“There’s a Whole Different Way of Working With Adolescents”: Interviews with Australian Genetic Counselors about their Experiences with Adolescent Clients

Cheryl Tse ¹

Margaret Sahhar ^{1 2 4}

Jane Wallace ^{2 4}

Rony E Duncan ^{1 2 3}

¹ *Department of Paediatrics, The University of Melbourne, Parkville, VIC, 3010, Australia.*

² *Murdoch Childrens Research Institute, Royal Children’s Hospital, Flemington Road, Parkville, VIC, 3052, Australia.*

³ *Centre for Adolescent Health, Royal Children’s Hospital, Flemington Road, Parkville, VIC, 3052, Australia.*

⁴ *Victorian Clinical Genetics Services, Royal Children’s Hospital, Flemington Road, Parkville, VIC, 3052, Australia.*

Correspondence to:

Dr Rony Duncan PhD

Centre for Adolescent Health

Level 2, The Royal Children’s Hospital

50 Flemington Road, Parkville, 3052, Victoria, Australia

Ph: +61 3 9345 6237

Fax: +61 3 9345 6502

Email: rony.duncan@mcri.edu.au

Running Head: There’s a Whole Different Way of Working with Adolescents.

Abstract

Adolescence is a developmental period marked by unique physical, psychological, cognitive, emotional, and social changes. Although training programs and guidelines related to working with adolescents are available to health professionals in other fields, there are few resources tailored specifically to the field of genetic counseling. The current qualitative study explored the experiences of genetic counselors who work with adolescent clients to determine whether challenges exist, and if further training and support are needed. Semi-structured interviews were conducted with 11 genetic counselors from Australia. Interview transcripts were analyzed using thematic analysis from which 7 key themes emerged: 1) Adolescents: A distinct client group? 2) Characteristics of adolescents; 3) Strategies for working with adolescents; 4) Confidentiality; 5) Parental involvement and presence in sessions; 6) Benefits of working with adolescents; and 7) The effectiveness of past training and education. The findings hold important implications for clinical practice and may inform future training programs and guidelines for genetic counselors internationally.

Key Words: Adolescent, Youth, Minors, Genetic Counseling, Professional Development, Qualitative Research, Interview.

Introduction

Adolescents have specific needs that differ from those of children or adults, as a consequence of their developmental stage. Adolescence is associated with a range of developmental tasks, including negotiating social protocols, developing a personal identity, navigating puberty, forming peer and intimate relationships, and establishing individual autonomy (Christie & Viner, 2005). For adolescents with health conditions, juggling these developmental tasks with the burden of illness can be highly complex. This can also lead to challenges for health professionals who work with adolescents.

There has traditionally been little consistency across countries when defining adolescence (Sawyer et al., 2012). However, international definitions of adolescence are moving towards a broad range encompassing those aged 10-24 years (Sawyer et al., 2012). For the purposes of the current study, we use a more narrow range, defining adolescents as individuals between the ages of 12 to 18 years.

Adolescents might require access to genetic counseling services for a range of reasons: prenatal advice (e.g. to discuss risk of chromosomal abnormalities in their fetus); metabolic advice (e.g. to discuss the management of glycogen storage disorders); or information related to early onset cancers (e.g. Familial Adenomatous Polyposis). Adolescent clients are also often referred to genetic counselors when genetic predispositions to certain health conditions exist within their families. In these cases ethical considerations often add to the complexity as controversy exists about the eligibility of young people to participate in certain types of predictive genetic testing, for example, testing for adult onset conditions where no preventative means or treatment exists (Duncan, 2004; Gaff, Lynch & Spencer, 2006).

Within some fields of medicine, educational kits and guidelines exist for practitioners about working with adolescents (Chown, Kang, Sanci, Newnham, & Bennett, 2008; Oetzel & Scherer, 2003; Royal Australasian College of Physicians, 2008). These guidelines provide information on adolescence as a developmental stage, outline difficulties that adolescents might face when accessing healthcare and provide advice to clinicians about how best to assess and work with this client group. However, within the field of genetic counseling, there are no such guidelines or educational kits tailored specifically for genetic counselors.

Currently, only a small subset of papers discuss the challenges associated with genetic counseling for adolescents and the best approaches for engaging and working with this client group (Callard, Williams, & Skirton, 2011; Griswold, Ashley, DeLany Dixon, & Scott, 2011; Duncan et al., 2009; Gaff et al., 2006; Peters-Brown & Fry-Mehlretter, 1996). These studies use a range of different research methodologies.

Peters-Brown and Fry-Mehlretter (1996) presented two case-studies involving pregnant adolescent clients to explore potential challenges that might be faced by genetic counselors working with this client group. These included communication barriers due to psychosocial issues faced by adolescent clients (e.g. lacking full knowledge about options and being overly concerned with peer approval and social expectations) and the difficulty in facilitating their decision making process. The authors proposed techniques and strategies to assist with these challenges and suggested incorporation of the proposed techniques in genetic counseling and graduate training (Peters-Brown & Fry-Mehlretter, 1996). In another study, Gaff et al. (2006) explored the professional issues and unique difficulties faced by genetic counselors when 18-year-olds request predictive testing for Hereditary Non-Polyposis Colorectal Cancer

(HNPCC). These issues were also discussed through investigation of two case-studies, highlighting the influence of family systems on adolescents' decision-making processes, and the dilemmas faced by genetic counselors when trying to balance the needs of adolescent clients with the needs of parents.

