Autonomy

In the United States, Human Rights Watch has documented widespread inappropriate use of antipsychotic drugs in older people in nursing facilities, often without informed consent. Our report, "They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia," is based on visits to 109 nursing facilities, mostly with above-average rates of antipsychotic medication use, in six states.

Every week, more than 179,000 people in nursing homes in the United States are given antipsychotic drugs even though they have not been diagnosed with any condition for which their use is approved. Often, facilities administer the drugs without making any effort to seek informed consent. Many nursing homes use these drugs not to treat a specific medical condition—such as psychosis or a neurological disorder—but because of their sedative effect. Antipsychotic drugs make nursing home residents easier to control by pacifying and sedating them.

While these symptoms can be distressing for the people who experience them, their families, and nursing facility staff, evidence from clinical trials of the benefits of treating these symptoms with antipsychotic drugs is weak. More importantly, studies find that on average, antipsychotic drugs almost double the risk of death in older people with dementia. When the drugs are administered without informed consent, people are not making the choice to take such a risk.

The federal Nursing Home Reform Act does not provide for express, written informed consent. However, it provides for the right to be fully informed of one's health status; the right to participate in treatment planning; the "right to be informed in advance, by the physician or other practitioner or professional, of the risks and benefits of proposed care, of treatment and treatment alternatives or treatment options and to choose the alternative or option he or she prefers"; and the right to refuse treatment.[1]

Human Rights Watch, however, found that even in cases where it clearly would have been possible for nursing facility staff and attending physicians to seek informed consent, doctors and facility staff failed to seek it from the individual or their proxy. In some cases where a health proxy was heavily involved in the individual's care, the facility or practitioner sought consent but never provided sufficient information for consent to be informed.

Our research suggests that in other cases, facilities that purport to seek informed consent put pressure on individuals, or play on feelings of guilt, to obtain consent. This is a serious abuse of the right to informed consent and of several federal regulatory requirements.

[1] Resident Rights, Code of Federal Regulations, Title 42, https://www.law.cornell.edu/cfr/text/42/483.10 sec. 483.10(c).

International human rights standards require that medical interventions should be carried out only with free and informed consent.[2] This right arises from an individual's right to decide what is done with his or her own body.[3] In 2013, Juan Mendez, then the UN special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, warned of the danger of human rights violations in the healthcare setting where the perception persists that "medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose, may constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned."

We have recommended that US regulators, to the greatest extent of their authority, require free and informed consent from the individual whose care is concerned, including with support as needed in the decision, or their appointed representative, as long as this representative is chosen freely and is tasked with reflecting the individual's will and preferences.

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[2] Please see Section V of "They Want Docile," "International Human Rights and US Law," at p. 93. "'Dignity Must Prevail' – An Appeal to Do Away with Non-consensual Psychiatric Treatment World Mental Health Day," press release, UN Office of the High Commissioner for Human Rights, October 10, 2015, http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16583 (accessed September 11, 2017); Human Rights Council, Report of the special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, February 1, 2013, A/HRC/22/53, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf para. 28 ("Guaranteeing informed consent is a fundamental feature of respecting an individual's autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services.").

[3] *Schloendorff v. Society of New York Hospital*, Court of Appeals of New York, No. 105 NE 92, 211 NY 125, Judgment, April 14, 1914, para. 4. ("Every human being of adult years and sound mind has a right to determine what shall be done with his body, and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.")