cancer and, in fact, asked me to pray for her as I left her room that day.

Two days later Dr. C performed a partial glossectomy (surgical removal of part of the tongue) and a modified radical neck dissection, as well as a gastrostomy to provide artificial nutrition and hydration during CS's recovery. This relieved her of the immediate pain caused by the tongue tumor and enlarged neck nodes. Her spirits were high post-operatively, and she did well at first. She was discharged from the hospital after four days; her pregnancy was then estimated to be about to enter its 19th week. CS's mother had apparently managed to find a new apartment quickly and agreed to take her daughter in temporarily while she convalesced. CS was scheduled to begin routine radiation therapy six weeks later when her pregnancy would have been at about 25 weeks, but as that date approached she suddenly developed new nodes in the operated neck. It was determined that no treatment could be of any curative value at that time, that palliative measures alone were called for, and the scheduled radiation protocol was canceled.

When she returned to the clinic for the six-week post-op visit, her mother and 12 year-old daughter both accompanied her. On that visit she no longer claimed that God was going to heal her, and she expressed a real fear of dying, at one point breaking into tears. Her daughter then movingly and convincingly became mother to the child, taking her mother's hand, looking her directly in the eye, calling her mother by her first name, and saying with all the confidence of someone twenty years older, "It's OK, C\_\_\_\_\_, everything's going to be OK." It was clear to her physicians, however, that she was obviously dying of her disease.

By this time CS required increasing amounts of narcotics to control her pain, but she could not be relied upon to follow the prescribed dosages and would use up her supply before time for renewal. It was unclear where she was living at this point, but perhaps her mother had again taken her in on a temporary basis. She did begin radiation therapy for palliation, but after several weeks was taken into the hospital in a rapidly deteriorating condition. The severity of her pain required that she be sedated, but this and the use of other medications had to be titrated carefully so as to minimize effects on the baby.

At this point CS's mother asked that all efforts to keep her daughter alive be discontinued. "My daughter made it clear to me several weeks ago that if she ever ended up in a condition where she was clearly dying, she wanted to have all life support stopped!" she said. Inasmuch as pregnancy now made itself the primary medical issue in this case, an obstetrician had become the attending physician. He categorically refused the mother's request for withdrawal of all life support stating that he had "an obligation to save the baby." The mother asserted, nonetheless, that her daughter's wishes were not being respected, and that in any case, "I will not care for 'another crack baby' as I have done twice before. The new baby will have to go into foster care with the three-year-old." CS's mother thus effectively walked away from her daughter's situation.

CS was then at approximately 30 weeks of pregnancy, and it was at that point that I saw her for the last time. The afternoon I visited the ICU a technician was monitoring the baby who appeared to be doing fine. The sedation being administered to CS for pain rendered her unable to communicate, but her movements suggested sedation might not have been sufficient to relieve all discomfort. Several days later the baby showed signs of distress. A C-section was performed, and a viable infant was delivered and placed in the NICU. All life support for CS was then discontinued, and she expired within 48 h. The infant remained in the NICU for 3 months before being discharged to foster care.

### **Discussion Questions:**

1. Is it possible for health care professionals to put aside stereotypes and biases and treat patients without these influences?
2. Is it possible to fully acknowledge the autonomy of a pregnant woman whose end-of-life treatment preferences might compromise optimal conditions for her fetus?
3. What is the appropriate relationship between law and ethics? Must ethical judgment always follow the law? Should law follow ethical principles?

### **A Bioethicist Responds**

One might at first be tempted to view this case as one of those "no-brainers." After all, what is there really to discuss here? This is an unfortunate situation where a young woman, by her own admission, has made terribly poor choices her entire life such that not only she, but now four children, her family, and even society must pay