Duncan et al. (2009) explored the perspectives of adolescent clients regarding the issue of predictive genetic testing. This qualitative study involved ten in-depth interviews with adolescents who had undergone predictive testing for Familial Adenomatous Polyposis (FAP). The authors outlined a range of ethical challenges associated with genetic counseling for adolescent clients including addressing the adolescent's stage of development and negotiating the conflicting interests of adolescents and their families. They argued for improvements in developmentally appropriate care.

More recent studies by Callard et al. (2011) and Griswold et al. (2011) have also highlighted challenges faced by genetic counselors when working with adolescent clients. Through the analysis of two case-studies, Callard et al. explored some of the difficulties that may be faced when counseling adolescents about genetic testing. The difficulties discussed in the study correspond with those reported in previous studies by Gaff et al. (2006) and Peters-Brown and Fry-Mehlretter (1996), with a particular focus on the influence of family systems on the decision making process of adolescent clients. Griswold et al. investigated the experiences of 128 prenatal genetic counselors with adolescent clients, using a survey. The survey was designed to examine the genetic counselors' perceptions of sessions with adolescent clients in comparison to adult clients. A majority of participants reported that their adolescent clients often had more difficulty understanding prognosis information compared to adult clients. They also reported that while adult clients often attended sessions by themselves, or with a

significant other, adolescent clients were accompanied by their family and/or friends. The authors noted that this could create a different dynamic within the genetic counseling session, as the genetic counselor may have to address the needs of multiple people within the session. The authors also stressed the importance of acknowledging the unique developmental stage of adolescence, which may influence the prenatal genetic counseling session (Griswold et al., 2011).

Some information is also available about adolescent development and counseling strategies in text books aimed at genetic health professionals. Weil (2000) provides a range of suggestions regarding counseling techniques for adolescents in his book about psychosocial genetic counseling. Austin (2010) has also written a chapter about practical counseling strategies for use with children and adolescents in a book more broadly focused on advanced skills for genetic counselors. She emphasizes choice and equality when working with adolescent clients. Sullivan and McConkie-Rosell (2010) also have written a chapter on communicating with children in a book concerning family communication about genetics. They advocate for a parent-practitioner partnership.

The present study aimed to explore the first hand experiences of genetic counselors in Australia when working with adolescent clients. A qualitative methodology was chosen to allow in-depth examination of these experiences in order to better understand both the challenges and benefits associated with adolescent clients as well as any gaps in genetic counselors' current knowledge and thus opportunities for targeting future training.

Methods

Participants

Eligible participants were genetic counselors working in Victoria, Australia with prior professional experience working with adolescent clients.

Recruitment

Purposive sampling was employed. A list of contact details for genetic counselors in Victoria, Australia was readily available through the professional networks of the research team. In the first stage of recruitment, a brief survey was sent out to genetic counselors working within Victoria. The aim of the survey was to identify a pool of eligible participants for the study (i.e. those with experience working with adolescent clients who would be willing to take part in an interview). A total of 24 eligible participants were identified. In the second stage of recruitment, the first author, CT, contacted the departmental heads of the genetic units in which eligible participants were employed. This was to inform them of the study, and of our intention to contact genetic counselors within their unit about participating in our study. After an acknowledgement had been received from departmental heads, the third stage of recruitment was initiated. In the third stage, emails were sent out to 24 potential interview candidates conveying the details of the research study, inviting them to participate, and attaching a detailed plain language statement and consent form. Eleven genetic counselors provided informed consent to participate in the study (response rate 46%). CT then contacted them again via email to arrange a time and location for the interview. Ethics approval was received from the Royal Children's Hospital Human Research Ethics Committee and the Peter MacCallum Cancer Centre Human Research Ethics Committee.

Data Collection

A pilot interview was conducted by CT with a volunteer genetic counselor prior to initiating data collection for the study in order to trial the interview process and content. In 2010 and 2011, CT conducted 11 interviews. Interviews were conducted using a semi-structured interview guide, which was developed by the research team. The aim of the guide was to provide some structure to the flow of the interviews and ensure no key topics were missed, yet to simultaneously allow the interviews to progress naturally, according to issues raised by participants. Key topics included: whether or not genetic counselors viewed adolescents as a distinct client group; perceived challenges and benefits associated with their work with adolescents; granting confidentiality to adolescent clients and managing parental involvement; and suggestions for future genetic counseling training programs. Interviews were audio taped and transcribed verbatim, with pseudonyms designated for each participant and all identifying information removed.

Data Analysis

Data were analyzed using thematic analysis, categorizing the data into groups using open coding, which is "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (Strauss and Corbin, 1990, p. 61). These codes stayed close to the genetic counselors' words in order to ensure that developing themes were grounded in the original data obtained from the interviews. Axial coding was then employed where initial codes were grouped and examined for commonalities to produce overarching themes. Major themes identified were coded further to develop sub-themes. This process continued until a strong theoretical understanding of the phenomenon had emerged. All members of the research team (JW, MS & RED) reviewed the initial three interviews for content and structure. Three

additional transcripts were also co-coded by all authors and discussed as a team to achieve consensus about codes and themes.

