MEDICAL PRACTICE

Contemporary Themes

Are patients with abnormal cervical smears adequately managed?

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Abstract

The outcome was assessed for all 1062 women in Nottingham who had a first report of abnormal cervical cytology in 1981. Satisfactory follow up could be found for only 628 (59%) of them. For 275 (26%) one subsequent normal smear had been reported but no further follow up requested. For 43 (4%), no subsequent test, after the abnormal smear, had been requested by the patient's general practitioner. Thirty patients (3%), 22 of whom had been tested at a special clinic, had not responded to a request for follow up. Even after extensive efforts we could not find the outcome in the remaining 86 (8%) of the patients.

Adequate follow up of patients with abnormal cervical cytology is not being achieved. Improvements in the records systems and some changes in procedure should be made to reduce this problem.

Introduction

The number of cervical smears taken annually in England and Wales rose from 700 000 in 1965 to 2 900 000 in 1980,[1] yet between 1968 and 1980 the death rate from cervical cancer fell by only 16%.[1] Much larger falls in mortality have been seen in countries with more carefully organised screening programmes, such as Denmark, Sweden, Finland, Iceland, and parts of Canada.[2,3] Commentaries on the relative ineffectiveness of the British screening programmes have emphasised the lack of an initial call system, the inadequacy of records systems and recall systems for women found to be normal, and the resulting effect that most smears are performed in relatively low risk, younger women.[4] The few women who yield abnormal smears have been implicitly assumed to be adequately treated, and we cannot find any recent study that has assessed the completeness of follow up in women with abnormal smears. As Nottingham has the advantages of one centralised cytology laboratory with a long established and fairly constant staff, we were disturbed to find in 1982 that we had difficulty in assessing the follow up management of women in whom smears had been positive. We therefore investigated the outcome for all women in Nottingham in whom abnormal cervical cytology had first been reported in 1981.

Methods

The pathology department of the City Hospital, Nottingham, has the only gynaecological diagnostic cytology laboratory in the city and serves the population of the Nottingham Health District (roughly 600 000) and adjacent areas of Derbyshire and central Nottinghamshire. The laboratory was set up in 1963 and in 1981 processed 55 599 smears. It has a staff of 10 full time equivalent technicians and three clerks shared with the histopathology laboratory and is served by two part time consultant histopathologists providing about 20 hours each week. The records system is manual, consisting of a day book in which all incoming smears are recorded, a positive cytology register into which all new positive cases and subsequent reports are entered, a corresponding file of request cards, and a large file of all negative smears, which are kept for two years.

When the service was started responsibility for follow up of women with abnormal smears was accepted as remaining with the referring clinician, as was the usual practice in the United Kingdom, but the laboratory undertook to remind the originator of a positive smear classified as "highly atypical" or "malignant cells present" if follow up cytology or histological material had not been received in the department after six months. It was also clearly stated that the laboratory could not be responsible for initiation of follow up of patients with lesser abnormalities unless a non-manual record system and additional resources were made available. The register of women with positive cytology served to remind referring clinicians of women with severe

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abnormalities but was created primarily for the prospective study of the natural history of cervical epithelial abnormalities in the district.

The laboratory's recommendations for the follow up of new women in whom smears were positive for the first time were as follows. All abnormal smears were seen and reported on by a pathologist, and patients with severe abnormalities or highly atypical or carcinoma cells present were recommended for referral to a gynaecologist. Mild to moderate abnormalities were reported with a recommendation for a follow up smear after a suggested interval, usually of three, four, or six months. For minor abnormalities found during pregnancy, one normal smear obtained postnatally was accepted as sufficient; for those found at other times a minimum of two subsequent sequential normal smears was required. Thus adequate follow up was defined as: gynaecological referral and further assessment or treatment or, for milder positive cases found in pregnancy, one normal smear; and, for other mild or moderate cases, two consecutive normal smears.

