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REVIEW PAPER

Predictors of Genetic Testing Decisions: A Systematic Review and Critique of the Literature

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Abstract Genetic testing is increasingly available in medical settings and direct-to-consumer. However, the large and growing literature on genetic testing decisions is rife with conflicting findings, inconsistent methodology, and uneven attention across test types and across predictors of genetic testing decisions. Existing reviews of the literature draw broad conclusions but sacrifice nuanced analysis that with a closer look reveals far more inconsistency than homogeny across studies. The goals of this paper are to provide a systematic review of the empirical work on predictors of genetic testing decisions, highlight areas of consistency and inconsistency, and suggest productive directions for future research. We included all studies that provided quantitative analysis of subjective (e.g., perceived risk, perceived benefits of testing) and/or objective (e.g., family history, sociodemographic variables) predictors of genetic testing interest, intentions, or uptake, which produced a sample of 115 studies. From this review, we conclude that self-reported and test-related (as opposed to disorder-related or objective) predictors are relatively consistent across studies but that theoretically-driven efforts to examine testing interest across test types are sorely needed.

Keywords Genetic testing · Decision-making · Intentions · Systematic review · BRCA1/2 · Direct-to-consumer

Genetic testing provides people with potentially life-saving information about their susceptibility to dozens of health conditions and genetic disorders. Genetic counseling is becoming increasingly common in hospitals and other medical settings (Fulda and Lykens 2006), and a growing number of companies provide a direct-to-consumer (DTC) opportunity to simply mail in a sample of saliva and receive information about one's risk for nearly 100 heritable conditions in as little as 6 to 8 weeks. The increasing availability of genetic testing in various settings raises a critical question: Who is getting tested? Widely-adopted models of health behavior (e.g., health belief model, Becker 1974; protection motivation theory, Rogers 1983) point to some likely predictors of genetic testing decisions, including subjective risk or susceptibility, perceptions of severity, and perceived barriers and benefits to testing (Janz and Becker 1984). To the extent that genetic testing can be broadly defined as a health behavior, one might expect that the predictors of genetic testing decisions would be fairly consistent across tests and populations. However, the evidence for such consistency remains elusive.

The goal of this paper is threefold. First, we provide a systematic review of the literature on subjective and objective predictors of genetic testing interest and decisions. Second, we build on this review by drawing attention to areas of agreement within the literature, which are few and far between, as well as the vast areas of disagreement and inconsistency. Finally, we close by proposing directions for future research that are likely to move the field toward a clearer understanding of decisions about genetic testing.

Our Approach

Genetic tests can be divided into eight basic categories: diagnostic tests, predictive and pre-symptomatic tests, carrier tests, prenatal tests, pre-implantation tests (in the context of in vitro fertilization), newborn screening, pharmacogenic tests, and research tests (National Institutes of Health 2013). In this

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article, we review research on diagnostic, predictive/presymptomatic, carrier, and research testing decisions, which are the only tests that involve a personal testing decision on the part of the test "subject" (in the case of prenatal testing, the parent makes a decision about testing the fetus, not the parent him- or herself, and therefore prenatal testing is not included in this review). Within these categories, some of these tests are of dubious value (e.g., Alzheimer's; Hiraki et al. 2009), not widely available (e.g., deafness; Smith and Hone 2003), or not yet developed (e.g., prostate cancer, Culler et al. 2002). Our review includes any study that examined quantitative predictors of decisions about diagnostic, predictive/presymptomatic, carrier, and research testing decisions without evaluation of the validity or availability of the particular test. Although issues of validity and availability are of significant concern to genetic counselors, such issues are outside the bounds of our inquiry, which examines genetic testing from the psychological perspective of the decision-maker.

Several reviews addressing predictors of genetic testing decisions already exist (Etchegary 2004; Gooding et al. 2006; Lerman et al. 2002; Meiser 2005; Rahman et al. 2012). However, the approach taken by these reviews, though beneficial for some purposes, sacrifices nuance in favor of drawing broad conclusions about predictors of testing decisions. As an example, most reviews conclude that perceived risk predicts decisions about predictive testing, such that people who believe themselves to be more at risk for a particular disorder are more likely to pursue genetic testing related to that disorder. However, a closer look at the findings for perceived risk reveals inconsistent support for its relationship with testing decisions, even within studies addressing the same testing procedure (e.g., BRCA1/2 testing: Culver et al. 2001; Durfy et al. 1999, and Helmes 2002 find a positive relationship; Andrews et al. 2004, Cameron and Reeve 2006, and Durfy et al. 1999 find no relationship). Our review takes a more thorough and systematic approach to reviewing the relevant empirical findings, with the ultimate goal of drawing attention to the clear need for a more cohesive approach to this research area.

Method of Qualitative Review

Our approach to reviewing the literature on genetic testing decisions began in September 2009 with searches in the PubMed, PsycInfo, and Google Scholar search engines using the combination of "genetic testing" and "decision" as initial search terms. Subsequent searches targeted specific genetic tests (e.g., "BRCA," "Huntington's," "Alzheimer's"), with a final search date of February 2013. We had several criteria for exclusion in our review. First, we omitted any study that did not assess either uptake of genetic testing or genetic testing intentions or interest. Second, we omitted non-empirical papers (e.g., commentaries, opinion pieces, discussions of ethical issues) from our formal review, although we briefly discuss the findings of qualitative papers addressing self-reported reasons for or against testing below. In total, 115 studies from 113 papers provided quantitative tests of predictors of genetic testing interest, intention, or uptake. Table 1 presents study characteristics for all studies included in the review.

Of note, we opted to conduct a qualitative systematic review rather than a quantitative (i.e., meta-analytic) review. Our ability to discuss the wide array of considerations that influence genetic testing decisions, many of which rely on statistical procedures that are difficult or impossible to properly synthesize (e.g., multiple regression, structural equation modeling), would be limited by the requirements of meta-analytic procedures. A list of papers included in our review and a table with detailed characteristics of each study are available as supplemental materials online.

We would also note that we included studies that assessed not only uptake of genetic testing but also interest and intentions, which are more likely to be biased or inaccurate (e.g., Nisbett and Wilson 1977). We include studies of interest and intentions in part due to the large numbers of studies that use only such measures. Uptake is more difficult to track and thus less common in the literature. We reasoned that a review of only uptake studies would be quite limited and would not provide a complete picture of the state of the literature on genetic testing decisions. That said, we highlight studies that assess uptake because such studies almost certainly provide stronger examinations of predictors of testing.

The process of reviewing the literature on genetic testing decisions revealed that many studies are qualitative in nature, focusing on patients' self-reported explanations of their motivations for or against testing rather than quantitatively examining the relative merit and strength of one or more predictors of testing. In brief, these qualitative findings suggest that patients' explanations for their testing decisions are fairly consistent, with few to no contradictory findings across studies. As reasons for testing, patients typically cite the motivation to reduce uncertainty (*BRCA1/2 testing*: Bernhardt et al. 1997; *CRC*: Graham et al. 1998; Warner et al. 2005; *deafness*: Withrow et al. 2008), opportunities for preventive action (*BRCA1/2*: Bernhardt et al. 1997; Cameron and Reeve 2006; Meijers-Heijboer et al. 2000; Ramirez et al. 2006), increased ability to plan for the future (*Huntington's*: Craufurd et al. 1989; Yaniv et al. 2004; *BRCA1/2*: Ramirez et al. 2006; *CRC*: Warner et al. 2005; deafness: Withrow et al. 2008), and family considerations (*BRCA1/2*: Bernhardt et al. 1997; Ramirez et al. 2006; Warner et al. 2005). As reasons not to test, patients typically cite emotional considerations (*Huntington's*: Meiser and Dunn 2000; Yaniv et al. 2004; *BRCA1/2*: Ramirez et al. 2006), concerns about risks of the testing procedure (*BRCA1/2*: Bernhardt et al. 1997; Culver et al. 2001), a perception that testing would not be useful (*BRCA1/2*: Culver et al. 2001;

