An "Infobutton" for Enabling Patients to Interpret On-line Pap Smear Reports

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We describe the development of a prototype application that would allow patients with little or no medical background to understand their Pap smear reports. This information button, or "infobutton", is attached to on-line text reports describing Pap smear results present in a medical record system intended for patient access (PatCIS). The infobutton application generates an explanation of terms present in the report and a list of questions related to the terms in the report, which link to publicly accessible resources on the Web.

INTRODUCTION

The Patient Clinical Information System (PatCIS) is a Web-based system being developed at New York Presbyterian Hospital to provide patients with access to health information, including their own medical records.[1] Assessing and providing for the information needs of patients viewing their own raw medical reports is a major challenge in implementing such a system. Most medical reports use language and terminology intended for trained medical personnel and are not fully comprehensible to a non-medical audience. Yet, the increasing prevalence of systems that can deliver medical data and reports directly to patients means more patients may have access to parts of their record they do not understand, and more patients will be seeking information from outside resources, including the Web. Ideally, patients with such information needs would be quickly guided to high quality information resources. Prototype applications that rapidly link on-line medical reports to information resources have been previously termed "infobuttons".[2]

In this paper we describe the development of an infobutton attached to on-line Papanicolaou (Pap) smear reports in PatCIS. A Pap smear, which detects cervical cancer in women, is based on a cell scraping taken from the cervix, which is then read by a pathologist who writes a brief report. The Pap smear is very commonly done, but the results are often ambiguous and the need for follow-up sometimes is unclear. Despite recent changes in Pap smear terminology, the clinical implications of even the more common findings have not been elucidated in some cases.[3,4,5] This can further compound patient confusion when reading a report. Therefore, our objectives were:

1) to understand the information needs of patients reading their own Pap smears,
2) to provide patients with an explanation of the terminology used in their report,
3) to link them directly to specific resources based on their Pap results that can help to explain the implications and the next step, and
4) to link them to general resources such as the annual Pap smear reminder service provided by the College of American Pathologists (CAP).

METHODS

The information needs of Pap smear patients without a medical background were determined by developing a survey instrument. Eleven distinct Pap smear reports representing a wide variety of findings were selected and given to 50 women, who were asked to provide their impression and questions. They were provided only with a brief definition of what a Pap smear is and instructed to read each report as if it were their own. The survey results were compiled and used to assist in developing the style and content of the infobutton application.

The "Diagnosis" sections from 1000 sequential Pap smear reports were parsed into sentences, which were then ranked, based on frequency of occurrence. Web resources best explaining the concept in each sentence were selected based on quality and appropriateness for patients. Resources used were found by a combination of search engines, links, and known resources. When no resource could be found that focused specifically on the question of interest, a more general page providing an adequate explanation was selected.

Table 1. Examples of questions arising from Pap smear survey.

Survey Response Category	Examples
Explain the Term.	• What's "normal limits"? • Does inflammation mean an infection is present? • Sounds serious. What is cervical intraepithelial neoplasia?
Why do we want to know that?	• Why does the date of last period have significance? • Is there a such thing as TYPICAL squamous cells?
Is this abnormal?	• Explain neoplasia to me & the risks related to atypical cells, if any. • How serious are endocervical cells? Is it the same as CIN?
What is the next step?	• Should I be tested again? • What is going on? Has the PAP smear given any specifics or just raised a general alarm? Explain the next step. • Do I need medication?

The infobutton is designed as a Web-based common gateway interface (CGI) application. Briefly, the report text is scanned for specific sentences and phrases, and a new browser window is opened with content dependent on the text in the patient's report. Included are an explanation of terms, links to resources specific to the findings, general resources related to Pap smears, and a disclaimer.

RESULTS

Most of the survey responses fell into one of the four categories listed in Table 1. Our objective was to answer these questions for all possible concepts present in the reports. Sample Pap smear reports appear in Figures 1a and 2a, with the corresponding infobutton output appearing in Figures 1b and 2b. We found that the most frequent concepts could easily be explained in one line, with additional information provided by links to web resources, if necessary. For example, the concept "Within Normal Limits" was not clear to many women. Therefore, we chose to use the sentence, "'Within normal limits' means there was no evidence indicating cancer" to explain it (Figure 1).

Figure 1. Simplified screen shots of a sample Pap smear report from PatCIS **(a)** and the corresponding frame that appears after evoking the infobutton **(b).** The Infobutton appears in the report header of (a) as a small letter "i" within a circle.

a

Papanicolaou Smear 1992-06-09

Previous Specimens: BS93-405 CG92-34056
(Most recent three)

SPECIMEN: Papanicolaou Smear

DIAGNOSIS(ES):

Within normal limits
Endocervical cells present
Severe inflammation

Reviewed by: Rxxxx M. Rxxxxxx, M.D.

Report Date: 06/15/92
Tech/Clerk: AS/EL
TECH1,1 C1,1 WG9,1 U20,1

b

Your Information Regarding Papanicolaou Smear 1992-06-09

IMPORTANT. Please discuss the report with your doctor to confirm all information.

- "Within normal limits" means there was no evidence indicating cancer.
- "Endocervical cells" are normally present in a PAP smear.
- "Inflammation" means white blood cells were seen. This is common, sometimes caused by an infection, such as bacteria, but occasionally by another irritant.

Resources:

How often do I need a PAP smear?
Sign up for annual PAP smear reminder.
I would like to learn more about PAP smears.
Tell me more about reading the results of my PAP smear.
Compare the terminology used in PAP smear reports.
Help me understand the next step.
See a picture resembling my PAP smear.