TABLE I—*Ages of patients with abnormal cytology first recorded in 1981. Age was not recorded for 16*

Age:	≤20	−25	−30	−35	−40	−50	−60	≥61
No of patients:	156	217	202	179	116	89	45	42

records. When the woman had evidently not been followed up or was unaware of the positive result of the smear test we made no comment at the interview but brought the situation to the notice of her general practitioner.

Results

Abnormal cytology had been recorded for the first time in 1062 women in 1981. Of them, 754 (71%) were aged 35 or under (table I). Four hundred and eleven (39%) had been tested in hospital (mainly antenatal) clinics, 232 (22%) by general practitioners, 181 (17%) in district clinics, 118 (11%) in special clinics, 65 (6%) in family planning clinics, 22 (2%) in private clinics, and 31 (3%) elsewhere. Information was not available for two. Carcinoma cells were present in 27 (2·5%), and 238 (23%) had highly atypical lesions, 260 (24%) atypical lesions, 495 (47%) dysplasia, and 42 (4%) other abnormalities. Of these 1062 patients, 628 (59%) were shown to have been adequately followed up (table II). A definite diagnosis had been made and treatment given in 440 of these; four had had other treatment such as elective hysterectomy; 108 had yielded either one normal smear postnatally or two normal smears; active follow up was continuing in 74 patients; and two had died of unrelated causes.

For 275 patients (26% of the total) one normal smear had been reported but the laboratory had not made specified requests for further follow up. For

TABLE II—*Outcome to December 1983 for 1062 patients with first abnormal cytology seen in 1981*

	Total No of records	No of reports obtained from:				
		Cytology and hospital records	Special clinic records	Family practitioner committee	General practitioner records	Interview
Satisfactory follow up (n = 628)						
Definitive diagnosis and treatment	444	440			4	
Adequate normal smears	108	99	2		3	4
Continuing follow up	74	74				
Deceased owing to other causes	2			1	1	
Follow up not requested (n = 275)						
One negative and no mention of earlier positive	57	28			17	12
One negative and no request	218	218				
Follow up not performed (n = 43)						
General practitioner and patient unaware of positive	14					14
Patient not told result	20					20
Patient told result normal	5					5
Patient had no knowledge of having had smear	4					4
Follow up refused by patient (n = 30)						
Patient refused follow up	30	1	22			7
Outcome still unknown (n = 86)						
Moved and new address unknown	67	24	5	1	10	27
Transferred to other care	6		5		1	
No records found	6		2	4		
Patient refused interview	4					4
Patient not located	1					1
General practitioner refused cooperation	1				1	
No response from general practitioner	1				1	
Total	1062	884	36	6	38	98

An initial assessment of the adequacy of follow up was made using the laboratory records alone for the years 1976-80. Positive smears had been recorded in 4280 patients. The laboratory records showed that a firm diagnosis had been made from further investigations in 1774 of them (dysplasia in 862, cervical intraepithelial neoplasia grade III (CIN III) in 696, and microinvasive or invasive lesions in 216); adequate evidence of subsequent normal smears was found for 936; and inadequate evidence (no follow up or only one negative smear) was found for 1570 (37%). As this audit was restricted to a fairly rapid assessment of the laboratory records alone we then studied in more detail all patients in whom positive cytology had first been reported in 1981. This year was chosen because follow up procedures should have been complete by the time of the study (autumn 1983) and difficulties in finding records and tracing patients minimal. Patients were traced through the laboratory records, hospital records, general practitioner records (with the help and approval of the local medical and family practitioner committees), and, finally, by a home interview. Sufficient information was obtained from cytology records and those of the hospital for 884 patients, from special clinic records for 36, and from the family practitioner committee and general practitioner records for 44. For the 98 remaining patients, we obtained the general practitioner's permission to interview them and then approached them at home, using a semi-structured questionnaire dealing with cytology in the context of general medical care. When the interviewee reported having had smears of which we had no record we checked back to the general practitioner and laboratory

57 of them this occurred because the previous positive cytology had not been mentioned on the request form and for 218 because a request for a second follow up smear had not been made when the laboratory reported a first normal follow up smear after an abnormal smear done outside pregnancy.

