The implications of genetic testing

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In the past decade major developments have been made in cancer genetics with the identification of inherited mutations, along with advances in cancer screening, surveillance and prevention. However with these advances come significant cultural, ethical, social and psychological implications.

University of Adelaide School of Psychology PhD student Amaya Gilson, and her co-authors, conducted the first review of the roles and rights of individuals, families and the broader community when it comes whether or not to find out about inherited cancer risk.

The paper was published this month in *Advances in Medical Sociology*.

"In Australia, up to five percent of breast, bowel, ovarian and melanoma cancers are said to be caused by an inherited mutation. But, even if genetic testing identifies a familial cancer related mutation, there is no way of predicting if or when a familial cancer will occur," says Ms Gilson.

"There are many reasons why someone would want to know, or not know, if they are predisposed to cancer.

"Someone might want to know so they can take preventative surgical measures, like a mastectomy in the case of breast cancer. Knowing about an increased risk of cancer may also influence when to have children or perhaps not to have children at all.

"For others it may be too distressing to find out they are at an increased risk of developing cancer. They may also be concerned about discrimination by family members, and relevant health and life insurance consequences such as increased premiums," she says.

Ms Gilson says one of the issues with current laws surrounding genetic testing is that someone may be told they are at increased risk of an inherited condition even if they don't want to know.

"Much of the debate surrounding genetic testing has been focused on issues of privacy among people in relation to medical information when they are unable to exercise choice," says Ms Gilson.

"In 2006, the Australian Federal Government amended privacy legislation so that a health practitioner can now disclose genetic information to biological family members 'at risk' without any prior consent, if they feel it will lessen or prevent a serious threat to life or health.

"Once an individual receives a letter informing them that a familial cancer mutation has been found in a relative and that they may be 'at risk', this knowledge cannot be undone. Currently, the ability and decision whether to know, or conversely, to not know, is ethically fraught in the case of inherited cancer.

"We need to make sure the social, legal, ethical and cultural implications of genetics don't get left behind the scientific advances. As a society, we need to engage in rich debate to ensure the rights of individuals are protected," she says.

More information: "The Right to Know or Not to Know: Risk Notification and Genetic Counselling." www.emeraldinsight.com/doi/ful … 7-6290201500000160 09

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