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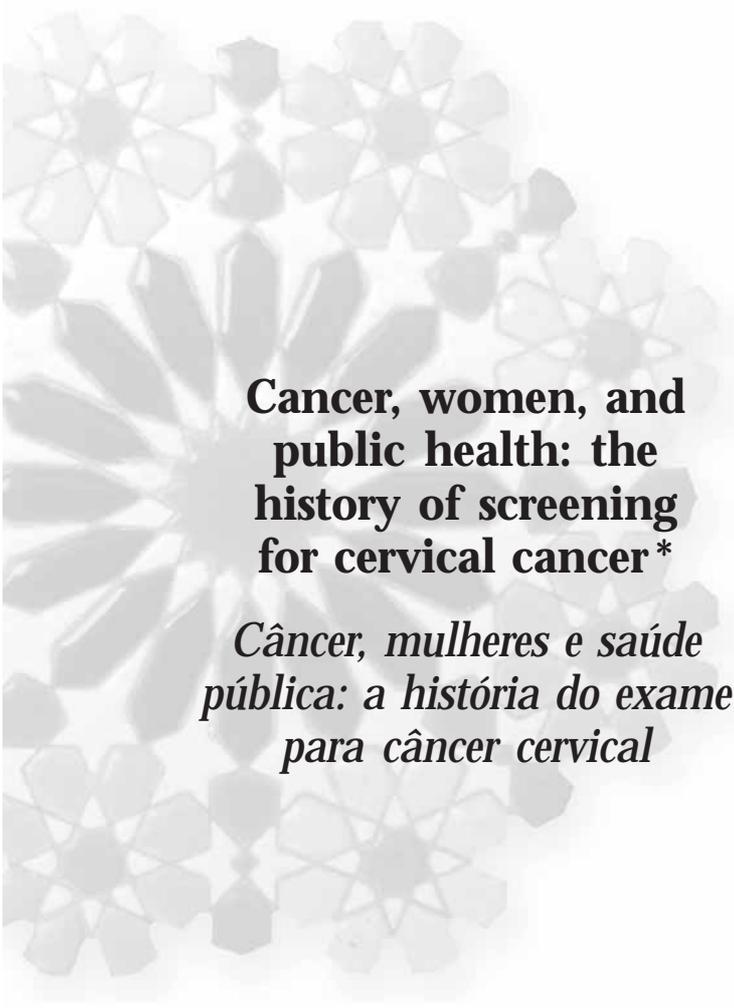
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Cancer, women, and public health: the history of screening for cervical cancer *

Câncer, mulheres e saúde pública: a história do exame para câncer cervical

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Abstract

Cytological screening for cervical cancer (the Pap smear), the first attempt at mass screening for a human malignancy, is often presented as a non-problematic demonstration of the feasibility of such screening. Screening for this tumor became a model for screening for other malignancies: breast, colon and prostate. My text follows the early history of the Pap smear and the conditions that led to its transformation into a routine screening test, despite persistent problems in stabilizing the readings of microscopic slides. It then analyzes the consequences of diffusion of the Pap smear, controversies surrounding this test, the mutual shaping of diagnostic tests and the disease cervical cancer, and the problematic extension of the lessons learned in screening for cervical tumors to other malignancies.

Keywords: cervical cancer; Pap smear; cancer screening; cancer activism; public health.

Resumo

O exame citológico para verificação do câncer cervical (teste de Papanicolau), primeira tentativa de investigação em massa de um câncer humano maligno, é com frequência apresentado como demonstração não problemática da exequibilidade do exame. Ele se tornou um modelo para outros tumores malignos: seio, cólon, próstata. O presente artigo analisa a história inicial do teste de Papanicolau e as condições de sua transformação num exame de rotina, apesar de dificuldades de estabilizar as leituras das lâminas microscópicas. Analisa as consequências da difusão da técnica, as controvérsias a esse respeito, a modelagem articulada do teste diagnóstico e da doença câncer cervical e a problemática aplicação a outros cânceres das lições aprendidas com o exame de tumores cervicais.

Palavras-chave: câncer cervical; teste de Papanicolau; exames para câncer; campanhas contra o câncer; saúde pública.

Cervical lesions: “cancer,” “precancer,” or “cancer risk”?

Cytological screening for cervical cancer (the Pap smear), the first attempt at mass screening for a human malignancy, is often presented as a demonstration of the feasibility of such screening. Screening for this tumor became a model for screening for other malignancies: breast, colon and prostate. My text follows the early history of the Pap smear, its diffusion, and its transformation into “the right tool for the job” (to quote Monique Caspar and Adele Clarke), despite persistent problems in stabilizing the readings of microscopic slides and the multiple meanings of these readings (Casper, 1998). It analyzes the consequences of the stabilization of the Pap smear, remaining controversies surrounding this test, the mutual shaping of diagnostic tests and the disease “cervical cancer,” and problems with the extension of lessons learned in screening for cervical tumors to other malignancies.¹

The first instrument that allowed physicians to look directly at the cervix – the speculum – was developed in the early nineteenth century. Gynecologists equipped with a speculum were able to perform cervical biopsies. Pathologists who studied such biopsies occasionally uncovered superficial (that is, non-invasive) lesions of the cervix. Probably the first description of such a lesion was made by British professor of midwifery John Williams in 1886. In his Harveian Lectures on uterine cancer, published in 1888, Williams described a lesion of the cervix, “the earliest condition which is recognizable as cancer. It presented no distinctive symptoms, and was discovered accidentally.”²

This last statement is important. Lesions identified as “early cancers” and later described as “precancerous” do not induce symptoms. They can be discovered either by chance or through a deliberate effort. In the 1930s, Viennese gynecologist Walter Schiller (1933) became interested in superficial proliferative lesions of the cervix. He was the first to follow the development of such lesions over time. Serial biopsies from the same patient displayed several stages of transition from a normal epithelium to a malignant one. Observation of such intermediary stages, Schiller argued, proved that preinvasive lesions of the cervix were the true precursors of malignant tumors. Schiller was persuaded that his series of slides demonstrated without any possible doubt that superficial lesions of the cervix are very early stages of cervical cancer. He proposed therefore to call these changes “young carcinoma” and strongly rejected the argument that the term “carcinoma” should be reserved for invasive lesions only:

the objection that the carcinomateous layer is not carcinoma because it does not penetrate deeply is equivalent to saying that the embryo of a mouse has not the characteristics of a mouse because the embryo does not breathe through his lungs as a grown-up mouse does. [...] We do not speak about “prehuman” embryo but a “human” embryo, and I believe that the same thing applies to cancer: there is a “carcinomateous” layer, but not a “precancerous” layer (Schiller, 1933, p.214).

