

Opinions of health care professionals and laypeople in Greece about informed consent for research on medical practices regarding Tourette syndrome

Vaitsa Giannouli¹

¹School of Social Sciences, Hellenic Open University

Background and aim:

Attitudes towards persons with Tourette syndrome and informed consent for research on medical practices has not been investigated in Greece in the general population as well as in health care professionals including physicians, psychiatrists, psychologists, nurses and social workers.

Methods:

Participants completed a translated modified version of a survey questionnaire by Cho et al. (2015) consisting of 43 questions, which were divided into four groups: general questions, questions regarding a medical records review scenario, questions regarding a diagnosis such as Tourette syndrome and its treatment, and questions about a more serious hypothetical health condition (without the presentation of relevant videos as was the case in the original study by Cho et al. study) along with a detailed demographics questionnaire.

Results and Conclusions:

- Results revealed statistically significant differences in the responses for all aspects of attitudes toward informed consent between these two groups.
- Greek participants with no formal healthcare education reported more negative attitudes when compared with the attitudes of healthcare professionals.
- In addition, most of the participants reported lack of educational experience regarding informed consent in general and more specifically in Tourette syndrome.
- The possible implications of personal beliefs over the ethics of informed consent and pharmacological management are discussed regarding children and adults with Tourette syndrome.
- Relevant initiatives by the Greek State, private institutions, and/or the Greek Medical Societies should refocus and emphasize on educational programs concerning the dissemination of relevant scientific information on informed consent processes.
- Future research should further investigate in more depth the complex influence of additional social and/or psychological factors for the reported differences in different cultural contexts.

Response	Laypeople (n=100)	Healthcare Professionals (n=98)
Trust Q3: We would like you to think about patient trust experienced by patients with Tourette Syndrome. To maintain their trust as a patient, how important is it that the doctor tells them when he/she is uncertain about which treatment is best for them? Very important to maintain their trust Moderately important to maintain their trust Somewhat important to maintain their trust Not at all important to maintain their trust	34 18 26 21	2 10 49 36
Q5: My health system uses an ethics committee to oversee research activities for patients with Tourette Syndrome. Very important to maintain their trust Moderately important to maintain their trust Somewhat important to maintain their trust Not at all important to maintain their trust	49 10 20 20	39 16 34 10
Understanding of research on medical practices Q7: Doctors usually agree about which treatment for health problems linked to the diagnosis of Tourette Syndrome is best. True False	37 63	42 56
Q8: A doctor's decision about what medication to prescribe for patients with Tourette Syndrome is based on multiple influences. True False	96 4	95 3
Q9: Sometimes there is not enough information for doctors to know which standard medical practices are best for patients with Tourette Syndrome. True False	91 9	70 28
Attitudes toward and experiences with research Q13: To find out which standard medical treatments are best for Tourette Syndrome, health systems should conduct research. Strongly agree Somewhat agree Somewhat disagree Strongly disagree	25 27 40 8	49 31 18 0
Medical records review scenario Q18: If you were newly diagnosed with a Tourette Syndrome and a research using medical record review were happening in your health system, how would you prefer to be notified about this research? I would not need to be notified about this research using medical record review My health system would give me a document containing general information about this research Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate Doctors or other medical personnel would discuss this research using medical record review with me and then ask for written permission or consent to participate	39 21 15 25	34 39 19 6
Q19: Who would you prefer to ask for your permission or consent to participate in this research using medical record review? My doctor A researcher or research nurse who is not involved in my care No preference	69 31 0	42 31 25
Q20: If getting written permission or consent would make a research using medical record review too difficult to carry out for persons with Tourette Syndrome and you had this diagnosis, how would you prefer to be notified about this research? I would not need to be notified about this research using medical record review My health system would give me a document containing general information about this research Doctors or other medical personnel would discuss this research with me and then ask for verbal permission to participate I would prefer this research using medical record review not be conducted	10 19 70 1	4 12 82 0
Q21: If getting verbal permission or consent would make a research using medical record review too difficult to carry out for persons with Tourette Syndrome, how would you prefer to be notified about this research? I would not need to be notified about this research using medical record review	1	3