A Systematic Review of Literature About the Genetic Testing of Adolescents

Lynn Rew, Michael Mackert, and Daniel Bonevac

PURPOSE. Mapping of the human genome raises interest in and concern about the genetic testing of adolescents. Our purpose was to determine the attitudes and knowledge adolescents and their parents have about genetic testing.

DESIGN AND METHOD. This paper is a report of a systematic review of the research literature (n = 56) about the attitudes and knowledge adolescents and their parents have about genetic testing.

RESULTS. The majority of studies, which were descriptive in design, focused on a specific heritable disorder, were conducted in the United States, and over sampled well-educated White females.

PRACTICE IMPLICATIONS. Results suggest that adolescents and their families have relatively positive attitudes about genetic testing and may experience both harms and benefits from testing. Nurses may be in positions to assist adolescents and their families in making decisions about genetic testing, remaining sensitive to family dynamics and issues of privacy and autonomy.

Search terms: Adolescent, family, genetic testing

Adolescents are maturing in the era of the Human Genome Project and will be the first generation of adults to make decisions about a wide array of genetic testing for themselves and their families. As adolescents, they may have opportunities to participate in various types of genetic testing, ranging from newborn screening for metabolic disorders, such as phenylketonuria, to confirmational diagnoses of disorders for which they may have symptoms, such as Marfan syndrome (National Institutes of Health [NIH], September 19, 2008). While they remain adolescents, they may also seek genetic testing for adult-onset disorders or be urged by family members or friends to engage in such testing. Presymptomatic genetic testing is now available for adults for a number of heritable disorders including various types of cancer, cardiac disorders, and Huntington Disease (HD; Kalman et al., 2007). Results of presymptomatic testing enable some individuals to engage in health-promoting behaviors or seek early treatment for symptoms, depending on the disorder (Beery & Williams, 2007). Persons at-risk for HD, for example, may decline genetic testing because it threatens their sense of self-preservation, identity, and hope for the future (Quaid et al., 2008).

What health information will adolescents need to make wise decisions about genetic testing? To answer this question we need to answer other questions: (a) What do adolescents and their parents know about genetic testing?; (b) What are their attitudes about genetic testing?; and (c) How receptive are they to information about genetic testing? The answers to these and many other questions will be needed as society grapples with “the intersection of the genetics era and information age” (Johnson, Case, Andrews, & Allard, 2005, p. 323). For adolescents, the Internet has become not only a social environment for instant communication with a network of friends, but also it provides health information on a variety of topics including genetic testing (Gray, 2005, 2008; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Greenfield & Yan, 2006). Unfortunately, access to genetic testing sites via the Internet poses risks (e.g., test results given without access...
to professional genetic counseling) that may affect adolescents adversely (Guttman & Collins, 2003).

A body of literature already exists to address some of these questions. For example, there are many studies that focus on gene mutations associated with specific disorders (Beetz et al., 2008; Orth et al., 2007). Few studies focus explicitly on adolescents’ or their parents’ views about genetic testing, though many others might shed light on these issues tangentially.

**Purpose**

The purpose of this paper is to report the findings from a systematic review of literature about the genetic testing of adolescents. We sought to determine the attitudes and knowledge adolescents and their parents have about genetic testing.

**Methods**

Four databases were simultaneously searched: Cumulative Index of Nursing and Allied Health Literature, Educational Resource Information Center, Medline, and PsychInfo. The database search returned articles that included key terms of adolescent, genetic testing, and either parents or family. To maximize the number of articles included, no time parameters were placed on the search. Criteria for inclusion in the systematic review were the following: (a) study sample included adolescents between the ages of 11 and 21 years (American Academy of Pediatrics, 2008) and/or their parents, either explicitly (e.g., studies focusing specifically on parents of adolescents) or implicitly (e.g., large cross-sectional surveys of adults that would include parents of adolescents); (b) a research method could be identified; (c) published in peer-reviewed journals; and (d) written in English. These inclusion criteria, specifically the restriction of peer-reviewed journals, were designed to leverage the peer-review process and help ensure the validity of included studies. Exclusion criteria were similarly selected to help ensure the validity of the final sample of articles. Exclusion criteria were the following: (a) books, book chapters, book reviews, or conference proceedings because these reports often do not match the rigorous selection process of peer-reviewed journals; (b) opinions, essays, editorials, or interviews—such articles, even in peer-reviewed journals, do not necessarily undergo full peer review and may not be based on original research data; and (c) epidemiological reports of screenings for mutations or heritable syndromes because these reports would not address attitudes and the family, which were the focus of this review.

