SOCIODEMOGRAPHIC PREDICTORS OF ATTITUDE TO GENETIC COUNSELING AMONG PATIENTS WITH CHRONIC ILLNESS.

Abstract

The utilization of genetic counseling has been widely explored, showing a significant percentage of people who need genetic counseling but do not utilize it. However, there seem to be no agreement in data about the factors that influence the attitude of patients to genetic counseling. This study aimed to research on the sociodemographic predictors of attitude to genetic counseling among patients with chronic illness. One hundred consecutively selected patients across five departments (cardiology, endocrinology, renal, surgery, hematology) were included in the study. One-way Analysis of Variance (ANOVA) revealed significant influence of age ($F(4, 95) = 3.52$; $P<.05$) on attitude to genetic counseling among patients with chronic illness. However, there was no significant influence of illness type ($F(3,96) = 1.69$; $P> .05$), educational qualification ($F(4,95) = .07$; $P>.05$) on attitude to genetic counseling among patients with chronic illness. It was however concluded that patient age is helpful in determining a patient's attitude to genetic counseling.

Keywords: Sociodemographic; Attitude to Genetic Counseling; Nigeria; Chronic illness, illness type, patients.

Introduction

The impact of chronic diseases on the lives of people is such that can cause a complete change in the life of the person, one that can utterly influence their life experiences and alters their bodies. Aspects of life such as identity and self-esteem are usually affected in cases of chronic illnesses (Roing and Sanner, 2015). People suffering from one chronic illness which could be cancer,

arthritis, heart diseases or others are typically coerced into adjusting their lifestyle, which they often experience as losing control. In order to minimize this loss of control, they have a feeling that they need to rally resources, in order to plan and prioritize their life (Kralik et al., 2004). For such people, availability of information can mean a lot to them. Usually, when people are down with chronic illnesses, their thoughts about their new condition and experiences can be a huge determinant of how well they will cope (Benkel et al., 2019). For chronic illnesses that are genetic, which is the focus in this study, genetic counseling is seeing as a very important support for such patients.

Genetic counselling (GC) generally gives people who are at greater risk of developing a disease or medical condition a chance to evaluate their situation and to make decisions with respect to genetic testing. In GC, one of the main focus of discussion is available risk management choices, such as screening and reduction of perceived risk (Meiser and Halliday, 2002). Additionally, there is the provision of decisional and emotional support as well as assistance in discussing genetic risk of such condition with the individual's family. For people who are going through genetic testing, it is generally advised and sometimes mandated to undergo GC. For example, doing this has been proven to improve perception about the risk of developing cancer with no long-term psychological misery (Meiser and Halliday, 2002; Smerecnik et al., 2009).

Genetic counseling is designed to mainly assist individuals with chronic illnesses and their families to gain a better understand about diseases that are genetic in nature and their risks, especially the risk of transmission to children; critically talk over options that are available to manage the disease and its risks; and then elucidate what genetic testing entails: the risks and benefits (Wonderlick and Fine, 1997). Through GC, there is the possibility of obtaining important information and insight about a medical condition or disease for a particular individual (Rajech et al., 2015). For

example, an individual undergoing genetic counseling can get to know what level of risk he or she has of developing a disease condition and the chances that he or she will pass the disease on to their children. Fundamentally, sessions of genetic counseling concentrate on making sure that the participating individuals get critical and balanced information as well as nondirective support while they make their decisions (Adejumo et al., 2015); however, there is little information on patients' attitude to genetic counseling. The decision to utilize genetic counseling services is influenced by various factors. For example, in a country like Israel with multiple cultures, genetic counseling service has been available since 1991, there are many different responses to genetic counselling that are expected and witnessed in the country which have been seen to be greatly influenced by personal and family backgrounds of individuals with one chronic illness or another (Zlotogora et al., 2006).

Because there is no concrete consensus on what influences the uptake of genetic counseling, it is crucial to identify the factors that can possibly influence patient attitude to genetic counseling to better tailor genetic counseling programs and educational materials to meet their individual needs (Bakur et al., 2020). For example, Religion has been known to be a key player in the lives of both Muslims and Christians. Nevertheless, despite the noticeable influence of this factor on the health behaviors and decisions of these group of people, there has only been only a few research studies on how much influence religion has on the uptake and participation of people with genetic disorders in genetic counseling. Generally, existing proof puts it forward that patients differ in how much their decision-making processes are subjected to the influence of their religion (White, 2009). On the other hand, the religious affiliations of patients have been demonstrated to occasionally bring about a dislike for pursuing medical guidance, which goes ahead to affect their capability to manage their diagnosis and their succeeding health related decision-making process

(Kinney et al., 2002). While genetic health professionals have a good understanding of the importance and values that their patients place on their religious beliefs which largely have extended impacts on how they make decisions and cope with their disease conditions, we still do not have sufficient evidence on the perspectives of medical experts about how the religious affiliations and attachments of patients affect counseling sessions.

