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Genetic Risk, Perceived Risk, and Cancer Worry in Daughters of Breast Cancer Patients

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Abstract

This study explored relationships between worry, perceived risk for breast cancer, consulting a genetic counselor, having genetic testing, and genetic risk for women whose mothers had breast cancer. Analyses involved data from a community-based phone survey of women whose mothers had breast cancer. Participants were categorized as having low, intermediate, or high genetic risk based on their reported family history, in accordance with an accepted classification scheme. The Lerman Breast Cancer Worry Scale measured worry, and participants reported their perceived lifetime likelihood of breast cancer, risk compared to others, and chance from 1 to 100. ANOVA, chi-square, and multiple regression analyses were conducted as appropriate. One hundred-fifty women participated. Mean age was 38 years, and 81% were Caucasian. Fifty-two women had low, 74 had intermediate, and 24 had high genetic risk for breast cancer. There were no significant differences in worry or perceived risk by hereditary risk category. Most high-risk women (91%) had not spoken with a genetic counselor, and no one had previous genetic testing. These findings suggest perceived risk, worry about breast cancer, and use of expert consultation do not match the genetic contribution to risk. There is a need for effectively stratifying and communicating risk in the community and providing tailored reassurance or referral for high-risk assessment.

Keywords

Breast neoplasm; Risk perception; Worry; Genetic testing; Genetic counseling

Introduction

Communicating breast cancer risk is important because perceived risk can influence healthy behaviors such as mammography (Diefenbach et al. 1999; Edwards et al. 2006; McCaul et al. 1996; Pilarski 2009). Furthermore, risk for breast cancer is a key component of decision making about when to offer genetic counseling for breast cancer (Nelson et al. 2005; Palomaki et al. 2006; Robson et al. 2010) and appropriate management strategies (Saslow et al. 2007). Having a family history of breast cancer, especially a mother with breast cancer, can increase perceived personal risk and worry about breast cancer (Diefenbach et al. 1999; Erlich et al. 2000; Kash et al. 1992; Katapodi et al. 2005; Mosher and Danoff-Burg 2005; Raveis and Pretter 2005; Sanders et al. 2003; Sheinfeld and Albert 2003; van Oostrom et al. 2006; Wellisch et al. 1992). Increasing awareness of family histories, including family history of breast cancer, remains a national priority to ensure high-risk women are offered genetic counseling and appropriate management (Berg et al. 2009), and it has been proposed as an objective for Healthy People 2020 (G HP2020-2) (Office of Disease Prevention & Health Promotion, U.S. Department of Health and Human Services 2009).

While the identification of a positive family history is important for risk assessment, most daughters of women with breast cancer will *not* have hereditary risk. Only about 5% of breast cancers are strongly hereditary (Garber and Offit 2005; Stadler et al. 2010). Recent evidence suggests referral for breast cancer genetic testing will most benefit women who meet specific high-risk criteria, estimated to include about 2% of women in the population (Nelson et al. 2005). Thus, the vast majority of daughters of breast cancer patients could benefit from both reassurance about their risks and encouragement to practice prevention. Overestimates of risk for these women could lead to inappropriate referrals for genetic counseling and/or testing. Excessive worry about breast cancer could actually hinder preventive practices (Andersen et al. 2003; Miller et al. 1996), though recent evidence has not supported this concern (Hay et al. 2005; Moser et al. 2007).

Although much of the previous literature suggests family history predicts perceived risk (Acheson et al. 2010; Katapodi et al. 2004), worry (Acheson et al. 2010), and genetic testing referral/uptake (Ropka et al. 2006), little is known about differences in these variables by specific family history-based clinical guidelines for genetics assessment. Do women's risk perceptions, worry, and uptake of genetic counseling vary by the extent of family history? At least one study has documented that most women with "intermediate" familial breast cancer risk overestimate their chances of breast cancer and feel they are appropriate candidates for genetic testing (Burke et al. 2000). A study in the United Kingdom suggested patients at low or moderate genetic risk still desired "inappropriate" and costly genetic testing for breast cancer risk (Griffith et al. 2009). These findings point to a concerning group of "worried well" who are interested in having genetic testing, but unlikely to come away with clinically informative test results. Increasingly, referral for genetic counseling and recommendations for breast cancer screening and prevention are tiered by genetic risk (cf. National Comprehensive Cancer Network guidelines for identifying and managing hereditary breast cancer). To the extent that patients prefer to take on an active role in decision making about their health and healthcare referrals, patient-provider discussions might be influenced by the congruence (or not) of patients' perceived risks, worry, and the extent of their genetic risk as