Results

Participant Demographics

The eleven genetic counselors interviewed for this study had varying levels of experience with adolescent clients, ranging from seeing five young clients in their professional history, to working with young people closely for over ten years. Five of the eleven genetic counselors had completed a Master of Genetic Counselling degree, whilst the remaining six genetic counselors had completed a Graduate Diploma in Genetic Counselling. The length of time that the genetic counselors had been working in the field ranged from ten months to fifteen years, and some also had varying levels of work experience in other fields, for example, nursing, research, and family therapy. There were ten female participants and one male participant. Given the small sample size, we have deliberately chosen not to present these details in a table linked to each participant as this might compromise the anonymity of the genetic counselors who participated in the study.

Interview Themes

Seven major themes emerged from the interviews and are described in detail in this section. Verbatim quotations are provided to illustrate each theme.

Theme 1. Adolescents: A distinct client group?

Most genetic counselors viewed adolescents as a separate client group, distinct from other clients.

“I think there definitely is a difference...they are a pretty special kind of group.”

(P#10)

Within this group, a few genetic counselors believed that a different skill set was required to work with adolescents.

“There’s a whole different way of working with adolescents that, as genetic counselors, we are not very well equipped to do. I think it’s almost a sub-specialty in itself, because such different skills are required...” (P#9)

“I would be mindful that the way to go about the session would be different. Or how they would relate to me, would be different from how an adult would relate to me.” (P#4)

A few genetic counselors said that while they did recognize adolescence as a developmental stage, they had not noticed a significant demarcation in their experience with adolescent clients in comparison to their experiences with adult clients.

“I’m really against the whole idea of just labeling people as adolescents or adults and saying there should be a different approach.” (P#11)

“I think the best [approach] is actually going in and trying to think that there is a range of ways people might be when they’re at a certain age. It’s really hard to say that “every 16 year old is like this”.” (P#4)

All the genetic counselors agreed that adolescent clients should nonetheless be viewed as individuals and thus presumptions should be avoided.

Theme 2. Characteristics of adolescents

Each genetic counselor identified specific characteristics associated with adolescence. These characteristics fell within the categories of cognitive capacity regarding genetic knowledge, communication, and psychosocial issues. Most of the genetic counselors expressed that in recent decades adolescents have become more “genetically savvy,” due to the growing

amounts of information easily available to them through the education system and via the internet.

“I guess maybe when I think of 20 years ago, there’s a huge difference. In the more recent past there’s a whole lot more access to information.” (P#7)

Some genetic counselors observed that many of their adolescent clients had a sound knowledge of genetics when they first presented to genetic counseling sessions.

“...young people that come in having done an assignment in school on the condition that affects their family...and as a result, they know a lot of up to date, accurate information that probably wouldn’t have been so accurate if it had been based on family experience...who themselves are perhaps basing their knowledge on misinformation as well, so I guess they are better informed as a result of that.” (P#1)

On the issue of comprehension, a few genetic counselors expressed concern about the ability of their adolescent clients to comprehend medical information.

“It’s not that I don’t think they can understand medical language, I just feel that it’s better for them to hear things put in a ‘younger way’.” (P#8)

Three challenges regarding communication with adolescent clients were identified: a short attention span, an unwillingness to engage, and truncated responses. A few genetic counselors felt that some adolescents tended to reject discussions about long-term management of their conditions or the consequences of their decisions.

“(For) a lot of young people, it’s not the sort of stuff that they talk a lot about. And they don’t often think long-term.” (P#7)

Most of the genetic counselors raised psychosocial issues faced by the adolescent clients they worked with, such as peer pressure and the desire to fit in socially. These were identified as common challenges that adolescent clients experienced and often talked about during consultations.

“And I said to him, ‘Why don’t you tell people? Why don’t you wear a medical alert bracelet?’ and he said, ‘I want to fit in, not advertise to my friends that I am actually different, so I won’t wear it’.” (P#5)

Some genetic counselors noted that adolescents had very different concerns and worries from adult clients. These concerns were sometimes surprising to the genetic counselors.

*“Small things can often act as a barrier to adolescents so for example, speaking with an adolescent talking about prenatal testing, I’ve had an experience where one client was only focused on the needle. She had a fear of needles...there may be small barriers to the communication to look out to be identified that could hinder how they’re able to communicate.” (P#11)**“Things like how are they going to tell their friends what a colonoscopy is, or what is the drink going to taste like. Things that older people just kind of accepted and go with it...” (P#8)*

Theme 3. Strategies for working with adolescents

The genetic counselors gave examples of a range of ways in which they modified their practice with adolescents. Several of these related to communication strategies.

“ I find that I use different language when I speak to adolescents...I find sometimes it can be really difficult to engage them ... they are often not willing to disclose a lot of information, so really taking the time to build rapport with them is really important, I’ve found. “ (P#3)

“...how to best engage with them so they don’t feel like they are fighting against you to be heard” (P#1)

“Be as open minded and honest as I possibly can be and really hoping to impart to them that they are being heard and that I am willing to help facilitate whatever it is they are asking for” (P#2)

Most genetic counselors emphasized that honesty was also very important as it built rapport and trust.