In a study that assessed the factors that influence the decision of Arab pregnant women to either take up or refuse genetic counseling (Rajech et al., 2015), there was reported no substantial correlation between socio-demographic variables and the decision to take up genetic counseling among the participants. Although, while this was the case generally, it was observed that participants with lower income level underutilized genetic counseling services (Rajech et al., 2015). Consequently, disparities in income level were predicted to be an essential element that can show low family income as a cause of rejection of genetic counseling. Additionally, the study observed that economic situation was a main cause for disparities in medical services (Daoud et al., 2009; Rajech et al., 2015). Also, in the US, studies found that women who earn higher were more probable to get recommended to take part in appropriate genetic counseling compared to women who earn lower (Bellcross et al., 2013).

There are studies that have shown that immigration status of individuals with chronic illnesses can affect their decision to either accept or reject genetic counselling. Typically, there usually exist an information barrier for people of different cultural backgrounds, and this questions the applicability of the information that are made available during sessions (Thompson et al., 2002; Sussner et al., 2009; Joseph & Guerra, 2015; Cheng et al., 2018). When participants are overloaded with information that they can’t make meaning of, especially in situations where there is a huge language constraint, they continually end up appearing to not want the information being provided

(Joseph & Guerra, 2015). Additional research has thus shown that individuals still make decisions based on imperfect understanding and erroneous information (Jun et al., 2018). This can ultimately lead to a reduction in the level of interest to go for genetic counseling even when required.

Although there is not so much that is known about the impact of sociodemographic factors on decisions about whether to utilize genetic counseling services, there are propositions here and there that seem to provide directions to factors that can be highly implicated, and as a result, this study aims to identify potential sociodemographic barriers to broad utilization of genetic counseling.

Purpose of the Study

The goal of this study is to identify the sociodemographic factors that influences patient's attitude to genetic counseling. Specifically, the objective of the study is to discover if there is a relationship between the patient sociodemographic factors and their attitude to genetic counseling.

Research Methodology

This explorative survey utilized an ex post facto design. The sociodemographic variables of the study are sex, age, religion, marital status, educational qualification and illness type. The dependent variable is attitude to genetic counseling among patients with chronic illness. This study relied on quantitative data from 100 participants which was conducted at University of Medical Sciences Teaching Hospital (UNIMEDTH; Ondo, Nigeria) from January 2022 to March 2022. The data was collected using a 17-item questionnaire that entails their sociodemographic information and attitude to genetic counseling scale (Adejumo and Olaoye 2018) among patients with chronic illness such as chronic kidney disease, hypertension, diabetics, sickle cell and cancer. A convenience sampling technique was used to select patients with chronic illness from five clinics or departments at UNIMEDTHC—the Surgical Outpatient Clinic, Endocrinology Clinic,

Cardiology Clinic, Renal Clinic and Hematology Clinic. Patients with a confirmed diagnosis of these illness were approached by the researcher. Those who met the eligibility criteria and agreed to partake in the research signed the informed consent and filled the questionnaire. The eligibility criteria include the following.

1. Individuals registered as patients and being managed by the University of Medical Sciences Teaching Hospital (UNIMEDTHC).
2. Patients diagnosed and being managed for chronic illness (cancer, sickle cell, hypertension, diabetics, chronic kidney disease).
3. Individuals who are managed on out-patients' basis
4. Individuals who can communicate in English, Yoruba or Pigin English.
5. Patient personally willing to participate and consent by signing the participants (consent) form.

Research Instruments

This study utilized a self-report questionnaire, which was divided into two sections. Section A of the questionnaire tapped information on respondents' sociodemographic characteristics such as age, religion, ethnic group, academic qualification, marital status, and type of illness being managed with.