measured by family history. Further, the relationship between perceived risk and worry is still somewhat unclear, even in the context of similar family histories. While many studies show a direct relationship between worry and perceived risk [e.g., Kelly et al. (2009)], others have suggested their relationship is less clear, or at least influenced by different factors. For example, Price et al. (Price et al. 2007) found low levels of cancer worry even among high-risk women who reported their lifetime risks averaged 50%. They postulated that, although perceived risk and worry are correlated, relevant factors such as knowing genetic test results and family history may contribute independently to perceived risk and worry. To our knowledge, the relationships between perceived risk and worry and having genetic counseling and/or testing have not been established within a single population-based sample.

This study involved secondary data analyses from a community-based sample of women whose mothers had been diagnosed with breast cancer. The goals of these analyses were to explore breast cancer worry, perceived risk, and past use of genetics resources (consulting a genetic counselor, and having genetic testing) as a function of the extent of family cancer history.

Methods

Data Collection

This manuscript reports secondary data analysis from participants in a cross-sectional, community-based study including daughters of women who were diagnosed with breast cancer. Participants were recruited via flyers distributed throughout the Richmond, Virginia, area; through clinics at Virginia Commonwealth University Health System; local breast cancer support and advocacy groups; and classrooms at local colleges. Flyers informed potential participants that the study was seeking daughters of women with breast cancer to learn about their experiences through a telephone interview. The flyers included a number for participants to call to leave contact information. The recruitment period was approximately 4 to 5 months in 2005. The target sample size for the study was 150 participants. Sample size was originally determined to achieve 80% power to identify differences ($OR > 2.0$) in preventive behaviors. The analyses presented in this paper were not considered in the original study design, and thus, we present secondary data analyses.

Eligible participants were adults (at least 18 years of age) whose mothers had been diagnosed with breast cancer within the last 25 years. Women who had a personal history of breast cancer were not eligible. Participants completed a structured phone interview and were offered a gift certificate in appreciation of their enrollment. Prior to completion of the phone interview, participants verbally consented to the study over the phone. Interviews were conducted by two research assistants with previous experience conducting structured research interviews by telephone. The protocol was approved by the Virginia Commonwealth University Institutional Review Board.

Measures

The primary predictor in all analyses was genetic risk for breast cancer as measured by participants' reported family history. For all blood relatives, participants reported site of

cancer diagnosis, age at diagnosis, and their biological relationship to the relative, including if the relative was related through the mother or father. Interviewers did not prompt participants for any specific cancer site. For analyses, participants were categorized as having “high,” “intermediate,” or “low” hereditary risk for breast cancer according to the following criteria: Participants who met the United States Prevention Services Task Force criteria for *BRCA1/2* genetic counseling referral (Nelson et al. 2005; Palomaki et al. 2006) were assigned “high” risk. (This assignment was limited because the surveys did not ask about Jewish ancestry, bilateral disease, or positive genetic test results in family members, all of which would affect genetic risk classification.) If a woman’s only family history of breast cancer was her mother’s cancer diagnosed at age 50 or older, she was classified as having “low” risk. Women not falling into either of these groupings were assigned “intermediate” risk.

Three different measures of perceived risk were used. One interview item asked, “On a scale of 1-5, where 1 is *very unlikely* and 5 is *very likely*, how likely do you think you are to develop breast cancer sometime in your lifetime?” Another measure asked, “On a scale of 1-5, where 1 is *a lot lower* and 5 is *a lot higher*, compared to other women your age, what are your chances of developing breast cancer?” A final item asked, “On a scale from 1 to 100, what are your chances of developing breast cancer sometime in your lifetime?” Worry about breast cancer was assessed using the summed scores of items from the Breast Cancer Worry Scale (Lerman et al. 1991). This measure includes three items that measure frequency of worry: “How frequently do you worry about getting breast cancer?”, “How frequently does worry about breast cancer affect your mood?”, and “How frequently does worry about breast cancer affect your daily functioning.” Possible response options are “Rarely or never,” “Sometimes,” “Often,” and “All the time.” A fourth item asks “How concerned are you about breast cancer?” Response options are “Not at all,” “Somewhat,” “Moderately concerned,” and “Very concerned.” Summed scores could range from 4 (low worry) to 16 (high worry).

