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A Study on Providing Support for Decision-Making about Contralateral Risk-Reducing Mastectomy in Women with Hereditary Breast and Ovarian Cancer in Japan

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Contralateral risk-reducing mastectomy (CRRM) is an option for women with hereditary breast and ovarian cancer (HBOC). This procedure reduces the risk of subsequent breast cancer and is expected to improve the survival of patients with unilateral breast cancer. However, it has been reported that CRRM can have adverse psychosocial effects such as changes in body image and in sexual relations with a partner. Therefore, it is important that patients themselves decide whether to undergo CRRM or not. There have been few studies on CRRM in Japan, and little is known about the required decision-making process. We therefore surveyed intentions to undergo CRRM in patients with HBOC in Japan, considered factors associated with such decision-making, and examined a way to provide support for that decision-making process.

Initially, we investigated the effect of undergoing *BRCA 1/2* genetic testing on decision-making for risk-reducing surgery, including CRRM. Our findings suggested that patients with suspected HBOC who hoped to undergo *BRCA1/2* genetic testing in the future had the possibility of risk-reducing surgery in mind. From this result, we concluded that patients in Japan considered that risk-reducing surgery is an important option after a mutation in the *BRCA 1/2* gene has been identified.

Next, we investigated the implementation of CRRM among patients with HBOC. About 13.3% of the patients with HBOC and with a history of one-sided breast cancer had undergone CRRM. We found that patients who had undergone CRRM were more likely to undergo risk-reducing salpingo-oophorectomy (RRSO) as well than patients who had not undergone CRRM. We also found that all patients who had undergone CRRM have undergone *BRCA 1/2* genetic testing after establishing the system that can practice CRRM in Showa university hospital. Furthermore, we investigated the intentions of CRRM regarding possible surgery in the future among patients with HBOC who had not undergone CRRM yet. We found that about 22.5% of such patients considered undergoing this procedure. Our data suggested that there were the significant number of patients who wanted to take CRRM amongst those who had not undergone CRRM. In particular, mothers

with *BRCA1/2* mutations who have very young children tend to have an intention to undergo CRRM. Additionally, we found a trend for unmarried women to be more indecisive about whether to undergo CRRM.

This research was carried out at a single facility and the number of respondents was small. Thus our findings cannot validly be considered to represent the overall picture of Japan. Joint multicenter research is required to ascertain this trend in Japan and will be conducted in the future. However, from the results of this study, we can reasonably conclude the following five factors that affects decision-making on CRRM by patients with HBOC: (1) expectation that risk of further cancer/mortality rate will be decreased by CRRM, (2) economic constraints, (3) ease of access to medical facilities in which CRRM is performed, (4) presence of spouse, (5) existence of a child/children under 10 years of age. To date, effectiveness of CRRM in Japanese patients remain uncertain and the diagnosis and treatment system in Japan is being developed. From the five factors listed above, we conjectured that patients making decisions about CRRM consider their own values, including the optimal timing of the procedure with regard to various social and medical factors, in conjunction with the benefits and risks of CRRM.

On the basis of the consideration above, we decided to make a tool for clarifying patient values and thus supporting decision-making about CRRM. This tool incorporates a worksheet that aims to provide medical information about CRRM, including the benefits and risks of undergoing versus not undergoing CRRM. Eleven out of 16 medical staff involved in diagnosis and treatment of HBOC to whom we distributed this tool expressed a strong intention to provide the one to their patients, leading us to conclude that they had positive attitude toward introducing the tool. Before implementation this tool in clinical practice, a further study of the impact of the tools amongst HBOC patients with HBOC is required. We believe that the tool for supporting decision-making made in this research is a first step towards providing comprehensive support for decision-making on CRRM amongst women in Japan.