

Quality of Care from a Patient Perspective in Population-based Cervical Cancer Screening

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In Stockholm, population-based cervical cancer screening is offered free of charge to all women between 23 and 60 years of age. A survey to assess satisfaction with care using a previously validated questionnaire was conducted with 73 women receiving abnormal Pap smear results through the screening program. Thirty-seven women received results of screening within a feasibility project, in which they had extra contact with a midwife prior to receiving standard information and medical follow-up by a gynaecologist. The other 36 women were a matched sample receiving standard information. The results indicate generally high perceptions of quality of care, with particularly high ratings of perceived gynaecological knowledge and medical information provision. Low perceptions of quality were found regarding several aspects of psychosocial care. Higher levels of self-reported psychological well-being were found among the women who had extra midwifery contact. The results indicate that more attention to psychosocial aspects might optimize the screening program.

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BACKGROUND AND PURPOSE

The European Union's Advisory Committee on Cancer Prevention recently recommended that cancer screening be offered only in organized programs affording good information about benefits and risks, and quality assurance at all levels (1). The intermediary period between initial smear and follow-up is known to be of particular concern in efforts to avoid pathological effects of preventive interventions, especially for women with unclear or positive smear results (2–10).

The study reported here is from a well-organized, population-based, outreach cervical cancer-screening program, in the county of Stockholm, Sweden. Screening is non-selective, in that the entire eligible population of approximately 400 000 women, based on registry data of all inhabitants, is invited to take a Pap smear for screening for cancer of the uterine cervix (11–16). The population-basis for screening reflects dominant principles of the Swedish healthcare system, i.e. equal access to care (17–19).

In this screening program, women are invited by letter, indicating appointment time, place and information about the smear and its purpose, to their local antenatal health clinic (ANHC) to take a free Pap smear at regular inter-

vals from age 23 through age 60. The Pap smear itself is taken by a midwife at one of 61 ANHCs at specific clinic screening times. In July 1993, the screening program was placed under the regional Stockholm–Gotland Oncologic Centre and the system for calling, registration and follow-up of all women was computerized. All screened women with 'normal' smears now receive the results of the Pap smear by standard letter. Women with any level of 'abnormal' morphology are referred directly to one of 25 gynaecological outpatient clinics serving the local ANHCs for information on the test results and further assessment. The ANHC midwife has no further responsibility for, or contact with, the woman during further assessment and treatment.

The most recent available data (from 1998) show that 109 405 women were called for screening after elimination of 15% of the population of possible women from screening because of the existence of a recently registered Pap smear result. Nineteen percent of the women invited for screening contacted Stockholm–Gotland Oncologic Centre with a refusal (total attrition rate 48%) and a total of 57 307 Pap smears were conducted within the screening program. Seven cases of malignant changes (less than 0.01% of those tested), and 141 cases of cancer in situ or

severe abnormalities were found (0.25%). A total of 552 tests (1%) indicated either mild or moderate dysplasia.

Little is presently known about the manner or effectiveness of each gynaecological outpatient clinic in contacting the appropriate women for follow-up after screening in the Stockholm–Gotland area, or about the number of women responding to the follow-up letter. In 1994, of the total number of women with abnormal Pap smear results, the time until morphology from further assessment was registered (approximately one week after a biopsy is performed) exceeded 3 months for 148 women (over 14% of women with abnormal smear results) and for 62 women of these women, the time exceeded 6 months (approximately 6% of women with abnormal smear results). Thus with consideration given to quality assurance, particularly concerning ethical and psychological aspects, screening follow-up should be studied with respect to how the experiences of the women involved are affected.

The aim of this study was thus twofold. The primary aim was to describe how quality of care in the population-based cervical cancer-screening program was perceived by a sample of women with ‘abnormal’ Pap-smear results. A secondary aim was to explore possible differences in reported perceptions of quality of care, which correlate to differences in organizational form for informing women of ‘abnormal’ results of the Pap smear.

Feasibility project for improved information on abnormal Pap-smear results

In 1996, Stockholm–Gotland Oncologic Centre initiated a feasibility project aiming to improve care for women receiving ‘non-normal’ Pap smear results, by facilitating the provision of initial information about the abnormal smear results. In the feasibility project, women who received any type of abnormal or unclear results through the screening program in the catchment areas of four ANHCs between April 1996 and June 1997 were contacted by a midwife at the ANHC at which the Pap smear was taken. Each woman was then offered the opportunity for a first information visit with a midwife. This represents an offer of extra information, intended to complement but not in any way replace the information and gynaecological contact provided later by the physician. Midwives at the four ANHCs involved received a two-day intensive training programme as preparation.