Whether participants had consulted with a genetic counselor was assessed by their response to the following interview question: “What sources have you used to get breast cancer information?” Participants were given “genetic counselors” as a potential source. It is important to note that participants were not directly asked if they had undergone formal genetic counseling. Finally, previous genetic testing was assessed by asking participants, “Have you ever had genetic testing for breast cancer?”

Data Analyses

Analysis of variance (ANOVA) assessed the differences in mean perceived risk (Scale: 1 to 100) by genetic risk group. Adjusted analyses used general linear modeling for this outcome. Because of small numbers, the 5-point scales of perceived risk were collapsed to 3-point scales. Chi-square tests of contingency tables were conducted to look for differences in perceived risk compared to other women, and perceived likelihood of breast cancer by genetic risk group. Ordinal logistic regression was used for adjusted analyses. Differences in mean worry by genetic risk group were assessed by ANOVA in bivariate analyses, and general linear modeling was used for adjusted analyses. Finally, differences between genetic

risk groups in talking with genetic counselors and having genetic testing were assessed with chi-square tests for bivariate analyses and logistic regression for adjusted analyses. Covariates in adjusted analyses included race (African-American, Caucasian, or other), education (less than a college degree, college degree or more), and age. Because previous studies have reported an association between perceived risk and age of the daughter at mother's diagnosis (van Oostrom et al. 2006), we assessed this association and adjusted for age of the daughter at diagnosis when bivariate associations were identified. All analyses were conducted using SAS 9.2 (2002-2008). Alpha (p) values $<.05$ were considered significant.

Results

Sample Characteristics

Analyses included all 150 study participants. A description of the sample is summarized in Table 1. Most participants (81%) were Caucasian, and their average age was 38 years ($SD=12.3$). About two-thirds had at least a college degree. On average women were 28 years old when their mothers were diagnosed with breast cancer ($M=28.1$ years, $SD=12.9$). Age of the daughter at time of diagnosis was significantly associated with perceived risk of breast cancer compared to other women [$F(df)=3.48(2)$, $p=.033$], but it was not significantly associated with other measures of perceived risk nor with breast cancer worry. Twenty-four participants (16%) met the USPSTF criteria for genetic counseling referral based on reported family history. Of the high-risk participants, the most common criterion met was having more than two first- or second-degree relatives with breast cancer ($n=17$; 70.8%). Four high-risk participants (16.7%) met the criterion of having breast and ovarian cancer among first- and second-degree relatives. Five high-risk participants (20.8%) had at least two first- or second-degree relatives with breast cancer, with one diagnosed below age 50. Three (12.5%) had a family history of male breast cancer, and 1 high-risk participant met the criterion of more than one first- or second-degree relative with ovarian cancer.

Perceived Risk

Participants' perceived risk for breast cancer is presented in Table 2. On a scale from 1 to 100, overall participants on average estimated their lifetime risk of breast cancer to be 63.5 ($S.D.=22.8$). Mean perceived risk did not vary by family history which, in adjusted analyses, was 64.2 (95% $CI=52.8$ to 75.5), 65.4 (55.2 to 75.5), and 69.0 (56.3 to 81.6) for low, intermediate, and high genetic risk groups, respectively [$F(df)=.33(2)$, $p=.719$]. There was a significant association between genetic risk group and perceived risk on the 3-point likelihood scale ("unlikely" to "very likely") [$\chi^2(df)=11.2(4)$, $p=.025$]. Most participants (65%) said they were "very likely" to get breast cancer, and the proportions within each group were 52%, 68%, and 82% among the low, intermediate, and high risk genetic groups, respectively. However, differences were no longer significant when accounting for covariates [$\chi^2(df)=3.4(2)$, $p=.186$]. Specifically, the adjusted odds ratio for having high perceived risk for the high-risk group compared to the low-risk group was 3.0 (95% $CI=0.9$ to 10.2), and odds ratio for the intermediate-risk group compared to the low-risk group was 2.7 (95% $CI=0.8$ to 9.3). By the 3-level measure of perceived risk compared to other women, overall 70% reported higher-than-average risk. There was no statistical association between genetic

