

Misconceived bioethics?: The misconception of the “therapeutic misconception”[☆]

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Abstract

Bioethics needs to include study of the social and historical context in which ethical meanings in medical encounters make sense. It needs to do this in order to remain relevant, vibrant, and aware of how it might unwittingly facilitate the agendas of others. As an illustration, this paper critiques some of the accepted meanings and purposes of the idea of the Therapeutic Misconception (TM) which has been an increasingly attractive concept with which to organize thinking about experimentation ethics. By considering the history of alternative viewpoints against which TM was offered as a replacement, this paper suggests that TM, and bioethics more generally, may contribute to increasingly technocratic and standardized practices in medicine.

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Historians, anthropologists, and sociologists are beginning to focus more concerted criticism and concern over the practice of “bioethics”. (Evans, 2002; Hoffmaster, 2001; Martenson, 2001; Belkin, 2001, 2004; McCullough, 2000; Chambers, 1998). The concern is that the increasingly formalized and institutionalized set of writings, methods, and organizations that fall under the bioethics umbrella may be missing salient aspects of what makes a moral dilemma, a dilemma. Work in bioethics is often reduced in practice to spinning analytic normative constructions or building consistent networks of theory or principle isolated from how commitments to the rightness or wrongness of a given medical intervention actually form and cohere in the real world. Personally specific, emotionally and psychologically shaped, and culturally and historically situated, knowledge and practice often does, and should, resolve contentious medical decision making. But what the “bioethicist” supposedly knows does not generally include serious familiarity with or exploration of such psychological, cultural, and social factors. This critique echoes challenges from some prominent thinkers working within moral philosophy itself, such as Charles Taylor’s insistence that moral beliefs are things one *has* rather than *proves*, challenges within bioethics to focus on more context-based, casuistical, care, and narrative ethics approaches, and prominent skepticism in the popular press as to what bioethicists really “know”. (Taylor, 1984, Stolberg, 2001; Satel & Stolba, 2001; Smith, 2000; Shalit, 1997.).

We need more efforts to understand ethical claims as social, cultural, psychodynamic, and historical events that are incompletely understood and debated via the methods and questions bioethics has generally brought to the table. As an example of how such alternative perspectives, in this case historical ones, might change and expand the ethical

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discussion, I will focus here on one prominent idea in the bioethical toolkit, particularly in American discussions, that of the Therapeutic Misconception (TM). Coined by Applebaum and colleagues in the pages of this journal over two decades ago, TM is a central part of the lexicon of experimentation ethics. What might be gained by using historical research to think about TM? Revisiting the conditions that spawned questions and conclusions different than those TM reflects, alters how we should regard TM, and perhaps bioethics more generally. Rather than being the fruit of ethical maturation, TM may instead conceal and further larger, concerning, historical changes: specifically the standardization and commodification of medical practice. These are changes especially prominent in the American context. This in turn highlights the possible technocratic, rather than democratic or introspective, consequences of bioethics.

1. The therapeutic misconception

It is almost impossible to discuss the ethics of experimentation without some explicit or implicit reflection on TM. This is because it neatly captures and orders a variety of ethical concerns, such as how much an “experiment” should benefit its subject, deviate from usual treatments, address important scientific questions, or pose risk.

TM organizes thinking about these issues by focusing on the degree that research is different from usual clinical practice. Briefly put, TM describes the misconception subjects may have that research is treatment. The TM conception of research practice is that what makes research ethically unique is that it involves interventions not primarily intended to be of optimal value to subjects. It is never ethically equivalent to treatment. Treatment choices made outside of a research context can be tailored to meet the needs of individuals in ways that research, even so-called “therapeutic” research, is restrained from doing. Research is an artifice created primarily to pose questions in rigorous ways, not to meet the needs of subjects. TM seems, to many, to resolve perceived limitations encountered when relying on other ethical frameworks or emphases—such as distinguishing between research that involves treatment and that done “just” for gaining knowledge, or focusing on the comparison between the level of risk of a research project with its scientific value.

An ethical emphasis on TM reflects skepticism about the therapeutic–nontherapeutic distinction that guided, and often still guides, discussions of experimentation ethics. But that distinction faced criticism as inadequate conceptual scaffolding upon which top rest a commitment to the primacy of subject autonomy that increasingly characterized discussions of human subjects ethics through the 1970’s and beyond. TM instead focuses on the belief that human subjects research, whatever the beneficial byproduct to individual patients or to society, however *similar* to accepted treatment, and regardless of how low the risk or great the value, still remains a use of subjects for the purposes of others. At a minimum, then, research can only be justified when research subjects can fully recognize that they are being “used”. Participation by subjects should not be merely consented, but *willed*. No matter how much a patient may benefit from, or appropriately receive treatment within, a research protocol, a protocol inherently describes a way of being treated that is distinct from real treatment. The integrity of research is fundamentally tested in its ability to convey this stark fact. This logically follows as an extension of the precept to treat others only as ends in themselves, and to enhance the agency of the willing subject.

This set of commitments summarized under the thumbnail phrase of “TM” plays an important role in increasingly effective efforts to move away from the previously dominant risk/value or therapeutic/non-therapeutic distinctions which shaped discussions of research ethics and deliberations of Institutional Review Boards (IRB’s). For example, attempts to question the false therapeutic promise of clinical trials (Miller, 2000; Miller & Brody, 2003) as well as calls for required independent review of competency to consent for mentally ill participating in studies posing more than minimal risk irrespective of therapeutic benefit, reflect such efforts (National Bioethics Advisory Commission, 1998). Indeed, widely (and heatedly) discussed efforts by President Clinton’s National Bioethics Advisory Commission in the United States to require such competency review (a subsequently growing practice), explicitly connected itself to a history of evolving efforts to question received rules governing IRB guidelines which relied upon therapeutic/non-therapeutic distinctions. (National Bioethics Commission, Appendix I, 1998; Capron, 1999). While the Commission disbanded with the election of George W. Bush, such heightened scrutiny has been widely pursued and advocated since, and the degree such a prominent effort explicitly invoked an apparent historical evolution away from reliance upon therapeutic/non-therapeutic distinctions, deserves attention.

That particular use of history was a superficial one. As I will discuss here, a more careful history leaves us with far more ambiguous conclusions about what should count as welcome ethical “progress”. Bioethical writings frequently make historical claims to celebrate and justify the appearance of the field, rather than to examine and perhaps

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