Section B of the questionnaire measured the attitude to genetic counseling of the participants. The Attitude to Genetic Counseling Scale (AGC) developed by Adejumo and Olaoye (2018) was used. The 10-item AGC scale is a well-validated scale that measures attitude to genetic counseling. The AGC has a Cronbach's Alpha of .71, showing good internal consistency. This scale has a Likert response format ranging from 1 to 5 with 1 indicating a response of *strongly disagree* and 5 indicating *strongly agree*. According to the authors, a score above the mean of 18.74 and SD= 3.76

indicate favorable attitude to genetic counseling and a score below the mean of 18.74 and SD= 3.76 indicate unfavorable attitude to genetic counseling.

Data Collection Procedure

The researcher obtained an ethical permission from the University of Medical Sciences Ethics Committee to conduct the study. Thereafter, the researcher sent the questionnaire for further institutional review and discussed the protocol with the physicians of the selected clinics. Each of the managing physician ascertained that the research is of minimal psychological and physical harm (if any at all); and thereafter gave permission to conduct the study.

The health records of the participants were reviewed to identify potential participants that meet the eligibility criteria. During the participants' clinic, the researcher gave the questionnaire to the prospective participants, including a detailed informed consent document. Only willing and consenting patients in attendance in the clinics were recruited as research participants. While waiting to see their managing physician, they were allowed to read the questionnaire and respond accordingly. This took an average of 10 minutes. A total of 105 questionnaires were given out at the five clinics with only 100 correctly and filled. Completed questionnaires were sorted, coded, and entered the Statistical Package for Social Sciences for data analysis.

RESULTS

This section presents results on gathered data regarding the socio-demographic determinants of attitude to genetic counselling. Results is presented in sub-sections.

Table 1: Demographic Distribution

SN	Variables	N	%	Mean	F	P
1	*Age*					
	Less than 35 years	7	7	9.14		
	35-44 years	14	14	11.43		
	45-54 years	28	28	13.07	3.52	<.05
	55-64 years	28	28	13.36		
	65 years above	23	23	13.70		
2	*Sex*					
	Male	38	38	13.13	.61	>.05
	Female	62	62	12.58		
3	*Religion*					
	Christianity	76	76	12.74	.08	>.05
	Islam	24	24	12.96		
4	*Marital status*					
	Married	90	90	13.00		
	Single	8	8	10.88	1.73	>.05
	Separated	2	2	11.00		
5	*Ethnicity*					
	Yoruba	83	83	12.89	.43	>.05
	Non-Yoruba	17	17	12.29		
6	*Highest Educational Qualification*					
	O'Level	13	13	13.00		
	National Diploma/NCE	40	40	12.90		
	Higher National Diploma	14	14	12.50	.07	>.05
	University first degree	25	25	12.80		
	Postgraduate	8	8	12.38		
7	*Illness Type*					
	Hypertension	45	45	13.24		
	Diabetics	28	28	13.25	1.69	>.05
	Sickle Cell	9	9	11.22		

Cancer	18	18	11.72
Total	100	100	

Table 4.1 presents results on demographic distribution among respondents. It is shown that more of the respondents 28% were between 55 and 64 years old, another 28% were between 45 and 54 years old, 23% were 65 years and above, 14% were between 35 and 44 years old, while the other 7% were less than 35 years old.

As regards sex distribution, it is shown that more of the respondents 62% were females, while the other 38% were males. Further, more of the respondents 76% were Christians, while the other 24% were Muslims.

Frequency distribution according to marital status showed that more of the respondents 90% were married, 8% were single, while the other 2% were separated. In addition, more of the respondents 83% belong to the Yoruba tribe, while the other 17% were non-Yoruba. Educational qualification revealed that more of the respondents 40% were National Diploma Certificate holders, 25% were University degree holders, 14% were Higher National Diploma Certificate holders, 8% were postgraduate certificate holders, while the other 13% were O'level certificate holders.

Finally, more of the respondents indicated to be diagnosed with Hypertension, 28% were managing Diabetics, 9% were sickle cell patients, while the other 18% were cancer patients.

Hypothesis Testing

Hypothesis one stated that there will be significant difference in attitude towards genetic counselling across illness type. This was tested using One-Way Analysis of Variance and the result is presented on Table 2.

Table 2: One Way ANOVA Summary table showing results on the influence of illness type on attitude towards genetic counselling

Source	SS	df	MS	F	P
Between Groups	57.86	3	19.29	1.69	>.05
Within Groups	1098.73	96	11.45		
Total	1156.59	99			

Table 2 presents results on the influence of illness type on attitude towards genetic counselling. It is shown that illness type had no significant influence on attitude towards genetic counselling [F (3, 96) = 1.69; P> .05]. This negates the stated hypothesis, hence, was rejected in this study.