risk group and the perceived risk compared to other women in bivariate [χ^2 (df)=2.4 (4), p =.664] and adjusted [χ^2 (df)=2.5 (2), p =.281] analyses; 62% of women with low genetic risk thought their risks were higher than average, as did 72% of intermediate risk women, and 79% of high-risk women. The corresponding adjusted odds ratio for higher-than-average perceived risk was 2.8 (95% CI=0.8 to 9.7) for the high-risk group compared to the low-risk group. Odds ratio was 2.4 (95% CI=0.6 to 8.9) for the intermediate-risk group compared to the low-risk group.

Breast Cancer Worry

On the scale ranging from 4 to 16, mean worry about breast cancer among all participants was 7.4 (SD=1.9) (Table 2). The standardized Cronbach alpha for this scale in our sample was 0.694. In analyses adjusted for race, age, and education, there were no significant differences in worry between low (7.9, 95% CI=7.0 to 8.8), intermediate (7.8, 95% CI=6.9 to 8.6), and high (8.0, 95% CI=6.9 to 9.0) genetic risk groups [F (df)=.13 (2), p =.882].

Past Use of Genetic Counseling and Genetic Testing

Of the 150 participants, 144 reported using outside resources for information about breast cancer. Of these, 9 reported talking with a genetic counselor about breast cancer risk (Table 2), and there were no significant differences by genetic risk group in adjusted or unadjusted analyses (2% of low-risk participants, and 9% of both intermediate- and high-risk participants) [χ^2 (df)=3.2 (2), p =.200, adjusted]. Reported family histories of cancer for these 9 participants are given in Table 3. None of the 150 participants reported having had genetic testing for breast cancer risk.

Discussion

Among this community-based sample of women whose mothers had breast cancer, there was no evidence for an association between the extent of familial risk and either perceived risk, worry about breast cancer, or utilization of clinical genetic services (i.e., having spoken with a genetic counselor about breast cancer risk, or having had genetic testing). Overall these women had high perceived risk, but relatively low worry about breast cancer. Few women in any risk category reported having talked with a genetic counselor, and none of these women reported having genetic testing.

The finding of high perceived risk is consistent with the broader literature about risk perceptions and family history of breast cancer. Most women overestimate their risks of breast cancer when asked to characterize their chances using quantitative measures of absolute risk, such as a scale from 1 to 100 (Burke et al. 2000; Katapodi et al. 2005; Sanders et al. 2003). Similarly, in the present study, most women thought they were “likely” to develop breast cancer, in spite of empirical evidence suggesting most of these daughters will not get breast cancer. It is noteworthy that we did not ask participants to estimate the likelihood of breast cancer among women without a mother with breast cancer. If study participants perceived all women were likely to get breast cancer, regardless of family history, their response to this item would not necessarily represent a heightened perceived risk.

However, study participants' responses to the item about risk compared to other women suggest these women did perceive their risks to be elevated above average. In terms of risk compared to other women, previous studies have shown that, in general, women have an optimistic bias (i.e., they feel their risk is lower than average) (Clarke et al. 2000; Katapodi et al. 2005); however, these studies also demonstrate this bias does not necessarily hold for women with family histories of breast cancer, and our findings support this caveat. The present results extend what is currently known in the literature, by demonstrating that perceived risk for cancer does not appear to vary significantly as a function of the extent of family history. Rather, it may be that any family history of breast cancer leads to a stable, increased perceived risk. This elevated perceived risk could be helpful for daughters, as recent research has shown increased endorsement of breast cancer prevention, especially screening mammograms and clinical breast exams, among daughters whose mothers had breast cancer (Sinicrope et al. 2009).

Worry about breast cancer is one aspect of the emotional context. The overall mean worry scale score in the present study was remarkably similar across genetic risk groups. Though there are no accepted clinical thresholds for this worry scale (Hopwood et al. 2001), the worry experienced by these women might be considered moderate, and most women did not report worrying "often" or "all the time" about breast cancer. These levels are similar to worry about breast cancer found in other studies of women with familial risk. Henderson et al. (2007) found no difference in cancer worry between women with moderate (17% to 30% lifetime chance) and high (>30% lifetime chance) familial breast cancer risk. Brain et al. (2002) also found similarities in breast cancer worry between familial risk groups. Indeed, a study by Gramling et al. (2005) suggested that asking about family history might actually lead to reduced worry about breast cancer, although those researchers did not use the Cancer Worry Scale to assess worry.

