WHEN EPIDEMICS COLLIDE: OCD AND AIDS

By Fred Penzel, Ph.D.

Our planet is currently in the throes of a major health crisis. I am referring to AIDS. The average person's life has been influenced in a number of ways by this modem-day plague. Unlike previous decades, individuals no longer feel as free to have unprotected or casual sex. Medical and dental facilities have become far more careful about disease control. Blood supplies must be constantly screened. Police now wear gloves when searching certain suspects, as do food workers when serving meals.

There is also a place where this epidemic unfortunately crosses paths with another, less well-known epidemic: Obsessive-Compulsive Disorder. There are those with OCD who have obsessive thoughts about contracting AIDS, and the results can be extremely punishing. These fears are actually part of a larger group of obsessions about contamination. One of the main features of OCD is that sufferers have difficulty in determining just how risky certain things are. Sufferers often confuse possibility with probability: if something can happen, it will happen, no matter how unlikely. Unfortunately, for those with fears of AIDS, there happens to be a lot of media hysteria concerning the disease and how it can be contracted. As a result, it is not unusual for even the average individual to have unreasonable fears of people with AIDS. Even so, the average person's worries still do not tend to be as exaggerated or illogical as those of someone with OCD.

OCD sufferer's notions of how the disease can be contracted don't usually stop at the three most common ways: sharing infected needles, having unprotected sex, and receiving contaminated blood transfusions (which all happen to be direct blood-to-blood contacts). For the obsessively doubtful, almost anything that anyone else has touched can become a potential source of the disease.

The following situations are quite typical of this type of OCD, and are seen as high risks for contracting AIDS:

- Touching any red specks or spots anywhere, because they could be blood from an infected person
- Being near anyone who looks unwell or is very thin, or is disheveled or homeless, or who could be an addict

- Having blood drawn or having injec-tions, even with new, packaged needles
- Going to hospitals, doctors' offices, dentists, medical labs, or any place where ill persons gather or medical procedures are done
- Being near people who are, or who in the sufferer's mind, appear to possibly be, homosexual
- Being near health-care workers
- Touching doorknobs, light switches, or handrails in public places
- Getting cuts or scrapes where the virus could enter
- Fearing that they may be stabbed or struck by someone carrying an infected needle, or having thoughts that they may have stepped on a discarded syringe lying on the ground (they may even have false body sensations that this has happened)

This list is by no means complete.

A common variation on the fear of get-ting AIDS is the fear of contracting it, giving it to someone else, and then having to live with the guilt of having caused an innocent person's death. These sufferers may also have other problems with feeling overly responsible for others, another main theme among those with OCD. For these people, you could add this to the list above:

- Touching loved ones or touching anything else in public or in their homes (if giving AIDS to family members is the problem).

Getting and staying uncontaminated can be an excruciating 24-hour-a-day job. When sufferers are contaminated, they worry about getting perfectly clean. When clean, they worry about staying that way. They can only begin to feel comfortable when they are in control of everyone and everything around them. They wash and shower to excess when they believe they have touched something containing the AIDS virus, and they can often be spotted by their bright red, chapped hands. They will usually only touch feared things using barriers such as tissues, paper towels, or gloves. Every little cut or scratch may have to be covered with medication and a Band-Aid to keep the virus out. Anything possibly contaminated must be washed or disinfected, or else it must be thrown out. (Actually, most of these descriptions could be applied to the majority of people with contamination fears.)

To try to make this impossible task easier to manage, sufferers create "dirty" and "clean" worlds for themselves. They have places they can go and things they can do only when they are in a "contaminated state." The same is true for when they feel "clean." Certain rooms or locations can only be entered when sufferers themselves are "clean." One of my patients even had a

"clean" car and a "dirty" car. When family members fall under a sufferer's control, they have to wash and change clothes whenever they enter the house, or else face a lot of upset or arguing.

Obviously, all this gets to be debilitating as the disorder takes over. Leaving the house can become extremely difficult. Some people stop socializing, or stop going to work or to school. In addition, sufferers tend to avoid or put off needed visits to physicians and dentists, and they may develop other health problems. In reality, all of the above are solutions designed to escape the doubt and anxiety, but they only end up helping in the short run. Unfor-tunately, in the long run, as sufferers use these methods, they only train themselves to be better avoiders who keep their fears going. Avoiding only convinces them that the fears are real, and it prevents them from actually seeing that the dreaded consequences never occur. Ironically, what starts out as a way to help control the anxiety ends up controlling and damaging their lives via a downward spiral of fear and avoidance. For those who do not suffer from these anxieties, it is difficult to appreciate just how gut-wrenching and debilitating they can be.

So, what do you do to get out of this kind of predicament? The answer (one that sufferers do not usually want to hear) is to learn to face the fearful obsessive thoughts while resisting the compulsions to escape and avoid. Behavior therapy is the key to accomplishing this. If you are a regular reader of this newsletter, you probably know that the type of behavioral therapy known as Exposure and Response Prevention (E&RP) is presently the best and most thoroughly proven way to do this. Success rates have been shown to be 75 percent or better.

