Episode 71: Widows of Injecting Drug Users in North East India

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JENNIFER COOK
Hello and welcome to Up Close coming to you from the University of Melbourne, Australia. I'm Jennifer Cook. More than two and a half million people have HIV Aids in India. And in this episode of Up Close we are going to be taking an in-depth look at just how this disease has impacted the lives of women. The wives of injecting drug users often contract the disease themselves, which apart from the devastating health consequences can bring great stigma and shame to them and their families. This is compounded for widows who are often blamed for contracting the disease or are labelled as prostitutes. Then there is the plight of the women who turn to sex work to escape the cycle of poverty. We are speaking today with experts from the Nossal Institute for Global Health about some of the innovative programs that are helping women in the northeastern states of Nagaland and Manipur rebuild their lives in the wake of HIV Aids. This region, which has the highest levels of infection in India, also has its own special challenges being geographically, culturally and ethnically diverse. With me in the studio is Dr. Michelle Kermode, a senior research fellow with the Nossal Institute for Global Health. And senior program officer, Prarthna Dayal. Also, joining us by phone is David Humtsoe, the Nagaland state co-ordinator of Project Orchid. A project of the Emmanuel Hospital Association in India. Welcome to the program.
PRARTHNA DAYAL
Thank you.

MICHELLE KERMODE
Good Afternoon.

DAVID HUMTSOE
Hullo.

JENNIFER COOK
Michelle, if I could begin with you by asking you to outline briefly for our listeners just what it is about Manipur and Nagaland that makes this region so different to the rest of India.

MICHELLE KERMODE
Well the people of Manipur and Nagaland are indigenous people of India that come from a range of different tribal groups. They are ethnically, culturally and linguistically quite separate from India. And in fact more like Burmese, perhaps. Both states border with Burma. They see themselves as quite different. They are predominantly Christian which certainly distinguishes them from the majority Hindu of mainland India. Also, they are geographically quite isolated; they are connected to mainland India by a thin land corridor. So, there are a whole lot of factors that make them feel quite separate and distinct from the rest of the country.

JENNIFER COOK
And Prarthna, also language-wise, they are very diverse.

PRARTHNA DAYAL
Yes there are several dialects within each of those states and between the two states they have between 50-60 different dialects spoken, and many, many official languages.

JENNIFER COOK
And also, I'm wondering, Michelle if you could in clear focus for us just how big is the HIV Aids problem in this region.

MICHELLE KERMODE
In both of these states which as you mentioned are the two highest prevalent HIV states in the country. The prevalence of HIV in the general population exceeds 1%. It is 1.7% in Manipur and 1.3% in Nagaland. In some districts, amongst pregnant women, it is as high as 6%, among injecting drug users it is around 20% in Manipur and 2.5% in Nagaland. And particularly of concern is the HIV prevalence among sex workers. One study among sex workers in Dimapur, which is a large town in Nagaland, has found that between 2004 and 2006, there was an increase from about 4.5% HIV prevalence to 16.5%.

JENNIFER COOK
That’s an alarming rise. It seems that after you have outlined the complexities of this community, there are so many layers that have to be considered when it comes to this affect HIV Aids, I suppose, beginning to take it right back to how it begins with drug use, can you tell us a little bit about that?

MICHELLE KERMODE
So, historically in this part of the world, the HIV epidemic has originated through the practice of injecting drug use. Around 1-2% of the population have injected drugs at some stage or other which is very high. And, so, it has traditionally been thought of as a drug use induced epidemic. But increasingly sexual transmissions becoming very important. As evidenced by the fact that in some districts the rates of infection amongst women attending anti-natal care is quite high.

JENNIFER COOK
That was an extraordinary figure; I just want you to highlight that again, the number of pregnant women?

MICHELLE KERMODE
In some districts it is very low.

JENNIFER COOK
Yes.

MICHELLE KERMODE
But, in some districts it has been registered as high as 6%, which is quite high.