Quality of care from a patient perspective

Patients’ views on what is important in connection with the care they receive may be seen as one aspect of quality of care and patient satisfaction has increasingly come to be seen as an indicator of quality of care (20–22). Fylan points out that few studies have examined women’s satisfaction with the care provided in cervical cancer screening programs (23). It may be postulated that satisfaction is indicated by other factors influencing attendance at cervical

screening. These factors have been described as partly intrinsic, including knowledge, beliefs and attitudes, as well as extrinsic, including factors related to organization and delivery of services (24). Orbell & Sheeran’s review of 30 years of research on cervical screening (25) highlights, for example, the significance of service provision issues, not only in terms of organization, but also in terms of provider behaviour. They also found consistent and reliable associations between negative evaluations of the screening test and screening history/intentions. One theme addressed by Marcus & Crane in their review of intervention research on cervical cancer screening (26) relates to the use of nursing staff, which is said not only to decrease costs, but also to accommodate the documented preference of many women to meet a female healthcare provider in cervical screening situations. Fylan’s review suggests additional factors related to satisfaction with cervical screening, such as waiting time, the patient’s confidence in the clinician’s ability, and increased provision of information (23).

In this study, we used the model for quality of care systematically developed by Wilde and colleagues (27). In this model, quality of care is understood in the light of two conditions, the resource structure of the care organization and patients’ preferences. Within this framework, patients’ perceptions of quality of care may be considered from four dimensions: the medical-technical competence of the caregivers, the degree of identity-orientation in the attitudes and actions of the caregivers, the physical-technical conditions of the care organization, and the socio-cultural atmosphere of the care organization. The questionnaire, Quality from the Patient’s Perspective (QPP), used in the study presented here is based on this theoretical model (see (28, 29)), and is described in more detail below.

MATERIAL AND METHODS

Study design and sample selection

All women who had received any type of ‘non-normal’ Pap-smear result and had been involved in the feasibility project receiving extra midwifery contact, still residing in the catchment area ($n = 57$; 92% of all women receiving abnormal Pap smears in the catchment area during the 15 months of the feasibility project, 1996–1997) were mailed a questionnaire during June 1998 (to be called the ‘midwife’ [M] group). Fifty-seven women from a similar catchment area in terms of income and Swedish/immigrant population (based on (30)) who had received ‘non-normal’ Pap-smear results during the same period, without extra contact with a midwife, were also mailed a questionnaire (to be called the ‘standard care’ [SC] group). The SC group was matched with the women in the M group for age. The matched SC catchment area had a somewhat larger population, to facilitate the matching process (78% of women with ‘non-normal’ Pap-smear results in this area during the same time period were included).

One questionnaire from the M group was returned as address unknown. Reminders were sent to 26 women in the M group and to 25 women in the SC group, 2–3 months after the first letter. Thirty-seven QPP questionnaires were returned from the M group (response rate 65%), and 36 from the SC group (response rate 64%).

Measures

Data on patients' perceptions of quality of care were collected using the QPP questionnaire (28, 29), modified to suit the outpatient cervical cancer screening situation. In addition to socio-demographic data, the modified questionnaire contained 26 items measuring 8 factors in three QPP dimensions and one context-specific factor constructed for this study (4 items; example: the gynaecologist had knowledge about the gynaecological cell test). The dimension 'Physical-Technical Condition' was excluded, as this was of minor relevance for this study. The QPP dimension 'Medical-Technical Competence' was assessed by two factors, 'Medical Care' (2 items; example: I received the best possible medical examinations and test [as far as I can judge]) and 'Treatment Waiting Time' (2 items). The dimension 'Identity-oriented Approach' was assessed by the factors 'Respect' (3 items; example: I had the feeling that the gynaecologist treated me with respect), 'Empathy' (3 items), 'Commitment' (2 items), 'Participation' (3 items), 'Information before Procedures' (2 items) and 'Information after Procedures' (3 items). The third dimension, 'Socio-Cultural Atmosphere' included the factors 'Secluded Environment' (2 items) and 'General Atmosphere' (4 items; example: the clinic was well organized).

The respondent evaluated each item in two ways. To measure perceived reality of quality of care, each item was related to the sentence 'I had...' (for example, I had the feeling that the gynaecologist treated me with respect). A four-point response scale was used for these items, ranging from 1 (Do not agree at all) to 4 (Fully agree) with an additional alternative for 'not applicable'.

The second type of evaluation concerned the subjective importance the person ascribed to the various aspects of care. Here, each item was related to the sentence 'This is how important it was for me to have...' (for example, 'the feeling that the gynaecologist treated me with respect...'). A four-point response scale ranging from 1 (of little importance) to 4 (of very great importance) was used.

