Review Of Knowledge And Attitudes Towards Human Genomics And Testing

Jonathan J. Odukoya, Dare Ojo Omonijo, Henry Oratue; Ibitayo Yvonne Adebigi

Abstract: This study reviewed published work related to knowledge and attitude of people towards human genomics. It was poised to answer the following research questions; what are people’s attitude towards human genomics? What is the level of knowledge about benefits of human genomics? What are peoples view on sharing genomics information via social networking sites? The results showed that in some countries, the awareness of benefits from genomics was from advertorial online platforms while in some others, their knowledge about genomics is restricted to sickle cell genotype and paternity testing. Culture and belief system were implicated as a major factor that influences the acceptance of genomics testing and its treatment protocol. Almost all the studies isolated that people were concerned about third party access of their result. The study recommends massive online and offline awareness campaign on genomic testing that will take into cognizance of people’s cultural differences.

Keywords: Knowledge, Attitude, Human Genomics

1 INTRODUCTION
Genomics is the study of a person’s gene and its interaction with the individual's environment. It was also defined an interdisciplinary branch of biology that is interested on the structure, function, mapping, evolution and editing of genomes (National Human Genome Research, 2010). The advancement of technologies in medical research has made genomics tests more obtainable for use in clinical settings (Fabbemiro and Adebarnowo 2014). In many countries, companies have key into the development of platforms that can assess, store, predict and make impression about an individual's genetic profile. It is germane to bisect studies on knowledge and perception of individuals towards human genomics. This will help to identify the existing gaps in knowledge about human genomics and proffer workable solutions on improving human genomic testing and treatment. Zimmerm and Khoury (2012) posted that public health and genomics are interwoven. The public knowledge about human genomics and its consequence benefits will help to increase confidence and remove perception of mistrust from the population. Knowledge of human genomics can help to illuminate the dynamics and interactions among things, like the environment, innate characteristics and behavioral dispositions. The theoretical assumptions of health belief model helped to explain people’s perception and attitude towards genomic treatments. This model developed by social psychologist Irwin Rosentock and Godfrey Hochbaum in 1950 proposed that people’s belief about their problems including their perceived benefit of action, barriers to action and self-efficacy explains engagement in health promoting behavior (Siddiqui, et al. 2016). It further stated that the perceived severity can be said to be one’s subjective appraisal on the extent of health problems and its possible consequences (Glanz, rimer and Viswanath, 2008). Thus, this model hypothesizes that individuals that discern their susceptibility to an ailment will engage in behaviours that will minimize the likelihood of having health problems while individuals with lower perceived susceptibility will probably dismiss the risk of contracting an ailment (Rosentock, 1974). From this foregoing, the health belief model can be employed to develop competent interventions to modify health-related attitudes and behaviors by concentrating on various aspects of the model’s important constructs. Targeting on awareness of severity of health challenges and perceived benefits can help to enthrone genomic treatments and its concomitants. The limitation of this model is that it did not take into cognizance the concept of individual differences, and beliefs. But it can be amenable, by cross-cultural adaptation of the model key variables to determine what works in an area of interest and exploit it in awareness campaign of human genomics. The salient questions this study wants to review includes: what are people’s attitude towards human genomics? What is the level of knowledge about benefits of human genomics? What is people’s view on sharing genomics information via social networking sites? Providing feedbacks to these aforementioned questions will help to increase the global acceptance of human genomics and its treatment protocol. It will help to increase the direct economic benefits to the biotechnology sector, which has an income generating potential of above 8.2 billion dollars.

2 ATTITUDE TOWARDS GENOMICS
Fishein (1967) cited in Adetola and Omonijo (2019) views attitude as a learnt behaviour that shows people’s reactions to objects, either in a positive or negative way. In determining the attitude of people towards genomics, Mahlmann, et al., (2016) reported a survey conducted on 181 men and women between the age of 60-89 with a voluntary anonymized paper and pencil. It shows that one-third of the participants have knowledge of personal genomics and more than half were interested in undertaking personal genomics examination. The primary motivation for the participants was their curiosity in determining predisposition to a disease, and also the desire to help in addition of knowledge in scientific research. Forty-four percent were not keen to undertake human genomic test because they believe that the results might be upsetting, and also concerns about the results validity. Furthermore, Vermeulen et. al (2013) investigated public attitudes and concerns in genetic examination and assessment of risk in family history. In the cross-sectional study, 12 statements on 5-point Likert scale were used to collect data from 1399 health care consumer representatives in Dutch population. Vermeulen et. al (2013) posited that about half of the participants showed interest in genomics test to avert some condition like (cancer, cardiovascular disease, diabetes or dementia), low level educated participants were more interested than higher-educated participants. Most of the participants believed that genetics testing should be offered
concurrently with regular healthcare. However, Jochemsen, Nonyane, Reinecke, and Zaaiman (2014) conducted a qualitative research in South Africa to determine people’s attitude and perception on metabolomics and genomics in respect to treatment of HIV. A conducive sampling was utilized in selecting participants for the interview. The results of this study are shown in the Table I.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Responses</th>
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<tbody>
<tr>
<td>5 Participants</td>
<td>Witchcraft</td>
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<tr>
<td>4 Participants</td>
<td>Curses</td>
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<tr>
<td>3 Participants</td>
<td>Ancestors</td>
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<tr>
<td>5 Participants</td>
<td>Don’t know the cause</td>
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<tr>
<td>Others</td>
<td>Natural and biological factors</td>
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Source: Adapted from the studies of (Jochemsen, et al., 2014).

