Familial Cancer (2010) 9:27–35
DOI 10.1007/s10689-009-9294-0

# The challenge of developmentally appropriate care: predictive genetic testing in young people for familial adenomatous polyposis

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Published online: 17 September 2009


**Abstract** Predictive genetic tests for familial adenomatous polyposis (FAP) are routinely offered to young people during early adolescence. While this is not controversial, due to the medical benefit conferred by the test, it is nonetheless challenging as a consequence of the stage of life of the young people, and the simultaneous involvement of multiple family members. Despite these challenges, it is possible to ensure that the test is offered in such a way that it actively acknowledges and facilitates young people's developing autonomy and psychosocial well-being. In this paper we present findings from ten in-depth interviews with young people who have undergone predictive genetic testing for FAP (four male, six female; five gene-positive, five gene-negative; aged 10–17 years at the time of their predictive test; aged 12–25 years at the time of their research interview). We present five themes that emerged from the interviews which highlight key ethical challenges associated with such testing. These are: (1) the significance of the test; (2) young people's lack of involvement in the decision to be tested; (3) young people's limited understanding; (4) provision of the blood test at the first visit; and (5) group testing of family members. We draw on these themes to make eight recommendations for future practice. Together, these recommendations highlight the importance of providing developmentally appropriate care to young people undergoing predictive genetic testing for FAP.

**Keywords** Genetic predisposition testing · Child · Adolescent · Qualitative research · Ethics · Familial adenomatous polyposis · Informed consent

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## Introduction

Predictive genetic testing in young people remains controversial; unless testing provides medical benefit [1]. In cases where the test provides an opportunity for prevention or treatment of the genetic condition, as is the case with familial adenomatous polyposis (FAP), testing in young people has been considered relatively uncontroversial [1, 2]. This is not because such tests escape the potential for psychosocial harm, but because concerns about possible harm are overridden by the medical benefit conferred by

the test [3]. Accordingly, young people with a family history of FAP routinely undergo predictive genetic testing from the age of 10–12 years [4, 5].

In contrast, predictive tests in young people that do *not* confer medical benefit, such as tests for Huntington disease, remain controversial because of concerns surrounding informed consent, competence, autonomy and psychosocial harm [2, 6–8]. Notwithstanding the potentially life saving role of predictive testing in FAP [4], young people's autonomy and psychosocial well-being also matter. It is possible that because of the presence of medical benefit, we have not paid enough attention to protecting these other values when it comes to predictive genetic testing in young people for FAP.

In this paper we utilise findings from 10 in-depth interviews with young people who have undergone predictive genetic testing for FAP in order to highlight some of the key ethical challenges associated with such tests. We do not wish to raise doubt that predictive testing for FAP in young people should continue to form part of routine medical care. However, we do suggest that there are currently many missed opportunities for promoting young people's developing autonomy and psychosocial well-being during the testing process. We conclude with recommendations for future practice. These recommendations highlight the importance of developmentally appropriate care for young people undergoing predictive genetic testing for FAP. They relate to the way in which information is provided to young people, the timing of the test, the presence of other people during the testing process, opportunities for young people's input and the way in which young people are followed up throughout their adolescence, after testing.

## Background

A plethora of guidelines and position papers have been published about predictive genetic testing in young people [1]. These demonstrate surprising unanimity, indicating that medical benefit should be the primary justification for testing. For conditions that present in childhood and for which preventative therapies exist, such as FAP, professional recommendations about the timing of testing are somewhat open to interpretation. In practice testing rarely occurs at an age earlier than the earliest onset of the condition [1, 5], which is commonly known as the 'rule of earliest onset' [9].

