



Episode 31: Genetic Testing and Young People

Genetic Testing and Young People

VOICEOVER

Welcome to Melbourne University Up Close, a fortnightly podcast of research, personalities, and cultural offerings of The University of Melbourne, Australia. Up Close is available on the web, at upclose.unimelb.edu.au. That's upclose.unimelb.edu.au.

ERIC VAN BEMMEL

Hello, Eric van Bommel here from the Up Close podcast production team. As we enter the summer holidays here in the southern hemisphere, Melbourne University Up Close presents a special summer season of science. A mini-season of three specially produced fortnightly episodes, each featuring a young scientist in brief conversation on their specialised area of research. In this episode, the third and final of the summer season, we join Up Close science host, Dr Shane Huntington as he speaks with medical ethicist Dr Rony Duncan of the Murdoch Children's Institute, here at the University of Melbourne, Australia. Dr.Duncan's research looks at the ethical implications of medical science, especially in adolescent health.

RONY DUNCAN

Hello Shane, how are you?

SHANE HUNTINGTON

I'm good. Now you work in medical ethics, and I'm glad to get the term 'ethicist' out in one go, it is a little hard to say, now, not getting on to your work just yet, what sort of effects do we see of medical ethics out there in the community?

RONY DUNCAN

It depends on who is working in medical ethics and what their aims are, given their background. So, someone with a philosophy background working in medical ethics might be doing a lot of theoretical work, trying to understand, what the logical arguments around an issue might be. So, for example, what are the logical arguments for and against stem cell science? Or, abortion, or any of the controversial topics that you might see in the media. So, someone like that might be

working on the purely theoretical aspect of it ? so, understanding what the arguments are, which arguments are rational and which are not. Maybe looking to other similar cases in society and trying to work out whether a current position is consistent with previous positions and that stays in the theoretical aspect. Other people working in medical ethics, work in a much more practical way in terms of perhaps actually conducting research, empirical research and trying to add to the evidence base for medical issues. So, they might look at public opinion for example about stem cell science and add that area of research to the current debate. They might also work with policy makers, or politicians, doctors, counsellors, anyone working in an area where they face ethical issues, which let?s face it, is most areas of work, especially when we talk about medicine and science. And to help those people understand the issues and to understand what evidence we would need to come to a decision that society will be okay with.

SHANE HUNTINGTON

Now this is your half of the medical ethics world, the more empirical research part, and you work predominantly with young people.

RONY DUNCAN

Yes, definitely. So, I started my interest in ethics with a background in genetics and the topic that captured my interest to start with was the topic of genetic testing in children and genetic testing in adolescents, so, it is a very controversial area and it is written about quite a lot in the ethics literature. But obviously has a very practical focus in terms of genetics and counsellors and clinicians who are working with young people in the area of genetics. And so, I guess, through the process of doing a PhD project on that topic, working in ethics, I came to develop a strong interest in adolescent health, because I had to do a lot of reading around adolescent health and what happens as a teenager and why genetic testing might be more difficult for a teenager than it might be for an adult for example. So, I am now working at the Centre for Adolescent Health bringing my ethics expertise to that specific area of health.

SHANE HUNTINGTON

So, let?s get into some specific examples of that, I mean, I can imagine genetic testing being applied to young people where there is a family history or something to that effect, what are the ethical issues around that and why is it different for children or for young adults?

RONY DUNCAN

It is a great question. And it is fair to say that some people think it is different for teenagers and other people think that it isn?t any different for them. And I guess that is why it is a controversial topic. But to give you a brief run down, the example that we like to use, because it is a very easy example and quite black and white in many ways is, is the example of Huntington disease. So, someone with a family history of Huntington disease would be able to undergo a genetic test which would be called a ?predictive genetic test?, and that would give them information about whether they would go on to develop Huntington disease or not in the future, even though at the

time they have the genetic test they wouldn't be symptomatic. So it is really just giving information about their future health.

SHANE HUNTINGTON

So, I guess, it gives them an indication, a chance.

RONY DUNCAN

Absolutely. And Huntington disease is used as the example often because if you have a gene positive test for Huntington disease, meaning that you carry the mutation and that you will go on to develop it, there is a 100% certainty that you will go on to develop the condition and if you don't have the mutation you can be 100% that you will not go on to develop it. So it is very black and white. Whereas many other types of genetic tests we are dealing much more with probabilities and it is not quite so black and white.

SHANE HUNTINGTON

But it doesn't tell you when you will develop it, presumably?

RONY DUNCAN

It doesn't tell you when. It can give you an indication because Huntington disease is caused by a triplet repeat, and the greater number of repeats that you have, the earlier you tend to start developing symptoms, but it is very difficult ? it is far from being able to give you a specific age. And at this stage, unfortunately, we don't have any treatment or preventative means that we can offer people in relation to Huntington disease and the outcome is fatal after an awful 10-15 years of neurological symptoms getting worse.

SHANE HUNTINGTON

So, from the ethical standpoint, what is the question that you are asking with regards to, I guess, telling or not telling a young adult?

