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Choosing Whom to Trust: Autonomy versus Reliance on Others in Medical Decision Making among Plain Anabaptists

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Abstract: The idea of patients as autonomous agents dominates the medical ethics literature in Europe and America. I maintain that Plain Anabaptists allow their communities to influence medical therapy decisions more than the typical American does. They choose differently whom to trust. This is relevant to medical professionals interacting with them, especially when Plain Anabaptists make decisions at variance with standard medical recommendations. The typical American doctor will often mistake the area of disagreement, assuming that the presentation of more facts will sway the patient. However, the emphasis on community and acceptance of authority means that Plain Anabaptists will have a correspondingly different approach to decision making. It may be true that the patient does not have all relevant data or does not realize the relative trustworthiness of different information sources. Yet, often Plain Anabaptists will come to a different decision because of a different value system. They are making their own decision about who or what to trust. [Abstract by author]

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What is autonomy? Are we really autonomous? In this article, I argue that in the general medical ethics literature in America, the idea of patients as autonomous agents is dominant. I then maintain that Plain Anabaptists (aka “Plain People”) allow their communities to influence medical therapy decisions more than the typical American does. They choose differently whom to trust. This is relevant to medical professionals interacting with them, especially when Plain Anabaptists make decisions at variance with standard medical recommendations.

As a physician with an interest in bioethics, I attend conferences of the American Society of Bioethics and Humanities. Here, the dominant approach to medical decision making is in evidence: the “principle approach.” This is based on the four principles of autonomy, justice, beneficence, and nonmaleficence (Beauchamp and Childress 2013). In an older tradition, nonmaleficence was primary; Hippocrates is famous for insisting “First do no harm.” More recently, however, autonomy trumps all. The primacy of autonomy fits with western individualism and the conviction that we as individuals can and must choose for ourselves (Highfield 2015). In the extreme, such a view asserts that we each chose our own morality, our own value system. This dominant ethic acknowledges no external moral framework which we should allow to guide our decisions. Instead, we must each create our own moral framework in the act of making moral decisions. We must choose for ourselves. Then, whatever decision an individual makes is right by virtue of the fact that the individual made that decision. It follows that the only legitimate input another could have into another’s decision making is the provision of information. Going beyond that, doing anything that resembles directing another’s decision is inappropriate.

Any such summary of current bioethical thinking without more nuance or historical context risks being not a synopsis but a distortion. I both accept this risk and present another generalization: I will refer to TAD, the “Typical American Doctor.” Dr. TAD “would recommend this” refers to my judgment of what the typical American doctor would do.

The previous sketch is sufficient to provide contrast with Plain Anabaptists. In Dr. TAD’s model, where is the space for community? Plain People do not do community perfectly, and not all plain people are Hutterites, who own their be-

longings in common. Certainly, Plain People are influenced by the surrounding culture’s emphasis on autonomy and individual decision making. But there are several aspects of plain communities that continue to promote emphasis on group decision making. Understanding these aspects will provide service providers with greater insight, especially when Plain People make a decision at variance with a medical recommendation.

Let’s start with the Bible. Plain Anabaptists accept the authority of the Bible. They detect in it an external moral structure which should shape decisions. We are born to discover morality, not to create it, they might say. In the physical world, after we are born, we discover that we have two legs and do not have three eyes. This is a given, not something that we choose. Rebelling against the physical structure of the God-designed world brings pain. Not accepting the authority of the God-given Bible will also only bring hurt, Plain Anabaptists hold. Children learn not to touch a hot stove and adults are free to choose to jump off a roof, but we are not free to choose the consequences. The consequent pain is an inbuilt aspect of the system. When it comes to moral decisions, we may also choose. We are free to choose but not free to choose the consequences of our choice.

Another factor that binds certain Plain Anabaptists together in making decisions about healthcare is that they are bound together in paying for that healthcare. Some Plain Anabaptist groups allow participation in commercial insurance and Medicare. But notably among the Amish, there is a significant amount of cost sharing within the community, among church families. Apportioning the burden of payment makes it clear what is at stake; if an expensive medical intervention is chosen, everyone is impacted. As a hospital-based physician, I see this at work in the question of how long a patient should remain hospitalized. Since the patient came in to the hospital, he or she judges there is potential benefit. But the decision of when the expense outweighs the benefit is a decision that will be made differently by someone who knows that his decision is affecting the pocketbook of his closest friends.

When confronting a health crisis, Plain People understand God to be in control. This is not fatalism, but more like a yielding, an acceptance of factors outside our control. This is relevant in medical decision making, particularly at the end

of life. “This world is only a temporary dwelling; we are living for heaven,” they may explain.

