

Ethics and Antimicrobial Resistance

Anti-microbial resistance could turn out to be the biggest health crisis of our lifetimes. Few of us even remember pre-antibiotic days, when people routinely died of TB, pneumonia and even STDs. Plus, our experience of modern health care has been one of steady progress. New and better therapies and procedures are developed constantly, and those we have get better, cheaper and more readily accessible. Loss of antibiotics would be an unprecedented step backwards. Not only would our ability to fight infection not improve, it would return to levels that in the past allowed catastrophic health crises such as the Black Plague.¹ Medical problems like Lyme disease and MRSA could become crises overnight.

There are several aspects to the ethical questions that surround antimicrobial resistance. The most obvious is the threat that it poses to present populations. Lack of effective treatment for infectious disease is something like pollution – it affects everyone. Pandemics are a very direct threat to the common good. They affect not only health, but education, employment, and even defense. So it seems government has a duty to do what it can to prevent such outbreaks.

Another issue is stewardship. How did we get to the point of such widespread anti-microbial resistance? How did it happen that this incredibly valuable resource was overused – often not even on humans, but on livestock to prevent disease and accelerate the move to market?

Who has authority to allocate and control the use of such resources? The market? National governments? A global agency such as WHO or the UN? There are important efforts to address the issue by government and religious organizations, but they are not widely publicized.²

Another important question is who owns these antibiotics and the resources to produce new ones? Public health in the United States is constrained by a highly proprietary approach to pharmaceuticals. Others have noted that the profit motive drives most decisions about research and production. This creates a bias toward the development of new drugs that treat chronic illnesses so that there will be a long-term market for them. New drugs for diabetes are a prime example.

In the case of new antibiotics, there is less incentive, since new products would be used only as long as the infection is present and then discontinued. They would probably be kept as a last resort and so there would not be a strong market demand for them.

Other options might include calling on international health groups or even on single governments to fund development. But in the U.S., attitudes toward government involvement in health care and budget cutbacks make this unlikely.

What about our responsibility to future generations? In their analysis of the ethics of microbial resistance Jasper Littmann and his colleagues cite global solidarity and hint at eschatology as they talk about our responsibility to the future:

In addition to expanding our scope of care and concern beyond our own citizens and national borders to low and middle-income countries we also need to recognize that our current actions and policies will affect our microbial environment to such an extent that we have to include both current and future populations as part of our AMR response. The possibility of an impending post-antibiotic era means that future generations face a risk of being significantly worse off if bacterial infections can no longer be treated effectively, and it raises questions about the obligations we have to future people to preserve effective antibiotics.³

The issue here, they go on to say, is “whether persons who do not currently exist can make claims on current persons.” This is a difficult question,

since we have a hard enough time determining what justice claims living people can make on one another.

Another question is who would allocate new medications, and on what basis. Would they go to the sickest, the richest, the most influential? Would their use be limited to prosperous industrialized countries where they are likely to be developed? What would happen if an effective drug happened to be discovered in a developing country? Would that country be allowed to retain ownership of it and profit from it? (This is not as unlikely as it seems. Many antibiotics come from dirt, and focused research is taking place that analyzes dirt to find anti-microbial agents⁴).

These are classic rationing questions. At least in the U.S., we are not accustomed to thinking that there won't be enough of one commodity. The possibility of rationing is rarely even mentioned by politicians and policy makers, let alone considered as part of a health care policy.

There are resources in the Catholic tradition that can help us think through these dilemmas. First of all is the notion of justice and what Pope Benedict referred to as “the universal destination of human goods.” Pope Francis used this idea to talk about the environment. It is our home, it belongs to all of

us, and therefore all of us have a duty to protect it. The skills and resources of health care, like the environment, belong to us all; they are the result of massive human collaboration, suffering, and learning over the centuries. Even though there are some key players who deserve compensation for the research that led to these discoveries, they do not radically own them.

Another resource is our notion of the communion of saints. This is a belief that we are in solidarity with the living and the dead and that all of us together seek a common home in God, who is our source and our eternal destiny. If we believe that, then we do have an obligation to future generations, and we do have a duty to protect these essential goods of creation for their use.