FAP is an autosomal dominant condition which is responsible for 1% or less of all colorectal cancers [4, 10]. It is caused by mutations in the *APC* gene and it is characterised by hundreds to thousands of adenomas in the colorectum that develop during childhood and adolescence [4]. Almost all individuals with FAP will develop cancer by the age of 40–50 years [4]. If surveillance is undertaken and total colectomy performed, the risk is markedly reduced [11]. Predictive genetic testing for FAP became available in 1993 and is routinely offered to young people from the age of 10–12 years [4, 12, 13]. Surgery is usually offered between the ages of 15 and 25 years when adenomas are seen [13]. Studies indicate that the majority of individuals who are eligible for predictive testing for FAP choose to undergo testing [13]. Concerns about one's future health and/or concerns about one's children are the primary factors that motivate individuals to undertake such testing [13]. In rare cases, children much younger than 10 years of age present with symptoms of FAP. In cases where family history is indicative of an 'early onset mutation', the traditional recommendations to defer testing until the early teenage years may be revised [14].

Predictive genetic tests for FAP have not always been linked with appropriate counselling. In 1995, a survey of individuals undergoing *APC* gene testing by a commercial laboratory in America found that only 18.6% of all individuals tested for FAP received formal genetic counselling beforehand [15]. In Australia, guidelines for predictive genetic testing for familial cancer recommend that the results of genetic tests be given only to those who have received adequate pre-test counselling [5]. Petersen and Brensinger [16] have articulated what they believe a typical genetic counselling session for predictive testing for FAP should entail. This includes: detailed education, an exploration of family history and experiences, exploration of risk perception, disclosure of results and a follow-up session.

It is not entirely clear how such protocols should be translated for testing of minors (under the age of majority) for FAP. It has been suggested that in the case of young people it is vital that the whole family is involved in the decision, which entails parents and children jointly being informed and educated [17]. It has also been argued that genetic testing of minors requires additional effort to ensure that minors reach an adequate level of understanding about FAP and the predictive genetic test [18]. Clinicians have been encouraged to specifically elicit minors' understanding of the clinical and social meaning of the gene test [18], yet reminders to be careful about excessive information provision have also been made, with the aim of avoiding unnecessary anxiety in young people [17]. It has also been proposed that parental consent as well as the assent of the young person be obtained [17]. Recommendations to disclose results to parents first, without children present, have also been published [16, 17]. It is not clear what aged 'children' this advice specifically refers to.

The rare nature of FAP and the difficulties associated with research concerning minors have resulted in a shortage of evidence specifically concerning predictive testing for FAP in young people [2]. A small number of studies

have been carried out which shed light on the experiences of young people and provide evidence for future protocols. Michie et al. [19] performed in-depth interviews with a couple who had their two-year-old and four-year-old daughters tested for FAP. No obvious harms occurred and the knowledge of their children's genetic status appeared to be beneficial for the parents [19]. This study was not able to draw conclusions about direct impacts for the children, given their age. Codori et al. [20, 21] performed a prospective study concerning the psychological effects of predictive testing for FAP in young people aged 5–17 years and their parents. Impacts of testing were investigated at a mean of 38 months after test provision. It was concluded that most children did not suffer clinically significant psychological distress after testing [20, 21]. A separate study by Michie et al. [22] assessed the psychological impact of predictive testing for FAP in 60 young people aged 10–16 years and compared this with the impacts in adults [22]. Once again, there was no evidence of clinically significant harm for the young people undergoing testing.

In 2008 we reported on the harms and benefits associated with predictive testing in young people for FAP [3], as identified through analysis of qualitative interviews with young people who had undergone such testing. Harms associated with testing included knowledge of future illness, witnessing distress in parents, and negative effects on family relationships and friendships. Benefits included knowledge of gene-negative status, positive effects on family relationships and friendships and relief from uncertainty. Analysis of these same interviews forms the basis of the current paper.

## Materials and methods

Ten young people who had undergone predictive genetic testing for FAP participated in in-depth interviews as part of a larger study concerning predictive genetic testing in young people [3, 23]. Four participants were male and six were female. Five participants had received a gene-positive test result and five had received a gene-negative test result. The participants were aged 10–17 years at the time of their predictive test and 12–25 years at the time of their research interview. Interviews were conducted during 2004. The time between participants' genetic tests and their research interviews ranged from 2 to 9 years. Participants therefore would have undergone predictive testing between 1995 and 2002. All ten participants had undergone testing at the same genetics service in Melbourne, Australia. Approval for the study was granted by the Royal Children's Hospital Ethics in Human Research Committee, Melbourne.

