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### HIV and the Costs of Non-Disclosure

Disclosure, a complex problem if you are HIV positive. You are listening to ReachMD XM 157, the channel for medical professionals. Welcome to the clinician's roundtable. I am your host Dr. Maurice Pickard, and joining me today is Dr. Robert Klitzman. Dr. Klitzman is the associate professor of Psychiatry at Columbia University, New York, Director of Ethics and Policy Core of the HIV Center for Clinical and Behavior Studies, Columbia University, and also the bestselling author of When Doctors Become Patients. He has also written Mortal Secrets – Truth and Lies in the Age of AIDS and Being Positive – The Lives Of Men And Women With HIV.

#### DR. MAURICE PICKARD:

Thank you very much doctor for joining us.

#### DR. ROBERT KLITZMAN:

You are welcome, I am pleased to be here.

#### DR. MAURICE PICKARD:

With there being evidence now that the disclosure of HIV status often has beneficial effects on AIDS epidemics, can you tell me what your research can add to this statement?

#### DR. ROBERT KLITZMAN:

Well, there are few issues. We know that disclosure can be good, that is, if someone has HIV, they tell their sexual partners in particular; however, we know that a lot of people do not disclose and they do not disclose and then proceed to engage in high-risk behavior. One person said to me, "well I told my wife that I am HIV positive, but I have not told the other chicks I sleep with," which I found very disturbing, "but why not?" "Well they are just chicks I sleep with" (1:30) and this person had all kinds of rationalizations, but you can imagine that when he does not tell these other women that he is having sex with that he is positive, they may not take precautions or ask him to take precautions, that is to wear a condom, and as a result they too may become infected. So especially since we now have good treatment, people may not even think they are at risk because no one has told them that they are positive when they are having sex with them.

**DR. MAURICE PICKARD:**

So people who are HIV positive continue to not disclose and also may continue to have unsafe sex. In your clinic, do you have evidence of this?

**DR. ROBERT KLITZMAN:**

Yes, and I should say not everyone by any means, and I would say most people overall do disclose and then there are issues if they do not disclose, many of those people perhaps most engage in use of condoms, but for instance in one study we did of gay men or men who have sex with men in four cities around the United States who are HIV positive, about 20%-25% did not disclose and engaged in high-risk sex with partners who they did not know were also positive, in other words, sometimes they will say, well the partner was also positive and that is why did not tell, but here, there are people who they did not know what the partner's HIV status was, they just did not disclose and they then engaged in unsafe sex; that is 20%-25% of people, that is a concerning number of people, and when you think that there are now 40 million people around the world infected with HIV (03:00) and that everyone who got it, got it from someone who is also infected. Technically, HIV is a very preventable disease, in other words, you do not get it from the air, right? So if everyone who is now positive said that they would not spread HIV to their partners, the epidemic would stop immediately.

**DR. MAURICE PICKARD:**

So you are saying that even though AIDS has become a chronic disease, there has not been a change in sexual practices either with a regular partner or with casual sex.

**DR. ROBERT KLITZMAN:**

Well, there has been some change, but I would argue not enough. So I think that, as I said, arguably probably most people either disclose or decide they are going to practice safer sex, but there are people who do not, and even if it is just 10% of people, that is 4 million people, and it is in the United States that is 100,000 people; we have about a million cases of HIV in the US or close to that, so, lets say well you will get the idea that even if it is 20% of the people, still that would be 200,000 people who are continuing to spread HIV so that is of concern and is a public health measure and of course people who were then infected and have not been told may then continue to spread it to other people and the problem is of course that it is a preventable disease, that is a shame of it and just think if we had pushed further 10 years ago when the epidemic was much smaller than the 40 million it is now, we would have had even less of a problem, so these are ongoing issues.

**DR. MAURICE PICKARD:**

With highly active anti-retroviral treatment, has this changed sexual practices, you touched on this. (04:30) Now that there are medications, has this changed safe and unsafe sex practices?

**DR. ROBERT KLITZMAN:**

Yes, it does and it does not, and I should say, by the way, as you mentioned in your introduction my book *Mortal Secrets – Truth and Lies in the Age of AIDS and Being Positive – The Lives Of Men And Women With HIV*, those two books both go into these issues in

greater depth, but it cuts both ways. On the one hand, there are some people who say "we know AIDS, now its treatable disease, it's no big deal, I don't have to tell people." Because, it's so what they get infected, they can go get treatment. At the same time, people may feel "You know I don't know sick, I don't feel sick, I am pretty healthy and we are not going to talk about sex," so there are people who say "well, my partner said are you healthy and I said yeah, so we had unsafe sex because I feel healthy, sure I am HIV positive, but I take my treatment, my viral load is 0, so I don't need to tell people." So a number of issues here, right? So one is how do people talk about this and how should they talk about it and the way in which there is huge ambiguity if we talk about this. So people may say are you healthy, yes, even though I am HIV positive someone may say right because they feel healthy. So we do not define these terms specifically. They are hard to talk about. They are taboo. There is a lot of stigma. There is discrimination, which I should say is why there are these problems with disclosure. People are afraid they will get rejected and these issues continue so on the one hand treatment is good, people feel healthier, you told that they have a positive attitude, but on the other hand some people may say (06:00)"well I don't need to tell now because I feel healthy and it's a treatable disease" and in the past when people looked sick or looked more ill they may have felt more stigmatized and felt more stigma and felt more of an obligation to tell or the fact that they were sick, people would come up, people would say well you have HIV. Whereas now the people look healthy, it is more out of sight and out of mind and that is a concern that people because of the treatment in fact may not tell.