“I’ve always told them that regardless, I am going to tell you the truth...and I think long-term you will develop that trusting, open relationship where you say ‘Look, I won’t tell anybody’ and they’re like ‘Oh, ok!’ and sometimes you can be floored by some of the open questions they have thrown at me.” (P#5)

When describing successful strategies to communicate with adolescents, many genetic counselors pointed to language as a key factor. A majority explained that they modified their language in some way when interacting with adolescent clients.

“...like the kind of tone and words I would use within a session, would reflect how I communicated when I was an adolescent, or what I think would get through to that particular adolescent.” (P#6)

This modification of language was motivated by several factors, including: concern that the adolescent client may not comprehend medical terminology; an innate instinct to make the session more comfortable for the adolescent by avoiding serious medical terms like “sudden death”; and an attempt to better connect and empathize with the adolescent client.

“I try to be very relaxed, very casual as I try to make this not such a big deal. So I try not to sound like a really scary medical person, and try to sound like just another person that they are talking to.” (P#8)

One significant factor that emerged was the interview setting. A genetic counselor suspected that a traditional face-to-face consultation in a clinical environment might intimidate an adolescent. This led to further consideration of methods of communication more likely to put adolescents at ease.

“I suspect the consultation, I would think that it would be quite a challenging environment...I suspect they feel somewhat intimidated by the way in which we operate...but not everyone’s like that. The things I think about are is it easier to communicate via SMS or a chat room.” (P#7)

Several other communication strategies were noted: adapting the session according to the adolescent's mannerisms and genetic condition; empowering adolescents whenever possible by encouraging them to make active decisions; avoiding a condescending tone of voice, and granting confidentiality whenever possible.

Theme 4. Confidentiality

The issue of confidentiality was identified as a vital but contentious issue in genetic counseling with adolescents.

"I think it's hard to gain their trust. You are unable to assure them of confidentiality." (P#10)

Often adolescents were not afforded complete confidentiality due to their age and their family being involved in the counseling sessions. Most of the genetic counselors said that they tried their best to maintain confidentiality where possible, and they also discussed the issue of confidentiality with their adolescent clients.

"One of the things I do...is talk about confidentiality to them. And explain that what we talk about we wouldn't speak to their parents about. It would be only if they wanted to do that." (P#9)

Theme 5. Parental involvement and presence within consultations

A theme that was closely associated with confidentiality was parental involvement and the physical presence of parents during consultations. The need to see adolescent clients on their own was emphasized by most of the genetic counselors. One offered the following sentiment in support of this practice.

"I guess in some ways it might make me feel like they've had an opportunity to say stuff about how this information may have impacted upon them in the absence of their parents." (P#2)

Most of the genetic counselors identified challenges associated with parental involvement in their interactions with adolescent clients:

“Where parents and young people are on the same page, that’s fine. But where you’ve got parents who are somewhat more involved than you would expect for the developmental stage of the young person, and not encourage the young person to be the person who is in charge of their health care.” (P#7)

A few genetic counselors found parental involvement helpful in their counseling sessions with adolescents, and often relied on the presence of parents to “get more of a dialogue” out of their adolescent clients. In some cases where a genetic counselor had previously seen the adolescent’s parent(s) as a client, a few genetic counselors expressed a difficulty in distinguishing the adolescent as a separate client.

“Particularly when they are in secondary school I find that the main contact is with the parent...” (P#3)

“...you often have a relationship with the parent before you have a relationship with the adolescent...you have often met with them prior and built a relationship with them...it’s almost like you have to redefine who the client is, or who your primary client is.” (P#9)

A minority of genetic counselors did not view the issue of parental involvement as significant within their profession.

“I have to confess in my experience, I’ve rarely had...there are a few cases I can think of where...it has been difficult to, meet the needs of both of those groups.” (P#2)

Theme 6. Benefits of working with adolescents

Most of the genetic counselors cited a sense of professional satisfaction as a benefit of working with adolescent clients.

“I think there is more sort of a professional satisfaction in working with a group of people who are so different from the majority of patients that we see.” (P#9)

A few genetic counselors also expressed a personal satisfaction in being able to help adolescents become better informed.

“There is some satisfaction in knowing mostly you have tried to help this young person make a decision or at least understand the implications of a test that’s been suggested or that they’ve had.” (P#2)

Most of the genetic counselors referred to adolescents as a pleasant group of clients to work with on a personal level.

“And I find that often adolescents are quite honest in the information they give you as well, so...and they are quite resilient as well, so they seem to take all the information that you are giving them quite well.” (P#6)

“...we have adults that are sort of down in the dumps, or their parents, who are negative. But here we have this great young person – with a smile on their face and making their plans, always looking to the future, with fresh hopeful eyes. I love them (laughs)!” (P#5)

Theme 7. Effectiveness of past training and education

During the interviews, genetic counselors were asked to identify aspects of their previous training in genetic counseling and other areas that have contributed towards helping them work with adolescent clients. In general, the genetic counselors found the following components of their academic training helpful: role-play exercises; clinical placements; attending talks and tutorials by experts in adolescent health during the course; and volunteering in school screening programs. These activities taught the theory and skills of counseling and communication, and integrated the knowledge into practice. Being taught

about the theoretical frameworks that underpin our understanding of adolescence was also identified as a useful training tool.

