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## **Children Predictive Genetic Test for Hereditary Cancer: A Position Statement**

Hazem Al Azzam<sup>a\*</sup>, Majd T. Mrayyan<sup>b</sup>

<sup>a</sup>*B.Sc. RN, Royal Medical Services, Oncology Nursing Master's Student, the Hashemite University, Faculty of Nursing, P.O. Box 150459, Zarqa 13115, Jordan*

<sup>b</sup>*Professor, Consultant of Nursing, Department of Psychiatric and Mental Health Nursing, the Hashemite University, Faculty of Nursing, P.O. Box 150459, Zarqa 13115, Jordan*

<sup>a</sup>*Email address: hazem81jor@yahoo.com*

### **Abstract**

Predictive genetic testing for children is charged with controversy since development of the bacterial inhibition to test phenylketonuria by Robert Guthrie in 1960s. Hereditary cancer accounts approximately 5% to 10% of all cancer. Predictive genetic testing to detect cancer risk for children in advance is surrounding with many problems and debates. Through review the opponents and proponents of researchers about this debatable issue, the purpose of this position statement is to argue and support predictive genetic testing for children in order to prevention, early detection, and management of cancer. Predictive genetic test for children to detect hereditary cancer is a very important aspect for primary health care centers that focus on prevention of diseases rather than treatment. Based on this review paper, more need to be done in the areas of health care procedures legislations, disease prevention and community awareness when it comes to fighting cancer disease through any type of these pre-symptomatic procedures like predictive genetic testing for children. However predictive genetic test should be encouraged to get all the possible facilities by health care providers and health care institutions in order to prevent or manage hereditary cancer through early detection in childhood stage.

**Keywords:** predictive genetic testing; genetic testing; inherited cancer and children.

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\* Corresponding author.

E-mail address: hazem81jor@yahoo.com.

## **1. Introduction**

Hereditary cancer accounts approximately 5% to 10% of all cancer [7]. The researchers reported that patients with hereditary cancer are exposed to recurrent or secondary cancer and their family members also are exposed to the same gene mutation. Moreover, most cancers start because of gene mutations that happen sometime during a person's lifetime. Thus, detection of these gene mutations required looking at structure of chromosomes and genes [1]. However, predictive genetic testing is the study of genetic information to know for the future the risk for getting a particular disease or specific cancer, such as breast, ovarian, and colorectal cancer [1,7].

Predictive genetic testing to assess risk of developing cancer depends on person's autonomy; not compulsively. The individuals decide if they want to know their cancer risk or not [1]. But in case of predictive genetic testing for children, the situation is still controversy. The debates are varied about the benefits and harms of this test for this age group, and if this test can be delayed to adulthood stage [9]. In addition, it is debated if the parents have right to decide upon their children to get this important test or not [9]. Also, the debate about when, how and what scheme of children should undergo this test and must be put in concern [9].

Position statement is a brief, concise statement developed by experts, convened to review the research literature for the purpose of advancing the understanding of an issue, upon a given topic) [6]. It consists of substantive information and policies regard particular topic important in committee [6]. Also, it position represents the collective opinions of the convened experts contribute in share of viewpoints between countries [6]. Therefore, the purpose of this position statement paper is to present opponents and proponents' viewpoints regarding predictive genetic test for children to detect hereditary cancer.

## **2. Background**

The genetic testing for children is charged with controversy since development of the bacterial inhibition to test phenylketonuria by Robert Guthrie in 1960s [9]. The purpose of this literature review is pinpoint different opponents and proponents' positions regarding predictive genetic test of children for early detection of hereditary cancer.

## **3. Results**

### ***3.1 Proponents of Predictive Genetic Test for Children to Detect Hereditary Cancer***

Worldwide, professional organizations are on the same page regarding their recommendations to do the predictive genetic testing of children for the purpose of knowing conditions which may develop in the future [11]. The American Society of Clinical Oncology (ASCO) has a significant role in raising awareness for health care providers and oncologists regarding the importance of detecting the risk of hereditary cancer in the practice field of oncology and in the primary prevention settings of cancer [5]. Predictive genetic testing may be recommended for a child with a positive hereditary family history for a specific genetic disease, especially if early detection or therapeutic interventions may affect morbidity or mortality rate [9].