JENNIFER COOK
So, what we are seeing here, Michelle is this flow-on effect of drug use: the men contract the HIV, the unprotected sex with their partners, they then in turn contract the HIV and then have children.

MICHELLE KERMODE
So, I think we could say that it is transitioning, or has transitioned from being an epidemic primarily of drug users to an epidemic that is increasingly infiltrating into the general population and affecting women more and more.

JENNIFER COOK
Prarthna, I’d like to ask you, just what is it like for these women with HIV, living within this community?

PRARTHNA DAYAL
Well, sometimes they are blamed for it. If their partners pass away, the women share a lot of the blame for it from the in-laws and from the rest of the family and in the most extreme cases, are sometimes being thrown out of the house and not having a source of income or not having economic support for their children for themselves. But there is a lot of stigma that is attached to a woman whose husband has died of HIV and has HIV herself.
JENNIFER COOK
On top of the usual amount of stigma of being a woman in India?

PRARTHNA DAYAL
The hardships of being in that situation.

JENNIFER COOK
You’re listening to Up Close coming to you from the University of Melbourne, Australia. And I’m talking with Dr. Michelle Kermode, Prarthna Dayal and on-phone from Nagaland, the state co-ordinator of Project Orchid, David Humstoe. And so, how do they survive? How do they manage to continue to care for their children? That is on the physical level, but I am also thinking about their mental well-being. How do you get up and how do you function?

MICHELLE KERMODE
One of the projects we did, in combination with Project Orchid was to introduce a program to promote the mental health and well-being of widows of injecting drug users. Because a lot of these injecting drug users are young men and they have died from HIV or overdose of drug related issues. A large contingent of widows, some of whom are HIV infected themselves and some of their children are HIV infected. A lot of these widows are still living with their in-laws, but often under sufferance. But some of them are no longer with their in-laws and can’t return to their own natal families for reasons of stigma and discrimination and so a small group of widows may be engaging in sex work. Also of course, women who themselves are drug users will be engaging in sex work to raise money for their drug use. But one of the projects that we did, in 2006, was a participatory intervention in that it involved a lot of IDU widows in a series of meetings with the sole aim of promoting their own mental health and well-being. When we had done a situation assessment in 2004, we found these widows were often living in poverty, were very stressed, were very concerned about their future and the well-being of their children. But, while our interest was HIV prevention that wasn’t very high on their priority list. So, we decided to do an intervention that would connect more directly to their felt-needs.

JENNIFER COOK
And what were those needs?

MICHELLE KERMODE
Well the concept of mental health promotion is not about the treatment of mental illness. It is something separate. So in order to promote the mental health of individuals and communities there are really three determinants or three factors that influence that. And that is: social inclusion, freedom from discrimination and violence, and economic participation. So we designed this intervention around those three thematic areas. So, social inclusion, freedom from discrimination, and violence and economic participation. Initially it was very difficult to bring the women together. They all were very isolated, they had nothing to do with each other, but with the support of the NGOs and we had two very good research officers, one in Manipur and one in Nagaland. We were able to bring together groups of women for them to participate in
this process that was led to some extent by some of the women that we had trained. Some of the widows themselves that we trained to lead the groups. The women took to this passionately. And, for some of the women, there was some transformation in the lives as a consequence of discovering the power of coming together of getting the support of other women. We also made sure that in this program there was actually a lot of fun and joy.

JENNIFER COOK
And tell me how you did that? I’m really interested in the transformative power of this group? How did you make it fun and tell me how they changed?

MICHELLE KERMODE
Well, they did the transformation, we didn’t.

JENNIFER COOK
Well, you can’t really wave a magic wand.