On the basis of the relationship between each individual's scores on perceived reality and subjective importance of a given item, a personal quality index score (PQI) was calculated for the entire group (29). Higher PQI scores indicate higher perceived quality of care, and lower PQI scores indicate lower perceived quality of care. The highest PQI score is obtained if a person gives the highest ratings (i.e., 4) on both perceived reality and subjective importance for an item. The lowest PQI score is obtained if a person gives the lowest rating (1) on perceived reality and

the highest rating (4) on subjective importance. PQI scores can range from -8 (lowest quality) to 16 (highest quality).

Factor scores were calculated by summing the raw mean scores on the items representing the factor and dividing the sum by the number of items in the scale. This procedure was followed separately for the perceived reality and the subjective importance scales. The Cronbach alphas for perceived reality factors ranged from 0.79 to 0.96, and for subjective importance factors from 0.44 to 0.92. The Cronbach alpha for the context specific factor was 0.72 for the perceived reality scale and 0.47 for the subjective importance scale. It should be noted that the lower values are for those factors with only two items.

In addition, subjects completed self-rating scales on physical health and psychological well-being. Two single items were used with a five-point scale ranging from Very poor (1) to Very good (5). For the purposes of analysis, the two scales were recoded, with responses from 1 to 3 as a less favourable category, and responses from 4 to 5 as a more favourable category. The questionnaire ended with a few questions about the manner in which information was received, the length of time between taking the Pap smear and receiving results, accessibility to caregivers as well as four open-ended questions in which participants were asked to list aspects of care they found most and least satisfactory. Detailed reporting of the open-ended questions is beyond the scope of this article and is used here solely to further understanding of the quantitative results.

Data analysis

Statistical analysis. Differences in means between subgroups were tested for statistical significance using Mann-Whitney U-tests; χ^2 tests were used to test the significance of differences in proportions between subgroups. Statistical significance was assumed at $p \leq 0.05$.

RESULTS

Background characteristics of participants are shown in Table 1.

Most of the women received information on Pap-smear results by letter (86% of the M group and 84% of the SC group), while a minority reported receiving information during a personal visit to a healthcare facility (14% of each group). Most women reported receiving Pap-smear results within 4 weeks of taking the smear (74% of the M group, 68% of the SC group). Eight percent of the SC group reported receiving results 2–3 months after testing and an additional 3% of this group after 3 months. None of the women in the M group reported waiting more than 8 weeks before receiving smear results.

The results of quality of care from the total group, as shown by the perceived reality and subjective importance scales on factor level, are presented in Table 2, with a comparison of the M and SC groups.

Table 1
Characteristics of participants

	Total group	'Midwife' group	'Standard care' group
Mean age (SD) range	36.9 (9.1) 25–60	36 (9.6) 25–59	36.8 (8.9) 26–60
Education (n%)			
9 years or less	13 (14.3)	7 (18.4)	4 (10.3)
Secondary school	21 (27.3)	10 (26.3)	11 (28.2)
Post-secondary school, at least one year (no degree) or occupational training	24 (31.2)	13 (34.2)	11 (28.2)
Academic degree	21 (27.3)	8 (21.1)	13 (33.3)
Living situation (n%)			
Lives with partner	51 (66.2)	24 (63.2)	27 (69.2)
Lives alone	16 (20.8)	9 (23.7)	7 (17.9)
Lives with other, i.e. children	10 (13)	5 (13.2)	5 (12.8)
Children (n%)			
No children	24 (31.2)	10 (26.3)	14 (35.9)
One child	14 (18.2)	8 (21.1)	6 (15.4)
Two or more children	39 (50.7)	20 (52.6)	29 (48.7)
Mean psychological well-being score (SD)	4.1 (1.1)	4.4 (1.0)	3.9* (1.1)
Mean physical health score (SD)	4.4 (0.9)	4.5 (0.8)	4.3 (0.9)

* Difference between 'midwife group' and 'standard care group': $p \leq 0.05$.

The highest mean scores on perceived reality for the total group were found for the factors medical care, information before procedures, respect, and secluded environment. The least favourable rankings for perceived reality in the total group were found for the factors participation, commitment, empathy and information after procedures. The SC group tended to have lower scores on these factors, and on the context-specific factor, although of these only the factor 'commitment' was found to differ significantly. Significant differences were also found between the M and SC groups on the context-specific factor and the factor, 'secluded environment'. Three of the four context-specific items were ranked significantly more favourably in the M group ('the gynaecologist seemed knowledgeable about the gynaecological cell test', 'the gynaecologist gave correct and factual information' and 'I had the possibility to speak with the midwife about my health'), as was the item 'I had the possibility to talk with the midwife in private' in the secluded environment factor (not shown in the Table).

