Sex Education: Practices and Insight From Pediatric Genetic Counselors

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Presented to
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Graduate Program in Genetic Counseling
David Rintell, Ed.D., Advisor

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Master of Science
in
Genetic Counseling

by
Carly Murphy

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ABSTRACT

Sex Education: Practices and Insight From Pediatric Genetic Counselors

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
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Waltham, Massachusetts

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Intellectual disability with or without other anomalies is a common referral for genetic counseling. Sessions may include discussions of reproductive implications and other issues related to sex education. Patients with intellectual disability (ID) regularly meet barriers when trying to obtain sex education due to the beliefs and practices of unaffected individuals such as caregivers, family members, and health professionals. We surveyed genetic counselors to explore the frequency with which they are asked to provide sex education counseling and their comfort in doing so for patients with ID ages 9 – 17. Caregivers and patients most frequently asked about puberty, sex abuse prevention, and reproductive health. Genetic counselors were most comfortable when they could provide sex education counseling within the context of a particular condition or constellation of features. They were least comfortable when there was a lack of familiarity with the patient, caregiver, or the family’s culture. The most frequently cited barriers that prevented genetic counselors from providing sex education counseling were lack of time, lack of training, the patient’s ID being too profound, and the thought that genetic counselors should not be
responsible for providing sex education counseling. While many respondents recognized that providing sex education counseling is not considered within the scope of a genetic counselor’s practice, respondents also acknowledged that they should be prepared for such discussions and were interested in having access to specific online and print resource guides specifically designed for use by genetic counselors to provide to patients with ID and their caregivers. Genetic counselors as well as medical professionals of all disciplines are encouraged to embrace the role of advocate and broach the issue of sexual health with caregivers and patients by directing them toward educational resources, if not providing sex education themselves to effectively serve the needs of patients and caregivers.

Keywords: sex education, intellectual disability, genetic counselor, pediatric, adolescent, barrier
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INTRODUCTION

Intellectual disability (ID) is described by the American Psychiatric Association as decreased adaptive functioning in conceptual, social, and practical domains that occurs prior to 18 years of age (APA, 2013). The diagnosis of ID is made through a combination of clinical assessment of adaptive functional skills and standardized intelligence testing. ID is considered to be an IQ score of approximately two standard deviations below the mean, or a score of 70 or below (Robert L. Schalock, 2010). ID is classified as mild, moderate, severe, and profound. The prevalence of intellectual disability in the general population is approximately 1 – 3% (Shevell et al., 2003). Individuals diagnosed with mild ID account for 85% of the population with ID (King, Toth, Hodapp, & Dyken, 2009). Persons with mild ID are able to be educated up to a 6th-grade level, are usually capable of maintaining a steady job, and can live in the community with minimal supervision while those with profound ID can achieve education lower than 1st-grade and are unable to consistently perform daily activities with independence (Morano, 2001).

Causes of ID include but are not limited to genetic abnormalities, infection, trauma, complications of prematurity, and various exposures. Genetic abnormalities are causative for 17.4 – 47.1% of ID (Moeschler & Shevell, 2006). Trisomy 21 is the most common chromosomal abnormality and Fragile X is the most common single gene disorder which cause ID (Rauch et al., 2006). As such, ID with or without other anomalies is a common referral in the genetic counseling field. Genetic counselors often meet with patients and
families to discuss, amongst other topics, the cause of ID and associated recurrence risks for a particular condition. The discussion of reproductive implications therefore opens the potential for discussions regarding sex education.

Sex education empowers individuals with intellectual disability to enjoy and pursue personal sexual fulfillment and to protect themselves from abuse, unplanned pregnancies, and sexually transmitted diseases (Gürol, Polat, & Oran, 2014). The preponderance of sex education for individuals with ID occurs in four ways: public education through school or community program, parents or caretakers, peers, or the media (Neufeld, Klingbeil, Nelson Bryen, Silverman, & Thomas, 2002). It is important for individuals with ID to have access to correct and appropriate sex education information and reference materials in order to develop an accurate understanding of sexual concepts. Counseling on sexual issues is crucial for the successful education of patients with ID as they are capable of pursuing sexual relationships (Koetting, Fitzpatrick, Lewin, & Kilanowski, 2012).

The majority of individuals with ID will develop secondary sexual characteristics but the onset of puberty varies widely (Morano, 2001). Adolescents with ID have been described as individuals whose reproductive ability, sexual interests, and sexual activity are identical to the range observed in the general population (Johnson & Johnson, 1982). Despite the development of secondary sexual characteristics and interest in sexual activity, the concept of educating individuals with ID about sexual health can be controversial.

People with disabilities are often incorrectly deemed as childlike, asexual, or in need of protection (Murphy & Elias, 2006). On the other end of the spectrum they may also be viewed as inappropriately sexual or as having uncontrollable urges (Neufeld et al., 2002).
These perceptions of unaffected individuals such as parents, guardians, and medical professionals can limit the access to sex education for individuals with ID (McCabe, 1993) as some believe that providing sex education to individuals with ID would then encourage deviant sexual behavior rather than promote health and wellbeing (Pownall, Jahoda, & Hastings, 2012). This combination of barriers results in limited sexual knowledge, lack of relevant sexual health education, and restricted social and sexual opportunities for individuals with ID (Thompson, Stancliffe, Broom, & Wilson, 2014).