“Developmental stage, I think that is important to have...from a theoretical base, underpinning what you do, so that you have some understanding of adolescence, and the stage that they are at, and the sorts of things that are unique to them.”
(P#10)

A few genetic counselors attributed much of their confidence in communicating with adolescent clients to their previous work in a variety of fields, including family therapy and nursing.

“Nurses in those days were there at their bedside clinically doing things because it wasn’t as complex as now with lots of machines. So you were there at the bedside physically caring for someone – their emotional needs, listening to them, talking to them.” (P#5)

“I’m thinking about my time in [family therapy institution], certainly we had some training around children and adolescent counseling. The theory was quite good.”
(P#10)

However, most of the genetic counselors expressed the belief that they lacked competency in dealing with adolescent clients.

“I think more and more we are working with adolescents, and we don’t have the skills and expertise that are required. We are kind of fumbling our way through some cases.” (P#1)

“There’s a whole different way of working with adolescents that, as genetic counselors we are not very well equipped to do.” (P#9)

The genetic counselors offered the following suggestions for additional training in future genetic counseling programs: more role-play exercises; emphasizing the developmental stages of adolescence within tutorials; inviting adolescent health experts to give more talks within

genetic counseling programs; and increasing the amount of interaction students have with adolescent clients, whether in a simulated environment, or through practical experience.

Discussion

The current study explored the experiences of eleven genetic counselors about working with adolescent clients, to determine whether adolescent-specific challenges exist, and if further training and support are needed.

All the genetic counselors in this study identified more than one challenge associated with working with adolescents. Difficulties faced by genetic counselors in the current study included: trying to engage adolescents; providing adolescents with confidentiality; modifying language used when discussing complex issues with adolescent clients; separating the adolescent from his/her parents to assess adolescents' needs; and working effectively with a diverse group of adolescents who vary in age, background and maturity.

The challenge of getting adolescents to engage effectively was raised by every genetic counselor in this study. Difficulties associated with engaging adolescents can arise for a variety of reasons. These include: an inappropriate environment for adolescents; feelings of intimidation, uncertainty and fear; a lack of adequate communication skills from the genetic counselor in the session; or the power dynamic that can exist between adolescents and adults. An unwillingness to engage may also be due to some adolescent clients attending the genetic counseling session involuntarily (e.g. as a result of parents' insistence). This raises an important question about the extent to which it is appropriate for genetic counselors to "push" adolescents to engage and communicate in sessions. Determining this will in part be

dependent on a careful assessment of the adolescent's reasons for not engaging. For example, the adolescent may be asserting their autonomy as a consequence of their developmental stage, failing to speak because they do not understand the content of the discussion, or resisting because they have been forced to attend by their parents, with little personal interest or motivation.

Some advice is available to genetic counselors within textbooks and published papers regarding techniques for engaging adolescents effectively and these might be of use in altering an unhelpful dynamic within sessions (Austin, 2010; Peters-Brown & Fry-Mehlretter, 1996; Sullivan & Mcconkie-Rosell, 2010; Weil, 2000). An increasing body of literature is also emerging related to the process of transition from child to adult services for adolescents with genetic conditions. Resources such as these could potentially be used by genetic counselors to gain a sense of how to communicate with young people and what information to provide to adolescents at various stages of development (Children's Hospital Boston, 2010).

Confidentiality was another common challenge identified by genetic counselors. Genetic counselors in this study found it difficult at times to assure adolescent clients of confidentiality within sessions as adolescents are legally minors, and parents are often involved in the adolescent's ongoing health management. Literature from the field of adolescent health more broadly emphasizes the high importance that young people place on confidentiality in the medical setting. Research demonstrates that concerns about confidentiality can often prevent adolescents from seeking health care (Cheng, Savageau, Sattler, & DeWitt, 1993; Ford & Bearman, 1999; Klein, Wilson, McNulty, Kapphahn, & Collins, 1999; Reddy, Fleming, & Swain, 2002). Research also demonstrates that when

assurances of confidentiality are provided to adolescents, they are more likely to disclose sensitive information and return for future visits (Ford, Millstein, Halpern-Felsher, & Irwin, 1997). International guidelines published by the Society for Adolescent Health and Medicine (SAHM) also recommend that adolescents have access to confidential consultations with health professionals, without their parents present (Society for Adolescent Medicine, 2004). To our knowledge, no specific guidance is available to genetic counselors regarding appropriate limits to confidentiality with adolescent clients. However, the general consensus in medicine is that confidentiality should be breached when there is a legal obligation to do so or when there is a serious and immediate risk of harm that can only be averted through disclosure. (Society for Adolescent Medicine, 2004). SAHM advises that all health professionals delivering healthcare to adolescents should educate them and their families about the meaning, importance, scope and limits to confidentiality (Society for Adolescent Medicine, 2004). Laws in different geographic regions may also dictate confidentiality limits for minors.