Schiller (1933) was a great proponent of the detection of such superficial lesions of the cervix through colposcopy and the Lugol test (painting the cervix with a diluted iodine solution). He affirmed that the only acceptable treatment for a “young carcinoma” was a radical hysterectomy by Wertheim’s method, followed by radiotherapy. Not all gynecologists

adopted Schiller's point of view. Some were not persuaded that superficial proliferative lesions of the cervix were indeed early stages of a carcinoma. They proposed a more conservative treatment of such lesions: either local removal of zones of proliferation or the amputation of the cervix alone (Novak, 1929; Martzloff, 1932). The observation that some of the women who underwent conservative surgery developed invasive cervical tumors, however, led to a change of policy and to a wider adoption of an aggressive treatment of superficial lesions of the cervix.³

At the same time, gynecologists had found that in spite of important progress in the treatment of cervical cancer (radiotherapy, radiation therapy, surgery, and combinations of these), cure rates for this malignancy stabilized at approximately 30%. The main reason for the persistence of high mortality rates, many specialists argued, was the absence of symptoms of early cervical cancer; when symptomatic, the disease has often already spread. Hence the need to find a way to detect presymptomatic cancer through regular gynecological visits and, Schiller proposed, regular colposcopic examinations (annual or, even better, bi-annual). This was, however, an expensive proposal. Moreover, the colposcope (invented in Germany in the 1920s by gynecologist Hans Peter Hinselmann) was popular only in German-speaking countries; doctors elsewhere were not familiar with use of the colposcope, and they might have resisted the performance of time-consuming routine tests. The solution came from an unexpected direction: the development of a test ("exfoliative cytology") grounded in the examination of vaginal smears.

"Excessive proliferation": cells and potential patients

Exfoliative cytology of the cervix was later named the Pap smear after New York pathologist Dr. George Nicholas Papanicolaou, the physician who developed it. Papanicolaou first observed abnormal cells in vaginal smears in 1928.⁴ In 1941, together with gynecologist Herbert Frederick Traut, he published a more extensive description of his diagnostic approach. The Pap smear was rapidly adopted by gynecologists. Women with suspicious vaginal smears were subjected to a biopsy by curettage, a cervical biopsy, or both. In many cases this method led to a diagnosis of previously unsuspected malignancies. At first, the sole aim of exfoliate cytology was the detection of invasive carcinoma (McSwezy, 1948). However, with the generalization of this method, many women who underwent biopsy following an abnormal Pap smear were diagnosed with either well-defined pre-invasive cervical lesions (carcinoma in situ), or less pronounced proliferative changes (dysplasia). Both diagnoses were problematic, because experts were not sure what the status of such lesions was. Gynecologists initially believed that cervical lesions were irreversible and always led to malignancy. However, epidemiological data, which juxtaposed the prevalence of in situ tumors and invasive malignancy, indicated that the prevalence of cervical dysplasia was much higher than the prevalence of cervical malignancies. These data strongly suggested that the majority of cervical lesions did not progress to malignancy, but might stabilize, or even disappear.

In spite of uncertainties about the fate of non-invasive cervical lesions, in the 1940s and 1950s, gynecologists usually promoted radical treatment of such lesions. They assumed

that even if some of these lesions grew so slowly that they would never produce invasive cancers in the woman's lifetime, it was safer to view them as true malignancies and treat them accordingly.⁵ This conviction was grounded in solid clinical data. Practically all women diagnosed with "stage 0" carcinoma of the cervix in the early 1950s and treated by hysterectomy remained cancer free.

Some specialists were nevertheless reluctant to perform hysterectomies on young, fertile women diagnosed with superficial cervical lesions. Moreover, the readiness of doctors to perform radical hysterectomies varies greatly. This operation was (and continues to be) very popular in the United States, while it was less popular in some European countries, such as France (Weisz, 2005).

Among the specialists who disagreed with systematic radical treatment of superficial cervical lesions was Jens Nielsen, director of the Radium Centre in Copenhagen, who in 1943 complained about the lack of data as to how often, with how long a latent period, and in what manner the so-called precancerous became frank cancer. In order to provide such data, Nielsen's collaborator Olaf Petersen (1955) initiated a prospective clinical study of the development of precancerous lesions of the cervix. Petersen identified 212 women diagnosed with an epithelial hyperplasia with nuclear abnormalities. Nearly all these women came to the Radium Centre clinics with gynecological complaints. All underwent cervical biopsies and were diagnosed with precancerous conditions. Eighty-five of these women – mainly those diagnosed with borderline malignancies – underwent treatment, usually a radical one (radium therapy or hysterectomy). One hundred twenty-seven women were left untreated, but underwent an annual gynecological and clinical examination and a cervical biopsy. It is not clear on which basis women were allocated to each group, but this was not a randomized clinical trial. The majority of the women were recruited circa 1943 and observed for ten years. Petersen's study ended in 1953.

One third of non-treated patients selected for this study developed invasive cancer of the cervix. The frequency of malignancies increased with time. After three years, thirteen women in the non-treated group developed cancers, while all those in the treated group remained cancer free. The clinical experiment continued however. After five years there were twenty-two cancers among the non-treated women and one case among the treated ones. In spite of the great number of malignancies, the observation of the non-treated group continued for an additional four years, in which twelve more women in the non-treated group (and none in the treated group) developed cervical cancer.