Levy and Packman (2004) described genetic counselor’s practices in exploring issues of sexual abuse prevention with pediatric patients with ID. They found that a majority of responding genetic counselors acknowledged the issue of sex education and sexual abuse prevention is important and relevant for their patients. While the study provided age appropriate recommendations for genetic counselors to introduce sex education and abuse prevention into their sessions, there was no report on the practices of genetic counselors in providing sex education counseling to pediatric and adolescent patients with ID.

The aim of this pilot study was to determine if genetic counselors were being asked to provide sex education counseling on a variety of topics to patients with ID ages 9 – 17 and what barriers prevented them from doing so. The study also addressed genetic counselor’s comfort level with providing sex education counseling in certain contexts and also gauged their interest in obtaining suitable resources and training.
METHODS

Recruitment

The Brandeis University Institutional Review Board approved the research study. Recruitment notifications were sent via email to all members of the National Society of Genetic Counselors (NSGC). Notification occurred through the NSGC’s email blast service to approximately 2900 members. An initial notification email included a description of the study, participation requirements, and a link to the survey. A reminder email was sent one week after the initial notification and included the same information. The online survey was anonymous and was made available through Qualtrics software for two weeks. Participants consented by initiating the survey.

Eligibility required participants to be a genetic counselor and have experience in counseling patients with ID ages 9 – 17 in a clinical setting outside of an internship encounter. Respondents did not need to be currently practicing as a genetic counselor or in the field of pediatrics in order to participate. The survey required participants to read and write in English. Respondents were offered the opportunity to enter a random drawing for one of three $50 Amazon.com gift cards.

Instrument design

The instrument consisted of 25 total questions and was designed to gather information in the following sections:
1. Demographics and background information.

2. History of being asked to provide sex education counseling to caregivers and patients with ID ages 9 – 12 and 13 – 17.

3. Comfort in providing sex education counseling to caregivers and patients with ID ages 9 – 12 and 13 – 17 in specific scenarios.

4. Perceived barriers to providing sex education counseling to caregivers and patients with ID ages 9 – 12 and 13 – 17.

5. Interest in additional sex education training and resource identification.

The questions included a combination of multiple choice, Likert-scale, and open-ended responses. Sections 2, 3, and 4 asked the same questions with regard to the two different age groups to determine if there were any differences in practice or opinion due in a younger versus older age range.

Section 2 addressed sex education topics that genetic counselors may have been asked to provide, including abstinence, contraception and condoms, developmentally appropriate sexual behavior, puberty, reproductive anatomy, reproductive health, reproductive rights, and sex abuse prevention. Counselors were then asked to identify to whom they provided the information: the patient’s caregiver, the patient, both, or neither.

We designed hypothetical clinical scenarios for section 3 to allow respondents to critically assess their comfort levels in providing sex education counseling based upon their relationship with the patient (establishment of rapport), knowledge if the patient is sexually active or in a romantic relationship, the patient’s gender, the patient’s condition,
degree of fertility, presence of a physical disability, familiarity with the patient’s culture, and the severity of the patient’s ID.

**Data analysis**

Data analysis included frequencies, descriptive statistics, and correlation analyses using SPSS software version 22. Thematic analysis was utilized with the open-ended responses.

We asked respondents about the most commonly requested areas of sex education that professionals are sometimes called upon to address. For each of these areas, we asked respondents to indicate how often they have been asked to provide information during their sessions with patients with ID ages 9 – 12 and also ages 13 – 17. Responses included ‘Never’, ‘A few times’, ‘Sometimes’, ‘Frequently’, and ‘Always’. Due to the nature of similarity of ‘A few times’ and ‘Sometimes’, the two categories were merged into one for data analysis and renamed as ‘Sometimes’.

In order to determine if demographics (age, years of experience in counseling patients with ID ages 9 – 17, type of clinic, and region) impacted counselors experiences, comfort, or perceptions with being asked to provide sex education counseling, we used independent sample t-tests to compare values for dichotomous variables. Correlations were performed using Pearson Correlation and Kendall’s tau-b.
RESULTS

After completion of data collection, 38 surveys were used for analysis. There were three surveys with a lack of response for the questions on being asked to provide sex education counseling for the age group 13 – 17. Responses from these three surveys were included in the analysis. We have indicated when the response number was less than 38 for a particular item. Open-ended responses to the questionnaire are noted with quotation marks and italicized text.

Demographics and background information

In response to whether respondents currently see patients with ID ages 9 – 17 in a clinical setting, 31/38 (81.6%) responded yes and 7/38 (18.4%) responded no. Of the seven who were not currently seeing patients with ID ages 9 – 17, we asked how many years have passed since they last had. The responses ranged from 0.5 to 4 years (mean = 2.35, median = 2, standard deviation = 1.38). We then asked how many years in total have respondents counseled patients with ID ages 9 – 17 in a clinical setting. The responses ranged from 0 (new position) to 30 years (mean = 7.68, median = 4.5, mode = 3, standard deviation = 8.52).

The majority of respondents were female (37/38; 97.4%), with only one male respondent (2.6%). Thirty-seven respondents indicated their ages, which ranged from 25 to 59 (mean 33.95, median 32, mode 27, standard deviation 8.81). Respondents’ races
were White or Caucasian (35/38; 92.1%), Asian (3/38; 7.9%), and one self-identified as Ashkenazi Jewish (1/38; 2.6%). One respondent was of Latino origin (2.6%) while the rest were not (97.4%).


