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Marta Meana

*University of Nevada, Las Vegas, [marta.meana@unlv.edu](mailto:marta.meana@unlv.edu)*

Donna E. Stewart

*University Health Network Women's Health Program, [Donna.Stewart@uhn.on.ca](mailto:Donna.Stewart@uhn.on.ca)*

Gordon M. Lickrish

*Women's Health Program and Department of Gynecological Oncology*

Joan Murphy

*Women's Health Program and Department of Gynecological Oncology*

Barry Rosen

*Women's Health Program and Department of Gynecological Oncology*

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## Patient Preference for the Management of Mildly Abnormal Papanicolaou Smears

MARTA MEANA, Ph.D.,<sup>1</sup> DONNA E. STEWART, M.D., F.R.C.P.(C),<sup>2</sup>  
GORDON M. LICKRISH, M.D., F.R.C.S.(C),<sup>2</sup> JOAN MURPHY, M.D., F.R.C.S.(C),<sup>2</sup>  
and BARRY ROSEN, M.D. F.R.C.S.(C)<sup>2</sup>

### ABSTRACT

Our objective was to investigate patient knowledge, desire for participation in medical decision making, and preference for the management of mildly abnormal Papanicolaou (Pap) smears (low-grade squamous intraepithelial lesions [LGSIL]) in the context of the continuing controversy between active (immediate colposcopy and biopsy) and surveillance (repeat Pap smears) management strategies. One hundred thirty-six women referred for a diagnostic colposcopy with a first-time mildly abnormal Pap smear result completed questionnaires before contact with either the nurse or physician. They were given the State-Trait Anxiety Inventory, the CESD Depression scale, and a knowledge about dysplasia quiz. They were then presented with the two management options and asked to state a preference, if any. They then completed the Problem Solving-Decision Making Scale, a measure of desire for involvement in medical decision making. The majority of women in this sample opted for the active management strategy. Management preference was related to anxiety, with the most anxious women more likely to choose the active management strategy. Management preference was not related to knowledge or to desire for an active role in decision making, although the more knowledgeable women also reported a desire for an active role in the decision-making process. Given the current controversy over the management of mildly abnormal Pap smears (LGSIL), as well as the fact that there is no conclusive evidence to support one strategy over another, the informed management preference of women affected by these decisions should be factored into the equation.

### INTRODUCTION

ALTHOUGH THERE IS A NEAR CONSENSUS that women with moderate to severe cervical dysplasia (high-grade squamous epithelial lesions [HGSIL]) on a Papanicolaou (Pap) smear

should be evaluated and treated immediately if the degree of HGSIL is confirmed, the appropriate management of borderline abnormalities, such as squamous atypia and low-grade dysplasia [low-grade[LG] SIL/CIN I), remains controversial. The controversy centers on two opposing

<sup>1</sup>Department of Psychology, University of Nevada, Las Vegas, Nevada.

<sup>2</sup>Women's Health Program and Departments of Gynecological Oncology, The Toronto Hospital, University of Toronto, Toronto, Ontario, Canada.

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management strategies. One strategy is based on cytological surveillance (repeat Pap smears) until low-grade abnormalities revert to normal, reserving histological evaluation and biopsy only for those abnormalities that persist or progress to higher grades. The alternative strategy is to refer all abnormalities for colposcopic evaluation and biopsy immediately. As recently as 1993, a nationwide (U.S.) survey of physicians showed that 40%–45% recommend early colposcopy and biopsy in patients with atypical squamous cells of undetermined significance on Pap smear, whereas the rest of the respondents favored a less aggressive approach.<sup>1</sup> Clinical guidelines in the United States and Canada have at times favored a cytological surveillance strategy with atypia and low-grade abnormalities.<sup>2,3</sup> The 1992 National Cancer Institute (NCI) Workshop interim guidelines for the management of abnormal cervical cytology suggested that women with low-grade Pap smear may be followed by repeat Pap smear.<sup>2</sup> On the other hand, the 1993 American College of Obstetricians and Gynecologists Technical Bulletin 183 on the evaluation and management of cervical cytology abnormalities recommended either proceeding directly to colposcopy for LGSIL or using the "conservative approach" for patients who are "carefully selected and considered reliable for follow-up."<sup>4</sup> Clearly, there is a lack of consensus on which is the most appropriate strategy.

