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ORIGINAL ARTICLE

Women's experience of coping with a positive Pap smear: a register-based study of women with two consecutive Pap smears reported as CIN 1

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Background. In Sweden approximately 40 000 women receive information annually that their Papanicolaou (Pap) smear test showed dysplasia and about 400 women are diagnosed with invasive cervical cancer. The aim of this study was to evaluate women 5 years after two consecutive Pap smears diagnosed with mild dysplasia (CIN 1), by describing their experience of receiving information about the results of the smear and how examinations, treatment and follow-up had affected them.
Methods. A questionnaire was sent in 1999 to 329 women who according to the Department of Clinical Pathology, Karlstad, had two consecutive Pap smears reported as mild dysplasia (CIN 1) during 1993 and who as a result of this finding should have undergone colposcopy and biopsy according to an agreed general program.
Results. The questionnaire was completed by 242 women (74%). The finding of mild dysplasia was obtained at a screening test in 95%, and 96% reported that they had participated in the follow-up program. One hundred and eighty-four women (76%) experienced follow-up in a positive way. Seventy-two percent considered they understood the meaning and consequences of having mild dysplasia. Nevertheless, feelings of worry and anxiety affected 59%. For 30% it affected everyday life between being informed of the result of the first Pap smear test and subsequent further investigation. Twenty women (8%) reported a remaining negative influence on sexuality and their experience of sexual intercourse as a consequence of the management of mild dysplasia. This finding was correlated with less satisfaction with follow-up and a negative influence on self-esteem.
Conclusion. Women felt vulnerable when being investigated for intraepithelial neoplasia, but this did not influence willingness to participate in follow-up. The discovery created unnecessary worry and a negative experience that may be solved by a better-developed educational program at the time of screening. There were no signs of remaining anxiety 5 years later, but 8% of women reported a remaining negative influence on their sexual life.

Key words: Papanicolau smear; knowledge; coping; dysplasia/CIN 1; information

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As a result of the nationwide cervical cancer screening program in Sweden (1,2), about 40 000 women per year receive information that their Papanicolaou (Pap) test showed signs of dysplasia (3). Abnormal cells can prestage an oncogenic process but are even found in the smears of numerous women never destined to develop cervical cancer (4). Annually, about 400 women are diagnosed with an invasive cervical carcinoma (3), which is more than a 50% reduction in the reported number of cases since the screening program started (5).

Several studies have previously described how information about an abnormal Pap smear creates stress, sometimes on a level that affects daily living (6–8) and that fear may affect compliance with follow-up (8,9). The aim of this study was to evaluate women with repeated consecutive cytological mild dysplasia (CIN 1) by describing their experience of receiving information about the atypical findings. Furthermore, the aim was to evaluate how examinations, treatment and follow-up had affected them, and to describe how they viewed their present situation 5 years after the first abnormal Pap smear.

Materials and methods

This study refers to the outcome of the Pap smear screening program in Värmland, a Swedish county with about 280 000 inhabitants. In the county investigated all women between 20 and 59 years of age were recalled every third year, and during the period 1994 to 1997 90% of all female inhabitants aged 20–62 years had at least one Pap smear registered (10). A second Pap smear was taken if the first test showed signs of mild dysplasia. No further investigation was done if the second smear was normal and the woman then returned to the population-based screening program. However, if the second smear still showed CIN 1 a colposcopy with biopsy and electrocoagulation was performed. Women were then offered continued follow-up with more frequent Pap tests as suggested by the National Board of Health and Welfare (11), as local treatment of dysplasia has not been shown to prevent invasive disease in all cases (4,10).

Women who had two consecutive Pap smears with mild dysplasia (CIN 1) during 1993 were identified from the records of the Department of Clinical Pathology in Karlstad, which evaluates all cytology in the county investigated. In total, 354 women were identified as having had repeated mild dysplasia during 1993. A questionnaire was constructed based on knowledge from previous studies and reference literature. In 1999 addresses were available in the Population Registrar for 345 of these women (seven women were deceased and two women had protected identity). The questionnaire included information on relevant basic characteristics of the woman and questions related to the woman's experience of coping with a positive Pap smear. The questionnaire together with information about the aim of the study was mailed to the 345 women in August 1999. Sixteen questionnaires were returned because the recipient had moved to an unknown address. Thus a total of 329 women were available for assessment. A reminder was sent out after 2 weeks. The regional ethics committee approved the design of the study and the questionnaire.

Statistical methods

The χ^2-test was used for the statistical calculations. Qualitative data that could be obtained from individual comments were used to support the quantitative data.