Semi-structured, in-depth interviews were conducted by the first author (RED) at either the Royal Children's Hospital, or at participants' homes. RED was not aware of participants' genetic status prior to conducting each interview. Interviews were recorded using a digital audio recorder and files were downloaded onto a computer and transcribed verbatim.

Interview transcripts were analysed using a combination of interpretive content analysis and thematic analysis [24]. Interpretive content analysis focused on harms and benefits of testing. Thematic analysis used open coding to capture the lived experience of being tested. This process was organised using the qualitative research software package NVivo (QSR International Pty Ltd, Victoria, Australia). Additional detail concerning recruitment and methodology has been published elsewhere [3, 23].

## Results

Here we present five themes that emerged from the interviews that highlight key ethical challenges associated with predictive testing in young people for FAP. This is not an exhaustive presentation of all themes that emerged, but rather a selection of those that best convey the ethical issues. At the end of each quote, we use a code to provide key information about the young person quoted: *Pseudonym: Gender: Age at Interview: Age at Test: Test Result*.

### Theme 1: significant event in life

Young people were asked to compare their predictive genetic test to something else in their life in order to help convey the meaning it held for them. Their responses indicated that it constituted a major life event. This is important in shaping our ideas about young people's involvement in the testing process because if young people experience their predictive test as a significant event, there is an associated ethical obligation to ensure they are adequately supported in this awareness through the provision of appropriate counselling and education.

> "One of the worst days of my life, finding out that I had it, because it was something that I have for life and could kill me… Nothing else could really compare to that." *Harry:M:14:12:+ve*
>
> "It was sort of the same thing as putting our dog down." *Kylie:F:20:14:+ve*
>
> "I'd compare it to passing my VCE [final year of high school]". *Doug:M:18:14:−ve*
>
> "Oh I don't think you could really compare it 'cause it's that bad I s'pose, I don't know, it's not the same feeling, anytime." *Mark:M:21:16:+ve*
>
> "Passing my VCE [final year of high school] … in comparison to that." *Amy:F:19:14:−ve*

"Probably just getting an exam result, a really good one, a positive one." *Sally:F:25:17:−ve*
"I don't think I could compare it to anything…. 'cause this is like a major thing in your life, or it could become a major thing in your life." *Emily:F:21:14:−ve*

Theme 2: lack of involvement in the decision to be tested

Several young people described a lack of involvement in the decision-making process that led to their predictive genetic test for FAP. Instead, they described situations in which they were informed by their parents that the test was going to occur. This is important because a failure to engage young people in the decision-making process conveys a sense of powerlessness to them, in turn making it less likely they will be actively engaged in subsequent phases of testing. It also fails to respect their developing autonomy.

"I was 12 when I was told that I had to have the test… I didn't want to have it, but then I sort of had to." *Harry:M:14:12:+ve*
"All I actually can remember is I think mum did sit us down and tell us we had to go for a genetic testing". *Kylie:F:20:14:+ve*
"Dad just organised it, and I just had to come in, get the blood test." *Mark:M:21:16:+ve*
"They didn't ask us do you want to, they said you know, you have to go get a blood test." *Amy:F:19:14:−ve*
"Mum and dad, they decided that they wanted to just see if we had it or not." *Liz:F:17:10:−ve*

Theme 3: limited understanding

It was clear from the descriptions provided by young people that, at the time of their test, many had a limited understanding of the process and consequences of testing. In some cases they also had little interest in knowing more. This is significant because it means that young people were not engaged in a way that was meaningful to them during the testing process. This risks them being disempowered through their lack of knowledge and potentially risks their anger at the time when full clinical and ethical implications become clearer.