The mean subjective importance scores indicate that these women generally rank most aspects of care as important. The only significant difference between the groups was the higher ranking of the factor participation in the SC group, influenced particularly by one of the three items in the factor, i.e. 'I had the feeling that my knowledge of my illness was taken into consideration'.

The factors with the highest mean perceived reality scores also had the most favourable PQI scores, indicating highest perceived quality of care in terms of consistency between the individual's perception of reality and the subjective importance it is deemed to have (not shown in

the Table). The same pattern of factors with low perceived reality scores having the least favourable PQI scores was also found. The lowest and highest mean PQI scores for the total group are shown by item in Tables 3 and 4. With two exceptions, the items with lowest mean PQI scores belong to factors under the dimension identity-oriented approach (Table 3). The items with highest mean PQI scores are more variable, representing all the measured dimensions (see Table 4).

The greatest mean difference between groups was found in the PQI value for the context-specific item 'I had the possibility to talk with the midwife about my health'. The PQI for the M group (8.8) indicates moderate satisfaction with care, whereas the PQI for the SC group (0.8) shows the lowest satisfaction with care of all items ($p \leq 0.000$). The M group was also significantly more satisfied with information from the gynaecologist on self-care procedures, the physical environment of the gynaecological clinic, and the gynaecologist's knowledge about the cell test (not shown in the Tables). Despite these differences, the level of satisfaction was quite low for the first two items and particularly high for the third item in both groups.

In order to identify possible confounders, Mann-Whitney U-tests were used to compare the two groups in terms of self-reported physical health and psychological well-being. A χ^2 test was used for testing differences in proportions of reported educational level. As shown in Table 1, no statistically significant difference in mean scores was found for self-rated physical health, nor were any significant differences in proportions found for educational level reported in the two groups. Statistically significant differ-

Table 2

Comparison of midwife group and standard care group on factor level

Dimensions and Factors	Total group			Midwife group			Standard care group			z
	n	M	SD	n	M	SD	n	M	SD	
Medical-Technical Competence										
Medical care										
Perceived reality	53	3.3	0.86	29	3.2	0.84	24	3.4	0.89	0.71
Subjective importance	65	3.8	0.49	33	3.7	0.47	32	3.8	0.51	0.37
Treatment waiting time										
Perceived reality	48	3.1	1.00	25	3.0	1.03	23	3.3	0.98	0.79
Subjective importance	65	3.7	0.57	33	3.6	0.56	32	3.7	0.58	0.55
Identity-Oriented Approach										
Information before procedures										
Perceived reality	61	3.3	0.77	31	3.3	0.78	30	3.3	0.76	0.52
Subjective importance	70	3.6	0.54	34	3.5	0.52	36	3.6	0.55	1.13
Information after procedures										
Perceived reality	43	2.9	0.84	24	3.0	0.77	19	2.8	0.92	0.57
Subjective importance	63	3.4	0.57	31	3.3	0.53	32	3.5	0.61	1.23
Respect										
Perceived reality	74	3.3	0.78	36	3.4	0.73	38	3.2	0.82	1.04
Subjective importance	75	3.7	0.41	37	3.7	0.48	38	3.8	0.32	1.25
Empathy										
Perceived reality	61	2.9	0.94	31	3.0	0.91	30	2.7	0.95	1.38
Subjective importance	70	3.5	0.56	35	3.4	0.60	35	3.6	0.50	0.57
Commitment										
Perceived reality	62	2.8	0.97	32	3.0	0.94	30	2.6	0.96	1.93*
Subjective importance	72	3.5	0.59	36	3.4	0.60	36	3.5	0.58	1.01
Participation										
Perceived reality	50	2.7	0.96	25	2.8	0.93	25	2.7	1.01	0.32
Subjective importance	63	3.4	0.73	33	3.3	0.66	30	3.5	0.78	2.00*
Socio-Cultural Atmosphere										
Secluded environment										
Perceived reality	56	3.3	0.97	33	3.5	0.72	23	2.9	1.15	2.25*
Subjective importance	66	3.6	0.58	36	3.7	0.49	30	3.4	0.67	1.49
General atmosphere										
Perceived reality	45	3.1	0.70	26	3.1	0.71	19	3.2	0.71	0.36
Subjective importance	69	3.5	0.47	35	3.4	0.50	34	3.5	0.43	1.47
Context-Specific Questions										
Perceived reality	53	3.1	0.72	33	3.3	0.65	20	2.8	0.71	2.71**
Subjective importance	62	3.6	0.39	35	3.6	0.41	27	3.6	0.36	0.09

Statistical significance for differences between groups * $p < 0.05$. ** $p < 0.01$.

ences in mean scores were noted on the item designed to measure well-being. The mean score for women in the M group was more favourable for self-reported well-being than that for women in the SC group (4.37 versus 3.90, $p \leq 0.05$).