MICHELLE KERMODE
No. We facilitated that process, but the local research officers and the women themselves who were peer facilitators worked with the other women in the group, using some guidelines that we would send through for each session? but they would adapt it, the peer facilitators and the research officers would meet beforehand and decide what would be the content of that day. So, there was some structured input about what’s mental health, what contributes and promotes mental health for women. They would have obviously a lot of debriefing themselves about some of the issues they had in their own lives, whether it was domestic violence or poverty or concerns about their children or trouble getting treatment for their HIV and they also would play games, sing songs. There were ten meetings all together spread over 20 weeks. And part of the process was for them to start as a group, collectively planning for how that group could be sustained and how they might as a group promote their own mental health and well-being in an on-going way. And for a lot of these women, their situation is constructed by them and their society and by us at times with them as victims and powerless. And we really wanted them to realise that there isn’t going to be a knight in shining armour who is going to ride in and rescue them and give them a large amount of money and make their life nice. That the strength had to be found within them. So, it is a strength-based approach. So, we didn’t spend a lot of time on what were their problems and difficulties and how terrible it all was. We tried to get them to build on their strengths and recognise what they were capable of. And to gather together collectively and take action.

JENNIFER COOK
That came through very clearly in one of the research papers that I read. I was struck by the story of a woman who talked about her anger. She had this terrible anger at the position she was in, how unfair it was and she talked about how she took that out on her children. And just through meeting other women through this Project Orchid, she realised she wasn’t alone. And that she could actually do something about her situation. That she could change her own attitude. That must be tremendously
rewarding when you hear that.

MICHELLE KERMODE
Sure, sure. And I think there were many similar stories for the women there where they came to realise, one, they weren?t alone, and that they didn?t have to necessarily be totally passive and a victim in that situation. And that they could take actions? sometimes only small actions to change their lives. So some of the groups started to do some income generating activities together. Others have just continued to meet as support groups for each other. There is one in Manipur that is meeting still, this is three years later without any funding, essentially, whereas initially there was some funding for them to travel to meet. And there are some quite startling examples. I?ll tell you about one woman in particular, when she was first brought to meet me, she was shaking. And crying. Because she was being harassed by her brothers-in-law for sex. In the home. And she just didn?t know how to deal with this. She was brought to meet us by the NGO, because they said, was there any way we could help her? And so, we put her in the role of peer facilitator in one of these groups. And she now works for an NGO for herself, as a worker, helping other women and through that process of those meetings and changing that way of thinking about herself and her role, she actually did come to make some negotiations with her family that stopped the parents-in-law being so hard on her and kept the brothers-in-law away. She was able to negotiate a way through that rather than just feel totally the victim of it. I still, every time I go back, I still see her. And she is definitely really grown through that process and feels much stronger and much more able to manage in her day-to-day life.

JENNIFER COOK
And that was just through that first step of sitting down with you, and I suppose, and telling someone about it and being heard.

MICHELLE KERMODE
I think more the coming-together with the other women and the going through the process of how can we promote our own mental health and well-being and taking some action to do that. And also being given that role of the leader of the group and she really stepped up to that role very strongly. It definitely has been transformative for her. She is a stellar example of the impact of this. Because this whole project, this whole particular project was just a pilot study to see how it would go. And at the beginning, many people were sceptical about it because they said, ?mental health? and ?HIV?, really, ?what?s the relationship?? But in fact, many people with HIV have mental health issues and many people who have mental health issues are at greater risk of HIV. So, there is a connection. And even though not all of these women were HIV infected, they were all widows of injecting drug users.

JENNIFER COOK
I just find it extraordinary, that the connection wasn?t so obviously apparent. If someone is struggling with a disease or the effects of it, especially a disease you have contracted through your husband, who then dies and leaves you? it is going to affect your mental health and well-being, isn?t it?
MICHELLE KERMODE
Absolutely. Especially in a context where there isn?t a lot of support and you feel very lonely and isolated.

JENNIFER COOK
That?s right. And add the layer of poverty to that as well. And then, the stigma and discrimination. You?re listening to Up Close coming to you from the University of Melbourne, Australia. I?m Jennifer Cook. And I?m talking with Dr. Michelle Kermode, Prarthna Dayal and on-phone from Nagaland the state co-ordinator of Project Orchid, David Humstoe. David, could you tell me about the story of some of the people that you have dealt with, which illustrates or shows us, how Project Orchid has made a difference to their lives?