Results

Two hundred and forty-two of the 329 women who were available for this 5-year follow-up completed the questionnaire (74%). Failure of some respondents to answer particular questions resulted in missing values for certain variables with an average of missing answers of 2.6% (range 0.8–14%). Figure 1 illustrates the age distribution of the responders when answering the questionnaire. The mean age of the responders was 45 years (range 24–81 years) compared to a mean age of 42 years for the nonresponders (range 22–79 years). The youngest responding girl was 19 years of age at the discovery of mild dysplasia. Seventy-five percent of the women were married or cohabiting. Thirty-four percent were living in the county's main city. Twenty-four percent had completed university studies and/or a degree, compared to the county's general level of 11% (12).

The Pap smear samples indicating signs of a mild dysplasia, that had been taken 5 years earlier, were to a large extent taken at screening. Only 11 women (5%) reported a sample being taken because of symptoms that could be assigned to possible dysplasia. Two hundred and thirty-three women (96%) reported attendance to investigation following the mild dysplasia. One hundred and seventy-eight of 233 women (76%) reported that investigation included biopsy.

Forty-six women (19%) could not remember further investigation with a biopsy but only an additional visit to the doctor for a new Pap smear. Six women (3%) reported no investigations apart from an additional Pap smear taken by the midwife. Fourteen women (6%) reported no further follow-up with a Pap smear after the investigation and treatment and 10 women (4%) did not remember when they last had a smear. Among women who did not remember having a biopsy, 11 of 56 (20%) reported that they were disturbed in their everyday life compared to 60 of 176 (34%) among the women who remembered having a biopsy ($p < 0.05$).

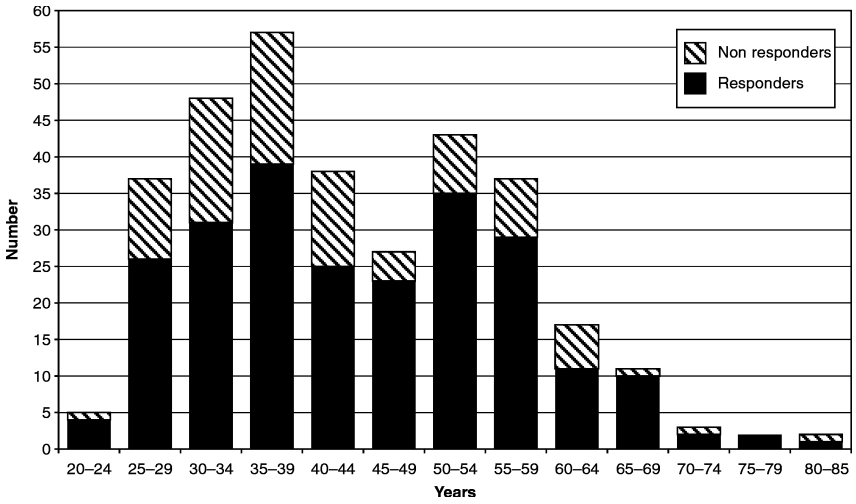

Fig. 1. The age distribution of the responders ($n = 242$, four women who did not reveal their age are not included in this figure) and non-responders ($n = 87$).

Table I shows data about the follow-up period and how the women had coped with the fact that they had had atypical Pap smear tests. In general, women reported a good or very good experience regarding the gynecologic examinations performed following the discovery of the atypia. Thirty-seven women reported poor/very poor/partly poor experience of the gynecologic examination. This involved the perceived quality of the encounter between the woman and the midwife/physician, lack of information or pain. There was a linear relationship between the woman's reported experience regarding the gynecologic examination and age, where older women reported a better experience of the gynecologic examination than younger women did.

Feelings of worry and anxiety about possible cancer and thoughts regarding future infertility and the possibility of premature death affected 142 women (59%) when they received the information about the first atypical Pap smear. Thirty-five women (14%) did not answer this open question. Twenty-seven women (11%) denied any concerns at all about the mild dysplasia. Fifteen women (6%) had desired support but had received none. The remaining 200 women (83%) had received the support they desired from the health care system and/or relatives. The knowledge regarding the atypical Pap smear had disturbed everyday life for 72 women (30%) during the time that elapsed between being informed regarding the result of the first Pap smear and subsequent investigation and treatment. Forty-six of the women who reported disturbed everyday life claimed they understood the meaning of mild dysplasia (64%) compared to 78% of the others ($p < 0.05$). Forty-two of them (58%) reported that they had very good/good confidence