Petersen's data may be read as a persuasive argument in favor of radical therapy of non-invasive cervical lesions. On the other hand, such radical treatment was far from innocuous. Two of the eight women who underwent radical hysterectomy died from complications of this operation, and six among the sixty-six women treated with radium suffered severe side effects from this therapy; one remained permanently incapacitated. Among the thirty-four patients who developed cancer in the non-treated group, five died of the disease; others went into a remission after treatment. Peterson's main conclusion was that the treatment of non-invasive lesions of the cervix was not an emergency. When a woman who complains about irregular bleeding or other gynecological problems is diagnosed with a non-invasive cervical lesion, there is no need to make hasty decisions.

The patient can be safely observed for a year at least, ... to see if her lesions regress or progress before deciding which treatment will suit her best (Petersen, 1955).

In the 1950s, oncologists grappled with the clinical meaning of cervical carcinoma in situ. They knew that some – but by no means all – carcinoma in situ lesions may progress to become invasive cancer, while others remain stationary or regress. The estimates of the percentage of lesions that progress to cancer varied widely. Moreover, and more disturbingly, there is no safe way of separating the indolent from the potentially aggressive lesions. Gynecologists were unable to uncover stable correlations between a morphology of a lesion and its fate (G. Koss et al., 1963). The unavoidable conclusion was that gynecologists should treat all cervical lesions, however superficial, although such treatment is not an emergency: cervical lesions usually grow very slowly (Gad, 1976; Galvin, 1952).

The growing consensus about the need to intervene in each case of proliferative cervical lesions did not lead to an agreement about the nature of such an intervention. At many places, (especially German speaking countries and the US) preinvasive epithelia carcinomas were treated as aggressively as the “most locally advanced but still operable cases” – that is, with extensive elimination not only of the uterus, but also surrounding tissues and lymph nodes (O’Donnel, 1998, p.172-175). In other countries, gynecologists favored more conservative approaches. Gradually, however, radical surgery was phased out everywhere and replaced by local treatment of cervical lesions. This shift is related to two independent events: (1) the finding that cervical lesions were very fragile and were frequently destroyed by a diagnostic biopsy, and (2) the parallel rapid increase in the number of women – often young and fertile – diagnosed with superficial lesions of the cervix, thanks to the wide diffusion of the Pap smear (Koss et al., 1980; Benedet et al., 1982).

Saving women: pressures to generalize the Pap smear

The Pap smear was initially promoted by gynecologists and cancer experts, but charities, women’s organizations, and politicians soon became interested in this test.

The publications of the American Society for the Control of Cancer (ASCC) were from the very beginning (the 1910s and 1920s) mainly dedicated to female cancers: breast and uterus (Reagan, 1997). One of the goals of the ASCC’s educational campaigns was to fight the false modesty that prevents women with signs of a gynecological disease from consulting doctors. In 1930, Joseph Colt Bloodgood, one of the leading cancer experts in the United States, founded the Amanda Sims Memorial Fund (ASMF), named after the wife of the donor who helped to establish it, the carpenter John E. Sims. This fund was dedicated nearly exclusively to raising women’s awareness about cervical cancer. ASMF’s director, Florence Becker, a nurse and public health activist, efficiently spread the message about the need to pay attention to gynecological symptoms among women’s organizations and women’s clubs (Gardner, 2006). The educational campaigns of both ASCC and ASMF (the two organizations collaborated frequently) were at least partly successful. While Bloodgood complained in the 1930s that less than 10% of women visited their gynecologist regularly, newspapers in the 1950s reported that women then went for their pelvic examinations as casually as they went shopping (Gardner, 2006; Reagan, 1997).

ASCC's and ASMF's campaigns were aimed at the detection of already existing, symptomatic, cervical malignancies, but they familiarized women with the idea of frequent gynecological examinations and opened the way to screening for asymptomatic (clinically silent) cervical lesions. In light of ASCC's long-standing interest in early detection of cervical cancer, it is not surprising that its heir, the American Cancer Society (ACS), became strongly committed to the early detection of cancer and promoted the slogan "every doctor's office is a cancer detection center" (Day, 1959, p.448-451; Breslow, 1959).⁶ From the early 1950s on, the ACS energetically supported diffusion of the Pap smear.⁷ The ACS sponsored the First National Cytology Conference (Boston, 1948) and funded the training of pathologists by George Papanicolaou. The generalization of exfoliative cytology was also supported by the National Cancer Institute and the U.S. Public Health Service (Vayena,1999).⁸

At first the early detection campaign of the leading British cancer charity, the British Empire Cancer Campaign (BECC), covered all malignant tumors. Doctors who worked with BECC acknowledged, however, in their internal publications, that indiscriminate use of the early detection slogan might be problematic: early detection of stomach or liver cancer does not improve chances of survival.⁹ The BECC experts therefore elected to focus on cancers in which early detection (that is, the detection of small, localized tumors) is strongly correlated with a better prognosis. Lecturers for the BECC campaign were told in the 1930s to focus on breast and uterine cancer, especially if the public was feminine: "by contrast, it is a poor idea to speak about stomach cancer. There is no early diagnosis, and people with slight indigestion will believe they have cancer."¹⁰ In the United Kingdom, advocacy of early diagnosis became increasingly understood as a call for the detection of women's malignancies.

In spite of BECC's interest in early detection of female tumors, this charity, unlike the ACS, did not play an important role in the diffusion of Pap smear in the United Kingdom. BECC's director, Malcolm Donaldson, visited the United States in 1950 and was impressed by the ACS- sponsored network of 125 cancer detection clinics, dedicated mainly to the diagnosis of cervical malignancies.¹¹ He believed, however, that such an initiative was not possible in Britain because the National Health Service could not be persuaded to make a substantial investment in cancer screening. He was overly pessimistic. A grassroots initiative of a group of women, the Medical Women Federation, an association founded in London in 1879 to promote women in medicine, led to the establishment of a national screening program in the United Kingdom. In the 1960s, the MWF became the main organized force behind the Women's National Cancer Control Campaign. The idea to start such a campaign emerged from a February 18, 1964 meeting of the Stoke Newington Liaison Committee of Women's Peace Group, in which a doctor, invited to speak about women's health, explained that 3,000 women die yearly in the United Kingdom from an easily preventable disease. One of the participants at this meeting decided to found a committee dedicated to the promotion of the Pap smear. She contacted the MWF, who was immediately interested. A Labor parliament member, Joyce Butler, joined the MWF's committee for cervical cancer screening and helped to put this issue on parliament's agenda.¹²