Genetic counselors in the current study also articulated a range of common strategies that they regularly use for effective communication with adolescent clients. These strategies included: (1) avoiding being paternalistic; (2) having an open and honest communication style; (3) tailoring information and language to suit adolescents; (4) assuring adolescent clients of confidentiality where possible; and (5) trying not to make presumptions about an individual just because he or she is an adolescent. An important point all genetic counselors highlighted when counseling adolescent clients was to never make sweeping assumptions about adolescents. They reasoned that although adolescence is a common developmental stage, every adolescent is unique in their own way with their own personality and character. This view is supported by material in other fields related to communication with adolescent

clients (Chown et al., 2008; Oetzel & Scherer, 2003). Thus, despite the range of challenges that genetic counselors described being associated with adolescent clients, there appears to be an evolving body of experiential knowledge that is currently developing within the field. This is supported by the small but growing literature specifically focused on this topic of adolescent clients within genetic counseling practice (Callard et al., 2011; Gaff et al., 2006; Griswold et al., 2011; Peters-Brown & Fry-Mehlretter, 1996). Most of the genetic counselors also expressed that they derived both professional and personal satisfaction from working with adolescent clients. Similar findings have been reported in studies exploring the level of work satisfaction experienced by professionals in general medicine and adolescent psychiatry (Martin, Volkmar, & Lewis, 2007; Silber, D'Angelo, & Greenberg, 1989).

Genetic counselors reflected upon the influence of their previous work experience prior to becoming a genetic counselor, and they credited a significant amount of their confidence and skill in working with adolescents to this previous work and training. Their past experience contributed to the development of a range of adolescent-specific communication skills. This is important because it highlights that not all individuals beginning a course in genetic counseling are starting from the same knowledge base or skill level. This is positive for both the learning environment and the field as a whole, but it simultaneously makes training and education difficult, as it can be a challenge to cover enough ground for those with little previous knowledge, while also maintaining a high level of interest and motivation for those with greater previous knowledge and experience. It also reminds us that many other related fields are providing training to their students in aspects of adolescent health, theory and communication, which could be a positive addition to genetic counseling training. This therefore begs the question; does the field of genetic counseling need to provide further

training in adolescent health and development to current students, future students or perhaps even current professional genetic counselors?

Perhaps as a consequence of the range of skills and expertise that existed amongst genetic counselors in the current study, a range of views were articulated about whether genetic counselors require more training specifically about working with adolescent clients. However, most of the genetic counselors put forward the view that genetic counselors do not possess the necessary skills to work effectively with adolescents. Two key reasons cited were a lack of specific communication skills and a lack of confidence when working with adolescents due to limited previous exposure to them. One genetic counselor noted that working with adolescents is “*almost a sub-specialty in itself, because such different skills are required.*” Most of the genetic counselors in the current study also saw a majority of adult clients. As a result, they often used the same set of skills and techniques for adult clients when counseling adolescent clients. For some genetic counselors this was sufficient, as they did not perceive adolescent clients to be significantly different from adult clients in a clinical setting. Others felt a need for further training and skills in order to engage more effectively with adolescents and navigate difficult aspects such as when and how to provide confidential care.

One potential drawback of genetic counselors relying heavily on previous work experience is that while this may be useful at times, the skill-set they draw on may not always be completely appropriate or tailored to a genetic counseling situation. Relying on a range of previous skills from different fields could also cause practice to be varied within the profession. It therefore seems appropriate that genetic counselors should be able to draw on strategies and skills specifically designed for their own field when it comes to working with

adolescents. However, given the range of skills that already exist within the field (as a consequence of previous training and also evolving experiential knowledge within the field), the best way to provide further training for working with adolescents is not clear. There is a range of possible options for training genetic counselors about how best to work with adolescent clients. Such training could become part of course syllabus, it could be offered as professional development courses for those who have a specific interest in the area, or it could be provided in written documents, as it is in other fields, such as educational kits, guidelines or recommendations for best practice (Chown et al., 2008; Royal Australasian College of Physicians, 2008). The results of the current study are not sufficient to base such recommendations for training upon. However, they do suggest that the field of genetic counseling as a whole would benefit from assessing these options in a timely and considered manner.

Reflective practice

Given the current interim between highlighting a potential need for training genetic counselors about working with adolescents, but not yet having determined what form such training should take, the notion of reflective practice becomes vital. The role of reflective practice was highlighted in the current study and to demonstrate this, an extended quote is presented below.

