HHS Public Access

Author manuscript

Hisp Health Care Int. Author manuscript; available in PMC 2021 January 20.

Published in final edited form as:

Hisp Health Care Int. 2014 ; 12(4): 183–188. doi:10.1891/1540-4153.12.4.183.

Cardiac Genetic Testing: A Single-Center Pilot Study of a Dominican Population

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Abstract

The impact of undergoing genetic testing in a Dominican population is not well understood. The objective of this investigation was to evaluate the psychological well-being and perceived cardiac risk among Dominicans who underwent genetic testing. Participants completed a qualitative interview and the Short Form-36 (SF-36) questionnaire after cardiac genetic testing. There were 31 subjects evaluated (mean age 42 ± 11 years). Participants revealed three common themes: (a) fear of dying prematurely, (b) guilt of possibly passing on a mutation to their children, and (c) fear of having an implantable cardioverter defibrillator (ICD) shock. Physical components of the SF-36 were within normal limits (46.2 ± 6.6) but elevated for mental components (59.9 ± 5.3). The quality of life and specific themes results determined in this investigation warrant further research in the Dominican population.

El impacto de la experiencia de someterse a pruebas genéticas no está claramente conceptualizado en la población Dominicana. El objetivo de esta investigación fue evaluar el bienestar psicológico y los riesgos cardíacos percibidos en los Dominicanos que se sometieron a pruebas genéticas. Los participantes, después de la realización de sus pruebas genéticas cardiacas, completaron una entrevista cualitativa y el cuestionario de calidad de vida SF-36. Treinta y un (31) sujetos fueron evaluados (edad media 42 ± 11 años). Los participantes revelaron tres temas en común: (a) el miedo de morir prematuramente, (b) la culpabilidad de trasmitir posiblemente una mutación genética a sus niños y, (c) el miedo de tener un choque del ICD. Los componentes físicos del SF-36 se encontraban dentro de límites normales (46.2 ± 6.6) sin embargo los componentes mentales se encontraron elevados (59.9 ± 5.3). Los resultados de esta investigación, calidad de vida y temas específicos, ameritan la realización de nuevas investigaciones con la población Dominicana.

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Keywords

cardiac genetics; quality of life; Dominican; self-reported themes

The Hispanic population is currently the fastest growing minority population in the United States with especially rapid growth in the New York City region (U.S. Census Bureau, 2013). This ethnic group is encompassed in the 300,000 sudden cardiac death (SCD) casualties each year (Ackerman, 2005; Ackerman et al., 2011; Tester & Ackerman, 2011). The increased availability and declining cost of cardiac genetic testing now allows practitioners to use genetic testing more readily for the confirmation of inheritable cardiac channelopathies or cardiomyopathies (Gollob et al., 2011). In addition, the targeted screening of family members who may have a cardiac genetic mutation and remain silently at risk is now recommended by current American and European clinical guidelines such as the Heart Rhythm Society, American Heart Association, and the European Society of Cardiology (Ackerman et al., 2011; Gollob et al., 2011; Priori et al., 2013; Zipes et al., 2006). Identification of those individuals with an underlying inherited cardiac condition can lead to appropriate and timely treatment and management aimed at the prevention of SCD. Such treatments include medications (i.e., beta-blockers) or placement of an implantable cardioverter defibrillator (ICD) in certain high-risk subgroups (Maron, 2002; Priori et al., 2013; Zipes et al., 2006).

Although efforts to reduce health disparities and target specific genetic disorders are now underway, multi-ethnic representation in genetic studies is needed in all sub-populations, including Hispanics (Chen et al., 2012). In addition, there is insufficient data representing how Hispanics integrate a positive cardiac genetic diagnosis into life choices and their perceptions of cardiac risk and overall well-being. Specifically, the impact of emotional responses, such as worry about risks to children and guilt resulting from cardiac genetic testing, on this population is unknown. Effective genetic counseling and education are universally represented because critical components guide the use of cardiac genetic testing and the reporting of findings (Gollob et al., 2011). The purpose of this research investigation was to evaluate quality of life (QoL) and common themes experienced by Dominicans who underwent clinically indicated cardiac genetic testing for an inherited arrhythmia or cardiomyopathy.

We are proposing to evaluate the physiological well-being and perceived cardiac risk among Dominicans who underwent genetic testing. The specific questions for this investigation are the following: (a) What is the overall QoL among Dominican individuals who have undergone cardiac genetic testing? and (b) What are the specific themes that emerge after undergoing cardiac genetic testing and receiving a positive cardiac genetic test result?

Materials and Methods

A prospective survey of consenting Dominican patients who were attending a cardiac clinic visit was obtained. Quantitative data was collected using the validated Medical Outcomes Study Short Form-36 (SF-36 QoL) English and Spanish questionnaires, along with baseline demographic, screening visit-related data, and clinical data.

