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Human rights in patient care: a theoretical and practical framework

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Introduction

Patient care is a discrete and important aspect of the right to health that merits attention and scrutiny as a human rights issue. A vast and severe range of human rights violations occur in the patient care context that violate rights in addition to the right to health, including many civil and political rights. In response to growing concern about this abuse in many parts of the world, the phrase and concept "human rights in patient care" has recently grown in usage as a framework for monitoring, documenting, and analyzing abuses in patient care settings, and in some cases, holding governments and other parties accountable. This article outlines a framework for human rights in patient care that is closely related both to the right to health and to the more colloquial notion of "patients' rights" but is distinct from them—as well as from complementary frameworks such as patient safety and bioethics—in important ways.

Instead of the humane and appropriate health care expected, patients and health providers in many settings encounter a variety of abuses that affront basic human dignity and jeopardize health outcomes. These abuses range from pervasive violations of patients' rights to informed consent, confidentiality, privacy, and non-discrimination to more egregious abuses, including torture and cruel, inhuman, and degrading treatment. Health providers likewise may face abuses such as unsafe working conditions, sanctions for providing evidence-based health care, limits on their freedom of association, and denial of due process when patients make complaints against them. The concept of human rights in patient care refers to the theoretical and practical application of general human rights principles to the patient care context, particularly to interactions between patients and providers. It applies rights principles universally to a context or setting. While centered on patients, it does not limit rights to a particular group of people.

Monitoring

Dorland's Medical Dictionary defines "patient care" as "the services rendered by members of the health profession and non-professionals under their supervision for the benefit of the patient." This differs from "health care," where services are provided "for the purposes of promoting, maintaining, monitoring, or restoring health." Patient care highlights patients as fundamental agents and the ultimate beneficiaries of services. The focus on patients, while not exclusive, is consistent with the way the human rights approach helps to identify and address vulnerabilities. The human rights lens reveals issues of discrimination and social exclusion that often underlie abuse against patients. This is critical, since abuses against groups such as people living with HIV, ethnic minorities, sexual and gender minorities, people who use drugs, and people with disabilities are especially rife in health settings.3 Often these abuses are related to the perception of groups as deviant or in need of curative forms of "treatment," leading to horrific abuses in psychiatric facilities, drug rehabilitation centers, detention centers for sex workers, and similar settings.

In a recent report, the Special Rapporteur on torture recognized the particular vulnerability of marginalized groups to torture and ill treatment in health settings, citing "[s]tructural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination." The Campaign to Stop Torture in Health Care, launched in 2011 by a coalition of organizations working in the fields of health and human rights, highlighted some of the most egregious of these abuses such as forced sterilization of Roma women and women living with HIV, forced detention and punishment of people who use drugs, and unjustified denial of pain relief.