A Context for Ethical Care in Mental Health Research

A review of

Ethics in Mental Health Research: Principles, Guidance, and Cases
by James M. DuBois

Dialogues in Behavioral Health Research Ethics: A DVD Series to Facilitate Ethical Action
James M. DuBois and Jean Campbell (Directors)

Reviewed by
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One of the most challenging aspects of our work as researchers in the mental health field is understanding and navigating the complex issues of ethical care of research participants. The challenge involves balancing care and respect for human participants with our research mandate to generate new knowledge. As noted by DuBois in the introduction to *Ethics in Mental Health Research: Principles, Guidance, and Cases*:

> The main ethical conflict in human research is not typically between good and evil, but between competing goods—such as the good of safe research and the good of knowledge gained from research. Balancing competing goods can be extremely difficult in a world categorized by uncertainty, a world with a history of surprising harms and serendipitous discoveries. (p. 6)

In a thoughtful and methodical way, DuBois lays a foundation for (a) reviewing the history of research ethics in the social and behavioral sciences, (b) recognizing the variety and complexity of ethical issues at every stage of the research enterprise, (c) understanding the social context and pressures that influence research design decisions, and (d) making informed ethical decisions based on prioritized principles for research ethics. By providing a clear and concise text (*Ethics in Mental Health Research*), a three-disk DVD set (*Dialogues in Behavioral Health Research Ethics: A DVD Series to Facilitate Ethical Action*), and a user-friendly website (http://www.emhr.net/), DuBois succeeds in providing a comprehensive and interactive course on research ethics. Let me state at the outset that this compendium of resources is a landmark contribution to the mental health field.

James M. DuBois is the Hubert Mader Endowed Chair and department chair in health care ethics at Saint Louis University in St. Louis, Missouri. His recent book and DVD (the latter coproduced with Jean Campbell) were developed as part of an ethics course funded by the National Institute of Mental Health (NIMH). DuBois says that the course is designed for people who conduct and review mental health research, which I interpret to include a broad and expansive group: students in the behavioral, social, and medical sciences, professional journal readers, journal board members and editors, grant reviewers, institutional review board (IRB) members, and community (including culturally indigenous) elders and research advisors.

**Text and DVD Organization and Flow**

*Ethics in Mental Health Research* is a manageable length (236 pages) for a full-semester course (my preferred use). The book has two major sections and 10 chapters. Part 1 includes the first three chapters and lays a thorough theoretical foundation for Part 2, which presents seven chapters on applied topics. More specifically, Part 2 addresses informed consent,
decision-making capacity and the involvement of surrogates, risk–benefit analyses, recruiting participants, research design, privacy and confidentiality, and managing conflicts of interest.

Part 1 of the text highlights the critical need for mental health research. For example, DuBois quotes from an NIMH survey that found that “an estimated 26.2% of Americans ages 18 and older—about 1 in 4 adults—suffer from a diagnosable mental disorder in a given year” (p. 3). The need for expanded mental health research, and the corresponding need for the profession and society to protect participants involved in research, is made quite clear. The scope of the book's coverage, namely research on participants who have mental health disorders (including substance-abuse and developmental disorders), is delineated in Part 1, and a thorough historical review of research ethics and regulatory procedures is presented.

In this regard, DuBois covers significant ethical codes, commissions, and reports, and notes the context for their development. For example, he reviews how the Nazi doctor trials led to the Nuremberg Code, how the Tuskegee study of untreated syphilis led to Congress's establishment of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and the ensuing landmark Belmont Report, and so on.

Though reading about various commissions, reports, and official documents can be tedious, DuBois brings the discussion alive in the DVDs, where he, Jean Campbell, and assorted expert guests talk the viewer through the text material. I found the DVDs to be riveting and well paced; they helped me integrate the material and understand the historical and cultural context that gave shape to our evolving ethical codes and procedures.