a price of some magnitude, and there is suffering all around. What could possibly be done to avoid any of it, especially at the bitter end, other than to grant CS's mother's request for withdrawal of all life support prior to delivery of the baby? The mother had stated that such would have been in keeping with CS's autonomous request, but there is clear state law prohibiting a proxy acting in such a manner for an incapacitated pregnant patient.<sup>1</sup> Thus, there would seem to be little left to say. We might look to a recent case in Texas, where state law required that Marlise Munoz, a brain-dead pregnant woman, be maintained on life support until such time as her fetus could be safely delivered (Fernandez and Eckholm 2014a, b). Both Munoz's parents and husband believed that this was not only against her treatment preferences, but also a ghastly spectacle that only served to prolong and publicize their private tragedy. Ms. Munoz, 33, was only 14 weeks pregnant when she arrived at the hospital. After her 22nd week of pregnancy, doctors found that the fetus was not viable, which the hospital acknowledged in court documents. The fetus suffered from hydrocephalus—an abnormal accumulation of fluid in the cavities of the brain—as well as a possible heart defect, and the lower extremities were deformed. With sufficient time and publicity, the medical facts prevailed: A brain-dead woman was not a suitable incubator for a developing fetus, and once this was established medically, life support was allowed to be discontinued.<sup>2</sup>

Yet if law, albeit one legitimately established for good reasons, becomes the deciding vote in difficult cases, we may deny ourselves the benefit of careful reflection that could prove beneficial in thinking through other thorny issues. This is not to suggest one fault the obstetrician, and propose instead that he should have granted CS's mother's request despite his resulting commitment of an obvious crime, but it is to serve as a reminder that law ideally *follows* ethics, not the reverse, and that this case should not, therefore, be summarily dismissed without further discussion. Following the letter of the law in this case does not automatically mean that ethics has been given its due.

The case is noteworthy in the first instance because of the very character of the patient. The narrator in the case had been primed by the head and neck attending physician to expect to see a particular "type" of 37 year-old woman, a prostitute, who had already given birth to three children, who was now pregnant again and in her 17th week, and who was also an admitted 20-year drug user. He is likely to form a certain image, no doubt taken from TV and movies, of what this type of woman might look like, how she might behave, how much education she might have, what level of society she might come from, what her values might be, how she talks, and what kind of language she might use. But what he found was a person very different from the one he had anticipated: He finds an intelligent, articulate individual who, with surprising insight, it appears, blamed neither other people nor society for her plight but rather held herself accountable for making bad choices. Moreover, she seemed to believe that God would heal her, and she asked for prayer on her behalf. This may well be "fox-hole religion," or nothing more than denial, but one would have to be severely myopic were one not to see that CS was clearly a victim crying out for help now that she was in the hospital, in considerable pain, and about to undergo very serious surgery.

Fortunately for CS, she happened upon a highly skilled and very kind, caring head and neck surgeon who would do whatever it took to save her life or to give her the best quality of life possible for what may remain of it. Yet he was only part of the team that must care for her. People like CS, with their lifestyles and histories of bad choices, especially when those choices affect others such as their own infants, are not always viewed as the most desirable patients. This is especially true when they are unfunded, as was CS. Whether we wish to admit it or not, and regardless of how well-intentioned we would hope for all those interacting with CS to be, discrimination in some form will inevitably enter this picture. This could be anything from indifferent or rude treatment by clerical personnel in business offices or clinics, to delayed attention or nonchalant attitudes regarding pain or symptom relief on the part of physicians. Add to that her long-standing addiction, thus making physicians wary of her reliability in following instructions for taking narcotic pain medications, her almost predictable early requests for refills, only to the chief resident's frustration, and she soon becomes *persona non grata*.

Another ethical issue this case presents is how we might respect the autonomy of a terminally ill pregnant woman, while still adhering to the legal (and ethical) requirement to protect the health and life of the fetus. The head and neck team demonstrated exemplary compassion, and offered her the best care and treatment a teaching hospital in a major metropolitan medical center could, with fairness and justice despite the fact that she had virtually no resources whatsoever, knowing that their story together would come to its natural conclusion when her disease eventually escaped their control and raced ever faster toward its own predictable end. The team was hardly unaware that there were, in fact, two patients in this case, but although they must do no harm to the one as yet unseen, their primary concern was for the one they had been charged to see and had come to know.

