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Comprehensive Breast Cancer Adjuvant Digital Summary

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Background: **Patients with breast cancer often fail to recall the details of their original diagnosis and adjuvant therapy with the passage of time. Subsequent follow-up and treatment at a later time and a different institution wastes valuable time and effort to retrieve the original data.** ***Patients and Methods:*** **Twenty-five consecutive patients with breast cancer of all stages admitted for adjuvant/neoadjuvant treatment and surgical excision were entered on study. An individualized comprehensive visual evaluation summary sheet (VESS) was created that detailed initial diagnosis, preceding relevant investigations, drug scheduling, and dosages of adjuvant therapy. Completion of a VESS required a computer, a digital camera with connection to a microscope, and radiology images over the PACS system. The completed one-page summary can be printed or stored.** ***Results:*** **A VESS takes up an average of 4.4 MB (1.24–8 MB), each containing 11.5 images (range, 4–23 images), spanning a time period of around 216 days (range, 125– 558 days).** ***Conclusions*** **Patients received a complete summary of pertinent information concerning their diagnosis and adjuvant therapy.**

KEY WORDS: Breast cancer, Adjuvant/neoadjuvant therapy, Medical record, Visual evaluation summary sheet

INTRODUCTION

Oncology is a rapidly evolving field. With completion of the draft sequence of the human genome project, it is envisioned that many new targets will be identified for targeted therapeutic manipulation in the near future.[1] Accordingly, breast cancer diagnosis and treatment has become very complex because of the increasing number of prognostic and predictive factors,[1–3] whether clinically recognized or still experimental; with resultant expansion and increased diversity in the corresponding armamentarium of chemotherapeutic, hormonal, and biological agents.[2] Histological diagnosis starts from a simple hematoxylin-and-eosin slide, identification of tumor type and size, associated grading,[3] enumeration of involved lymph nodes,[2] determination of the presence of estrogen and progesterone receptors, her-2/*neu* oncogene amplification, associated topoisomerase II α gene amplification, *p53* gene mutation, thymidylate synthase expression, and many more.[1–3] Radiology workup involves a mammogram and/or sonar of the breast, with performance of liver and bone scans if indicated. In addition, there is an abundance of written notes and laboratory data to assimilate into making a diagnostic and management decision.

Many patients with breast cancer live a very long disease-free interval after diagnosis.[1–3] Details of the original diagnosis and subsequent treatments may have dimmed in the patient's memory,[4] disappeared with time, rotation of

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medical staff, or even unexpected catastrophes. Data retrieval of information emanating from different medical institutions and different time periods could be potentially cumbersome and time-consuming. The latter often results from poor design of medical records, the fundamental problem being that records are organized to assist data entry but not retrieval;[5] therefore, alternate medical record formats need to be considered[6] to help doctors find relevant information rapidly and interpret it without error.[7,8] The cornerstone of good design is to make the format support data use.[5] Physicians consult medical records to gain an overview of a patient, search for specific details, or to prompt/explore hypotheses, and this involves a process of skimming, skipping, and reading.[7,8] Information presented in a certain pattern/layout,[9] structured according to a time line,[10,11] or creation of an index page[6,12] should facilitate the searching process. Experiments have shown that decision making is faster and less error-prone if all data needed to support a decision can be viewed on one page.[13]

Current electronic information and communication systems offer potential advantages over paper for storage and retrieval of patient data.[14] However, computerization *per se* does not make an improved record; success depends on information design aimed at making it usable and accessible. Many computer-based oncology patient management programs have been developed according to a disease management approach, but these are often expensive and require a high level of technical sophistication to maintain, and suffer from the handicap of being institution-bound. Another important issue pertaining to electronic records is that of maintaining confidentiality.[15] In spite of programs designed to safeguard confidentiality with password restriction, it is not impossible for an experienced hacker to break in and gain access.

The aim of this study was to compile an adjuvant management summary for each and every patient newly diagnosed with breast cancer—by using a personal computer, digital camera, color ink jet printer, and commonly available word-processing software or spreadsheets, to be printed out on one page of paper, and the information can be stored on a disk for the physician and patient. In addition, after conversion to a *pdf* file (which greatly compresses memory size), content copying, extraction, or modification can all be restricted.

