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Guiding a Patient With Huntington's Disease

DISCLOSURE AND THE DIFFICULT PROBLEMS OF HUNTINGTON'S DISEASE

The uniqueness of being a genetic counselor in an adult-onset inherited life-limiting illness.

You are listening to ReachMD XM157, The Channel for Medical Professionals. I am your host, Dr. Maurice Pickard and joining me today is Dr. Robert Klitzman, the Associate Professor of Clinical Psychiatry at the Columbia College of Physicians and Surgeons. He co-founded and for 5 years co-directed the Columbia University Center for Bioethics and is currently the Director of Ethics and Policy Core of the HIV Center.

DR. MAURICE PICKARD:

Thank you very much for joining us.

DR. ROBERT KLITZMAN:

You are very welcome, pleased to be here.

DR. MAURICE PICKARD:

Today we are going to be discussing the very difficult problems of disclosing information to patients when you suspect or believe they might be a carrier of Huntington's disease. Tell me what is the process that you would go through initially in disclosing this kind of information?

DR. ROBERT KLITZMAN:

Well there are several issues. If you find out that you have the gene for Huntington or if you find out your risk, that is that one of your parents had Huntington's disease, you have to decide, who you should tell, when you should tell them, what you should say, whether you should say something, etcetera. So let's say that I find out my father who I just thought was a little nuts, turns out has Huntington's disease. Well that means that I have a 50% chance of having the gene and if I have the gene, if I don't die of something else first, I will die of Huntington's disease at about the same age that he did. So I then need to decide, will I get tested or not and will I give the fact that I am at risk, like give that information to my children, my spouse, my significant other, my siblings, my cousins, that they are at risk. It is a

whole set of issues and people may decide to tell older adult children, but not tell adolescents for instance you tell an 18-year-old you want that hanging over their head. So these are very difficult issues.

DR. MAURICE PICKARD:

Now you have the information and you want to be tested, how do you go about doing that?

DR. ROBERT KLITZMAN:

Well there is a problem, in that there is a shortage of genetic counselors in this country. There are about 1800 genetic counselors in the whole country and so some doctors in some areas work with a genetic counselor, who know one, others don't.

DR. MAURICE PICKARD:

Where do a doctor such as myself get this information. People are going to come to me and ask me to be tested and I am going to be poorly prepared, especially if I have been out of medical school for as long as I have. To really answer their questions or stay up to the current standard of information.

DR. ROBERT KLITZMAN:

Yes it's a major problem. I think CME classes. I think that there a lot of things published, books, journal articles, review articles. These are all very important things and its not only the science, but how do you talk to people. In many ways, this is akin to the early days of HIV testing and I as you know, recently wrote a book called Mortal Secrets - Truth and Lies In The Age of AIDS, in which I look at how physicians and patients deal and dealt with issues of should someone get tested. Whom do they tell, do they tell, what if they don't want to tell a sexual partner. What do you do with the fact that there is stigma and discrimination around, both genetic diseases and HIV and Huntington's disease, etcetera and what do people do in terms of risk behaviors that may transmit the either HIV to spouses or children or genetic disease to children. Should you have children, should you, if I have, lets say had the gene for Huntington, the mutation, should I adopt, should I abort, should I not have kids. Should I undergo preimplantation genetic diagnosis in which we screen embryos before they implant into a woman. These are all very difficult issues and I think clinicians need to just like, as I described in the book about HIV deal with a whole range of social, psychological, ethical, and legal complications.

DR. MAURICE PICKARD:

In another one of your books, When Doctors Become Patients, you talk about how difficult doctors are when they are given information. Now you have a group of people, who aren't even doctors and are given what one would consider very difficult information to process. How do they do it. Where do they turn, what is the next step in other words to get help. Is it a team approach that we should offer them?

DR. ROBERT KLITZMAN:

Well ideally team approach would be great, but we know that a lot of doctors don't work with a full team, so they may not have a genetic counsel there or a social worker or someone who could be comfortable dealing with these issues and I would argue that they need to find out who the genetic counsel in their community is, but there may not be a genetic counselor in their community or where they work

and so they need to be able to feel comfortable to at least begin to deal with these issues when patients raise them. As you pointed in the book *When Doctors Become Patients*, I found that many doctors would make assumptions about how much risk a patient would be willing to undertake and found they were wrong and that, in fact, the assumptions that doctors when they became patients found that their doctors made about them were often wrong. One doctor said that when he was diagnosed with a rare cancer. He found out that there was a new treatment that had been tried on one patient on the West Coast and he flew out to be the second patient. I said well would you ever suggest that for a patient of yours. He said, well of course not, but you know I can handle the risk and benefits. Well may there are patients who would also want to handle the risks and benefits and so as physicians we are trained to think well these are the risks and the benefits, but in fact how we weigh those may be different from patient to patient or how as patients weigh them maybe quite different. So similar with this, whether or not someone wants to take the risk of having a child with Huntington's disease. Whether someone wants to take the risk of lets say I have the mutation for breast cancer. Do I want to have prophylactic surgery done to remove breasts or remove ovaries. Should women have this done. These are very complicated issues. Let's say there is a woman who has been symptomatic in 1 breast and has a strong family history, she may decide to have surgery, but there may be women who have no symptoms, but maybe have 1 or 2 female relative who have had breast cancer, ovarian cancer decide to have prophylactic surgery done. So again as you described in the book, we need to discuss these issues closely with our patients. Understand how our patients look at them, how they would look at a positive test if they were to undergo testing and have a positive test, what their values are, who they would tell if they were positive and again we need to be prepared to have these conversations as a clinician.