Figure 2. A second example of a Pap smear report from PatCIS **(a).** and the corresponding frame that appears after evoking the infobutton **(b).** The Infobutton appears in the report header of (a) as a small letter "i" within a circle.

a

Papanicolaou Smear 1992-06-09

Physician: Dr.
Copy to: Dr.

Previous Specimens: BS93-405 CG92-34056
(Most recent three)

SPECIMEN: Papanicolaou Smear

DIAGNOSIS(ES):

Epithelial cell abnormalities.
Atypical squamous cells of undetermined significance.
Suggestive of a squamous intraepithelial lesion.

Reviewed by: Rxxxx M. Rxxxxxx, M.D.

Report Date: 06/15/93
Tech/Clerk: AS/EL
TECH1,1 C1,1 WG9,1 U20,1
Status: signed, Accno: CG931597PH

b

Your Information Regarding Papanicolaou Smear 1992-06-09

IMPORTANT. Please discuss the report with your doctor to confirm all information.

- "Epithelial cell abnormalities" indicates some abnormality in the cells lining the cervix. There can be a number of possible causes, ranging from infection to cancer.

Resources:

What are atypical squamous cells of undetermined significance?
What is the significance of atypical cells?
What is a "squamous intraepithelial lesion (sil)"?
How often do I need a PAP smear?
Sign up for annual PAP smear reminder.
I would like to learn more about PAP smears.
Tell me more about reading the results of my PAP smear.
Compare the terminology used in PAP smear reports.
Help me understand the next step.
See a picture resembling my PAP smear.

Many women were confused by "Endocervical cells present", thinking that this was an abnormality, which we explained by "'Endocervical cells' are normally present in a PAP smear." For other concepts such as "cervical intraepithelial neoplasia" and "squamous intraepithelial lesion", which required a more lengthy explanation, the infobutton generates a question such as "What is a squamous intraepithelial lesion (SIL)?", which links directly to Web resources.

We used 1000 sequential Pap smear reports to elucidate the sentences and concepts likely to appear to patients viewing their reports in the PatCIS system. The "diagnosis" section of the 1000 reports contained 1410 total sentences, of which 75 were unique. The 20 most common sentences appear in Table 2. The 75 unique sentences could be collapsed into 34 unique concepts. Many of the concepts included words such as "atypical", "abnormal", or "inflammation" with no explanation of why or whether treatment was required.

The most common concept, "Within Normal Limits", appeared in 921 reports. Frequently this phrase was not clearly understood, and sometimes occurred along with other concepts such as "squamous metaplasia" or "inflammation" which made its meaning more confusing, as was shown in Figure 1. Another common concept, "atypical squamous cells of undetermined significance" (ASCUS) almost always required an explanation or follow-up information. Another concept that frequently caused confusion was the mention of inflammation, which prompted numerous concerns about the cause and need for treatment, never addressed in the Pap reports. An example of a report covering ASCUS, and the resulting infobutton output appears in Figure 2.

DISCUSSION

We have developed an infobutton as part of a patient-accessible medical record system that enables patients to understand terms in their own Pap smear reports. The first step in developing this application was a user survey to find out actual concerns in order to anticipate them during the development phase. The system is designed to answer questions and address thoughts occurring to non-medical patients as they read their own report. Since the reports are written for a medically savvy audience, as are most medical reports, the infobutton application needed to incorporate a few unexpected features, such as explaining "within normal limits" and "acellular smear" which some patients interpreted as a bad diagnosis.

Table 2. The 20 most common sentences in 1000 sequential Pap smear reports with frequency of occurrence.

921	Within normal limits
59	Epithelial cell abnormalities
57	Patient pregnant
53	No endocervical cells present consistent with status post-hysterectomy
41	Atypical squamous cells of undetermined significance
36	Fungal organisms morphologically consistent with candida species
20	HORMONAL EVALUATION: Moderate estrogen level
16	Comment: Not otherwise specified
13	Benign cellular changes
13	Predominance of coccobacilli consistent with shift in vaginal flora
13	Specimen labeled vaginal
12	Reactive cellular changes associated with inflammation
10	No neoplastic cells identified
10	Overgrowth of coccoid bacilli
8	Low-grade squamous intraepithelial lesion (cin 1)
7	Comment: A few poorly preserved atypical squamous cells are present
7	Comment: Suggestive of a low-grade squamous intraepithelial lesion (cin 1)
7	HORMONAL EVALUATION: High estrogen level
6	Trichomonas vaginalis
5	Severe inflammation

How such patient-targeted interpretive information systems affect patient outcomes (such as future Pap smear frequency) and patient satisfaction are important questions. There is evidence that providing patients with additional information motivates adherence to plans and improves satisfaction.[6]

One thousand sequential Pap smear reports were used to establish the list of concepts covered by the infobutton. While we feel that this number of reports is sufficient to have seen most possible concepts, the actual rate of certain diagnoses may be less. It was found that among the 1000 reports, only 79 reports were not considered to be within normal limits, and 34 of the 75 unique sentences occurred only once. So it is possible that a few concepts were missing from our analysis. However, the granularity of the Web-based information resources frequently was not so fine as to be restricted to a single concept. In fact, more general resources were intentionally included (such as "Compare the terminology used in Pap smear reports" in Figure 2b) to cover new concepts. Some resources, such as the annual Pap smear reminder and "I would like to learn more about Pap smears" were included for all Pap smears.

ACKNOWLEDGMENTS

This work is supported by training grant LM07079-08 and National Information Infrastructure contract N01-LM-6-3542 from the National Library of Medicine.

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