Each article that met inclusion criteria was reviewed by at least two of the three authors, using the data collection tool (see Table 1) developed to tally characteristics of each article such as the purpose, setting, and whether or not adolescents were included in the sample. The validity of studies included in this review was determined in a number of ways. For those with quantitative analyses, we examined the article for evidence of representative samples, response rate for surveys, use of valid instruments with adequate reliability, use of statistics congruent with study purpose and design, and acknowledgement of limitations. For qualitative studies, we examined the article for a full description of the design used and its appropriateness to address the purpose of the study, description of an audit trail for data collection and analysis, direct quotes from participants congruent with identified themes or categories, and acknowledgement and discussion of limitations.

**Table 1. Genetic Testing of Adolescents Data Collection Tool**

| Country of origin | specify |
| Setting | specify |
| Family focus | yes no |
| Genetic testing defined (how) | specify |
| Purpose of study | specify |
| Study design | specify |
| Conceptual model or theoretical framework | specify |
| Adolescents in sample | yes no |
| Addressed genetic testing of adolescents | explicitly versus implicitly |
| Validity and reliability of scales in quantitative studies | yes no |
| Statistics appropriate for method | yes no |
| Limitations of method identified | yes no |
| Findings/themes addressed | specify |
| Implications for genetic testing of adolescents | yes no |

The database search returned a total of 222 articles published between 1975 and June 2008. After excluding those that did not meet the criteria for inclusion ($n = 166$), a total of 56 articles published between 1975 and 2008 were reviewed (see Appendix). Of the 166 excluded articles, one third ($n = 55$) focused on clinical samples recruited for the purpose of identifying genetic mutations for a specific disorder. The majority of the studies included in the final sample ($n = 38, 67.9\%$) addressed the issue of genetic testing of adolescents indirectly, such as through the use of a large cross-sectional survey of adults that would include parents of adolescents as well as adolescents (samples ranged in age from 15 to 97 years), rather than focusing directly on adolescents and/or their parents ($n = 18, 32.1\%$). The focus of this review is on the
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18 studies that dealt directly with adolescents and/or their parents. Of these 18 (see Table 2), four studies (7.1%) focused directly on and elicited data from the adolescents themselves.

Ten of the quantitative studies were of questionable validity. Six of these studies either reported no evidence of reliability or validity of survey instruments used (Finlay et al., 2008; Schaller, Moser, Begleiter, & Edwards, 2007; Segal, Polansky, & Sankar, 2007; van Korlaar et al., 2005), created scales for use in the study but did not report their psychometric characteristics (Nyrhinen, Hietala, Puukka, & Leinon-Kilpi, 2007), or used scales with low reliability (Bowen, Bourcier, Press, Lewis, & Burke, 2004). One of the 10 studies was compromised by using a historical cohort to provide outcome measures (Suthers, Armstrong, McCormack, & Trott, 2006); one was based on showing future lawyers and physicians a single emotion-laden video to elicit attitudes toward genetic testing (Elger & Harding, 2006); and one limited the survey to individuals with working telephones (Rose, Peters, Shea, & Armstrong, 2005). In another of these studies, a low response rate of 17.5% adversely affected power (Satia, McRitchie, Kupper, & Halbert, 2006).

Only one of the qualitative studies failed to demonstrate validity (Thomas et al., 2007). The qualitative design/method was not specified, no demographics were provided to describe the sample, and few details were given about data analysis. However, this study did provide quotations from participants to support the themes, and limitations were appropriately identified.

As shown in Table 3, more than half (58.9%) of the studies were conducted in the United States. None of the studies was completed in Eastern Europe, Southeast Asia, South America, or Central America. Table 4 presents a summary of the various settings or sites for the studies. Slightly more than one in three (35.7%) were associated with cancer and genetics clinics, and slightly fewer (26.8%) were conducted in communities at large. Only four projects (7.1%) were conducted in children’s hospitals.

The majority of studies (n = 30; 53.6%) reviewed were cross-sectional, and very few were longitudinal (n = 4; 7.1%) or randomized controlled trials (n = 2; 3.6%). As can be seen in Table 5, nearly one third (n = 17, 30.4%) were qualitative (n = 12, 21.4%) or case studies (n = 5, 8.9%).