The surveillance strategy is based on the belief that the majority of cervical abnormalities will revert to normal spontaneously and that, even in the minority of the cases that progress, progression is generally slow.<sup>5–7</sup> The argument further posits that reserving colposcopic referral for persistent or progressive abnormal smears would result in a significant reduction in healthcare expenditures and would lessen the anxiety often evidenced in women undergoing these procedures.<sup>8–10</sup> Proponents of the active strategy primarily argue that we do not understand sufficiently the factors that influence the progression or remission of mild abnormalities to forego histological evaluation. They further suggest that (1) a significant number of mildly abnormal smears have underlying higher grade dysplasia, (2) patient noncompliance with follow-up Pap smears would increase the risk of cervical carcinoma, (3) financial costs would ultimately be equivalent, as many of these women would eventually require

colposcopic evaluation, and (4) the wait would result in increased anxiety for the women involved.<sup>11–13</sup>

There are strong arguments in favor of either strategy, but there is no clear-cut evidence indicating that one management strategy is necessarily better than the other, which is precisely why the controversy persists.<sup>11,14</sup> In the absence of results from a randomized clinical trial that could possibly settle the issue, clinicians must continue to make decisions and recommend strategies to their patients.

The management of mildly abnormal Pap smears is an important women's health issue, as 5%–10% of the more than 28 million Pap smears performed in the United States every year are evaluated to be abnormal, and 95% of these abnormalities are low-grade abnormalities. This means that at least 1.33 million women in the United States alone are affected by these decisions on a yearly basis.<sup>11</sup> Considering the large number of women affected and the lack of overwhelming evidence to support one strategy over another, it seems curious that patient preference has only rarely been mentioned as a variable worthy of further study or of incorporation into medical decision making.<sup>11,12</sup>

This study sought to investigate management preference and desire for decision-making involvement in women who have received a first mildly abnormal Pap smear result. Of secondary interest was the extent to which management preference and desire for involvement in decision making were related to psychological distress and knowledge about their condition and the procedures involved in the evaluation and management of borderline cervical abnormalities.

## MATERIALS AND METHODS

Consecutive English-speaking women with a first-time mildly abnormal Pap smear (atypia, human papillomavirus [HPV] effects, LGSIL) referred to a metropolitan clinic for a diagnostic colposcopy were approached immediately after registration and before contact with either a nurse or the physician. They were asked if they would be willing to complete a series of questionnaires. Consenting women were given a short package of questionnaires that they were instructed to complete in a predetermined order before contact

with any health professional. The research assistant was nearby to answer questions they might have while completing the study packet. The study protocol was approved by the Ethics Review Board of The Toronto Hospital.

The first questionnaire in the packet inquired about age, educational level, marital status, number of children, the type of doctor who referred them, whether they had known anyone who had had a colposcopy, and whether they had ever read an article or seen/heard a TV/radio segment on Pap smears. Women then completed the State-Trait Anxiety Inventory (STAI),<sup>15</sup> a 40-item self-report scale that measures state and trait levels of anxiety reliably, and the Center for Epidemiological Studies Scale for Depression (CESD), a 20-item self-report scale that screens for the presence of depression in the general population.<sup>16</sup> These were followed by a knowledge quiz, adapted from Stewart et al.,<sup>17</sup> that required women to circle answers in a multiple choice format for eight questions regarding cervical dysplasia, colposcopy, management options, and follow-up regimens. Patient preference was determined by presenting women with a description of the two opposing management strategies, preceded by a statement stating that neither had been proved superior at curtailing the development of cervical cancer. They were then asked to choose the management strategy they preferred or to indicate that they had no strong preference for either strategy. Finally, women were asked to complete the Problem-Solving Decision-Making Scale (PSDM),<sup>18</sup> which is a psychometrically sound scale that presents patients with six questions about who should determine diagnosis, treatment options, risks and benefits, probabilities, utilities, and what should be done. The two factors that emerge from this measure are problem solving (the first four questions) and decision making (the last two questions). The scale scores are 1 = "doctor alone," 2 = "mostly the doctor," 3 = "the doctor and you equally," 4 = "mostly you," 5 = "you alone."

Univariate analyses of variance (ANOVA) were used to probe for differences between the management preference groups on psychological distress variables, knowledge, and problem-solving decision-making variables. Pearson correlations were used to probe for relationships between psychological distress and knowledge and decision-making variables. Finally, chi-square

analyses were performed for discrete variables to test for management group differences. Sample size was set for a power of 0.80 in detecting medium size effects at  $p = 0.05$ .