This solidarity with the saints extends to our lives on earth as well. Unless our view of the human person is radically monistic, we must acknowledge that we share the condition of human frailty and mortality with everyone else, whether or not we know them personally. This view of solidarity leads us to say that if one of us is suffering, we all suffer. This is especially apparent in pandemics where another person's illness puts me at direct risk: their illness today could become my illness tomorrow. Infectious disease is a stark and unpleasant aspect of human solidarity.

Our view of the role of government is also important. If government is seen as a necessary evil, then the less of it the better. The Catholic tradition is more sanguine about the role of government than some. With due respect for subsidiarity, we see government as a necessary tool for maintaining peace and assuring basic human needs like health care and education. It seems to me that responsible government agencies with a lot of public involvement are the only bodies with enough money and resources to develop new antibiotics and prevent their misuse.

Insurance Coverage and Transgender Care

Insurance coverage is just one of the ethical issues in the multi-faceted question of health care for transgender persons. For every element of care – from a broken arm or cancer, to pre- and post-transition hormone treatment, psychotherapy and surgery, there is a corresponding question about who will pay.

Insurance coverage for transgender care, and particularly for procedures related to transition, is relatively new. In fact, expansion of coverage may itself be a significant factor in growing public awareness of transgender persons, especially as they gain access to more extended treatment.

The history of insurance funding for transgender procedures is recent. It was first funded by Medicare only in 2013; the Veterans' Administration announced they would fund some procedures in early 2016, but in November of the same year dropped their plans to do so. They did not drop the payments for ethical or medical reasons, but rather for budgetary reasons. Their November 14, 2016 statement said that since 1999 the VA has "provided many services for transgender veterans that include hormone therapy, mental health care, preoperative evaluation and long-term care following surgery," even if they do not provide surgical procedures.⁵

Many states (e.g., Oregon, California, Vermont, Connecticut, Massachusetts, Washington, Illinois, New York and the District of Columbia as of 2015) have passed non-discrimination laws that require insurance companies to provide transgender health coverage. A number of private insurance companies have begun covering transgender procedures when they determine them to be "medically necessary." Aetna, for example, has provided some coverage since 2009; it currently covers hormone therapy and psychological counselling and some surgeries. Their website⁶ lists the following criteria for "medical necessity" for mastectomies for female-to-male patients:

- a) A single letter of referral from a qualified mental health professional;
- b) Persistent and well-documented gender dysphoria;
- c) Capacity to make a fully informed decision and to consent to treatment;
- d) Age of majority (18 or older);
- e) Control of significant medical or mental health concerns.

Requirements for *hysterectomies and gonadectomies* (oophorectomy or orchiectomy) are similar but require two referral letters and at least twelve months of continuous hormone therapy.

Requirements for *genital reconstructive surgery* include everything above plus 12 months living in a gender role that is congruent with the patient's gender identity.

Children present a special case both because of consent issues and because of unknown long-term effects of hormone therapy before puberty. For these reasons, insurance coverage for those under 18 appeared later. According to one study, only in 2015 were all requests for puberty blockers approved by insurance for patients.⁷

These developments present several challenges for Catholic health care. First of all, rapidly expanding

coverage by government and private insurance lends credibility to claims for care by transgender persons. Second, increased coverage is based on an implicit anthropology that sees human sexuality and gender as fluid, possibly variable and not irrevocably determined by phenotype. This view contrasts sharply with the traditional Catholic view. The fact that insurance companies are providing coverage certainly does not mean that these treatments, or even the diagnosis, are clinically appropriate or morally acceptable. But changes in attitude and protocols challenge ethicists to expand our inquiry into actual clinical experience and to begin to formulate an educational strategy that helps our providers to better understand the theological implications of transgender care.

Geriatric Sexuality

These two words might have at one time seemed like the title of a comedy film. Indeed in 1992 there was a film adaptation of Muriel Sparks' novel "Memento Mori" about a group of elderly people (including Maggie Smith, Stephanie Cole and Michael Hordern, all of whom you would recognize as stellar British actors). The story revolves around their reactions to a mysterious caller who says simply, "Remember that you must die." Some react with fear, others with indifference, others with humor. But the film also contains some hints of how the elderly residents dealt with sexuality.

