

ABC of health informatics

How computers can help to share understanding with patients

Frank Sullivan, Jeremy C Wyatt

In the second article of this series (*BMJ* 2005;331:625-7) Ms Patel found a lot of material on the internet and spoke to family members about their health and the causes of death of some family members. Ms Patel discussed this information with her general practitioner (GP), who then referred Ms Patel to a clinical genetics centre. The genetics clinic team converted Ms Patel's understanding of the situation into a genogram using Risk Assessment in Genetics software (RAGs).

A cancer registry was used to find the cause of death of Ms Patel's older sister because she had died overseas. By integrating multiple sources of information the genetics clinic team could advise Ms Patel that her lifetime risk of developing breast cancer was about 30%, and that she would probably benefit from further investigation. If Ms Patel was investigated and shown to carry the BRCA1 gene, the risk estimate for Ms Patel's nieces would be higher.

Before doctors introduce information to patients they should determine the way in which patients want to look for information, discover their level of knowledge on the subject, elicit any specific concerns they have, and find out the information that they need. Interactive health communication applications, such as decision support tools and websites, give doctors and patients additional ways to share understanding of patients' reasons for consulting, and they can then work together to solve patients' problems. The benefits to patients of using interactive health communication applications include a better understanding of their health problems, reduced uncertainty, and the feeling that they are getting better support from their carers.

Many of these tools are new and unfamiliar to patients and doctors. The best way to use them to achieve better outcomes for patients during the time available in consultations remains to be established. Research indicates that patients would like to be directed to a high quality interactive health communication application at diagnosis, and at any decision point thereafter (E Murray, personal communication, 2004).

Access to images, audio, and animation

The mammogram, like other clinical images, is available as hard copy or as an archived picture delivered to the desktop of any clinician authorised to view it. The image may be presented with extra material to help explain the nature of the problem. Archived images are more likely to be available than a film, and serial display of archived copies allows comparison.

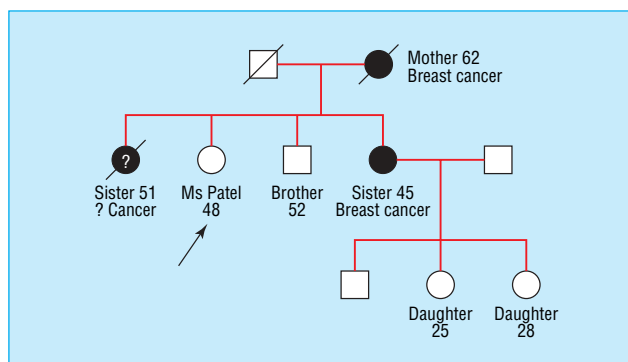
Many patients like explanation in the form of a diagram or in simple, often anatomical, terms. Some patients, however, prefer more detailed descriptions (for example, pathological explanations) of what is happening to their body. This information can be provided by clinicians on their computer screens, using digitised slide libraries, CD Roms, or material on websites.

Multimedia information retrieval

Large documents can be stored and transferred rapidly over electronic and optical fibre networks. These documents may include pictures, sound, video, or computer programs, such as

This is the fifth in a series of 12 articles
A glossary of terms is available at <http://bmj.com/cgi/content/full/331/7516/566/DC1>

Ms Amulya Patel is a 48 year old accountant whose mother and possibly two sisters have had breast cancer. Because of her family history, clinical examination and mammography were undertaken. Mammography indicated an area of microcalcification in the upper outer quadrant of her left breast



A patient's view of risk, presented as a three generation genogram

Patient information

Patients need information to

- Understand what is wrong
- Gain a realistic idea of prognosis
- Make the most of consultations
- Understand the processes and likely outcomes of tests and treatment
- Help in self care
- Learn about available services and sources of help
- Provide reassurance and help
- Help others understand
- Legitimise their concerns and the need to seek help
- Learn how to prevent further illness
- Identify further information and self help groups
- Identify the best healthcare providers

simulators. Textbooks, journal articles, clinical guidelines, image libraries, and material designed for patient education are increasingly becoming available electronically. Discussing individual electronic health records and relevant reference material with patients is preferable to discussing general information about their problem. If Ms Patel and her surgeon are discussing whether she may need a lumpectomy or a simple mastectomy, then the ability to view a relevant image and brief text making the comparison will probably be more effective than a comprehensive treatise on all the possible procedures.