Table 1 Study Characteristics for all studies included in systematic review

Reference	*N*	Test Type	Average Age	Age Range	% Women	Description of Sample	Country	Dependent Measure
Aktan-Collan et al. (2000)	381	CRC	43	18–79	51 %	Family members of people with a genetic predisposition to CRC	Finland	Behavior
Andrews et al. (2004)	60	BRCA1/2	47	24–78	100 %	Women of Ashkenazi Jewish background who underwent GT	Australia	Intentions
Andrykowski et al. (1996)	649	BRCA1/2	47	18–88	55 %	Participants in the annual Kentucky Health Poll	USA	Intentions
Bates et al. (2011)	104	General GT	40	19–79	0 %	African-American males at a national fraternity meeting	USA	Intentions
Biesecker et al. (2000)	172	BRCA1/2	40	18–75	54 %	Participants enrolled in familial cancer study by National Cancer Institute	USA	Behavior
Binedell et al. (1998)	54	HD	39	–	46 %	Adult children of one parent with Huntington's disease	UK	Behavior
Bloch et al. (1989)	51	HD	39	–	71 %	At-risk for Huntington Disease and had enrolled in a predictive testing program	Canada	Intentions
Bosompra et al. (2000)	622	Cancer risk	46	–	59 %	Community members contacted through random digit dialing	USA	Intentions
Bosompra et al. (2001)	622	Cancer risk	–	18–75	59 %	Community members contacted through random digit dialing	USA	Intentions
Bottorff et al. (2002)	1016	BRCA1/2	–	20–79	100 %	Woman from the general public and women with a BC diagnosis	Canada	Intentions
Botoseneanu et al. (2011)	1824	General GT	45	–	52 %	Participants in U.S. Public Knowledge & Attitudes About Genetic Testing Survey	USA	Intentions
Braithwaite et al. (2002)	292	CRC & BRCA1/2	36	18–60	50 %	Patients registered with participating general practitioners	UK	Intentions
Bratt et al. (2000)	110	Prostate	–	40–72	0 %	Men who had a family member with prostate cancer	Sweden	Intentions
Bunn et al. (2002)	1836	CRC	45	18–75	60 %	Adult community members recruited through random digit dialing	USA	Intentions
Cameron and Diefenbach (2001)	180	BRCA1/2	19	18–25	100 %	Female undergraduate psychology students at a private university	USA	Intentions
Cameron and Reeve (2006)	303	BRCA1/2	38	18–82	100 %	Women attending general practitioner clinics, university students, and first degree relatives of women with BC	New Zealand	Intentions
Cameron et al. (2009)	752	Multiple scenarios	26	16–75	70 %	Students and staff at universities and snowball recruitment	New Zealand, Australia, UK	Intentions
Cappelli et al. (1999)	110	BRCA1/2	–	18–50	100 %	Women diagnosed with BC at a young age & general population	Canada	Intentions
Cappelli et al. (2001)	169	BRCA1/2	–	18–50	100 %	Women diagnosed with BC at a young age, high-risk relatives, and general population	Canada	Intentions
Cappelli et al. (2002)	541	CRC	59	–	54 %	Ashkenazi Jews (participated, declined, or did not respond	Canada	Intentions
Chaliki et al. (1995)	982	BRCA1/2	49	–	100 %	Women at a radiologic practice or at an OB/GYN group practice	USA	Intentions
Cherkas et al. 2010	4050	DTC	54	17–91	89 %	Adult volunteers from the TwinsUK register	UK	Intentions
Codori et al. (1994)	98	HD	38	–	58 %	Community members recruited through mailing and phone calls	USA	Behavior
Codori et al. (1999)	258	CRC	47	19–83	58 %	First-degree relatives of CRC patients	USA	Intentions
Cragun et al. (2012)	91	CRC	65	35–93	41 %	Cancer registry patients diagnosed with CRC	USA	Intentions
Craufurd et al. (1989)	191	HD	–	–	–	Adults at risk for HD and those who spontaneously sought out predictive testing	UK	Behavior
Croyle et al. (1995)	271	BRCA1/2	20	18–30	100 %	Female undergraduates	USA	Intentions
Croyle and Lerman (1993)	401	CRC	44	18–99	61 %	Community members recruited through random digit dialing	USA	Intentions
Culler et al. (2002)	267	Prostate	–	21–84	0 %	Men present in waiting rooms of a urology clinic in an urban area.	USA	Intentions
Culver et al. (2001)	97	BRCA1/2	46	30–60	100 %	People with a positive, borderline, or negative family history of BC but with a close friend with personal history	USA	Intentions
Cutler and Hodgson (2003)	258	Alzheimer's	50	40–60	66 %	Adults with a living parent with a diagnosis of probable AD and a comparison group	USA	Intentions
Cyr et al. (2010)	558	CRC	–	–	39 %	Community members in rural and frontier settings	USA	Intentions
DiLorenzo et al. (2006)	434	Multiple scenarios	38	–	59 %	Community members recruited in the cafeteria of a medical center	USA	Intentions
Durfy et al. (1999)	543	BRCA1/2	43	18–74	100 %	Women with a family history of BC	USA	Intentions
Etchegary et al. (2010)	560	General GT	35	19–50	100 %	Women with at least one child 10 or under who received inpatient care	Canada	Intentions

Table 1 (continued)

Reference	*N*	Test Type	Average Age	Age Range	% Women	Description of Sample	Country	Dependent Measure
Evers-Kiebooms et al. (1989)	162	HD	–	17–65	49 %	Adults at risk for HD and their partners	Belgium	Intentions
Evers-Kiebooms and Decruyenaere (1998)	113	HD	–	–	–	Adults at risk for HD	Belgium	Behavior
Fisher et al. (2012)	231	DTC	19	17–42	61 %	Undergraduate students	Australia	Intentions
Foster et al. (2004)	309	BRCA1/2	41	21–86	76 %	Adults from clinical genetic centers with BRCA1/2 mutation in their family	UK	Intentions
Frost et al. (2001)	449	Alzheimer's	–	–	56 %	Undergraduate students; manipulated information about genetic risk (positive test = 50 %/90 % chance of AD)	UK	Intentions
Glanz et al. (1999)	426	CRC	50	19–84	51 %	Siblings and adult children of patients with adenocarcinoma of the large bowel	USA	Intentions
Godard et al. (2007)	334	BRCA1/2	–	–	86 %	Individuals from high-risk BC families who declined genetic testing	Canada	Behavior
Gray et al. (2012)	767	BRCA1/2	37	18–80	100 %	Community members recruited via Craigslist, a cancer resource website, and local ads	USA	Intentions
Gwyn et al. (2003)	518	BRCA1/2	62	52–91	100 %	Community members recruited through a mailing	USA	Intentions
Hadley et al. (2003)	104	CRC	–	18–83	57 %	People with CRC, a family history of CRC, or family history of genetic predisposition	USA	Intentions
Hailey et al. (2000)	51	BRCA1/2	41	24–58	100 %	Women who had or did not have a first degree relative with BC	USA	Intentions
Hall et al. (2009)	379	BRCA1/2	–	–	100 %	Women with a family history of BC or with histologically-proven diagnosis of BC	UK	Intentions
Harel et al. (2003)	361	Tay-Sachs & hypercholes-terolemia	17	16–18	50 %	Students in grades 10–12 attending high school in Rhode Island	USA	Intentions
Helmes (2002)	330	BRCA1/2	40	18–64	100 %	Women with low to moderate risk recruited through a physician network	USA	Intentions
Helmes et al. (2006)	340	BRCA1/2	41	18–64	100 %	Women with no personal history of breast/ovarian cancer	USA	Intentions
Hiraki et al. (2009)	293	Alzheimer's	58	–	71 %	First-degree relatives of people with Alzheimer's	USA	Intentions
Holloway et al. (2008)	433	BRCA1/2	–	–	56 %	Relatives of individuals who tested positive for BRCA1/1 mutation	Scotland	Behavior
Hughes et al. (1997)	407	BRCA1/2	–	18–75	100 %	African Americans & Caucasians with a family history of BC or ovarian cancer	USA	Intentions
Jacobsen et al. (1997)	74	BRCA1/2	44	32–59	100 %	Women with 1+ first-degree relatives with BC recruited before a routine mammogram	USA	Intentions
Jacopini et al. (1992)	102	HD	–	18–57	55 %	Members of the Italian Huntington Association	Italy	Intentions
Julian-Reynier et al. (2000)	419	BRCA1/2	–	–	79 %	At-risk first and second degree relatives of patients at BC family clinics	France	Behavior
Kasparian et al. (2009)	119	Melanoma	50	18–60	52 %	Individuals with a strong family history of melanoma and a known genetic mutation	Australia	Behavior
Kelly et al. (2004)	106	BRCA1/2	49	18–83	100 %	Ashkenazi Jews with a personal or family history of BC or family history of BRCA1/2	USA	Behavior
Keogh et al. (2004)	91	BRCA1/2		25–94	77 %	Women with personal history of BC and their male relatives	Australia	Behavior
Kinney et al. (2000)	95	CRC	44	18–72	64 %	First-degree relatives of CRC patients	USA	Intentions
Kinney et al. (2001)	95	BRCA1/2	43	18–78	77 %	Adults with a "kindred" relationship with someone who has had a history of cancer	USA	Intentions
Klitzman et al. (2007)	21	HD	–	–	43 %	Patients with HD or their family members	USA	Intentions
Laegsgaard et al. (2009)	397	Psychiatric	–	18–60	70 %	Participants in genetic studies with diagnosed mental illness	Denmark	Intentions
Lee et al. (2002)	258	BRCA1/2	–	–	100 %	Female patients seen at a breast and ovarian surveillance service	USA	Behavior
Lerman et al. (1996)	279	BRCA1/2	43	–	67 %	Adult male and female members of families with BRCA1-linked breast-ovarian cancer	USA	Behavior
Lerman et al. (1997)	149	BRCA1/2	44	21–84	63 %	Adult male and female members of families with BRCA1-linked breast-ovarian cancer	USA	Behavior
Lerman et al. (1999)	208	CRC	47	–	55 %	At-risk adult members with a risk conferring genetic mutation	USA	Behavior
Lipkus et al. (1999)	266	BRCA1/2	–	–	100 %	African American women with or without a family history of BC	USA	Intentions
Lynch et al. (2009)	1574	BRCA1/2	53	–	54 %	Adult male and female members of families with BRCA1/2 mutation	USA	Behavior

Table 1 (continued)

Reference	*N*	Test Type	Average Age	Age Range	% Women	Description of Sample	Country	Dependent Measure
Mastromauro et al. (1987)	131	HD	32	19–53	57 %	Adults at risk for HD seen for genetic counseling and/or neurologic evaluation or with a close relative seen or at risk	USA	Intentions
McGuire et al. (2009)	1087	DTC	35	18–81	73 %	Members of TrueSample and invited to take a survey through Zoomerang.com.	USA	Intentions
Meijers-Heijboer et al. (2000)	682	BRCA1/2	–	–	60 %	Families with a BRCA1/2 mutation undergoing DNA analysis	Netherlands	Behavior
Meiser et al. (2000)	461	BRCA1/2	41	–	100 %	Women with a family history of BC	Australia	Intentions
Meissen and Berchek (1987)	56	HD	37	23–55	63 %	People at risk for HD	USA	Intentions
Metcalfe et al. (2009)	416	BRCA1/2	58	20–79	100 %	Patients in Ontario who had been diagnosed with epithelial ovarian cancer	Canada	Behavior
Myers et al. (2000)	413	Prostate	–	–	0 %	African American men with no personal history of prostate cancer	USA	Intentions
Nordin et al. (2004)	828	CRC	44	18–75	59 %	Families with familial adenomatous polyposis and general population.	Sweden	Intentions
Olaya et al. (2009)	213	BRCA1/2	49	16–84	98 %	High-risk patients referred to a breast health center for BRCA testing	USA	Behavior
Oster et al. (2008)	1001	HD	42	–	69 %	Individuals at risk for HD	USA & Canada	Behavior
Paglierani et al. (2003)	181	General	20	16–41	100 %	Undergraduate women	USA	Intention
Ramirez et al. (2006)	48	BRCA1/2	–	19–80	67 %	Hispanics without BC but who had a family member with BC	USA	Intentions
Reitz et al. (2004)	377	BRCA1/2	43	21–65	100 %	Women in the general public without a personal or family history of BC.	Germany	Intentions
Roberts (2000)	203	Alzheimer's	54	30–92	75 %	Referrals from geriatric care organizations	USA	Intentions
Roberts et al. (2004)	289	Alzheimer's	55	30–82	71 %	Adult children of a person with Alzheimer's	USA	Behavior
Romero-Hidalgo et al. (2009)	859	BRCA1/2 & prostate	–	30–74	54 %	Outpatient women and men who attended tertiary care hospitals	Mexico	Intentions
Salkovskis et al. (1999)	104	Hemochrom-atosis	37	17–78	50 %	General public approached on the street; manipulated information focus (positive, negative, control)	UK	Intentions
Salkovskis et al. (2010)	120	Schizophr-enia risk	30	18–67	–	Adults stopped on the street; manipulated information (pos, neg, both, or control)	UK	Intentions
Sanderson et al. (2008)	61	Lung cancer	49	26–79	62 %	Smokers who had previously contacted a stop smoking service	UK	Behavior
Sanderson et al. (2010)	116	Lung cancer	–	20–54	54 %	Relatives of smokers who were also smokers with no personal history of cancer	USA	Behavior
Schwartz et al. (2000)	290	BRCA1/2	–	–	100 %	Adult BC patients	USA	Behavior
Shiloh et al. (1998)	150	BRCA1/2	37	–	100 %	Jewish women with no personal history of BC at clinics or at work and public places	Israel	Intentions
Shiloh et al. (1999)	209	Hypothetical	37	23–60	89 %	Professionals working in the educational system	Israel	Intentions
Smith and Croyle (1995)	383	CRC	45	–	–	Random-digit dialing for members of the Church of Jesus Christ of Latter Day Saints	USA	Intentions
Smith et al. (2008)	126	BRCA1/2	42	22–70	100 %	Women considering BRCA1/2 testing with personal cancer history or cancer history in a first-degree relative	USA	Behavior
Struewing et al. (1995)	140	BRCA1/2	–	19–73	65 %	Members of inherited breast-ovarian cancer families	USA	Intentions
Susswein et al. (2008)	768	BRCA1/2	–	–	100 %	White and African American women from a clinical database	USA	Behavior
Sweeny and Legg (2011)	99	DTC	37	19–78	80 %	General population recruited through Craigslist	USA	Intentions
Tambor et al. (1997)	473	BRCA1/2	–	–	100 %	Women who had received two or fewer mammograms in a 3-year period	USA	Intentions
Tibben et al. (1993)	70	HD	32	18–61	64 %	People at risk for Huntington disease (HD) and their partners	Netherlands	Intentions
Trippitelli et al. (1998)	90	Bipolar	48	–	–	Participants in a bipolar disorder genetic study or members an affective disorders association or group	USA	Intentions
Ulrich et al. (1998)	1450	BRCA1/2 & prostate	–	18–80	58 %	Community members recruited through random digit dialing	USA	Intentions
	103	HD	31	18–61	66 %	Members of the Dutch Huntington Association who were at risk for HD	Netherlands	Intentions

