

No one told me I had a choice

→ Claire Laurent

The right of every patient to play a full role in decisions relating to their treatment remains more of an aspiration than a reality, according to a recent survey of breast cancer patients. For the situation to improve, doctors will need to take more time and learn better ways to communicate, particularly with their more elderly and less educated patients.

Many women with breast cancer are poorly informed about treatment and its consequences, with many not even being told about available treatment choices. As a result they are less likely to be involved in decisions that might affect their life expectancy and quality of life. Older women with a low level of education and without Internet access receive least information.

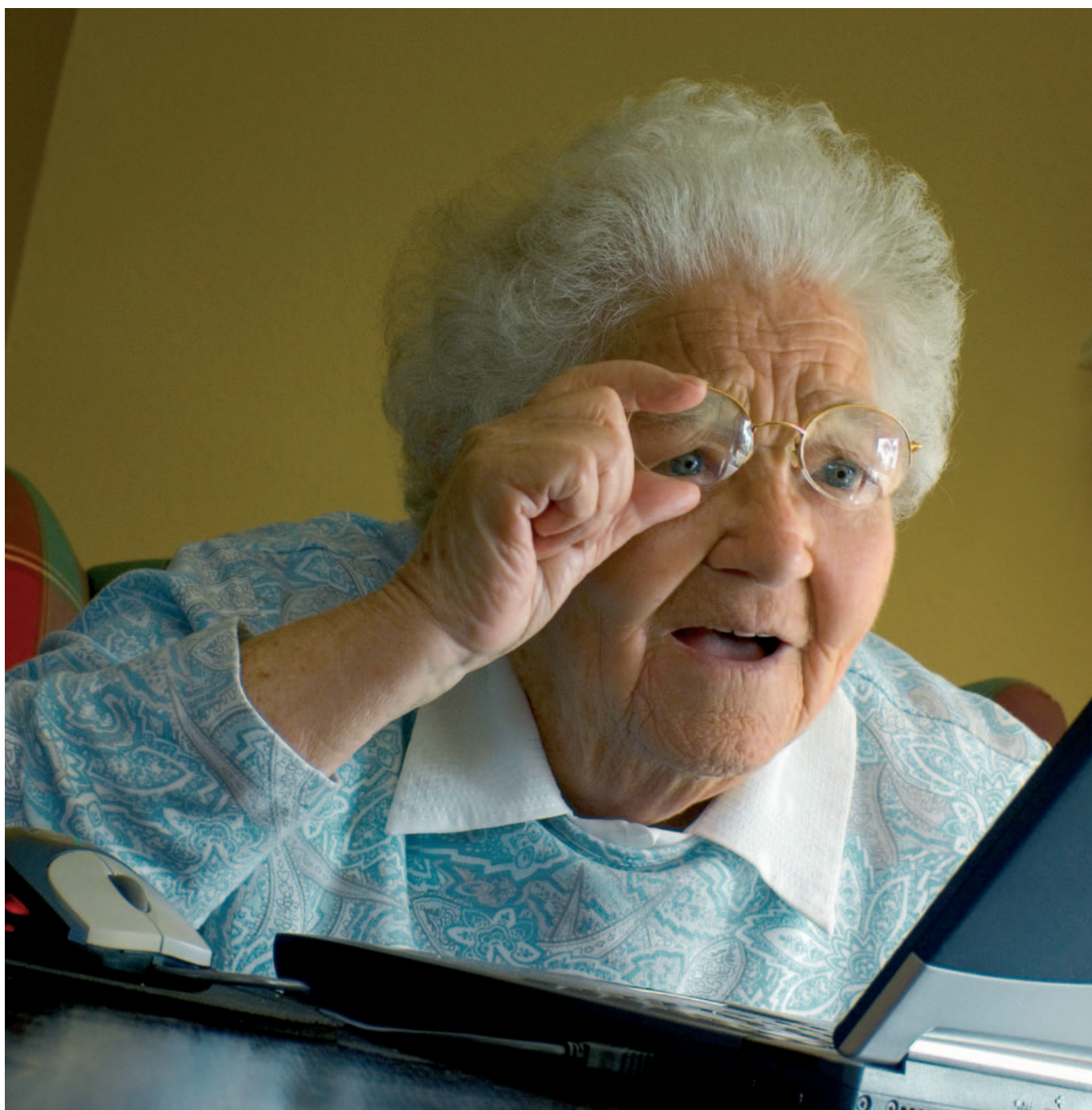
These were the principal findings of a survey conducted last year of European women with early breast cancer. The survey formed part of the GAEA (Gathering Information on Adjuvant Endocrine Therapy) initiative*, and involved 547 post-menopausal women with early breast cancer in nine European countries. It was designed to find out how much patients know and understand about adjuvant endocrine (hormone) therapy and about their risk of recurrence, their involvement in

treatment decision making and their information and support needs.