By dichotomizing the response scales on the self-rated physical health and well-being items, it was found that 94% of the participating women rated their physical health as better and 6% as worse. The corresponding figures on the psychological well-being item were 82% and 18%, respectively.

Comparisons using Mann-Whitney U-tests of women reporting more or less favourable well-being showed that women with a more favourable score on well-being reported a higher mean score on 10 out of 30 items, all related to identity-oriented aspects of contact with the

gynaecologist. One significant difference was found related to subjective importance, i.e. satisfaction with information about the medical examination and Pap test was ranked as more important by the women reporting less favourable well-being.

As a higher well-being score per se was associated with more favourable scores on the perceived reality scales, and as the M group had a significantly higher mean score than the SC group on the well-being item, an additional comparison was made. In the M group, all but three women had ranked their psychological well-being as 'Good' or 'Very Good'. In the SC group, all but 11 women had marked these response alternatives. In order to control for the potential influence of psychological well-being on the comparison between the two groups, these were compared (Mann-Whitney U-tests) selecting only the women who

Table 3*Items with lowest mean personal quality index (PQI) scores, representing low satisfaction with care*

Items	PQI score
I received satisfactory information regarding self-care procedures; that is, how I best can take care of myself. (Information after...)	4.7
The clinic was a pleasant physical environment rather than a cold and sterile one. (General atmosphere)	5.5
I had the possibility to talk with the midwife about my health. (Context-specific)	5.7***
I had the possibility to participate in the decision-making process regarding my personal care. (Participation)	6.1
I had the feeling that my own knowledge of my illness was taken into consideration. (Participation)	6.7
I had the possibility to participate in the decision-making process regarding my medical care. (Participation)	6.8
The gynaecologist showed interest in my concerns and hassles (Commitment)	7.1
The gynaecologist showed a sense of commitment and 'cared about me'. (Commitment)	7.2

*** $p \leq 0.0001$ for differences between 'midwife group' (8.8) and 'standard care group' (0.8).

had endorsed the 'Good' or the 'Very Good' alternatives. This did not result in any change to the patterns previously found.

DISCUSSION

This study reports on patients' perceptions of quality of care based on a sample of women participating in a population-based, cervical cancer-screening program in urban Sweden, who had received information about abnormal Pap-smear results in two different ways. The results of this retrospective study indicate that these women generally report being satisfied with the quality of the care received and rate most aspects of the care investigated as important. Particularly high ratings for perceived reality and high personal quality index scores were found among women in both forms of care in relation to the gynaecologist's knowledge and information provision about Pap smears. The items with highest PQI scores, thus indicating highest satisfaction with care, were all primarily related to aspects of medical technical competence and basic aspects of the screening program, which nevertheless have not, to our knowledge, been thoroughly investigated earlier. Several aspects of care that suggest least satisfaction in terms of both perceived reality and PQI scores

concern rating of the possibility of participating in some aspects of care. These aspects include women's experience of lacking possibility to discuss and participate in decision-making about personal care and about medical care, a lack of adequate information about self-care, and a feeling that one's own knowledge about experienced illness was not taken into consideration. Other aspects of care that these women were especially dissatisfied with concerned the lack of commitment and lack of interest they perceived from the gynaecologist. It is notable that these items all belong to the areas of Wilde et al.'s model which represent an 'identity-oriented approach' (29).

A secondary aim of the study was to explore possible differences that could be correlated to the different organizational forms for informing women of abnormal Pap-smear results. This study was not planned to optimize investigation of differences between women in the different forms of care. The small sample, lack of randomized control, lack of baseline assessment of physical health and psychological well-being and the relatively longtime frame between initial contact with the screening program and response to the questionnaire were all factors that could obscure differences between groups and which led to difficulty in inter-

Table 4*Items with highest mean personal quality index (PQI) scores, representing high satisfaction with care*