Part 1 also includes an excellent discussion of the Belmont principles and DuBois's extended and “humanized” interpretation and application of these principles. DuBois anchors his ethical framework for mental health research around the core principle of “respect for human beings” (p. 31) and then segues into a clear discussion of linked principles of autonomy (humans as rational and self-determining), beneficence (humans as finite and in need of goods), nonmaleficence (humans as vulnerable to harm), justice (humans as equal in value to one another), and relationality (humans as intrinsically related to one another and community).

This final principle, relationality, is an additional principle (not discussed in the Belmont Report) that highlights the expanded cross-cultural application of DuBois's ethics framework. Some of the original ethical principles could be criticized as applying more to a Western or Anglo worldview, one that prioritizes self and individualism over self–other interconnectedness and collectivism (see Ponterotto & Grieger, 2008; Ponterotto, Utsey, & Pedersen, 2006). Thus the principle of relationality might be central to collectivist cultures, such as representatives of Native American, African, and Asian value systems. The level of cultural awareness, sensitivity, and knowledge demonstrated by DuBois and his DVD guests is a noteworthy strength of this “ethics course.”
The last chapter of Part 1 and all of Part 2 rely on a case study approach to explore critical areas for ethical consideration. Details of cases used as discussion points include the Willowbrook hepatitis study (highlighting the case study approach to analyzing ethics theory), withholding information on a study's purpose (highlighting informed consent), questionable consent and waiving parental permission (decision-making capacity and the use of participant surrogates), suicidality with at-risk teens (weighing potential harms versus benefits), reimbursing participants for their time in a psychotherapy trial and a case on a biological study of aggressive behavior in preteens (justice in recruitment and research), the ethics of placebo controls (study design questions), and confidentiality and mandatory reporting (privacy and confidentiality).

The final chapter of the book reviews the importance of identifying and managing potential conflicts of interest or competing interests in research. Each of these chapters presents an overview of major issues, an up-to-date review of the related literature, and a thoughtful application of DuBois's ethical framework to the case. Once again, the DVDs flesh out the discussion of these critical ethical issues in an engaging and thorough manner.

**Strengths of the Book and DVD Set**

As I have hinted throughout this review, there are many unique strengths to this ethics training package. I summarize these below.

1. Taken together, the book, DVD set, and website provide a comprehensive and accessible course on research ethics in mental health research. The book is fluid, well written, meticulously copyedited, and extremely up to date in terms of regulatory mandates, empirical research, and classic and new ethical case studies. Furthermore, the DVD set is professionally produced and a pleasure to watch and navigate. Seeing and hearing DuBois, Campbell, and a host of renowned ethics research experts (i.e., Diane Scott-Jones, James Korn, Dorothy Webman, Joan Sieber, Vetta Thompson, Gerry Koocher, and Phil Candilis) talk about ethics history, issues, and challenges made the learning for me (and the students to whom I showed parts of the DVD) more personal and meaningful. Throughout the DVD there are clips of focus groups that allow us to hear research participants' perspectives, experiences, and suggestions for proper ethical treatment of participants.

   Finally, I found the website (www.emhr.net) to be a valuable resource for expanded discussion on the many issues covered in the text and DVDs. The website includes virtually everything a student, researcher, or mental health administrator could ask for, including ethical codes of various professional organizations, reviews of a wide variety of cases across the spectrum of ethical principles, and a supporting bibliography for additional reading.

   2. Both the text and DVDs demonstrate good balance in terms of highlighting the ethical pros and cons of possible research design decisions. In most cases, the ethical issues
and research design decisions are not clear-cut, and numerous factors must be weighed as researchers and review boards evaluate a project's goals and methods. Ethical challenges and research designs are embedded within a chronological and cultural context.

For example, it is easy now to condemn early studies on electroshock therapy or lobotomy, yet DuBois and his colleagues describe the Zeitgeist that led to desperate attempts to relieve intense human suffering (in fact, the developer of the frontal lobotomy technique was awarded the Nobel Prize). Similarly, we can now easily question the ethics of the Milgram shock studies or Zimbardo's Stanford prison studies, yet these researchers were trying to design studies to help understand what could lead humans to treat other humans so inhumanly (e.g., trying to understand “obedience to authority” common in the Nazi treatment of Jews and others). DuBois highlights that ethical challenges are always evolving and researchers must have a solid, principle-based framework to help guide them as they weigh research choices and decisions, and potential study benefits and risks.