Plain People tend to be very pragmatic. Pragmatism is not unique to Anabaptists, but when responding to their decision making, keeping this in mind will help. Decisions will be based on what is most practical and efficient with less emphasis on what is cosmetically pleasing. My wife, a dental hygienist, observes this. Plain Anabaptists want functional teeth, with less emphasis on the look. They may especially discount considerations of how the look of one’s teeth will make one feel about oneself.

Another aspect of decision making is this: Plain Anabaptists accept the authority of their community. Not to a complete extent, but they are more open than my other patients to accepting substantial input into their medical decisions. This can be overemphasized or exaggerated. The extent of group decision making will depend on the age of the patient, details of the family, and the seriousness of the disease. But medical professionals should understand that making decisions as a group is still alive in some communities in the USA.

Doesn’t it make sense to have some degree of group decision making? It seems reasonable that everyone who is affected by a decision would have input into the decision. But it is challenging to operationalize this ideal. Dr. TAD’s approach insists that the individual gets to make the decision and everyone else must accept it. Dr. TAD knows no other way. Plain communities, because they are communities, get closer to the ideal of having those affected by a decision participate in that decision. Yes, there may be potential for abuse of power or other downsides to a group approach. Maybe the decision making will take longer. But the positive side is that a degree of group decision making is not only a result of a community but also will contribute to building the community.

An example of this happened in my community. A boy with autism developed liver failure. It is likely that he ate some poisoned mushrooms, although we were never quite sure. He was in the intensive care unit and a liver transplant was recommended. Along with the patient’s family members, there was a near constant presence of church members in the patient’s hospital room. The medical team was ready to arrange helicopter transport to Philadelphia. I was doing my residency training

in Baltimore and called the Pennsylvania hospital to talk with the father. I wanted to make sure that he didn’t regard a liver transplant as a cure but rather as exchanging an acute disease for a chronic disease, a point my training emphasized. The phone conversation was extensive. I followed Dr. TAD’s approach of mere information provision. Eventually, I realized that the father was looking for a recommendation. Not only was he not interested in all my background details about possible outcomes of various decisions, but he was unable to follow all those details. Then it also turned out that the family had already decided against a liver transplant. The decision had been easier because of input from the community gathered in the hospital room. Moreover, the family was more comfortable with the final decision precisely because others had input.

So far in this article, I have contended that Plain Anabaptists are willing to have their decisions influenced by people they trust. Yet trust can be misplaced, and that is what I will consider in the second part of this article. Some Plain Anabaptists are particularly vulnerable to health fads. Openness to input from others risks unreliable input. Perhaps less education may be related to gullibility. It makes sense that less exposure to potentially contradictory health claims may mean a more trusting approach. I know this first hand from my Question & Answer column in *Family Life*, a magazine published by Amish based in Ontario. Some of the questions from readers reveal a simple knowledge deficit. However, often I detect that what is at issue is not just a lack of knowledge but a different way of responding to or interacting with health information—a different way of assessing what should even count as evidence. How do I respond when what is at issue is a disparate value system? What is the proper balance between informing and directing?

I will approach this by stepping back and arguing that we are all in this together. Have not all of us at some point found it challenging to evaluate a health claim? We may have a hard time processing all the relevant scientific details. Or worse, the details may be presented in a biased way. Pharmaceutical companies, hospital systems, and research authorities have all at times proven untrustworthy, legitimating skepticism not only among Plain Anabaptists. Since none of us is an expert on everything, we all need to choose some-

one to trust. We cannot, as my radiology professor in medical school trumpeted, “Trust no one, believe no one!” None of us can live like that. As I see it with Plain Anabaptists, the issue is not necessarily more or less trust but a different calculus of choosing whom to trust. Plain Anabaptists value what the Bible commands and what their community directs. But in addition, part of their identity is defined against the broader culture. They are more likely to trust people like themselves. This is true for everyone to some extent but is especially true for those who believe that the difference between themselves and the broader culture is a deep spiritual one.

So how do we respond when Plain Anabaptists make choices about medical therapy that we as professionals think are unwise? Consider a patient (“Mr. Sickman”) who travels to Mexico for vitamin C infusions, forgoes chemotherapy, or piles 20 herbal supplements on top of standard medical therapy. We may be quick to criticize a choice based on an untrustworthy source. But how do we balance that with the broader culture’s insistence that an individual (sick or not) can make any choice he or she wants? Who is to say that the patient’s trust is misplaced?

