



How risks of breast cancer and benefits of screening are communicated to women: analysis of 58 pamphlets

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Informed participation in population based screening programmes requires an explicit sharing of information about risks and benefits.¹ However, many factors influence perceptions of risk and the value of risk reduction promised through screening. Campaigns that selectively quote incidence to “frighten” women into undergoing mammography have been criticised.² Perceived risk, not objective risk, explains readiness to undergo screening in most models of health behaviour. Furthermore, the willingness of health purchasers to fund mammographic screening has been shown to be significantly influenced by the way in which data about effectiveness are presented: a programme achieving a 30% reduction in relative risk was more likely to be funded than two others described in terms of absolute risk reduction or numbers needed to screen to avert one death from breast cancer, even though all three were objectively identical in effectiveness.³ No studies have examined how risks of breast cancer and benefits of screening are communicated to women themselves.

Methods and results

In July 1997 we telephoned all cancer organisations, health departments, and mammographic screening programmes throughout Australia and asked for any information leaflets currently available for women about mammography. For each brochure, EKS used a 10 item score sheet to record its content. Independent assessment was performed by another staff member. Discrepancies were noted and resolved by consensus.

All organisations responded, resulting in 58 brochures. Independent agreement between the assessors was 98.9%. Lifetime risk of developing breast cancer was the most commonly stated risk (table), with considerable variation of estimates ranging from one in 11 to one in 16. Only one brochure provided information about the risk of dying from breast cancer. Three provided information about survival from breast cancer but only as “more than 70% of women survive,” “two thirds of women survive,” and “most women outlive this disease.”

Relative risk reduction was the epidemiological information most often provided to communicate the benefits of mammographic screening (table), but the estimates included “about 30%,” “about 40%,” and “up to 50%,” and six pamphlets from one state advised unequivocally that “women who have regular screening mammograms every two years halve their chances of dying from breast cancer.” No pamphlets expressed

benefit as absolute risk reduction or numbers needed to screen.

Information about the accuracy of screening tests was provided only occasionally. Sensitivity was expressed as: “mammograms pick up 90% of breast cancers.” Six brochures stated that mammograms “are not 100% accurate (or foolproof)” without giving any detail.

Comment

Our study is the first to show the emphasis on incidence rather than mortality to communicate the risk of breast cancer to women. Since mammographic screening reduces mortality but not incidence,² this partiality is worrying. In addition, mammographic screening increases the incidence of breast cancer by detecting innocuous disease that would never become clinically important. Thus, it is a circular argument to encourage participation in mammographic screening only because of an increasing number of cases.

The benefits of mammography were reported inconsistently and only ever as relative risk reduction and never as absolute risk reduction or numbers needed to screen to change an outcome for one woman. In a compelling reflection on mammographic screening in the United Kingdom, Maureen Roberts argued for a “truthful account of the facts” to be given to women: “It will not be what they want to hear.”⁴ Ominously, perhaps, the provision of specific risk information discourages participation in mammography.⁵ If, like purchasers’ willingness to pay,³ women’s participation in screening can be manipulated by partial disclosure of epidemiological data, then informed

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Information about risks and benefits of mammographic screening in 58 Australian pamphlets for women

| Information provided | No (%) of pamphlets |
|--|---------------------|
| Lifetime risk of developing breast cancer | 35 (60) |
| Lifetime risk of dying from breast cancer | 1 (2) |
| Survival from breast cancer | 3 (5) |
| Relative risk reduction | 13 (22) |
| Absolute risk reduction | 0 |
| Numbers needed to screen to avoid one death from breast cancer | 0 |
| Proportion of screened women who would be recalled | 8 (14) |
| Proportion of breast cancers detected by mammography (sensitivity) | 15 (26) |
| Proportion of women without breast cancer who would have a positive mammogram (specificity) | 0 |
| Proportion of women with a positive mammogram who would have breast cancer (positive predictive value) | 0 |

decision making by consumers necessitates a disinterested presentation of all pertinent facts.

Inspiration for this study was provided by the Sydney Breast Cancer Foundation, particularly Janet McDonald, Harriett Harrison, Frances Randall, Liz Story, and Lyn Trumbull.

