Evolving Misconceptions in Research

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Refinements, Elaborations, and Clarifications

- Confusion over the purpose of research is a central component
- Some elaborations incorporate overestimation of benefits and underestimation of risks
- Problems in elaboration
  - Types of beliefs (frequency vs belief)
  - Distinctions among different types of misunderstandings and misconceptions

The Therapeutic Misconception: Informed Consent in Psychiatric Research

Paul S. Appelbaum, Loren H. Roth, and Charles Lidz*

Concept | Definition
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Therapeutic Misconception | The research subject conflates research with clinical care.
Therapeutic Misestimation | The research subject underestimates risk, overestimates benefit, or both.
Therapeutic Optimism | The research subject hopes for the best personal outcome.

The Original Description of TM
A Departure from ‘Personal Care’

“research subjects will assume (especially, but not exclusively, in therapeutic research) that decisions about their care are being made solely with their benefit in mind… This mind-set on the part of subjects we shall refer to as “the therapeutic misconception.”

The Research Misconception
Joseph R DeMarco and Maurie Markman

“good research is consistent with good therapy; that often trials are good therapy; and that a blanket attack on clinical trials as non-therapeutic creates a research misconception.”
A Consensus Definition of TM

“Therapeutic misconception exists when individuals do not understand that the defining purpose of clinical research is to produce generalizable knowledge, regardless of whether the subjects enrolled in the trial may potentially benefit from the intervention under study or from other aspects of the clinical trial.”


And more?

- HIV Cure research
  - Curative misconception
  - Arguably TM
- Pragmatic clinical trials
  - Investigational misconception
  - Experimental misconception

Misconceptions in Pragmatic Research

- Investigational misconception
  - All research tests new, unvalidated interventions
  - All research involves placebo-controlled trials
  - The goal of all medical research is to prepare new treatments for the market
- Experimental misconception
  - People have significant difficulty understanding aspects of pragmatic trials of commonly used medical practices

Preventive Misconception

“the overestimate in probability or level of personal protection that is afforded by being enrolled in a trial of a preventive intervention.” There are likely two general subtypes of PM: (1) overestimation by the research participant of the probability that he or she receives the experimental intervention rather than placebo, and (2) overestimation by the research participant of the “personal effectiveness” of the experimental intervention.


Emerging Data about Potential Misconceptions in Pragmatic Research

- Investigational misconception
  - Kraft et al: 3% (60/2163)
- Experimental misconception
  - Weinfurt et al: 59%
Some Preliminary Observations

- Misunderstandings are prevalent in many types of research and clinical practice
- These misunderstandings are understandably influenced by context
- Misconceptions in pragmatic research paradoxically suggest some ‘research literacy’ or at least conventional research familiarity (in contrast to concerns sometimes raised with TM)

Towards Understanding Potential Misconceptions in Pragmatic Research

- Need for clear definitions that are sensitive to lessons learned in grappling with other ‘misconceptions’ in research
- Important to assess the nature of such potential misconceptions in the context of actual research and whether they differ with increased familiarity and experience with pragmatic research