

PUBLIC INFORMATION CAMPAIGNS IN THE FIELD OF PUBLIC HEALTH GENOMICS

Dokova K, S. Popova

Key words: awareness, knowledge, public, genetic risk, familial risk, genetic risk factors.

INTRODUCTION

The WHO report on “Genomics and world health” clearly and directly states that “... it would be extremely unwise for any form of “genetic medicine” to be introduced into countries in which there is a low level of knowledge about genetics among the public...”. So it is vital that all societies prepare themselves, and all sectors of society, including politicians, health care professionals, educators and the public, need to be educated about the fundamental principles of genetic research, its inherent risks and the ethical issues that it raises. This statement requires answers on at least two main questions:

1. What is the level of knowledge of our society about genetics
2. What studies have been carried in the field of increasing public awareness and knowledge in the field of genomic

The aim of the present study is to review the literature on these two problems.

METHODS

A systematic literature search on the above stated two problems has been carried in the databases Pubmed, Web of Science, Embase, Proquest, as well as Bulgarian scientific journals in the field of public health, social medicine, genetics and molecular biology have been searched for the period from January 2000 to January 2010. The following key words or their combinations have been used: awareness, knowledge, public, genetic risk, familial risk, genetic risk factors.

RESULTS

Two main issues have been posed in the literature:

- What is desirable and ‘adequate’ knowledge, which individual members of the general public need in order to engage in proper decision-making concerning genetic problems.
- What is the level and content of public awareness/knowledge about genetics at the present moment.

Address for correspondence:

*K. Dokova, MU-Varna, Dept of Social medicine and health care organization, 55 Marin Drinov str., 9000 Varna, Bulgaria
e-mail: klaradokova@gmail.com*

The first question has been defined as important both for theoretical and for practical purposes (e.g. in the assessment of information campaigns the achieved level of knowledge among the public has to be compared with the desired or adequate aiming to be achieved). We were not able to find in the literature an answer to that question and a definition of what exactly is a desired/adequate level of knowledge.

The second question has received more attention and a number of studies have been published both theoretical and empirical. From the theoretical papers the authors of a review on public’s knowledge on genetics propose and prove that the Rogers’ conceptualization of knowledge is helpful when analyzing this problem. The Roger’s framework distinguishes between three types of knowledge with increasing complexity: “awareness knowledge,” which refers to knowledge about the existence of e.g. genetic risk factors for common diseases with multiple causes; “how-to knowledge,” which is practical knowledge concerning the proper use of an innovation; and “principles knowledge,” or knowledge of the underlying theoretical principles of the innovation.

A number of empirical studies have examined the question of whether the public is aware of genetic risk factors of different diseases. We found one review examining public awareness of the genetic risk factors of multifactorial diseases in a wide variety of countries.² It suggests that the general public is reasonably aware of the genetic risk factors of multifactorial diseases, with approximately 59% (range, 17.6–93.3%) of the sample being aware of the existence of genetic risk factors, although much lower and much higher proportions have also been observed. For example 60% of the public were aware of genetic risk factors for breast cancer, while for cervical cancer these are only 20%.

A more recent study among 1,747 British adults reports that one third of the respondents identified genetic factors as influencing cancer (35%) and heart disease (36%) risk. The authors suggest that people who recognize that genetics influence chronic disease risk appear more, not less, likely to recognize the role of lifestyles. This contradicts suggestions that the public takes an ‘either ‘deterministic’ view of the etiology or people believe that the disease risk is largely dependent on lifestyle and ‘external’ factors.

Another study explored the knowledge about genetic risk of disease, inheritance, biology, determinism among 1009 Western Australian citizens. The conclusion is that most members of the Western Australian community are aware of basic genetic concepts and the link between genes, inheritance, and risk of disease, but significantly fewer understand the biological mechanisms underlying these concepts

and there was some misconception around the meaning of 'increased genetic risk'.

A study on the causal beliefs about obesity among 3,534 individuals in the USA, reports that only 19% of the respondents indicated that inheritance has 'a lot' to do with causing obesity. The rest 72% of respondents endorsed the belief that lifestyle behaviors have 'a lot' to do with causing obesity. A Japanese study on Public awareness of risk factors for cancer reports that 35% of all cancers are attributed to genetic risk factors.

Much more limited is the knowledge of the public in relation to the "how – to" knowledge - how genetic risk factors influence the risk of development a disease. One of the things which the general public seem to understand is that having a genetic predisposition implies heightened, but not absolute risk.

Information on the public's "principles knowledge" referring to the knowledge of the underlying working mechanisms through which genetic risk factors affect disease development (e.g., knowing that certain polymorphisms create a genetic predisposition that interacts with other factors to develop the disease) is extremely scant. Only one study was identified in the cited review observing this most complex knowledge level. It concludes that although participants recognized the increased risk owing to genetic risk factors, their knowledge of the working mechanisms of genetic factors was (highly) inadequate, largely insufficient and superficial.

It seems also that individuals are only interested in the consequences of genetic risk factors and how to manage them, and are not at all interested in the underlying genetic principles. E.g the public has no need for detailed information on the working mechanism of DNA, but is interested in the signs of a genetic predisposition to cancer.

2. Effect of information on decision- making and engaging in preventive behavior.

Research examining the effects of mass media genetic health messages on preventive behavior is also scarce. At the same time without such insight, genetic-based public health campaigns may 'do more harm than good'.