Item	PQI score
The gynaecologist had knowledge about the gynaecological cell test. (Context-specific)	12.9
Only authorized staff had access to my medical records. (General atmosphere)	12.3
The gynaecologist gave me correct and factual information about the gynaecological cell test. (Context-specific)	12.0*
I had the possibility to talk with the gynaecologist in private. (Secluded environment)	11.8
The gynaecologist seemed to give me straightforward answers to my questions (Respect)	11.4
I received satisfactory information regarding medical examinations and tests so that I understood their relevance as well as how they would be done. (Information before...)	11.0
I received the best possible medical treatment (as far as I can judge). (Medical care)	10.9
I received satisfactory information regarding medical treatments so that I understood their relevance as well as how they would be done. (Information before...)	10.7
I received the best possible medical examinations and tests (as far as I can judge). (Medical Care)	10.7

* $p \leq 0.05$ between 'midwife group' (13.1) and 'standard care group' (11.0).

preting results. Despite these weaknesses, some interesting results were found indicating issues that should be more stringently investigated in the future.

Women who had extra contact with a midwife prior to seeing a gynaecologist ranked care received on three of the four context-specific questions more favourably than women receiving standard care. In addition to reporting satisfaction with having the possibility to speak to the midwife compared with women who had no extra midwifery contact, they also reported higher values on items assessing the gynaecologist's knowledge and information provision about the Pap smear. One interpretation of this is as a 'spin-off' effect, in that women receiving extra healthcare contact perceive several facets of care more favourably than those women receiving standard care. As responses to open questions highlight a perceived distinction between the role of the gynaecologist as representing medical-technical competency, and the role of the midwife in providing psychosocial care (31), this difference may also be the result of a comparison with what is perceived as the midwives' competence in such issues.

The role of the midwife in providing psychosocial care is supported by the finding that women in the SC group report statistically significantly lower self-rated psychological well-being than women in the M group. Although this study design using single items cannot exclude the possibility that the groups differed at baseline, no other differences between the groups were found to support this explanation. As earlier studies of quality of care tend to show that people who assess their psychological well-being more positively also tend to assess quality of care more positively (32–37), we controlled for the effect of differential assessment of well-being. A comparison of only those women reporting positive well-being in the M versus the SC groups showed that the results presented above are not explained by differences in psychological self-assessment.

It is also noteworthy that when the ratings of well-being were dichotomized, 18% of the women responding to the questionnaire had self-assessed well-being categorized as 'worse' rather than 'better'. It is difficult to interpret this in relation to cervical screening without the existence of either a baseline assessment or a comparison group. We are aware of only two other studies in Sweden with women with abnormal Pap-smear results from screening (38, 39). Waldenström (39) found that 20 out of 40 Swedish women interviewed in 1980 at the time of medical follow-up examination after receiving a positive Pap smear through screening responded with extreme anxiety, which is in line with results of many studies (23). Björk & Hagström (38) recently found the same proportion of women with abnormal Pap-smear results in Western Sweden reporting extreme anxiety/chaos on a questionnaire retrospectively sent to women with first-time reports of abnormal Pap smears from screening. They found no differences in anxiety related to

degree of cellular abnormality. Both studies emphasize that there were major problems with conveying information to the women, indicating that in many cases the degree of anxiety was not in proportion to the degree of cellular abnormality. Although the women in the study reported here show moderate levels of satisfaction with the medical aspects of information, the nature of the problems found here are parallel, despite the use of different methods and time points for assessment. Our data indicate that the links between medical information and its implications for the individual may need more attention. This is supported by recent work by Forss (40) indicating that information is conveyed to women about abnormal Pap-smear results not only explicitly, but also communicated by professionals unintentionally through what is not said. Forss (40) found that information was first seen as meaningful by women with abnormal Pap-smear results when it was seen to be relevant to their concerns. Twinn & Cheng (41) found that satisfaction with care, especially regarding communication, was higher in a group of Hong Kong Chinese women attending nurse-run cervical screening than those screened by a female physician. In the UK, a qualitative interview study (42) was conducted to complement a randomized trial using a nurse-based educational intervention to diminish anxiety in women with mild dysplasia. Although the intervention did not diminish anxiety as hoped (43), positive aspects of the contact with a nurse for screening were highlighted in the interviews, particularly as related to interpersonal skills.

Anxiety and concern about the results of screening can arise from lengthy waiting times (8). The feasibility project described here was initiated in part to minimize the time between taking the Pap smear at screening, and receiving information about the presence of unclear or abnormal findings and what the results imply. It was found that whereas 11% of the SC group reported receiving Pap-smear results more than 2 months after taking the smear, none of the women in the M group reported waiting longer than 2 months. While it is unclear if this is due to the feasibility project per se, with earlier information provided by a midwife, or due to other organizational factors, the shorter time frame may be postulated to have a positive psychosocial effect.