Hypothesis two stated that respondents with older age will significantly report more favorable attitude towards genetic counselling than those in the middle or younger age. This was tested using One-Way Analysis of variance and the result is presented on Table 3.

Table 3: One Way ANOVA Summary table showing results on the influence of illness type on attitude towards genetic counselling

Source	SS	df	MS	F	P
Between Groups	149.15	4	37.29	3.52	<.05
Within Groups	1007.44	95	10.61		
Total	1156.59	99			

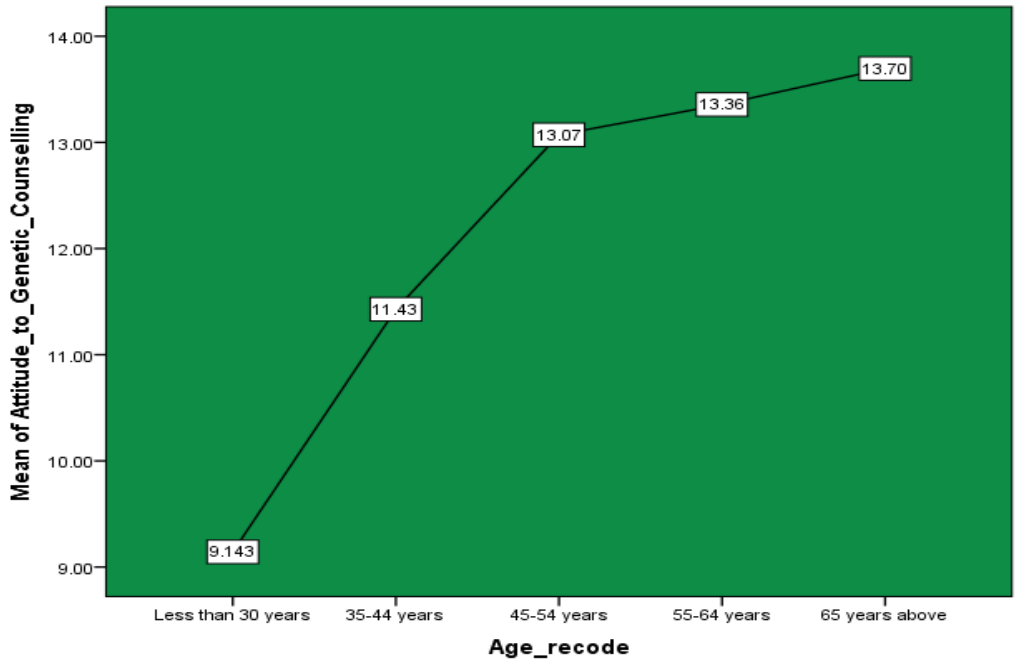
Table 3 presents results on the influence of age on attitude towards genetic counselling. It is shown that age had significant influence on attitude towards genetic counselling [F (4, 95) = 3.52; P<.05]. Further analysis is presented on Table 3a.

Table 3a: Post-Hoc Analysis & Descriptive of the Influence of Age on Attitude towards Genetic Counselling

SN	Age	1	2	3	4	5	Mean	SD
1	Less than 35 years	-					9.14	2.04
2	35-44 years	2.29*	-				11.43	3.80
3	45-54 years	3.93*	1.64	-			13.07	2.92
4	55-64 years	4.21*	1.93	.29	-		13.36	3.59
5	65 years above	4.55*	2.27*	.62	.34	-	13.70	2.25

Table 3a presents results on the descriptive of the influence of age on attitude towards genetic counselling. It is shown that respondents who are 65 years old and above reported more favorable attitude towards genetic counselling (Mean = 13.70; SD = 2.25), while respondents who are less than 30 years old (Mean = 9.14; SD = 2.04), as presented on Figure 1. This confirms the stated hypothesis, hence, was retained in this study.

Figure 1: Age and Attitude towards genetic counselling



Hypothesis three stated that respondents with higher educational qualification will significantly report higher on favorable attitude towards genetic counselling than those with low level of educational qualification. This was tested using One-Way Analysis of Variance (ANOVA) and the result is presented on Table 4.