**Chart 1. Distribution Of Respondents By Region**

| Region 1 (CT, MA, ME, NH, NY, RI, VT, Canadian Maritime Provinces, Quebec) | 6 |
| Region 2 (DC, DE, MD, NJ, PA, VA, WV) | 7 |
| Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN) | 3 |
| Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario) | 5 |
| Region 5 (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan) | 4 |
| Region 6 (AK, CA, HI, ID, NV, OR, WA, British Columbia) | 13 |

Respondents were asked to describe the type of institution where they have counseled the majority of patients with ID ages 9 – 17. Thirty-six (94.7%) respondents selected a hospital (includes private, public, or university setting), 1 (2.6%) selected laboratory, and 1 (2.6%) selected private practice. For the type of clinic where the majority of the session occurred, 16 (42.1%) selected specialty clinic and 22 (57.9%) selected
general practice.

**On being asked to provide sex education counseling**

Respondents indicated how often caregivers or patients asked them to provide information on commonly requested areas of sex education. We asked the same set of questions regarding two age groups: 9 – 12 and 13 – 17 (Table 1).

Consistent themes in the open-ended responses included genetic counselors finding parents and caregivers hesitant to ask about these topics. When discussions did occur, they were often not in front of the patient. Respondents had the following input about being asked to provide sex education for the 9 – 12 age group:

“When the primary caregiver was someone other than a parent, I received more requests for contraception discussions. I did counsel several families about their child’s reproductive rights but not with their child present.”

“Questions have mostly been asked by the parents and not the patients themselves. The parents have asked children to leave the room to discuss these issues without their child present.”

The topic asked about with the highest “Frequently” incidence for the 9 – 12 age group was sex abuse prevention (34.2%). There were 35 total respondents for the 13 – 17 age group. The topics that were asked about with the highest “Frequently” incidence were puberty (25.7%) and sex abuse prevention (25.7%).

Questions about sex education, contraception, and condoms were most likely to come up with the 13 – 17 age group as compared to the younger group.

“This group typically appears much more likely to bring up the topic themselves, it seems to me caregivers often defer to GC/MD in this case to discuss information and reinforce safe/developmentally appropriate practices. This is the age group where
Table 1. Sex Education Questions Asked By Caregivers Or Patients During Genetic Counseling Sessions

1A. Patients with ID Ages 9 – 12

<table>
<thead>
<tr>
<th>Topic</th>
<th>Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex Abuse Prevention</td>
<td>18.4%</td>
<td>42.1%</td>
<td>36.8%</td>
<td></td>
</tr>
<tr>
<td>Reproductive Rights</td>
<td>10.5%</td>
<td>31.6%</td>
<td>57.9%</td>
<td></td>
</tr>
<tr>
<td>Reproductive Health</td>
<td>18.4%</td>
<td>34.3%</td>
<td>44.7%</td>
<td></td>
</tr>
<tr>
<td>Reproductive Anatomy*</td>
<td>10.8%</td>
<td>32.5%</td>
<td>51.3%</td>
<td></td>
</tr>
<tr>
<td>Puberty</td>
<td>34.2%</td>
<td>44.8%</td>
<td>18.4%</td>
<td></td>
</tr>
<tr>
<td>Developmentally Appropriate Sexual Behavior</td>
<td>13.2%</td>
<td>42.1%</td>
<td>42.1%</td>
<td></td>
</tr>
<tr>
<td>Contraception and Condoms</td>
<td>5.3%</td>
<td>42.1%</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>Abstinence</td>
<td>2.6%</td>
<td>26.3%</td>
<td>71.1%</td>
<td></td>
</tr>
</tbody>
</table>

*Percentage values are from 37 respondents

1B. Patients With ID Ages 13 – 17

<table>
<thead>
<tr>
<th>Topic</th>
<th>Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex Abuse Prevention</td>
<td>25.7%</td>
<td>37.1%</td>
<td>37.1%</td>
<td></td>
</tr>
<tr>
<td>Reproductive Rights</td>
<td>14.3%</td>
<td>37.1%</td>
<td>48.6%</td>
<td></td>
</tr>
<tr>
<td>Reproductive Health</td>
<td>22.9%</td>
<td>54.2%</td>
<td>22.9%</td>
<td></td>
</tr>
<tr>
<td>Reproductive Anatomy</td>
<td>8.6%</td>
<td>39.9%</td>
<td>48.6%</td>
<td></td>
</tr>
<tr>
<td>Puberty</td>
<td>25.7%</td>
<td>51.4%</td>
<td>22.9%</td>
<td></td>
</tr>
<tr>
<td>Developmentally Appropriate Sexual Behavior</td>
<td>14.3%</td>
<td>47.6%</td>
<td>37.1%</td>
<td></td>
</tr>
<tr>
<td>Contraception and Condoms</td>
<td>17.1%</td>
<td>51.4%</td>
<td>28.6%</td>
<td></td>
</tr>
<tr>
<td>Abstinence</td>
<td>5.7%</td>
<td>40%</td>
<td>54.3%</td>
<td></td>
</tr>
</tbody>
</table>

*Percentage values are from 35 respondents
we are often telling caregivers (especially parents) that female contraception (pill, ring, shot) is not only okay but safe and appropriate in many circumstances.”