For 43 patients (4%) we have unequivocal evidence that a recommendation for follow up was made by the laboratory but no follow up was undertaken. These patients were interviewed and their knowledge of the situation assessed. Four had no recollection of ever having undergone smear testing, despite being given at the interview several descriptions of what the test entailed, and had received no advice for follow up. Five patients reported that they had been told that the result of the test was normal. Thirty four patients indicated that they had been told nothing about the results of their smear test. For 14 of these 43 women, the patient's general practitioner did not have any record of the result of the test, 10 of which had been done in antenatal clinics and three in other hospital clinics; for one the laboratory had not reported the result of a smear test that the general practitioner had performed. For eight the record of the positive smear test was in the general practitioner records but no action had been taken. In the remaining 21 we could not assess the general practitioner records.

For a smaller number of patients (30 (3%)) the reason for lack of follow up lay with the patient. Twenty two of these had been tested at a special clinic (for the assessment and treatment of sexually transmitted diseases) and had not returned to the clinic despite intensive attempts to make contact with them by the staff of the clinic. Another four patients told us at interview that

they had been requested to return to their general practitioner for follow up but had not done so, two stating that this was because they had been frightened to do so. Another had been asked to make a gynaecological outpatient appointment but had not done so out of fear. The three remaining defaulters were notified to us by their general practitioner in two cases and by the gynaecology clinic in the third; the two notified to us by their general practitioner reported at interview having received no requests to attend for follow up, in conflict with their general practitioners' information.

We were unable to find records of follow up for 86 patients (8%). In 40 cases the records of either the cytology laboratory, special clinic, family practitioner committee, or the previous general practitioner showed that they had moved but no information on their new address or new general practitioner could be found. For 27 patients the records did not show any move, but we failed to locate them at the last recorded address despite considerable efforts, including visiting the last known address several times and talking to neighbours. Of the 66 patients we interviewed, 33 were, however, successfully traced in this way to a new address that was not included in any of our records. Six patients had been transferred to other care to which we could not gain access, four patients refused interview, one was not contacted despite five visits to the recorded address and no indication that they had moved, one was not contacted because the general practitioner refused us permission to do so, and one was not contacted because no response was obtained from the general practitioner despite letters and telephone calls. A recorded address could not be found for six patients.

We thus identified 43 patients who had not received any follow up management because they had not been told it was necessary, and eight (seven at interview and one through records) who had disregarded requests for follow up, excluding special clinic patients, follow up of whom had already been attempted. We informed the general practitioners of these 51 patients and reassessed their situation in May 1984, six months after the interviews. This showed that after our notification 30 of these patients had been followed up (six had undergone cone biopsies showing lesions of cervical intraepithelial neoplasia grade II, two had been referred for a gynaecological opinion, and 22 had had further smear tests; for 18 we still had no record of a further smear being done. All seven patients classified as defaulters after interview had responded to the further request from their general practitioner.

Discussion

One of the essential conditions for the operation of a screening programme is that effective treatment is efficiently offered to all patients who have abnormal results on screening. When screening is actively proposed to asymptomatic people, the authorities encouraging the screening could be said to have a responsibility not only to provide such treatment services but also to document and monitor their effectiveness.

Although the natural history of preinvasive cervical cancer is usually long, adequate follow up of women with abnormal cytology is essential. Kinlen and Spriggs found 10 cases of invasive and three of microinvasive carcinoma in 70 women with abnormal cytology who had not been followed up for at least two years[5]; the death rate was 5%, compared with only 0·3% in women treated for cervical intraepithelial neoplasia grade III or more advanced lesions in British Columbia.

We have shown that even to document the fate of patients with abnormal cytology is difficult and almost impossible in the context of a routine workload. The Nottingham record system is probably similar or better than that of most other areas using manual systems and has the great advantage of being based on only one laboratory; the problems of follow up would be much greater if several laboratories with separate records systems were covering the same area.