“I did do a genetic counseling session with a pair of young, seventeen year old adolescents. They had just had a baby who has a severe illness. And this child is sort of now primary school age, who is heavily, developmentally, intellectually handicapped – full on care. And here were these two people who had met at school, got pregnant, and had this child. And I was listening to people talking about these young people like ‘Oh my gosh, ohhh adolescents,’ and how awful

this is...and almost in a sense prejudging them. And yet this couple have gone on, they lived at home individually with mum and dad, then had this baby, and they showed the most incredible insight, maturity, and love to this young child they had, and still have. They have gone on to marry, they have struggled through adversity, and I think sometimes when I see their child I think 'Boy you're lucky to have these people as your parents.' They admitted...they struggle, but they seek help when they need it. They are knowledgeable, they are not frightened to ask questions, and if they don't want to know anything, when they ask the question, they specify, 'I don't want to go there. I want this'." (P#5)

Discussions with a supervisor after each session with this adolescent couple facilitated reflection on the genetic counselor's process. Over time, the genetic counselor's perception of the couple changed. By the last session, the genetic counselor's impression of them had transitioned from one of immaturity and irresponsibility to respect and admiration as she saw them shouldering responsibility for their actions and their future child's welfare. Reflective practice and the use of supervision within genetic counseling are useful tools for working with adolescents in the absence of field-specific training or recommendations for best practice. Being reflective means to constantly evaluate one's own practice either with a supervisor, or peers, to identify any areas that potentially need to be improved and to continually strive towards best practice. In the constantly evolving field of genetic counseling, this critical self-reflection requires genetic counselors to examine their experiences, make necessary changes in their conceptual frameworks and compare their personal beliefs and values with the professional values they are expected to uphold. There is currently a lack of training opportunities for genetic counselors who seek development in the area of communication with adolescents. In the interim, a key component of high quality genetic counseling practice with adolescent clients is reflective practice.

Research recommendations

As the sample of the current study were all genetic counselors practicing within Victoria, it would be valuable to conduct a similar study with broader groups, for example, those working throughout Australia and also internationally, to expand upon and validate the findings of this study. The findings of the current study also highlight the need to begin developing and trialing some initiatives to increase the knowledge and skills of genetic counselors regarding working with adolescent clients. Lastly, conducting further research with adolescents who are seeing genetic counselors would be valuable in providing a client-based perspective of this issue.

Study Limitations

There are three key limitations to the current study. The first limitation concerns the small sample size. A larger sample size might have led to additional themes being identified from the data. Moreover, qualitative data are not intended to be generalized to an entire population, in this case, to all genetic counselors. Secondly, the eleven genetic counselors who chose to take part in this study may differ in salient ways from those who did not participate. For instance, they might represent genetic counselors who are more opinionated about the topic of adolescents and have given the topic more deliberation. Thirdly, the genetic counselors within this study were all practicing within Victoria. As different states and countries may have different genetic counseling practices, and training programs, the results are not necessarily applicable to genetic counseling practice outside Victoria.

Practice Implications

The results of the current study provide a valuable contribution to the genetic counseling literature, as they represent the first qualitative findings about genetic counselors' experiences

with adolescent clients in Australia. Table 1 presents a summary of the key findings from this study and their implications for genetic counseling practice.

[Insert Table 1 approximately here]

Conclusion

Genetic counselors in the current study faced common challenges in their varied experiences with adolescent clients, while simultaneously drawing on a range of strategies as well as previous training to manage these challenges. There is a need for the field of genetic counseling as a whole to consider how to respond to the challenges associated with working with adolescent clients, and how to equip existing and future genetic counselors with the necessary skills for navigating these, while also harnessing the experiential knowledge that has already developed within the field. In the interim, reflective practice will be an important tool for genetic counselors to employ. Ongoing research documenting the experiences of genetic counselors internationally will also be vital.

Acknowledgements

Rony Duncan is partly supported through a Fellowship from the Invergowrie Foundation.

This study was supported by the Victorian Government's Operational Infrastructure Support Program. This study was completed in partial fulfillment of the requirements for the Master of Genetic Counselling, University of Melbourne, Victoria, Australia.

References

- Austin, S. (2010). Developmentally based approaches for counseling children and adolescents. In B. S. Leroy, P. M. Veach, & D. M. Bartels (Eds.), *Genetic Counseling Practice: Advanced Concepts and Skills* (pp. 253-280). Hoboken: Wiley-Blackwell.
- Callard, A., Williams, J., & Skirton, H. (2012). Counseling adolescents and the challenges for genetic counselors. *J. Genet. Couns.*, 21, 505-9.
- Children's Hospital Boston (2010). Children's Hospital Boston Transition Toolkit. Retrieved April 3rd, 2013, from <http://newenglandconsortium.org/for-families/transition-toolkit/>
- Cheng T. L., Savageau J.A., Sattler A.L., & DeWitt T.G. (1993). Confidentiality in health care. A survey of knowledge, perceptions, and attitudes among high school students. *JAMA*, 269, 1420-24.
- Chown, P., Kang, M., Sanci, L., Newnham, V., Bennett, D.L. (2008). *Adolescent Health: Enhancing the skills of General Practitioners in caring for young people from culturally diverse backgrounds. GP Resource Kit*. 2nd Edition. Sydney: NSW Centre for the Advancement of Adolescent Health and Transcultural Mental Health Centre.
- Christie, D., & Viner, R. (2005). ABC of adolescence: Adolescent development. *British Medical Journal*, 330, 301 – 304.
- Duncan, R. (2004). Predictive genetic testing in young people: When is it appropriate? *Journal of Paediatrics and Child Health*, 40, 593 – 595.
- Duncan, R., E., Gillam, L., Savulescu, J., Williamson, R., Rogers, J. G., & Delatycki, M.B. (2008). "You're One of Us Now": Young people describe their experiences of predictive genetic testing for Huntington Disease (HD) and Familial Adenomatous Polyposis (FAP). *Am. J. Med. Genet., Part C (Seminars in Medical Genetics)*, 148C, 47-55.