We recognize that conclusions about risk perception from our study are limited by the measures used. Risk perception is a complex construct, and we attempted to capture this complexity by encompassing affective (i.e., worry) and cognitive (i.e., comparative risk and perceived likelihood) appraisals of risk. Previous work by our group suggests multiple cognitive measures, such as the ones we have used, may reflect a common construct (Quillin et al. 2006); however, multiple other important aspects of risk perception exist (Pilarski 2009) such as numeracy, personal experience with cancer, and media exposure, that were not measured and might have provided a more complete assessment of perceived risk.

Related literature supports the present findings that utilization of clinical genetics services (i.e., having genetic testing, or talking with a genetic counselor) does not match with familial risk. Generally, that literature has focused on *underutilization* of services by high-risk individuals (Brown et al. 2005; Foster et al. 2004; O'Neill et al. 2006). This study supports underutilization of genetics services among high-risk women, with only 2 of 24 (8%) reporting meeting with a genetic counselor, and none having genetic testing. It is possible that women who met with genetic counselors were advised to pursue testing for family members who had cancer first. However, we did not collect information about genetic counseling and testing for other family members, and this is a limitation of the current study.

There might be a concern, too, about *overutilization* of genetic services, though less attention has been paid to this aspect of hereditary cancer care (Burke et al. 2000; Nelson et al. 2005; Palomaki et al. 2006). In the present sample, most women who had spoken with a genetic counselor did *not* meet USPSTF criteria for genetic counseling referral for hereditary breast cancer. Thus, these findings potentially provide evidence of concerns for both under- and overutilization of cancer genetics services, although future studies are needed to better understand the interactions of participants with genetic counselors; the present study only queried whether participants used genetic counselors as a resource to learn about breast cancer, but the context of this learning (e.g., attendance at a community educational forum, formal genetic counseling visit) is unknown. Further, we recognize that accepted clinical criteria are not always the only, or even the most important, indications for referral to genetic counseling. A recent case series of errors in cancer genetic services by non-genetics professionals (Brierley et al. 2010) highlights the need for access to expert genetics services whenever cancer genetic testing is being considered. Access to genetic counseling could ensure appropriate genetic testing and provide reassurance and related psychosocial benefits for women who are not at high risk.

Study Limitations

This study has a number of additional limitations that deserve note. The sample was drawn primarily from the Richmond, Virginia, area, so the findings might not generalize to other locations. Even within the geographic location there appear to be some volunteer biases. The sample was primarily Caucasian (81%). This is higher than the proportion of Caucasians in the state of Virginia (73%), and much higher than the city of Richmond (38%) (U.S. Department of Commerce 2010). Although breast cancer is more prevalent among Caucasians (American Cancer Society 2009), a lack of non-Caucasians in the sample might limit diversity in assessed measures. Similarly, the sample was highly educated, and results might be different for women with less educational background.

The presented analyses were not pre-specified as part of the study design (i.e., they represent secondary analyses). This has implications for potential spurious findings, and it also means that we were limited by the sample size, which was not targeted to address our analyses. The large width of 95% confidence intervals for many of the results demonstrates the limited ability of this study to detect small differences.

The study design was cross-sectional; thus, although we can report associations, we cannot clearly determine causation. All of the data were self-reported and are subject to related biases. In particular, we did not check medical records or consult family members to confirm the reported cancer history. For example, one of our participants reported a maternal uncle with breast cancer at 18 years old. Although unlikely, even for hereditary breast cancer, we did not have a way to (dis)confirm this reported family history. In general, breast cancer appears to be accurately reported by family members, though accuracy is lower for other types of cancer, including ovarian cancer, and is less reliable for more distant relatives (Ziogas and Anton-Culver 2003). We also note that our analyses of association with genetic risk are dependent on our chosen risk classification scheme. While many different family history criteria are available (Palomaki et al. 2006), we chose to use the USPSTF criteria to