Interpretive phenomenology (or how a person interprets a given event) was chosen as the qualitative method in this study because it offers insights into an individual's personal experience in undergoing cardiac genetic testing. Qualitative data was collected through semistructured interviews. These interviews were conducted in either English or Spanish (subject's preference: 78% English and 22% Spanish) by a bilingual/bicultural research coordinator with significant research experience working with the local community. Direct narrative accounts allowed the coordinator to collect information on everyday living experiences and also allowed the individuals to express what they were feeling since receiving their cardiac genetic diagnosis. All data were collected, transcribed, and coded by the bilingual/bicultural coordinator and then analyzed in English by an independent member of the study team using NVivo software (QSR International Inc., Burlington, MA, USA). This investigator was blinded to the ethnicity and mutation status of the subjects enrolled and reported the common themes.

Subjects and Setting

This study received approval from the Institutional Review Board at Columbia University Medical Center. A convenience sample of participants (age 18 years or older) was recruited from the cardiovascular services and ICD clinic at New York-Presbyterian Hospital, Columbia University Medical Center between 2009 and 2013. All participants self-identified their ethnicity as Dominican (of Dominican origin) and reported they lived in the local Washington Heights/Inwood community of New York City. All subjects received their health care at New York-Presbyterian Hospital, Columbia University Medical Center and were previously seen in our cardiac clinic. They were asked to consider participation if they had undergone prior clinical cardiac genetic testing and counseling for a cardiac condition and were willing to complete the SF-36 QoL health-related questionnaires (listed and described in the following text) as well as participate in a 30–40-min genetically focused, semistructured interview.

Qualitative Interview

The interviews were conducted in a private room at New York-Presbyterian Hospital, Columbia University Medical Center and lasted approximately 1–1.5 hr in duration. Field notes were taken, and an interpretive file was created for each subject. All captured data (including interview data, clinical and demographic data) were coded. Methodological and analytical documentation included the identification of key phrases, similar experiences, common themes, and documentation of the rationale for health and family decisions. Data collection continued until saturation, and all interviews were audiotaped and then transcribed by an independent coder. Upon completion of the transcriptions, each subject was given the opportunity to review, reflect, and clarify their transcript to ensure it accurately reflected their feelings regarding cardiac genetic testing, their test results, and the impact on their lives and that of their families.

Short Form-36 Item Quality of Life

QoL and psychological well-being were assessed using the Medical Outcomes Study SF-36, a widely used, well-known, self-reported scale (Ware & Sherbourne, 1992). The SF-36 has been standardized and validated for both English- and Spanish-speaking individuals

(Alonso, Prieto, & Antó, 1995; Ware et al., 1998). It has also been used successfully in various patient populations, including those with a cardiac genetic diagnosis and ICDs (Christiaans et al., 2008). The questionnaire contains 36 items and yields 8 domain scores, including physical functioning, physical role limitations, emotional role limitations, bodily pain, general health perceptions, vitality, social function, and mental health. The SF-36 primarily employs five-choice response scales that patients can select from. Physical and mental health summary scores are calculated using linear T-score transformations with $M = 50$ and $SD = 10$ (Ware, Kosinski, Hatoum, & Kong, 1996; Ware & Sherbourne, 1992). Psychometric testing of the SF-36 has established construct, predictive, and known-groups validity as well as good reliability and sensitivity to change (Kosinski et al., 1999; Ware et al., 1998; Ware & Sherbourne, 1992). Scores are standardized to population norms (score of 50) using published algorithms. Higher scores indicate better perceived QoL.

Perceived Risk of Developing a Future Life-Threatening Cardiac Event

The perceived risks of experiencing a serious cardiac event, of developing (more) symptoms, and of developing limitations in daily activities were measured with two responses for each item, assessing (a) the risk of that event occurring on a scale ranging from 0% to 100% and (b) the perceived severity of the risk of that event occurring on a similar scale; responses were characterized as ranging from *very small* to *very large* (Moss-Morris et al., 2002). For each of the items queried, a total perceived risk score was calculated by averaging the two scores.

Results

We evaluated 31 Dominican adult subjects, 22 males and 9 females, with a mean age of 42 ± 11 years; 33% had a family history of SCD prior to age 50 years (see Table 1). All subjects had received their cardiac genetic diagnosis at least 1 year prior to study measures as well as had a preexisting ICD. The SF-36 physical component summary scores averaged lower than normal (46.2 ± 6.6), whereas the mental health component summary scores averaged higher than normal (59.9 ± 5.3; see Table 2). Patients felt their perceived risk of experiencing serious cardiac events was high (82.0 ± 33.7%) and reported their perceived risk for developing additional symptoms (62.0 ± 36.6%) and developing limitations to daily living (55.0 ± 27.6%).