Contributors: JEW conceived the study and supervised protocol development, including design of rating scale, by EKS. EKS collected data and analysed pamphlet content. JEW and EKS jointly wrote the paper. Terry Slevin, Corry Dobson, Lynne Flemming, and Julie Sladden assisted with telephone calls. Vincenza Colaluca assessed reliability of rating of pamphlets. JEW is guarantor for the paper.

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Evaluation of readability and accuracy of information leaflets in general practice for patients with asthma

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Printed education materials are often used to augment healthcare professionals' verbal information to patients. Asthma is one of the commonest chronic diseases managed in general practice, and many leaflets have been produced on its diagnosis, prognosis, management, and treatment, but these have been subjected to little critical review.

Subjects, methods, and results

We evaluated the readability and accuracy of patient information leaflets available in general practice for asthmatic patients. We invited 70 general practices from the Wessex Research Network to send one copy of each of the leaflets they had on asthma: 168 different leaflets were received from 49 practices. We reviewed the leaflets for readability using the simple measure of gobbledegook (SMOG) formula, which estimates the level of education required to understand the text.¹ AF reviewed the leaflets for congruency with current British Thoracic Society guidelines² and accuracy in other areas.

The reading grade for these publications ranged from 5 to 12 (mode 8, mean 8.66 (SD 1.79)) (table), and 39 (23%) contained inaccuracies.

The British Thoracic Society guidelines were not applicable to 78 of the leaflets. Of the rest, 58 were fully congruent, 21 were >90% accurate, and 11 were inaccurate. Six inaccurate leaflets were produced by charities, the other five by drug companies. Seven of

these leaflets contained therapeutic advice that was out of date. One recent publication ignored the effects of chronic exposure to cats. Another denied the presence of inflammation in mild disease. Three of the inaccurate leaflets had no publication date, and all but one of the rest were at least six years old; several practices sent a leaflet 13 years old.

Thirty four leaflets (20%) contained inaccurate or misleading statements about areas outside the society guidelines. These included unreasonable advice on the need to see a doctor, exaggerating the role of cola drinks as a trigger, inexact advice on avoiding house dust mite allergens, incorrect information on the efficacy of desensitising injections, wrong contact addresses and telephone numbers, and misinformation about obtaining a peak flow meter and not acknowledging the wide range of devices available.

Comment

Five and a half million people in Britain have reading difficulties,³ and considerably more (22% of the working population) have a low level of literacy.⁴ Text with SMOG scores under 5 will be understood by most people (information from Basic Skills Agency, 1992), and it is recommended that health literature should be written at a SMOG score ≤ 5 .⁵ To attain high levels of reader comprehension would require revision of 97% of the leaflets we reviewed. Rather than attempting wholesale revision, it is more realistic to match readers with existing materials and to strive for low readability scores in replacement leaflets.

Readability formulae have limitations; ideally, testing with patients should also be done as reading is a complex process and ability to comprehend a text is influenced by presentation (organisation, print, illustrations), situation (stress), and reader characteristics (motivation, maturity). Formulae based on word length disregard patients' familiarity with the vocabulary associated with their illness, thereby overestimating the difficulty of the text.

None of the inaccuracies highlighted posed a serious threat to patient wellbeing, but patients deserve to receive complete, current information about treatment and health education. Practices sent copies of every leaflet that they had, so this may have included leaflets

Readability of patient information leaflets about asthma

| SMOG grade* | No (%) of leaflets (n=104)† | Cumulative % |
|-------------|-----------------------------|--------------|
| 5 | 3 (2.9) | 2.9 |
| 6 | 10 (9.6) | 12.5 |
| 7 | 12 (11.5) | 24.0 |
| 8 | 27 (26.0) | 50.0 |
| 9 | 19 (18.3) | 68.3 |
| 10 | 18 (17.3) | 85.6 |
| 11 | 5 (4.8) | 90.4 |
| 12 | 10 (9.6) | 100.0 |

*Simple measure of gobbledegook (SMOG) readability grades 3-8 are equivalent to reading ability of people with a primary level of education, grades 9-12 are equivalent to those with secondary level education.