## RESULTS

One hundred forty-five consecutive women were approached. Four refused and five did not have time to complete the questionnaire before their diagnostic colposcopic examination. Thus, 136 women signed the consent form and completed the questionnaires. The mean ( $\pm$  standard deviation [SD]) age of the sample was  $33.40 \pm 10.81$  years. The educational level of the sample was primary school in 2 (1.5%), high school in 29 (21.3%), postsecondary school in 86 (63.2%), and postgraduate study in 19 (14%). Sixty-two women (45.6%) were single, 13 (9.6%) were separated/divorced, 60 (44.1%) were married/cohabiting, and 1 (0.7%) was widowed. Thirty-eight (27.9%) had a Pap result of atypia, 86 (63.2%) had LGSIL/CIN I, and 12 (8.8%) had HPV effects. Twenty-six (19.1%) women had been referred by their gynecologist, 96 (70.6%) by their primary care physician, and 14 (10.3%) by someone other than their gynecologist or family doctor.

In terms of psychological distress, the mean for depressive symptomatology on the CESD was 11.62 ( $\pm 8.45$ ), which is well below the score of 16 at which depressive symptomatology is considered significant. Ninety-eight women (72%) scored below 16, and 38 (28%) could be considered to be significantly depressed. The mean for state anxiety was 43.46 ( $\pm 10.14$ ), which is considered a moderate level of anxiety in comparison to norms. Eleven women (8.2%) reported very little state anxiety, 40 (29.9%) reported mild levels of state anxiety, 69 (59.7%) reported moderate levels of state anxiety and 14 (10.4%) reported severe to very severe anxiety. The mean for trait anxiety was 37.24 ( $\pm 9.53$ ), which is considered a mild level of anxiety. The difference between state anxiety and trait anxiety was significant ( $T^2 = 7.33$ ,  $df = 133$ ,  $p = 0.0001$ ), indicating that women perceived themselves to be significantly more anxious just prior to colposcopy than they regularly felt.

In terms of knowledge about dysplasia, colposcopy, management options, and follow-up regimens, the mean score on the quiz (8 being a

TABLE 1. CORRECT RESPONSE FREQUENCIES FOR DYSPLASIA KNOWLEDGE QUIZ

Knowledge of	Correct responses (n = 136)	
	n	%
What abnormal Pap smear results from	74	54.4
The type of abnormality found on personal Pap test	63	46.3
What a colposcopic examination is	63	46.3
Smoking as a risk factor	21	15.4
Unprotected sex as a risk factor	66	48.5
Management options	69	50.7
Progression likelihood if untreated	86	63.2
Follow-up recommendations	18	13.2

perfect score) was 3.40 ( $\pm 1.87$ ). Knowledge was lowest regarding smoking as a risk factor for cervical dysplasia (15% were aware) and what the follow-up recommendations are for abnormal Pap results (13% were aware), but approximately 50% of women were unable to correctly respond to most other questions (Table 1). Women who reported they knew someone who had undergone a colposcopy scored significantly higher on the knowledge quiz than women who did not ( $F(1,132) = 12.34, p = 0.001$ ). The same was true for women who had been exposed to media coverage of Pap smears ( $F(1,132) = 21.46, p = 0.0001$ ).

When presented with the two opposing management strategies and the declaration that there was no solid evidence to support one strategy over another, the majority of women chose the histological evaluation and likely biopsy option (active strategy). Eighty-seven (64%) stated that they preferred the active strategy, 24 (17%) stated a preference for the cytological surveillance strategy, and 23 (17%) stated that they had no strong preference for either management option.

In terms of problem solving and decision making, the women in this sample responded similarly to other patient groups<sup>18</sup> in that they preferred to leave the diagnosis, determination of treatment options, and determination and probability estimates of treatment risks and benefits mostly to the physician (problem solving mean was  $2.08 \pm 0.53$ ), but they want to be more involved in the estimation of utilities (the value placed on risks and benefits) and the final decision (decision making mean was  $3.27 \pm 0.92$  (Figs. 1, 2, 3, 4, 5, and 6).

There were two main significant relationships between measures. Management preference was related to state anxiety when state anxiety was treated as a discrete variable. Women reporting moderate to severe anxiety were more likely to choose the active management strategy than women who only reported very little to mild anxiety ( $\chi^2(1,134) = 3.64, p = 0.05$ ). Management preference was not related to knowledge about dysplasia nor to level of participation desired in medical decision making. Score on the knowl-

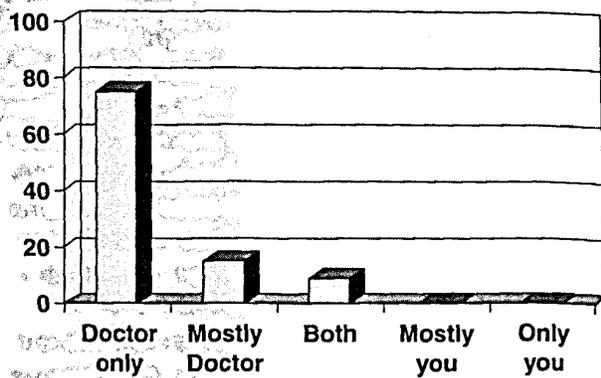


FIG. 1. Who should determine if your Pap smear is abnormal?