As our life expectancy grows, many of us will have the opportunity experience a second or third generation of sexual feelings. This is a private and personal issue that would ordinarily involve one's confessor or spiritual director. It is another thing entirely for persons in communal living arrangements, from assisted living to skilled nursing.

It is entirely natural for senior citizens to continue to desire and seek out intimate relationships. Friendships are the most important thing in life, and we appreciate them more as we age. Sometimes these relationships are a remedy for loneliness that is a part of old age. This is exacerbated by the loss of a spouse.

Children of elderly parents are sometimes surprised, and usually amused, to see that their mom or dad has taken up with a new companion. Staff sometimes find themselves in an awkward position if they are aware of shared afternoon naps or evening visits that last well into the night. Are they complicit in non-marital sex or even adultery if the spouse of one of the partners is disabled? Are they obligated to intervene? Should they tell family, or keep the secret?

These incidents can be complicated by routine memory loss or loss of inhibition. They become more serious ethically when true dementia sets in. There is literature on these questions including suggestions from the National Institute on Aging.⁸ There are also resources for spouses of Alzheimer's patients, who sometimes complain their needs and their ability to cope with the changed circumstances of their marital relationship are not taken into account.⁹

Douglas Wornell, M.D. surveys the ethical issues surrounding sexuality in dementia patients. He notes that while sexual desire "often diminishes as dementia progresses," there can still be instances of disrobing, masturbation, or inappropriate sexual aggression.¹⁰

He says that forbidding residents of care facilities to express their sexuality, especially with a spouse, may be abusive; however, it is also possible that *allowing* them to engage in sexual activity with a spouse suffering from dementia may be abusive, especially if memory loss is so severe that the spouse is no longer familiar to the patient. If the patient is no longer able to recognize his or her spouse, an attempt at sexual activity, even within marriage, could be considered a form of rape.¹¹

Three or four ground rules may be helpful.

- a) Education is essential, both for staff and families, so they know what to expect. Families should be advised at admission of the possibility of sexual acting out as the disease progresses. Families and supervisors should be notified if there are instances of inappropriate behavior.
- b) Respect the marital relationship as far as possible. The church is committed to protecting this privileged, sacramental form of friendship at all costs. Its conjugal expression should only be limited as necessary because of privacy concerns or because of concerns about consent.¹²
- c) Non-marital or extra-marital *friendships* are natural and probably contribute to the patient's spiritual and mental health. These should be celebrated as long as they appear to be healthy and non-coercive. Non-marital *sex* should not be encouraged; however, this may be difficult to monitor or control in the relative independence of an assisted living facility if residents have individual apartments.
- d) Adequate spiritual care for residents and patients is important to help them integrate their sexuality into their spiritual lives as they age. Sexuality may not have the same

urgency in old age as it does for teenagers, but it is nonetheless an important aspect of human existence and should not be ignored.

Access to Health Care during Medicaid Expansions

As I write this, the Senate is in the process of re-writing the Affordable Care Act so that funding for Medicaid expansion will probably be severely limited going into the future. One of the arguments for this change is that the Affordable Care Act (aka Obamacare) has failed. But at least one study suggests otherwise.

One of the problems that the Obama administration set out to address with the Affordable Care Act was the problem of access to care. Until then, no insurance meant no access to care except through the emergency room. So expanded access to care is a key indicator of the success of the reform.

Sara Miller and Laura Wherry studied 60,766 U.S. citizens who qualified for insurance coverage because they were at or below 138 percent of the federal poverty level.¹³ They compared those in states with Medicaid expansion with those in states that did not accept expansion funds. They found a significant decrease in reports of inability to afford

needed follow-up care, and reduced worry about paying medical bills. A much smaller study in Massachusetts showed clear gains in coverage, but less clarity about access to care. However, they also found increased waiting times for care, which is probably the result of the inadequate number of primary care providers.¹⁴ This problem has been noted in other places where access was expanded.¹⁵

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¹ The plague is not just a historical curiosity. For a contemporary outbreak, see “Plague is Found in New Mexico. Again.” *New York Times* June 27, 2017.

