

Letters to the Editor

Women's perception of mammography screening

From J-L BULLIARD¹ and F LEVI^{1,2}

Sirs—In their study on women's perception of the benefits of mammography screening in four countries, Domenighetti and colleagues found an overestimation of the benefits of mammography screening.¹ While every effort to tackle the difficult but essential issue of balanced risk information in health prevention is commendable, we have serious concern about two aspects of this study, i.e. its design and conclusions.

Two of the three questions on which the study is based addressed, respectively, the perceived relative (Q2) and absolute (Q3) benefits of regular mammography screening. As the wording of both questions suggests that mammography screening reduces breast cancer mortality and the correct answer is systematically the smallest positive effect among the proposed answers, underestimation of the quantification of the beneficial effect of mammography screening is virtually impossible in this study.²

Further, the restriction to one correct or most appropriate answer for Q2 and Q3 is also questionable. Reporting of the impact of regular mammography screening on breast cancer mortality ranges from none^{3,4} to about a 50% reduction.^{5,6} When, as is the case for mammography screening, disseminated messages about the effect are heterogeneous, reflecting in part the diverging opinions held by health professionals on the issue, it is not surprising to observe comparable variations in the perceived quantification of the benefits among the female population. The complexity of Q3 may furthermore require a particularly astute mind, from unprepared respondents, to work out the mathematics behind it (trying this question on work colleagues is informative in this respect).

Question 1, which highlights what screening cannot achieve (primary prevention), with a misleading statement, further emphasizes the crucial importance of wording and selection of answers for closed questions, and the distorting effect that apriorism can have on a study design.² In the Swiss canton of Vaud where organized screening has been offered to 50–69 year old women for a decade,⁷ the question 'What is the purpose of mammography screening?' was asked in two consecutive random phone surveys of 50–69 year old females, with different allowed answers. One objective was to assess the possible confusion around the term prevention which was believed to be understood by some as 'prevents the development of a breast cancer toward a fatal outcome'. When 'to prevent cancer' was a proposed answer, a majority of respondents opted for this choice with only 43% of females agreeing that mammography screening enables detection of a lesion and the offer of a less-aggressive treatment (data available on request). However, 93%

of respondents adequately stated that screening enables detection of a breast anomaly when 'to prevent cancer' was replaced by the probably less confusing 'to avoid cancer' (4% of respondents elicited this answer) in the second survey conducted about 4 months later. Adequate quantification of current misconceptions about screening⁸ is necessary to assess the effectiveness of future strategies aimed at improving public understanding.

Conclusive criticisms of 'ill informed' procedures are restricted to breast screening programmes, even though no data on the source of screening information appear to have been collected.¹ Sensitization to regular mammography examination generally occurs from several complementary partners, with various incentives to do so. In the Vaud telephone survey, most (59%) women were informed and sensitized about the importance of breast screening by their treating physicians (GPs or gynaecologists) with only 20% reporting the regional screening programme as her source of information. Further, having had a mammography in the last 2 years, whether for screening or diagnostic purpose, is not an appropriate surrogate for participation in organized screening programmes.

While these 'ill formulated' questions cannot adequately measure women's perception of the benefits of mammography screening, as might have simpler, open-ended questions, they nevertheless enable two observations to be made: (1) An overwhelming majority of women knew and agreed with a beneficial effect of repeated mammography screening (5% stated that regular mammography screening hardly reduces breast cancer deaths, Q2). (2) The lay public remains confused in appreciating absolute versus relative risks, and these statistics need to be demystified. In our increasingly risk conscious society, valid studies are urgently needed to further elaborate how risk information can be conveyed simply and objectively for improving presentation and content of mammography screening messages,⁹ so that women could make informed, autonomous choices.

Acknowledgements

This work was performed during the tenure (by J-LB) of a Fellowship from the Swiss Science Foundation (Nr. 32-63130.00). The Service Cantonal de Recherche et d'Information Statistiques (SCRIS, Mr Y Ammann) made available the data of the Vaud population surveys.

References

- ¹ Domenighetti G, D'Avanzo B, Egger M *et al.* Women's perception of the benefits of mammography screening: population-based survey in four countries. *Int J Epidemiol* 2003;**32**:816–21.
- ² Abramson JH. *Survey Methods in Community Medicine*. 2nd Edn. Edinburgh: Churchill Livingstone, 1979.

¹ Cancer Epidemiology Unit, University Institute of Preventive and Social Medicine, Lausanne, Switzerland. E-mail: jean-luc.bulliard@hospvd.ch

² Vaud Cancer Registry, University Institute of Preventive and Social Medicine, Lausanne, Switzerland.

