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Written Informed Consent: The perspective of Young, University-Educated Users.

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Abstract

Background: According to the Consensus Conference on Written Informed Consent (WIC) organized by the Spanish Ministry of Health and Consumer Affairs in 1993 and the WIC agreement adopted by Regional Governments in 1995, the policy objectives of implementing WIC are to assure quality health care, to inform patients and their relatives, and to help patients participate in the clinical decisions affecting them. A previous study of physicians' perspectives of WIC in hospitals of the Region of Madrid highlighted 2 crucial patient-dependent factors in the process of transmitting information and decision making: patient age and educational level. This paper focuses on the perspective of young, university-educated hospital users about WIC.

Objective: To explore what young hospital users with university- level education think about WIC and how they perceive their own role and the physician's role in the WIC process.

Methods: Qualitative research techniques: A structurally representative sample was designed, and 2 discussion groups were held with hospital patients under 45 years of age and with university studies, residing in the Region of Madrid. Patients must have had contact with a hospital in the Region during the 6 months before the study began. The resulting discourse was subject to semiological analysis to explore the users' social representation and perception of WIC.

Results: These hospital users identify WIC as a tool to protect physicians from judicial action/control in case they make a mistake in handling a patient. They do not believe it is used to involve the patient in decision making. The kind of information offered in WIC is considered to be inadequate and even harmful: the aim is more to obtain permission than to make an informed decision. Users feel obliged to sign WIC forms because they have become *sine qua non* for access to treatment. The information in WIC forms is seen not as empowering but as threatening, thus many patients prefer to ignore it and just sign whatever is requested. They affirm that physicians do not usually get involved in this process and that WIC is most often administered by auxiliary staff. Some patients do, however, describe situations in which they have received relevant information and have been at least able to understand the physician's choice. These cases rarely result from the physician's initiative, but are more often the consequence of the patient's willingness to know. The discourse of those hospital users is much richer regarding how to get information from physicians than about decision making. They are asked to decide only about "trivial" matters. In the patients' view, such a lack of experience in participating in substantive decisions causes them to have weaker opinions regarding decision making. Thus they are unsure about the importance of patient involvement in clinical decision making.

Conclusions: From the user's point of view, WIC is completely separate from communication, information and decision making. The information related with WIC is not empowering but threatening for the patient. WIC is recognized only for its defensive function, so that it serves the needs of physicians more than patients. Users' even tend to consider WIC as a betrayal of their basic right to register a complaint if something goes wrong.

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