Table I. Women's experience, thoughts and feelings at follow-up

	20–39 years		40–59 years		60–80 years		Total	
	$n = 100$	%	$n = 112$	%	$n = 26$	%	$n = 242$	%
The respondent felt that she had understood the information first given about the atypical Pap smear	51	51***	97	88	23	93	175 (4)	72
The respondent was negatively affected by the result	67	67*	61	54	10	38	142 (4)	59
The respondent shared neutral/positive thoughts	18	18*	34	30	13	50	65	27
Good or very good experience of the gynecologic examination	72	72**	99	88	25	96	200 (4)	83
Positive/very positive feelings of the follow-ups	69	69	92	82	19	73	184 (4)	76
Negative feelings towards follow-up	3	3	6	5	3	11	12	5
Feelings of security by continuing with Pap smears controls	83	83	95	85	22	85	200	85
The respondent apprehended her good/very good at the time of answering the questionnaire	87	87	85	75	19	73	192 (1)	79
The respondent had shared her experience with others	68	68	77	69	15	58	163 (3)	67
Good confidence in the health care system	65	65	79	71	24	92**	171 (3)	71

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$
Four women who did not reveal their age are shown in the total column in parentheses

in the health care system compared to 125 of the 161 women who did not report disturbance of everyday life (78%) ($p < 0.05$). The women who reported disturbed everyday life had not to a greater extent been lacking support, or had been affected with genital disease, including dysplasia, during the past 5 years.

Forty women (17%) reported that their personal encounter with the health care system regarding the abnormal smear tests had affected their self-esteem and for 26 of these women this was a negative experience while for 14 self-esteem increased. Twenty women (8%) reported a lasting negative influence on sexuality and on their experience of sexual intercourse as a consequence of the management of mild dysplasia and this was independent of the woman's age. The follow-up management had been experienced as very positive/positive for 11 of the 20 women who reported an influence on sexuality (58%) compared to 173 of the remaining 212 women who reported no influence on sexuality (81%) ($p < 0.01$). For eight of the 20 women who reported an influence on sexuality (42%) the encounter had influenced their self-esteem compared to 32 of the remaining 212 women who reported no influence on sexuality (15%) ($p < 0.01$). When they thought about future Pap smears, seven of the 20 women who reported an influence on sexuality (35%) were filled with worry compared to the rest, where 20 out of 212 (9%) shared that feeling ($p < 0.01$). Eleven of the 20 women reported reduced sexual desire. Ten of the 20 women (50%) had had additional gynecologic complaints compared to 59 of the 212 remaining women (28%) ($p < 0.05$). The reported complaints were itching, burning pain, dry mucous membranes, or total cessation of sexual intercourse. The additional complaints did not include recurrent dysplasia. In total, 70 women (29%) reported gynecologic complaints or illnesses that led to a consultation during the 5-year observation period. The most prevalent complaints were recurrent dysplasia ($n = 29$), irregular bleeding ($n = 20$) and itching/discharge ($n = 19$). No one reported condylomas.

One hundred and ninety-two of the women (79%) considered their current health as good/very good. This opinion was negatively affected in women who reported recurrent dysplasia during the 5-year follow-up period, where only 19 of 29 (66%) assessed their health as good or very good ($p < 0.01$). Women with recurrent dysplasia seemed to be as confident about the health care system as women with no recurrence. There was no lasting apparent difference in the women's experience of the investigation program and follow-up between women with or without recurrent dysplasia. The possibility of being able to participate in a follow-up program with regular Pap smear controls in the future generated a sense of security for 206 of the women (85%) but created anxiety for 22 (9%).

The sources of general information about gynecologic Pap smear screening and atypia, indicated by the respondents, are listed in Table II. Doctors and midwifes were the main source of information. Media was an uncommon source of information in the age group 20–39 years and this finding was even more apparent in the subgroup of women aged 20–29 years, where no women indicated media as a source of information.

One hundred and seventy-three women (73%) considered they understood the meaning and consequences of the diagnosis of dysplasia and 184 (76%) had experienced the investigation program and follow-up in a positive/very positive manner. Twenty-eight women reported that they were satisfied with the regularity of controls, which created a sense of security and a sense of support provided by the doctors and other staff. A return visit to the same doctor was also appreciated. Experience of a negative character mentioned by 10 women was when promised controls failed to materialize, when the women herself had to write/call to remind about the control, when

Table II. Women's sources of information about mild dysplasia

	20–39 years		40–59 years		60–80 years		Total	
	$n = 100$	%	$n = 112$	%	$n = 26$	%	$n = 242$	%
The physician	62	62	73	65	22	85	160 (3)	66
The midwife	34	34**	18	16	0	0	52	21
Media	9	9*	25	22	4	15	41 (3)	17
Written information from the health care system	7	7	14	13	1	4	22	9
School education	4	4	3	3	0	0	7	3
Friends or relatives	25	25**	11	10	0	0	37 (1)	15

*$p < 0.05$, **$p < 0.01$

Four women who did not reveal their age are shown in the total column in parentheses

the doctor questioned the need for further controls or when one was denied more controls because of age limitations. Ninety-five women (40%) spontaneously reported that they wanted better information about dysplasia at the screening appointment. Many of them also pointed out that a test result that showed dysplasia should always be delivered at a personal appointment or at least over the telephone. They described the shock and fear they felt when reading the letter when lacking the possibility to obtain more information and ask questions.