### **DR. MAURICE PICKARD:**

If you are just joining us, you are listening to the clinician's roundtable on ReachMD XM 157, the channel for medical professionals. I am your host, Dr. Maurice Pickard and I am speaking with Dr. Robert Klitzman the author of the bestselling book *When Doctors Become Patients* and we are discussing the disclosure issues in HIV.

I look back at one of your first books *Being Positive – The Lives Of Men And Women With HIV* and there is a chapter in particular that caught my eye, "Disclosure," and I believe this book was written in 1997, so even in 1997 there was an issue with disclosure and I thought about all the men who are coming out and making a disclosure about the very fact that they were gay and that was something that was new to them. Now they have to disclose an entirely different issue, but you would think that having gone through it once, that might even be easier the second time and then I thought about you know if you came out and you said you are gay and suddenly you went through this stigma and isolation (07:30) that goes along with that possibly, you might be so hurt and burned by that first experience that you might not want to disclose about now I am HIV positive.

### **DR. ROBERT KLITZMAN:**

Yes, exactly. It is complicated because you think that people would say, I have been through that, I want to avoid secrecy, on the other hand some people realize that there are benefits to being closeted. You do not have to deal with stigma, you can pass as normal, so it can cut both ways. You would hope though that people would see the benefits of openness, but I should say here the people get rejected. People have told me now on, you know, I was not sure should I tell on the first date, the second date; if I tell on the first date there will never be a second date or may well never be a second date, if I wait too long, if I wait six months into relationship someone may say "well what's wrong with you, why didn't you tell me right away?" So in some ways it is still very, very difficult. I do not want to underestimate the degree to which one can face stigma and discrimination, how hard it is, face rejection, face ostracization, so it is a very difficult issue and I think a point here is that we need to be better as physicians, as clinicians in helping patients deal with this issues, to help them walk through what their fears are and have them realize, at least make an informed decision that realize, they should not just say "well I don't want to tell to be rejected, <\_\_\_\_> how would you bring it up later and weigh these different issues and I should say since I have started doing the work on disclosure of HIV, I have been involved with research and disclosure genetic issues and it is a similar issue. Do you tell someone that you are at risk of Huntington disease (09:00) or have the genes for breast cancer, when do you tell a spouse that you had different mutations that you might pass on to your children, for instance, and again physicians do not deal well with these issues there too. So I think the whole issue of as physicians' responsibility that we have to help patients deal with talking about their illnesses when they may be relevant with partners and family members is a very important issue that I think we need to give more attention to.

**DR. MAURICE PICKARD:**

I am going to ask you, just to shift a little, does disclosure help with patients adhering to their drug management or does it actually interfere?

**DR. ROBERT KLITZMAN:**

Again, it cuts both ways actually and I think that in some ways we hope that people feel better on medications that they will therefore see the benefit of taking the medication and they will not feel as shameful, as depressed, as anxious, and therefore they will be able to live more comfortably with being HIV positive and therefore they will feel less ashamed of it and be able to be more comfortable with it and integrate it more into their lives. On the other hand, one can imagine where someone may say, you know if I take the medication; I should say this is more when the medications first came out and had to be taken several times during the day, some people said "God! people see that I am taking medications at work, they wonder what it is, may be I should not take it or taking the medication may in fact out people, at least with people with work, so it can be complicated. I would hope though that being more comfortable with it if other people in your family know that you are positive, (10:30) they may be able to be source of support and encourage you to take the medication as well. So I think there are two behaviors that I think are linked in a complex set of ways, but hopefully can be synergistic.

**DR. MAURICE PICKARD:**

One of the things that caught me in your research was often disclosure is made in the format of when a general discussion is going on with the disease rather than when the topic is confined to sexual practices only. I wonder if we can learn something from this. That, in, as you would say HIV land, discussion of the disease itself and all its effects. That time would be the best time for disclosure rather than on a date.

**DR. ROBERT KLITZMAN:**

Yes, exactly right. I think that disclosing in context is very important. I should say one other area that comes up I think is of interest is disclosing at the work place, and here, again based on interviews I have done with other diseases, there is a whole set of issues about you tell people anyone at work that you have HIV or breast cancer or Huntington disease gene or a whole bunch of other illnesses and how we navigate these things and on the one hand we would like to get some social support if we need to take time off from work. On the other hand, we do not want to be discriminated against and so I think the example of HIV that is described in the books I think can help us navigate a whole other set of issues that we all face about what is public and what is private, how do we draw that line, where are their trade-offs in shifting the line being more public or more private about certain things about ourselves, (12:00) about disease or something else, substance abuse whatever it is.

**DR. MAURICE PICKARD:**

Well, I think we can say that whatever policy, law, or regulations come into effect, everyday moral norms and beliefs are going to make the difference and will be most significant in getting patients to disclose. I want to thank Dr. Robert Klitzman who has been our guest today and we have been discussing disclosure in the field of AIDS and HIV disease.

I am Dr. Maurice Pickard and you have been listening to the clinician's roundtable on ReachMD XM 157, the channel for medical professionals. To listen to our on-demand library, visit us at [www.reachmd.com](http://www.reachmd.com). Thank you very much. If you have any comments or suggestions, call us at 888-XM-157. Again, thank you very much for listening.

This is Col. Dr. David Crudo, Deputy Surgeon at US Army Pacific. You are listening to ReachMD XM 157, the channel for medical professionals.