The clear benefit of the predictive genetic testing is to well understand of the chance to get a particular disease, and that will help to make an appropriate decision about the person health future in case of the test result is positive. Also, the predictive genetic testing helps to decrease the risks of diseases through changing some of unhealthy behaviors based on recommendations of the genetic councilors. The predictive genetic testing has a pivotal role in early detection and early treatment, and in turn will alleviate anxiety and stress if the result of the test is negative [1]. Significant information may obtained through genetic testing will help the health care providers in prevention, early detection, treatment procedures, diagnosis and prognosis of disease, pharmacogenomics development in order to improve selection of the appropriate drug and reduce the drug adverse effects, and lifesaving such as in case of detecting a gene related to hereditary cancer [8].

Annually, just in United States of America (USA), around four million infants undergo newborn screening to identify various abnormalities, for which early detection and early treatment for purpose of prevent or minimize morbidity or mortality [10]. However, because of the importance of performing predictive genetic test in reduce morbidity and mortality, the barriers should be tackled [8]. Also, parents should be educated about the process and the goal from this test to be able to decide upon their children [8]. Multi factors are considered to take the best interest decision for the child in purpose of take recommendations to perform a predictive genetic test to increase the welfare for a child future [4]. In addition to parents, social workers and health care professionals also should be involved in the enhancement of a decision making to perform a predictive genetic testing for a child [4]. However, in order to preserve all rights of children and to motivate parents of children who undergoing in performing genetic test, the national law protect their rights by prohibiting genetic test discrimination through keeping health insurance active even if the result is positive, and preserve the confidentiality of genetic test information [1].

According to study conducted in the United Kingdom (UK), in which they reported that 47% of participants confirmed on right of parents to decide genetic test for their children even if there is therapeutic interventions or not, and 60% agreed the choice of possibility of parent to test their children if they are carriers of a genetic disease or not [11]. Such high percentage return to the explanation that parents may able to do something with test results such as change life style, change diet, be alert to symptoms and interventions, and prepare them and their children to adapt with this situation[11]. Therefore, from ethical and legal view points, parents should be involved because this test may lead to psychological and social impacts for all family members [10]. According to [2], parents are interested to know more about child's risk to develop inherited cancer and desire to detect disease early before it start to improve chance of prevention of cancer and to minimize risk. On another hand, in case of debate between parents and providers to perform this test especially when the parents refuse to test their children and ignore the provider's recommendations, the providers would need to argue in the court that parent's decision was abusive and neglected for children health [9].

### ***3.2 Opponents of Predictive Genetic Test for Children to Detect Hereditary Cancer***

Predictive genetic test for children have various actual problems; these should be considered before undergoing the test. One of these problems is the limited perfect answers, because genetic test does not always give precise answers about some of inherited disease such as breast and colon cancer. Also, this test is exposed to errors as

any other test such as false positive and false negative which may lead to physical and psychosocial harms, in addition to loss of child's privacy [1].

Other study reported that the most common explanations of health care professionals for not preferring to perform genetic test for child's is to maintain future autonomy [4]. In the UK, the law recognizes the child's future autonomy without looking to claim of parents to know family history regard genetic status except there is clear cut benefits from the test for child [3]. Also, predictive genetic test should be delayed until adulthood stage unless therapeutic interventions in childhood stage reduce rates of morbidity and mortality [10].

Positive predictive genetic test for serious inherited disease may cause some of potential psychological problems such as anxiety, altered self-image, change perceptions of the child, guilty feeling, ineffective coping methods, family stress, depression, social isolation, disability in insurance, and reproductive harms [8]. Also, this test may lead to serious physical harms like taking strong decisions such as prophylactic mastectomy based on faulty result of the test [2].