"It's like information overload. I can't remember hardly anything of what we talked about, all I remember is getting the piece of paper and she was writing down the Y's and X genes or something…. I think it was more nerves than anything." *Kylie:F:20:14:+ve*
"I would have rathered have it now, but not that early, cause I didn't really understand it completely, like I do now." *Harry:M:14:12:+ve*
"All I can remember that I knew about it was that it's something to do with dad's guts pretty much and that something had to happen." *Emily:F:21:14:−ve*
"Leading up to it we didn't really know much, just had to go get a blood test as far as we were concerned…. my parents … I don't think they wanted to scare us too much …. they didn't really want to tell us too much." *Amy:F:19:14:−ve*
"At that time… you're just young, you're naïve, you get told and you're just like yeah yeah, all right I got it, you know, you think you know everything…. I don't think I realised how serious it was until I saw my parents, how upset they were that I had it." *Ali:F:24:15:+ve*

Theme 4: blood test at first meeting

All the young people who were interviewed explained that their blood was taken at the first meeting. This was the same meeting in which they met their genetic health professional for the first time and were educated about the predictive testing process and FAP. This is important because it means that young people had little time to digest the information they were presented with prior to their genetic test. This is therefore a potentially ineffective process for successful education and counselling.

"They just went over what would happen if I had it, and what I'd have to do. Basically all of the things to do with it…and yeah, I had the blood test". *Harry:M:14:12:+ve*
"They took the blood sample…. and I think it was about 3 h where we went to this counselling thing." *Kylie:F:20:14:+ve*
"I think it was just, went in for the blood test, and then for the results we had to come back—just two [visits]." *Mark:M:21:16:+ve*
"All we remember was a bit of counselling, how do you feel, how would you feel if the result was positive, how would you feel if the result was negative, how would you feel… then they took our blood …. and we all went home." *Sally:F:25:17:−ve*
"We went in and met someone and then we had the test done and then they gave us booklets and had a chat to us all." *Emily:F:21:14:−ve*
"We all went in… and just got our blood taken and yeah, I think that was pretty much it that day." *Liz:F:17:10:−ve*

For many of the young people, fears about the needle used for the blood test overshadowed other concerns at this first meeting.

> "The actual taking of the blood bit was the worst bit I was looking out for." *Jason:M:22:14:+ve*
> "The worst thing was the needle". *Kylie:F:20:14:+ve*
> "Not having the needle would have been good" *Doug:M:18:14:−ve*
> "I was more scared about the needle than anything else." *Emily:F:21:14:−ve*

Theme 5: group testing

Several young people were tested at the same time as their siblings. This meant that they all went in for the blood test together and all received their test results on the same day. This highlights a lack of opportunity for individual attention and support that in turn may complicate young people's understanding and reactions.

> "They interviewed us as a whole, one big family, all 5 of us."
> *Kylie:F:20:14:+ve*
> "[brother] was told first, and he didn't have it, and then I went in and I had it, and then [sister] went in and she didn't have it". *Mark:M:21:16:+ve*
> "We had the test together." *Sally:F:25:17:−ve*
> "All 3 of us went in together [for the test]." *Emily:F:21:14:−ve*
> "I remember [sister 1] didn't [have the familial mutation] 'cause she came back and she wasn't like upset or anything, she was pretty relieved, then [sister 2] came back and she was crying so I knew she did and then… I went in and I was negative." *Liz:F:17:10:−ve*

## Discussion

Predictive genetic testing in young people for FAP is an ethically challenging undertaking. The 'rule of earliest onset' means that tests for FAP are routinely provided to young people just as they are embarking on adolescence; too young to be involved in the same way autonomous adults would be, yet at the same time sufficiently competent not to be disregarded or overlooked. It has been noted that adolescent clients provide specific challenges for genetic counselling [25]. Gaff et al. [26] state that "not only does adolescence add complexity to genetic counselling, but genetics adds complexity to counselling adolescents" [26]. Counselling adolescent clients is complex because of the developmental tasks of adolescence more generally. Peters-Brown and Fry-Mehltretter [25] provide a summary of these tasks which, they suggest, include adaptation to physical changes, separation from family, establishment of meaningful peer-relationships, individuation, identity formation, development of confidence and self-esteem, acquisition of understanding and control of impulses, ability for abstract thinking and the selection of future goals.