†Sixty leaflets were too short to analyse (<30 sentences), four leaflets were excluded because they were not written in English.

not normally used. Less desirable leaflets may not be given to patients, but while these remain in the practice there is the potential that they may be used.

To ensure that patients receive good advice we recommend that healthcare professionals read leaflets before giving them to patients to ensure that the content is accurate and up to date; assess patients' reading abilities and select material to suit; and, perhaps most importantly, review stocks of leaflets regularly and discard those that are out of date or inaccurate to reduce the risk of misinforming patients.

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and participated in writing the paper. SG coordinated the collection of data, undertook the analysis of readability, and participated in writing the paper. RB participated in data interpretation and in writing the paper. AF provided expert review of the leaflets' accuracy and participated in writing the paper. HS is guarantor for the paper.

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Netlines

Back to basics

- As it is now some three years since my introductory articles on the internet were published in the *BMJ*, in this edition of Netlines I will review some of the issues raised in those articles and see what has changed since they first appeared. The articles, with recently updated references, can now be purchased as the booklet *Guide to the Internet* (<http://www.bmjpg.com/data/b98gmed/guideint.htm>) from the BMJ Bookshop (<http://www.bmjpg.com/data/shop.htm>).

More and more diseases online

- In the first of my articles I searched for what I thought was a fairly obscure subject, Recklinghausen's neurofibromatosis. Not only are there now many more and better sites covering this condition (such as <http://neurosurgery.mgh.harvard.edu/NFR/>), but the search engine Yahoo lists sites for dozens of other rare conditions in its Diseases and Conditions section (http://www.yahoo.co.uk/Health/Diseases_and_Conditions/), ranging from Möbius's syndrome (<http://www.ciaccess.com/moebius/front.htm>) to maple syrup urine disease (<http://www.msud-support.org/>) and from berylliosis (<http://www.nationaljewish.org/beryllium/ber.htm>) to blue rubber bleb nevus syndrome (http://www.swmed.edu/home_pages/brbns/).

Unix on a PC

- That "powerful but unfriendly operating system" that underlies much of the internet can now be run free of charge on a PC, thanks to the invention by Linus Torvalds of a new incarnation of Unix called Linux. So you can turn your PC into an internet server and never have to hear the chimes of Windows again. See the Linux Journal on <http://www.ssc.com/linux/>, or the Linux website on <http://www.linux.org/>.

Free email accounts via the web

- The recent development of free email services accessible via the web (<http://www.netaddress.com>, <http://www.mailexcite.com>, and <http://www.hotmail.com/>) means that you can send and read email from any machine with a web browser and a connection to the internet. This is useful if you don't have your own computer or internet account—you can still send email from a machine in the nearest library—or if you travel a great deal and want to read your email on the hoof.

The internet is bigger

- According to the Internet Domain Survey (<http://www.nw.com/zone/WWW/report.html>), in January of this year there were nearly 30 million computers connected to the internet compared with the 16 million of a year before (but note that the counting methods have changed).

Spam

- Unfortunately, junk email is no longer rare, and "spam"—unsolicited email and inappropriate postings to newsgroups and mailing lists—constitutes one of the major nuisances of life on line. For further information, see the Net-abuse FAQ (<http://www.cybernothing.org/faqs/net-abuse-faq.html>), the junk email resource page (<http://www.junkemail.org/>), and the article "Spam!" (<http://www.research.att.com/~lorrie/pubs/spam/spam.html>).

Newsgroups

- DejaNews (<http://www.dejanews.com>) allows you to search, using the web, an archive of messages posted to network newsgroups. In recent years the site has improved so much that it represents a serious alternative to reading network news through a local news server—you can now reply to postings, customise your view of the site, and even subscribe to selected newsgroups.

Searching the web

- Yahoo (<http://www.yahoo.com>), which provides a hierarchical index of websites, now has a local, faster version for the UK: <http://www.yahoo.co.uk>. The same is true of the search engine Lycos, now available on <http://www.lycos.co.uk/>. The AltaVista search site (<http://www.altavista.digital.com/cgi-bin/query/>) is growing ever more sophisticated, with links to online news, bookshops, travel information etc. You can now even search the web in Chinese, Japanese, or Korean.

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