Dr. TAD has a ready response to this, which I want to present, then try to parse out which aspects of the response are required because of his training but may be inconsistent in ways he might not realize. Dr. TAD is sensitive to his duty and training. Remember, he learned in his philosophy and ethics classes that we each create our own morality. Moreover, this creation by choice is unavoidable, not just an optional human activity. “In truth,” Dr. TAD’s professors declaimed, “it is the very act of choosing that makes us human. A choice is right for you precisely because you chose it.” Dr. TAD thus will not respond to what he judges is a poor choice by direct critique. Instead, he will declare that his goal is simply to provide health information. “Mr. Sickman, when you undergo the expensive trip to Mexico for vitamin C infusions, I am not saying that you are making the wrong decision. I want to support you in whatever health goal you autonomously choose. You declare that your goal is to get better. Yet, I can inform you that what you are doing is not providing the maximum chance for that. It has been demonstrated that vitamin C is not therapeutic for cancer!” Dr. TAD concludes.

This is a legitimate critique by Dr. TAD. It would be a convincing critique if all that was at issue were facts, evidence. But it misses the critical point that what is at issue is the very decision making process itself. When Plain Anabaptists refuse chemotherapy or otherwise do not go along with a physician’s recommendation, it is not just a matter of lack of education or of believing misinformation about the benefit of vitamin C. It is actually thinking in a different way, having different processing with the same information, admitting different things as evidence. It is a different kind of valuing of choosing whom or what to trust.

I sometimes sense an undercurrent of disapproval from the medical system about lines of therapy that Plain Anabaptists pursue. Is the larger culture here inconsistent when criticizing decision making of Plain Anabaptists? This is the crux of the matter—and worth dwelling on a bit more because it is relevant to all decision making. I think Dr. TAD often fails to see that disagreement often goes beyond questions of risks and benefits, related to assessing what painful or expensive medical intervention Mr. Sickman will accept for what benefit. Dr. TAD is facile in that domain. If he judges that the patient mistakenly assesses how burdensome an intervention is, he may assure the patient that this is a new kind of chemotherapy which does not cause nausea or make one’s hair fall out. These data might directly address Mr. Sickman’s uncertainty. If so, the patient’s position will shift, and he will be more likely now to accept the recommended therapy.

But there is a different level of disagreement that derives from another domain; that is, a different weighting of evidence. This disagreement will not be resolved by simply presenting more facts. Judging exactly where the disagreement lies is often challenging for Dr. TAD. He presents facts when he judges that Mr. Sickman’s actions are not consistent with his goals. “Vitamin C infusions will not cure cancer!” Mr. Sickman’s response could be: “I cannot, and will not directly try to, controvert your facts. I am not so much disagreeing with your evidence as putting emphasis on different evidence. My methodology involves trusting my kind of people. Does not your methodology involve trusting your kind of people? The people who delineate hierarchies of evidence, deciding which kinds of evidence must supersede other evidence (Guyatt, et al. 2015)? As for me, I have

my own way of grading the evidence. I value what my sister says, and she knows someone who got better after receiving vitamin C infusions (Sister 2018). I trust her.”

How can Dr. TAD respond, especially if Mr. Sickman had continued further, to point out that on this way of thinking, he can even “choose what counts as evidence?” Can Dr. TAD legitimately criticize even this extreme statement, if Mr. Sickman’s way of evaluating evidence derives from a variant value system, and all our valuations are radically personal?

On some days, Dr. TAD’s response is to bristle and say “But this issue was decided a long time ago, starting with Francis Bacon who delineated the scientific method. Your personal valuations are only forceful in domains like ethics, that cannot be disputed or addressed by science. The question of whether vitamin C addresses cancer is an area of public fact that can be and has been addressed by the scientific method.” This path of argument is well-trodden, but does not take into account the changes that have happened in our culture since Bacon, summarized at the beginning of this essay.

On other days, Dr. TAD sighs. “OK, that’s true, and I can’t legitimately critique your decision while also saying that you can choose your own value system. But I am worried that you will infect others with your ideas about Vitamin C.”

In summary, all service providers to Plain Anabaptists could benefit by remembering that some variation in decision making is not amenable merely to the presentation of more facts. As a subculture, Plain Anabaptists have an emphasis on community and acceptance of authority. It follows that they will have a correspondingly different approach to decision making. It may be true that the patient does not have all relevant data, or may not realize the relative trustworthiness of different information sources. Yet often Plain Anabaptists will come to a different decision because of a different value system. They are making their own decision about whom or what to trust.

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