Risk prediction tools

During the discussion of a potentially serious problem like breast cancer, the issue of prognosis will probably arise. Until recently prognostication has been largely implicit, and it was based on the clinical experience of similar patients with the same kind of problems and comorbidities. In a few cases (such as head injury or seriously ill patients in the intensive care unit) accurate, well calibrated clinical prediction rules like the Glasgow coma scale are available. Databases that contain information about patients with known characteristics are being developed, and this information is available across a range of specialties to augment clinicians' experience with the type of problem they are dealing with.

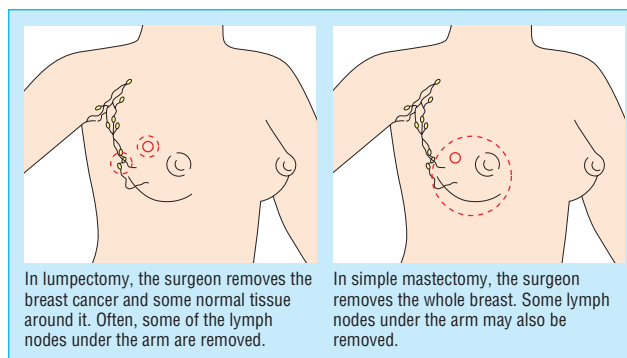
Problems with information retrieval during consultations

Although much information is at hand, it is often difficult to find the most clinically relevant items. Studies measuring the use of information resources during consultations showed individual clinicians accessed the resources only a few times a month. To encourage clinicians to make more use of these information resources, other approaches to information retrieval during the encounter are being studied.

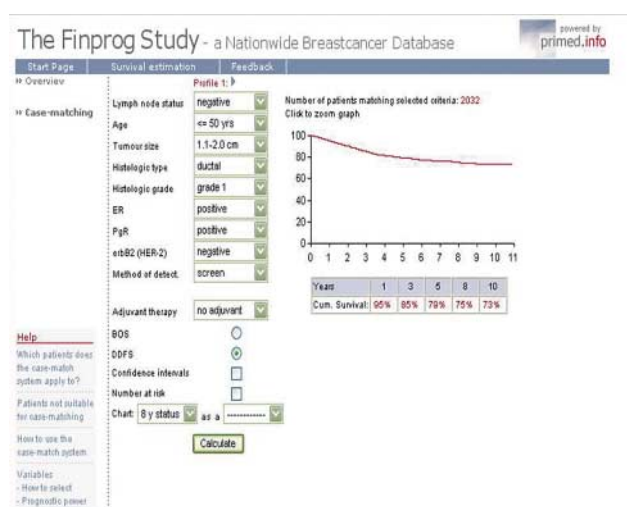
- Email or telephone access to a human searcher—An example is the ATTRACT question answering service for clinicians working in Wales
- Human annotation—This approach uses links between relevant documents and a selected set of common queries that are manually assigned by a peer group (for example, by all the breast surgeons in Scotland or a group of radiologists in New England) for mutual reference
- Case based reasoning—A generic approach to problem solving developed by researchers in the field of artificial intelligence. Problems are solved by adapting new solutions to similar problems that have already been solved
- Automatic query construction—Information from an electronic medical record is used to construct the query, partially or fully. Approaches include interactive user selection of terms, automatic recognition of MeSH index terms in the text of medical records, and developing generic queries that can be filled in with terms from the record
- Search by navigation—In this approach it is possible to search for information by traversing links between information items rather than constructing a query. Fixed links may be organised in a hierarchical menu or as hypertext. Links may also be created dynamically to reflect the changing needs of the user.

