



Risk-reducing mastectomy in BRCA mutation carriers: survival is one of the issues—author’s reply

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Words can do a lot of harm. One wrong headline in the lay press, shared on social media, can lead to a lot of misery. Misery for the women who underwent preventive breast surgery in the past and now could read in the news that this drastic operation may have been unnecessary. Misery for all dedicated clinicians who had to reassure these women that they had made the right decision, and also frustration for all investigators involved in the original paper who saw their message being framed so wrongly.

We recently reported lower overall and breast cancer-specific mortality rates among *BRCA1* mutation carriers opting for bilateral risk-reducing mastectomy (BRRM) than among those under surveillance. For *BRCA2* mutation carriers, BRRM was non-significantly associated with lower overall mortality when compared with surveillance. Additionally, we observed more favorable characteristics of *BRCA2*-associated breast tumors, which eventually may lead to comparable breast cancer-specific mortality rates after either BRRM or surveillance. We concluded that our findings may support a more individualized counseling, based on *BRCA* mutation type, regarding the difficult choice between BRRM and breast cancer surveillance [1].

We certainly did not conclude that women carrying a *BRCA2* mutation should be informed that BRRM is an over-treatment, as was presumed by Neven et al. [2]. Indeed, to our great dismay the results of our study have been distorted in the Dutch newspaper *Algemeen Dagblad* edition 29/07/2019 with the headline “Preventive breast surgery appears not to be necessary”, as already noted by Evans et al. [3].

We understand and share the concern of our colleagues from Leuven and Manchester that our message was framed so wrongly in the lay press and thus has upset many women and their physicians. Immediately after the appearance of the news article, we and colleagues from several medical centers and from patient advocate groups have been busy in all kinds of media—radio, television, newspapers, websites for *BRCA* mutation carriers—to unnerve the headline and reassure women that their decision to opt for BRRM to prevent breast cancer was a right decision—as is the decision of other women to remain under intensive surveillance.

In the current counseling process, BRRM and surveillance are discussed as two reasonable options for healthy *BRCA1/2* mutation carriers. The wish to avoid a breast cancer diagnosis and resultant treatment and the anxiety related to the frequent and ongoing surveillance—with unchanged high breast cancer risks—are recognized as the main reasons for women to decide for BRRM. Thus far, mortality rates have had no significant impact on the decision process—probably also because reliable figures were lacking. In this study, we showed that for *BRCA1* mutation carriers’ life expectancy is somewhat higher after BRRM. In our opinion, this finding may be relevant in the difficult individual decision-making process between both options.

On behalf of all co-authors,

B.A.M. Heemskerk-Gerritsen and M.J. Hooning

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2. Neven P, Punie K, Wildiers H, Willers N, Van Ongeval C, Van Buggenhout G, Legius E (2019) Risk-reducing mastectomy in BRCA carriers: survival is not the issue. *Breast Cancer Res Treat*
3. Evans DG, Howell SJ, Howell A (2019) Should unaffected female BRCA2 pathogenic variant carriers be told there is little or no advantage from risk reducing mastectomy? *Fam Cancer* 18(4):377–379

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