The National Cervical Cancer Prevention Campaign was founded in January 1965. It was sponsored by the MWF and also supported by the National Council of Women and

the Women's British Legion. Joyce Butler was named the Campaign's president. The MWF had links with multiple political associations: the Labor Party, Association for Maternal and Child Welfare, the Family Planning Association, National Council of Women, British Society for Clinical Cytology, and the Communist Party's Women Committee. One of the Campaign's first successes was to promote debates on screening for cervical cancer in the Parliament and the House of Lords. The British government decided to encourage screening through providing financial compensation for doctors who collect samples and the opening of cytological laboratories. The number of screened women tripled between 1964 and 1966, as did the number of technicians who read cervical smears. In 1966, screening for cervical cancer was proclaimed a national service by the British government, and the National Health Service (NHS) established local co-coordinating committees to implement such screening, along with regional laboratories that centralized the collection of vaginal smears and their reading.¹³ This approach did not work very well and in the early 1970s British health authorities decided that the most efficient solution would be to switch the responsibility for Pap screening to general practitioners, supervised by public health physicians (Singleton, 1993).

Even in countries such as France, where there was no "extra-professional" pressure to introduce the Pap smear, public health experts stressed the importance of screening for cervical lesions to improve women's health (Sicard, 1996; Garnier et al., 1997). The old image of cervical cancer as a "mother killer" was then combined with newer demands, of feminist inspiration, to replace the universal male body as a standard for "normal" by paying greater attention to the specific health needs of women.

Saving the uterus: from radical to conservative surgery

Before diffusion of the Pap smear, cervical dysplasia, superficial cervical lesions, and "carcinoma in situ" – a term that was contested by some specialists – were seen as rare and unusual conditions (known as "zebras" in medical jargon; doctors joke that when a medical student hears the sound of hooves, he immediately thinks "oh, it must be a zebra"). With the development of the Pap test, zebras became horses, that is, a rare diagnosis became a very frequent one. It was difficult to propose hysterectomy or radiotherapy to all the women diagnosed with such lesions.

One of the key questions opened by the generalization of the Pap smear and consecutive cervical biopsies was the percentage of in situ lesions that progress to cancer, compared with those that remain stationary or regress. To complicate this issue even more, gynecologists noticed that a biopsy, the technique that makes cervical lesions visible to doctors, usually destroys these lesions (Stewart, 1980). The great fragility of cervical lesions was a major obstacle for studies of their natural history: lesions observed by doctors disappeared as a result of manipulations that made them visible. Such fragility was, however, an obvious advantage in treating these lesions. The semi-accidental observation that carcinoma in situ of a cervix can be readily eradicated by a variety of minor surgical interventions led to a generalization of local treatments. The initial aim of screening for cervical tumors was the cure of a potentially aggressive early cancer with an equally aggressive

surgical approach. Later, however, the aim of screening was redefined as the identification and elimination of weak, poorly established cervical lesions (Welch, 2004).

Agreement on the principle of treatment of all lesions did not put end to debates on what counts as a “cervical lesion”; the local treatment of surgical excision by conical biopsy or destruction of a lesion by thermocoagulation (and more recently by laser treatment) is less aggressive than radical treatment, but it is not an entirely benign procedure. It was therefore important to define the boundary between the normal and the pathological in cervical cytology, not an easy task. In 1956, twenty-five pathologists were sent twenty identical borderline slides and were asked to determine how many of the lesions were precancerous and how many should be classified as true malignancy. The results displayed a perfect Gaussian distribution: three pathologists found no cancer, three a single case of malignancy, and, on the other end, four had found nine cases of true cancer, one found twelve cases, and one found thirteen such cases (Sieler, 1956). Because pathologists were not able to agree what a preinvasive lesion of the cervix was, they provided widely divergent estimates on the occurrence of such lesions in the general population. In the 1950s, such estimates varied between 0.02% and 3.5%. At first sight, disagreements of that magnitude between the specialists should have become an insurmountable obstacle for the development of mass screening campaigns. This was not the case, however. The absence of homogenous diagnostic and prognostic criteria did not hamper a rapid diffusion of the Pap test and the generalization of screening for premalignant cervical lesions.

The Pap smear was never truly standardized or made fully reliable. It was also never tested in randomized clinical trials. It became, however, “the right tool for the job.” The criteria of differentiation between dysplasia and *in situ* cancer remained fluid. In the 1970s too, pathologists readily acknowledged that “one man’s dysplasia is another man’s carcinoma *in situ*” and that the progression of a precancerous lesion to invasive cancer is an unpredictable process. They proclaimed nevertheless their confidence in the efficacy of screening for cervical malignancies.

Casper and Clarke (1998) explain the practical success of exfoliative cytology as a result of the development of an efficient division of labor between cytotechnicians and pathologists, the replacement of attempts to create universally valid classifications by a locally negotiated order, and the regulation of laboratories. One can add two additional elements: the role of colposcopic examinations and cervical biopsies and the acceptability of a high level of overtreatment. The Pap smear became gradually perceived as a prescreening rather than a true diagnostic test. A positive result was seen above all as an invitation for a further exploration, usually by colposcopy and, if necessary, cervical biopsy. In the interwar era, the colposcope was seen mainly as a research tool (Petersen, 1955:27-28). The diffusion of the Pap smear led to a wider use of colposcopic examinations, often coupled with a cervical biopsy, and to the development of a new group of specialists: gynecologists who specialized in colposcopic diagnosis of cervical lesions (Gronroos, et al., 1967; Koss, 1989). The routine use of colposcopy following an abnormal Pap smear reduced the need to make the Pap test accurate. It also eliminated the objection that exfoliated cervical cells are not representative of the tumor. The presence of such cells was transformed from a demonstration of a malignant transformation to a warning sign that something may be wrong (Curtial, 1952).