The internal consistency of the perceived reality scales on the factor level, including the newly developed four-item context-specific factor, was acceptable. However, the Cronbach alpha values for the subjective importance scales for those factors with only two items were low. The Cronbach alpha for subjective importance scale of the context-specific factor was 0.47. This was due to the item assessing the possibility of talking with the midwife about one's health. When this item was excluded, the resulting Cronbach alpha increased to 0.69, despite only three questions remaining on the scale. This same item also had the lowest PQI score among women in the SC group. The PQI score for the item

in the M group indicated considerably higher satisfaction with this facet of care. These findings add further support to the argument that the role of the midwife is perceived differently from that of the gynaecologist in the screening program.

In conclusion, this study indicates that there is a relatively high level of satisfaction with care in the medical aspects of this population-based cervical cancer-screening program. There are indications, however, that more attention could well be given to psychosocial aspects, such as participation, empathy and commitment, in order to optimize the program. The feasibility project using extra contact with a midwife should be developed and more stringently evaluated for effectiveness toward this end. This is in line with Waldenström's recommendation, formulated 20 years ago (39), for personal contact with a knowledgeable person in conjunction with an increased awareness of psychosocial factors. It is also well in line with more recent conceptualizations of healthcare provision as moving from 'post-office model(s) of receipt and delivery' (44) to more participatory, processual and empowering exchanges between layperson and expert.

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REFERENCES

1. Advisory committee on cancer prevention. Position paper: recommendations on cancer screening in the European Union. *Eur J Cancer* 2000; 36: 1473–8.
2. Fisher S. In the patient's best interest: women and the politics of medical decisions. New Brunswick, NJ: Rutgers University Press, 1986.
3. Foster P. Women and the health care industry. Buckingham, UK: Open University Press, 1995.
4. Kaplan C, Bastani R, Belin T, Marcus A, Nasseri K, Hu M-Y. Improving follow-up after an abnormal Pap smear: results from a quasi-experimental intervention study. *J Women's Health Gender-based Med* 2000; 9: 779–90.
5. Lerman C, Rimer BK, Engstrom PF. Cancer risk notification: psychosocial and ethical implications. *J Clin Oncol* 1991; 9: 1275–82.
6. Campion MJ, Brown JR, Mccance DJ, et al. Psychosexual trauma of an abnormal cervical smear. *Br J Obstet Gyn* 1988; 95: 175–81.
7. Posner T. Ethical issues and the individual woman in cancer screening programmes. *J Adv Health Nurs Care* 1993; 2: 55–69.
8. Reelick NF, de Haes WFM, Schuurman JH. Psychological side-effects of the mass screening on cervical cancer. *Soc Sci Med* 1984; 18: 1089–93.
9. Rajaram SS, Hill J, Rave C, Crabtree BF. A biographical disruption: the case of an abnormal Pap smear. *Health Care Wom Int* 1997; 18: 521–31.
10. Conway K. Attitudes to Papanicolaou smears. *J Psychosom Obstet Gyn* 1996; 17: 189–94.
11. Celentano D, Klassen A, Weisman CS, Rosenshein N. Duration of relative protection of screening for cervical cancer. *Prev Med* 1989; 18: 411–22.
12. Engels H, Nyongo A, Temmerman M, Quint WGV, Van Marck E, Eysenbosch WJ. Cervical cancer screening and detection of genital HPV-infection and chlamydial infection by PCR in different groups of Kenyan women. *Ann Soc Belg Med Trop* 1992; 72: 53–62.
13. Lynge E, Madsen M, Engholm G. Effect of organized screening on incidence and mortality of cervical cancer in Denmark. *Cancer Res* 1989; 49: 2157–60.
14. Mishra NK, Sinha TK. Cytologic screening for the detection of cancer in the uterine cervix—a survey in Patna (India). *Cancer Lett* 1990; 52: 21–7.
15. Nasca P, Elish N, Caputo T, Saboda K, Metzger B. An epidemiologic study of Pap screening histories in women with invasive carcinomas of the uterine cervix. *N Y State J Med* 1991; 91: 152–6.
16. Pettersson F. Efficacy of cervical cancer screening. *Med Oncol Tumor Pharmacother* 1991; 8: 175–81.
17. Lalltorp J. Priority-setting and the decision-making process in health care: some postwar characteristics of health policy in Sweden. Doctoral dissertation. Uppsala University, Department of Social Medicine, 1989.
18. Hollingsworth JR, Hage J, Hanneman RA. State intervention in medical care: consequences for Britain, France, Sweden and the United States, 1890–1970. Ithaca New York: Cornell University Press, 1990.
19. Johansson L. Caring for the next of kin: on informal care of the elderly in Sweden. Doctoral dissertation. Uppsala University, Department of Social Medicine, 1991.
20. Cleary PD, McNeal BJ. Patient satisfaction as an indicator of quality of care. *Inquiry* 1988; 25: 25–36.
21. Davies AR, Ware JE. Involving consumers in quality of care assessment. *Health Affairs* 1988; 7: 33–48.
22. World Health Organization. Quality assurance of health services. Copenhagen: WHO, Regional Committee for Europe, 1988.
23. Fylan F. Screening for cervical cancer: a review of women's attitudes, knowledge and behaviour. *Br J Gen Pract* 1998; 48: 1509–14.
24. Twinn S, Cheng F. A case study of the effectiveness of nurse-led screening programmes for cervical cancer among Hong Kong Chinese women. *J Adv Nurs* 1999; 29: 1089–96.
25. Orbell S, Sheeran P. Health psychology and uptake of preventive health services: a review of 30 years' research on cervical screening. *Psychol Health* 1993; 8: 417–33.
26. Marcus A, Crane LA. A review of cervical cancer screening intervention research: implications for public health programs and future research. *Prev Med* 1998; 27: 13–31.
27. Wilde B, Starrin B, Larsson G, Larsson M. Patients' view on quality of care: a grounded theory study. *Scand J Caring Sci* 1993; 7: 113–20.
28. Larsson G, Wilde Larsson B, Munck I. Refinement of the questionnaire 'Quality of Care from the Patient's Perspective' using structural equation modelling. *Scand J Caring Sci* 1998; 12: 111–8.
29. Wilde B, Larsson B, Larsson M, Starrin B. Quality of care: development of a patient-centred questionnaire based on a grounded theory model. *Scand J Caring Sci* 1994; 8: 39–48.
30. Statistics Sweden. Living conditions—living conditions and inequality in Sweden: a 20-year perspective 1975–1995. Stockholm: Official Statistics of Sweden, 1997: Report No. 91.
31. Tishelman C, Widmark C, Lundgren E-L, Forss A. The engendered role of the nurse-midwife in cervical cancer

