

INFORMING AND COUNSELLING OF RELATIVES IN FAMILIES WITH HEREDITARY CANCER WITHOUT CONSIDERING THE INDEX PATIENT

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In familial cancer syndromes, the relatives are usually offered genetic counselling, follow up examinations and/or predictive genetic testing via the index counselees (cascade screening). Approaching the relatives in this way has been considered important and even necessary as it safeguards privacy of the index counselee.

In many families, however, there are branches that cannot be approached by this method, as some of the relatives have no contact with each other. The purpose of our study was to evaluate the consequences of direct contact to relatives in HNPCC-families (hereditary non-polyposis colorectal cancer) without asking help or even consent from the index counselees. This was technically possible as we had constructed the pedigrees with the help of Finnish Population Register Centre and Finnish Cancer Registry as a part of our (previous) research project. Ethical Review Board of Jyväskylä Central Hospital approved our research plan.

We approached 247 high risk HNPCC family members by a letter explaining that we do research in hereditary cancer and would like to have their written consent to receive a phone call from our research assistant (KP). After the phone call, 144 (46%) accepted to come to genetic counselling and fill in pre- and post-counselling/post-test questionnaires. Those accepting were younger, male and married or co-habiting more often than their counterparts. In the counselling, we did not reveal any health data of the relatives but just stated that we knew that there was HNPCC in the family and we believed that the individual concerned had a 50% risk of having inherited the mutation. Of those accepting, 97% knew that a near relative had cancer, 3/4 felt that there was more cancer than usual in the family and 9/10 thought that directly contacting them was a good thing.

Predictive genetic testing is an emerging medical activity and the present ethical concepts and laws concerning confidentiality and the right not to know do not necessarily fit into this activity. It has even been stated that, in agreement with the paradigm that genetic information can be considered to be the property of the family, the professionals have a moral duty to try to inform relatives if the proband is unwilling to do so (De Wert: Whose information is it anyway? *Eur J Hum Genet* 2005;13:397-398). The opinions of family members collected in this study encourage us to suggest that in cancer families direct contact to the relatives without considering the index counselee's opinion is acceptable.