“Unfortunately, there are much better options to offer my female patients and a Mirena IUD is, generally, our birth control of choice, as it doesn’t require the patient to remember to do anything and it lasts for 5 years with few side effects, in most patients. For men, we can’t offer much beyond condoms, at this point. This is especially distressing for male patients [who] express that they have problems with impulse control and have concerns that they may not be able to remember to use a condom.”

We also asked respondents to whom they provided the sex education: caregiver, patient, both, or neither. Overall, respondents had provided sex education to both the primary caregiver and patient for all topics and ages, if they were asked. The topic to which genetic counselors more often provided sex education only to the primary caregiver was developmentally appropriate sexual behavior for the 9 – 12 age group. 52.6% of respondents provided information on developmentally appropriate sexual behavior to the primary caregiver, compare to 26.3% providing this information to the patient.

Respondents were asked which professionals should be prepared to provide sex education counseling to patients with ID ages 9 – 17. Twenty-seven of 38 respondents (71.1%) thought that genetic counselors should be prepared for sex education counseling. However, 94.7% thought that physicians should be prepared for discussions. Respondents also thought nurses (92.1%), educators at school (86.8%), and social workers (71.1%) should also be prepared for such discussions. Respondents had the following observations:

“... I don't think it's practical for GCs to go into depth about this issue. I DO think GCs should have a basic understanding of the issue and refer when appropriate.”

“I provide information about sex education far more than I ever anticipated going into my position as the genetic counselor for a specialty clinic.”
“I think in pediatric clinics we have a responsibility to provide information on a variety of topics not just genetics. There is no way to be sure that other providers are having this discussion so we should be prepared to.”

**Comfort with providing sex education counseling**

Respondents were asked about their comfort in providing sex education counseling under specific scenarios. We asked the same set of questions for two separate age groups: 9 – 12 and 13 -17 (Table 2). Respondents were more comfortable when providing sex education counseling when it was directly related to a genetic condition like maternal phenylketonuria (PKU), where an affected mother’s poorly controlled diet could have negative effects on the developing fetus. One respondent noted that they would be very uncomfortable with providing sex education counseling in this scenario for each age group. The remaining respondents were either comfortable (55.3% and 45.7%) or very comfortable (42.1% and 51.4%) for the 9 – 12 and 13 – 17 age groups respectively. One respondent noted:

“I only feel comfortable doing so in the context of genetic issues.”

Discomfort with certain topics was about equal with regard to both age groups. Respondents were frequently uncomfortable or very uncomfortable when they were unfamiliar with the patient’s culture (55.3% and 51.4%), they had never met the patient or primary caregiver before (44.7% and 41.7%), and if the patient’s ID was severe to profound (36.1% and 34.3%) for the 9 – 12 and 13 – 17 age groups respectively.

“Had one particular patient with extremely inappropriate behavior, which has been an ongoing discussion with parents. Specialty clinic setting is helpful, since most patients and families who attend are well known to me and the MDs.”
<table>
<thead>
<tr>
<th></th>
<th>Patients with ID Ages 9 – 12</th>
<th>Patients with ID Ages 13 – 17</th>
<th>Would refer to another health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very comfortable</td>
<td>Comfortable</td>
<td>Uncomfortable</td>
</tr>
<tr>
<td>Have never met the patient/caregiver</td>
<td>6 (15.8%)</td>
<td>11 (28.9%)</td>
<td>10 (26.3%)</td>
</tr>
<tr>
<td>Have established rapport with the patient/caregiver</td>
<td>13 (34.2%)</td>
<td>19 (50.0%)</td>
<td>4 (10.5%)</td>
</tr>
<tr>
<td>Aware the patient is involved in a romantic relationship</td>
<td>12 (31.6%)</td>
<td>20 (52.6%)</td>
<td>4 (10.5%)</td>
</tr>
<tr>
<td>Unaware if the patient is sexually active</td>
<td>8 (21.1%)</td>
<td>18 (47.4%)</td>
<td>10 (26.3%)</td>
</tr>
<tr>
<td>The patient is female</td>
<td>13 (34.2%)</td>
<td>23 (60.5%)</td>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>The patient is male</td>
<td>7 (18.4%)</td>
<td>20 (52.6%)</td>
<td>8 (21.1%)</td>
</tr>
<tr>
<td>The patient is female and has the potential to become pregnant, which could have reproductive implications</td>
<td>16 (42.1%)</td>
<td>21 (55.3%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>The patient has reproductive potential</td>
<td>13 (34.2%)</td>
<td>20 (52.6%)</td>
<td>4 (10.5%)</td>
</tr>
<tr>
<td>The patient is infertile</td>
<td>7 (18.4%)</td>
<td>23 (50.5%)</td>
<td>7 (18.4)</td>
</tr>
<tr>
<td>The patient has a physical disability</td>
<td>6 (15.8%)</td>
<td>25 (65.8%)</td>
<td>6 (15.8%)</td>
</tr>
<tr>
<td>Familiar with the patient’s culture</td>
<td>11 (29.7%)*</td>
<td>21 (56.8%)*</td>
<td>4 (10.8%)*</td>
</tr>
<tr>
<td>Unfamiliar with the patient’s culture</td>
<td>1 (2.6%)</td>
<td>15 (39.5%)</td>
<td>18 (47.4%)</td>
</tr>
<tr>
<td>The patient’s ID is mild to moderate</td>
<td>10 (26.3%)</td>
<td>23 (60.5%)</td>
<td>3 (7.9%)</td>
</tr>
<tr>
<td>The patient’s ID is severe to profound</td>
<td>7 (19.4%)**</td>
<td>16 (44.4%)**</td>
<td>12 (33.3%)**</td>
</tr>
</tbody>
</table>