3 KNOWLEDGE OF HUMAN GENOMICS

Some Studies recommend that health literacy may impact the understanding of personal genomic risk (Lea et al., 2011). (Haga et al., 2013) posited that many participants had some knowledge about medical application of human genetics, nevertheless their educational status did not have any influence on the knowledge of the social consequences of human genetic testing. Aniwa et al. (2018) reported physician’s attitude and perception in genomics. It studied 285 physicians from the Implementing Genomics in Practice (IGNITE) sites. The participant’s attitude and perceptions as to the clinical applicability of genetic information and also their willingness to incorporate genomics into practice was evaluated with comparability to the type of research happening at the physician’s institution. The majority of the participants are of the view that testing in genetics is clinically advantageous. However, only a third of the participants are convinced to have garnered competent training to take care for genetically “high-risk” patients. Also, physicians involved in pharmacogenetics initiatives are extra supportive towards the practice of genetic testing. They discovered it to be clinically suitable and felt more qualified and convinced in their competence to adopt it into their practice. This is in contrast to the participants working in disease genetics initiative. Fagbemiro and Adebamowo (2014) analyzed the level of awareness and attitude to genomic testing among Nigerians. The study utilized qualitative data analysis to examine (8) eight focused group discussion and used (27) twenty-seven key informant interview in districts of FCT, Abuja. It expounded that most of the research participants initially showed limited knowledge of genomics but their awareness of the test was enhanced after an explanation of its idea. It further stated that participants manifested positive attitude in relation to genomics but were concerned about consumer genetic examination, disclosure of result about them to third party and testing of unborn babies.

<table>
<thead>
<tr>
<th>Focus Group Themes</th>
<th>Participants Responses</th>
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<tr>
<td>Knowledge of Genomics</td>
<td>Knowledge is limited to paternity and sickle cell genotype but understanding increased, when being taught about basic genomics. Participants saw it as a professional activity that should be run in health clinics. While some female youths said that educated participants should be trained to have direct access to genomics test. This will reduce time for patients to see an expert. Some Participants believe that genomic test is important, though there is no access to treatment protocol that would ameliorate the diagnostic impression. All the participants are willing to submit to genomic testing if it is not expensive. Generally, They discouraged the revelation of test result to another party but younger participants were of the view that the result should be displayed to their partners. Some elderly respondents were ready to disclose their genomic result to their life insurance companies. Some of the women were of the view that unborn baby should be pretested so that the parents can make informed decision about aborting it. Across all ethnic groups, most of the participants claim that attitudes to genomic tests were affected by impact of culture and religion particularly as it concerns testing of unborn babies.</td>
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<tr>
<td>Regulation of Genomic test</td>
<td>Effect of religion and culture.</td>
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<td>Perception about importance of genomic test in Nigeria.</td>
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<tr>
<td>Willingness to do genomic testing</td>
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<tr>
<td>Exposure of genomic to third parties</td>
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Source: Adapted from the study of Fabgemiro and Adebamowo (2014).

Sundy et. al (2018) used mixed methods to examine the attitude of inclusion of children in genomics research. The result shows that the respondents generally were optimistic about inclusion of children genomic research. The informants in the interviews emphasized that the children’s age is an important condition when revealing genetic information. They also stressed on the importance of right to choose on participation, the emotional stress on both the parents and the child, and the chance of collecting favorable clinical knowledge about the eventual future health of the child. Furthermore, no concession was established on who can obtain the results between either the parent or the child. But majority of the participants acceded that significant and incidental result should be taken back to the parents and to the child when they are of legal age. The study confirms that in genomic research, having children did not affect the stakeholder’s behavior and perception on the involvement of children as experimental subjects.
Adapted from the study of Sundby et al. (2018)