Table 1 (continued)

Reference	*N*	Test Type	Average Age	Age Range	% Women	Description of Sample	Country	Dependent Measure
Van der Steenstraten et al. (1994)								
Vernon et al. (1999)	269	CRC	–		44 %	People diagnosed with CRC	USA	Intentions
Wade et al. (2012)	270	Multi-gene testing	35	25–40	52 %	Insured White or African American adults	USA	Behavior
Welkenhuysen et al. (1997)	167	HD	22	20–28	74 %	Psychology students and medical students	Belgium	Intentions
Welkenhuysen et al. (2001)	329	BRCA1/2	38	19–65	100 %	Female students at an adult education institute	Belgium	Intentions
Westmaas and Woicik (2005)	186	Lung cancer	19	–	49 %	Psychology undergraduates who smoked at least 5 cigarettes per day; manipulated risk scenarios (high vs. low)	USA	Intentions
Wilde et al. (2010)	1046	General GT	51	18–88	61 %	Community members recruited through random digit dialing	Australia	Intentions
Wilson et al. (2008)	2925	DTC	53	18–95	55 %	Patients at general practices	UK	Behavior & intentions
Wolff et al. (2011)	874	Hypothetical	42	18–65	54 %	Random sample of the population	Norway	Intentions
Wroe and Salkovskis (1999), Study 1	67	BRCA1/2 & heart disease	–	20–55	100 %	Women stopped on the street for participation	UK	Intentions
Wroe and Salkovskis (1999), Study 2	78	BRCA1/2 & heart disease	–	25–75	50 %	Women stopped on the street for participation	UK	Intentions
Wroe and Salkovskis (2000)	120	Heart disease	–	18–75	50 %	People stopped on the street in England	UK	Intentions
Yaniv et al. (2004), Study 1	167	Similar to HD	–	22–40	–	Social science students and employees in a Jerusalem-based organization	Israel	Intentions
Yaniv et al. (2004), Study 2	120	Similar to HD	–	–	–	Social science and humanities undergraduates	Israel	Intentions

– indicates that the information was not provided; BRCA1/2 = Testing for genes that increase risk of breast and ovarian cancer; *CRC* test for genetic susceptibility to colorectal cancers, *HD* Huntington's disease, *DTC* direct-to-consumer testing, *BC* breast cancer

Ramirez et al. 2006; *CRC*: Warner et al. 2005), and fear of discrimination based on test results (*BRCA1/2*: Ramirez et al. 2006; *CRC*: Warner et al. 2005).

In some sense, this qualitative approach is the most direct way to understand decisions: simply ask people why they chose to test or not to test. However, because people typically have an incomplete and even inaccurate understanding of the motives for their behavior (Nisbett and Wilson 1977), our review does not include these narrative explanations, and we will not mention them further except to compare conclusions from quantitative studies with conclusions from patients' self-reports in our discussion. With our inclusion criteria in mind, we organized the findings into two broad categories: 1) quantitatively supported subjective predictors of testing decisions (i.e., people's subjective perceptions of the relevant disorder or genetic test), and 2) quantitatively supported objective predictors of testing decisions (i.e., trait-like individual differences and sociodemographic variables). In the following sections we simply present the findings without delving into potential explanations, but we provide interpretation and implications in the general discussion at the end of the paper.

Results of Systematic Review

Subjective Predictors of Testing Decisions

An examination of the subjective predictors of genetic testing decisions reveals a broad and surprisingly disjointed picture. Many of the most commonly studied predictors have inconsistent support at best, even across studies that examined the same genetic test within similar samples, and many other predictors are supported by only a handful of studies. In an effort to organize the literature into a comprehensive and comprehendible review of the predictors of genetic testing, we identified two general categories of predictors: *disorder-related predictors* and *test-related predictors*. Disorder-related predictors are subjective perceptions of the disorder for which the genetic test provides risk information, and test-related predictors are subjective perceptions of the test itself or of the appeal of testing. Table 2 provides a depiction of the studies that found positive and negative relationships or no relationship between each subjective predictor and genetic testing interest or uptake. The table is intended to provide a visual impression of the relative empirical attention each predictor has received, as well as the consistency (or lack thereof) in the findings for each predictor. The table also highlights studies with small (fewer than 150 participants) and large (more than 1,000 participants) samples with smaller and larger font, respectively, as well as studies that assessed testing uptake (indicated by an asterisk) rather than interest or intentions.

Disorder-Related Subjective Predictors

In this section we present findings regarding perceived risk, disease-specific worry, perceived control, and perceived severity.

Perceived Risk The first disorder-related predictor of genetic testing decisions is one's perceived risk of developing a heritable disorder. Researchers typically measure perceived risk by simply asking participants to rate either how likely they are to have the relevant disorder or how at risk they feel for developing the disorder in a given time frame. Our review revealed mixed support for the relationship between perceived risk and genetic testing, although a majority of studies found that people who feel more at risk for a particular heritable disorder are more likely to pursue genetic testing to learn their actual risk for the disorder. Specifically, perceived risk predicted interest in genetic testing for melanoma (Kasparian et al. 2009) and a fictitious genetic test for general cancer risk (Bosompra et al. 2000); inconsistently predicted interest in testing for Alzheimer's disease (*support*: Roberts 2000; *no support*: Frost et al. 2001), colorectal cancer (CRC) risk (*support*: Codori et al. 1999; Croyle and Lerman 1993; Glanz et al. 1999; Graham et al. 1998; Bunn et al. 2002; *no support*: Aktan-Collan et al. 2000; Braithwaite et al. 2002; Cragun et al. 2012; Cyr et al. 2010; Kinney et al. 2000), BRCA1/2 testing (i.e., testing for the set of genes that increases risk for breast and ovarian cancers; *support*: Culver et al. 2001; Durfy et al. 1999; Helmes 2002; Jacobsen et al. 1997; Kinney et al. 2001; Lipkus et al. 1999; Meiser et al. 2000; Reitz et al. 2004; Schwartz et al. 2000; Struewing et al. 1995; *no support*: Andrews et al. 2004; Braithwaite et al. 2002; Cameron and Diefenbach 2001; Cameron and Reeve 2006; Lee et al. 2002; Shiloh et al. 1998; Welkenhuysen et al. 2001), and general interest in genetic testing (Wilde et al. 2010; Wolff et al. 2011); did not predict for risk of Huntington's disease (Welkenhuysen et al. 1997) or hemochromatosis (Salkovskis et al. 1999); and predicted in the opposite direction for interest in testing for prostate cancer risk (Bratt et al. 2000; Myers et al. 2000).

Interestingly, objective risk is quite a poor predictor of genetic testing. We found no documented effects of objective risk on genetic testing decisions, and several studies documented the lack of relationship between objective risk and interest in BRCA1/2 (Andrews et al. 2004; Durfy et al. 1999; Struewing et al. 1995), general genetic testing (Paglierani et al. 2003), and a test similar to that for Huntington's disease (the researchers did not name a disease in their testing scenarios but intended it to be similar in nature to Huntington's disease; Yaniv et al. 2004). Objective risk is not a subjective predictor, but we note here the lack of evidence for objective risk as a predictor of genetic testing decisions simply as a contrast to the more widely studied (and clearly subjective) predictor of perceived risk.