*Calculated from 37 responses, ** calculated from 36 responses, † calculated from 35 responses, ‡ calculated from 34 responses.
Perceived barriers to providing sex education counseling

Respondents were asked to identify the three most significant barriers to providing sex education counseling to the 9 – 12 and 13 – 17 age groups (Table 3). The most frequently
noted barriers were that there was not enough time to provide sex education counseling, a lack of training on how to provide sex education counseling, the patient’s ID is too profound, and that genetic counselors should not be responsible for providing sex education counseling. One barrier that was noted for the 9 – 12 age group and not for the 13 – 17 age group was that the patient was too young. Respondents expressed the following about providing sex education counseling:

“I do not think this is an appropriate role for genetic counselors—this is not what we are trained to do. Our clinic time is so limited, we really need to focus on providing the services that we are uniquely trained to provide.”

“One anecdote— a family declined birth control for their daughter because they felt that they wouldn’t know if she had been sexually abused unless she became pregnant/got an STD. This was an interesting conversation, and I really wasn’t sure how to discuss those concerns with the family.”

We conducted t-tests using the dichotomous yes/no responses to each barrier as the independent variable and the ages and years of experience of the respondents as the dependent variables. There were no significant differences in the responses to barrier questions based on the counselor’s age or years of experience.

**Interest in additional sex education training and resource identification**

We surveyed respondents’ interest in sex education training and resource identification. Respondents were least interested in specific training to provide sex education counseling to patients with ID ages 9 – 12 (31.6%). Respondents were most interested in a print sex education resource guide designed specifically for use by genetic counselors (84.2%) and were more interested in resources than a policy or guideline statement from the NSGC (71.1%).
“I think some training on how to address [sex education] could be helpful, but it is not our area of expertise or our main scope of practice. I think making the recommendation to follow up with the pediatrician or other providers is likely most appropriate in the majority of situations, however it is bound to come up in some sessions and GCs should be prepared for that.”

For all of the survey questions, there were no statistically significant differences in responses based upon the counselor’s age, years of experience, type of clinic, or region.
DISCUSSION

Our pilot study was designed to learn if genetic counselors were being asked to provide sex education counseling during their sessions with patients with ID ages 9 – 17 and how comfortable they were in providing such counseling. We found that genetic counselors are being asked to provide sex education counseling on a variety of topics in their sessions with pediatric and adolescent patients with ID, and that their comfort in providing sex education is dependent upon external factors like the level of the patient’s ID and knowledge of their culture.

Questions about puberty and sex abuse prevention were most frequently posed to genetic counselors for both age groups. Puberty is understandably more likely to arise in the framework of genetic counseling sessions as a question of if or when puberty will occur as it relates to a particular condition or constellation of features. Sex abuse prevention is a concern of many parents and primary caregivers but may not be asked about as frequently as puberty due to the difficult nature of the subject matter. Adolescents with ID are about 5.5 times more likely to be sexually abused than the general population (Verdugo, Bermejo, & Fuertes, 1995) and creating awareness by providing information to individuals with ID and their families or primary caregivers is a critical step in increasing patient knowledge and autonomy in understanding appropriate and inappropriate relationships (McEachern, 2012).
Counselors were most comfortable providing sex education when they could do so in the context of a genetic condition. Our scenario described maternal PKU, in which the developing fetal brain and heart are acutely susceptible to high concentrations of phenylalanine when the mother has a poorly controlled diet. Women with PKU may or may not have ID based upon their adherence to a low phenylalanine diet. The proposed scenario allows for a logical progression from genetic condition to discussion of reproductive health, contraception, and the other topics reviewed in Table 1. Genetic counselors may want to consider using recurrence risks to segue into gauging patients’ and caregivers’ interest in sex education counseling if they are otherwise concerned about how to broach discussions. One respondent offered their experience:

“While I agree that sex ed is not, strictly, a genetic counseling issue, we ultimately need to do what is best for our patient and that includes sex ed. Discussion of recurrence risk is often a great lead-in to a discussion about sex ed, when needed, so genetic counselors are well poised to do this.”

A theme identified in the open-ended responses was that respondents did not want to assume that the caregiver or patient is interested in sex education. Such assumptions could be the result of a lack of rapport or understanding of the patient or caregiver’s cultural practices. Our study identified that respondents were least comfortable when they had not established rapport with the patient or caregiver and when they were unfamiliar with their culture. Caregivers and patients may be reluctant to address issues regarding sexuality and sexual health during genetic counseling sessions because they are not provided the opportunity. Even though it may be uncomfortable for genetic counselors to raise the topic of sex education during a counseling session, especially if they are unfamiliar with the caregiver or the caregiver’s culture; however, families may not realize they can raise questions about sexuality if the counselor does not bring it up.
“I think often caregivers (especially parents) are hesitant to ask/raise the topic so we often raise the topic for them without being asked and then provide further information based on the level of interest and functioning of the patient/caregiver.”