Table 6 depicts the major themes of the studies reviewed. Consistent with our purpose, the majority of our included sample focused on attitudes toward genetic testing of adolescents by the adolescents themselves, their parents, hospital or clinic patients or families of such patients, and professionals. Attitudes of adolescents themselves toward genetic testing were primarily positive. For example, Duncan and colleagues (2007) interviewed eight young people who had undergone genetic testing for HD between the ages of 17 and 25 years. They found that, regardless of the outcomes of the testing, none of the participants “regretted undergoing predictive testing” (p. 1984) and they felt as if the testing had removed some of the uncertainty they faced in growing up. In another study of 20 younger adolescents, ages 11–17 years, Tercyak, Peshkin, Streisand, and Lerman (2001) found that 90% were interested in learning about their risk for developing cancer so they could make more informed decisions and pay closer attention to their health.

Parents, in general, were also positive about testing their children if there were immediate benefits. Moreover, parents believed that testing would help them make more informed decisions regarding their children’s health. Less than half the studies focused on the impact of genetic testing, including its harms and benefits, on communication, primarily disclosure of results to family members. Duncan and colleagues (2008) described the impact of genetic testing of adolescents and young adults who had undergone predictive genetic testing for HD or familial adenomatous polyposis. Specifically, they identified several harms associated with receiving gene-positive test results that included witnessing the distress of their parents, feeling angry, or feeling anxious about other people gossiping about them. They also identified harms associated with receiving gene-negative test results that included feeling guilty and worrying about the implications for their siblings. With respect to communication, studies reviewed here addressed the importance of communicating results to close relatives. Participants in one study were reluctant to share findings to more distant relatives because they did not feel close to them, did not want them to worry, and they feared these relatives would not know how to interpret the findings (Stoffel et al., 2008).

Fewer studies addressed knowledge, ethical principles, beliefs, or decision-making. For example, studies of knowledge addressed the issue of information needed to fully comprehend what would be done in genetic testing and how to interpret the outcomes. The principles of privacy and equality were examined in a study that included diagnostic genetic testing of children. Other ethical principles examined were autonomy and confidentiality.

The primary limitations of the studies were the emphasis on specific heritable disorders and demographics of the populations studied (see Table 7). Fully two thirds (67.9%) of the studies focused on genetic testing for a specific heritable disorder (i.e., breast cancer [BRCA], colon cancer, or HD); this could limit the generalizability of those findings to other disorders with different genetic characteristics (e.g., from an X-linked or polygenic pattern of inheritance). Many studies (48.2%) included samples that were only females, such as those that addressed testing for ovarian cancer (Benkendorf et al., 1997; Biesecker et al., 2000), and studies in which the majority of participants were female. Only one study focused on men at-risk for prostate cancer (Doukas, Fetters, Coyne, & McCullough, 2000). Participants in the studies reviewed here were largely well educated with fully one third (33.9%)
<table>
<thead>
<tr>
<th>Authors (date)</th>
<th>Design/Methods</th>
<th>Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arribas-Ayllon, Sarangi, and Clarke (2008)</td>
<td>Qualitative/ Interviews</td>
<td>Parents (N = 20)</td>
<td>Decisions about genetic testing are complex and present ethical dilemmas within families.</td>
</tr>
<tr>
<td>Bradbury et al. (2008)</td>
<td>Qualitative/ Interviews</td>
<td>Parents (ages 28–66) (n = 53) and offspring (ages 18–33) (n = 22) (N = 75)</td>
<td>Fifty-two percent of BRCA1/2 carriers and their offspring oppose or have concerns about testing for mutation carrier status; 24% supported for potential to impact health behaviors; 61% of offsprings’ opinions differed from their parents’.</td>
</tr>
<tr>
<td>Bradbury et al. (2007)</td>
<td>Qualitative/ Phone interviews</td>
<td>Parents (ages 28–66) who were BRCA mutation carriers (N = 42)</td>
<td>Fifty-five percent reported risk to one or more children, some had negative reaction to disclosure. Older children more likely to understand implications than younger children.</td>
</tr>
<tr>
<td>Demarco et al. (2008)</td>
<td>Longitudinal/ Interviews and scales</td>
<td>Mothers (mean age = 45.9 years) (N = 177)</td>
<td>Quality of parenting relationship affects decision-making.</td>
</tr>
<tr>
<td>Holt (2006)</td>
<td>Phenomenology/ Home Interviews</td>
<td>Eight members of two families (ages 10–60 )</td>
<td>One family chose to disclose family risk for HD with children and the other did not. All adult children preferred early disclosure and open communication with parents.</td>
</tr>
<tr>
<td>Li et al. (2007)</td>
<td>Psychometric/ Survey</td>
<td>Parents (ages 18–64) (N = 119)</td>
<td>All children had bilateral sensorineural hearing loss. Genetic Attitude Assessment Tool was validated, sensitive to changes in parents’ attitudes with counseling.</td>
</tr>
<tr>
<td>Nyrhinen, Hietala, Puukka, and Leino-Kilpi (2007)</td>
<td>Cross-sectional/ Questionnaire</td>
<td>Patients or pediatric patients’ parents (n = 106) and hospital staff (n = 162) (N = 268) Sample ages = 16–76 years</td>
<td>Patients and parents differed from staff in identifying greatest ethical principle. For patients and parents of pediatric patients, equality (e.g., planning care) after testing was most important, but for staff, privacy prior to testing was most important.</td>
</tr>
<tr>
<td>Peters et al. (2006)</td>
<td>Descriptive survey/ Correlational</td>
<td>Family members (ages &gt;19 years) (n = 229)</td>
<td>Majority (66%) of family members at risk for familial testicular cancer favored genetic testing, when available, particularly younger with high levels of social support.</td>
</tr>
<tr>
<td>Petersen and Boyd (1995)</td>
<td>Descriptive/ Interviews</td>
<td>Parents (n = 47) and minorsa at risk for FAP (n = 38) (N = 85)</td>
<td>Genetic counseling before and after testing are important in management of persons at-risk.</td>
</tr>
</tbody>
</table>