An additional element was the relative ease of elimination of suspicious cervical lesions. Surgical pathologists agree that a fine-grained cytological diagnosis of such lesions has a restricted role in the management of these lesions:

If one accepts that the cervical intraepithelial neoplasia [in situ lesions] is a continuous process, then the grade of de-differentiation is principally a statement of probability of development of an invasive carcinoma, but such an aggregate probability statement is meaningless for the individual patient. The important element for a woman diagnosed with a proliferative lesion of the cervix is the ease of elimination of a suspicious lesion and not details of its histological diagnosis.¹⁴

The demonstration that destruction of cervical lesions was as efficient as hysterectomy in eliminating the danger of malignancy led to a greater acceptability of overtreatment. This development decreased the need for an accurate diagnosis of cervical lesions even more. With the generalization of the conservative therapies, the main problem of screening became to reduce the number of false negative diagnoses. An unnecessary minor surgery following an incorrect diagnosis of proliferative lesion of the cervix is less distressing than a failure to detect a potentially lethal disease. Accordingly, screening techniques (reading of Pap smears and biopsies) were calibrated for high sensitivity (low number of false negative results) and low specificity (higher number of false positive results).

The transformation of the Pap test into the “right” tool for the diagnosis of preinvasive cervical lesions – or rather the right tool for the selection of women who need to be seen by a specialist – did not put an end to debates on the natural history of cervical lesions, or the scope of desirable medical intervention. Debates on this topic continue in the early twenty-first century. Evaluations of the rate of progression of premalignant lesions to cancer continued to differ widely, and the distinction between dysplasia and in situ cancer remains fluid (Springgs, 1984; Anderson et al., 1991; Payne et al., 1996; Koss, 1978, 1989). On the other hand, clinical guidelines that reinforced the principle of physical elimination of every suspicious cervical lesion diminished even more the practical importance of an accurate classification of these lesions. Such guidelines accentuate the importance of careful colposcopic evaluation of every doubtful case. The slightest suspicion of anomaly should lead to a further investigation and, when the doubt persists, to an excisional procedure, preferably a cold knife conization (Salomon et al., 2002; Wright et al., 2002). “When in doubt, cut it out.”

“Not an entirely benign procedure”: the cost of screening

In the second half of the twentieth century, screening for cervical cancer was transformed into a demonstration of the validity of the early detection principle. “Low cost” therapeutic interventions – in monetary terms, but also in terms of their consequences for screened and treated women – efficiently reduced the danger of malignancy. The low cost of elimination of cervical lesions is not, however, a zero cost. Conization biopsy or a laser therapy of cervical lesions may be experienced as traumatic events even when the patient receives efficient anesthesia, good postoperative follow-up, and an adequate explanation of the whole process. In addition, the elimination of cervical dysplasia has a non-negligible

complication ratio and may occasionally induce sterility or problems during pregnancy (Outcome..., 1980; Mc Cormick, 1989).¹⁵ Some experts criticize an indiscriminate use of a minor but not-entirely-benign surgical procedure, a practice fueled, especially in the United States, by doctors' apprehension of litigation (Ruba et al., 2004).¹⁶

In a culture with a high level of fear of cancer, especially among women, screening for cervical cancer may have an important psychological cost as well. One of the rarely discussed drawbacks of such screening is an irreversible generation of apprehension (Kaufman, 2000). The detection and the elimination of cervical lesions greatly reduces the danger of a future malignancy and is therefore highly beneficial for women with proliferative changes in the cervix. Such an individual benefit has, however, a collective price. Screening provides important advantages for a small number of women – those who escaped cervical cancer – but it may change the sense of body and self of many other women who do not personally benefit from the screening. It may also unsettle those who find themselves with unclear diagnoses, prognoses, and futures (McKie, 1995). Women who received abnormal results of a Pap smear described themselves as being in a liminal situation. Diagnosed with a potentially threatening condition with an uncertain meaning, they are not sure if they should see themselves as sick or as healthy (Fors et al., 2004). This is especially true for women diagnosed with a persisting presence of atypical cells. Submitted to an intensive medical surveillance (frequent colposcopies, smears, HPV tests, sometimes biopsies), they may remain for a long time in a limbo produced by medical technologies (Welch, 2004).

The great majority of the experts, but also of activists, enthusiastically endorsed screening for cervical cancer, and their point of view is sustained by epidemiologic data. This does not mean, however, that such screening is problem-free. A positive result of a screening test, medical sociologist Nicky Britton proposed, may radically change one's view of the body. When she learned about the presence of abnormal cells in her cervical smear, she was unable for several days to think about anything but death. And, she adds, "the experience has not left me unchanged. It is as if, having allowed the possibility of one disease to enter my body, a host of other conditions have crowded behind it. ... I lost an innocence of outlook" (Britten, 1988: p.296).

Britten believes that screening for cervical cancer is a good and necessary public health measure. She wished only to attract attention to some of its more problematic aspects. The important point, she argued, is to inform women about the hazards of screening to one's mental and physical health, in order to allow them to make truly informed choices (Britten, 1988). The sociologist Naomi Pfeffer agrees. She believes that since health promotion interventions such as screening for cancer are neither neutral nor innocuous, they should be submitted to the same informed consent rules as other medical acts (Pfeffer, 2004).

Other researchers are less sure that all the problems raised by the generalization of screening for cancer and cancer risk can be solved by providing more accurate information about procedures and outcomes and explaining individual choices more clearly. Living in a screening culture limits the possibilities of opting out of it and increases the price of such "irrational" behavior for those who choose to do so.

Screening for cancer focuses attention on selected elements and makes others less visible. The selective grid of cancer screening often "screens out" side effects of biopsies

(pain and postsurgical complications), psychological consequences of coping with an ambivalent diagnosis, overtreatment (surgical elimination of lesions that will never become cancerous), uncertainty about medical interventions and the unique experience of screened people. The latter are invited to perceive themselves at the same time as healthy and complete and as (potentially) unhealthy and (de facto) flawed. In an optimistic view of the twenty-first century “bio-risk culture,” a new focus on embodied risks makes room for the shaping of new identities, responsibilities, alliances between people, social links, and creative ways of being in the world (Rose, 2000). In a more pessimistic vision, the new accent on the management of cancer risk may also undermine people’s – and especially women’s – confidence in their bodies (Lupton, 1995) .