Adjuvant endocrine therapy (AET) is given after breast cancer surgery to reduce the risk of recurrence, and is usually continued for at least five years. It is given as an insurance policy; most women who take it would never have gone on to develop a recurrence in any case. For some, therefore, it is a life-saver, while for others it may mean years of suffering side-effects for no benefit.

There are two main therapeutic options. One is tamoxifen, which is associated with increased risk of stroke, thromboembolic events, uterine cancer, and uncomfortable and embarrassing side-effects such as hot flushes and vaginal bleeding. The other is an aromatase inhibitor (AI) – there are a number to choose from. These also cause hot flushes and vaginal bleeding, though not as badly as tamoxifen. The main problem with AIs, however, is that they cause pain in the joints and can weaken bones, leading to an increased risk of fractures. AET must be

* The GAEA (Gathering Information on Adjuvant Endocrine Therapy) initiative is a collaboration between the European School of Oncology (ESO), the European Oncology Nursing Society (EONS) and Novartis Oncology, with Europa Donna, the European Breast Cancer Coalition, acting as patient advocacy resource. Full results of the survey can be found at www.gaeainitiative.eu



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taken for at least five years – a long time for a woman to cope with burdensome side-effects. Perhaps not surprisingly, women can find it difficult to adhere to their treatment.

Whether a patient would do best to opt for AET, and which AET would be best for them, depends on their attitude towards their particular risk of recurrence and the impact of the attendant side-effects on their quality of life. If they are not told, or don't understand, their level or risk or the nature of the possible side-effects, it will be impossible for them to take an informed decision.

The finding that only 46% of women surveyed said they had been told that there were treatment options is therefore rather worrying; 47% said they had not been told and a further 7% could not recall. Of equal concern is the finding that only 22% of patients reported being ‘fully’ or ‘highly’ involved in the decision to start AET; a figure that fell to 15% among women in their 60s. Among the over 70s, only 11% reported having been ‘fully’ or ‘highly’ involved, while 80% said they had had little or no involvement at all.

Ingrid Kössler, who has played a leading role in the Swedish Breast Cancer Association for many years, and is president of Europa Donna the European Breast Cancer Coalition, says the results of the survey match the experiences she has encountered amongst older women in Sweden. “Elderly women don't know enough about their diagnosis or treatment. They don't ask so many questions because they think the doctor's word is law and they are not used to interrogating and looking for better treatment.”

Doctors, she says, must make sure that their patients have the information they need to be involved in the decision making. “It should not be up to the patient. It's the responsibility of the doctor. The patient needs to have enough information to understand why they are being offered a particular treatment.”

She accepts, however, that there are many

patients – and they are often older people – who want the doctor to tell them what they need. “Patients are different. Some of them want to know every detail associated with their illness, cure and treatment, and so on and some of them don't involve themselves in it. They are more fatalistic,” says Kössler.

