

Hep C Conference – May 12, 2010 A Consumer's Perspective

Introduction

Good afternoon. My name is Pam Clifton and I am the Outreach Coordinator for the Colorado Criminal Justice Reform Coalition. I am here to talk to you about Hep C and a community folks don't often know how to help. This is the incarcerated community.

Nobody knows how many inmates in Colorado have Hep C. By some national estimates, around 40 percent of the 2.2 million in jail and prison are affected compared with just 2% of the general population. We know that a lot of people in prison/jail have Hepatitis C. A lot of people in prison/jail don't know that they have it. We also know that a lot of people give it to other people while they are there and those people give it to others when they get out. Over 95% of the people who are in prison will be released into community. Experts say that this will eventually become a crushing expenditure on an already overburdened public health care system.

The reality is that for those that are infected, very few can actually tell you when or where they were infected. Many have lived with the disease of addiction and many have lived around those with the disease. There are hundreds of ways to contract the virus. And many were unaware that the disease existed and didn't know how it could be contracted or how to protect themselves.

Personal History

In 1997 my husband died from a cardiac arrest. He was 40 years old when it happened. When his autopsy came back Hep C was also listed one of the problems that they found. I personally did not handle his death well and a few months later I was arrested on a drug possession charge and sent to prison myself. I was told after testing at the Department of Corrections that my viral load was high but there was never any follow up, so I didn't think about it again until years later. I went to the doctor in 2007 because I wasn't feeling well and after testing we discovered that I was infected with HEP C. I don't know for sure when I was infected but it was probably the year that my husband and I were married. He was a heroin addict in his former life and had been in recovery for 8 years when we met. Where did he get infected? Where didn't he get infected?

In The System

When people begin their journey through the criminal justice system it usually begins at the county jail level. The Denver County Jail, for example does not currently have the budget to offer testing proactively and unless you are presenting signs of liver disease doesn't have the resources to provide treatment either. If you are merely serving a county jail sentence then you probably won't find out if you have HEP C. At this point there is also the issue of continuity of care for people who are in treatment and then may be locked up for a short time. The risk factors for contracting the disease are the same in jail as they are in prison.

Prisons and tattoos and drugs often go hand in hand. Other dangers include unprotected sex and just the simple fact that you have hundreds and sometimes thousands of people living jammed together in a very small place. I asked some people I know that have had those prison/tattoo experiences about why people put themselves in the position where they might get infected. I wanted to know why men get tattooed in prison. Tattooing is not as prevalent in a women's prison. It's a practice but it's not nearly as common as in the male facilities. The answers I got were not unexpected or too far off track from what I assumed.

On the streets when young men join gangs they must often wear the brand of the group that they belong to. When you enter prison you may have to be able to show who you are aligned with, and that ink does the trick. Serving dual purposes it can actually save your life or get you killed. Many men become gang members while in prison because gangs offer protection. In order to be affiliated they must get that ink and there are no sterilized tattoo shops in any American prison that I am aware of. There are also tattoos of significance. Your children's or loved ones names are always popular. In some cases, it's remembering the one good thing that you have in the life you left behind. Whether it's a spider web or a tear drop they all mean something. It's a silent form of communication but one that is important.

It's difficult and it's illegal to give or get tattoos while in prison. The materials used have to be smuggled and assembled or handmade. Folks can't just go out and buy new needles after each tattoo so there is always significant risk involved. They will use whatever they can find or manufacture. There is a long and slightly disturbing list of materials used to give tattoos: Needles from sewing kits, staples, safety pins, pencil leads, guitar strings or paper clips. Tattoo guns are made from old shavers, walkmans or tape recorders. And ink? Ink can be made from rust, cigarette ashes, toothpaste, hair shampoo and pen ink. Do people who engage in this behavior know how risky it is? Usually, but they don't realize how far reaching the disease is or how easily it is transmitted. Bandages, towels and the ink itself are all breeding grounds, not just the needles themselves. The reckless lifestyle they may have led to may have slowed down once they got locked up but, in most circumstances nothing that has happened since they got to prison has changed their attitude.

In some cases it's more about immediate daily survival because of the protection that comes with the tattoos and they don't really care about the possibility of a chronic disease they don't know much about or don't understand very well. They may just be worried about making it through the night not what their liver is going to look like in twenty years.

Personal health is not the primary focus for people who are in prison. The simplest part is the fact they can avoid many of the substances that aggravate their disease such as alcohol and drugs but even if they wanted to make a change they still can't eat healthy or even obtain supplements and vitamins that could at least stave off the progression until a time came when they could properly take care of themselves. People are paid between 25 and 60 cents a day in prison and then 20% of that is taken out for Child Support and

Restitution payments. They are required to pay for everything they need including basic hygiene items (soap, shampoo, toothpaste etc.) to supplies required to write letters home. The prison prices are about the same as things cost at a seven-eleven. Doctor visits are \$5. So, sixty percent of a month's pay would be spent because you need to see the doctor. Many will just go without medical attention.