Table 4: One Way ANOVA Summary table showing results on the influence of illness type on attitude towards genetic counselling

Source	SS	df	MS	F	P
Between Groups	3.62	4	.90	.07	>.05
Within Groups	1152.98	95	12.14		
Total	1156.59	99			

Table 4 presents results on the influence of educational qualification on attitude towards genetic counselling. It is shown that educational qualification had no significant influence on attitude towards genetic counselling [F (4, 95) = .07; P>.05]. This negates the stated hypothesis, hence, was rejected in this study

Discussion

This study investigated the independent influence of sociodemographic variables on attitude to genetic counseling among patients with chronic illness. It was observed that sociodemographic variables partially influenced attitude to genetic counseling. The results of the One-way ANOVA revealed that age had significant influence on attitude to genetic counseling among patients with chronic illness. This finding corroborates with that of Christiaans et al. (2008) who demonstrated a 56.1% uptake of genetic counseling among individuals aged 10-18 years for hypertrophic cardiomyopathy and a 37.2% uptake in older people. The finding in these studies goes ahead to demonstrate the disparities in uptake of genetic counseling among different age groups. Educational qualification did not significantly influence attitude to genetic counseling among patients with chronic illness. Contrary to this finding is the report by Mogilner et al. and MacNew et al. that people who have a higher degree/level of education have greater level of knowledge about cancer and genetic testing, and as such are more inclined to take up genetic counseling compared to people who have lower levels of education. Additionally, the high educational background of the participants compared to general population in the study of Staudigl et al. (2016) could imply that education may provide people with the knowledge, skills and confidence to look for specific information and therefore attend genetic counseling. Moreso, it was also revealed that illness type did not significantly influence attitude to genetic counseling. The findings in this study suggest the need for a greater attention to age and other variables such as psychological variables

in achieving favorable attitude to genetic counseling among patients with chronic illness. Also, the disparity between the findings of this study and past study regarding education qualification suggests the need for further studies to look for more concrete correlation between educational level or qualification and the uptake or utilization of genetic counseling.

Hypothesis one which stated that there will be significant difference in attitude towards genetic counselling across illness type was rejected in Table 2. Hypothesis two which stated that respondents with older age will significantly report more favorable attitude towards genetic counselling than those in the middle or younger age was accepted in Table three, however, comparing this with the finding by Christiaans et al. (2008), the hypothesis was rejected in that study as older age reported less favorable attitude towards genetic counseling compared to younger age. This difference could imply the presence of more underlying sociodemographic or psychosocial factors that may need to be explored more.

Previous studies investigated sociodemographic, psychosocial and clinical factors associated with uptake of genetic counseling for hereditary cancer (Amanda, Sian, Bettina, Mandy, David, Mary-Anne 2016). The discovery that sociodemographic variables partially influenced attitude to genetic counseling is therefore evidence supporting this hypothesis among patients with chronic illness. This implies that in considering possible factors influencing attitude to genetic counseling, it is important to take patient's age into account.

Hypothesis three which stated that respondents with higher educational qualification will significantly report higher on favorable attitude towards genetic counselling than those with low

level of educational qualification. It was however revealed in the study that educational qualification had no significant influence on attitude to genetic counseling. This result was however supported with the findings of Lobb, Gaff, Meiser (2009); Caruso, Vigna, Bigazzi, et al. 2011 which also stated that educational qualification was not significant in predicting favorable attitude to genetic counseling. On the other hand, this factor was implied by the study of Mogilner et al. (1998), MacNew et al. (2010), and Staudigl et al. (2016) to be important for a positive attitude towards genetic counseling. Thus, further research is required. In conclusion, while this study has established the level of influence of different sociodemographic factors in the utilization of genetic counseling, the findings can be said to require more and expanded research in order to make a more conclusive conclusion about the influence of sociodemographic factors on the uptake and utilization of genetic counseling. This is reasoned as there exist some level of agreement and disagreements with other studies that explored the same topic. Could there be more factors that work together with sociodemographic factors in influencing genetic counseling utilization? This and many more questions are questions that will guide further research.

References

Adejumo PO, Oluwatoson AO, Ogundiran T, et al. (2015). Establishing a cancer risk and prevention clinic in Nigeria: Lessons from the field. AORTIC International Cancer Conference, Marrakech, Morocco, November 18-22, 2015

Bakur K, Jumana A, Zuhair A, Brooks H, Clancy T, Takroni S, Ulph F. (2020). Role of religion/spirituality in the context of genetic counseling: health professionals' experiences in an Islamic country. *Journal of Biochemical and Clinical Genetics*. 3(2):60–70.

Bellcross CA, Leadbetter S, Alford SH, et al. (2013). Prevalence and healthcare actions of women in a large health system with a family history meeting the 2005 USPSTF recommendation for BRCA genetic counseling referral. Cancer Epidemiol, Biomarkers Prev: a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology 22:728–35.