Table 2 Support and non-support for subjective predictors of genetic testing decisions

	Positive Relationship	Negative Relationship	No Consistent Effect
Perceived risk	[a]Kasparian et al. 2009	Bratt et al. 2000	[a]Aktan-Collan et al. 2000
	[a]Schwartz et al. 2000	Myers et al. 2000	[a]Lee et al. 2002
	Bosompra et al. 2000		Andrews et al. 2004
	Bunn et al. 2002		Braithwaite et al. 2002
	Codori et al. 1999		Cameron and Diefenbach 2001
	Croyle and Lerman 1993		Cameron and Reeve 2006
	Culver et al. 2001		Cragun et al. 2012
	Durfy et al. 1999		Cyr et al. 2010
	Glanz et al. 1999		Durfy et al. 1999
	Graham et al. 1998		Frost et al. 2001
	Hadley et al. 2003		Kinney et al. 2000
	Helmes 2002		Paglierani et al. 2003
	Jacobsen et al. 1997		Salkovskis et al. 1999
	Kinney et al. 2001		Shiloh et al. 1998
	Lipkus et al. 1999		Struewing et al. 1995
	Meiser et al. 2000		Welkenhuysen et al. 1997
	Reitz et al. 2004		Welkenhuysen et al. 2001
	Roberts 2000		Wolff et al. 2011
	Struewing et al. 1995		Yaniv et al. 2004
	Wilde et al. 2010		
Disease- specific worry	[a]Kelly et al. 2004	Bratt et al. 2000	[a]Evers-Kiebooms and Decruyenaere 1998
	[a]Lerman et al. 1997		Salkovskis et al. 1999
	Andrews et al. 2004		
	Andrykowski et al. 1996		
	Cameron and Diefenbach 2001		
	Cameron and Reeve 2006		
	Chaliki et al. 1995		
	Codori et al. 1999		
	Croyle and Lerman 1993		
	Glanz et al. 1999		
	Graham et al. 1998		
	Durfy et al. 1999		
	Foster et al. 2004		
	Kinney et al. 2001		
	Lipkus et al. 1999		
	Reitz et al. 2004		
	Vernon et al. 1999		
Perceived control	Chaliki et al. 1995		Frost et al. 2001
	Kinney et al. 2000		Lipkus et al. 1999
	Myers et al. 2000		
	Roberts 2000		
	Shiloh et al. 1999		
	Wroe and Salkovskis 1999		
Perceived severity	Cameron et al. 2009	Durfy et al. 1999	[a]Evers-Kiebooms and Decruyenaere 1998
	Helmes 2002		Salkovskis et al. 1999
	Reitz et al. 2004		Welkenhuysen et al. 2001

Table 2 (continued)

	Positive Relationship	Negative Relationship	No Consistent Effect
Perceived benefits	[a]Sanderson et al. 2010 [a]Lerman et al. 1996 [a]Godard et al. 2007 Bosompra et al. 2000 Bunn et al. 2002 Cameron et al. 2009 Cameron and Reeve 2006 Chaliki et al. 1995 Cherkas et al. 2010 Cutler and Hodgson 2003 Cyr et al. 2010 Frost et al. 2001 Graham et al. 1998 Laegsgaard et al. 2009 Meiser et al. 2000 McGuire et al. 2009 Myers et al. 2000 Ramirez et al. 2006 Reitz et al. 2004 Salkovskis et al. 2010 Shiloh et al. 1999 Sweeny and Legg 2011 Tambor et al. 1997 Vernon et al. 1999 Welkenhuysen et al. 2001 Wroe and Salkovskis 1999 Wolff et al. 2011		
Perceived barriers		Bosompra et al. 2000 Bunn et al. 2002 Cameron et al. 2009 Cyr et al. 2010 Durfy et al. 1999 Nordin et al. 2004 Roberts 2000 Sweeny and Legg 2011 Vernon et al. 1999 Welkenhuysen et al. 2001 Wroe and Salkovskis 1999	Braithwaite et al. 2002 Glanz et al. 1999
Subjective norms	Braithwaite et al. 2002 Cameron et al. 2009 Frost et al. 2001 Klitzman et al. 2007		Gwyn et al. 2003 Wolff et al. 2011
Attitudes toward testing	[a]Sanderson et al. 2010 [a]Wade et al. 2012 Botoseneanu et al. 2011 Braithwaite et al. 2002 Meissen and Berchek 1987		Bates et al. 2011

Table 2 (continued)

	Positive Relationship	Negative Relationship	No Consistent Effect
	Nordin et al. 2004 Reitz et al. 2004 Welkenhuysen et al. 2001		
Knowledge	[a]Lynch et al. 2009 [a]Sanderson et al. 2010 Bates et al. 2011 Bottorff et al. 2002 Welkenhuysen et al. 1997	[a]Botoseneanu et al. 2011 Helmes et al. 2006	Bosompra et al. 2000 Bunn et al. 2002 Cappelli et al. 2001 Hall et al. 2009 Helmes 2002 Kinney et al. 2001 Reitz et al. 2004 Welkenhuysen et al. 2001
Perceived risks of testing		[a]Binedell et al. 1998 [a]Codori et al. 1994 [a]Oster et al. 2008 [a]Sanderson et al. 2008 Cameron et al. 2009 Cameron and Diefenbach 2001 Cappelli et al. 2001 Durfy et al. 1999 Evers-Kiebooms et al. 1989 Frost et al. 2001 Glanz et al. 1999 Hadley et al. 2003 Kinney et al. 2001 Laegsgaard et al. 2009 Meiser and Dunn 2000 Reitz et al. 2004 Tibben et al. 1993 van der Steenstraten et al. 1994 Vernon et al. 1999 Sweeny and Legg 2011 Wilde et al. 2010 Wolff et al. 2011	Cameron and Reeve 2006 Salkovskis et al. 1999

Studies with a [a] assessed testing uptake rather than intentions or interest. Citations in large font (8.5 pt.) included >1,000 participants. Citations in small font (6.5 pt.) included <150 participants

Disease-Specific Worry The second disorder-related predictor of genetic testing interest is disease-specific worry. Although this construct is related to perceived risk (DiLorenzo et al. 2006), disease-specific worry captures the emotional aspect of contemplating one's risk for a heritable disorder rather than the risk perception itself. Researchers typically measure disease-specific worry by asking participants to specify their level of distress or worry about the relevant genetic disorder or the degree of intrusiveness of distressful thoughts or feelings.

Our review revealed mixed support for the relationship between disease-specific worry and genetic testing, although a majority of studies found that people who are more worried are more likely to express interest in or pursue genetic testing. Specifically, disease-specific worry predicted interest in testing for CRC (Codori et al. 1999; Croyle and Lerman 1993; Glanz et al. 1999; Graham et al. 1998; Vernon et al. 1999) and BRCA1/2 testing (Andrews et al. 2004; Andrykowski et al. 1996; Cameron and Diefenbach 2001; Cameron and Reeve 2006; Chaliki et al. 1995; Durfy et al. 1999; Foster et al. 2004; Kelly et al. 2004; Kinney et al. 2001; Lerman et al. 1997; Lipkus et al. 1999; Reitz et al. 2004), but predicted in the opposite direction for interest in testing for prostate cancer risk (Bratt et al. 2000). Findings are inconsistent for Huntington's

disease (Evers-Kiebooms et al. 2000) and are null for hemochromatosis risk (Salkovskis et al. 1999).

Perceived Control The third disorder-related variable is perceived control, which includes the sense of having control over both prevention and management of a heritable disorder. Researchers typically measure perceived control by asking participants to indicate the degree to which they feel that they have control over the prevention and/or management of the disorder for which they are considering testing. Although we focus in this section on subjective perceptions of control over preventing and managing disease, heritable health conditions vary widely in objective controllability. Some conditions present few or no options for direct control once a genetic marker is found (most notably Huntington's disease), whereas other conditions present myriad strategies for reducing the likelihood of developing the disorder or experiencing its worst possible outcomes (e.g., breast cancer, lung cancer).

Regarding perceived control, once again the evidence is mixed. People who perceived greater control over prevention or management of a disorder were more interested in testing for CRC susceptibility (Kinney et al. 2000), prostate cancer risk (Myers et al. 2000), heart disease (Shiloh et al. 1999), and a hypothetical, fictitious disease (Wroe and Salkovskis 1999), but the findings are mixed for interest in testing for Alzheimer's disease (*support*: Roberts 2000; *no support*: Frost et al. 2001). A proxy measure of perceived control, namely knowledge of risk factors for breast and ovarian cancer (controllable factors as distinct from genetic factors) did not predict interest in BRCA1/2 testing (Lipkus et al. 1999), but a more direct measure of perceived control did predict interest in this type of testing (Chaliki et al. 1995).

Perceived Severity The fourth and final disorder-related predictor of genetic testing interest is the perceived severity of the disorder. Perceived severity typically is measured as a self-reported assessment of the extent to which a genetic disorder has the potential to cause pain, suffering, or other negative health consequences. Although perceived severity is a key piece of many health behavior theories (Becker 1974; Rogers 1983), the empirical relationship between perceived severity and genetic testing decisions is inconsistent. Studies of perceived severity have found that people who perceive the disorder to be more severe were more interested in testing for a variety of disease scenarios (Cameron et al. 2009), but the relationship is inconsistent for interest in BRCA1/2 testing, with some studies finding a positive relationship (Helmes 2002; Reitz et al. 2004), one a negative relationship between perceived severity and testing interest (Durfy et al. 1999), and one no relationship (Welkenhuysen et al. 2001). Two studies found no relationship for Huntington's disease (Evers-Kiebooms and Decruyenaere 1998) and general genetic testing (Salkovskis et al. 1999).

Test-Related Subjective Predictors

Our discussion of subjective predictors now shifts from a disorder-focus to a test-focus. In this section, we review findings on perceived benefits of testing, perceived barriers to testing, subjective norms surrounding testing, attitudes about the test, knowledge about testing, and perceived risks of the test itself.

Perceived Benefits The first test-related predictor, and one that has received a great deal of empirical attention due to its prominence in the health belief model (Becker 1974), is the perceived benefit of a particular genetic test. Perceived benefit refers to the perception that genetic testing provides some significant advantages or gains, whether medical or psychosocial. Studies that include measures of perceived benefits typically assess the construct either as a general assessment of the extent to which the participant might benefit from testing or by asking specific questions about particular benefits of the relevant genetic test. In contrast to the largely inconsistent support for disorder-related predictors of genetic testing decisions, empirical support for the role of perceived benefits in testing decisions has been quite consistent: People who perceived greater benefits from testing indicated more interest in tests for susceptibility to CRC (Bunn et al. 2002; Cyr et al. 2010; Graham et al. 1998; Vernon et al. 1999), BRCA1/2 (Cameron and Reeve 2006; Chaliki et al. 1995; Godard et al. 2007; Lerman et al. 1996; Meiser et al. 2000; Ramirez et al. 2006; Reitz et al. 2004; Tambor et al. 1997; Welkenhuysen et al. 2001), Alzheimer's disease (Cutler and Hodgson 2003; Frost et al. 2001), prostate cancer (Myers et al. 2000), psychiatric conditions (Laegsgaard et al. 2009), risk of heart disease (Wroe and Salkovskis 1999), risk of lung cancer (Sanderson et al. 2010), direct-to-consumer testing (Cherkas et al. 2010; McGuire et al. 2009; Sweeny and Legg 2011), hypothetical genetic tests (Bosompra et al. 2000; Salkovskis et al. 2010; Shiloh et al. 1999; Wolff et al. 2011), and a set of generic genetic test scenarios (Cameron et al. 2009).