The difficulties with follow up are primarily difficulties of communication, and the remedies are simple to prescribe, although more difficult to implement. Ensuring that all patients yield at least two normal smears before being removed from active follow up requires record linkage. The laboratory procedure at the time of this study depended on the smear request form: if the patient was noted to have had a previous positive smear a manual search of the positive file was undertaken. In 57 of the 275 instances when follow up was not requested no such notification was made so no search was done. This difficulty could be overcome if all incoming negative smears were checked against and linked to a file of previous positive smears, but this would be feasible only if computer systems and record linkage techniques were used, and the problems of changes in name and address and of misspellings would still be difficult to overcome.

The 218 patients with no further follow up requested after yielding one normal smear were the largest group to be inadequately followed up. This could be avoided if a more careful procedure was used or, more reliably, if cytology reports were printed by computer and always accompanied by a recommendation for future follow up. Our criterion here is strict. A single negative smear is of considerable value, but the risk of a false negative from clinical or laboratory error or a true but temporary normal phase remains. Nasiell *et al* found that many patients with persistent dysplasia yielded some normal smears and that in 4% of patients normal cytology was recorded for over 12 months.[6] In addition, over the past 20 or so years management of patients with epithelial abnormalities of the cervix has changed considerably. In earlier years avoidance of overtreatment with the resultant morbidity of cone biopsy or hysterectomy, or both, coloured recommendations for intervention in earlier stages of the natural history of the disease. The advent of colposcopy with guided biopsy, accurate delineation and evaluation, and more conservative methods of eradication then encouraged a more active approach to management. Original policies for follow up of lesser cytological abnormalities have as a result been reviewed and changed to a longer period of active observation with repeat smears; we now regard two sequential normal smears to be essential after all abnormalities, including those detected postnatally.

The 43 patients who were unaware of their positive smear show more dramatically the failure of the service. In many (at least 14) instances the smear had been taken at a clinic providing episodic care and no report had been sent to the general practitioner who could ensure continuing care. Efforts should be made to ensure that all reports on smears done in clinics should go to the patient's general practitioners, and this might be most easily done from the cytology laboratory rather than from each clinic. The problem of those reports that do reach the general practitioner but result in no action is more difficult. In addition, if a linkage system between incoming and old smears existed in the laboratory, a regular, perhaps three monthly, check could be carried out and a reminder about any outstanding positive smears could be sent to the general practitioner. This would probably be effective, as the results from this study in which general practitioners were informed or reminded of such patients show.

Default in follow up due to the patient is a major problem in patients attending special clinics. In the present study the extensive efforts made by the clinic concerned to trace these patients show the difficulty of the situation. The special confidentiality precautions taken in special clinics do, however, hamper follow up. Patients attending special clinics are at high risk of cervical cancer, and the risk of progression from premalignant to invasive disease may be particularly high in such women if only because of their youth; a more rapid progression in young patients has been suggested.[7,8] Default is rarely due to patients other than those attending special clinics. Fear was expressed by three women as a reason for default; emphasis on the newer, effective, and fairly simple methods of treatment of preinvasive disease might help.

Lack of a regular source of medical care was not a reason for failure of follow up. Of the 50 women interviewed because no follow up measures could be determined from laboratory or general practitioner records, 49 were registered with a general practitioner, 42 had been registered with the same general practitioner for more than a year, and 43 had visited their general practitioner in the previous year.

Finally, even with the special efforts of this study many patients could not be traced, mainly because of changes in address. To verify the extent of this problem we assessed the changes in name and address of all 142 women who were not adequately documented in the cytology records alone and were not attending special clinics. Eighty (56%) of these patients had changed their address at least once, and for 24 (17%) we were able to find a change in name since 1981 that had not been recorded in the cytology records. Continuity of care for cervical cancer must not be lost because of a move or change in name, and closer liaison, including computer linkage, between the records systems of the cytology laboratory and the

family practitioner committees would assist this. Such linkage is of course essential if active call and recall systems are to be implemented to initiate screening. Linkage between districts to maintain continuity when patients move is also necessary.