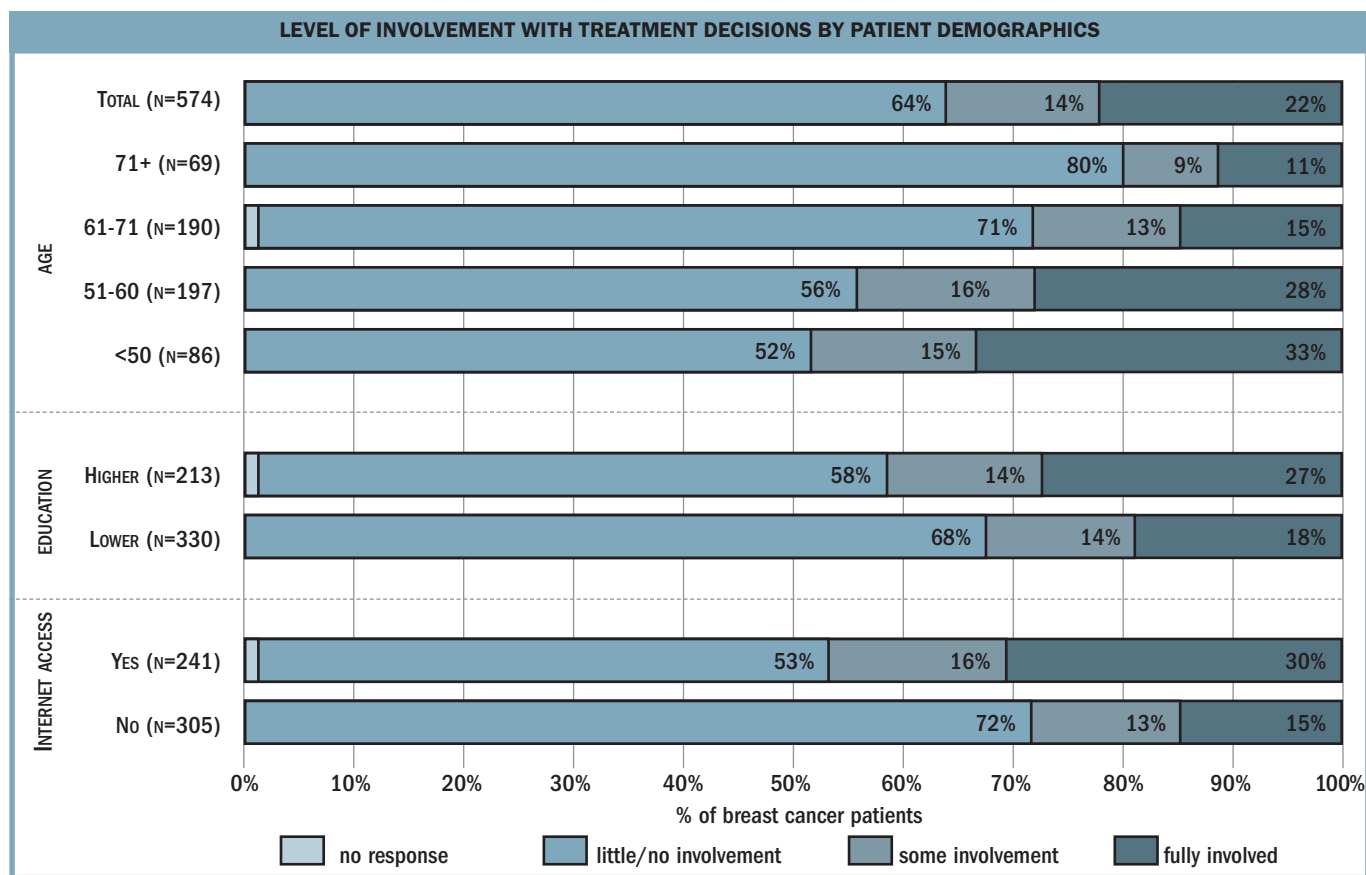
For such patients it is harder for health professionals to judge just how much information to give. It is likely a proportion of patients choose not to be involved in decisions about their treatment at the time, and it is only with hindsight, perhaps when they are feeling fitter, that they wish they had.

TAKE IT SLOWLY, KEEP IT SIMPLE

Some of the answers to this involve simplifying the language used, giving patients more time at appointments and involving trusted friends or family members, says Kössler. “Information is not what the doctor says but what the patient understands. It is easier for doctors to use common language than for patients to learn medical language. I think it's important for patients to get their family involved, maybe a son or daughter, if you are an elderly woman. They can help you find out more about your treatment and accompany you to the doctor.

“As a newly diagnosed patient you won't even know what questions to ask, and even if you try and find the information on the Internet you don't have the background to evaluate it. I think we need to spread the information that breast cancer is not just one disease. There are so many varieties and that's why treatment differs,” she says.