Perceived Barriers The flip-side of perceived benefits is perceived barriers to testing, which also appears in the health belief model (Becker 1974). Perceptions of barriers to testing are measured by either a general assessment of the extent to which people believe that testing would be difficult or costly or by asking specific questions about particular benefits to pursuing the relevant genetic test. Like perceived benefits, perceived barriers are a robust predictor of genetic testing decisions. General perceptions of barriers to testing predict decreased interest in testing for BRCA1/2 (Durfy et al. 1999; Welkenhuysen et al. 2001), heart disease risk (Wroe and

Salkovskis 1999), and susceptibility to CRC (Cyr et al. 2010; Bunn et al. 2002; Vernon et al. 1999; although one study found no relationship; Glanz et al. 1999), Alzheimer's disease (Roberts 2000), a fictitious test of general cancer risk (Bosompra et al. 2000), a variety of disease scenarios (Cameron et al. 2009), and direct-to-consumer testing (Sweeny and Legg 2011).

Perceived behavioral control is a construct similar to perceived barriers that derives from the theory of planned behavior and captures the belief that one is capable of engaging in a particular behavior (in this case, genetic testing; Ajzen 2002). To clarify, we distinguish between perceived behavioral control and perceived control (above, with disorder-related predictors) in that perceived behavioral control refers to the ability to seek testing, not control over the prevention or management of the genetic disorder. Thus, it is conceptually similar to (albeit the inverse of) perceptions of barriers to testing. Perceived behavioral control predicted increased interest in testing for susceptibility to CRC in a study of testing decisions (Nordin et al. 2004) but did not predict interest in a second study that examined interest in testing for both BRCA1/2 and susceptibility to CRC (Braithwaite et al. 2002).

Subjective Norms A third test-related predictor, and one that comes from the theory of planned behavior (Ajzen 2002), is subjective norms. This construct captures the overall social acceptability and prevalence of genetic testing in a particular population. Although relatively few studies have examined the relationship between subjective norms and testing interest, perceptions of positive norms toward testing predicted interest in testing for: Alzheimer's disease (Frost et al. 2001), BRCA1/2 and susceptibility to CRC (Braithwaite et al. 2002), testing uptake for Huntington's disease (Klitzman et al. 2007), and testing for a variety of disease scenarios (Cameron et al. 2009). Subjective norms did not predict interest in a hypothetical genetic test (Wolff et al. 2011). Interestingly, although physician recommendations would seem to serve as a cue indicating the normative choice, one study found that physician recommendation did not predict interest in testing for BRCA1/2 (Gwyn et al. 2003). Of course, this conclusion is tentative, as it is based on a single study and thus requires replication.

Attitudes Toward Genetic Testing A fourth test-related predictor, and another construct that appears in the theory of planned behavior (Ajzen 2002), is attitudes toward genetic testing, including general attitudes and attitudes about a particular genetic test. We found relatively few quantitative studies of genetic testing interest that measured attitudes toward testing, all of which supported a relationship between attitudes and interest in testing for BRCA1/2 (Braithwaite et al. 2002; Reitz et al. 2004; Welkenhuysen et al. 2001), lung cancer (Sanderson et al. 2010), CRC susceptibility (Braithwaite et al. 2002), multiple gene testing (Wade et al. 2012), and for an unspecified heritable disorder (Nordin et al. 2004). Findings are inconsistent for the relationship between testing attitudes and interest in genetic testing in general (*support*: Botoseneanu et al. 2011; *no support*: Bates et al. 2011).

Knowledge A fifth test-related predictor is knowledge about genetic testing. Knowledge is typically operationalized either by interventions to increase knowledge or by self-reports of the extent of participants' knowledge about testing or about a specific test. Greater knowledge predicted testing interest for lung cancer risk (Sanderson et al. 2010) but was unrelated to interest in testing for CRC risk (Bunn et al. 2002) and Huntington's disease (Welkenhuysen et al. 1997), nor was it related to interest in a fictitious test of general cancer risk (Bosompra et al. 2000). Knowledge inconsistently predicted interest in testing for BRCA1/2 (*support*: Lynch et al. 2009; Bottorff et al. 2002; *no support*: Cappelli et al. 2001; Hall et al. 2009; Helmes 2002; Kinney et al. 2001; Reitz et al. 2004; Welkenhuysen et al. 2001). In fact, although one type of intervention to increase knowledge about genetic testing for BRCA1/2 was found to increase uptake (Lynch et al. 2009), other research has found that an educational intervention actually decreased intentions to test relative to a control condition (Helmes et al. 2006) or had no effect on intentions (Hall et al. 2009).

Perceived Risks of Testing A sixth and final test-related predictor of genetic testing is perceptions of physical or psychological risks related to testing. Measures of test-related risks typically address concerns about the consequences of learning unpleasant test results. Although a perception that testing involves substantial psychological risk might serve as a barrier to testing, for the purposes of this paper we draw a distinction between factors that make the physical act of pursuing genetic testing more difficult (barriers) and concerns over consequences of receiving test results (risks). We also discuss these concerns separately from disease-specific worry (above, with disorder-related predictors) because disease-related worry refers to worry or anxiety about a genetic disorder that precedes testing, which is distinct from worry or anxiety that might result from a positive test result.

Empirical support for the role of test-related risk perceptions in genetic testing decisions is fairly consistent, such that concern over the emotional and psychological consequences of learning test results generally predicted less interest in testing for Alzheimer's disease (Frost et al. 2001), Huntington's disease (Binedell et al. 1998; Codori et al. 1994; Evers-Kiebooms et al. 1989; Meiser and Dunn 2000; Oster et al. 2008; Tibben et al. 1993; Van der Steenstraten et al. 1994), susceptibility to CRC (Glanz et al. 1999; Hadley et al. 2003; Vernon et al. 1999), BRCA1/2 testing (Cameron and Diefenbach 2001; Cappelli et al. 2001; Durfy et al. 1999; Kinney et al. 2001; Reitz et al. 2004), risk of psychiatric illness (Laegsgaard et al. 2009), a set of genetic test scenarios

(Cameron et al. 2009; Sanderson et al. 2008), a hypothetical test (Wolff et al. 2011), and direct-to-consumer testing (Sweeny and Legg 2011). However, three studies found no relationship between risks of testing and interest in BRCA1/2 (Cameron and Reeve 2006) and general genetic testing (Salkovskis et al. 1999; Wilde et al. 2010).

Summary of Subjective Predictors

We organized the large literature on subjective predictors of genetic testing decisions into two broad categories: disorder-related predictors and test-related predictors. In general, test-related predictors have received more consistent support than disorder-related predictors. Specifically, perceived benefits of and barriers to testing, risks of the test procedure, and attitudes toward testing consistently predicted testing decisions, albeit with varying amounts of empirical support. Subjective norms and knowledge about the test were less consistent predictors.

In contrast, although disorder-related predictors have received significant empirical attention, these predictors are far less consistent in their support. Perceived risk of the relevant genetic disorder only inconsistently predicted testing decisions, and even then studies have found support for both increased and decreased testing interest related to higher perceived risk. Perceived control over disease incidence and progression and perceived severity of the genetic disorder received mixed support, although these predictors were directionally consistent (i.e., findings were either consistent in direction or null). Disease-specific worry is the only disorder-related predictor with largely consistent support, such that people who are more worried are generally more likely to test.

Objective Predictors of Testing Decisions

This section addresses research findings related to individual differences and sociodemographic variables that predict genetic testing decisions. We call these predictors "objective" for two reasons: 1) to distinguish them from the highly personal and subjective perceptions discussed in the previous section, and 2) to convey that these predictors are generally outside of one's personal control. These include family and personal health history, general health motivation (which may be partly within a person's control but is not a subjective perception), and trait-like individual differences, as well as the sociodemographic variables of gender, age, education level, socioeconomic status, employment status, marital and parental status, and religiosity. We do not include studies examining race or ethnicity in our review due to the widely varying target groups in such investigations, which rendered impractical (and likely unreliable) any general conclusions about the relationship between race or ethnicity and testing decisions. Table 3 provides a depiction of the studies that found positive and negative relationships or no relationship between each objective predictor and genetic testing interest or uptake, with small studies (fewer than 150 participants) and large studies (more than 1,000 participants) highlighted with smaller and larger font, respectively, and studies that assessed testing uptake rather than interest or intentions with an asterisk.

Family History

People with a family history of a genetic disorder are typically more likely to undergo testing for that disorder, with some exceptions. Evidence for this relationship was consistent (albeit limited) for interest in testing for hypercholesterolemia (Harel et al. 2003) and general cancer risk (Bosompra et al. 2000); inconsistent for interest in BRCA1/2 testing (*support:* Bottorff et al. 2002; Gwyn et al. 2003; Hailey et al. 2000; Harel et al. 2003; Kinney et al. 2001; Lerman et al. 1996; Lipkus et al. 1999; Metcalfe et al. 2009; Ruddy et al. 2010; Welkenhuysen et al. 2001; *no support:* Cameron and Diefenbach 2001; Culver et al. 2001; Gray et al. 2012; Julian-Reynier et al. 2000; Keogh et al. 2004; Olaya et al. 2009), testing for CRC susceptibility (*support:* Cappelli et al. 2002; Nordin et al. 2004; *no support:* Braithwaite et al. 2002; Bunn et al. 2002; Codori et al. 1999; Cyr et al. 2010; Glanz et al. 1999; Kinney et al. 2000; Smith and Croyle 1995; Vernon et al. 1999), and testing for prostate cancer risk (*support:* Culler et al. 2002; *no support:* Myers et al. 2000; and nonexistent for Huntington's disease (Welkenhuysen et al. 1997) and a variety of disease scenarios related to obesity (Segal et al. 2007).

Personal History

People with a personal history of a particular disorder are often more likely to undergo genetic testing for related disorders, but this relationship is less consistent than the relationship between family history and interest in testing. Personal history predicted testing for genetically-based psychiatric illnesses (Laegsgaard et al. 2009) and general interest in genetic testing (Wilde et al. 2010); generally predicted BRCA1/2 testing (*support*: Andrews et al. 2004; Cappelli et al. 1999; Kinney et al. 2001; Lerman et al. 1996, 1997; Lynch et al. 2009; Olaya et al. 2009; Susswein et al. 2008; *no support*: Gray et al. 2012; Jacobsen et al. 1997; Julian-Reynier et al. 2000; Keogh et al. 2004); and fails to predict interest in testing for CRC susceptibility (Lerman et al. 1999) or prostate cancer risk (Myers et al. 2000). Yet other studies suggest that experience with cancer may even decrease interest in genetic testing for BRCA1/2 (Bottorff et al. 2002) and CRC susceptibility (Croyle and Lerman 1993).