In addition to this 'in-between' status that young people who undergo predictive testing for FAP generally inhabit, their parents and sometimes siblings are commonly involved in their testing process as well. Meeting the conflicting needs of members of a single family can be highly challenging [27]. It has been suggested that the familial nature of genetic information complicates autonomous decision-making, as obligations to family members exist and may create undue influence upon an individual [27]. It is also known that one of the risk factors for psychological distress following genetic testing is receiving a result that differs from those of siblings [28]. Genetic health professionals involved with testing young people for FAP are therefore charged with the difficult task of negotiating multiple and often conflicting interests within the one family.

Despite current challenges, there is scope to adjust current practice in such a way that it actively acknowledges and facilitates young people's developing autonomy. That is, to provide developmentally appropriate care. In the remaining sections, we consider the key ethical issues highlighted by young people's descriptions of their predictive genetic tests for FAP. We then use these insights as a basis for future recommendations.

The predictive genetic test for FAP was a significant event in the lives of young people who were interviewed. Noteworthy were comparisons of a gene-positive test result to the death of a pet and a gene-negative test result to passing final high-school exams successfully. This information gains further importance when placed alongside the fact that many of the young people articulated a poor understanding of the genetic test and its implications and that few had any part in the decision-making process that led to genetic testing. In other words, the emotional significance of the predictive test was something that young people identified accurately, even if they did not understand the facts. Presumably, it is harder to cope with emotional reactions when these are not accompanied by understanding and support. Therefore, acknowledgment of the significance that predictive testing for FAP holds for young people must also entail a commitment to provision of adequate education and support.

The lack of understanding conveyed by young people about the reasons for their predictive test and the

implications of the test at the time it occurred was remarkable. It was common for young people to describe confusion about what they were told by parents and genetic health professionals at the time of their test. Many also struggled to remember exactly what was said, describing a sense of being overwhelmed by the information presented and lost in the detail. One participant suggested that the cause of her inability to understand the information presented may have been her nervousness. Another suggested he was too young at the time of testing to understand what was presented, while another conveyed a distinct lack of interest in the information being provided. This lack of comprehension at the time of the predictive test makes two other findings even more significant. First, the fact that for most young people interviewed, the blood test was performed at the same visit during which they received education about FAP, and second, the finding that for many young people, the overwhelming concerns on the day of their test were fears of the needle, rather than the reason for the test or the test result.

It is known that panic and anxiety can significantly impair people's ability to hear and grasp information [29]. Therefore, young people's apprehension about the needle may have significantly impacted upon their ability to focus on and recall the information presented to them at the same visit. It is also possible that anxiety about the test in general, separate from fears about the needle, could have impacted upon comprehension of the information at this first visit. Given the time that had elapsed between young people's tests and the interviews conducted as part of this research, it is also possible that young people's understanding may have been better at the actual time of their test but has faded over time. Of course, if understanding has declined over time, with limited opportunities for revisiting relevant information, this raises a different set of concerns for those who tested gene-positive.

The young people interviewed as part of this study did not receive adequate time and space to digest the information that was presented to them regarding FAP and the predictive testing process. It has been noted that counselling practices for familial cancer often follow a modified version of protocols for Huntington disease predictive testing [26]. This involves an appointment with a genetic counsellor, followed by a period of reflection, then a second appointment for further discussion and blood collection and, finally, a third appointment for disclosure of results. Follow-up then occurs either at an additional appointment or by telephone [26, 30]. It is not clear why young people taking part in this study received their pre-test counselling and education at the same meeting during which their blood was taken, without a period of adequate reflection. Given that some participants underwent testing up to 9 years prior to their research interview this finding may reflect a past policy that has since changed. It is also possible that parents insisted on this process as many families live significant distances from the genetic testing service and may have wanted to avoid multiple trips to the clinic.