In study conducted in UK found that 20% of participants disagree the statement of "parents have right to decide upon their child's to performing genetic test." The researchers found that most common explanations to delay test till adulthood stage was that participants worry about keeping the child misinformed because they are not involved in the decision making from the beginning, In addition to the fear from discrimination, and ignorance of child's autonomy in future [11].

In summary, predictive genetic test for children to detect hereditary cancer is debatable and controversial. One of the most important debates is whether there are any benefits from this test or not, and if this test can this test will introduce new things to the children in prevention and treatment of disease or not, and what is the appropriate time to do this test. Another important debate is the balance between benefits and harms and the burdens of this test on child and on family members, and if the parents have right to decide upon their children to perform this test or delay test till adulthood to preserve child's future autonomy. Finally, there is always fear from genetic test discrimination such as playing with health insurance for children who undergo this test particularly in case of positive result of inherited disease like hereditary genetic cancer.

#### **4. Position Statement**

The current author is supporting doing predictive genetic test for children for purpose of early detection of hereditary cancer because this test will minimize a lot of children suffering if they are exposed to cancer. This test carry a lot of happiness in case of preventing cancer or contributing in an introducing the optimal management for cancer. In addition to probability of avoid next generation from getting cancer gene mutation. This will help pharmacists to develop more effective and less adverse effect drugs for cancer.

However, in order to resolve the most important problems which stand as barriers in front of performing predictive genetic test for children to enhance early detection of cancer, the current research articulates the following recommendations which consists some of possible solutions for problems or barriers of performing predictive genetic test for children to early detect or prevent inherited cancer:

1. Predictive genetic test should be encouraged and supported to get all the possible facilities by health care providers and health institutions in order to prevent or manage hereditary cancer diseases through early detection in early childhood stage.
2. Predictive genetic testing for children should be supported and protected by governmental laws for families with history of cancer gene mutations.
3. Predictive genetic testing for children to early detection of hereditary cancer should be encouraged under formal and informal umbrella of health care institutions.
4. The governmental laws should support the rights of children to live free from inherited cancer diseases and facilitate any chance to prevent it.
5. The governmental laws must protect the children against genetic discriminations such as playing in health insurance and confidentiality of genetic information; to make this actual the physicians must be obligated legally and ethically in confidentiality of genetic results.
6. Health care providers should work to increase the society awareness about process of predictive genetic testing.
7. In order to tackle obstacles facing genetic testing, the laws must support the parents' rights to decide upon their children to do this test even if there are therapeutic interventions on spot or not.
8. Health care providers should make a balance between benefits and harms of such genetic test and should clarify this to parents with clear recommendations.
9. Health care providers should assess the parent's decision with considering the child health.
10. Health care providers should preserve child's autonomy when this does not affect adversely on the health of the child because health is more important than autonomy.
11. Health care providers should legally argue the abusive or neglected parents who refuse performing the genetic test particularly if there is predicted harms or loss of benefits for child if not doing the test in term of legal accountability.
12. Health care providers should encourage the best interest standers as the guidance for make a decision regard the child health.
13. The local and global health institutions must introduce all patterns of support, financial, legal, ethical, social, and technology for the purpose of developing such a test and to avoid errors in results.

## **5. Summary and Conclusions**

Predictive genetic testing for children to detect hereditary cancer is controversial. The purpose of this position statement paper was to present opponents and proponents' viewpoints regarding predictive genetic test for children to detect hereditary cancer. There are various benefits and harms of predictive genetic testing; these should be balanced for the benefits of the child. The current author supports performing predictive genetic test for children detect as early as possible hereditary cancer. Recommendations and possible solutions for problems facing performing predictive genetic testing of children were discussed

### **Conflict of interest**

We have read and understood the journal policy on declaration of interests and declare that we have no competing interests.

*This position statement was approved by the Faculty of Nursing-The Hashemite University, and in the process to be sent for approval of the Jordanian Nursing Council (JNC).*

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