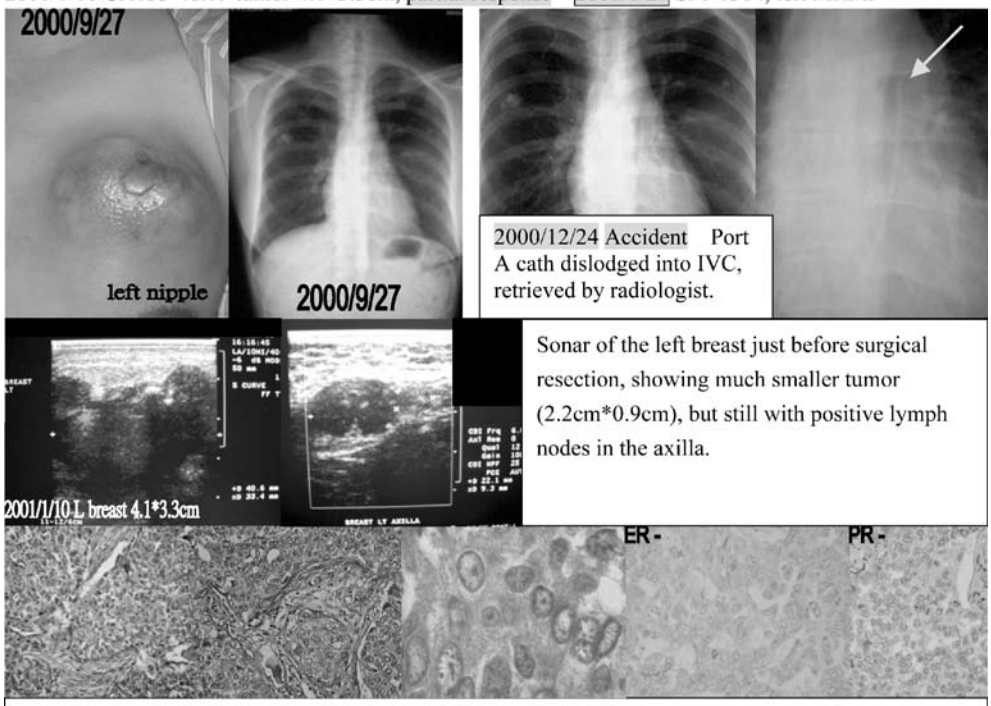
MATERIAL AND METHODS

Twenty-five consecutive patients who were newly diagnosed with breast cancer and admitted to an oncology referral center were included in the study (an adjuvant summary was created for each patient). Information recorded in the one-page visual evaluation summary sheet (VESS)[16] is divided into four

Table 1. Comparison between data documentation among a multitude of patient forms and the one-page adjuvant summary sheet

Patient chart	VESS
ADMISSION NOTE : demographic data, present and past history, physical examination, previous therapy. Chief complaint and present illness	BASIC DATA Listed in brief
	PRESURGERY WORKUP
Many print out reports (x-ray, CT scan, sonar, bone scan, mammogram, lab slips of chemistry, cell counts, tumor markers etc.). Printed out radiology films. Handwritten notes and orders	Images (CXR, mammogram, selected CT and sonographic images, bone scans) and pertinent written laboratory data
	OPERATION NOTE AND PATHOLOGY INFORMATION
Handwritten or typed operation and pathology notes	All relevant pathology images, including ER/PR and other markers
	POSTOPERATIVE THERAPY
Chemotherapy: many prescription sheets, chemotherapy administration sheets, toxicity on separate sheets	Chemotherapy: dates, regimen, dosages, schedules, toxicity incurred
Radiotherapy: extensive and detailed information filed in the radiotherapy department	Radiotherapy: date, area and dosages, toxicity incurred
Hormone therapy: separate outpatient follow-up notes	Hormone therapy: drug, dose and starting dates, toxicity incurred