The descriptions provided by young people in this study emphasised situations in which opportunities for autonomy were complicated by the involvement of other family members. Several young people described the decision to be tested as something that they had no part in. Instead, many conveyed a situation in which they were instructed to have the test by their parents. It was also common for young people to be tested at the same time as their siblings. Circumstances were described in which all family members attended the first meeting together and education was provided to the group as a whole with little opportunity for individual attention or focus. When test results were disclosed, siblings were often called into a room one after another. This limits the space and time that each individual can be afforded and mixes reactions about personal test results with those concerning test results of siblings. Few young people articulated an experience in which they had time to speak with a genetic health professional on their own. In their description of best practice regarding predictive testing for FAP, Fernandez-Suez et al. [17] note that there are advantages and disadvantages to disclosure to all family members together. Providing results to an individual is more private and allows the subject to express doubts, worries and fears in confidence. On the other hand, when consulting the whole family as a group, errors of interpretation and meaning are less common [17]. Of course, it can be highly challenging to negotiate time alone with young people in a clinical setting, particularly in situations where a relationship has previously been formed with the family as a 'whole'. In such cases, asking a parent to leave the room can be difficult or feel inappropriate [27].

Of relevance to this discussion of young people's emerging autonomy is a consideration of their legal rights and interests. In Australia, young people are able to obtain their own Medicare card from the age of 15 years. This allows them to access health care, and receive associated financial rebates, without parental knowledge. However, this does not imply that young people are able to consent to all medical procedures from the age of 15 years. The age at which a young person is sufficiently mature to consent to treatment depends not only upon the individual's level of competence, but also upon the type of procedure in question [31]. Specific laws differ between jurisdictions. In Australia, the concept of 'Gillick competence' prevails. This requires individual assessment of young people's capacity for providing informed consent. An individual

must demonstrate "sufficient understanding and intelligence to enable him or her to understand fully what is proposed" [31]. Importantly, the right to consent to certain medical treatments under the age of 18 years (the age of majority) does "not as a corollary confer the right to refuse treatment" [32] (p76). Thus, in the case of predictive genetic testing for FAP, if a young person was deemed to be a 'mature minor', that is, to demonstrate Gillick competence, he or she could legally be offered predictive genetic testing without parental consent and, potentially, may also be legally able to refuse such testing. However, in reality, the age at which most young people undergo predictive testing for FAP means that in the vast majority of cases parents or guardians will be closely involved.

## Recommendations

Based on our interviews with young people who have undergone predictive genetic testing for FAP, we suggest a range of measures that could be incorporated into the provision of such tests in the future. These would need to be substantiated through further research prior to formal integration into testing protocols. Given that the tests discussed by young people in our study occurred between 1995 and 2002, it is possible that some of our recommendations may have already been incorporated into practice at various sites around the world, although there is currently no formal guidance reflecting these recommendations. Table 1 summarises our recommendations.

Information and support about FAP should be provided to young people prior to their genetic test, allowing adequate time for the information to be digested and reflected upon. Ideally, information should be provided at a face-to-face meeting. If this is not possible, information could be sent to young people instead or provided via the internet. Information provided to young people should be youth-friendly, that is, written in ways that are meaningful to young people, and addressed specifically to them rather than parents. These measures will assist in ensuring that young people reach an adequate level of understanding regarding their predictive test and its associated implications. The measures will also help to engage and empower young people from the initial stages of testing. In order to achieve these goals, extra time will be required on the part of both genetic health professionals and families. Parents may ask to combine multiple aspects of testing into one visit in order to minimise time commitments, and young people may resist engagement with information provided to them. To counteract these possibilities, it will be important to provide a detailed justification to families of the reasons behind such processes.

Genetic health professionals should ensure that they see young people alone as a routine part of each consultation. This mirrors current wisdom in adolescent health more generally and will assist in empowering young people and allowing for honest and individually-focused communication [33]. It also increases the likelihood of rapport and trust building between young people and their genetic health professional(s), which will assist with ongoing communication in the future. Young people should also be tested at a separate time from other family members, particularly siblings. This will allow young people time and space to react to their own genetic test result without the interference of results being simultaneously provided about others. It is possible that families will challenge such processes. Parents and young people are likely to be surprised by a policy of seeing young people alone for part of each consultation. This should therefore be clarified when appointments are first arranged to provide warning and explanation. Similarly, it is likely that some parents may want to test all their children at the same time. Once again, genetic health professionals will need to allow adequate time to explain the reasons behind a policy of testing each