**Figure 1: Bar chart showing attitude of parents towards children participation in genomic research**

Leila et al. explored the attitude of participants towards confidentiality of genomic information. The study used 30 participants sampled in the unit protocols in genomic sequencing from two National Institutes of Health research. The mode of data collection was a semi-structured phone interview. The results posited that the participants allotted value on the confidentiality as a mode of control over detailed information about themselves. Among the participants that were interviewed, control was valued as a shield to counter partiality in an environment of unpredictability about the forthcoming benefit of individual genome data. The participant’s attitude as regards to data sharing were linked to the objectives of research and specifics of participants personal lives. The outlook of confidentiality, confidence in the researcher, and an eagerness to make progress in science were typical logic for consent to contribute measurable data with researchers. Mostly, all participants are contented with giving personal data that had been de-identified. Social Networking and Sharing genomic information Behaviors among Consumers Social network has the ability to connect people all over the world. It offers easy and swift communication between people. Social media statistics show that about 3.2 billion people around the world login and converse online (Emarsys, 2019). The ubiquitous use of the internet by the public has fuelled the proliferation of companies that provide personal genetic information (PGI) direct-to-consumers (Lee & Crawley, 2009). In checking the ethical implication of social networking around PGI, it will be important to consider its benefits to individual consumers (Lee & Crawley, 2009). Soo-Jin, et al (2013) explored how consumers give out their personal genetic data and attitudes as related to social networking behaviors. The participants selected in the study are aged between 23 to 72 years old, and they have purchased direct-to-consumer genetic testing from a personal genomics industry. They were administered a web-based survey concerning their data sharing activities and social networking behaviors as it concerns to the result of personal genetic test. The result shows that 45% shared their results on Facebook social networking site and 50.9% described meeting or reconnecting with more than 10 other persons through the sharing of data about their genetic result. In order to understand their results, about 70.4% used websites and online sources, in comparison to 22.7% that sought for advice from their healthcare providers. Amongst participants, 51.8% disclosed that they presume the confidentiality of their genetic data and information provided would be invaded in the future. (Morin, 2009) conducted 12 focus groups with members of the public in five cities across Canada on commercialization of dietary supplement and nutritional advice on the internet by some laboratories. The participants were recruited by telephone by a third party. Each session included approximately eight participants, totaling about 90 adults representing a mix of gender, income, marital status, and ethnicity. Some participants commented that companies are likely more interested in financial gain than health promotion, although other individuals retained a favorable view of companies. There was general discomfort with purchasing a test online and participants expressed a clear preference for in-person testing at a clinic or laboratory, especially where they could have direct interaction with a health care professional. Overall, Internet based nutrigenomic services raised “buyer beware” instincts. Health care professionals were skeptical of the information and services presented on the mock Web site. Physicians and pharmacists in particular questioned whether sufficient scientific evidence supported such tests. Professionals advocated regulatory oversight of direct-to-consumer nutrigenomic services, and believed health care professionals should be involved in counseling patients.

**4 CONCLUSION/RECOMMENDATION**

Studies by Ostergen et.al (2015) has linked old age with limited capacity to process information from various media platform. However, Mählmann et al. (2016) questions the claims because one-third of older Swiss adults are aware of the genomic testing and services which is online. Classical survey on internet use conducted by shelling and Seifert (2010) has reported a significant use of internet by 68% by Swiss adults aged between 60-69 years and 40.6 percent for those that are 70 years and older. This has shown that massive media attention in Swiss has contributed immensely on the awareness of genomic testing and services. This is at variant with some countries, where awareness is from family and healthcare professionals. Jochemsen et al., (2014) has shown the inadequate knowledge of genomics and its treatment paradigm in South Africa. They identified the role of cultural factors in modifying individual’s belief system to be in sync with tradition. Hence, this affects the perception of genomics. This study gave an insight into the social and behavioural factors that will help in successful application of a comprehensive genomics and metabolomics investigation in South Africa. This has aided to discover the massive influence of traditional religious belief in Africa. For effective health framework, the template must be all encompassing and must take cognizance of cultural factors and belief system Omonjo et al., (2019). Fagbemiro and Adebamowo (2014) has portrayed in their classical studies that most of the participants do not have a proper understanding of genomics prior to the research. However, participants showed positive attitude towards genomic testing. This has brought to limelight the need to create more awareness on genomics in Nigeria. Although, the use of only qualitative data to generate data is one of the limitations of the research and the participants is not a true representation of Nigeria population. A template that encompasses the belief system and socio-cultural factors must be developed to.
help disseminate the information on benefits of genomics. This review paper showed that opinions about the privacy of individual’s information and data sharing are connected to the anticipated advantages and reward of joining a research project. Participants wants to know the gains of participating in a research and the level of confidentiality their personal data has. This also provides insight that researchers most tailor their informed consent to be sensitive to culture, and belief system of a population. The proliferation of direct-to-consumer (DTC) genetic testing industries and ubiquitous internet connectivity of social networking site has contributed to understanding of information on the result of personal genetic test. This suggests an urgency for meticulous examination of policy objectives because of the present uncertainty in the parameters for regulation on consumers sharing behaviour. From this foregoing, the gaps that has been identified in this review are the inadequate data on extent of awareness of genomics on online platforms in some countries in Africa. Also, how culture and belief system can be harnessed to influence the acceptance of genomics testing and its treatment protocol needs to be investigated. Effort should be channeled on how to provide assurance of confidentiality and third-party access of genomic test result. This study reviewed some of the articles on the knowledge and attitude towards genomics. The goal of this work is to identify the level of knowledge and attitude of individuals in genomics. It was discovered that in Africa, culture and belief system affects the perception of genomics. Also, there is inadequate knowledge of the benefits of genomics unlike in other Western Countries. It was also found out that Online awareness is apt in the campaign and inculcating knowledge of genetic testing and its benefits to health. The study recommended massive campaign on the benefits of human genomics on health sector.

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6 REFERENCES