While respondents acknowledged that they were comfortable with providing sex education counseling in specific scenarios, we identified what barriers prevented genetic counselors from doing so. Uniform for both age groups included lack of time during genetic counseling sessions, lack of training, the patient’s level of ID is too profound, and the thought that genetic counselors should not be responsible for providing sex education counseling. The barriers we identified were consistent with a prior study of other medical professionals. That study cited time constraints, lack of appropriate training/skills/knowledge base, and the belief that patients were either not sexually active or not interested in sex education as barriers to providing sex education counseling to patients with ID (Schaafsma, Kok, Stoffelen, Van Doorn, & Curfs, 2014).

Our open-ended responses demonstrated that counselors understood individuals with ID were sexually active and would have interest in sex education. However, responses revealed a dichotomy between counselors feeling as though they should be prepared for providing sex education counseling but that it is not within their scope of practice. Genetic counselors, while not likely to offer thorough and repeated sex education services directly, can address the need for accurate sexual health knowledge within the context of other genetic counseling services provided (Levy & Packman, 2004). Genetic counselors can assess individual sex education needs for patients with ID and provide suitable resources and referrals to those competent in sex education instruction. The only policy statement of the NSGC in regard to disability states: “It is the goal of the genetic counseling profession to advocate for all individuals and families according to their unique physical, medical,
cultural, educational, and psychosocial needs. The NSGC believes that no person should be discriminated against because he or she has a disability” (NSGC, 2011). Because sexual health can be part of a patient’s physical, medical, educational, and psychosocial needs, genetic counselors should be prepared to address multiple aspects of sex education with patients and their families. If counselors are not comfortable with providing sexual health education, they may want to consider utilizing suitable resources and reference material for patients and families.

Respondents expressed an interest in obtaining online and print resource guides to aid in either providing sex education themselves or referring caregivers and patients to appropriate reference material or local sex education professionals. The interest in resource identification was consistent with respondents acknowledging that a lack of training was a key barrier to providing sex education counseling. Future efforts could compile both print and online resources for genetic counselors to aid in their provision of sex education counseling and resource identification. Resources could be for general use, dependent upon genetic conditions, or could vary between states or regions to reflect availability of professionals who provide sex education specifically designed for individuals with ID.

Genetic counselors can find reasonable recommendations for initiating age appropriate discussions of sex education and abuse prevention outlined in the Levy and Packman article. The following websites provide sex education material designed for those with ID and are grouped by specific diagnoses and various sex education topics: http://www.parentcenterhub.org/repository/sexed/ is prepared by the Center for Parent

In addition, the NSGC could create learning modules or lectures on sex education as part of standard of care. Presently, the NSGC provides access to the Cultural Competence Toolkit where one module focuses on an adult female with mild ID who is pregnant. The module could be expanded to include additional scenarios where the patient is a younger age and male. The modules could also include patients with moderate, severe, and profound ID to provide a more diverse learning experience for genetic counselors.

The limitations of this pilot study include the small sample size and that the structure of the survey was not clear to a number of respondents. One responder wrote in response to an open-ended question, “Sorry, I didn’t realize you were asking about different age ranges.” Another responder emailed their confusion, thinking the survey was repeating itself and did not notice the designation of the two different age groups. Responders who did not finish the survey may have been discouraged, thinking the survey was malfunctioning, which could have contributed to the small sample size. However, the more likely contributing factor for the small sample size was the nature of the topic itself. We also did not address if the gender of the caregiver or parent had an affect on respondents’ comfort.

Medical professionals of all disciplines are encouraged to embrace the role of advocate by broaching the issue of sexual health with the caregiver and patient and
directing them toward educational resources, if not providing sex education themselves. Having referral contact information and resources readily available for further education and counseling on sexual issues is imperative for the successful education of patients and caregivers. Our study demonstrated that topics of sexual health are being addressed in the genetic counseling session and it would be practical for clinicians to respond proactively rather than reactively.
REFERENCES


Schaafsma, D., Kok, G., Stoffelen, J. M. T., Van Doorn, P., & Curfs, L. M. G. (2014). Identifying the important factors associated with teaching sex education to people with


**APPENDICES**

**Appendix A: Recruitment Notification**
Greetings NSGC member,

**Do you have experience in counseling adolescent patients with intellectual disability in a clinical setting?**

We ask you to please consider participating in a research study to identify specific barriers that genetic counselors face when providing *sex education counseling to patients with intellectual disability (ID) ages 9 - 17*. Participation is open to genetic counselors with any experience in counseling adolescent patients with ID in a clinical setting. You do not have to be currently practicing in this area to participate.

Should you decide to participate, you can access the brief, anonymous, online survey through the provided link. The survey takes approximately 15 minutes to complete. Participation is voluntary and you may exit the survey at any time. There are no foreseeable risks associated with this study. However, if you experience any negative effects from this survey, Dr. David Rintell, a licensed psychologist, is available by telephone (617-734-6778).

At the end of the survey, you will be asked if you would like to enter a random drawing for one of three $50 Amazon.com gift cards. An email address is required for the drawing only and not for participating in the survey. Your email address will not be connected to your survey responses and will only be accessible to the student researcher.

Please consider forwarding this notification to any of your genetic counselor colleagues that are not NSGC members and who may be interested in participating in this survey.

The Brandeis University IRB has approved this study.