Health Motivation

Intuitively, it may seem that people who are generally more motivated to be healthy would also be more likely to pursue

Table 3 Support and non-support for objective predictors of genetic testing decisions

	Positive Relationship	Negative Relationship	No Consistent Effect
Family health history	[c]Lerman et al. 1996 [c]Metcalfe et al. 2009 Bosompra et al. 2000 Bottorff et al. 2002 Cappelli et al. 2002 Chaliki et al. 1995 Culler et al. 2002 Gwyn et al. 2003 Hailey et al. 2000 Harel et al. 2003 Kinney et al. 2001 Lipkus et al. 1999 Nordin et al. 2004 Ruddy et al. 2010 Welkenhuysen et al. 2001		[c]Julian-Reynier et al. 2000 [c]Keogh et al. 2004 [c]Olaya et al. 2009 Braithwaite et al. 2002 Bunn et al. 2002 Cameron and Diefenbach 2001 Codori et al. 1999 Culver et al. 2001 Cyr et al. 2010 Glanz et al. 1999 Gray et al. 2012 Kinney et al. 2000 Myers et al. 2000 Petersen et al. 1999 Segal et al. 2007 Smith and Croyle 1995 Vernon et al. 1999 Welkenhuysen et al. 1997
Personal health history	[c]Lerman et al. 1996 [c]Lerman et al. 1997 [c]Lynch et al. 2009 [c]Olaya et al. 2009 [c]Susswein et al. 2008 Andrews et al. 2004 Cappelli et al. 1999 Kinney et al. 2001 Laegsgaard et al. 2009 Wilde et al. 2010	Bottorff et al. 2002 Croyle and Lerman 1993	[c]Julian-Reynier et al. 2000 [c]Keogh et al. 2004 [c]Lerman et al. 1999 Gray et al. 2012 Jacobsen et al. 1997 Myers et al. 2000
General health motivation	Andrykowski et al. 1996 Codori et al. 1999 Ulrich et al. 1998	Myers et al. 2000	Bosompra et al. 2000 Bunn et al. 2002 Glanz et al. 1999 Kinney et al. 2000 Paglierani et al. 2003
Monitoring (vs. blunting)	Culler et al. 2002 Roberts 2000 Shiloh et al. 1999 Westmaas and Woicik 2005		Meiser et al. 2000 Shiloh et al. 1998 Vernon et al. 1999
Positive outlook	Bosompra et al. 2000 Bosompra et al. 2001 Bunn et al. 2002 van der Steenstraten et al. 1994		[c]Biesecker et al. 2000 Andrews et al. 2004 Andrykowski et al. 1996
Discomfort with uncertainty	Braithwaite et al. 2002 Croyle et al. 1995		
Decisional preference	Glanz et al. 1999		Bosompra et al. 2001

Table 3 (continued)

	Positive Relationship	Negative Relationship	No Consistent Effect
Gender[a]	[c]Aktan-Collan et al. 2000 [c]Holloway et al. 2008 [c]Julian-Reynier et al. 2000 [c]Lerman et al. 1996 [c]Lerman et al. 1997 [c]Lerman et al. 1999 [c]Lynch et al. 2009 Bloch et al. 1989 Glanz et al. 1999 Hadley et al. 2003 Harel et al. 2003 Hiraki et al. 2009 Kinney et al. 2000 Meiser et al. 2000 Nordin et al. 2004 Ramirez et al. 2006 Romero-Hidalgo et al. 2009 Smith and Croyle 1995 Vernon et al. 1999	[c]Wilson et al. 2008 Roberts 2000	[c]Binedell et al. 1998 [c]Codori et al. 1994 [c]Craufurd et al. 1989 [c]Keogh et al. 2004 [c]Roberts et al. 2004 Cragun et al. 2012 Foster et al. 2004 Kinney et al. 2001 Laegsgaard et al. 2009 Salkovskis et al. 1999 Segal et al. 2007 Shiloh et al. 1999 Sweeny and Legg 2011 Trippitelli et al. 1998 Wroe and Salkovskis 2000
Education	[c]Aktan-Collan et al. 2000 [c]Lerman et al. 1996 [c]Lerman et al. 1999 Andrykowski et al. 1996 Bloch et al. 1989 Cappelli et al. 2002 Codori et al. 1999 Culver et al. 2001 Foster et al. 2004 Ruddy et al. 2010 Segal et al. 2007	Cameron and Reeve 2006 Foster et al. 2004 Hughes et al. 1997 Ulrich et al. 1998	[c]Binedell et al. 1998 [c]Codori et al. 1994 [c]Lerman et al. 1997 [c]Wilson et al. 2008 Andrews et al. 2004 Culler et al. 2002 Laegsgaard et al. 2009 Glanz et al. 1999 Gwyn et al. 2003 Jacobsen et al. 1997 Kinney et al. 2000 Meiser et al. 2000 Myers et al. 2000 Nordin et al. 2004 Paglierani et al. 2003 Ramirez et al. 2006 Sweeny and Legg 2011 Tambor et al. 1997 Vernon et al. 1999
Employment status[b]	[c]Aktan-Collan et al. 2000 [c]Wilson et al. 2008	[c]Binedell et al. 1998	[c]Lerman et al. 1996 Bloch et al. 1989 Braithwaite et al. 2002 Foster et al. 2004 Ramirez et al. 2006 Tambor et al. 1997
Income	Hiraki et al. 2009		[c]Olaya et al. 2009 [c]Roberts et al. 2004 [c]Wilson et al. 2008

Table 3 (continued)

	Positive Relationship	Negative Relationship	No Consistent Effect
			Bosompra et al. 2000 Bosompra et al. 2001 Bunn et al. 2002 Culler et al. 2002 Cragun et al. 2012 Kinney et al. 2001 Ramirez et al. 2006 Smith and Croyle 1995 Tambor et al. 1997 Ulrich et al. 1998 Vernon et al. 1999
Age	[c]Biesecker et al. 2000 [c]Binedell et al. 1998 Lynch et al. 2009 Bottorff et al. 2002 Cyr et al. 2010 Glanz et al. 1999 Jacobsen et al. 1997 Meiser et al. 2000 Myers et al. 2000	[c]Godard et al. 2007 [c]Meijers-Heijboer et al. 2000 Codori et al. 1999 Croyle and Lerman 1993 Foster et al. 2004 Jacopini et al. 1992 Kinney et al. 2001 Mastromauro et al. 1987 Ruddy et al. 2010 Salkovskis et al. 1999 Segal et al. 2007 Tambor et al. 1997	[c]Aktan-Collan et al. 2000 [c]Codori et al. 1994 [c]Craufurd et al. 1989 [c]Keogh et al. 2004 [c]Lerman et al. 1996 [c]Lerman et al. 1997 [c]Lerman et al. 1999 [c]Lynch et al. 2009 [c]Olaya et al. 2009 [c]Roberts et al. 2004 [c]Smith et al. 2008 [c]Wilson et al. 2008 Andrews et al. 2004 Andrykowski et al. 1996 Bosompra et al. 2000 Bunn et al. 2002 Cameron and Reeve 2006 Cappelli et al. 1999 Culver et al. 2001 Durfy et al. 1999 Gwyn et al. 2003 Hadley et al. 2003 Kinney et al. 2000 Laegsgaard et al. 2009 Nordin et al. 2004 Paglierani et al. 2003 Ramirez et al. 2006 Roberts 2000 Shiloh et al. 1999 Smith and Croyle 1995 Sweeny and Legg 2011 Tibben et al. 1993 Ulrich et al. 1998 Vernon et al. 1999 van der Steenstraten et al. 1994 Welkenhuysen et al. 2001

Table 3 (continued)

	Positive Relationship	Negative Relationship	No Consistent Effect
Marital/parental status[b]	[c]Aktan-Collan et al. 2000 [c]Biesecker et al. 2000 [c]Binedell et al. 1998 [c]Lerman et al. 1999 [c]Meijers-Heijboer et al. 2000 Bloch et al. 1989 Cappelli et al. 2002 Foster et al. 2004 Laegsgaard et al. 2009 Meiser et al. 2000	[c]Binedell et al. 1998 [c]Evers-Kiebooms and Decruyenaere 1998 Mastromauro et al. 1987	[c]Aktan-Collan et al. 2000 [c]Codori et al. 1994 [c]Craufurd et al. 1989 [c]Lerman et al. 1997 [c]Olaya et al. 2009 [c]Roberts et al. 2004 Foster et al. 2004 Gwyn et al. 2003 Hughes et al. 1997 Jacobsen et al. 1997 Kinney et al. 2000 Meissen and Berchek 1987 Myers et al. 2000 Paglierani et al. 2003 Roberts 2000 Smith and Croyle 1995 Tibben et al. 1993 Vernon et al. 1999 Welkenhuysen et al. 2001
Religiosity		Botoseneanu et al. 2011	[c]Biesecker et al. 2000 [c]Olaya et al. 2009 [c]Schwartz et al. 2000 Laegsgaard et al. 2009 Kinney et al. 2001 Vernon et al. 1999

[a] Positive relationship indicates women more interested than men

[b] Positive relationship indicates employed/married/parents most interested

Studies with a [c] assessed testing uptake rather than intentions or interest. Citations in large font (8.5 pt.) included >1,000 participants. Citations in small font (6.5 pt.) included <150 participants

genetic testing, but only mixed evidence supports a relationship between general health or other health behaviors and genetic testing decisions. Evidence supports a relationship between general health or health behaviors and interest in testing for BRCA1/2 (Andrykowski et al. 1996; Ulrich et al. 1998), but the relationship was inconsistent for CRC testing (*support:* Codori et al. 1999; *no support:* Bunn et al. 2002; Glanz et al. 1999; Kinney et al. 2000); nonexistent for interest in general genetic testing (Paglierani et al. 2003) and testing for general cancer risk (Bosompra et al. 2000); and reversed for interest in genetic testing for prostate cancer susceptibility (Myers et al. 2000).

Trait-Like Individual Differences

Researchers have examined several trait-like individual differences as predictors of genetic testing decisions. First, people differ in their general preferences for information, such that some people actively seek out information (monitors) and other people avoid information (blunters; Miller 1987). This tendency is assessed using Miller's (1987) widely validated Behavioral Style Scale. High monitors report greater interest in testing for Alzheimer's risk (Roberts 2000), prostate cancer susceptibility (Culler et al. 2002), and a hypothetical genetic test (Shiloh et al. 1999), but monitoring does not predict interest in BRCA1/2 testing (Meiser et al. 2000; Shiloh et al. 1998), or testing for CRC susceptibility (Vernon et al. 1999). Another dimension of informational preference is reward (vs. threat) sensitivity. One study of smokers found that those who were highly sensitive to reward were more likely to be interested in a genetic test for lung cancer than those who were more sensitive to threat (Westmaas and Woicik 2005).

