DES DAUGHTERS AND ABNORMAL PAP SMEARS

DES daughters are often worried about whether their DES exposure will cause them to develop squamous (flat) cell cancer of the cervix. This is the common form of cervical cancer found in women in their 30s and older. It is different from "clear cell adenocarcinoma", associated with DES exposure, which develops from glandular cells and is most commonly found in the vagina although it can sometimes begin on the cervix. From the best evidence we have so far, DES daughters are no more likely to develop squamous cell cancer of the cervix than other women.

STUDIES OF ABNORMAL PAP SMEARS IN DES DAUGHTERS

The studies of DES daughters carried out by the large DESAD (National Cooperative Diethylstilbestrol Adenosis) project funded by the US government have shown no higher rates of pre-cancerous cell changes in DES daughters than in unexposed women. The largest of these studies looked at pap smears in 4,589 women. Rates of abnormal pap smears in DES daughters and unexposed women of similar age and background were compared. DES daughters had a slightly lower rate of abnormal cells than the unexposed women to which they were compared. Rates for DES daughters were 1.8% during the time of the study, and 3.2% if abnormal pap results from before the time of the study were counted. In British Columbia, 4% of pap smears taken each year come back classified as abnormal. It's not surprising that the rates for abnormal paps in B.C. as a whole are a bit higher than the rates in this study, as the women in this study were mostly in their 20's, younger than the average age of women getting pap smears in B.C.

Most studies of abnormal pap smears in DES daughters have found low rates, ranging from 0-3% for all abnormal results, and 0-1% for dysplasia classified as moderate or worse.

However, several studies of DES daughters show much higher rates of abnormal pap smears, ranging from 6 - 18%. These have all been studies of much smaller numbers of women than those in the DESAD project, and the women have not been compared to a group of unexposed women of similar age and background.

ERRORS IN DIAGNOSIS

One explanation for the high rates of abnormal pap smears in some studies of DES daughters but not others is that cell changes which are normal for DES daughters are being misdiagnosed as dysplasia (abnormal cell changes).
Adenosis is the most common change DES daughters have in their vagina and on their cervix. Adenosis means that glandular cells normally found inside the cervix are found on the vaginal wall and on the outside of the cervix. A DES daughter who has adenosis will find that as she grows older the adenosis is gradually replaced with normal tissue. The process of replacement is complete by around the time a woman is 30. This replacement process is called 'squamous metaplasia' and it involves the growth of a layer of flat (squamous) cells on the part of the vagina and cervix previously covered by adenosis. As this growth gradually occurs, many of the new flat cells will be immature and they will look different from mature flat cells normally found on the surface of the cervix. Pap smears taken when this normal regrowth of the surface cells of the cervix is occurring can sometimes be mistaken for dysplasia, a term which refers to abnormal cell growth which in some instances may progress to cancer.

If the lab technician and the doctor taking the pap smear do not know that a woman is a DES daughter, they can be much more likely to confuse the changes on her cervix for dysplasia. She may be referred for a colposcopy, a microscopic exam of her cervix. Under the colposcope her DES-related changes can still look a lot like the changes that occur when an unexposed woman has dysplasia or carcinoma in situ (localized cancer of the cervix). Biopsies (small samples of tissue from the cervix) will be taken, but when the biopsy specimen is looked at in the lab, the colposcopy report is taken into consideration. If the colposcopy report looks bad, the person interpreting the biopsy specimen may be influenced to think that what she or he sees is worse than it really is.

If you are a DES daughter and have an abnormal pap smear result, be sure that the doctor taking the pap knows you are DES exposed and sends that information to the lab with your pap smear. It is also important to know how up-to-date your doctor is in her or his knowledge of the effects of DES. Have your pap smears taken as part of your regular DES exam with a doctor who is knowledgeable about DES exposure, if possible.

It is important for all women to get a culture to see if they have an infection at the same time as having a pap smear done, because an active infection can cause changes in the cells of the cervix which look similar to dysplasia. If you have an infection, treat it until it has cleared up and then go for another pap smear.

In one study of 37 DES daughters with abnormal pap smears, 43%-almost half- had infections on their cervix of the papilloma virus which causes vaginal and cervical warts. These women were followed without treatment for 14 months, and in two-thirds of the women the warts went away by themselves and the pap smears returned to normal. When a woman gets an infection of warts on her cervix, it is rare to get an actual raised lump like a wart on your skin, so it is important to insist on being tested for papilloma virus if you do get an abnormal pap smear result.

**COMPLICATIONS OF CRYOSURGERY AND CONE BIOPSY**

The most common types of treatment for abnormal pap smears are cryosurgery (freezing the abnormal tissue on the cervix to remove it) or cone biopsy (where a wedge-shaped piece of the cervix is cut off). DES daughters are
more likely to experience difficulties as a result of either of these types of surgery than women who have not been exposed to DES. It is thought that DES daughters have more problems from surgery on their cervix either because DES affected tissues heal differently than other tissues, or because the opening in the cervix (the cervical canal) can be narrower in DES daughters than other women.

In one study of 42 DES daughters who had cryosurgery performed, 74% of the women developed cervical stenosis. 10 In the same study, 3 of 5 DES daughters who had cone biopsies developed stenosis, as well as 1 of 4 women who underwent electrocautery.

Cervical stenosis is a condition in which the os, the opening of the cervix, no longer opens as wide as it should. In some cases the os can become completely blocked off so that a woman cannot menstruate and must have surgery again to open it up. Cervical stenosis is normally a very rare side effect of cryosurgery or cone biopsy. About 1% of the non DES-exposed women who had cryosurgery done developed stenosis in the same clinic in which three-quarters of the DES daughters who had cryosurgery developed it.