RONY DUNCAN

Well, in relation to teenagers, as an adult, if I wanted to have a test for Huntington disease, I could walk in as long as I had a family history and decide that I wanted to know that information about my future. But, at the moment, there are international guidelines that have been put out by the UK and Australia and Europe and the USA and they generally show consensus that they believe testing under the age of 18 years or under the age of majority, depending which country you are in, should be avoided. And that is because they are worried about the psycho-social harms that might occur for teenagers who find out that they are going to develop something like Huntington's or perhaps something like breast cancer or even in the future, perhaps something like Alzheimer's. And to find that information about your future as a teenager, when you are still developing, you are still developing close relationships with peers, you are still putting together ideas about what you might want to do for a career and for a future and in terms of having children and getting married perhaps that the concept is that it is very difficult to find that information out at that time of your life and therefore it should be avoided. There is also a big argument around

autonomy. And autonomy is a term that we use a lot in ethics. And I guess it generally refers to peoples' ability to and peoples' right to determine what happens in their own lives and to be in control of their own lives as long as those decisions aren't harming other people. And so when it comes to genetic testing in children and teenagers, the argument is that perhaps they are not mature enough and competent enough to be really making an autonomous decision about whether they want that information or not and if we allow them to have that information about their future or perhaps if we allow parents to test their children and therefore obtain that information what happens if those children then grow up and decide that they don't want that information and decide that they didn't actually make an informed choice?

SHANE HUNTINGTON

Now, you have been looking at this in empirical ways, so you've been presumably interviewing a lot of people and getting feedback on how real life situations have evolved or how this has occurred in one way or another, is that correct? And I guess, what are the outcomes of that?

RONY DUNCAN

Yeah, absolutely. So, I guess, when I came to this topic of genetic testing in children, there had been much written by lawyers and ethicists, clinicians and counsellors about the arguments for and against testing teenagers, but what I wanted to know when I started reading about the topic was what young people themselves thought. That seemed to me to be the first thing that I wanted to know when we were talking about all these very subjective impacts of having a genetic test, I wanted to know whether young people actually experienced those impacts themselves and how they felt about genetic tests that they had had. And it just seemed that there is very little empirical evidence about this topic out there. So I interviewed 18 young people between the ages of 12 and 25 who had actually been tested for either Huntington disease or another condition called FAP which stands for Familial Adenomatous Polyposis and that is another genetic condition that young people are routinely tested for. And so the idea was to interview these young people, to talk with them about what sorts of impacts that genetic tests had had for them, whether they felt any regret about them, whether it had changed their views on careers or relationships or all those aspects of life that would be impacted by knowledge about your future health and to try to understand the way that they had experienced the test and the time afterwards.

SHANE HUNTINGTON

Coming back to an earlier point, with regards to assessing competence to make these decisions, how do you go about assessing competence not just in young people but in general for them to take on such a load of information and react in, I'm not even sure what the term response means when someone tells you, you will have Huntington disease, how do you assess competence there?

RONY DUNCAN

Competence is a huge topic in medical ethics at the moment. And it is talked about very generally and you will hear people talk about competence assessments all the

time. But I guess in reality, when we are talking about competence, you have to relate the term to the situation that you are talking about as well. So, if we were talking about young persons? competence to vote or competence to consent to a genetic test, depending on what the situation is, the level of competence required and the types of cognitive processes that they would need to be able to go through are very, very different and so when we are talking about genetic tests for example, I guess, competence to make a decision about genetic testing would have to involve a range of things and they would include an ability to understand the nature of genetics an ability to think into the future and think in a very abstract way about what your future might hold and what sort of things your genetic information may affect. One of the examples is employment options or even insurance, health insurance discrimination, so, competence to understand those decisions and that information and also competence to understand, I guess, the impact the information will not only have for you on a personal level, but for your family and the people around you. And to think, not only about the information you would like today, sitting here, but what information you might like to have in 20 years time or what information you might not like to have in 20 years time. So, at the moment, in the rare cases that young people are tested for something like Huntington disease and for any adult who undergoes genetic testing, there is a certain process that they have to go through, which involves genetic counselling and involves multiple sessions with a genetic counsellor where people think through what it might be like to receive a gene positive test result, what it might be like to receive a gene negative test result and they think through all those issues over time to help prepare them and to think through those issues.

SHANE HUNTINGTON

Dr Rony Duncan, thank you very much for being a part of our summer series of Up Close.

RONY DUNCAN

Thank you, it has been wonderful.

ERIC VAN BEMMEL

That was Up Close science host, Dr Shane Huntington talking with medical ethicist Dr Rony Duncan. Melbourne University Up Close is brought to you by the Marketing and Communications Division in association with Asia Institute of the University of Melbourne, Australia. Relevant links, a full transcript, and more information on this episode can be found on our website at upclose.unimelb.edu.au. We also invite you to leave your comments or feedback on this or any episode of Up Close. Simply click on the ?add new comment? link at the bottom of the episode page. This program was produced by Kelvin Param and myself, Eric van Bommel, audio recording is by Craig McArthur and the theme music is performed by Sergio Ercole. Melbourne University Up Close is created by Eric van Bommel and Kelvin Param. Until next time, thanks for joining us. Goodbye.

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