Abstracts of Note: The Bioethics Literature

This section is meant to be a mutual effort. If you find an article you think should be abstracted in this section, do not be bashful—submit it for consideration to feature editor Kenneth V. Iserson care of *CQ*. If you do not like the editorial comments, this will give you an opportunity to respond in the letters section. Your input is desired and anticipated.

Richards HM, Schwartz LJ. Ethics of qualitative research: are there special issues for health services research? *Family Practice* 2002;19(2):135–9.

Although the volume of qualitative research published in medical journals has increased, along with discussions of its methodology, there has been relatively little discussion of the ethical issues surrounding this type of research. This is in marked contrast to the extensive debate over these issues in the social sciences literature. The British authors suggest that this lack of discussion may be due to the assumption among medical researchers and ethicists that qualitative research is unlikely to cause participants significant harm. Institutional research boards often have difficulty judging whether the qualitative studies they review are safe and ethical, in part because there are no standard guidelines for making these decisions.

The authors discuss four potential risks for participants in qualitative research studies: anxiety and distress, exploitation, misrepresentation, and identification of the participant in published papers. They then consider the ethical issues that arise when planning and carrying out qualitative healthcare research and offer a framework within which health services researchers can consider these issues. Their recommended strategies to reduce the risk of harm to patients include ensuring the study's scientific soundness, organizing follow-up care where appropriate, obtaining consent as part of the research protocol, ensuring patient confidentiality, and carefully analyzing the data. The authors recognize the reservations that many researchers have about applying strict ethical guidelines to qualitative research. However, they argue that research boards need agreed-on ethical standards so that the health services research community can adopt uniformly good practices. They also admit that empirical research is necessary to quantify the actual risks to participants in qualitative studies.

Bruera E, Willey JS, Palmer JL, Rosales M. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer* 2002;94(7):2076–80.

Physicians often believe that they know what their patients desire and so may limit their patients' participation in decisionmaking about their treatments. Yet studies of patient wishes have shown that even close family members often are unaware of an individual's desired treatments—including the most basic, such as whether this person wants resuscitative procedures when he or she is debilitated. That makes it almost axiomatic that patients and physicians will frequently disagree about patients' needs and the perceptions of their illnesses. The authors decided to assess how well physicians, who would be intensively caring for cancer patients, knew their patients' wishes regarding how involved they wanted to be in decisionmaking about further treatments. To do this, they surveyed 57 women with breast carcinoma after their first consultation with a medical oncologist specializing in breast cancers. At the end of the consultation, the patients were given a survey regarding their treatment decisionmaking preferences that included active, shared, and passive roles in decisionmaking. The patients' attending physicians also were given a survey regarding their perceptions of the patients' decisionmaking preferences.

Although approximately 89% of these women said that they preferred either an active or a shared role in decisionmaking, their physicians recognized the desire for such participation in only 24 cases (42%). The women's age, education, and income did not significantly influence their interest in participating in medical care decisions. The authors concluded that women with breast carcinoma appear to have a

Cambridge Quarterly of Healthcare Ethics (2003), **12**, 137–138. Printed in the USA.

strong desire for involvement in decisions regarding their treatment, but physicians do not appear to be consistently able to predict their patients' decisionmaking preferences. Not surprisingly, the authors suggested that improved communication would enhance patient satisfaction and, most probably, would also improve outcomes.

Kottow MH. Who is my brother's keeper? *Journal of Medical Ethics* 2002;28(1):24–7.

Third world countries often host clinical practices developed in and research designed by more developed nations. These practices have included performing placebo-controlled trials even though a "best-proven" treatment exists, distributing drugs that have not been approved in their country of origin, withholding existing therapies to observe the natural course of diseases, redefining and weakening equipoise in clinical trials, and denying the posttrial benefits of research medications to investigational subjects. Whereas developed, sponsoring countries have prohibited these practices—even in their own pockets of poverty with conditions comparable to third-world nations—the practices continue in poorer countries.

As Dr. Kottow from the University of Chile in Santiago points out, the latest version of the Helsinki Declaration decries a double standard for research protocols. He finds unsettling the number of recent articles by first-world scholars that have endorsed the policy of employing ethical norms for research and clinical practices in poorer host countries that sponsoring nations would deem unacceptable, both legally and morally. Although he admits that the actual practices have been subjected to frequent scrutiny and publicly decried when gross misconduct occurred (at least in some countries), he denounces the bioethics literature and its authors specifically for having developed ad hoc arguments that justify these practices through exceptions and variations from accepted moral standards. Rather than advocating moral relativism, Kottow argues that bioethicists should be endorsing a universal ethic to govern medical and pharmaceutical practices, research strategies, and biomedical research.

Gattellari M, Voigt KJ, Butow PN, Tattersall MH. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *Journal of Clinical Oncology* 2002;20(2):503–13.

Patient autonomy, with its element of informed patient decisionmaking, has become the basis for ethical medical practice in many regions of the world. These Australian authors attempted to determine the extent to which physicians informed their patients with incurable cancer about their prognosis and treatment options and how much they encouraged them to participate in treatment decisions. They tape-recorded the initial consultations of 118 cancer patients with incurable diseases with one of nine oncologists at two Sydney tertiary referral hospitals. They rated each interaction using a coding system to assess disclosure of information and to evaluate the doctor's encouragement of patient participation in treatment decisionmaking. The authors compared these results with a survey of the same patients' recall of the information provided, satisfaction, anxiety, and perceptions of their involvement in the medical decisionmaking process.

They found that the physicians informed most patients about the aim of anticancer treatment (84.7%), that their disease was incurable (74.6%), and about their predicted life expectancy (57.6%). Alternatives to anticancer treatments were presented to 44.1% of the patients, 36.4% were informed about how anticancer treatment would affect their quality of life, and 29.7% were offered a management choice. Yet, after delivering this often complicated and devastating information, the oncologists checked patient understanding in only 10.2% of the patients. Although greater information disclosure did not seem to elevate anxiety levels, greater patient participation in the decisionmaking process was associated with increased anxiety levels ($p = .0005$), which persisted over a two-week time span. These authors concluded that, although most of these patients were well informed, problems in how the oncologists presented information about prognosis and alternatives to anticancer treatment may suggest that the patients were being directed toward anticancer treatment.