Cervical stenosis can cause a woman to have very painful periods, and it can cause her to become less fertile or infertile. In one study of infertile DES daughters, 11 women had previously had surgery on their cervix, and of these 11, 9 developed endometriosis. Endometriosis is a condition in which the tissue lining the uterus, the endometrium, is also found outside of the uterus. When a woman menstruates each month, the tissue outside the uterus will undergo the same type of changes as the tissue in the uterus, and a woman may have some menstrual-type bleeding into her abdominal cavity. It is thought that women with cervical stenosis can develop endometriosis because some of their menstrual fluid may flow up and out of the fallopian tubes into the abdominal cavity because the opening in the cervix is partially or almost totally blocked.

It is therefore even more important for DES daughters to avoid unnecessary surgery on the cervix than other women. Because DES daughters may also be more prone to having their normal cell changes misdiagnosed as dysplasia, this means being very cautious if you have an abnormal pap smear result. You do not need to rush into a decision to have cryosurgery or a cone biopsy done if you have had an abnormal pap smear result. If you are being pressured by your doctor for an immediate decision, you have the right to refuse and to insist on time to think it over. Some women choose to try alternative treatments and improving their general health for a period of time, to see if their abnormal pap smear result reverts to normal. (See the article "A Feminist Approach to Pap Smears", available at the Women's Health Collective, for information on treatment options.) Obviously, this can be a difficult decision to make, and what you choose to do will depend on your particular situation. If you are convinced that you do need cryosurgery, it is important to be sure that the os is not touched if there is no abnormality on or around the os itself. Focal cryosurgery, which only removes those areas with abnormal tissue, can be done with the help of a colposcope.

PREVENTION

There are things you can do to lessen your chances of having an abnormal pap smear. If you are using birth control, don't take birth control pills;
use a barrier method such as a diaphragm or condoms and foam. If you are a smoker, try to quit. Some of the recent studies of cervical cancer have shown that smoking increases a woman's risk of developing it. Eating well—especially getting plenty of B vitamins, vitamin A, and vitamin C—can lessen your chances of getting an abnormal pap smear. Finding ways of reducing stress and getting enough exercise can also help improve your health so that your body is more resistant to all diseases, including cancer.

CONCLUSION

As a DES daughter, you are no more likely to develop squamous cell cancer of the cervix than a woman who has not been exposed to DES. However, you are more likely to be wrongly diagnosed as having dysplasia or what are called pre-cancerous changes on your cervix when the cells are going through normal DES-related changes. This is especially true if your doctor and the lab do not know you are DES exposed. You are also more likely to develop complications from surgery on your cervix.

It is important for all women to learn more about what abnormal pap smear results mean to be able to make an informed decision about what to do when a pap smear comes back abnormal. Often, the fear of cancer will push a woman into having surgery without thinking about other possibilities. Many women think they have cancer when they have abnormal cells, or dysplasia. It is misleading to call these changes 'pre-cancerous' because they sometimes turn into cancer with time and sometimes simply disappear. Doctors simply don't know enough about cancer to be able to guess whether the abnormal cells on a particular woman's cervix will become cancerous or not.

If you have an abnormal pap smear, it can be helpful to talk to other women who have been in the same position. The Vancouver Women's Health Collective (ph: 736-6696) provides supportive and informational counselling for women with abnormal pap smears. We also have files with more information on pap smears which you can come and look through.

Footnotes


PAP SMEARS: What Test Results Mean*

When reports are returned to the doctor or clinic that submitted them, they will include the following information:

- a class number between I and IV
- a written cytological interpretation (interpretation of the cells)
- it may include a possible diagnosis
- labelled mild, moderate or marked (severe)
- it may contain a recommendation for further investigation for example, repeat Pap in 4 months or colposcopy (microscope examination of the cervix).

In understanding the results, the written interpretation of the cells is more important and accurate than the class number. The meanings of the reports are as follows:

**Class X.** Sufficient cells not seen. This means either there were not enough cells on the cervix or the practitioner did not take an adequate smear.

**Class I.** No abnormal cells seen.

**Class II.** Abnormal cells are present. Inflammation may be seen (from infection, for example) or abnormal cell changes (dysplasia). There may also be a comment on the state of maturation (stage of cell growth). Some of the cells that are normally deeper in the surface layers of the cervix may be seen on the outside layer. These (dyskariotic cells) are growing at an abnormal rate because the usual growth pattern is to develop in the inner layer and move outwards.

**Class III.** This category shows very abnormal growth with evidence of severe dysplasia or carcinoma in situ (cancer contained in a localized surface area).

**Class IV.** This smear contains cells that may be similar to Class III, but with evidence the lab considers shows that the cancer has spread beyond the local area.

*From "A Feminist Approach to Pap Smears" by Robin Barnett and Rebecca Fox, Kinesis supplement, February 1983.
ABNORMAL PAP? WHAT YOU CAN DO *

When you receive notice of an abnormal Pap smear there can be many explanations for the result. Here are some suggestions about what to do when you hear the news.

1. Make sure that your doctor will help you take the cautious route. If s/he pushes you too much, maybe you should seek one who will help you approach this situation conservatively.

2. Ask for a copy of the PAP report so that you know exactly what it says. Sometimes the number classification is not as important as what the descriptions says.

3. Even if your smear report does not mention infection, check the culture. If there was none done, then do it now. Also remember that if you have had an outbreak of herpes, warts or any other genital/vaginal disease at the time of the smear, you should clear that up and then repeat the smear at mid-cycle.

4. Once you are sure that you do not have any infection or virus then you can consider the next step. If you receive a result of Class III or IV, or possibly a moderate to severe dysplasia, your doctor will then recommend that you have a colposcopy.

*From "A Feminist Approach to Pap Smears" by Robin Barnett and Rebecca Fox, Kinesis supplement, February 1983.