Computers in a consultation

The computer screen requires more attention than notes on paper, and clinicians spend less time interacting with the patient



Comparison of lumpectomy and mastectomy—simple diagrams with brief text can be effective in consultations. Adapted from http://medem.com/medlb/article_detailb.cfm?article_ID=ZZZSOTZD38C&sub_cat=57



The Finprog study uses data on a large number of patients with breast cancer to allow an individualised prediction of survival for a new patient by matching their disease profile to that of other patients whose outcomes are known. From the website www.finprog.org

Problems with real time searches during consultations

- Time is spent composing and typing queries for each resource
- Indexing vocabularies are designed by and for librarians and are inconsistent and non-intuitive for clinicians
- Search programs and their displays are designed for research and educational purposes, not for use at the point of care
- No provision for system initiative; that is, clinicians can only find what they choose to look for. A relevant document may exist in the clinical trials resource, but if the doctor thinks that finding a clinical trial is unlikely, then that resource will not be searched
- Although many clinical situations occur often, it is difficult to reuse or share retrieval success
- Managing and updating the information resources is an extra responsibility for the doctor

when they use information resources during consultations. Despite this, doctors who use computers during their consultations are viewed favourably by patients. Research is needed to investigate how additional electronic information resources can be integrated into the consultation, given that a patient centred consultation style is desirable.

After the consultation

It may be difficult, or impossible, to share understanding of all important issues with a patient during the limited time available in many clinical environments. Difficult, embarrassing, or additional questions may occur to the patient after leaving the clinic. Written material (preprinted or produced during the consultation), audiotapes of the consultation, or an email with relevant website links for the patient may provide another chance for them or their carers to revisit the issues or extend a line of inquiry that was partially dealt with in the consultation.

Summary

One of the most attractive features of integrating multimedia information into the consultation is that the process educates and empowers patient and doctor. Jointly, they retain control over the conduct and conclusions of the encounter. In particular, bringing information to the point of care allows the patient to participate in decision making, and encourages them to learn from the doctor's expertise in interpreting and critically appraising information, rather than depending on the doctor's memory and powers of recall.

At present sources of relevant, well prepared, evidence based material are insufficient. Systematic reviews and other assessments of health technology could be amended to include sections presenting information for patients on the choices of treatment that they have, with input from relevant patient groups. Guidance from NICE (the National Institute for Health and Clinical Excellence) always includes a detailed information leaflet, but this can only be as evidence based as the available research allows. Some patients will prefer to discuss their problems during consultations with a doctor they trust, but audiovisual aids can help that process during and after the consultation.

Further reading

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One hundred years ago

Bedside books

In a sermon preached in the Evangelical Church, Vienna, on the occasion of the death of Professor Nothnagel, Pastor Johann stated that when the famous physician was found dead in his bed a volume of Schiller's poems was found beside him open at *Das Ideal und das Leben*. Probably most men, except such as go in terror of their wives, read in bed, but the custom is generally felt, even by those who are its slaves, to require some excuse... As a rule, Wilkie Collins and other masters of plot-weaving should be avoided, as likely to murder sleep; Richardson, of whom Johnson said that anyone who should read him for the story would hang himself, is the great exemplar of bedside authors... Our own preference is for a writer whom long acquaintance has made so familiar that he can be dipped into at random with the certainty of finding something which is always better than one's remembrance. Having reached the period of old fogginess, Scott, Dickens, and Thackeray are our favourites... Sterne is too jerky to be restful, and the greater classics must be approached with an earnestness of devotion which bed scarcely helps to foster. The

bedside book must not be heavy, either in the figurative or in the literal sense... When reading is deliberately used as a means of wooing sleep, graver forms of literature may be chosen. On the whole, we think poetry of the sublime order the best for the purpose... For reading during convalescence literature that cheers but not inebriates should be prescribed. Writers whose style like that of George Meredith puts a constant strain on the understanding of the reader, or like that of Mr Maurice Hewlett irritates by its artificial glitter, or like that of Marie Corelli annoys by its frothy impertinence, are all alike contraindicated. Literature of a kind that depresses the mind or fills it with gloom should be banished from the sick room. Ibsen, Zola, Maxim Gorki, and Dostoiwsky should therefore be left to persons of robust mental digestion who can sup full of literary horrors without suffering from nightmare. For convalescents the best reading is that which carries them out of themselves, and helps them to maintain a healthy interest in life.

(*BMJ* 1905;ii:200)