3. While always presenting a thorough and balanced analysis of a particular ethical vignette, DuBois is not afraid to render his analysis and opinion regarding the preferred ethical choice of action. He is direct and clear in his systematic analysis of ethical issues presented in the each vignette.

4. It is important that racial/ethnic and cultural issues are infused throughout the text and DVD set. Additionally there is a full DVD segment on cultural competence. Focus group participants shown on the DVD represent a diverse racial and socioeconomic background.

**Limitations**

DuBois has achieved all he set out to accomplish in *Ethics in Mental Health Research*, and, with the cooperation of Jean Campbell, he has produced an engaging DVD series to flesh out discussion on the book's main points. DuBois's contribution has made learning about research ethics interesting and engaging. Though I do not see specific limitations to DuBois's recent contribution given his stated book goals, I would like to see his work and discussion extended to alternate research methodologies, especially qualitative research.

DuBois does note that his book and DVD do not include discussions of qualitative research. Nonetheless, I believe it is critical, given the increasing momentum of qualitative research in mental health (see various chapters in Willig & Stainton-Rogers, 2008), that a broadened discussion of research ethics ensues. Given the often intense, personal, and prolonged interaction between researcher and participants in many qualitative designs, additional and unique ethical challenges emerge (see Haverkamp, 2005).

Also, given DuBois's own principle of relationality (discussed earlier), quantitative research (e.g., experimental and survey designs) in and of itself raises methodological,
ethical, and cultural challenges when conducted in collectivist cultures. Mohatt and Thomas (2006) presented excellent examples of these challenges in their work with Alaska Native communities. For example, speaking to the limitations of quantitative research protocols, surveys, and instruments that attempt to isolate and measure particular behaviors, attitudes, or feelings, Mohatt and Thomas noted that

many traditional Native people or communities would not isolate behaviors, emotions, or cognitions and assign values to them, measure them, and interpret the results. Rather, many Natives believe in the connectedness of life, as an interesting balance between the autonomy of the individual and the importance of the community or collective. That is, they would not presume to isolate and identify behaviors, thoughts, or feelings with the intent to intervene in some manner. (p. 109)

Another mainstay of strong quantitative research, random sampling, poses additional challenges when applied in collectivist cultures. Speaking directly to this point, Mohatt and Thomas (2006) stated:

I believe that random sampling procedures violate a fundamental principle of every indigenous group with whom I have worked. It assumes that a statistical or mathematical rationale should determine whom we talk to or with whom we intervene…. [It is] exclusive and dangerous because not all members of the community would be included, and there would be no evidence of co-membership on the part of the researchers and therefore no sense of protection from harm. (pp. 110–111)

It is interesting that DuBois's (2008) extension of the Belmont principles through the addition of relationality provides a context to bridge his positivist anchored research discussion with collectivist-oriented cultural groups, and also to the myriad of constructivist–interpretivist qualitative methods that rest on intense researcher–participant interaction in the coconstruction of the participants' lived experiences. I would very much welcome and embrace a second edition of DuBois's book and DVD that would incorporate discussions of qualitative research.

In summary, the DuBois and Campbell collaboration represents a landmark contribution, not only to the mental health field, but to sociology, education, and nursing as well. The contents and cases covered by DuBois have many layers and are relevant across the social and behavioral sciences. The book and DVD are ideal for an undergraduate or graduate course in research ethics. I would pair the book with Trimble and Fisher's (2006) classic edited text on ethical research with ethnocultural populations to bring in more culturally diverse voices and a more balanced qualitative–quantitative coverage. The book could also be a supplemental text in general ethics courses that focus primarily on clinical
practice. I highly recommend the DuBois and Campbell ethics course package to my colleagues across disciplines.

References