Screening for cervical cancer: exemplary or exceptional?

The development of efficient screening tools for cervical malignancies was neither simple nor linear, and many aspects of such screenings are problematic: the precise definition of cervical dysplasia and levels of CIN (cervical carcinoma in situ), the lingering issue of ASCUS (“atypical squamous cells of undetermined significance,” a diagnosis which, translated into the vernacular, means “we have no idea what you have”), and the controversies surrounding the desirable threshold of intervention. Nevertheless, the story may be one of triumph of a medical technology. The history of screening for cervical cancer shows how tinkering with multiple and heterogeneous resources – cytological staining and the division of medical labor, scientific instruments and public policies, statistics, and activism – can transform imperfect diagnostic tests into “a good enough tool for the job.” The drastic decrease in mortality from cervical cancer in Western countries has been attributed to the generalization of screening for this malignancy. While some specialists contest this conclusion and propose that other elements might have contributed (in an unknown proportion) to the decline in mortality from cervical malignancies in populations, few will quarrel with the proposal that on the individual level, screening (today still mainly the Pap smear) helps to reduce the number of invasive cervical malignancies.

Seen as an evident success, the search for non-invasive cervical lesions became a general model for the efficacy of screening for malignant tumors. Screening for other common tumors – breast, prostate, or colon cancer – is, however, more problematic. Cervical lesions are accessible, fragile, and relatively easy to eliminate, a rare combination. In other tumors, lesions are less accessible to the physician’s gaze, increasing specialists’ reliance on imperfect indirect tests, while preventive interventions have higher costs to patients and the community, making overtreatment a less attractive option. At the same time, the relative ease of elimination of suspicious cervical lesions did away with the need to correlate morphological data with clinical outcomes. A precise prediction of the fate of a given lesion was not important, because its physical destruction put an end to uncertainty about its future. Other common tumors do not benefit, alas, from such a felicitous combination of biological traits: the main obstacle to preventive elimination of precancerous lesions of the gut is their visibility and accessibility; to preventive elimination of premalignant changes

in breast or prostate, the cost of the intervention for the patient; and to preventive elimination of lesions in other organs (lung, pancreas, liver), both (Aronowitz, 2007).

In spite of the practical difficulties of screening for malignancies, the professional and lay understanding of cancer was and is shaped by the aspiration to identify and eliminate precancerous lesions. The extraordinary viability of this idea reflects its plausibility, its ability to address well-entrenched fears, and its capacity to channel activities of multiple constituencies. It also points to the danger of using emotionally charged, simplified notions when dealing with complex phenomena.

Present-time medicine, the political scientist Louise Russell points out, aspires to detect pathological conditions before they produce symptoms: “A common theme runs through the articles, programs, and waiting-room brochures: catch it early, treat it early, and live longer. ... That common theme, played out in its many variations, is simple, direct, and misleading.” The recommendation presented in publications that promote early detection, Russell explains, are pseudo-truths that, like the pseudo-elements of the physical sciences, bear a deceptively close resemblance to the real thing: “they convey rules of thumb developed by experts and leave out the complexities and tradeoffs, the mixture of solid information and educated guesses, that have gone into their development” (Russell, 1994:1-2). Historical studies display such discarded complexities and tradeoffs and can therefore provide a glimpse of the “real thing” behind omnipresent, powerful, plausible, and oversimplified images.

NOTES

* Submission in English by the author. Portions of this article originally appeared in *Preventive Strikes: Women, Precancer, and Prophylactic Surgery*, by Ilana Löwy (Baltimore, The Johns Hopkins University Press, 2010). When the article was submitted to this journal for publication, the book had not yet been published (editor's note).

¹ The Pap smear may, however, soon be displaced, especially in developing countries, by testing for “carcinogenic” HPV strains (Schiffman, 2009).

² Williams added that such lesions remain superficial for a long time; he believed they could be cured through local treatment (Williams, 1888:12).

³ Before generalization of the Pap smear, superficial lesions of the cervix were usually diagnosed in women with clinical symptoms (bleeding, vaginal discharge, pain). It is not to be excluded that in some cases presumed premalignant lesions were in fact misdiagnosed invasive malignancies (Stevenson, 1938; Hoge, 1950).

⁴ Charles Stockard, the head of the department of anatomy at the Cornell Medical Center where Papanicolaou was employed, had a long-standing interest in eugenics and might have suggested to Papanicolaou to present his finding at a “race betterment” conference.

⁵ Carter et al. (1952). The results were first presented at the 75th annual meeting of the American Gynecological Society in Hot Springs, Virginia, May 12-14, 1952.

⁶ Day was the director of the division of preventive medicine of Sloan Kettering Institute for Cancer Research, New York.

⁷ See, for example, a letter from Edward Rimley to Charles Cameron, medical and scientific director of ACS, from July 6, 1955, on the importance of endorsing PAP smears by the ACS. Columbia University Health Sciences Library, Archives and Special Collections, Mary Lasker Papers, Box 98; letter of Eugene Pendegrass, chairman of the committee on professional and public education of ACS, to Mary Lasker, October 10, 1956, on the importance of including Pap smears in doctors' annual checkups. Mary Lasker Papers, Columbia University Health Sciences Library, Box 99.

⁸ Vayena's unpublished thesis is an excellent source of information on ACS's role in the implementation of the Pap smear in the United States.

⁹ Undated BECC internal document, probably early to mid-1920s; Memorandum on cancer, prepared by Departmental Committee on Cancer, appointed by the Minister of Health, and chaired by Sir George Numann, published July, 1923. Box 90, BECC papers, Wellcome Library, Archives and Manuscripts Department, Collection SA/CRC.

¹⁰ "Advice for medical lecturers who speak to lay public," leaflet, 1936. Box 90; BECC papers, Wellcome Archives.

¹¹ Malcolm Donaldson, "Education of the public concerning cancer," Medical Officer, September 9, 1950. Box 90, BECC papers, Wellcome Library, Archives and Manuscripts Dept, series SA/CRC. The ACS was especially active in promoting diagnosis of precancerous conditions, found in a high number of people who consulted cancer detection clinics.

