LORETTA M. KOPELMAN

CHANGING VIEWS OF PATERNALISM IN RESEARCH:
AIDS ACTIVISTS DEMAND CHANGE

I. INTRODUCTION

It is a pleasure to write on the occasion of a festschrift to honor the retirement of my longtime colleague and friend Stuart Spicker. The topic that I have chosen reflects his well-known interest in the activities of institutional ethics committees and institutional review boards. Developed over the last part of the twentieth century, these committees have several well-defined goals. They seek to educate people within their organizations on relevant moral and social issues, assess the moral justifiability of their institutions’ policies, and review troubling cases. Some of these committees evaluate the research conducted by their institutions and protect the rights and welfare of potential subjects in medical investigation, using the laws and social policies that have developed with the rising tide of medical research. There have been many changes in the area of medical research during Professor Spicker’s career. I will discuss how these research policies, although developed with many good intentions, have been challenged on the grounds that they are too paternalistic. While many identifiable groups have questioned these regulations, the most vocal has probably been the acquired immunodeficiency syndrome (AIDS) activists, and so their concerns are my main focus. AIDS has caused many changes over the last part of this century and altering research policy is one of the most important. The fight against unjustified paternalism and concern for people with AIDS are also longtime concerns of Professor Stuart Spicker, making this an even more appropriate topic.

Systematic evaluation of medical therapies was rare until the middle of the twentieth century when physicians demanded scientifically grounded means for determining what helped their patients. Consequently, more and more patients were enrolled in controlled testing of therapies. Some of these patients were helped and some harmed, but unquestionably the scientific evaluation of therapies resulted in great medical advances for society. Another result of this increased research was the development of social policies to protect the rights and welfare of potential subjects in medical investigation, using the laws and social policies that have developed with the rising tide of medical research.
of research subjects. These policies embody assumptions about how to gain informed consent and to protect people from harm. They also contain presuppositions about how to strike a balance between the importance of honoring people’s rights, the social utility of conducting good research, and the need to protect people who may be enrolled in medical investigations. In devising these policies defenders and critics often disagree about how to strike this balance. When do patients have enough protection from the enthusiasms of investigators? Do patients have so many “rights” that investigators cannot conduct safe and important research? Discussion of these policies and presumptions about how to balance important values have grown until a chorus of defenses and criticisms of these policies now raise fundamental questions about how to plan studies and to select, inform, and treat subjects. This confrontation reveals the important role of values in every aspect of medical research, including its methods and goals, and shows that values are not peripheral to science but integral to its methods and conclusions.

In what follows, I will consider how AIDS activists and investigators disagreed about how to balance the social utility of research with the need to find justifiable means to protect the rights and welfare of patients or research subjects. More specifically, they disputed whether to alter research policy about the selection of treatments to test, the design of studies, the selection of subjects, when to begin or end trials, and who should have a role in making these decisions. The debate, in part, was and still is about expertise but it is also about power and control.

Many investigators and policy-makers insist patient and research subjects need many protections for their own good, even where they may not understand that they need it. Activists, however, demand more control in the planning and testing of promising new treatments: they decry the paternalism of investigators who say they know best about when to test, who to select, and when to release promising new treatments. The AIDS activists have been among the most vocal in making demands that the establishment be more responsive to their concerns, and reject investigators’ claims that they best protect and assess subjects’ interests (Kopelman, 1994a, 1994b, 1994c).

I will argue that resolution of this debate centers upon whether research can be a cooperative venture between investigators and subjects or the advocates they select. Research should be viewed as a cooperative venture because subjects and their advocates bring other interests and considerations than those investigators may consider (Kopelman, 1994a, 1994b,