IFL 1304 b.1967/6, 33yrs old. Menarche-13, 4/28day. P1G1-27y/o. no FH. T4c N1 M0 stage IIIB
1999/11/18 left breast mass felt, excision biopsy done MKHospital, 3cm tumor, margin with tumor.
MRM advised but refused, took herbal meds for a year.
2000/9/27 large 12*14cm=T4, N3, M0 2000/9/22 bone scan N. 2000/9/23 CXR granulomatous lesions.
2000/9/23 EF(L/R) WM-57/39, normal wall motion. 2000/9/28 sonar abdomen normal.
2000/9/28 S89-1304 polygonal hyperchromatic cells mixed with fibroblasts and inflammatory cells, ER, PR and neu all negative.
Neoadjuvant Chemotherapy: $C_{600}A_{60}F_{600/m2}$ cumulative dose adriamycin-300mg/m^2 after 5 courses
$C_1D_1$2000/9/29 Hb-11.3 WCC-4500 Plat-202,000 LDH-430 CEA-3.82 CA153-71.79
$C_2D_1$2000/10/21 Hb-12.2 WCC-4700 Plat-347,000 LDH-287 CEA<3.7 CA153-140
$C_3D_1$2000/11/11 Hb-9.6 WCC-3300 Plat-253,000 LDH-282 CA153-97.54. tumor-7.5*11cm, partial resp.
$C_4D_1$2000/12/2 Hb-8.7 WCC-3200 Plat-254,000 LDH-199 CA153-69.66
$C_5D_1$2000/12/25 Hb-8.7 WCC-2800 Plat-231,000 LDH-184 CA153-49.27;
2001/1/10 CA153-48.19 tumor-4.1*3.3cm, partial response 2001/1/27 S90-1304, left MRM.



S90-1304, left MRM, tumor 6*6*4cm, infiltrating ductal carcinoma, histologic grade 3, no epithelial hyperplasia , tumor necrosis present, lymphovascular invasion present, <25% intraductal carcinoma within tumor, no intraductal carcinoma outside tumor, 2/18 nodes positive, with extracapsular spread, there is skeletal muscle invasion and is close to resection margin. ER-, PR-, neu-

$P_{25}F_{2200}L_{300}$ 2001/2/15; 4/5. $P_{25}F_{2200}L_{300}$ Taxotere$_{25}$ 2001/3/4 (CA153-14); 3/22; 4/22; 5/3; 5/16 (CA153-10.04); 6/5; 6/28 (CA153-10.13); 7/17.
2001/3/2-5/31 Radiotherapy:5320cGy, 180cGy/day, left chest wall, axilla, internal mammary chain, supraclavicular fossa. 2001/9 (CA153-9.76). 2002/3 (CA153-9.67)

Fig 1. A sample visual evaluation summary sheet in converted to a pdf le. The VESS starts with basic demographic data, the second section includes data acquired during workup prior to surgery, including neoadjuvant chemotherapy, followed by the operation note, pathology report with substantiating images, leading to events describing postsurgical management, including chemotherapy and radiotherapy. The original VESS Word document was 3.46 MB; after conversion to pdf, it was compressed to 163 kB.

Table 2. Demographic patient data

Parameter	Number
Age	48.2 years (30–66)
Stage	
I	2 patients
II A	9 patients
II B	1 patients
III A	10 patients
III B	1 patients
IV	2 patients
Duration of data collection	216.5 days (125–558)
Images inserted	11.5 Images (4–23)
Text boxes inserted	2.56 text boxes (1–5)
Chemotherapy regimen documented	2 regimen (1–4)
Radiotherapy recorded	15 patients
"VESS" file size	4.4 MB (1.24–8)

sections. The first section includes basic demographic data, name, age, menopausal status, marital and pregnancy history, personal medical and surgical illnesses, family history, and drug (including hormone consumption) history, followed by a short history of the chief complaint and present illness. The second section includes chest x-ray, CT/MRI scans, sonar of the breast, mammogram, bone scans, as well as results of blood tests, which include cell counts, chemistry, and tumor markers. The third section records relevant operative findings, and most importantly, tumor size, lymph node involvement, images of breast cancer histology, grading, estrogen and progesterone receptor data, images of Her-2/neu, and any other special studies. The final section documents the exact dates, regimen, and dosages of chemotherapy administered, toxicity incurred, dates and area to which radiotherapy is delivered, and also the type and proposed duration of hormonal therapy.

A VESS was constructed by using a computer (IBM® Aptiva) with a central processing speed (CPU) of 500 MHz, random access memory (RAM) of 64 MHz, a digital camera (Nikon® Coolpix 950) with image resolution ≥1,000,000 pixels and relay lens connection to microscope (Olympus® fluorescence microscope) was sufficient for taking all pathology images (including hematoxylin and eosin stain, immunohistochemistry, fluorescent in situ hybridization slides) by the pathologist. Digital radiographic images were retrieved over the hospital PACS (picture archiving and communications system). Image editing and optimization were carried out through the simple software included with the digital camera; all text and image data were subsequently put together via Microsoft® Word to formulate the VESS. After construction, the incomplete VESS was stored and updated every time new information became available. Final printout utilized an inkjet printer (Epson® Stylus photo 750) capable of producing photographic images with a minimum 720-dpi resolution on photo quality inkjet paper. The final VESS in Microsoft Word® format can be compressed into a pdf document (Adobe® acrobat writer), thereby reducing memory size to around 100–200 kB. All images and the final VESS printout were burned on a CD-ROM (for the patient) to serve as a permanent record. Oncology research nurses trained to monitor clinical trials were assigned to construct the adjuvant summaries.