- screening. In: Proceedings of the 10th biannual conference of WENR, 2000. Reykavik Iceland, 449–56.
32. Wilde B, Larsson G, Larsson M, Starrin B. Quality of care from the elderly person's perspective: subjective importance and perceived reality. *Aging Clin Exp Res* 1995; 7: 140–9.
 33. Samuelsson G, Edebalk P-G, Ingvad B. Quality attributes of Swedish home-help services—from a consumer perspective. *Z. Gerontol* 1993; 26: 202–7.
 34. Linn LS, Greenfield S. Patient suffering and patient satisfaction among the chronically ill. *Med Care* 1982; 20: 425–31.
 35. LeVois M, Nguyen TD, Attkinson C. Artifact in client satisfaction assessment. *Eval Prog Plan* 1981; 4: 139–50.
 36. Golant SM. Individual differences underlying the dwelling satisfaction of the elderly. *J Soc Iss* 1982; 8: 21–33.
 37. Costa PT, McCrae RR. Neuroticism, somatic complaints and disease: is the bark worse than the bite? *J Pers* 1987; 55: 299–313.
 38. Björk S, Hagström H-G. Vad betyder cellförändringarna? Dålig information om avvikande cytologprov skapar onödig oro (Anxiety caused by abnormal result of cervical smear test—two groups of women studied). *Läkartidningen* 2001; 98: 2796–800.
 39. Waldenström U. Gynekologisk hälsokontroll—hur tar vi hand om den oro den skapar? (Cervical cancer screening: how do we deal with the anxiety it creates?). *Läkartidningen* 1981; 78: 3255.
 40. Forss A, 2001. Cervical cancer screening from the lay perspective. Licentiate thesis, Karolinska Institutet, Stockholm.
 41. Twinn S, Cheng F. Increasing the uptake of cervical screening amongst Hong Kong Chinese women: the contribution of the nurse practitioner. *J Clin Nurs* 1999; 8:323–4.
 42. Somerset M, Peters TJ. Intervening to reduce anxiety for women with mild dyskaryosis: do we know what works and why? *J Adv Nurs* 1998; 28: 563–70.
 43. Peters T, Somerset M, Baxter K, Wilkinson C. Anxiety among women with mild dyskaryosis: a randomized trial of an educational intervention. *Br J Gen Pract* 1999; 49: 348–52.
 44. Olesen V, Lewin E. Women, health and healing: a theoretical introduction. In: Lewin E, Olesen V, eds. *Women, Health and Healing: Toward a new perspective*. London: Tavistock, 1985: 1–24.