

WOMEN WITH BREAST CANCER DO NOT GET POTENTIALLY LIFE-SAVING INFORMATION, NEWLY PUBLISHED SURVEY RESULTS REVEAL

- *Three-quarters of women were not told their risk of recurrence*
- *Older, less educated women or those without Internet access are particularly uninformed and uninformed*
- *New tools, better communication between health care professionals and patients needed to help close this gap*

Milan, Italy and Stockholm, Sweden, 24 May 2007 – New published data from a large pan-European survey indicate that the majority of postmenopausal women with early breast cancer taking post-surgical endocrine therapy are not involved in making key decisions about their treatment, nor are they given sufficient information to make informed treatment choices that could affect their long-term outcome.

Although 96% of the women surveyed said their health provider was their main source of information, only one-quarter reported being told their risk of breast cancer recurrence, less than half were made aware of treatment options, and nearly one-third did not receive information about possible side effects, according to the results published in *The Breast* (available online in April; print edition expected in volume 16, 2007). In addition, 2 out of 5 women (41%) reported they were not at all involved in the decision to start adjuvant endocrine therapy.

The survey, part of The GAEA Initiative, involved 547 post-menopausal women with early breast cancer from nine European countries. It was designed to find out women's knowledge and understanding about adjuvant endocrine (hormone) therapy and their risk of recurrence, their involvement in treatment decision-making and their information and support needs.

"The survey results clearly indicate that the information needs of women receiving adjuvant endocrine therapy are not being met. These women told us that they want more information about treatments, especially side effects," said GAEA steering committee member Yvonne Wengström, President of the European Oncology Nursing Society and from the Karolinska Institutet in Stockholm, Sweden. "Women rely on their health care professional for information, but they are not informed about why a particular treatment has been prescribed and the potential benefits and consequences of that therapy. It is alarming that many women were not even told about available treatment choices to reduce their risk of recurrence."

A woman's risk of breast cancer recurrence is a critical factor in weighing different treatments. Aromatase inhibitors, a newer class of endocrine drugs, have been shown to be significantly more effective than tamoxifen in reducing the chance of breast cancer coming back after surgery in postmenopausal women with hormone-sensitive early breast cancer.

Half of the women surveyed were being treated with tamoxifen, indicating that many women are not getting the most advanced treatment option. The survey results also revealed that older, less educated women or those without Internet access were less likely to receive information or be involved in decision making. In fact, 57% of older women (those over age 71) were not involved at all in their treatment decision, compared to 22% of younger women.

Insight obtained from the survey has helped identify gaps in informational and support needs and will guide the development of targeted educational and support initiatives for patients with breast cancer who are taking adjuvant endocrine therapy. The publication of the survey results is an important first step in raising awareness among health professionals that communication with patients is sub-optimal.

"Failing to involve our patients in making treatment decision and not giving them the information they need to make these decisions means that as doctors, we are not meeting our patients needs," said Dr Alberto Costa, Director of the European School of Oncology (ESO) and a member of the GAEA steering committee. "While these survey results are distressing, they provide ESO with the foundation to develop new tools that will help doctors communicate more effectively with their patients regarding their disease and its treatment."

Not surprisingly, women who were the most actively involved in the decision to start hormone treatment were provided with more information on side effects and treatment duration compared to women who were not involved. Actively involved patients also received more information on the benefits of taking long term adjuvant therapy and the risk of their breast cancer returning.

"We know that well-informed and active patients get better treatment, so it is encouraging to see at least some of the women surveyed fall into this category", said Ingrid Kössler, President of Europa Donna – the European Breast Cancer Coalition. "All patients deserve the best available therapy for their individual situation. However, there is clearly a knowledge divide among breast cancer patients, and we must develop new solutions to address the needs of older and less-educated women."

Breast cancer is the most common form of the disease among women in the Western world. Approximately 350,000 women in Europe are diagnosed with breast cancer each year and recurrence of the disease occurs in 20-30% of women who have undergone surgery aimed at curing it. Adjuvant endocrine therapy is taken to reduce this risk of recurrence.

For further information about The GAEA Initiative, please go to www.gaeainitiative.eu

Notes to editors

About The GAEA Initiative and Patient Survey

The GAEA Initiative is a collaboration between ESO, EONS and Novartis Oncology. The survey, which is part of the Initiative, set out to determine post-menopausal patients' knowledge about the risk of recurrence in early breast cancer, define their understanding of the purpose of adjuvant endocrine treatment, their attitudes towards adjuvant endocrine treatment and to identify their informational and support needs and how these can be met. Europa Donna, the Breast Cancer Coalition, acted as a patient advocacy resource to the GAEA Initiative.

The GAEA patient survey was conducted among post-menopausal breast cancer patients undergoing adjuvant endocrine therapy in nine European countries: Austria (n=34); France (n=92); Germany (n=82); Hungary (n=34); Italy (n=90); Spain (n=71); Sweden (n=36); Switzerland (n=12) and the United Kingdom (96). A total of 547 questionnaires were analysed. Women were eligible to complete the survey if they had been diagnosed with early breast cancer (defined as localised to the breast tissue and/or nearby lymph nodes), were post-menopausal, currently receiving adjuvant endocrine treatment that commenced at least one year ago.

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