



ASIP Public Affairs

1998 Patricia Backlar: Access to Archived Human Tissue (EB98)

Access to Archived Human Tissue: Are Current Procedures going to Change
(Concerns about the privacy of medical/genetic information when archived human tissues and medical information are used for research.)

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It is an honor to be invited to participate in this panel, and I thank Mark Sobel, Richard Lynch and the American Society for Investigative Pathology for inviting me. The program notes indicate that I am to speak about patient advocacy and the use of human tissues. I confess it is daunting to be expected to speak on behalf of patients generally and represent the vast array of interests and concerns that may be involved; I suspect that no one accurately may be able speak for all the individual members of a collective or community – let alone, be able to precisely define a community. Therefore, I speak only from my perspective as a patient and as a member of the National Bioethics Advisory Commission, I speak for myself – not for the Commission.

Last summer, I had a surgical procedure. A few days prior to the surgery, I had some tests. I was admitted to the hospital early in the morning, and a woman behind the desk asked me to sign a consent form. I read it through and one sentence caught my eye. As I remember it was something to the effect that "You give us permission to dispose of your tissue."

A few years ago – before I had read the Moore case at UCLA – I probably never would have even noticed a sentence that referred to tissue disposal. Or if I did, I might have surmised that the hospital was being sensitive to persons who had certain traditional or religious beliefs about disembodied parts of their person. But now being keenly aware of the "tissue issue," I pointed to the sentence and asked: "what do you mean by 'dispose?'" "I dunno," was the response, "I guess they mean 'throw away'."

Next, I was escorted into a small room where a nurse prepared me for the test. I asked her about the consent form. She eyed me somewhat askance, and said she had no idea what I was talking about. She



wheeled me into a room where the procedure was to take place. There were a few people in the room – nurses and technicians – and for a third time, I started to ask my question. But just as I was framing it, the doctor bustled in, and I thought to myself, "well, now I'm going to get a precise answer." No, he wasn't sure either. And furthermore it was clear that he wanted me to be quiet so he could get on with his work.

I did not sense that any of these people were intending to deceive me. My feeling is that they were as ignorant as I about what might be done with my tissue.

So, how do I feel about collection and use of my human biological material? Well, I feel very different about myself as an 'intact person' than I do about disconnected part of me. If something is going to affect my 'intact body' – whether it may be beneficial, may cause some harm, or even be indeterminate – I want to know about it. I want to be able to consent to or refuse the procedure – whatever the procedure may be. And that, of course, includes, taking my biological material from me.

However, once those 'biological materials' are not longer connected to me, the urgency to control the uses of the materials is somewhat diminished. But not completely, because, as we now well know, these disconnected pieces of myself contain my story, my medical information. And not only my medical information but also medical information that may be about my parents, about my children, about my grandparents, about my grandchildren, my uncles, my nephews, and "my sisters and my cousins and my aunts....,"

Like a pebble thrown skillfully into a placid pond, the ripples, which contain medical information gleaned from my biological material, may eventually touch near and distant shores. This medical information may be a two-edged sword. One side may cause risks of wrongs or harms and the other side may bring about benefits. In our society – in our country – the most immediate risks that come to mind are those that are connected to the way in which we achieve, or do not achieve, access to healthcare – in other words, our discriminatory insurance practices. Will public knowledge about this medical information cause me, and my family, to be denied health insurance? Will public knowledge about this information cause me to lose my job? And, therefore also lose my health insurance? Will public knowledge about some particularity embedded in this medical information have the power to stigmatize a specific group that I may be a member of – African American, Asian, Ashkenazi Jewish– thereby creating job and insurance risks not only for me but also for a now identified population.

But as we know, medical histories are difficult to hide. I have an adult son who suffers from schizophrenia. His brothers and sisters can't pretend that he isn't ill. We don't hide him upstairs in our attic. He is a part of our every day lives, and we love him dearly. But don't think I am not aware that perhaps other families are not so keen to have their children marry one of his siblings for fear that their grandchildren may be so afflicted. I believe, that even as things now stand, it is unlikely that we can contain and hold private much of our bad or good news.

On the other hand, I consider that there may be important benefits to be reaped from research with my biological material. I want to be informed if researchers garner knowledge that may be significant for my health and/or my family's health. I want to be informed if research on my biological materials reveals knowledge consequential to my and to my family's health. I don't want to be left out of the loop.



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Of course, being kept in the loop is just the beginning. According to this past week's report as was noted in the NY Times: more than 100,000 hospital patients die each year from adverse drug reactions (more than from diabetes, pneumonia, or other serious illnesses), being kept in the loop may not do me much good. As Roy Porter, dryly notes: "The prominence of medicine has lain only in small measure in its ability to make the sick well" (*The Greatest Benefit to Mankind*, New York: Norton & Company; 1997, p. 6). Furthermore, you are likely to have noticed that "the more medicine achieves, the less it satisfies" (p. 3). But that is another story.