DR. MAURICE PICKARD:

If you are just joining us, you are listening to the Clinician's Roundtable on ReachMD XM157, The Channel for Medical Professionals. I am your host, Dr. Maurice Pickard, and I am speaking with Dr. Robert Klitzman, and we are discussing the very complex issue of disclosing to patients that they are at risk from Huntington's disease and what to do about it and where to turn.

In your literature, you used a word thick description, meaning, trying to find out about a individual's own life and social situation. When you have that information, can you use it to the benefit of the patient.

DR. ROBERT KLITZMAN:

Yes, the notion of thick description is a term that anthropologists have used to describe a complete description of someone's world or aspect of someone's world. So if I want to find out, what is it like to have Huntington's disease and have to deal with these issues, I could talk to one patient for 5 minutes or I can try and understand the full range of issues involved from who you tell, when you tell them, and of course if you interview 25 people, as I did to rule out risk of Huntington's disease or had Huntington's disease. Each person's story is going to be different, but you look for patterns to understand the kinds of issues, the range of issues that patients state from the variabilities. So someone may not have any siblings. Someone else may be 60 and already had their kids. Someone else may be 32 and thinking of having kids. Someone may be unmarried and think well may be I shouldn't get married because I can't have kids. Someone may have symptoms, someone may not have symptoms. You want to understand what the range of issues are, and I would argue that to understand that range can be extremely helpful when dealing with patients because patients, who fit somewhere in the spectrum, right so you don't want to just focus on patients who have already their kids because you will find one who hasn't. So you want to try to understand the issues that patients are facing. If doctors were not well trained, to think outside our own point of view. We are trained this is how we should look at symptoms, but it turns out that patients who are dealing with these genetic issues in this case often look at these issues differently than we may assume.

DR. MAURICE PICKARD:

You mentioned 2 philosophers, Cecil Labach, who says you should never lie and David Nyberg, who seems to say what's so good about always telling the truth. Where do we stand with these 2 conflicting ideas when it comes to telling this kind of news.

DR. ROBERT KLITZMAN:

Well it is very difficult, my sense is that people try to do the right thing. On the other hand, they often are uncomfortable doing the right things. For instance I described in the book on HIV. There are mothers who don't want their 14-year-old daughter to know that she, that 14-year-old daughter has HIV, that she got from the mother at birth. So the mother may decide not to tell the truth, is that a lie, is that just a sin of omission versus one of co-omission. There is a range of approaches in attitudes and the problem is that patients may not tell siblings or not tell parents or not tell their children that they have these genetic mutations and they may justify and I think that doctors need to understand the range of issues involved. So the patient may say, I haven't talked to my sister in 20 years, why do I have to call her up and tell her she is at risk of Huntington's disease. Well a physician needs to know how to deal with that and these are often philosophical issues. So there is a range of feelings to understand alternate positions and present them to the patient is important. So if a patient says you know, I haven't even talked to her for 20 years, she didn't come to my wedding, why should I tell her that she might be at risk of Huntington's. Well may be there is a reason. Relationships in families are complicated. There is often tensions. There is often conflict. There is often very ambivalent feelings and parents may feel conflicted. On the one hand, they want to tell the child. They may feel guilty that they passed on this gene even though there is nothing they could have been done about it. Given these conflicts, people may not know what to do and so things end up getting blurred out because people haven't thought through carefully what to do. So that's correct, it often be it HIV or Huntington's or other genetic diseases, other mutations. People may say things without thinking what are the consequences of what I say. What should I say to this person. What if it is a 17-year-old or a 16-year-old, there is someone, who may not be able to fully process the information. There are people who would say, well you know I didn't know I was at risk of Huntington's so I was about to have kids and I was told my aunt or uncle who reportedly fell down the stairs and died, in fact, had Huntington's disease. So that may be too late in some ways to first tell someone after they are trying to have a child.

DR. MAURICE PICKARD:

You know, many of us think we know what we would do with prenatal information. I mean that's why PGD has become so well known in various types of in vitro studies are becoming so commonly used, but here we are talking about a disease that affects an adult, who may have enjoyed really many happy years and we are looking at only 1 disease and is it really fair to evaluate somebody's quality of life in the face of just 1 disease.

DR. ROBERT KLITZMAN:

That's a very good question and as I described in the book *When Doctors Become Patients*. Doctors when they become ill realize that they have looked at having a disease is quite different than what it is like to have the disease. That on the one hand patients often cope better on the other hand often spiritual issues often help patients more than doctors had thought beforehand. Often things like pain or nausea that we as doctors sort of don't really pay much attention to because they are nonspecific symptoms in fact are severely disturbing the patients and patients value that far more than the benefits they may be getting from say chemotherapy that may be ostensibly getting rid of cancer, but in fact, gives them a lot of side effects that they find worse. So and having the cancer in some cases or not even the side effects of medications, but are there medical problems. So, unfortunately we don't really know what its like to have a disease until we have that disease. That being said, as clinicians we obviously can't have every disease before we treat it nor we would want that on anyone. So we have to try to understand what its like to have a disease so we can be as empathetic as we can and that's partly why I have been doing the work I have, written the 6 books I have, writing about patients experiences to try to convey to physicians and trainees what the experience is like, so that they can be there for their patients as much as possible.

DR. MAURICE PICKARD:

Well many of use who practice and see patients everyday this kind of discussion makes us realize how important it is to begin to further

our information about being a genetic counselor. People are going to be coming to us. People are going to be asking us questions. People are going to get blood tests, on the internet and we have to be prepared. I want to thank Dr. Robert Klitzman for being our guest today and we have been discussing disclosure and the difficult problems of Huntington's disease. I am Dr. Maurice Pickard and you have been listening to the Clinician's Roundtable on ReachMD XM157, The Channel for Medical Professionals.

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This is Dr. Mich Cohen with Elma Family Medicine in Elma, Washington and you are listening to ReachMD XM157, The Channel for Medical Professionals.