¹² Wellcome Library, Archives and Manuscripts Dept, series SA/MWF, Documents of the Medical Women Federation, File F.13/3.

¹³ Press conference of Minister of Health, Kenneth Robinson, on cervical cytology, October 10, 1966. Documents of the Medical Women Federation, file F.13/4. Wellcome Archives.

¹⁴ Papers of the Arthur Purdy Stout Society of Surgical Pathologists, box 1, papers 1957-1986, folder 6. Undated, probably 1970s. Columbia University Health Sciences Library, Archives and Special Collections.

¹⁵ On a (rare) discussion of pain and suffering following "routine" biopsies, see Vered Levy-Barzilai, "Hey doc -it hurts," *Haaretz*, April 14,-2006.

¹⁶ The aggressive attitudes of some U.S. doctors towards prevention of gynecological cancers was studied by Fisher (1986).

REFERENCES

- ANDERSON, M.C; BROWN, C.L; BUCKLEY, C.H. et al.
Current views on cervical intraepithelial neoplasia. *Journal of Clinical Pathology*, London, v.44, n.12, p.969-978. 1991.
- ARONOWITZ, Robert.
Unnatural history: breast cancer and American Society. New York: Cambridge University Press. 2007.
- BENEDET, J.L. et al.
Colposcopy, conization and hysterectomy practices: a current perspective. *Obstetrics and Gynecology*, New York, v. 60, n.5, p.539-545. 1982.
- BRESLOW, Lester.
The prevention of cancer, Ronald W. Raven (ed) *Cancer*, London, Butterworth & Co, 1959, p.485-486.
- BRITTEN, Nicky.
Personal view: colposcopy. *British Medical Journal*, London, v.296, n.6630, p.1191. 1988.
- BURGHARDT, Erich.
Radicality in gynecologic cancer surgery: a historical perspective. *Gynecologic Oncology*, New York, v.70, n.2, p.172-175. 1998.
- CARTER, Bayard et al.
The methods of management of carcinoma in situ of the cervix. *American Journal of Obstetrics and Gynecology*, Saint Louis, v.64, n.4, p.833-849. 1952.
- CASPER, Monica J; CLARKE, Adele E..
Making Pap smear into the 'right tool' for the job: Cervical cancer screening in the USA, circa 1940-1995. *Social Studies of Science*, London, v.28, n.2, p.255-290. 1998.
- CURTIAL, J.
Sur le dépistage précoce des cancers. *La Lutte Contre le Cancer*, Paris, v.30, n.96, p.7-11. 1952.
- DAY, Emerson.
Value of simple procedures in cancer examination. In: Raven, Ronald W. (ed.). *Cancer*. London: Butterworth. p.445-457; p.448-451. 1959.
- FISHER, Sue.
In the patient's best interest: women and the politics of medical decisions. New Brunswick, N.J.: Rutgers University Press, 1986.
- FORS, Anette et al.
Women's experiences of cervical cellular changes: an unintentional transition from health to liminality?, *Sociology of Health and Illness*, Boston, v.26, n.3, p.306-325. 2004.
- GAD, C.
The management and the natural history of

- severe dysplasia and carcinoma in situ of the uterine cervix. *British Journal of Obstetrics and Gynecology*, Oxford, v.83, n.7, p.554-559. 1976.
- GALVIN, Gerald A; JONES, Howard W; TE LINDE, Richard W.
Clinical relationship of carcinoma in situ and invasive carcinoma of the cervix. *Journal of the American Medical Association*, Chicago, v.149, n.8, p.744-748. 1952.
- GALVIN, Gerald. A.; TELINDE, Richard W.
The present day status of non-invasive cervical carcinoma. *American Journal of Obstetrics and Gynecology*, Saint Louis, v.57, n.1, p.15-36. 1949.
- GARDNER, Kirsten Elizabeth.
Early detection: women, cancer, and awareness campaigns in the twentieth-century united states. Chapel Hill: University of North Carolina Press. p.53-92. 2006.
- GARNIER, Anne et al.
Une campagne de dépistage de cancer du col avec des frottis vaginaux. *Bulletin de Cancer*, Montrouge, v.84, n.8, p.791-795. 1997.
- GRONROOS, Matti et al.
Cytology and colposcopy in mass screening for cervical cancer. *Acta Cytologica*, Chicago, v.11, n.1, p.37-38. 1967.
- HOGUE, H. Randolph.
Carcinoma in situ of the cervix: a survey of its treatment in the United States and Canada. *Obstetrics and Gynecology*, New York, v.5, n.5, p.621-628. 1950.
- JONES, H.W.; BULLER, Richard E.
The treatment of cervical intraepithelial neoplasia by cone biopsy. *American Journal of Obstetrics and Gynecology*, Saint Louis, v.137, n.8, p.882-886. 1980.
- KAUFMAN, Patricia.
A screening the body: the pap smear and the mammogram. In: Lock, Margaret; Young, Allan; Cambrosio, Alberto (eds.). *Living and working with the new medical technologies*. Cambridge: Cambridge University Press. p.165-183. 2000.
- KOSS, Leopold G.
The Papanicolau test for cervical cancer detection: a triumph and a tragedy. *JAMA*, Chicago, v.261, n.5, p.737-743. 1989.
- KOSS, Leopold G.
Dysplasia: a real concept or a misnomer. *Obstetrics and Gynecology*, New York, v.51, n.3, p.374-379. 1978.
- KOSS, Leopold G. et al.
Some histological aspects of behaviour of epidermoid carcinoma in situ and related lesions of uterine cervix. A long term prospective study. *Cancer*, Philadelphia, v.12, p.1160-1211. 1963.
- LEVY-BARZILAI, Vered.
Hey doc – it hurts. *Haaretz*, Tel Aviv, 14 April, 2006.
- LUPTON, Deborah.
Taming uncertainty: Risk discourse and diagnostic testing”. In: Lupton, Deborah. *The imperative of health: public health and the regulated body*. London: Sage. p.77-105. 1995.
- MARTZLOFF, K.
Leucoplasia in cervix uteri. *American Journal of Obstetrics and Gynecology*, Saint Louis, v.24, p.57-67. 1932.
- MC CORMICK, James S.
Cervical smears: a questionable practice? *The Lancet*, London, v.334, n.8656, p.207-209. 1989.
- MC Kie, Linda.
The art of surveillance of reasonable prevention? The case of cervical cancer screening, *Sociology of Health and Illness*, London, v.17, p.441-457, 1995.
- MC SWEZY, Daniel; MC KAY, Donald G.
Uterine cancer: its early detection by simple screening methods. *New England Journal of Medicine*, Massachusetts, v.238, n.25, p.867-870. 1948.
- NOVAK, E.
The pathological diagnosis of early cervical and corporeal cancer. *American Journal of Obstetrics and Gynecology*, Saint Louis, v.8, p.2-24. 1929.
- O'DONNELL, Walter E.; DAY, Emerson; VENET, Louis.
Early detection and diagnosis of cancer. Saint Louis: Mosby Company. 1962.
- OUTCOME...
Outcome of pregnancy after a cone biopsy. *British Medical Journal*, v.280, n.6229, p.1393-1394. 1980.
- PAPANICOLAOU, George Nicholas.
New cancer diagnosis. In: Proceedings of the Third Race Betterment Conference, 1928, Michigan. *Proceedings of the Third Race Betterment Conference, January 2-6, 1928*. Michigan: Battle Creek. p. 528-534. 1928.
- PAPANICOLAOU, George Nicholas; TRAUT, Herbert Frederick.
Diagnosis of uterine cancer by vaginal smear. New York: The Commonwealth Fund. 1943.
- PAPANICOLAOU, George Nicholas; TRAUT, Herbert Frederick.
The diagnostic value of vaginal spears in carcinoma of the uterus. *American Journal of Obstetrics and Gynecology*, Saint Louis, v.42, p.193-206. 1941.