- ³ Gotzsche PC, Olsen O. Is screening for breast cancer with mammography justifiable? *Lancet* 2000;**355**:129–34.
- ⁴ Olsen O, Gotzsche PC. Cochrane review on screening for breast cancer with mammography. *Lancet* 2001;**358**:1340–42.
- ⁵ Kerlikowske K, Grady D, Rubin SM *et al.* Efficacy of screening mammography. A meta-analysis. *JAMA* 1995;**273**:149–54.
- ⁶ Duffy SW, Tabar L, Chen HH *et al.* The impact of organized mammography service screening on breast carcinoma mortality in seven Swedish counties. *Cancer* 2002;**95**:458–69.
- ⁷ Bulliard J-L, De Landtsheer J-P, Levi F. Results from the Swiss mammography screening pilot programme. *Eur J Cancer* 2003;**38**:1760–68.
- ⁸ Thornton H, Edwards A, Baum M. Women need better information about routine mammography. *BMJ* 2003;**327**:101–03.
- ⁹ Paling J. Strategies to help patients understand risks. *BMJ* 2003;**327**:745–48.

doi:10.1093/ije/dyh227

Advance Access publication 26 April 2004

Authors' response

From MARCEL ZWAHLEN,¹ BARBARA D'AVANZO,² MATTHIAS EGGER,^{1,3} FRANCO BERRINO,⁴ THOMAS PERNEGER,⁵ PAOLA MOSCONI⁶ and GIANFRANCO DOMENIGHETTI⁷

We thank Bulliard and Levi for their interest in our international population-based survey of women's perception of the benefits of mammography screening.^{1,2} Our survey showed that in the US and three European countries (UK, Italy, Switzerland) a high proportion of women overestimated the benefits that can be expected from screening mammography.

Bulliard and Levi argue that the questions used in our survey could not adequately measure perceptions and that simpler, open-ended questions should have been used. Survey questions can always be improved, particularly in the light of answers received, but we do not think that the use of open-ended questions would have led to different conclusions. For example, even when classifying the answer that biannual screening in women older than 50 years reduces breast cancer mortality 'by about half' as correct, 20% (Switzerland) to 38% (US) of women would overestimate benefits (Table 1 in ref. 2). These findings are in line with the results of a survey in the Canton of Geneva conducted in 1998.³

Bulliard and Levi believe that the wording of the question on whether screening 'prevents' or 'reduces' the risk of contracting breast cancer may have been misunderstood and that using the phrase 'avoids breast cancer' would have yielded more

appropriate responses. It is clear that the wording of closed questions can affect responses⁴ but the change suggested by Bulliard and Levi is subtle and unlikely to be of great importance. The question was asked in four different languages (English, Italian, German, French) and the frequency with which women erroneously chose to answer that 'regular mammography prevents' or 'reduces the risk of breast cancer' was above 50% in all countries. We think that a more plausible explanation for these results is the quality of the information that is disseminated on mammography screening. For example, an analysis of the contents of leaflets in Australia revealed a worrying emphasis on cancer incidence, despite the fact that the incidence of breast cancer is not reduced by screening.⁵ Similar results were recently obtained by Jørgensen and Gøtzsche who investigated relevant websites in Scandinavian and English speaking countries with national breast cancer screening programmes.⁶

Finally, Bulliard and Levi disagree with the conclusion that our results 'raise doubt on informed consent procedures within mammography screening programmes'. We agree with Bulliard and Levi that women's perception will be shaped by several sources of information, and we acknowledge that we did not ask about these sources. Nevertheless, women with misconceptions about mammography who participate in breast cancer screening programmes may well have given consent that is not truly informed. Interestingly, the number of correct answers among British women aged 50–59 (the women in our study with access to a national screening programme) was lower compared with women from Switzerland and the US, where opportunistic screening dominates. In Switzerland, when using the same question in a survey of women aged 50–69 living in the Morges district of the Canton of Vaud, where a pilot breast cancer screening programme has been in place since 1995, 80% of respondents believed that that regular mammography reduces or prevents breast cancer⁷ compared with 65% in the national survey.² These findings may reflect the dilemma that organized screening programmes face when attempting both to achieve high coverage and to provide balanced information.⁸ Indeed, the quality and the extent of the

¹ Division of Epidemiology and Biostatistics, Department of Social & Preventive Medicine, University of Bern, Bern, Switzerland. E-mail: zwahlen@ispm.unibe.ch

² Laboratory of Epidemiology and Social Psychiatry, Istituto di Ricerche Farmacologiche 'Mario Negri', Milan, Italy.

³ MRC Health Services Research Collaboration, Department of Social Medicine, University of Bristol, UK.

⁴ Epidemiology Unit, National Cancer Institute Milan, Italy.

⁵ Institute of Social and Preventive Medicine, University of Geneva, Geneva, Switzerland.

⁶ Unit for Research on Patients' Participation in Health Care, Laboratory of Oncological Clinical Research, Istituto di Ricerche Farmacologiche 'Mario Negri', Milan, Italy.

⁷ Cantonal Health Office, Via Orico 5, 6500 Bellinzona, Switzerland and Institute of Health Economics and Management (IEMS), University of Lausanne, Switzerland.