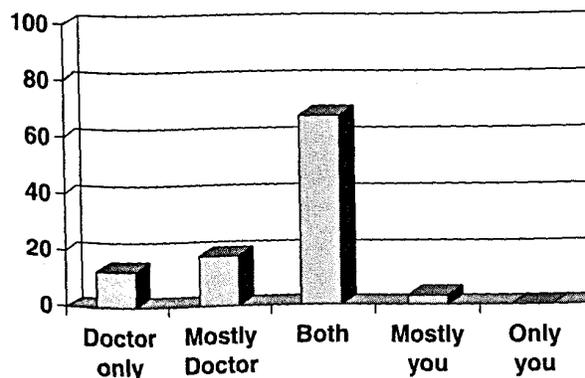


FIG. 2. Who should determine what the treatment options are?

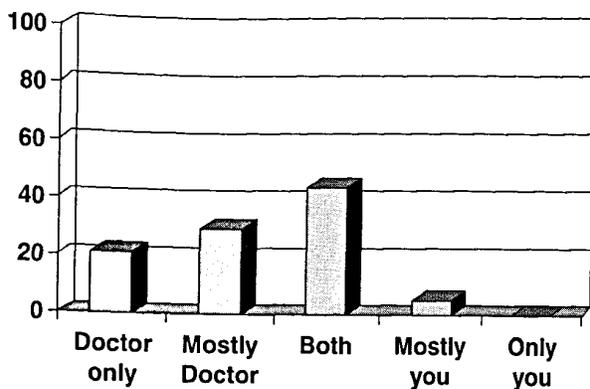


FIG. 3. Who should determine what the risks and benefits for each treatment option are?

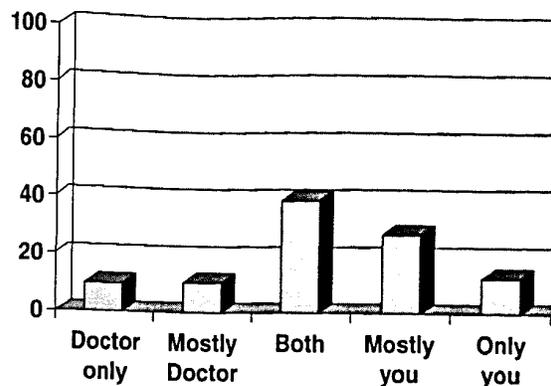


FIG. 5. Given the risks and benefits of these possible treatments, who should determine how acceptable those risks and benefits are to you?

edge quiz correlated positively with the desire for a more active role in decision making ( $r = .26, p = 0.002$ ).

### DISCUSSION

The majority of women in this highly educated sample preferred active management (histological evaluation) of their mildly abnormal Pap smears, although a substantial minority either opted for the surveillance strategy (cytological surveillance) or reported no strong preference. Considering that half of them were completely unaware of appropriate management strategies before our brief presentation of their options, these results constitute an on-the-spot decision based on little information and time. Preferences may have been different if women were given more details about the different management

strategies and more time to reflect. On the other hand, our brief presentation of the management options may reflect more accurately what may transpire during a consultation with the referring physician.

Furthermore, management preference in this sample was not related to knowledge but rather to level of state anxiety. This indicates that these decisions may be guided more by emotions than by facts. Research has shown repeatedly that abnormal Pap smears are associated with a significant amount of anxiety.<sup>19</sup> It could be that fear of invasive carcinoma weighs in heavily on the side of the active management strategy, despite knowledge of its being a low probability event. It would not be the first time that the emotional valence of a low-probability outcome outweighs that of a high-probability and just as serious alternative. Women's fear of breast cancer, associated in very low numbers with hormone re-

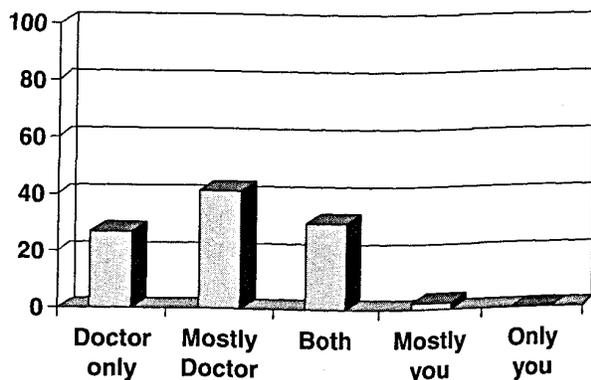


FIG. 4. Who should determine how likely each of the risks and benefits is to happen?

