

CASE STUDY

Ethical Issues in Research on Mental Disorders (Session IV 1430-1800)

Session Convener: Doug Wassenaar

Preamble

Several guidelines exist concerning research on mental disorders. These offer various approaches to some of the specific questions that arise in this area. However, several additional questions arise that are not always explicitly dealt with by such guidelines. These additional questions include ethical issues concerning disorders whose definitions are unclear and which themselves are the subject of ethical debate. There is also ongoing debate about the proper management of some of these disorders with regard to their impact on civil liberties. Some argue that the legal framework surrounding the treatment of mental illness is itself unethical. Furthermore, mental disorder and mental illnesses are the research focus of a wide and often competing range of disciplines ranging from criminology to neurology, employing a range of methodologies from focus groups to neurosurgery.

Some of the key issues addressed in most guidelines relate to ways in which research on mental disorders differs from research on other disorders. The research differences are based on the conceptualisation of ways in which mental disorders differ from other health and social problems. The main difference identified in most guidance relates to differences in competence and capacity to consent. Most of the special guidelines assert that capacity to consent is more likely to be impaired in mental disorders than in other health and social research. Most of these guidelines stipulate or recommend special procedures for researchers and investigators to follow in conducting research on persons with impaired capacity or competence. (In general, *capacity* is a clinical term referring to ability to understand, retain and use information in decision-making, while *competence* is a legal term which is much more categorical than the clinical term).

Note: This session of the GFBR should on the whole be confined to research with adults, as research with children with mental disorders typically raises a further level of complexity.

Purpose of the session:

The purpose of this session of the 8th Global Forum on Bioethics is to revisit and consider some of these ethical issues in the light of existing guidance, and also to determine their relevance to developing country settings.

Four small groups will be convened to debate and report on the following key questions:

- 1) From the point of view of researchers and research ethics committees, what, if any, are the major ways in which mental illness itself differs from other health problems?

- 2) What, if any, are the main ethical implications, for research, of the problems with capacity and competence that are likely to be associated with mental disorder?
- 3) Should there be special precautions and/or procedures for the ethical conduct of research with mentally disordered persons who have diminished capacity and competence? If so, what should these special precautions and procedures be?
- 4) Are there special issues in research on mental disorder that arise in developing country/under-resourced settings? If so, what are these and what additional measures do they require?
- 5) Each group would also be encouraged to report on any other issues that arise in its deliberations.

Format of the session:

1430-1440: Introduction to this session & introduction of plenary speaker

1440-1500: Plenary speaker **Rodrigo Salinas** (Chile)

1500-1515: Questions from floor.

1515-1630: Breakaway groups each addressing questions 1-4 above. Each breakaway group will be moderated by a mental health practitioner. Each group will appoint a moderator who will report back to the plenary session, preferably using electronic media to ensure capture of breakaway discussions.

Moderators: **Dafna Feinholz** (Mexico), **Athula Sumathipala** (Sri Lanka), **Dinesh Singh** (South Africa), **Joseph Millum** (USA).

1630-1700: Coffee/tea

1700-1745: Report back from breakaway groups via electronic media.

1745-1800: Discussion from floor & close.

(Session chair plus group rapporteurs to capture electronic notes and write up key points from breakaways and plenary discussion for later group publication of a discussion paper via GFBR secretariat.

1830 Dinner/social event

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References:

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