Re: Risk-Reduction Mastectomy: Clinical Issues and Research Needs

In their recent review, Stefanek et al (1) reviewed the available English language literature between 1995 and 2000 relating to risk-reduction mastectomy (RRM). They clearly state that all articles fulfilling their review criteria of effectiveness, perception, decision-making/follow-up, and satisfaction/psychological sequelae were included. Our group was a little unsettled that none of our publications in this area that fulfilled the review criteria had been referenced. Furthermore, these articles are included in the appropriate searches on PubMed® and MEDLINE® in the years reviewed (2–4). We are also concerned that other articles from the same and other European journals were not included. This omission therefore raises the following question: How extensive was this review? It is scientifically inappropriate to exclude articles within their review criteria. If foreign articles are to be ignored, this should have been clearly stated in the review. Admittedly, our articles were published in journals that are not widely available. If the authors were not able to obtain such references, this fact should have been stated, rather than leaving the readers with the impression that all available literature had been included.

In the study period, we reviewed the practice of RRM in 10 European centers with early reports on effectiveness in 174 women (2). We reported on the clinical follow-up and body image of 76 women after RRM (3) and published our detailed protocol, including early evaluation and uptake of the procedure in BRCA1/2 mutation carriers (4). The uptake in our center (50%) is very similar to that reported by the Rotterdam group (5) and, therefore, suggests that RRM appears most acceptable in Northern Europe. These cultural differences were alluded to in the review, which pointed out the low acceptability in France, in particular. The difference between Northern Europe, where subcutaneous mastectomy was relatively rare in the 1970s and 1980s, compared with the United States and the apparent backlash against the procedure in the United States in terms of uptake in mutation carriers could have been developed further. Who is responsible for the backlash? Is it the U.S. press, clinicians, or advocacy groups? After all, it was the commonplace nature of prophylactic mastectomy that allowed Hartmann et al. (6) to come up with the first good evidence for efficacy. We have also pointed out the important fact that some women are fabricating their family history to obtain RRM (2–4), another detail overlooked by the review. In a more recent article (outside the review period) (7), we demonstrated that the high uptake of RRM and the relatively low uptake (10%) for chemoprevention trials in women at 40% or greater lifetime risk are likely to be a problem in developing good alternative preventive strategies. It is also important to clarify that the median follow-up period in the Dutch study was 2.8 years, not months as stated. Although this letter may appear a little self-serving, it is important that the Journal’s readership be made aware that there is more work in this area than the review would have them to believe.

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RESPONSE

We thank the authors of this correspondence for their interest in our article and for the additional information that they provide on the topic of risk-reduction mastectomy. Specifically, the issue of women fabricating or inaccurately reporting their family history (e.g., benign breast disease reported as breast cancer) is appreciated. Although this is a rare occurrence (1), this finding, along with the possibility of Munchausen’s syndrome (2), certainly warrants careful confirmation of familial cases of breast cancer before surgical intervention.

We are familiar with the work that the authors indicate was neglected in our article (1,3,4). We chose not to include one of these articles (3) because it is essentially a description of a clinical protocol for women at high risk and does not fit our selection criteria. The other articles did include data on the effectiveness of risk-reduction mastectomy (1) and mental health and body image outcomes (4). We did not include the work by Evans et al. (1) because of the limited duration of follow-up of the women after mastectomy and the authors’ own acknowledgment that “follow-up of an extended cohort for more than 5 years will be necessary to address the issue of risk reduction” (1). Furthermore, no statistical analysis of the data related to risk reduction as a function of surgery was reported. Although Hopwood et al. (4) found no evidence of substantial emotional distress or body image problems after surgery, their findings were limited by the absence of ad-
equate psychometric data provided on the body image measure used, and missing data. However, it is reassuring that the findings related to both effectiveness of the procedure (1) and mental health and body image sequelae (4) were consistent with the conclusions in our review (5).

Again, we thank the authors for their contributions and urge readers interested in the topic of risk-reduction mastectomy to include articles from this group (1,3,4) as they review this research area.

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