- PAYNE, S; KERNOHAN, N.M; WALKER, F.
Proliferation in the normal cervix and in preinvasive cervical lesions. *Journal of Clinical Pathology*, London, v.49, n.8, p.667-671. 1996.
- PETERSEN, Olaf.
Precancerous changes of the cervical epithelium. *Acta Radiologica*, Stockholm, v. 127, suppl, 1955.
- PFEFFER, Naomi.
If you think you have a lump the'll screen you: Informed consent and health promotion. *Journal of Medical Ethics*, London, v.30, n.2, p.227-230. 2004.
- REAGAN, Lesley J.
Engendering the dread disease: women, men and cancer. *American Journal of Public Health*, Boston, v.87, n.11, p.1779-1787. 1997.
- ROSE, Nicolas.
The politics of life itself. *Theory, Culture and Society*, London, v.18, n.6, p.1-30. 2001.
- ROSE, Nicolas.
Genetic risk and the birth of the somatic individual. *Economy and Society*, London, v.29, n.4, p.485-513. 2000.
- RUBA, Sukeerat et al.
Adenocarcinoma in situ of the uterine cervix: screening and diagnostic errors in Papanicolaou smears. *Cancer*, Philadelphia, v.102, n.5, p.280-287. 2004.
- RUSSELL, Louise B.
Educated guesses making policy about medical screening tests. Berkeley: University of California Press. p.1-2. 1994.
- SALOMON, Diane et al.
The 2001 Bethesda system: terminology for reporting results of cervical cytology. *JAMA*, Chicago, v.287, n.16, p.2114-2119. 2002.
- SCHIFFMAN, Marc; WACHOLDER, Sholom.
From India to the world: a better way to prevent cervical cancer. *New England Journal of Medicine*, Massachusetts, v.360, p.1453-155. 2009.
- SCHILLER, Walter.
Early diagnosis of carcinoma of the cervix. *Surgery, Gynecology and Obstetrics*, Chicago, v.56, p.212-222. 1933.
- SICARD, A.
L'introduction des frottis cervico-vaginaux en France. *Bulletin de l'Académie Nationale de Médecine*, Paris, v.180, n.5, p. 1109-1113. 1996.
- SIELER, Edward E.
Microdiagnosis of carcinoma in situ of the uterine cervix. *Cancer*, Philadelphia, v.9, n.3, p.463-469. 1956.
- SINGLETON, Vicky.
Stabilizing instabilities: The role of the laboratory in the United Kingdom cervical screening program. In: Berg, Marc; Mol, Anne Marie (eds.). *Differences in Medicine; unraveling practices, techniques and bodies*. Durham: Duke University Press. p.86-103. 1998.
- SINGLETON, Vicky.
Actor networks and ambivalence: general practitioners in the UK cervical screening program. *Social Studies of Science*, London, v.23, n.2, p.227-264. 1993.
- SPRINGGS, A.I.
Precancerous states of the cervix uteri. In: Carter, R.L. (ed.). *Precancerous States*. Oxford: Oxford University Press. p. 317-353. 1984.
- STEVENSON, Charles Summers; SCIPIADE, Elmer.
Non invasive potential carcinoma of the cervix. *Surgery, Gynecology and Obstetrics*, Chicago, v.66, p.822-835. 1938.
- VAYENA, Eftychia.
Cancer detectors: an international history of the Pap test and cervical cancer screening, 1928-1970. Thesis, University of Minnesota, Minnesota, 1999.
- WILLIAMS, John.
Cancer of the Uterus: being the harveian lectures for 1886. London: H.K. Lewis. p.12 ; plate I, after p.119. 1888.
- WEISZ, George.
Divide and conquer. Oxford: Oxford University Press. 2005.
- WELCH, H. Gilbert.
Right and wrong reasons to be screened. *Annals of Internal Medicine*, Philadelphia, v.140, n.9, p.754-755. 2004a.
- WELCH, Gilbert.
Should I be tested for cancer: maybe not, and here's why. Berkeley: California University Press. 2004b.
- WRIGHT, Thomas C. et al.
Consensus guidelines for the management of women with cervical cytological abnormalities", *JAMA*, Chicago, v.287, n.16, p.2120-2129. 2002.

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