Qualitative Results

During the semistructured interviews, when asked to explain in “their own words” their inherited cardiac syndrome or cardiomyopathy, 85% of the subjects were able to correctly identify that they had an underlying “problem with a gene in their heart.” The remainder believed their genetic mutation was primarily because of lifestyle choices such as smoking, alcohol, and drug abuse. This then lead into individual discussions of how undergoing cardiac genetic testing and/or living with a positive cardiac genetic diagnosis had impacted their lives. Three common themes emerged from the interviews: fear of dying suddenly as a result of their cardiac conditions, guilt of potentially passing a mutation on to their children and grandchildren, and fear of their ICD firing (Table 3).

Individuals had a fear of dying suddenly because of a positive cardiac mutation and/or a prior out of hospital cardiac arrest, which was reported by several individuals with comments such as “you never know when your heart might go into a bad rhythm and stop” and “I worry every time I feel skipped beats in a row.” Another young woman reported that she felt “guilty” about passing on a genetic mutation to her young daughter.

All reported they had time to adjust to what the cardiac genetic diagnoses meant to their personal lives and health choices but still “feared the unknown.” One man reported that although he felt “protected with his ICD” he “feared it would shock him.” One woman with a positive mutation for hypertrophic cardiomyopathy reported feeling a “sense of relief” in knowing her diagnosis and that she could “protect” her children by bringing them in for regular cardiac checkups. In the interviews, most individuals (73%) in our population reported occasional symptoms.

The most common symptoms reported included palpitations, shortness of breath, and fatigue. All subjects indicated that they tended not to ignore symptoms related to their heart and would rest or slow down if they felt skipped beats or dizziness during their usual daily activities or while exercising. Participants understood the chronic nature of their inherited cardiac condition and its consequences but also felt that their illness was, at least partially, controllable by self-care (taking their medications as prescribed) and by seeking medical care when experiencing cardiac symptoms.

Discussion

This investigation focused on a unique population of minority (Dominican) patients who underwent cardiac genetic testing. All patients had previously suffered an out-of-hospital cardiac arrest, sustained ventricular arrhythmia, or loss of consciousness. To the best of our knowledge, the perceptions about overall QoL and cardiac risk have not been reported before in this population. The three major themes obtained from the semistructured interview were fear of dying suddenly, guilt of passing on a genetic mutation to one’s children, and fear of their ICD firing.

Our findings are consistent with those reported in White patients living with hypertrophic cardiomyopathy, where immediate and future concerns of a positive cardiac genetic diagnosis generates fear and concern for an individual with the illness and for other immediate family members who may be affected (Subasic, 2013). However, from the qualitative interviews, it was most women (88%) who feared passing on a mutation to their children, whereas most male patients (82%) reported they feared the occurrence of a life-threatening arrhythmia.

Interestingly, from the qualitative interviews, all of our subjects (male and female) still feared the occurrence of another cardiac event or dying prematurely from SCD, regardless of being on medication or having an ICD implanted to terminate any future arrhythmia, should they occur. This finding may be unique to this population or may be caused by a lack of knowledge regarding prescribed therapies such as ICD, beta-blocker, or antiarrhythmic drug

therapy because it relates to an individual's underlying cardiac genetic condition and the prevention of arrhythmias.

In addition, genetic misunderstandings can also affect coping and often reflect denial and desires for control (Klitzman, 2010). Thus, emotional needs can hinder understandings of genetics and health provider's input. Individuals often maintain nonscientific beliefs, which can have implications for care and public and professional education (Klitzman, 2010). Persistence of misunderstandings, despite realization of their inaccuracy, suggests that providers need to address not just cognitive facts but underlying emotional issues when caring for individuals and families. Although several recent studies have found that the general public holds a favorable view of diagnostic genetic testing, a significant lack of knowledge exists in understanding the basic principles of inheritance (Smerecnik, Mesters, de Vries, & de Vries, 2011).

In our investigation, all subjects were emotionally well-adjusted despite the knowledge of their positive cardiac mutation status associated with their underlying cardiac diagnosis. This is likely because they were more than a year beyond their initial cardiac genetic testing, diagnosis, and initiation of treatments.

While SF-36 summary scores for mental health were high, perceived risks for serious future cardiac events also tended to be high. This is somewhat different from the literature on the psychological well-being of patients at risk for breast and ovarian cancers, Parkinson's and Huntington's diseases, and other inherited conditions where anxiety, depression, and mental and physical well-being (QoL) return to baseline levels within a year after an initial diagnosis (Calsbeek, Morren, Bensing, & Rijken, 2007; Falcone, Wood, Xie, Siderowf, & Van Deerlin, 2011; Horowitz et al., 2001; MacNew, Rudolph, Brower, Beck, & Meister, 2010). This may be because all of these individuals were asymptomatic and then had a cardiac arrest or loss of consciousness that ultimately led to a genetic evaluation.