Yet when it was clear that the head and neck surgeons had done all they possibly could for CS and handed her off to obstetrics, everything about this case changed. The obstetrician's central concern naturally became delivering the healthiest infant possible. With CS sedated and very close to death at that point, she inevitably became a non-person in the eyes of the obstetrical team. This was not the result of coldness or lack of empathy, but rather an example of what happens when medical care is segmented by body part, diagnosis, and medical specialty. Everyone involved in CS's case looked after their own "part" and no one was charged with oversight of the whole situation. What a blessing, one might say, for there was nothing to be done at this point in any case about this terribly unfortunate individual and her tragic life; at least one could focus on rescuing a potential new life. And yet it is precisely here where a very significant ethical issue comes into focus, namely that even a terminally ill pregnant woman may not be treated as merely the means to an end. This was not just the end of a bad situation, the blessed relief, and the resolution to everything. This was in fact an epiphany, the realization that everyone had failed CS. One might do well, therefore, to ask *how*, *when*, and *where* CS could have been provided assistance that would perhaps have made her dying process better.

The complexity of CS's case, with its attendant frustrations, might in fact have been seen as the source of some resolution to what was viewed, most certainly by

CS herself, as her own tragic end. As mentioned in the case report above, she had been excited about this pregnancy, despite the fact that this would be her fourth baby without a stable home life, and despite the fact that the father had not once visited her in the hospital. CS also told me she had a male friend who had promised he was going to find an apartment for the three of them once the baby arrived. What this last statement of hers, coupled with her expression of joy at the impending arrival along with her new collection of baby clothes really told me fundamentally, however, was that she embraced a strong feeling of hope. And when I saw her in the clinic at the six-week post-op visit, with a huge nodal recurrence in her neck, her tears and the fear in her voice, as she said to me, pleadingly, “I don’t want to die!” reinforced the notion that she clung to some hope her life could be saved. In retrospect, I think we all missed an opportunity for healing for this patient.

CS had earlier expressed a faith in God. Foxhole religion? Perhaps, but whether she had a genuine faith or not, it would have been useful for a skilled chaplain or social worker at that point to begin working with this dying patient to assist her with the process of writing the remaining chapters of her life story, how she would like them to look, visioning them in a way that would be satisfactory both for her and for her new baby, both with and without one another, so that she did not have to simply be sedated without any benefit of closure. Had there at least been some attempt at something such as this, the case of CS would not have to be seen as just one more tragic case involving a person who is in great measure clearly responsible for her own situation. It could be seen instead as a situation with sufficient texture to provide the narrative threads with which CS just might be able to come to terms with her situation realistically and tell how she could see the end of her life and the beginning of her baby’s life in a way satisfying to her. And, in the best of all possible worlds, she might just be able to experience something of the distinction between curing and healing, all the while being healed as she died.

## **A Health Communication Scholar Responds**

The concept of framing, described in detail by sociologist Erving Goffman and employed throughout communication scholarship, suggests that how something (or someone) is presented to the audience (called “the frame”) influences the choices people make about how to process that information (Goffman 1974). Goffman suggested that people interpret what is going on through a primary framework which is taken for granted by the user. Primary frameworks can be further described as either *natural*, which identify events as physical occurrences taking place without social forces, or *social*, which view events as socially driven occurrences influenced by the goals and manipulations of other social players. Frames are abstractions that work to organize or structure the meaning one ascribes to the information that has been presented. The frameworks we invoke profoundly affect how information is interpreted, processed, and communicated. Framing sets boundaries around the topic at hand, and once a frame is established, it can be exceedingly difficult to pay attention to what may lie outside the frame. Once

meaning is ascribed to the information inside the frame it can be nearly impossible to see things any other way.

CS was poor and did not have health insurance. She had no stable living arrangements or a reliable partner, despite having three dependent children and a fourth on the way. Her mother and sister were tired of dealing with her and her problems, which included an occupational history as a prostitute, and drug addiction. These descriptors generally invoke a social frame that might let us see CS as a person whose own bad choices led to her present circumstances, an object lesson of how not to pursue adulthood. Indeed, her own mother suggests that such an interpretation would be appropriate. Her family's frustrations notwithstanding, however, the extent to which one's actions and past decisions are entirely under one's control is controversial. Can we control our own destinies, or are we the hapless products of our genes and our environment? Our puritanical American frameworks sometimes lead us to judgments that are less than charitable, and our culture at the present moment tolerates blaming a person's present circumstances on their inability to exercise sufficient self-control or good-enough judgment. Social policies such as welfare reform, loosening of affirmative action plans, and efforts to dismantle the Affordable Care Act, while outside the scope of this case, are evidence of our willingness as a society to let the chips fall where they may for the less fortunate members of society. Relying on this social framework may let us off the hook of being troubled by CS's fate, and allow us to be comfortable treating her as merely a convenient incubator for her unborn child without the need to respect her dignity.