**Table 1** Recommendations for predictive genetic testing in young people for FAP

1. Young people should be provided with individual pre-test counselling and information prior to their genetic test, allowing adequate time to digest the information
2. Young people should have an opportunity to see their genetic health professional alone as a routine part of each consultation
3. Young people should be educated about FAP and the genetic testing process in an age appropriate manner that takes into account their individual capacities
4. Young people should be tested separately from other family members, including siblings, allowing an opportunity for individual focus and support
5. The genetic test should be performed via cheek swab where possible instead of via blood sample to avoid additional anxiety concerning needles
6. Young people should be followed up throughout their adolescence to ensure they receive information that is relevant to their evolving developmental stage
7. Young people's developing autonomy should be respected throughout the testing process where possible, for example, deciding when the test will occur, who will be involved, and how the results will be disclosed
8. Genetic health professionals should receive formal training and supervision in working with adolescent clients

young person at a separate time so that families understand why this is important.

Where possible, the genetic test should also be provided via cheek swab instead of blood test to avoid the anxiety commonly associated with needles. Opportunities should be provided for follow-up with young people at regular intervals following the predictive genetic test. This would assist in ensuring that information provided is consistent with young people's growing capacity to take on more complex information as they mature with age [2, 12, 16]. Ongoing contact with families after genetic testing has occurred will require commitment on the part of both genetic health professionals and families. It is therefore important to openly discuss the practicalities of this process at the time of testing.

Genetic health professionals should aim to maximise opportunities for respecting young people's developing autonomy within the limits of current testing protocols and individual capacities. Although young people may not be able to refuse the predictive genetic test for FAP, they may be able to decide when they would prefer to be tested, who should accompany them for testing and how the results should be disclosed. For example, some young people may wish to be informed of their test results without parents present or with an older sibling present instead. Others may prefer to be told their test result by their parents, instead of a genetic health professional. Young people may also choose to undergo testing in school holidays, or at the end of the school year. The important message is that there are many decisions related to the testing process that young people are capable of making. Allowing them to do so increases the likelihood of engaging them meaningfully in the process and acknowledges their emerging autonomy. Ensuring that young people have the opportunity to make these types of decisions about the testing process may require a concerted effort on the part of genetic health professionals and will rely upon some of the previous recommendations, such as appropriate information provision to young people directly and allocated time for young people to see their genetic health professional alone.

Finally, genetic health professionals should receive specific training and supervision concerning approaches for working with adolescent clients. Peters-Brown and Fry-Mehltretter [25] have initiated a dialogue regarding strategies to assist with the challenges of genetic counselling with adolescent clients. These include assuring confidentiality, being patient, remaining nonjudgmental, using nonthreatening questions, using visual aids to help define risk and using therapy techniques designed to obtain self-revealing statements [25]. Further dialogue is required in order to build expertise about working with young people in the field of clinical genetics [26].

In considering these findings, the limitations of the current study should be noted. All participants were tested at the same genetic testing centre in Australia. Participants' tests ranged from 2 to 9 years prior to their research interview which may well have affected recall. The predictive genetic tests described in the interviews were carried out between 1995 and 2002, meaning that current practice and protocol may have varied over this period and changed substantially since.

## Conclusions

Predictive genetic testing in young people for FAP is an ethically challenging undertaking. Such tests occur at a time of life when young people sit in-between the stages of childhood and adulthood and involvement of other family members is common. The young people interviewed as part of this study spoke about their predictive test for FAP as a major life event, yet they had little part in the decision-making process, little understanding of the process or consequences and often missed out on opportunities to be treated in a manner that respected their developing autonomy. There remains scope for adjusting current practice so that young people are engaged in ways that acknowledge their competence, empower them and respect their emerging maturity. In this paper we have drawn on first-hand accounts from young people who have undergone predictive genetic testing for FAP to offer insight into their experiences and suggest recommendations for future practice. These recommendations serve to highlight the importance of providing developmentally appropriate care to young people undergoing predictive genetic testing for FAP.

**Acknowledgments** We thank the 10 young people who participated in interviews as part of this study. We also thank Professor Susan Sawyer for her helpful comments on this paper. MBD is an NHMRC Practitioner Fellow. RED is an NHMRC Postdoctoral Research Fellow.

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