You may access the survey here:
[https://brandeis.qualtrics.com/SE/?SID=SV_eS3xlbZ6k2YM4Op](https://brandeis.qualtrics.com/SE/?SID=SV_eS3xlbZ6k2YM4Op)

If you have any questions or comments regarding this study, you can contact the student researcher, Carly Murphy, or her thesis advisor, Dr. David Rintell.

Thank you very much for your time and consideration,

Carly Murphy, MS  
Student  
Genetic Counseling Program  
Brandeis University  
Waltham, MA  
860-933-4645  
carmurph@brandeis.edu

David Rintell, Ed.D.  
Faculty Member
Appendix B: Instrument

Dear Genetic Counselor,

Thank you for your time and participation in this study. The following questions will address your involvement in providing sex education counseling to pediatric patients with intellectual
disability. You are invited to participate in this study if you have any professional experience in providing genetic counseling to patients with intellectual disability ages 9 – 17 in a clinical setting. Please note that you do not have to be currently practicing to participate.

Throughout the survey, intellectual disability will be referred to as ID and will include patients with an IQ \( \leq 70 \). Also, primary caregiver will refer to anyone responsible for the care of the adolescent patient being seen for genetic counseling and who is also present during the genetic counseling session; this includes but is not limited to parents, family members, social workers, and healthcare aides.

Your responses will remain anonymous and confidential. Participation in all sections of the survey is voluntary and you may exit the survey at any time. You may also exit the survey and return at a later date. By clicking the arrows below you acknowledge that you have read the above information and that you wish to participate in the survey.

**Background info**

1. Excluding your graduate study placements, do you have professional experience in providing genetic counseling to patients with ID ages 9 – 17 in a clinical setting?
   - Yes
   - No [if no screen out]

2. Do you currently see patients with ID ages 9 – 17 in a clinical setting?
   - Yes
   - No

3. [If no to #2] How many years has it been since you have seen patients with ID ages 9 – 17 in a clinical setting?

4. In total, throughout how many years of your practice have you counseled patients with ID ages 9 – 17 in a clinical setting?

5. What is the month and year that you graduated from a genetic counseling program?

   - Still in school [if still in school screen out]

6. In which region have you most recently seen patients with ID ages 9 – 17 in a clinical setting?
○ Region 1 (CT, MA, ME, NH, NY, RI, VT, Canadian Maritime Provinces, Quebec)
○ Region 2 (DC, DE, MD, NJ, PA, VA, WV)
○ Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN)
○ Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario)
○ Region 5 (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan)
○ Region 6 (AK, CA, HI, ID, NV, OR, WA, British Columbia)
○ Other (please specify)

7. Which option best describes the type of institution where you have counseled the majority of your patients with ID ages 9 - 17?
○ Hospital (private, public, or university)
○ Laboratory (corporate, private, or university)
○ Private practice
○ Other (please specify)

Please select the type of clinic where the majority of these sessions have occurred:
○ Does not apply
○ Specialty clinic
○ General practice

**On being asked about sex education counseling**

8. The table below lists the most commonly requested areas of sex education that professionals are sometimes called upon to address. For each of these areas, please indicate how often have you been asked to provide information during your sessions with patients with ID ages 9 – 12:

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>A few times</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstinence</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Contraception and condoms</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Developmentally appropriate sexual behavior</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Puberty</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive anatomy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive health</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive rights</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
9. [If anything other than never is a selected for a response in #8 respondents will receive this question, otherwise they will be brought to #11]

The table below lists your selections from question #8 where you selected a frequency more than “never”. For each of these areas, indicate to whom you have provided this information: (Please select all that apply). As a reminder, primary caregiver refers to anyone responsible for the care of the adolescent patient being seen for genetic counseling and who is also present during the genetic counseling session; this includes but is not limited to parents, family members, social workers, and healthcare aides.

<table>
<thead>
<tr>
<th></th>
<th>Primary Caregiver</th>
<th>Patient</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstinence</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Contraception and condoms</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Developmentally appropriate sexual behavior</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Puberty</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive anatomy</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive health</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive rights</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Sex abuse prevention</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

10. [If anything other than never for #8] If you would like to share your thoughts or experiences on being asked to provide information on sex education during your sessions with patients with ID ages 9 – 12, please do so in the space provide below.
11. The table below lists the most commonly requested areas of sex education that professionals are sometimes called upon to address. For each of these areas, please indicate how often you have been asked to provide information during your sessions with patients with ID ages 13 – 17:

<table>
<thead>
<tr>
<th>Area</th>
<th>Never</th>
<th>A few times</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstinence</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Contraception and condoms</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Developmentally appropriate sexual behavior</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Puberty</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive anatomy</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive health</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reproductive rights</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Sex abuse prevention</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

12. [If anything other than never is a selected for a response in #11 respondents will receive this question, otherwise they will be brought to #14]

The table below lists your selections from question #10 where you selected a frequency more than “never”. For each of these areas, indicate to whom you have provided this information: (Please select all that apply). As a reminder, primary caregiver refers to anyone responsible for the care of the adolescent patient being seen for genetic counseling and who is also present during the genetic counseling session; this includes but is not limited to parents, family members, social workers, and healthcare aides.