- Duncan, R., E., Gillam, L., Savulescu, J., Williamson, R., Rogers, J. G., & Delatycki, M. B. (2009). The challenge of developmentally appropriate care: predictive genetic testing in young people for familial adenomatous polyposis. *Familial Cancer*, 9, 17-35.
- Ford, C.A., Millstein, S. G., Halpern-Felsher, B.L., & Irwin, C. E. (1997). Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care: a randomised controlled trial. *JAMA*, 278, 1029-34.
- Ford, C., & Bearman, P. J. M. (1999) Foregone health care among adolescents. *JAMA*, 282, 2227-34.
- Gaff, C., Lynch, E., & Spencer, L. (2006). Predictive Testing of Eighteen Year Olds: Counseling Challenges. *J. Genet. Couns*, 15, 245-251.
- Griswold, C.M., Ashley, S.S., DeLany Dixon, S., & Scott, J.L. (2011). Genetic counselors' experiences with adolescent patients in prenatal genetic counseling, *J. Genet. Couns*, 20, 178-191.
- Joint Adolescent Health Committee of the Royal Australasian College of Physicians. (2008). *Working With Young People: A Training Resource in Adolescent Health*, Sydney: Royal Australasian College of Physicians.
- Kang, M., Bernard, D., Booth, M., Quine, S., Alperstein, G., Usherwood, T., & Bennett, D. (2003). Access to primary health care for Australian young people: service provider perspectives. *British Journal of General Practice*, 53, 947-952.
- Klein, J., Wilson, K., McNulty, M., Kappahn, C., & Collins K. S. (1999). Access to medical care for adolescents: results from the 1997 Commonwealth Fund Survey of the health of adolescent girls. *J. Adolesc. Health*, 25, 120-30.
- Martin, A., Volkmar, F. R., & Lewis, M. (2007). *Lewis's Child and Adolescent Psychiatry: A*

- Comprehensive Textbook*, Philadelphia, PA: Lippincott Williams & Wilkins.
- Oetzel, K., B., & Scherer, D., G. (2003). Therapeutic engagement with adolescents in Psychotherapy. *Psychotherapy: Theory, Research, Practice, Training*, 40, 215-225.
- Peters-Brown, T., & Fry-Mehlretter, L. (1996). Genetic counseling for pregnant adolescents. *J. Genet. Couns*, 5, 155-168.
- Reddy, D., Fleming, R., & Swain, C. (2002). Effect of mandatory parental notification on adolescent girls' use of sexual health care services. *JAMA*, 288, 710-14.
- Sawyer, S. M., Afifi, R. A., Bearinger, L. H., Blakemore, S. J., Dick, B., Ezeh, A.C., & Patton, G. C. (2012). Adolescence: a foundation for future health. *Lancet*, 379, 1630–40.
- Silber, T. J., D'Angelo, L. J. & Greenberg, L. W. (1989). Career satisfaction in adolescent medicine. A survey of physicians trained over a 20-year period. *J. Adolesc Health Care*, 10, 126-8.
- Society for Adolescent Medicine. Confidential Health Care for Adolescents: Position Paper of the Society for Adolescent Medicine. (2004). *J. Adoles. Health*, 35, 160-67.
- Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. California: SAGE Publications, Inc..
- Sullivan, J. & Mcconkie-Rosell, A. (2010). *Helping parents to talk to their children*. In C. L. Gaff & C. L. Bylund (Eds.), *Family Communication About Genetics: Theory and Practice*. (pp. 227-242). New York: Oxford University Press.
- Veach, P. M., LeRoy, B., & Bartels, D. M. (2003). *Facilitating The Genetic Counseling Process: A Practice Manual*. New York, Springer-Verlag.
- Weil, J. (2000). *Psychosocial Genetic Counseling*. Oxford: Oxford University Press.

Table 1. Summary of key findings and implications for genetic counseling practice

Key Findings	Implications
1. A range of challenges exist when working with adolescent clients in the field of genetic counseling	This finding suggests the need for more comprehensive genetic counseling training curricula that target these challenges and the formalization of guidelines and recommendations for best practice with adolescent clients.
2. Some strategies for effectively communicating and working with adolescent clients already exist within the field, as a consequence of prior training and evolving experiential knowledge.	Guidelines and recommendations about communicating with adolescents in other fields, as well as existing expertise within the field of genetic counseling should be harnessed to inform future training and guidelines for the genetic counseling field.
3. Varied perceptions exist amongst genetic counselors about whether further training is needed in relation to working with adolescent clients	There is a need for the field as a whole to consider a range of possible training options for current genetic counselors as well as future students who want to increase their knowledge and skills related to working with adolescent clients.
4. Reflective practice is vital in this interim between identifying a need for further training but not yet knowing what form this training should take.	Ongoing critical self-reflection is a key factor in a genetic counselor's professional development and is likely to enhance genetic counselors' abilities to provide developmentally appropriate care to adolescents.