Effect of genetic consultation on genetic literacy: a 15 years-investigation in two countries

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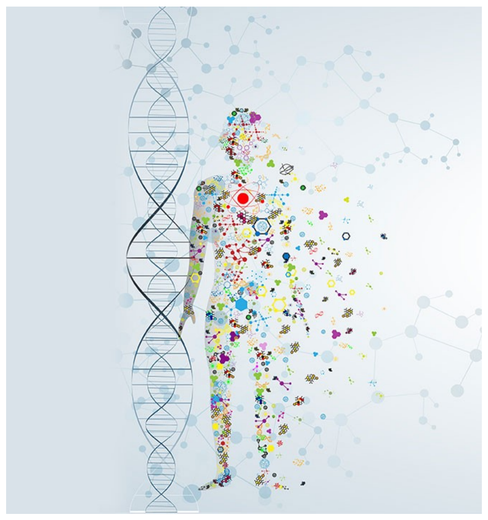
Background

With the evolving role of genetics and genomics in medicine and public health, genetic literacy is becoming crucial for promoting prevention and control for monogenic and multifactorial diseases at the individual and at the community level.

Given the increasing exposure of the public to genetic and genomic information through the media, it is not clear if and how genetic literacy has been changing over time. Moreover, it is not clear the role genetic counselling may play in improving understanding of disease prevention and control among mutation carriers and at-risk biological relatives.



https://www.nyas.org/events/2019/translating-genetics-into-medicine/

Aims

This study aims to achieve four objectives:

- ✓ To document how genetic literacy has been changing in the past 15 years over diverse, mostly community-dwelling samples
- ✓ To examine the effect of genetic consultation on genetic literacy and how genetic information has been passing on from mutations carriers, who had genetic consultation, to at-risk relatives
- ✓ To study variations of genetic literacy according to demographic and clinical characteristics with a time perspective
- ✓ To examine if difficulties in specific knowledge items persist over time and elements on which genetic consultation should emphasize

Methods

Cross-sectional study with a sequential design.
Descriptive data were collected from three family-based studies, two in the U.S. and one in in Switzerland at three time points.

Descriptive cross-sectional study
2007-2008

Baseline data from a randomized clinical trial
2012-2013

Cohort study
2017-2020

Overall Sample:

- ➢ Primarily females ≥18 years old at risk or confirmed for HBOC-associated mutations, who had received genetic counselling by a certified healthcare professional
- ➢ One or more at-risk biological relatives who did not have genetic counselling

Instruments:

Genetic literacy was measured with 25 items *("True", "False", "I don't know"*/Likert scale) based on validated instruments and grouped in five categories according to The Swiss Group for Clinical Cancer Research (SAKK) genetic counselling guidelines:

- Knowledge of:
  - non-genetic risk factors
  - genetic risk factors
  - signs of hereditary cancer
- Probabilities of developing breast cancer
- Genetic affinity

Data analysis is ongoing.

Preliminary results

Globally, N=1,875 individuals have been surveyed:

- ➢ 698 had genetic counselling (168 at the first time-point; 313 at the second; 217 al the third) – mean age 50.2±11.3
- ➢ 1,177 did not have genetic counselling (168 at the first time-point; 977 at the second; 32 at the third) – mean age 48.7±13.1
- ➢ No significant differences in demographic characteristics of the six groups

For almost all items and across all time points, people with genetic consultation have higher knowledge compared to ones who did not have.

With time passing by, genetic affinity, i.e., perceived knowledge and understanding of genetic information, increases probably due to contribution of the media

In general, in all groups and across time there are low scores in knowledge of non-genetic risk factors.

Having a previous cancer diagnosis and older age have been recognized as ubiquitous risk factors, across groups and across time.

The connection of ovarian cancer history to HBOC risk is not obvious to ones without genetic counselling:

"True" answers in 61.5% vs 76.2% in ones who had genetic counselling – p=0.001.

Having a male relative with breast cancer and having a family history of breast cancer from the father's side of the family, are hardly recognized as risk factors even for those who had consultation:

"True" answers in 65,7% and 70.5% in the two items respectively vs 54.3% and 59.0% in ones who did not have genetic counselling.

Conclusions

Preliminary data show that genetic counselling has a crucial role in improving genetic literacy in individuals who receive genetic consultation. However, this information is not always passed on to at-risk relatives.
The need to emphasize specific knowledge items in those who receive genetic counselling, also emerges.

FUNDING
U.S. Oncology Nursing Society, Breast Cancer Major Award 2007
Centers for Disease Control and Prevention (CDC), 5U48DP001901-03
Swiss Cancer League, KLS-4294-08-2017

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