The fact of CS's occupational choice to engage in sex work, if it truly was a choice, is both a reason to *not* treat her differently than those in other occupations, as well as a reason *to* treat her differently. Sex work presents a host of medical challenges, and sex workers are at risk for receiving sub-standard or no care for pregnancies and other injuries or illnesses. It is sobering to think that CS likely received better pre-natal care when pregnant with her fourth child than she had in the past because she was terminally ill. Respecting a patient's dignity means treating them with care, attention and compassion, no matter their diagnoses, past life choices, socioeconomic status, age, gender, race, religion or culture (Beach et al. 2006; Blanchard and Lurie 2004; Henry et al. 2015).

Prostitution is often exempted from the category of violence against women, but even a cursory consideration of the health consequences of prostitution demonstrates that sex work gravely impairs women's health and belongs firmly in the category of violence against women (Raymond 1999). Health consequences to women who work as prostitutes are often the same as those suffered by women subjected to other forms of violence such as broken bones, bruises, black eyes, and concussions. The sex of prostitution is physically harmful as well and can include sexually transmitted diseases (STDs) such as HIV/AIDS, chlamydia, gonorrhea, herpes, human papilloma virus and syphilis. Studies estimate that only 15% of the women working as prostitutes had never contracted one of the STDs, not including HIV/AIDS, most injurious to health (Farley 2003). General gynecological problems, including chronic pelvic pain and pelvic inflammatory disease, are also common among prostitutes.

Pregnancy is another occupational hazard. We do not know which of CS's children were planned or unplanned, conceived in romantic relationships, or were the result of professional liaisons. It is estimated that over two-thirds of the women working in the sex trades had an average of three pregnancies which they attempted to bring to term during their time in prostitution (Nutbrock 2004). Women working as prostitutes also suffer emotional health consequences including severe trauma, stress, depression, anxiety, and self-medication through alcohol and drug use. Substance abuse is common among female sex workers in large metropolitan areas; it is estimated that up to 93% of women arrested for prostitution test positive for illegal drugs (Raymond 1999). All of this is to say that CS's choice to work in the sex industry, and her willingness to accept the consequences for her actions, hide a potential multitude of factors over which she may have had little or no control. The same can be said for the social frame that allows us to see prostitutes as willing victims of their own bad choices.

CS is also viewed through the frame as a patient with advanced head and neck cancer. HPV, or human papillomavirus, appears to be responsible for the rise in cancers of the oropharynx (tonsil and base of tongue), and is related to oral sex, especially in younger patients; surely this counts as another occupational hazard of sex work.<sup>3</sup> Annually in the U.S., 10,000 new cases of head and neck cancer can be attributed to a certain strain of HPV. Tobacco and alcohol use are the leading causes of mouth cancers. Cigarette smoking increases the risk of head and neck cancer by 15 times compared to non-smokers, and people who use both tobacco and alcohol are at greater risk than people who use either alone. And unfortunately, 66% of the time, oral cancers will be found as late stage three and four diseases. Sex work, unplanned pregnancies, drug addiction, family issues, insufficient housing, limited access to health care—all contribute to a high level of chronic stress. Although the effect of stress on cancer growth is not fully understood, recent research has demonstrated that stress hormones, especially norepinephrine and epinephrine, can contribute to tumor progression and cancer recurrence (Palesh et al. 2007; Sood et al. 2010).

The social framework through which most patients similar to CS are viewed can make it easier to dismiss her tragic circumstances. Peering deeper into the frame as well as looking outside of it to adjust our notions of causality and choice can help restore CS's humanity (and our own). As it happens, CS was an intelligent, articulate individual who in many ways resisted categorization. Perhaps even stating surprise at how unlike our stereotypical frame CS appeared is also evidence of our inability or at least difficulty in seeing past these choices to the person who was suffering their consequences, just or not. Like all of us, CS was more than the social descriptors of her situation and past life choices, or the sometimes unconscious and automatic frameworks we invoke to make sense of our social world. We must take into account CS's talk of her excitement about the pregnancy, and her perhaps unrealistic belief that she and this child will have a stable life together. Her fears and hopes deserved to be heard. Both CS and her unborn child are entitled to our compassion and care; all of our biases, fears, and beliefs in natural consequences must be put aside.