Incoming inmates are screened for HEP C at the Denver Reception and Diagnostic Center. It is unclear what the follow up protocol is for folks who test positive. The Department of Corrections currently offers treatment for Hep C at the community standard. One barrier to Hep C treatment is the DOC requirement that people have to go through substance abuse treatment for six months prior to starting. The problem with that of course, is that substance abuse treatment is not available at all facilities. It doesn't matter if you never had a substance abuse problem either, you still have to go through the treatment. (FYI. Substance abuse treatment does not include AA or NA)

Folks who are closer to being released are going to get access first to substance abuse classes and Hep C treatment. The lists to get into substance abuse treatment programs are long and people closer to getting out are prioritized. Therefore if you have a lot of time to do it may take years before you can access substance abuse treatment and therefore years before you can access HEP C treatment.

I also believe another one of the big problems with going through treatment in prison is fear. Fear of what the side effects of treatment will be like and the inability to access the things that comfort the side effects of treatment. One of the issues with DOC is that they may not allow you to just stay home sick all the time. Is it possible to just be in your room and be sick and not go to work for days at a time without losing your job or getting in trouble for failure to work? That depends on a lot of variables.

DOC will most likely not let you live in your own room. Most facilities are double bunked. It would be difficult to live in a very small room with another person without some sort of mood stabilizer being afforded to you. Hep C treatment can make you vacillate between suicide and homicide. Vomiting, fevers, muscle aches and pains are difficult not only for the person who is going through it, but the person who is locked in a room with you. It is also possible that people refuse treatment because they the perception, whether it is valid or not is that if you are sick it will harm your chances to be released to community corrections or on parole.

When people are released into community it can happen through a couple of different avenues. You can be released back into the community through a halfway house/community correction facility. You will be required to sign off on paperwork absolving DOC and Community Corrections from any responsibility for your medical care. In this situation the Department of Corrections and/or community corrections is not responsible for providing you with any health care. If you don't have personal health insurance you are required to pay for everything yourself. When you get to the halfway house you are required to have a physical done and so you can at least find out how bad things are. It is important to realize the people who are released are mostly unemployed

and can be for quite some time. If and when they do find employment, if that position doesn't offer health insurance then they are still unable to access health care. People who are in community corrections aren't eligible for any public health programs like CICIP because they are still considered "inmates".

You can discharge your sentence and not be under any supervision or you can of course leave the Department of Corrections on parole. Under both scenarios you may apply for CICIP if you are indigent and may qualify for treatment depending on where you live and whether it's available. It's important to pay attention to those who are being released and not getting adequate care because when people are sick they often lose hope and the ability to fight when there just doesn't seem to be anyway they can win. There are so many barriers in place that there are folks who will actually commit criminal acts just to get sent to jail or prison so that they can get the medical or dental care that they need.

After I was off of parole and I went to work where I had health insurance, I was able to afford treatment which I successfully completed and have been virus free for three years. Thousands of people don't have that. We don't do enough to educate people in prison or jail about the disease and how to protect themselves. There are avenues we can take because it's important to realize that we release 10,000 people from prison annually. If the national estimate holds true then there are 4,000 people infected with HEP C every year being released into our communities. Forty percent of that 10,000 will return to the Denver metro area.

There are several things that we can do to help this population. Developing strategies and working with the prison to be more proactive. For example, in Canada there is a pilot program that was started about four years ago that has created vocational opportunities by operating tattoo shops in five or six different facilities. The shops are run by the inmates who must attend classroom instruction. The materials are sanitized and the artists are able to learn a viable career.

Putting condoms in prisons is another smart response. In the United States, only two state prison systems and five local jail systems make condoms available to inmates (the states are Mississippi and Vermont. The cities are Washington D.C., San Francisco, Los Angeles, New York, Philadelphia) for example, the prison-based condom-access program at the California State Prison in Solano. Originally there were concerns that condoms would be used as weapons or as a hiding place for drugs have not borne out in practice since the one-year pilot began in November. It costs about \$25,000 per year to provide medical care to one HIV-positive inmate, while the provision of condoms costs a fraction of that. Inmates are allowed one packaged condom at a time. The condoms are dispensed through seven machines in at the prison, where 1,000 inmates are housed.

The next big component is education. A few years ago CCJRC wrote a book called "Getting On After Getting Out". CCJRC is primarily a sentence and policy reform group but we are often called on to advocate and advise those who are in prison. Instead of trying to disseminate information and dispel myths one inmate at a time, we wrote the guide so that we could distribute them free to those who were currently incarcerated and

get the correct information out to people in regards to how they can successfully complete their prison sentences. Accessing health care and what people can and can't do was included in the guide. We distributed nearly 30,000 copies to prisons and community corrections facilities throughout Colorado. Perhaps a booklet on Hep C can be developed and brought to the prisons and jails. It is important to realize the limitations of the folks inside when it comes to education level and whether or not they can speak English. Putting information in every library and in medical office would be a great start. Posters or brochures. I know that the reality is that resources are limited. It may take some creativity to make this happen. I think the most important thing is that we don't forget about this population because they are coming home.