designate high-risk individuals given the systematic and peer-accepted methods for establishing evidence-based recommendations. Since the survey we used did not ask about Jewish ancestry, bilateral breast cancer, or *BRCA1* and *BRCA2* testing among relatives, some participants may have been misclassified in this study as having lower risk. Of the approximately 300,000 U.S. citizens, about 5 million (<2%) are Jewish, and the proportion is lower in the South (Berkowitz et al. 2003). Also, contralateral breast cancer may not be a specific marker for positive genetic testing (Keim and Ferguson 2007; Tilanus-Linthorst et al. 2006). Since none of the participants reported having genetic testing themselves, it seems unlikely that their relatives had genetic testing, but that is still a possibility. Finally, we note that the USPSTF guidelines are specific for hereditary breast cancer associated with *BRCA1* and *BRCA2*. Although changes in these genes account for most characterized genetic breast cancer, alterations in several other genes can include breast cancer risk (Eccles and Pichert 2005).

Research Recommendations

It is concerning that there were no associations between genetic risk classification and perceived risk, concern/worry about breast cancer, or utilization of genetic services in any of our adjusted analyses. Given the study limitations, it is important that these analyses are replicated. Specifically our findings suggest a future study should be larger and powered specifically to assess perceived risk, worry, and utilization of genetic services based on genetic risk. It would also be important to assess bilateral breast cancer and Jewish ancestry since our data set did not include this information. Finally, a future study would benefit from clearly distinguishing access of clinical genetic counseling. Our survey asked only if genetic counselors were accessed as a resource for breast cancer information. However, this could have included many contacts with a genetic counselor other than formal genetic counseling (e.g., hearing a genetic counselor speak in a public setting, or informally querying a friend who is a genetic counselor).

If subsequent research supports the findings of this study, those data would have important implications for risk communication and utilization of genetic services. Genetic counselors want to empower patients to make the most informed autonomous decisions about genetic testing and health management (Hodgson and Spriggs 2005). This includes ensuring patients have an accurate perception of their risks for cancer (Trepanier et al. 2004). The present study suggests utilization of genetics services for hereditary breast cancer might occur for reasons that are largely independent of familial risk. Thus, from a risk-tailoring vantage, access of these services may be allocated inappropriately.

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Table 1 Sample characteristics ($n=150$)

Characteristic	<i>n</i>	%
Genetic risk group ^a		
Low	52	35
Intermediate	74	49
High	24	16
Race		
African American	26	17
Caucasian	121	81
Other	3	2
Education		
Less than college degree	50	33
College degree or beyond	100	67
Age (Mean, SD)	38 (12.3)	

^aParticipants who met United States Prevention Services Task Force criteria for *BRCA1/2* genetic counseling referral (Nelson et al. 2005) were designated “High” risk. Participants having only a mother with breast cancer diagnosed at or after age 50 years were considered to have “Low” risk. All other participants were classified as having “Intermediate” risk

Table 2 Participants' perceived risk, worry, and contact with genetic counselors ($n=150$)

Variable	<i>n</i>	%
Perceived breast cancer risk		
Lifetime risk on a scale from 1 to 100 [mean (SD)]	63.5 (22.8)	
“Very likely” to get breast cancer	95	65
Higher than average risk	104	70
Breast Cancer Worry		
Score with possible range from 4 (low worry) to 16 (high worry) [mean (SD)]	7.4 (1.9)	
Talked with a genetic counselor	9	6

There were no significant differences by genetic risk category for any of the above variables

Table 3

Reported family histories of participants who talked with a genetic counselor about breast cancer

Case number	Family history	Genetic risk
140	Mother–breast, 85 YO	Low
157	Mother–breast, 46 YO	Intermediate
2	Mother–breast, 39 YO	Intermediate
9	Mother–breast, 45 YO Maternal Aunt–breast ? age	Intermediate
72	Mother–breast, 57 YO Maternal Aunt–breast, 48 YO	Intermediate
75	Mother–breast, 47 YO	Intermediate
76	Mother–breast, 43 YO	Intermediate
34	Mother–breast, 54 YO Sister–breast, 32 YO	High
52	Mother–breast, 87 YO Father–breast, 80 YO Daughter–breast, 41 YO	High