a. Minor means age < 18 years.
Table 2. Continued

<table>
<thead>
<tr>
<th>Authors (date)</th>
<th>Design/Methods</th>
<th>Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Segal, Polansky, and Sankar (2007)</td>
<td>Qualitative/ Focus Group or Phone Interviews</td>
<td>Parents (mean age = 40.7) ($n = 24$) and obese adults (mean age 32.42) ($n = 52$) ($N = 76$)</td>
<td>Majority responses to hypothetical scenarios about genetic testing of children for obesity were positive even if no drug treatment is available. Reasons were to assist in behavior change to prevent obesity. Few considerations for possible negative effects.</td>
</tr>
<tr>
<td>Sorenson, Jennings-Grant, and Newman (2003)</td>
<td>Qualitative/ Interviews, surveys</td>
<td>Patients with hemophilia (ages &lt;17–&gt;55 years) ($n = 87$) and relatives (ages 18–56+) ($n = 98$) ($N = 185$)</td>
<td>Information about genetic test results selectively communicated within family system.</td>
</tr>
<tr>
<td>Tercyak et al. (2007)</td>
<td>Cross-sectional/ Surveys</td>
<td>Mothers (mean age = 45.6) ($N = 187$)</td>
<td>Most undergoing BRCA1/2 testing requested literature, family counseling, and support groups to help them communicate test outcomes to children (ages 8–21 years).</td>
</tr>
<tr>
<td>Duncan et al. (2008)</td>
<td>Qualitative/ Interviews</td>
<td>Adolescents (ages 20–26) tested for HD or FAP ($N = 18$)</td>
<td>Described harms and benefits similar to those reported by adults, regardless of test outcomes.</td>
</tr>
<tr>
<td>Duncan et al. (2007)</td>
<td>Qualitative/ Interviews</td>
<td>Adolescents (ages 17–25) tested for HD ($N = 8$)</td>
<td>None regretted being tested; helped relieve uncertainty and going forward with living.</td>
</tr>
<tr>
<td>Gaff, Lynch, and Spencer (2006)</td>
<td>Case Study</td>
<td>Adolescents (ages 18) requesting testing for HNPCC ($N = 2$)</td>
<td>Counselors need to engage youth in reflection and consider family dynamics.</td>
</tr>
</tbody>
</table>

*No ages provided for sample.
BRCA, breast cancer; FAP, familial adenomatous polyposis; HD, Huntington Disease; HNPCC, hereditary non-polyposis colorectal cancer.