The GAEA survey showed that less than half of the women (44%) received information on how AET works. Only 25% were told of the possible severity of side-effects, 20% of the duration of side-effects and 22% of the risk of their cancer recurring when AET was stopped. Elderly patients, patients without Internet access and those with a lower educational level were less likely to have



A picture of inequality. The survey results show that a majority of women of all categories had little or no involvement in the decision to start adjuvant hormone treatment for breast cancer. In older women, those educated to a lower level and those without Internet access, the figures reached 80%, 68% and 72% respectively

Source: The GAEA Initiative, www.gaeainitiative.eu

received this sort of information from a doctor or nurse. The three variables worked independently, meaning that younger women with lower education and no Internet access tended to receive more information than older women in the same situation, but less than women of their own age and education who did have Internet access, and so on.

There seems, therefore, to be a cycle whereby women who start off being poorly informed, continue to be so, leading to a reduced involvement in decision making about their treatment and a poorer understanding of the risk of side-effects and recurrence.

Yvonne Wengström, the president of the European Oncology Nursing Society, said it was clear that patients who took part in the survey wanted more information about treatment and especially about side-effects. She pointed out that while the

patients tended to regard health professionals as a “highly trusted source of information,” these health professionals often failed to give them comprehensive information about the rationale for treatment and the potential consequences of treatment.

Wengström believes the survey results also show that women don’t know where to look for the information they need. “Many women were unaware of what options they had to inform themselves, such as patient groups for example. We tend to forget that the women we are treating today are not the ones brought up with the Internet – those are the patients of the future.”

For those patients there are a myriad of websites about breast cancer. In the UK, for example, there are a number of big cancer charities that provide information via the Internet. In Sweden, the Swedish Breast Cancer Association is developing

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a website to advise women on what questions they should ask their doctor regarding their treatment and care. But these information sources don't solve the difficulties that older women have about their treatment. And health professionals need to be imaginative in the ways they try and get information across to an age group that tends not to question the doctor.

Health professionals need to listen to patients, recognise their individual needs and take responsibility to ensure patients know where they can get information from, says Wengström. “We have to develop a professional approach to patient information and education and recognise the important role we play in the patient's treatment and decisions.”

DOCTORS ARE KEY

Alberto Costa is a breast cancer surgeon based at Pavia, and Director of the European School of Oncology, one of the GAEA collaborating partners. He argues that doctors are crucial to ensuring that patients are involved with decisions about their treatment. “As doctors we are clearly failing some patients by not involving them in the decision about starting adjuvant endocrine therapy and by not giving them the information they need to make these decisions.”

WHAT PATIENTS WANT

This is how patients in the GAEA survey summed up what they need from their health professionals:

- Explain things in simple terms
 - Take time to explain my disease and treatment
 - Encourage me to have faith in my treatment
 - Make sure I understand the importance of taking medication every day
 - Provide follow-up care and information when I leave hospital
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The study findings, he says, are borne out by his own experiences. “Patients who are actively involved in decision making have better psychological adjustment, are more satisfied with their treatment, and are more likely to adhere to treatment.”

The point is an important one, as studies have repeatedly shown that up to 40% of women on adjuvant treatment have problems sticking to their prescription, and that those who are well informed about their treatment are more likely to adhere to it. Patients are also more likely to report side-effects if they are better informed, because they will understand what they should be watching out for and can make the connection between the symptoms and the treatment. Accurate reporting of side-effects in turn helps doctors plan follow-up appointments. “There is a collaboration between doctor and patient to be accurate,” says Costa.

He argues that doctors need to be taught communication skills, not just in the classroom but in the clinic too. “It's not considered something you have to teach. We all know of the senior surgeon teaching surgery in the theatre to the junior surgeon, but he doesn't generally teach them how to talk to the patient. This consultation is still very often a private affair between doctor and patient,” says Costa. Teaching in the classroom remains theoretical; students need to witness conversations in practice and learn how best to ensure patients are informed and involved, he says.

Hospitals in general and cancer centres in particular need to reorganise in order to provide more time for discussion with patients, argues Costa. “Not just doctors but nurses and managers need to give much more importance to the moment of communication,” he says. “We have to consider the time spent with the patient to explain and answer questions as part of the medical activity. Some people think medicine is only about doing surgery, visiting and writing. Talking to the patient is seen as a ‘nice’ thing, but really it is part of the treatment and the care.”