To ensure effective and efficient management of all women found to have abnormalities on screening must be a priority, even before attempts to extend the coverage of first or subsequent screening examinations. We find our results disquieting as we believe the situation in Nottingham is likely to be better than in many other districts. Indeed, even to show the difficulties of follow up requires a fairly good records system. Most of the problems could be overcome by an appropriate computer based records system being set up in the cytology laboratory, linked ideally to family practitioner committee records, and some modifications in the ways cervical smears are requested and reported.

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Organisation of a programme for cervical cancer screening

ICRF COORDINATING COMMITTEE ON CERVICAL SCREENING

There are now good grounds for believing that a well organised programme of cervical cytological screening would lead to a substantial reduction in mortality from invasive cancer of the cervix.[1-5] In those Scandinavian countries that have such a programme the incidence of invasive disease has fallen by up to half of 1965 levels while otherwise similar countries without organised programmes (including the United Kingdom) have experienced either a negligible fall or a rise over the same period, despite a similar number of smears taken per woman. Nevertheless, Britain has a well designed policy for cervical screening centred on the proposal that all women in the age range at risk should be examined at five year intervals. The central policy could be implemented within the existing resources devoted to screening if there were an effectively managed screening programme.[6]

Hitherto all that has been done is to publish the policy, provide arrangements for recalling at five year intervals those women who have had a smear, and try to discourage the too frequent examination of younger women by restricting payment to GPs to those examinations that conform with the policy on age and frequency of screening. These arrangements have not been very successful: most smears have been taken from young women with a recent history of previous examination, while many older women have not been screened at all, and there remains a particularly poor coverage of those who are known to be at particularly high risk.[7]

We think that the time is opportune to recommend a more organised and systematic approach to cervical screening. The timing of such a proposal is enhanced by the decision to discontinue the national recall scheme and by the development of computer based administrative procedures for family practitioner committees.

The particular problems

At present screening tends to be applied differentially to women at least risk of developing cervical cancer while leaving those at high risk largely unscreened. The considerable published work on the reasons for this may be summarised as follows:

(*a*) most cytological examinations are performed during examinations carried out for obstetric or contraceptive purposes and women in the age range of maximum risk (40 and over) are therefore relatively neglected.

(*b*) the length of the prescribed screening interval and the lack of clear and well publicised arrangements for undergoing examination lead to women neglecting or forgetting to obtain a smear.

Nevertheless, there is no good evidence that women in the high risk categories are reluctant to accept examination if suitable arrangements are made.

Desiderata of a successful service

Examination of the successful Scandinavian screening programmes based on the use of updated computerised listings of the target population, an initiative from the service to arrange appointments for examination, and properly managed arrangements for further investigations of abnormal cytological findings, suggests that a successful service has at least seven requirements:

(1) adequate resources for taking, examining, and reporting on smears;
(2) arrangements for making and keeping appointments for examination;
(3) arrangements acceptable to women for the actual taking of smears—for example, the availability of choice between one's own GP or a clinic staffed by women;
(4) an updatable listing of women in the target population which can achieve complete initial call of all eligible women and ensure regular recall;
(5) an informed client population whose members know and understand the function of the procedure;
(6) a continuing scrutiny of the records of examinations to ensure that appropriate actions are taken on the results;
(7) the ability to monitor the efficiency and effectiveness of the programme and to adjust policies and procedures accordingly.

The requirements are not unlike those for a well managed programme of immunisations for infants and young children, for which computer aided management has been very successful. All that has been lacking is a suitable database.

The computerisation of the family practitioner committee lists of GPs and patients offers a potentially useful database in England and Wales. A much less satisfactory database might eventually be compiled from the records of those who have already had cervical

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