

Protagonist Corner

Marilyn Washburn

Rollins School of Public Health, Emory University, Atlanta, Georgia

Most of the agonizing pastoral issues and biomedical ethics dilemmas I face daily are created not by illnesses, but in voting booths and legislative halls. Mine is a plea for preachers and pastors to become involved in developing the public health policies that shape our ministries. Consider the story of Mr. Charlie Sharp, “patched” together from the lives of “typical” folk whose paths cross with mine on a regular basis.

Charlie is sixty-eight years old, and owns a construction company. He is a congregational leader whose skills have been honed in the world of a practical business. His wife is a teacher; they have had a long, healthy marriage, and have three grown sons. The eldest stayed in his college town, but remains close to his parents through frequent visits. The middle son has schizophrenia, and lives at home. His illness was most difficult in his early adulthood; on several occasions, he became threatening to himself or his family, and Charlie or his wife had to call the police...there was no crisis team at the time to deal with the situations medically. He lived on the streets for a while, and served some short jail terms. Now, however, he has “settled down,” as Charlie says, and participates in a day program regularly. Charlie and his wife feel blessed that their congregation was supportive and caring during those long years; they are aware that many families are shunned in such circumstances. They continue to worry about their son’s future, about where he will live when they cannot maintain their home, and about the care he will receive.

Charlie’s first grandchild, the daughter of his youngest son, was born with a genetic disorder and lived only a few months. Charlie and his wife were consumed with their grandchild’s care. Only his pastor is aware that the child’s care also consumed a significant portion of Charlie’s life savings, since Charlie’s son and daughter-in-law were unexpectedly “between jobs” when the baby was born. (They would like to have more children, but the “pre-implantation” testing they would need is not covered by insurance. Their only affordable option is to get pregnant, and then abort an affected fetus, and that is morally unacceptable to them.) Again, Charlie and his wife only say that they feel blessed to have resources to give, and wonder what additional suffering their son and his family would have endured if they had not been able to help.

Now, Charlie has lung cancer. He stopped smoking (again) three years ago, when his grandchild was on supplemental oxygen, but he had already accumulated over fifty pack years. Charlie was proud that he had provided health benefits to his employees; then his own illness threatened to push the price of insurance premiums beyond the reach of most of his workers. He dropped his own coverage, and retired, figuring that he could “get by” on Medicare. He had not realized he would have a completely different constellation of physicians and other caregivers. They have told him that he has about a 50/50 chance of surviving his illness with aggressive therapy, including surgery and chemotherapy. Whether or not he survives, the family savings will be depleted; Charlie’s wife will probably have to sell their home, find housing and care for their ill son, and manage on her very modest teacher’s retirement.

Over the years, Charlie and his pastor have become close friends. Charlie has talked about his business practices, the stress his son’s illness has caused in his

marriage, his concerns for his son's future care, his sense of guilt over his granddaughter's genetic illness and his grief over her death, his youngest son's decision not to risk having more affected children, and the difficulty of "kicking" his addiction to nicotine. Now, he wonders how much of the family's waning resources to risk on himself. During their last visit, he asked his pastor what she thought about assisted suicide, explaining simply and soberly that he couldn't see ruining the lives of his loved ones if his life were really over.

All those pastoral conversations were shaped by public policy as much as by the biology of his family's health. The programs which serve Charlie's son with schizophrenia are severely limited: not enough money for full day programming or the most promising medications, and strong community opposition to group housing development. Charlie's guilt and grief surrounding his granddaughter's illness were magnified by the secrecy his healthy sons requested; they are fearful that potential employers might be reluctant to hire persons whose family illnesses could reduce their productivity or wreck their benefits plans. Charlie began smoking as a teenager, encouraged by many of the same sorts of advertising practices and easy accessibility to tobacco which lead thousands of teenagers to become addicted every day, fifty years later. The organizations that offer smoking cessation programs and advocate for public smoking restrictions scrape along on promises and prayer....Charlie never knew they existed and could help him stop smoking the several times he tried. Charlie and his sons cannot afford any medical insurance that would offer them coverage with pre-existing schizophrenia, cancer, and genetic disorders in the family. Now, in the midst of the chaos that cancer has caused, Charlie is burdened with getting to know new caregivers and navigating a health system unfamiliar to him; he had always assumed he would die in the care of the family physician he knew and trusted most of his adult life. Charlie's story is an everyday story for scores of folks in our congregations. However, we are not helpless in changing those stories.

Getting involved in public health policy formation may be intimidating to pastors and preachers. In reality, however, it is something most of us have skills and knowledge to do. What follows are my suggestions and encouragement:

- 1) Believe you can do it! Anyone who can navigate the politics of church life can navigate the politics of health care reform!
- 2) Get to know the public health leaders in your congregation and community. Ask folks like Charlie who runs their programs. Go to lunch with a hospital administrator, Medicare or Medicaid administrator, or public health official. (Expect the occasion to be an important pastoral moment for your guest - many public health professionals understand their work to be their Christian vocations, and long for the interest and support of their faith communities.)
- 3) Choose one issue to focus on, something local and concrete, such as a cigarette vending machine ban, or a group home proposal facing NIMBY opposition. In this cyberspace age, networking with local friends and neighbors will soon put you in contact with state, national, and international activists, and your skills will be rapidly transferable to other issues.
- 4) Get informed: audit a course (or create one with folks you meet,) "surf the net," sit in on legislative hearings, call the national health ministry office of your denomination.
- 5) Be clear in your own mind about the biblical imperative for the work you are doing:

justice and healing are not optional for Christians.

6) Pray about your issue, and preach about it. Then, wear your button to the Rotary luncheon, and link your issue to those before the PTA and the local Christian Council. Practice “mutual mention.”

7) Consider gently suggesting involvement to families affected by your issue. There is, of course, a risk of overwhelming already overburdened families, or of encouraging them to become too busy to do the grief work or family systems work they need to do. Sometimes, though, knowing that you have spared someone else the suffering you have experienced is wonderfully healing.

8) Share your experiences. All of us who think we are alone in these ministries of healing need mutual support.

In public health, we often refer to the “Swimming Hole Model.” The swimming hole sits above a tall, rocky waterfall. Every now and then a swimmer goes over the falls, and is badly injured. The caring folks of the local community have organized a number of programs (read “ministries”) to aid the injured and their families: ambulance services, trauma centers, rehabilitation facilities. One day, these weary caregivers look up at the swimming hole above the falls, and realize their work is endless until they do something about the swimming hole: fence the end over the falls, ensure that visitors can swim, put up warning signs. We in churches have always done a good job of caring for the injured; that is one of our mandates, and that need will never disappear. We are also called to care for the swimmers, to ensure that the policies which govern our “swimming holes” make them places for recreation and community-building, rather than sources of unnecessary pain and suffering.