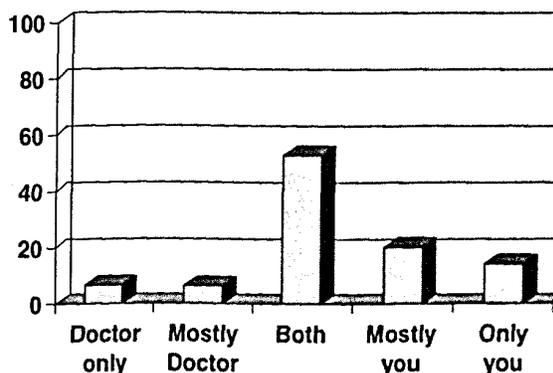


FIG. 6. Given all the information about risks and benefits of the possible treatments, who should decide which treatment option should be selected?

placement therapy (HRT), has consistently been shown to have a greater impact on their decision making than the much higher risk of coronary heart disease (CHD) when HRT is not adhered to after menopause.<sup>20</sup> Information has been shown to decrease anxiety related to abnormal Pap smears,<sup>17</sup> but it is currently unclear how that might affect patient preference for management strategies. Knowledge is clearly not a factor that has determined on which side of the controversy the myriad medical researchers investigating this issue stand.

This sample had a high educational level, which may be in part due to the clinic's proximity to the university. It would be expected that the high educational level of this sample might result in higher levels of knowledge about dysplasia than in the general population. Yet knowledge of dysplasia and colposcopy was low. Half of the women were ignorant of some of the most elementary facts, such as the level of abnormality indicated by the Pap smear and the most basic information about the procedure they were about to undergo. These results are not inconsistent with other studies on women's knowledge of Pap smears and colposcopy procedures.<sup>21,22</sup> One study noted that the three questions most important to women referred for colposcopy were: (1) What do the findings mean? (2) What is a colposcopy? (3) What will happen at the clinic?<sup>23</sup> Clearly, at least half of the women in this study did not have the answers to these questions before arriving at the colposcopy clinic. Also consistent with previous research was the finding that women's perception of information gained through personal contacts and media sources had a significant impact on what they actually knew.<sup>21</sup> Knowledge, however, was related to desire for participation in the decision making about the management of their Pap smear result regardless of management strategy preference. This suggests that although knowledge did not predict preferred management strategy, it did make women desire more active participation in decisions that would affect them.

All the women in this study had been referred for a diagnostic colposcopy. Clearly, their referring physicians (primarily family practice physicians) had left the decision about management strategy up to colposcopists rather than make it themselves. One limitation of this study is the possibility that the referring physicians, by deferring to colposcopists, had already biased these women toward

a more active strategy before their participation in our study. This seems unlikely, however, as this sample had minimal knowledge of dysplasia, colposcopy, and management options. Over half of them had no idea what a colposcopy is, and half of them were unaware of management strategies. There is, consequently, little evidence that the women were informed in any particular direction. Future studies could investigate the management preference of women before any diagnostic referral, as well the preferences of less well educated women. As this study was conducted in Canada, with its socialized healthcare, direct financial costs were not a factor in the management preferences of the women in this sample. An analogous study in the United States would be needed to investigate the extent to which financial concerns would affect women's preferences for the management of Pap smear results.

As gynecologists continue to evaluate the comparative medical efficacy of different strategies in the management of low-grade cervical abnormalities, it seems important that patient preference and psychosocial factors affecting preference be integrated into the evaluation process and incorporated into clinical practice. Regardless of the management strategy preferred or adopted, adherence to both screening and treatment regimens is requisite. The active participation of these patients in the management choice for their mildly abnormal Pap smears has the potential to significantly affect adherence to both screening and treatment regimens. Provision of knowledge about dysplasia and its management will be a part of the equation, as it has already been shown to have a significant impact on follow-up rates.<sup>24</sup>

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Address reprint requests to:

*Marta Meana, Ph.D.*

*Department of Psychology*

*University of Nevada, Las Vegas*

*4505 Maryland Parkway, Box 455030*

*Las Vegas, NV 89154-5030*