Table 3. Country Where Studies Were Conducted

<table>
<thead>
<tr>
<th>Country</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>6</td>
</tr>
<tr>
<td>Belgium</td>
<td>1</td>
</tr>
<tr>
<td>Canada</td>
<td>2</td>
</tr>
<tr>
<td>Finland</td>
<td>2</td>
</tr>
<tr>
<td>Germany</td>
<td>1</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>4</td>
</tr>
<tr>
<td>Switzerland</td>
<td>1</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>3</td>
</tr>
<tr>
<td>United States</td>
<td>34</td>
</tr>
<tr>
<td>Multinational</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>56</td>
</tr>
</tbody>
</table>

*Sites in more than one country.

Table 4. Settings for Studies About Genetic Testing of Adolescents

<table>
<thead>
<tr>
<th>Setting</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone/In-home/Community</td>
<td>15</td>
</tr>
<tr>
<td>Cancer Clinic/Cancer Risk Clinic</td>
<td>14</td>
</tr>
<tr>
<td>University Hospital/Medical Center</td>
<td>9</td>
</tr>
<tr>
<td>Genetics Clinic/Institute</td>
<td>6</td>
</tr>
<tr>
<td>University/High school</td>
<td>4</td>
</tr>
<tr>
<td>Unspecified clinic</td>
<td>4</td>
</tr>
<tr>
<td>Children’s Hospital</td>
<td>4</td>
</tr>
<tr>
<td>National Registry</td>
<td>3</td>
</tr>
<tr>
<td>National Disease Organization</td>
<td>1</td>
</tr>
<tr>
<td>Unspecified location</td>
<td>1</td>
</tr>
</tbody>
</table>

Total is >56 because some studies were conducted in multiple settings.
including people with at least some college education. Fifteen studies (26.8%) provided no description of race or ethnicity of the participants. Of the remaining 41 studies that included race or ethnicity, 44% had samples that were predominantly Caucasian. Seven (12.5%) studies were limited by their dependence on adults’ retrospective recall of events.

Finally, it is worth noting that the particular databases searched for this study may have excluded relevant studies where genetic testing simply provided the context for a study where the focus was in another field (e.g., a study of the marketing of genetic testing services to consumers that could have been published in an advertising or marketing journal). While the databases used in this review likely contained the bulk of the relevant articles, searches focused on a particular aspect of genetic testing of adolescents would likely uncover research not included in this review.

**Discussion**

Surprisingly, few of the studies reviewed addressed directly the issue of genetic testing of adolescents. This demonstrates a significant need for increased focus on this topic. But the prevalence of studies that indirectly studied genetic testing of adolescents—through cross-sectional studies of the general population, for example—suggests one productive avenue for quickly building knowledge on the issue of genetic testing in adolescents. Other research has likely been conducted that indirectly touches on this particular topic but was not originally intended to investigate attitudes or knowledge about genetic testing in adolescents; revisiting and publishing existing data with this issue in mind could make it possible for researchers to contribute quickly to this body of research.

The vast majority of studies focused on a few specific heritable disorders such as HD, BRCA, and colon cancer. These, of course, are disorders about which much is known. HD, for instance, is an example of an incurable monogenetic disorder with adult-onset. Current debate about the benefit of testing children and adolescents for this disorder focuses on reproductive planning and decision-making (Lashley, 2007). It also includes consideration of ethical principles such as autonomy and equity (Nyrhinen, Leino-Kilpi, & Hietala, 2004).

The ability to conduct cross-cultural comparisons of studies and findings was limited because of the fact that the majority of studies came from the United States, as well as the fact that only studies published in English were included in this review. Future reviews, incorporating studies published in other languages, could uncover cultural differences regarding genetic testing—such differences might exist between more individualistic and more collectivistic cultures, for example. An increased focus on intercultural differences might also contribute to further understanding of health disparities, even within the United States, some of which might be a result of varying levels of acceptance of genetic screening among different cultures (e.g., Satia et al., 2006).
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Most studies were cross-sectional surveys, which likely reflect the state of the science, which, for most heritable disorders, remains at the purely descriptive or exploratory level at this time. Only two of the studies were based on a theoretical model other than a general medical model of disease. These used the Health Belief Model as a framework (Becker, Kaback, Rosenstock, & Ruth, 1975; Peters et al., 2006). Although one study incorporated several concepts from the Theory of Reasoned Action and Planned Behavior, the authors did not explicitly cite this as the theoretical framework for the study (Satia et al., 2006). Because the issue of genetic testing of adolescents has an impact on other family members, including parents and siblings, the Family Systems Genetic Illness Model offers a framework for considering the dynamics of genetic testing of adolescents within the context of the family (Rolland, 2006; Rolland & Williams, 2005). Future research could usefully incorporate such established theoretical models in evaluating people’s understanding and attitudes regarding genetic testing of adolescents.