<https://www.nytimes.com/2017/06/27/science/plague-is-found-in-new-mexico-again.html?>

² For example see *Global Health and the Future Role of the United States*, The National Academy of Sciences, May 2017. (www.national-academies.org/USglobalhealth). The report highlights the importance of U.S. leadership in combatting AMR. A group of Catholic-inspired and other faith-based organizations met in Rome in December and issued a call to action. See “Combating the Emergence and Spread of Antimicrobial Resistance: A Workshop to Strengthen Faith-Based Engagement” (12-15 December 2016).

³ Jasper Littmann and A.M. Viens, “The Ethical Significance of Antimicrobial Resistance” *Public Health Ethics* 8, 3 (2015) 209-244, at 217. See also Thomas O’Meara, “Catholic Health Care’s Ministry to the Future,” in *Incarnate Grace: Perspectives on the Ministry of Catholic Health Care*. St. Louis: Catholic Health Association (forthcoming fall, 2017). O’Meara explores the eschatological dimensions of our ministry.

⁴ In 2015, researchers found a new antibiotic in dirt. See Anna Azvolinsky, “New Antibiotic from Soil Bacteria”, *The Scientist*, January 7, 2015. <http://www.the-scientist.com/?articles.view/articleNo/41850/title/New-Antibiotic-from-Soil-Bacteria/>

⁵ Rebecca Kheel, “VA Drops Plans to Cover Surgery for Transgender Vets,” *The Hill* (November 14, 2014).

⁶ “Gender Reassignment Surgery”, http://www.aetna.com/cpb/medical/data/600_699/0615.html; accessed 6/30/2017.

⁷ Jamie Stevens, Veronica Gomez-Lobo, and Elise Pine-Twaddell, “Insurance Coverage of Puberty Blocker Therapies for Transgender Youth” *Pediatrics* (136:6 December 6, 2015). The authors note that the most effective puberty blockers are gonadotrophin-releasing hormones (GnRH) agonist leuprolide (Lupron by AbbVie) or histrelin subcutaneous implants (Supprelin or Vantas from Endo Pharmaceuticals).

⁸ “Changes in Intimacy and Sexuality: Alzheimer’s Caregiver Tips”, <https://www.nia.nih.gov/alzheimers/publication/changes-intimacy-and-sexuality> (accessed 7/6/2017); see also a Factsheet on Sex and Intimate Relations published by the Alzheimer’s Society (Great Britain), (http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1801)

⁹ “Sexuality and Dementia,” Family Caregiver Alliance (<https://www.caregiver.org/sexuality-and-dementia>)

¹⁰ “Sexuality and Dementia,” *Today’s Geriatric Medicine* 7:2 (March /April 2014), 24:26 at 26.

¹¹ James Beauregard describes one such case, *State of Iowa v. Henry Vincent Raybons*, involving a charge of sexual abuse of his wife in the third degree. See “Sexuality, Dementia and Catholic Long Term Care,” *National Cath Bioethics Quarterly* 15 (Autumn 2015): 493-514, at 495ff.

¹² Beauregard gives a good overview of how to assess capacity for consent in the above article, at 504.

¹³ “Health Care Access to Care During the First 2 Years of the ACA Medicaid Expansions.” *NEJM* 376:10 (March 9, 2017): 947-956.

¹⁴ Danny McCormick, MD, MPH, Assaad Sayah, MD, Hermione Lokko, BA, Steffie Woolhandler, MD, MPH, and Rachel Nardin, MD, “Access to Care After Massachusetts’ Health Care Reform: A Safety Net Hospital Patient Survey”, *J Gen Intern Med.* 2012 Nov; 27(11): 1548–1554. Published online 2012 Jul 24. doi: [10.1007/s11606-012-2173-7](https://doi.org/10.1007/s11606-012-2173-7). “Access to care improved less than access to insurance following Massachusetts’ health care reform. Many newly insured residents obtained Medicaid or state subsidized private insurance; cost-related barriers to access were worse for these patients than for the privately insured.” This may have been in part due to cost sharing which was an obstacle for low income patients.

¹⁵ Massachusetts Medical Society, “MMS Study Shows Patient Wait Times for Primary Care Still Long: Half of Primary Care Practices Remain Closed to New Patients; Wide Variations in Wait Times Among Massachusetts Counties”, July 15, 2013.