<table>
<thead>
<tr>
<th>Area</th>
<th>Primary Caregiver</th>
<th>Patient</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

30
13. [If anything other than never for #11] If you would like to share your thoughts or experiences on being asked to provide information on sex education during your sessions with patients with ID ages 13 – 17, please do so in the space provide below

14. Which professionals do you think should be prepared to provide sex education counseling to patients with ID ages 9 – 17 and their primary caregivers? (Please select all that apply)

- Educators at school
- Genetic counselors
- Nurses
- Physicians
- Social workers
- Others (please specify)

**Comfort with providing sex education counseling**
15. If you were asked today to provide sex education counseling to **patients with ID ages 9 – 12** and their primary caregivers, how comfortable would you feel offering counseling in each of the following scenarios: (Please note each scenario is independent from one another)

<table>
<thead>
<tr>
<th>How comfortable would you feel if...</th>
<th>Very uncomfortable</th>
<th>Uncomfortable</th>
<th>Comfortable</th>
<th>Very comfortable</th>
<th>Would refer out to another health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have never met the patient and their primary caregiver</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>You have established rapport with the patient and their primary caregiver</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>You are aware the patient is involved in a romantic relationship</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>You are unaware if the patient is sexually active</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The patient is female</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The patient is male</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The patient is female and has the potential to become pregnant, which could have reproductive implications (ie. maternal PKU)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
The patient has reproductive potential

The patient is infertile

The patient has a physical disability in addition to ID

You are familiar with the patient’s culture

You are unfamiliar with the patient’s culture

The patient’s ID is mild to moderate

The patient’s ID is severe to profound

16. Based on your practice experience, what are the 3 most significant barriers to providing sex education counseling to patients with ID ages 9 – 12 and their primary caregivers? (Please select up to 3)

- Genetic counselors should not be responsible for providing sex education counseling
- The lack of institutional recommendations where you work
- The lack of recommendations from professional organizations like the NSGC
- The patient’s ID is too profound
- The patient is too young
- There is not enough time to discuss this during genetic counseling sessions
- You are not familiar enough with the patient’s culture
- You are not familiar with the patient’s sex education needs based upon their gender
- You are uncomfortable with the subject material
- You have a lack of training on how to provide sex education counseling
17. If you were asked today to provide sex education counseling to **patients with ID ages 13 – 17** and their primary caregivers, how comfortable would you feel offering counseling in each of the following scenarios: (Please note each scenario is independent from one another)

<table>
<thead>
<tr>
<th>How comfortable would you feel if...</th>
<th>Very uncomfortable</th>
<th>Uncomfortable</th>
<th>Comfortable</th>
<th>Very comfortable</th>
<th>Would refer out to another health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have never met the patient and their primary caregiver</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>You have established rapport with the patient and their primary caregiver</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>You are aware the patient is involved in a romantic relationship</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>You are unaware if the patient is sexually active</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The patient is female</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The patient is male</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The patient is female and has the potential to become</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
pregnant, which could have reproductive implications (ie. maternal PKU)

| The patient has reproductive potential | | | | | |
|----------------------------------------|---|---|---|---|
| o                                     | o | o | o | o |

<table>
<thead>
<tr>
<th>The patient is infertile</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The patient has a physical disability in addition to ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>You are familiar with the patient’s culture</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>You are unfamiliar with the patient’s culture</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The patient’s ID is mild to moderate</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The patient’s ID is severe to profound</th>
</tr>
</thead>
<tbody>
<tr>
<td>o</td>
</tr>
</tbody>
</table>

18. Based on your practice experience, what are the 3 most significant barriers to providing sex education counseling to patients with ID ages 13 – 17 and their primary caregivers? (Please select up to 3)

- Genetic counselors should not be responsible for providing sex education counseling
- The lack of institutional recommendations where you work
- The lack of recommendations from professional organizations like the NSGC
- The patient’s ID is too profound
The patient is too young
- There is not enough time to discuss this during genetic counseling sessions
- You are not familiar enough with the patient’s culture
- You are not familiar with the patient’s sex education needs based upon their gender
- You are uncomfortable with the subject material
- You have a lack of training on how to provide sex education counseling
- You have been directed to refer the patient and primary caregiver to other resources
- Other (please specify)
- I do not think there are any barriers

**Future Directions**

19. How interested would you be in the following?

<table>
<thead>
<tr>
<th></th>
<th>Not at all interested</th>
<th>Interested</th>
<th>Very interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific training for genetic counselors to provide sex education counseling to patients with ID ages 9 - 12</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Specific training for genetic counselors to provide sex education counseling to patients with ID ages 13 - 17</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>An online sex education resource guide designed specifically for use by genetic counselors</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>A print resource sex education resource guide designed specifically for use by genetic counselors</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>A policy statement or guideline from the NSGC on providing sex education counseling to patients with ID</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

20. Please share any further thoughts you have on the role of genetic counselors in providing sex education counseling to **patients with ID ages 9 – 17**:
**Demographics**

21. What is your gender?
   - Female
   - Male
   - Other (please specify)

22. What was your age on your last birthday?

   [ ]

23. What is your race? (Please select all that apply)
   - American Indian or Alaskan Native
   - Asian
   - Black or African American
   - Native Hawaiian or Pacific Islander
   - White or Caucasian
   - Other (please specify)

24. Are you of Hispanic or Latino origin?
   - Yes
   - No

25. Would you like to enter the random drawing for a $50 Amazon gift card? (Please note that entering the drawing will require an email address. Your survey responses will not be linked to your email address)
   - Yes [if yes, box appears to enter email address]
   - No