DAVID HUMTSOE
Okay. One lady, she is a sex worker and initially near [indecipherable] and then slowly with the continuous meeting with the person and trying to help her understand things. Slowly, she was also like the NGOs, the partner NGOs who was also like helping her to change her mentality from sex worker to non-sex worker. She slowly changed her mentality, with the way of, the system of working that was, speaking up, and then slowly she was trying to give her best. With the support that she got from the NGO. And she slowly, she was also in that sense, in the beginning as a peer educator and then she was elevated to office worker. And now she is doing fine. I mean, she is, she has changed her mentality and, earlier she was into the sex work activities and now she has given up. And she is doing well as one of the staff of one of the NGOs.

JENNIFER COOK
So, now she is helping who may be involved in sex work.

DAVID HUMTSOE
Yeah, that?s right. She is helping the other women.

JENNIFER COOK
It must be very satisfying for you to see those kind of results. Life changing results.

DAVID HUMTSOE
Yeah. We see this not only with this individual. But we see lots of changes taking place, like even in the houses, because of the program. Directly or indirectly, it has helped even the family members. You know, where there was lots of quarrelling, you know, theft within the house ? drug user stealing things, lots of quarrelling in the family. A complete unhappiness in the family, which has changed, the person going through the program has changed and then once again peace has come into the family. There is no more quarrelling. So, I mean the quarrelling ? misunderstanding is there, but not like before when the person was into drugs.

JENNIFER COOK
So, Prarthna, what is your experience and what have you taken out of being involved
with this project? And what are the stories that you remember and the women you remember?

PRARTHNA DAYAL
Yeah, one of the things that we are trying to do through this project is showcase, really the positives of the stories of how people with HIV can be successful. They can lead meaningful lives. And because there is a lot of fear associated with it. There is this feeling that once you are HIV positive you are really good for nothing and just waiting to die. And one of the things we found was the self-stigma attached to being HIV positive or being associated with HIV. So, it has been very interesting filtering some of those stories of women and men who have gotten over that phase and been supported by their families and been able to do something with their lives. One of the stories we have showcased in Manipur is of a woman who contracted HIV through her husband who was from the armed forces and he had got it through injecting drug-use. And passed it on to her. And he died within a few months of their marriage. And she sort of talks through how she got herself out of that feeling of completely, that her life is over. And works for an NGO. She has been supported by her in-laws in doing that. And her mission is now to work with other women and support them.

JENNIFER COOK
This focussing on the positive and thinking. ?Look life, it is what it is but, we are moving forward. And here is some help and support to do just that.? So, Michelle did you measure the impact of these interventions of these programs?

MICHELLE KERMODE
Yes we did. At the beginning of the process we measured quality of life amongst these women, we also took a short measure of their mental health and we asked them about a range of physical symptoms that they experience. Because in India a lot of women experience distress through physical symptoms. And so at the end we repeated these measures and there was definitely statistically significant differences in their quality of life. In their mental state and in their experience of the symptom of pain in particular they experienced a lot less pain at the end of the intervention.

JENNIFER COOK
That is so heartening. Now Michelle, Project Orchid has also conducted a very interesting study into pathways into sex work. How women first come into this.