Second, some people tend to have a more positive outlook than others, whether due to dispositional optimism or pessimism (Scheier and Carver 1985) or certain mental health disorders (e.g., depression). People high in dispositional optimism, low in dispositional pessimism, or low in depression report greater interest in testing for general cancer risk

(Bosompra et al. 2000, 2001), lung cancer (van der Steenstraten et al. 1994), and CRC susceptibility (Bunn et al. 2002), but studies have found only mixed support for a relationship with interest in BRCA1/2 testing (*negative relationship with dispositional optimism:* Biesecker et al. 2000; *no relationship with depression*: Andrews et al. 2004; Biesecker et al. 2000; *no relationship with mental health generally:* Andrykowski et al. 1996.

Third, people differ in the extent to which they are comfortable with uncertainty, such that people with a high need for certainty want to reduce ambiguity and seek out information (Dugas et al. 1998; Webster and Kruglanski 1994). Need for certainty predicted interest in genetic testing for CRC susceptibility (Braithwaite et al. 2002) and BRCA1/2 testing (Croyle et al. 1995), such that people who were more uncomfortable with uncertainty were more interested in testing.

Finally, some people tend to prefer a sense of independence in their decisions, and others prefer guidance from experts (Glanz et al. 1999). One study that included a measure of decision preferences found that people who preferred more independence in their decisions also reported greater intentions to pursue genetic testing for CRC susceptibility (Glanz et al. 1999), although a study testing for general cancer risk found no relationship between decision preferences and interest in testing (Bosompra et al. 2001).

Sociodemographic Variables

Perhaps more than any other predictor of genetic testing decisions, sociodemographic predictors are inconsistent across, and often within, various types of genetic testing. In this section we discuss gender, education level, income, employment status, age, marital status, parental status, and religiosity.

Gender Empirical support for gender differences in genetic testing interest is quite inconsistent, and the differences researchers find seem to depend in part on the type of testing studied. Women were more interested in testing than men in a study of genetic testing interest for Tay-Sachs disease and hypercholesterolemia (Harel et al. 2003), but the effects are inconsistent for BRCA1/2 testing (*women more interested:* Holloway et al. 2008; Julian-Reynier et al. 2000; Lerman et al. 1996, 1997; Lynch et al. 2009; Meiser et al. 2000; Ramirez et al. 2006; Romero-Hidalgo et al. 2009; *no gender difference:* Foster et al. 2004; Keogh et al. 2004; Kinney et al. 2001), Huntington's disease (*women more interested:* Bloch et al. 1989; Ramirez et al. 2006; *no gender difference:* Binedell et al. 1998; Codori et al. 1994; Craufurd et al. 1989), Alzheimer's disease (*women more interested:* Hiraki et al. 2009; *men more interested:* Roberts 2000; *mixed results:* Roberts et al. 2004), and direct-to-consumer genetic tests (*men more interested:* Wilson et al. 2008; *no gender difference:* Sweeny and Legg 2011), and gender does not seem to predict interest in testing for CRC susceptibility (Aktan-Collan et al. 2000; Cragun et al. 2012; Glanz et al. 1999; Hadley et al. 2003; Kinney et al. 2000; Lerman et al. 1999; Nordin et al. 2004; Smith and Croyle 1995; Vernon et al. 1999), psychiatric illness (Laegsgaard et al. 2009; Trippitelli et al. 1998), heart disease (Wroe and Salkovskis 2000), hemochromatosis (Salkovskis et al. 1999), a hypothetical test for obesity (Segal et al. 2007), or a genetic testing for a hypothetical disease (Shiloh et al. 1999).

Education More education predicted interest in testing for a hypothetical genetic test for obesity (Segal et al. 2007), but this relationship is inconsistent for Huntington's disease (*positive relationship with education:* Bloch et al. 1989; *no relationship:* Binedell et al. 1998; Codori et al. 1994), BRCA1/2 testing (*positive relationship:* Andrykowski et al. 1996; Culver et al. 2001; Foster et al. 2004; Lerman et al. 1996; Ruddy et al. 2010; *negative relationship:* Cameron and Reeve 2006; Foster et al. 2004; Hughes et al. 1997; Ulrich et al. 1998; *no relationship:* Andrews et al. 2004; Gwyn et al. 2003; Jacobsen et al. 1997; Lerman et al. 1997; Meiser et al. 2000; Ramirez et al. 2006; Tambor et al. 1997), and testing for CRC susceptibility (*positive relationship:* Aktan-Collan et al. 2000; Cappelli et al. 2002; Codori et al. 1999; Lerman et al. 1999; *no relationship:* Glanz et al. 1999; Kinney et al. 2000; Nordin et al. 2004; Vernon et al. 1999), and nonexistent for interest in testing for psychiatric illnesses (Laegsgaard et al. 2009), general genetic testing (Paglierani et al. 2003), prostate cancer (Culler et al. 2002; Myers et al. 2000), and direct-to-consumer testing (Sweeny and Legg 2011; Wilson et al. 2008).

Employment Status Relatively few studies have examined the relationship between employment status and genetic testing decisions, and the few that have reveal mixed support for a relationship with interest in testing for CRC susceptibility (*employed most interested:* Aktan-Collan et al. 2000; *no relationship:* Braithwaite et al. 2002) and Huntington's disease (*unemployed most interested:* Binedell et al. 1998; *no relationship:* Bloch et al. 1989), limited support for a relationship with interest in direct-to-consumer genetic testing (*employed most interested:* Wilson et al. 2008), and no support for a relationship with interest in BRCA 1/2 testing (Foster et al. 2004; Lerman et al. 1996; Ramirez et al. 2006; Tambor et al. 1997).

Income Income inconsistently predicted interest in testing for Alzheimer's disease (*positive relationship:* Hiraki et al. 2009; *no relationship:* Roberts et al. 2004) and direct-to-consumer testing (Wilson et al. 2008), and does not predict interest in testing for general cancer risk (Bosompra et al. 2000, 2001), BRCA1/2 (Kinney et al. 2001; Olaya et al. 2009; Ramirez et al. 2006; Tambor et al. 1997; Ulrich et al. 1998), prostate

cancer (Culler et al. 2002), or CRC susceptibility (Bunn et al. 2002; Cragun et al. 2012; Smith and Croyle 1995; Vernon et al. 1999).

Age The relationship between age and genetic testing decisions is complex. In one study, older men were more interested in testing for prostate cancer susceptibility than were younger men (Myers et al. 2000). On the other hand, younger people reported more interest in a hypothetical genetic test for obesity (Segal et al. 2007), and age does not predict interest in genetic testing for Alzheimer's disease (Roberts 2000; Roberts et al. 2004), psychiatric conditions (Laegsgaard et al. 2009), lung cancer risk (van der Steenstraten et al. 1994), general genetic testing (Paglierani et al. 2003), general cancer risk (Bosompra et al. 2000), or for a hypothetical genetic test (Shiloh et al. 1999). Age inconsistently predicted interest in testing for CRC susceptibility (*positive relationship:* Cyr et al. 2010; Glanz et al. 1999; *negative relationship:* Codori et al. 1999; Croyle and Lerman 1993; *no relationship:* Aktan-Collan et al. 2000; Bunn et al. 2002; Hadley et al. 2003; Kinney et al. 2000; Lerman et al. 1999; Nordin et al. 2004; Smith and Croyle 1995; Vernon et al. 1999), BRCA1/2 (*positive relationship:* Biesecker et al. 2000; Bottorff et al. 2002; Jacobsen et al. 1997; Lynch et al. 2009; Meiser et al. 2000; *negative relationship:* Foster et al. 2004; Godard et al. 2007; Kinney et al. 2001; Meijers-Heijboer et al. 2000; Ruddy et al. 2010; Tambor et al. 1997; *no relationship:* Andrews et al. 2004; Andrykowski et al. 1996; Cameron and Reeve 2006; Cappelli et al. 1999; Culver et al. 2001; Durfy et al. 1999; Gwyn et al. 2003; Keogh et al. 2004; Lerman et al. 1996, 1997; Lynch et al. 2009; Olaya et al. 2009; Ramirez et al. 2006; Smith et al. 2008; Ulrich et al. 1998; Welkenhuysen et al. 2001), general genetic testing (Salkovskis et al. 1999), Huntington's disease (*positive relationship:* Binedell et al. 1998; *no relationship:* Codori et al. 1994; Craufurd et al. 1989; Tibben et al. 1993; *negative relationship with age of parental onset:* Jacopini et al. 1992; Mastromauro et al. 1987), and direct-to-consumer testing (*mixed relationship:* Wilson et al. 2008; *no relationship:* Sweeny and Legg 2011).

Marital and Parental Status In light of the potential implications of genetic testing results for family planning, it seems logical that marital and parental status might predict genetic testing decisions. However, here again the support is mixed for a relationship between marital status and interest in BRCA1/2 testing (*married more interested:* Biesecker et al. 2000; *no relationship:* Foster et al. 2004; Gwyn et al. 2003; Hughes et al. 1997; Jacobsen et al. 1997; Lerman et al. 1997), testing for CRC susceptibility (*married more interested:* Aktan-Collan et al. 2000; Lerman et al. 1999; *no relationship:* Kinney et al. 2000; Smith and Croyle 1995; Vernon et al. 1999), and testing for Huntington's disease (*married more interested:* Binedell et al. 1998; Bloch et al. 1989; *single more interested:* Mastromauro et al. 1987; *no relationship:* Codori et al. 1994), and studies find no relationship between marital status and interest in testing for Alzheimer's disease (Roberts 2000; Roberts et al. 2004), prostate cancer risk (Myers et al. 2000), or general genetic testing (Paglierani et al. 2003).

The research on parental status (having a child or not) is similarly mixed. Being a parent predicted greater interest in BRCA1/2 testing (Foster et al. 2004; Meijers-Heijboer et al. 2000; Meiser et al. 2000) and testing for psychiatric conditions (Laegsgaard et al. 2009). The findings are mixed and even contradictory for Huntington's disease (*parents more interested:* Bloch et al. 1989; *parents less interested:* Binedell et al. 1998; Evers-Kiebooms and Decruyenaere 1998; *no relationship:* Codori et al. 1994) and testing for CRC susceptibility (*parents more interested:* Cappelli et al. 2002; *no relationship:* Aktan-Collan et al. 2000), and one study found no relationship between parental status and interest in general genetic testing (Paglierani et al. 2003).