E&RP is a retraining process. Basically, sufferers are encouraged to allow them-selves to be more and more unclean for longer periods of time as they try to carry out a growing number of average activities when they are "contaminated." By staying with what they fear, sufferers gradually become accustomed to acting in more normal ways in everyday situations, and they slowly begin to trust the idea that nothing catastrophic will happen. They learn that they can allow the fear to subside on its own, without taking any special actions, and that they can rely on this to happen. Double-checking, questioning, and asking others for reassurance or help in cleaning are discouraged and gradually eliminated. Friends and relatives are instructed to not participate or assist in these activities. They are shown that rather than helping or easing the suf-ferer's anxiety, they are only contributing to keeping that person in a helpless state.

The therapy process can sometimes be tricky as sufferers' obsessions work over-time to create more doubts about these issues. They ask, "How can doing the things I fear will give me AIDS help me to feel less anxious today, since it could take 10 years to find out if I will develop AIDS?" The answer, of course, is that the problem they are having doesn't really exist in the future, but within their own faulty judgment about taking risks in the present. OCD is not just a

set of biological or behavioral problems, it is also a set of information-processing problems. Learning to challenge illogical thinking is another important part of the process. I like to ask patients if there is any scientific evidence to support their self-protective actions, or any reports of AIDS contracted according to their special theories. I also question why average persons don't live as self-destructively as the sufferer lives, yet manage to live just as long. Sometimes sufferers will answer: "Most people are ignorant. If they knew what I know, they would do as I do." When questioned as to where they get their unique information from, they of course cannot point to anything other than the same TV shows or news articles available to the rest of the population. When pressed, some severe sufferers will even admit that having AIDS couldn't be much worse than the personal hell they have created for themselves.

Working with a trained behavior therapist, either in an intensive daily program or in weekly sessions, you practice doing the things you fear to do. At the start of therapy, you work with the therapist to construct a list of all the places and activities that would give you difficulty if you stayed with them and didn't avoid. Each item is rated on a scale of 0 to 100. This list is known as a hierarchy. Next, a program of behavioral assignments is laid out for you, based upon the listing you have made. No one forces you to do things or surprises you. Typical homework assignments may include the following: (these are in no special order):

- Shaking hands with others
- Eating in a restaurant and not wiping or cleaning the silverware
- Touching light switches, door knobs, mailbox handles, etc.
- Sitting on public benches, using public phones or rest rooms, taking public transportation
- Bringing home items from stores and not washing or wiping them
- Visiting a local hospital and sitting in the waiting room, using water fountains, phones, or rest rooms, or eating in the coffee shop
- Bringing such things as brochures or napkins home from a hospital and touching them to your belongings
- Touching books about AIDS in a bookstore or library and even buying or borrowing them so they can be used to "contaminate" things at home
- Allowing yourself to be near, or to touch people who look as if they could possibly have, AIDS
- Not washing or changing clothes immediately upon coming home from being outside, and allowing family members to do the same
- Limiting hand-washing to just a few times per day and to only 10 seconds per time
- Limiting showering to only 10 minutes per time, and to no more than once per day (even less often if this has been a serious problem)
- Listening to audio tapes several times daily telling you that you have AIDS (or will give it to others)
- Resisting putting band-aids and disinfectants on every tiny cut or scrape

This last type of assignment is gradually made more anxiety-provoking, and is designed to increase your tolerance of your obsessive thoughts to the point where you can feel free to disregard them. Not washing, wiping, or otherwise undoing assignments after they are carried out is extremely important. To do so would be to cancel out any benefit they may have.

Medication can often be important to overcoming OCD. It should not be an end in itself, but should be seen as a tool to help you take part in therapy. It can provide a level of improvement from which to begin working. Not everyone requires it, but there are many who could not carry out behavioral assignments without the symptom relief it provides. It may also reduce feelings of depression, which can then result in a person feeling energetic and having a more posi-tive and motivated attitude about working toward a recovery. Antidepressant drugs such as Anafranil, Prozac, Paxil, Zoloft, Luvox, Celexa, Serzone, and Effexor are all currently being used to relieve the symptoms of OCD and depression. There is no best drug as everyone responds differently to them. Medication for OCD has been discussed in other articles in past issues, so I will not go into further detail here.

Recovery from this problem is possible. Many have already achieved it. Don't feel helpless or give up hope. Find your-self a behavior therapist trained in the use of E&RP, as well as an experienced psychiatrist if you need one. Don't assume that every practitioner is qualified to treat OCD. Be a good consumer and find out how many cases of OCD they have actually treated and if they use the most up-to-date approaches. Call the OC Foundation for names of practitioners in your area, or get names at a local OCD support group.

If you would like to read more about what Dr. Penzel has to say about OCD, take a look at his self-help book, "Obsessive-Compulsive Disorders: A Complete Guide to Getting Well and Staying Well," (Oxford University Press, 2000). You can learn more about it at www.ocdbook.com