Our review indicates that we still have little general knowledge about genetic testing of adolescents, how it is described to potential users, and how the results are used and conveyed. This is particularly important as advances in genetic testing technology might outpace research into people’s attitudes toward genetic testing about one particular genetic condition or another. Ethical issues related to harms and benefits raise important questions for adolescents and their families to consider, but we know little about how much adolescents or their parents understand, what their attitudes are, or, therefore, what might best be done to prepare them to answer those questions and make the decisions they may be called upon to make. A substantial literature investigates ethical issues concerning genetic testing, but in almost complete isolation from empirical results concerning the knowledge and attitudes of those confronting those issues.

A substantial literature investigates ethical issues concerning genetic testing, but in almost complete isolation from empirical results concerning the knowledge and attitudes of those confronting those issues.

Common limitations to the studies reviewed point to promising directions for future research:

1. Clearly, the vast majority considered genetic testing for a specific heritable disorder. Little has been done to compare knowledge of and attitudes toward genetic testing for different disorders within the same study. Consequently, we know little about general knowledge of and attitudes toward genetic testing per se.

2. As many of these studies were about genetic testing for the genetic mutations of BRCA (BRCA1/2), one of the most common forms of genetic testing, it may not be surprising that so many samples had primarily females as participants. Future research could productively explore potential gender-based differences in genetic testing in general or regarding genetic testing for particular conditions.

3. Many of the samples appear to have overrepresented the well-educated. This may reflect the fact that most studies were conducted in settings associated with patients having insurance, access to regular resources for health care, and, in many cases, the ability to travel distances to elite, highly specialized institutions. An increased focus on lower-educated and underserved populations is necessary to arrive at a better understanding of what the public at large knows and needs to know about genetic testing and attitudes toward genetic testing advances.

4. Whereas this review’s inclusion only of studies published in English could explain study samples that were primarily Caucasian, more research is needed to explore potential ethnic and cultural differences in attitudes toward genetic testing. Only two studies examined racial differences (Doukas et al., 2000; Lerman et al., 1998). One study was devoted to genetic testing for colon cancer among African Americans (Satia et al., 2006).

5. Most studies that included adolescents or their parents presented results for only the entire sampled population. It is impossible to glean from the reported data information specifically about the knowledge and attitudes of adolescents or their parents.

A caveat: Beyond the inclusion only of studies published in English, this review was also limited to a subset of medical databases. As a result, related research in other fields (e.g., health communication) might not have been included in this review.

Conclusions

From this review, we conclude that knowledge about the genetic testing of adolescents is clearly skewed in the direction of studies of specific heritable disorders, with very little attention paid to what adolescents themselves think about the general notion of genetic testing. Only one of the studies (from Finland) was based on a representative sample, and few were based on any theoretical model except a medical model of heritable disease. There is a need in the near future for studies that examine health literacy, ethics, and the decision-making of adolescents and their families about the genetic testing of adolescents.
How Do I Apply This Evidence to Nursing Practice?

Nurses in a variety of settings, including pediatric clinics and schools, may be called upon to provide genomic information to adolescents and their families about the various types of genetic testing, their validity, and possible beneficial or harmful consequences. As the consumer demand for genetic testing increases, nurses may be asked to assist adolescents and their families in making important decisions about use of genetic services. This may have particular relevance to adolescents' future reproductive decision-making. As this review has shown, current attitudes of adolescents and their parents toward genetic testing are generally positive and may lead to greater self-responsibility and health surveillance among adolescents. However, issues such as family dynamics and communication patterns, privacy, and autonomy are paramount and must be considered by both health professionals and parents if a decision is made for an adolescent to have genetic testing.

Nurses may be in positions where they can directly refer adolescents and their families for genetic testing and counseling. Adolescents and their families will need to know that making an informed decision about whether or not an adolescent should agree to genetic testing should be done within the context of the family because the outcomes have implications beyond the individual being tested. Nurses who are certified in genetics or genetic counseling can assist families in making informed decisions and in considering how to communicate the results of testing to other concerned family members. As well, nurses may be a health resource for friends and extended family members and be expected to field questions from sources other than their patients.

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References


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Appendix: Articles Included in the Systematic Review of Genetic Testing of Adolescents


A Systematic Review of Literature About the Genetic Testing of Adolescents

Appendix: Continued