Benkel I, Arnby M and Molander U. (2019). Living with a chronic disease: preparation, information, talking and thoughts about the disease. *Int J Med Res Health Sci*. 8(2): 50–58.

Cheng JKY, Guerra C, Pasick RJ, Schillinger D, Luce J, Joseph G, & Joseph G. (2018). Cancer genetic counseling communication with low-income Chinese immigrants, 263–276.

Christiaans, I., Birnie, E., Bonsel, G. et al. (2008). Uptake of genetic counselling and predictive DNA testing in hypertrophic cardiomyopathy. Eur J Hum Genet 16, 1201–1207

Daoudd N, Soskolne V, Manor O. (2009). Educational inequalities in self-rated health within the Arab minority in Israel: explanatory factors. *Eur J Publ Health* 19:477–83.

Daoud N, Soskolne V, Manor O. (2009). Examining cultural, psychosocial, community and behavioural factors in relationship to socioeconomic inequalities in limiting longstanding illness among the Arab minority in Israel. *J Epidemiol Community Health* 63:351–8.

Joseph G, & Guerra C. (2015). To worry or not to worry: breast cancer genetic counseling communication with low-income Latina immigrants. *Journal of Community Genetics*. 6:63–76

Jun M, Thongpriwan V, Choi J, Sook Choi K & Anderson G. (2018). Decision-making about prenatal genetic testing among pregnant Korean-American women. *Midwifery* 56:128–134.

Kinney AY, Emery G, Dudley WN, Croyle RT. (2002). Screening behaviors among African American women at high risk for breast cancer: do beliefs about God matter?. *Oncol Nurs Forum* 29(5):835–43.

Kralik D, Koch T, Price K, et al. (2004). Chronic illness self-management: taking action to create order. *J Clin Nurs.* 13(2):259–267.

MacNew HG, Rudolph R, Brower ST, Beck AN, Meister EA. (2010). Assessing the knowledge and attitudes regarding genetic testing for breast cancer risk in our region of southeastern Georgia. Breast J. 16(2):189–92.

Meiserr B, Halliday JL. (2002). What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Soc Sci Med*. 54 (10): 1463-70.

Mogilner A, Otten M, Cunningham JD, Brower ST. (1998). Awareness and attitudes concerning BRCA gene testing. Ann Surg Oncol. 5(7):607–12

Rajech S, Jalal T, Abdelnaser Z, Esmael A, Muhammad A and Stavit A. (2015). Factors affecting the utilization of genetic counseling services among Israeli Arab women. *Prenatal Diagnosis.* 35; 1–6

Roing M and Sanner M. (2015). A meta-ethnographic synthesis on phenomenographic studies of patients' experiences of chronic illness. *Int J Qual Stud Health Well-being*. 10: 26279

Smerecnik CM, Mesters I, Verweij E, de Vries NK, de Vries H. (2009). A systematic review of the impact of genetic counseling on risk perception accuracy. *J Genet Couns*. 18 (3): 217-28.

Staudigl, C., Pfeiler, G., Hrauda, K. et al. (2016). Changes of Socio-demographic data of clients seeking genetic counseling for hereditary breast and ovarian cancer due to the "Angelina Jolie Effect". BMC Cancer 16, 436

Sussner KM, Thompson HS, Jandorf L, Edwards TA, Forman A, Brown K, Valdimarsdottir HB. (2009). The influence of acculturation and breast cancer-specific distress on

perceived barriers to genetic testing for breast cancer among women of African descent. *Psycho-Oncology*, *18*(9), 945–955.

Thompson HS, Valdimarsdottir HB, Duteau-Buck C, Guevarra J, Bovbjerg DH, Richmond-Avellaneda C, Brown K. (2002). Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. *Cancer Epidemiology Biomarkers and Prevention*, 11(12), 1579–1585.

White MT. (2009). Making sense of genetic uncertainty: the role of religion and spirituality. *Am J Med Genet C Semin Med Genet.* 151(1):68–76.

Wonderlick AL, Fine BA. (1997). Knowledge of breast cancer genetics among breast cancer patients and first-degree relatives of affected individuals. *J Genet Couns* 6:111-130

Zlotogora J, Barges S, Bisharat B, et al. (2006). Genetic disorders among Palestinian Arabs. 4: Genetic clinics in the community. *Am J Med Genet A.* 140:1644–6.