Smerecnik et al compared the effects of health messages communicating information about genetic risk factors for salt sensitivity and heightened cholesterol with general information without reference to genetic risk factors. The results reveal that unaware participants who received a genetic health message reported lower perceived susceptibility associated with lowered intentions to engage in preventive behavior, compared to those who received a general health message. No such effects were observed for the participants who were aware of the existence of genetic risk factors. The authors conclude that alerting the public to the existence of genetic risk factors may not necessarily be beneficial to the public health.

Another study examined the potential behavioral consequences of genetic feedback on obesity risk in normal weight individuals. Individuals who were told they were at increased genetic risk for obesity showed higher overall intentions to eat a healthy diet. However, individuals with low external weight locus of control had significantly lower

predicted intentions to eat a healthy diet when compared to those with high internal weight locus of control.

Other studies also prove that the provision of genomic information has an important influence on the audience. E.g. information about the population risk of inheriting a certain specific gene, substantially modifies the public's interest in genetic testing.

This suggests that researchers and educators should be very careful about the information provided to the public. Information on the existence of genetic risk factors should be accompanied by explanations for its meaning and consequences for the individual. Information on the population risk of inheriting different genes when discussing the discovery of these genes with the media may also have variable effect on behavior.

3. Existing genomic education for the public at the moment

The public at present has some access to information developed and provided by governmental organizations, academia, disease specific advocacy organizations, and the healthcare industry. Various organizations such as NIH, CDC, and academic institutions have websites and educational materials on genomic issues at least for those who are interested. New entrants to the field include companies, particularly those looking to market tests and information directly to consumers. It is reported that sources from which the public receives most of its genomic/genetic information are internet, television, radio, magazines, and newspapers.

A study examining the accuracy and nature of media coverage of genetic research found that most newspaper articles accurately convey the results of and reflect the claims made in scientific journal articles. However, the media do seem to overemphasize particular topics, such as behavioral genetics, underreports risks and puts an overemphasis on benefits. Such a trend may contribute to inflating the expectations of the general public and special interest groups such as patient groups and investors.

CONCLUSIONS

This short descriptive review can be summarized in several points

1. Research on public awareness of genetic risk factors is carried among different populations, but these are mostly populations from developed western countries
2. The proportion aware about genetic risk factors of different diseases differ among populations. The size of the proportion depends on the concrete disease of interest and the availability of positive family history of the disease
3. The public's awareness and knowledge of genetic risk factors is highly dependent on socio-demographic factors such as ethnicity, gender, and level of education (2),8
4. Future campaigns should first determine the target group's prior awareness and knowledge, and then build upon it to increase how-to and principles knowledge, ensuring accurate interpretation of the new information

5. There is not only risk but real discrepancy exists among countries with regards to research on public genetic awareness and access of the public to educational information
6. Adequate information aids should include materials on:
 - criteria for familial risk
 - genetic counseling, genetic testing, as well as the implications of genetic testing

REFERENCES

1. WHO Genomics and world health /report of the Advisory Committee on Health Research/, 2002, Geneva
2. Health Council of the Netherlands. Public awareness about genetics. The Hague: Health Council of the Netherlands, 2003; publication no. 2003/05. ISBN 90-5549-473-9
3. Smerecnik C. M. R., Mesters I., De Vries N. K. & De Vries H., (in press). Applying a theory-based framework to understand public knowledge of genetic risk factors: A case for the distinction between how-to and principles knowledge. *Public Health Genomics*.
4. Saskia C. Sandersona, Jo Wallerb, Steve E. Humphriesc, Jane Wardleb Public Awareness of Genetic Influence on Chronic Disease Risk: Are Genetic and Lifestyle Causal Beliefs Compatible? *Public Health Genomics*, 2010,
5. C. Molstera, T. Charlesa, A. Samaneka, P. O'Learya, Australian Study on Public Knowledge of Human Genetics and Health *Public Health Genomics* 2009, **12**:84-91
6. Catharine Wang¹ email and Elliot J Coups^{2,3} Causal beliefs about obesity and associated health behaviors: results from a population-based survey., *International Journal of Behavioral Nutrition and Physical Activity*, 2010, **7**:19
7. Manami Inoue email, Motoki Iwasaki email, Tetsuya Otani email, Shizuka Sasazuki email and Shoichiro Tsugane, Public awareness of risk factors for cancer among the Japanese general population: A population-based survey *BMC Public Health* 2006, **6**:2
8. Condit C. M., (2001). What is 'public opinion' about genetics? *Nature reviews: Genetics*, **2**, 811-815.
9. Smerecnik C. M. R., Mesters I., De Vries N. K. & De Vries H., (2009). Alerting the general population to genetic risks: The value of health messages communicating the existence of genetic risk factors for public health promotion. *Health Psychology*, **28**, 734-745.
10. Frosch DL, Mello P, Lerman C., Behavioral consequences of testing for obesity risk. *Cancer Epidemiol Biomarkers Prev* 2005, **14**:1485-1489
11. Graham I.D., Logan D.M., Hughes-Benzie R., Evans W.K., Perras H., McAuley L.M., Laupacis A., Stern H., How interested is the public in genetic testing for colon cancer susceptibility? Report of a cross-sectional population survey. *Cancer Prev Control*. 1998 Aug, **2**(4):167-72.
12. Geller G., Bernhardt B.A., Holtzman N.A., The media and public reaction to genetic research. *JAMA* 2002, **287**:773.
13. T. Bubela, T. Caulfield., Do the print media "hype" genetic research? A comparison of newspaper stories and peer-reviewed research papers *CMAJ* o April 27, 2004, **170** (9)