

Informed Consent in Medical Therapy and Research

Bernard Barber

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Reviewed by

Leslie H. Krieger

Department of Psychology

University of North Florida

Jacksonville, Florida 32216

Informed Consent in Medical Therapy and Research appears to be one of a series of books from Rutgers University which explores the nature of the relationship between human service providers and the consumers of their service. A 1978 work from Rutgers, *Client Participation in Human Services*, was a broad exploration of consumer rights and professional responsibilities which introduced the "Prometheus Principle: Knowledge, power, and responsibility should be shared by all parties engaged in offering human services with those receiving such services."

The current Barber book, while clearly within the Prometheus theme, is focused very narrowly on the single issue of informed consent in medical therapy and medically-related research. Unlike the writers of Prometheus who took a radical stance with regard to the restructuring of all professional-client relationships, Barber makes more modest proposals for allowing patient consent to what will happen to him/her without basically changing the traditional patterns of relating in a medical environment.

Barber's book is based on a great deal of scholarship and primary research findings, and this admirable rigor is at once both its strength and its limitation. When Barber draws a conclusion, that stance is grounded in extensive data collection, but somehow he never sees outside the traditional medical and legal sources to recognize the limitations they impose on his perspective. He does not argue as do the Prometheans, that the client be not only fully informed, but also a co-generator and owner of all that is learned about him/her and done with him/her. He settles instead for the recognition that if informed consent were truly given in the doctor-patient relationship, other components of that relationship would also improve.

Actually, in spite of the differences in scope and approach, there are

three important parallels between Barber's writings and those of the Promethean authors. First, each goes outside the immediate provider-consumer dyad to a broader context for analysis of what is really going on in the relationship. The Prometheus writers draw primarily from psychological constructs, probing the personal needs of dyad members and others in their social matrix. Barber employs a formal social systems analysis, looking carefully at each component which supports the roles of physician and patient.

Secondly, each acknowledges that professional practice is embedded in contextual values which support some practitioner behaviors while proscribing others. Barber looks to social philosophers and also public opinion polls for the sources of values which relate to providing informed consent. The Prometheans see values emerging both from our technology and our subconscious and find them forged in the inevitable confrontation of the two.

The final parallel is the identical discoveries that our contemporary concern for personhood is at the root of the present discontent with provider-consumer relations. More than anything else, Barber tells us, informed consent is designed to allow the individual some autonomy in decisions affecting his or her person.

Barber's book is a formal, well-worked-out presentation of the issues surrounding informed consent. After rejecting much earlier research as limited or naive because it failed to recognize that the entire social system in all its complexity supports any principle within that system, he spells out the approach he feels is necessary for understanding the status of informed consent. "We shall look at the values and norms, the legal principles and the rules, the communication structures and patterns of understanding and misunderstanding, the authority relations, and the contexts of informal and formal social control that determine the relations among the many participants in the medical research system and result in better or worse processes of informed consent."

As Barber explores the various social system components, it becomes clear that the principle of informed consent is often in competition with other principles equally worthy or compelling. The need to provide help in an emergency and the need for reliable scientific knowledge are examples of societal principles which may in some situations vie for primacy with informed consent. Barber presents no clear-cut value prescriptions for employment in such dilemmas; instead, he encourages open and frank dialogue among professional and lay people alike to sharpen sensitivities to the various principles and their supporting values.

Much of Barber's description of current medical practice and especial-

ly the powerlessness of the patient is frightening. Both his rigorous research findings and reported anecdotes point dramatically to the need for increasing patient understanding and autonomy in treatment and research situations. Yet Barber's remedies appear rather limited; increasing informed consent is seen as adequate solution to patient powerlessness and abuse. Never does he lift his vision beyond very traditional role conceptions; never does he propose redefinitions as radical as those offered by the Prometheans who preceded him.

Perhaps the difference in vision between Barber and the Promethean authors is related to the philosophical and political climates at the time each was writing. Prometheus first saw the light of day at presentations to the American Psychological Association in the early 1970's, a period when radical idealism was a viable stance. Barber's more limited perspective and remedies within the system reflect well the conservative realism of 1980.