Discussion

The most important findings in this study were that women were primarily poorly informed about the aim of cervical cancer screening and that the information given to them concerning a mild dysplasia created anxiety, but follow-up management subsequently enabled most women to recover confidence. However, almost one in 10 women reported that the suspected dysplasia had had a long-lasting negative influence on their sexual life.

In this study the women were interviewed several years after being diagnosed with abnormal cytology in order to evaluate long-term coping following mild dysplasia. Findings were based on a self-reported questionnaire 5 years after the discovery of mild dysplasia (CIN 1). The answer rates were 74% with an average of missing answers of 2.6%, which must be considered to be satisfactory as the subject is sensitive. A potential major problem with this kind of study is the risk of selective response, which could lead to bias. The fact that 24% of the women had completed university studies compared to the county's average level of 11% may reflect a tendency for well-educated women to be more likely to answer questionnaires. The women's reported opinion regarding their fear of cancer, level of anxiety and loss of self-esteem may also have been different if the women had been interviewed earlier, for example when abnormal cytology was diagnosed, during treatment, etc. There was, however, no pattern of forgetfulness in light of the 5-year perspective, indicating that the occurrence of mild dysplasia was an important event in women's lives. The experience of having a dysplasia had been verbally shared with other women by two out of three, indicating that talking about dysplasia is not taboo but is still not a totally natural subject for all women, and older women, in particular, had discussed this to a lesser extent. In this study, 72% considered they understood the meaning and consequences of a Pap smear with mild dysplasia. This is slightly more than has been reported in the general population of women where 62% of women reported that they had correct knowledge about the type of cancer Pap smear screening examines (13).

Every second woman was affected by feelings of worry and anxiety after receiving the abnormal Pap smear test result, and everyday life was disturbed until the subsequent investigation in one-third of the women. With a 5-year perspective, women who had not, as they remembered, undergone a biopsy reported less anxiety. Approximately one woman in 10 reported that the process had permanently affected her sexuality negatively and lowered her self-esteem. Gynecologic cancer and its treatment has previously been reported to affect women's sexuality (14). Our results confirm an earlier study indicating that the fear of cancer associated with the finding of mild dysplasia may also affect self-esteem and may result in a feeling of loss of control (15). The authors argued that self-esteem, however, could be re-established by adequate medical care and follow-up. It is apparent from our study that women put their trust in continued Pap smear controls. The present study also confirms previous studies (10,16,17) indicating that the majority of women who undergo treatment for dysplasia do not seem to be affected by long-lasting symptoms of either a physical or psychological character. Even though women felt vulnerable when diagnosed with dysplasia, there were no signs of hesitation to subsequent investigation and follow-up. Women were, however, worried when the follow-up system failed. In the long-term perspective the majority of women felt that they had been well taken care of.

Younger women understood information about the atypical Pap smear less well and they tended to be more negatively affected. They also had a more negative experience of investigation and treatment and less confidence in the health care system. The treating physician was the main source of information when mild dysplasia was already a fact and the majority of women received knowledge and reassuring information first after the positive Pap smear. The message that a mild dysplasia is not a diagnosis of cancer had not reached women in general before they were affected. Media and written information from the health care system and school education were of little importance as sources of information. The need for more and better information regarding cervical screening via the media as well as the importance of information material from the local health authorities was emphasized in a

report published by the National Board of Health and Welfare in 1998 (11). The program should include both personal communication and written information at the time of screening (16), as well as the use of the internet with information on a home page. Availability of telephone counseling (16,18–21) could bridge the information gap before the second Pap smear and further investigation is carried out. Women within the age group 20–39 years indicated that midwives in the primary health care clinic were one of the main sources of information. Midwives in primary health care in Sweden are responsible for antenatal care, family planning as well as the primary Pap smear screening program. The results of this study indicate that midwives should pay even more attention to information and education regarding the cervical cancer-screening program.

In summary, inadequate knowledge created unnecessary worry and negative experiences that could have been solved by a more well-developed educational program already in connection with the nationwide screening program. The important issue is how to disseminate knowledge and information, without creating anxiety, to women before the occurrence of an atypical Pap smear. Special attention should also be paid to women's needs of counseling regarding sexual matters.

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