MICHELLE KERMODE
Yes we did a survey with 220 women and interviewed a number of women about how they first engaged in sex work, what happened with the first event of sex work and what led them to that point in their lives. And so, we were interested in the pathways into sex work. And what we found were four quite distinct pathways into sex work. This study was only done in Nagaland, not Manipur. And the first is one that most people are familiar with and that was certainly for the majority of women, it was an economic decision. They were living in poverty, or they couldn?t provide for their family and it was an economic decision to go into sex work. The second pathway was what we have called ?the drugs pathway?. Women who were
dependent on drugs. Heroin in particular. And a few women who were dependent on alcohol who went into sex work to buy drugs. The third pathway was those women who gave a story of having been either forced, tricked, or coerced into sex work. And, so that was another group. And the fourth group was women they said they did it for pleasure. And so these women, not only were there these four distinct pathways, but these women themselves were very distinct from each other. So, for example, the economic pathway and the forced, tricked, coerced kind of pathway, those women were mostly from outside of the state. These women were much less educated. They earned less money from sex work. They had much less control over the lives in many ways. Whereas the women who were in the drugs and pleasure pathway were much likely to be from the state. They were much more educated. The women who came through the economic and coerced pathway had a much younger age of sexual debut compared to the women who came through the pleasure or drugs, they were women who had a much later age of first sexual experience. So, there were a number of ways in which these women were seriously different from each other. And that has implications for HIV prevention in a number of ways. First of all you have got to target your programs differently. Because there’re are different languages, different levels of education, they are different reasons for being there in sex work and perhaps different reasons for not using condoms or for using condoms. But also, one of the key interventions to prevent the spread of HIV is to mobilise the sex workers as a group, as a community so that they can take action on their own behalf. But, when these women are so diverse, culturally, linguistically, ethnically, and coming from such varied backgrounds, and in sex work for a number of different reasons and having different capacities to look after themselves, it is hard to get them to come together and mobilise.

JENNIFER COOK
And that is without taking into account the stigma of being a sex worker.

MICHELLE KERMODE
Absolutely.

JENNIFER COOK
A lot might be doing it in secret or not necessarily wanting to tell people.

MICHELLE KERMODE
And at first we thought maybe the women from the pleasure pathway who were much more educated, and clearly, they earned more, much less sex than the others and were more educated, that they would be the ones to lead the mobilisation, but in fact, they have much less need of the mobilisation. Because they are pretty well able to look after themselves anyway and they are mostly local women and so they are not going to self-identify. Whereas the women who are more disadvantaged who came through the economic pathway or the forced, tricked, coerced pathway, could probably more easily identify because they are from outside. Their families aren’t there in the state as such.

JENNIFER COOK
So, this kind of a study is giving you essential information, isn’t it? On how to reach these women, how to empower them, how to keep them safe? It is crucial.

MICHELLE KERMODE
Well, it is giving us information on about how we might work to ensure that there is adequate representation of all the groups together. That in the NGOs who work with them, on the staff perhaps, there is representation of women from outside the state. As well as representation of women inside the state. That the materials that are available in languages that are accessible to not just Nagamese women, there are women from Assam and other states. And to think about if you are going to mobilise the group how are you going to get representation for all the different women that make up the community of sex workers in Dimapur in Nagaland.

JENNIFER COOK
So you need that kind of information to make sure that your programs hold.

MICHELLE KERMODE
Yes. Absolutely.

JENNIFER COOK
We’ve been speaking with Dr. Michelle Kermode and Prarthna Dayal from the Nossal Institute for Global Health. As well as David Humstoe, the Nagaland state co-ordinator of Project Orchid, a project of the Emmanuel Hospital Association in India. Thank you for your time.

MICHELLE KERMODE
Thank you.

PRARTHNA DAYAL
Thank you.

DAVID HUMTSOE
OK. Thank you.

JENNIFER COOK
You’ve been listening to Up Close from 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. You can leave a comment about any episode of Up Close by clicking at the link at the bottom of the page. Melbourne University Up Close is brought to you by the Marketing and Communications Division, in association with Asia Institute at the University of Melbourne, Australia. Up Close was created by Kelvin Param and Eric van Bemmel. And this episode has been produced by Kelvin Param and Miles Brown. Our audio engineer is Miles Brown and our theme music was performed by Sergio Ecole. I’m Jennifer Cook, until next time, thank you for joining Up Close. Goodbye.

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