## Notes

<sup>1</sup>At the time, the statutes of the state in which this case occurred were clear that unless the legal proxy or court-appointed guardian could demonstrate that a third-trimester abortion was necessary to protect the health or save the life of an incapacitated mother, such action was not permissible. Given that CS's mother, albeit her legal proxy, could demonstrate neither condition, and given that her insistence upon withdrawal of all life support would effectively have guaranteed the death of a viable, near-term infant, the attending had little difficulty in refusing that request.

<sup>2</sup>There are some important differences between the case of CS presented here, and the case of Marlise Munoz referenced in our responses. In CS's case, her fetus was viable, unlike in the Munoz case. In the Munoz case the family immediately asked for discontinuance of the ventilator, and her husband had the legal and ethical right to make that decision on his wife's behalf. In CS's case, she retained the capacity to make her own decisions nearly to the end of her life, and did want life support continued to ensure her baby's survival.

<sup>3</sup>See the 2015 Fact Sheet. American Academy of Otolaryngology—Head and Neck Surgery for more information (<http://www.entnet.org/?q=node/1501>).

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## References

- Beach, Mary Catherine, Debra L. Roter, Nae-Yuh Wang, Patrick S. Duggan, and Lisa A. Cooper. 2006. Are physicians' attitudes of respect accurately perceived by patients and associated with more positive communication behaviors? *Patient Education and Counseling* 62: 347–354.
- Blanchard, J., and N. Lurie. 2004. R-E-S-P-E-C-T: Patient reports of disrespect in the health care setting and its impact on care. *Journal of Family Practice* 53: 721–730.
- Farley, Melissa. 2003. Prostitution, trafficking, and traumatic stress. *Journal of Trauma Practice*, 2 (3/4).
- Fernandez, Manny, and Erik Eckholm. 2014a. Pregnant and forced to stay on life support. *The New York Times*, January 7.
- Fernandez, Manny, and Erik Eckholm. 2014b. Texas woman is taken off life support after order. *The New York Times*, January 26.
- Goffman, Erving. 1974. *Frame analysis: An essay on the organization of experience*. Cambridge, MA: Harvard University Press.
- Henry, Leslie Meltzer, Cynda Rushton, Mary Catherine Beach, and Ruth Faden. 2015. Respect and dignity: A conceptual model for patients in the intensive care unit. *Narrative Inquiry in Bioethics* 5: 5A–14A.
- Nutbrock, Larry A., Andrew Rosenblum, Stephen Magura, Cherie Cillano Stephen, and Joynce Wallace. 2004. Linking female sex workers with substance abuse treatment. *Journal of Substance Abuse Treatment* 27: 233–239.
- Palesh, Oxana, Lisa D. Butler, Cheryl Koopman, Janine Giese-Davis, Robert Carlson, and David Spiegel. 2007. Stress history and breast cancer recurrence. *Journal of Psychosomatic Research* 63: 233–239.

- Raymond, J.G. 1999. Health effects of prostitution. Making the harm visible: Global exploitation of women and girls. <http://www.uri.edu/artsci/wms/hughes/myhealth.htm>.
- Sood, Anil K., Guillermo N. Armaiz-Pena, Jvotsnabaran Halder, Alpa M. Nick, Rebecca L. Stone, Hu Wei, Amy R. Carroll, Whitney A. Spannuth, M.T. Deavers, Julile K. Allen, Liz Y. Han, Aparna A. Kamat, Mian M.K. Shahzad, Bradley W. McIntyre, Claudia M. Diaz-Montero, Nicholas B. Jennings, Yvonne G. Lin, William M. Merritt, K. DeGeest, Pablo E. Vivas-Mejia, Gabriel Lopez-Berestein, Michael D. Schaller, Steven W. Cole, and Susan K. Lutgendor. 2010. Adrenergic modulation of focal adhesion kinase protects human ovarian cancer cells from anoikis. *Journal of Clinical Investigation* 120: 1515–1523.