Religiosity Given the central role of religious or spiritual beliefs in many people's lives, paired with the potential moral and ethical connotations often associated with genetic testing (Fulda and Lykens 2006), we might expect these beliefs to play a role in genetic testing decisions. However, neither religiosity nor spirituality (assessed using either the Spiritual Well-Being scale, Ellison and Smith 1991, the God Locus of Health Control scale, Wallston et al. 1999, single items assessing the strength or importance of participants' religious or spiritual faith, a comparison between participants who did and did not declare a religious affiliation, or a measure of frequency of attendance at religious services) predicted interest in BRCA1/2 testing (Biesecker et al. 2000; Kinney et al. 2001; Olaya et al. 2009; but see Schwartz et al. 2000 for mixed support), testing for CRC susceptibility (Vernon et al. 1999), or testing for psychiatric illnesses (Laegsgaard et al. 2009), although one study of general testing intentions found an indirect relationship between religious involvement and intentions mediated by attitudes toward testing (Botoseneanu et al. 2011).

Summary of Objective Predictors of Testing Decisions

Studies of genetic testing decisions typically include objective predictors, regardless of the study's primary focus, and thus the research base regarding these predictors is quite large. Unfortunately, few conclusions are warranted due to the consistently inconsistent findings regarding who is most likely to pursue testing. Family history is the most consistent objective predictor of decisions, such that people with a family history of a disorder are more likely to pursue genetic testing related to that disorder, but even this finding is inconsistent for BRCA1/2 testing, testing for CRC susceptibility, and testing

for prostate cancer risk. People who are high in monitoring orientation also tend to be more interested in genetic testing, although many studies have found no relationship between monitoring/blunting orientation and testing interest. Some evidence also suggests that people high in dispositional optimism, low in dispositional pessimism, or high in need for certainty may be more likely to pursue testing, but the findings for these predictors are mixed.

Even less useful are the findings for personal history, health motivation, religiosity, and sociodemographic characteristics. Studies not only provide inconsistent support for these predictors of genetic testing decision; they often produce contradictory findings, even within testing type. Taken as a whole, our review of objective predictors of genetic testing decisions makes clear that any conclusion regarding who is most likely to pursue testing is premature, and perhaps out of reach.

General Discussion

The goal of this review was to collect and organize the research on genetic testing decisions to highlight broad themes, common findings, and gaps or inconsistencies in the literature. The authors recognize the ambitiousness of these goals; however, we argue that such a paper is critical at this point in the field. As demonstrated throughout the paper, the field has experienced a vast proliferation of studies on genetic testing decisions with little or no recognition of the conflicting results across studies. Without a detailed review like the one presented here, it is difficult to imagine that much will change. Focused meta-analyses and reviews that seek broad generalizations certainly have value, but they cannot address the larger issues of identifying the many areas of conflict (and the few areas of agreement) within the literature or pointing toward areas that have received relatively extensive empirical attention and areas that have received relatively little attention. In fact, our organizational approach provides several key insights into the current state of the literature on genetic testing decisions.

First, people's self-generated explanations for testing (and not testing) are far more consistent than the findings from quantitative attempts to predict testing decisions. Qualitative studies may not provide the precision or statistical conclusiveness desired by many researchers, but our initial overview of the literature revealed the value in simply asking people why they made the decision they made. Considering the potential for interventions to increase interest in testing (to the extent that testing is beneficial in a particular context or for a particular person), the existing quantitative findings provide only a few appropriate targets (i.e., predictors that have received largely consistent support) for interventions. In contrast, qualitative studies paint a clear picture of how best to promote effective, informed and value-based decision making about genetic testing: emphasize the opportunity for prevention, planning, and benefits for family members, and assuage concerns about emotional trauma, risks of the testing procedure, and discrimination based on test results. Of course, we would note that studies assessing self-reported explanations for testing decisions are by necessity limited in most cases to genetic tests that are readily available.

Second, among quantitative predictors of testing decisions, test-related variables emerged as more consistent predictors than disorder-related or objective variables. In fact, our review revealed a high degree of overlap between the personal explanations for testing and the test-related predictors that have received empirical support. Specifically, people are more likely to test when they perceive many benefits of testing, few barriers to and risks of testing, and positive attitudes surrounding testing (subjective norms are a less consistent predictor). In contrast, variables related to the genetic disorder, most notably perceived risk, perceived control, and perceived severity, generally were poor or inconsistent predictors of genetic testing decisions (disease-specific worry was more consistent).

Individual differences and sociodemographic variables fared even worse. Although we recognize that such inconsistency may have many sources, the problem we identify is twofold. First, we found a number of studies that ostensibly examined the same genetic test in similar populations and yet found inconsistent support for various predictors (e.g., BRCA1/2 testing and perceived risk: Culver et al. 2001; Durfy et al. 1999, and Helmes 2002 find a positive relationship; Andrews et al. 2004; Cameron and Reeve 2006, and Durfy et al. 1999 find no relationship). Second, in the many cases in which moderators may be present (e.g., same test but different populations, different test but similar populations), we found very few attempts by the researchers to test or even identify such moderators. Thus, the current state of affairs, which our paper begins to rectify, is a very large and growing set of seemingly conflicting findings that remain unreconciled.

Third, our review revealed vast inconsistencies in the predictors of different genetic tests and few attempts to approach this topic from a more generalizable, theoretical perspective. This shortcoming is not unusual in medical and health behavior research, which tends to be disease- or procedure-specific rather than broadly theoretical. However, the result is a large and growing collection of disparate findings. Without a clear delineation of why and how genetic tests differ from each other in ways that might be important to decision-making, the field is left without a "guidebook" to assist in interpreting and applying findings across the array of available genetic tests. Thus, one productive direction for future research would be to identify differences between testing types and that may be contributing to the inconsistency across studies. For example, tests vary in their familiarity

to potential patients, the incidence of the genetic condition in the population, and the degree of certainty conferred by test results, among other variations. Studies that directly compare predictors of decisions for multiple test types would also contribute to this goal.

Our review also includes many contradictory findings within testing types, particularly for tests that have received the greatest empirical attention (e.g., BRCA1/2 testing, testing for CRC susceptibility), and therefore another productive direction for future research would be to identify methodological differences that might further contribute to inconsistency across studies. For example, the studies reviewed here vary in whether they operationalize a testing "decision" as general interest in testing, intention to test, previous testing, or subsequent testing uptake (see Table 1 for approach by study). In light of the often weak relationship between intentions and behavior (Ajzen and Fishbein 1977), it is likely that the predictors of testing interest and intentions are not perfectly aligned with predictors of testing uptake. However, a visual scan of Tables 2 and 3, in which studies that assessed uptake rather than simply interest or intentions are emphasized with an asterisk, does not immediately reveal a pattern of effects based on the nature of the dependent measure. Furthermore, we found significant variation in the operationalization of predictor variables (e.g., perceived risk, perceived benefits and barriers), which may be a further cause of inconsistency across studies, even when examining the same genetic test in equivalent populations.

Studies also vary in their quality, including method of recruitment and sample size, and these variations are other likely sources of inconsistency. Specifically, small studies typically produce less reliable results, so perhaps they should not be weighted as strongly in a systematic review. Tables 2 and 3 provide some insight into the relationship between sample size and prediction of genetic testing, taking note of the small studies (fewer than 150 participants) and the large studies (more than 1,000 participants) with varying font size. Although these cut-offs are arbitrary, they provide insight into the causes of inconsistency for some predictors. For example, attitudes toward testing are a consistent predictor of testing decisions, with the exception of a single study that found no effect; however, this study was relatively small. Similarly, disease-specific worry is a consistent predictor with the exception of three small studies, one of which found a negative relationship and the other two a null relationship. Thus, sample size (one proxy for study quality) may explain some variation among findings, but this metric is not sufficient to capture the large inconsistencies across the literature.

Limitations of this Review

We aimed to provide a thorough and nuanced review of the predictors of personal genetic testing decisions and to offer a critique of the literature that would point to productive directions for future research. As such, our review was necessarily limited in several ways. Most notably, our approach almost certainly raises more questions than answers. In valuing comprehensiveness over broad conclusions, this review risks coming across as a "laundry list" of findings with little sense of which findings are most reliable, most noteworthy, etc. However, the goals of this review are to eschew conclusions based on inconsistent findings and instead draw attention to the few areas of consistency (i.e., perceived benefits and barriers, subjective norms, attitudes toward testing) and the many areas of inconsistency across and within testing types. This review can serve as a critical point of reference for researchers interested in identifying important next steps for research on genetic testing decisions and for clinicians interested in identifying effective targets for intervention.

Two less central limitations deserve note. First, we did not include studies of prenatal, pre-implantation, or newborn testing in our review. Although many of the predictors identified in this article apply to such testing decisions, we limited our discussion to personal decisions regarding diagnostic, predictive/pre-symptomatic, carrier, and research testing for oneself. This decision followed an initial literature search that included prenatal testing, which quickly revealed the many considerations unique to these and similar testing decisions (e.g., consideration of abortion or destruction of an embryo prior to in vitro implantation). However, future research that aims to identify characteristics unique to specific testing types and consider methodological differences that might explain inconsistent findings across studies can incorporate prenatal testing decisions into these endeavors.

We also limited our review to the predictors of genetic testing decisions and did not delve into ethical issues surrounding testing or the relative value of certain tests over others, or of testing for certain people over others. Certainly these issues are critical as researchers develop interventions to increase (or decrease) interest in testing, but the goal of this paper was to understand when and why people choose to test rather than when they should test. The latter question requires detailed knowledge of the clinical outcomes of genetic tests and heritable disorders, topics that are outside the scope of this review.

Conclusions

Genetic testing increasingly is at the forefront of discussions about healthcare, health insurance, and disease prevention. Despite empirical and theoretical advances that were unimaginable before the start of the Human Genome Project (National Human Genome Research Institute 2011), the benefits and hazards of genetic testing remain

controversial and largely unclear. Worse, our review reveals that the field of health behavior research provides only a "blurry" and incomplete picture of decision-making surrounding genetic testing. Moving forward, it is essential that researchers build interdisciplinary collaborations to develop comprehensive studies and complex theories that are informed by medical, health behavior, and psychological perspectives. We hope our review provides researchers with an opportunity to take a proverbial "step back" and to direct a critical eye toward the vast literature on genetic testing decisions before embarking on further research endeavors.

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