RESULTS

From September 1999 to September 2000, 25 consecutive patients with breast cancer who were admitted to our oncology program for adjuvant therapy were offered an adjuvant summary sheet. The patients ranged in age from 30 to 66 years, and disease severity covered a spectrum from stage I to stage IV cases (Table 1). The VESS takes up around 1.24–8 MB of memory space, containing between 1 and 5 textboxes, 4–23 image files, with detailed description of chemotherapy and radiotherapy schema and dosages. Data collection for VESS spanned an average time period of 217 days (range, 125–558 days). Data are usually entered when they become available, but constructing a VESS *de novo* takes 10–30 min, depending on the volume of information available for incorporation into the summary. The final "VESS" file was converted into a pdf file using Adobe Acrobat, which reduced file size to 100–200 kB (Figure 1).

Table 2 compares VESS information to information that is usually available in a multitude of patient charts and reports. This comparison illustrates how a VESS draws information from innumerable charts, admission and daily progress notes, radiology films, pathology slides, laboratory printouts, operation notes, and prescription charts, with the added advantage of timely documentation of visible skin changes, drug-induced toxicity, and even accidents.

DISCUSSION

Modification of the VESS to become a one-page adjuvant summary for patients with breast cancer enables the patient to have a personal written as well as visual copy of the exact details of her original diagnosis and adjuvant management, facilitating future follow-up,[17] and provides a guideline to provide pertinent information to satisfy the specific needs of the patient.[17] This adjuvant summary sheet realizes the principles of "information design,"[18] to make the information understandable by patients and usable by physicians. It is comprehensive yet focused, incorporating important data entries on almost all patient charts. The visual enhancement and recording of pertinent data

makes it less ambiguous and easy to find and interpret,[8] thereby facilitating management decisions.

Confidentiality and privacy of electronic records have been a major concern from their inception. The larger the database and the greater the number of people with access to records, the greater the invasion on privacy. However, the VESS is different from major database systems, because it was designed as a simple, inexpensive, and convenient mechanism to create a comprehensive summary tailored to the patient, by using common computer hardware and software, with the aim of facilitating management decisions for the patient's physicians. Conversion to a simple database remains an option. A copy of the VESS can be obtained through the patient, or the physician in charge.

Physicians treating a patient may be concerned about potential medicolegal issues that may arise when a patient has a copy of her illness and treatment program, although this should not be so. Another concern is undesirable data modification or utilization—it is easy to copy and transfer image files pasted onto the original VESS in Microsoft® Word format. However, this vulnerability is overcome by compressing the VESS into a pdf file via Adobe® acrobat, after which the file is still printer-enabled, and all other modifications can be password-controlled, with the added advantage of substantial decrease in file size.

The VESS is not without shortcomings. Digital image resolution is inferior to conventional photography, and this is further compromised by trying to accommodate all images into a one-page summary. The image selection process is vulnerable to bias, because only selective and representative images are shown. However, this can be rectified by placing a signed approval of the physician-in-charge to verify data accuracy and authenticity. It should be emphasized that a patient's diagnosis is legally based on the official pathology report. Selected histology images only serve to substantiate and clarify the written report.[19] A VESS cannot replace a comprehensive pathology review or audit,[20] but should suffice to ensure correct tumor identity, type ER, PR receptor data, as well as substantiate the official radiological reports.[21] To the unskilled, it takes longer to enter information by computer than by writing, so that initially VESS formulation will be very time-consuming. This process becomes progressively faster with practice. Most databases are inundated with high data omission rates, because data entry is performed by staff not directly involved with care of the patient, and are thus unable to grasp the significance of pertinent information.[22] The VESS is a comprehensive and focused summary of the diagnostic process and adjuvant therapy for patients with breast cancer, its accuracy and relevance having passed the scrutiny of medical and nursing staff involved in the patient's care.

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