One limitation of the aforementioned studies was that many focused primarily on a White population (Subasic, 2013). Only a few investigations have studied a cardiac genetic population (Christiaans et al., 2008; Subasic, 2013); none of which have looked at the implications of cardiac genetic testing in an entirely minority population. The specific themes found in this investigation warrant attention when caring for minority patients, particularly because research has shown that certain genomic risks may be found in specific ethnic groups (Wang, Hickey, Taylor, & Gallek, 2013). Little is known about genomic risks in the Hispanic population. However, one study by Derby et al. in 2010 found significant heterogeneity in cardiovascular risk among Puerto Rican, Cuban, Dominican, Central American, and South American women (Derby et al., 2010). Although this study failed to examine Hispanic males, the findings provide insight into genetic heterogeneity related to cardiovascular risk. Educational programs are needed to enhance genomic knowledge among patients and providers in cardiovascular and primary care settings (Calsbeek et al., 2007; Christianson et al., 2010).

Future studies should investigate the physical and mental components of QoL, before and within a shorter duration of time after receiving a positive genetic mutation diagnosis, so that

tailored interventions aimed at genomic education and improving QoL can be implemented and evaluated. Targeted interventions aimed at increasing the understanding of the overall impact of a positive cardiac mutation, especially within minority populations, and how advances in cardiac genetic testing and treatment are integrated into individual/families' lives or personal health care choices require more investigation in the future. One specific intervention that might be helpful is describing clearly the process of the transmission of genes from parents to children and the specific details of the role of prescribed therapies in preventing the reoccurrence of cardiac arrhythmias.

Limitations

This was a small, qualitative study that investigated a convenience sample of minority Dominicans who underwent cardiac genetic testing for specific cardiac conditions, including hypertrophic cardiomyopathy, catecholaminergic polymorphic ventricular tachycardia (CPVT), arrhythmogenic right ventricular cardiomyopathy (ARVC), and Brugada and long QT syndromes. These conditions affect a relatively small number of individuals (1 per 500 to 1 per 3,000 annually; Ackerman et al., 2011) but nevertheless may have life-threatening outcomes. Moreover, no assessments or interviews were performed prior to the return of genetic test results. Determining the change in perceptions and attitudes over time is one area of future investigation. In addition, although this study offers a unique perspective on a minority population of Dominican origin, it may not be generalizable to other ethnicities.

Conclusions

This initial data was unique to a Dominican population and provides a critical first step in guiding future areas of investigation. In addition, the qualitative responses provided by subjects may aid in the generation of new hypotheses and development of innovative approaches to measure and capture future QoL data. Challenges exist around culture, language, genetic, and genomic literacy, and how these intersect with advancements in cardiac genetic technology. Interdisciplinary research will be important in understanding how individuals (particularly minority populations) receive, translate, understand, and incorporate cardiac genetics into their personal lives and health care choices.

Acknowledgments.

We would like to acknowledge the Robert Wood Johnson Foundation Nurse Faculty Scholar Awards given to Kathleen T. Hickey (Award No. 66515, 9/1/2009–2/28/13) and Jacquelyn Y. Taylor (Award No. 64193, 9/1/2008–2/28/2012).

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TABLE 1.

Demographics ($N = 31$)

Variables	
Mean age (years ± *SD*)	42 ± 11
Marital status (married)	23%
Education status	
High school	82%
Some college	10%
Income less than $55,000 per year	96%
Insurance through Medicaid	98%
Family history of SCD younger than the age of 50 years	33%

Note. SCD = sudden cardiac death.

TABLE 2.

Quality of Life Scores Using the Short Form-36 (SF-36; $N = 31$)

SF-36 Questionnaire	*M* ± *SD*
Physical component summary	46.2 ± 6.60
Mental component summary	59.9 ± 5.30
Health domains	
Physical functioning	45.8 ± 9.90
Role physical	47.3 ± 14.43
Body pain	52.2 ± 8.90
General health	44.9 ± 12.00
Vitality	48.4 ± 8.90
Social functioning	51.3 ± 8.80
Role emotional	50.1 ± 14.00
Mental health	53.6 ± 8.00

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TABLE 3.

Identified Themes

Themes From Semistructured Interview	Patients Reported
Fear of sudden death	89%
Guilt of passing on a genetic mutation to their children	77%
Fear of ICD firing	73%

Note. ICD = implantable cardioverter defibrillator.