

Differences in older versus younger women's experience and knowledge of adjuvant endocrine therapy for early breast cancer



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INTRODUCTION

Adjuvant endocrine therapy is used in the treatment of women with hormone responsive breast cancer to reduce the risk of recurrence. Women generally remain on adjuvant endocrine therapy for five years although there is emerging evidence that suggests the value of extending treatment duration. The GAEA (Gathering Information on Adjuvant Endocrine therapy) Initiative aims to delineate women's knowledge and experience of adjuvant endocrine therapy and develop programmes targeted at meeting their needs.

A survey was carried out as part of this initiative with the aim of determining breast cancer patients' knowledge about and attitudes towards adjuvant endocrine, ascertaining their informational and support needs while taking adjuvant endocrine therapy and defining how best to meet these needs. The survey involved a qualitative and quantitative phase and was conducted in 9 countries (Austria, France, Germany, Hungary, Italy, Spain, Sweden, Switzerland, and UK) that represent different regions of Europe and different size countries. The research was carried out by Adelphi International Research.

METHODOLOGY

A literature search was undertaken to define the issues to include in a qualitative discussion guide about women's experience of adjuvant endocrine therapy in early breast cancer. The discussion guide was piloted, translated into the survey languages (English, French, German, Hungarian, Italian, Spanish and Swedish) and face-to-face interviews were carried out with 32 patients currently taking adjuvant endocrine therapy for early breast cancer in 8 of the survey countries (Switzerland was not included). The aim of these interviews was to identify the correct parameters to explore, and language to use, in the quantitative survey.

A quantitative questionnaire was developed, pilot tested in the survey languages and then administered to a convenience sample of post-menopausal women that met the following criteria: diagnosis of early breast cancer and currently receiving adjuvant endocrine therapy for one year or more with any of the following drugs: anastrozole, exemestane, letrozole or tamoxifen.

Women were recruited via advertisements in the media, posters displayed in pharmacies and clinics, as well as through the GAEA collaborating organisations, other European patient advocacy groups and healthcare professionals. Participants were given the option of either self-completing the questionnaire or completing it by telephone or face-to-face interview. A total of 547 questionnaires were analysed (34 from Austria; 92 from France; 82 from Germany; 34 from Hungary; 90 from Italy; 71 from Spain; 36 from Sweden; 12 from Switzerland and 96 from the UK). To obtain aggregated EU results each country's data was weighted according to its size relative to the incidence of breast cancer across the EU, using figures from Globocan 2002 (WHO).

RESULTS

71% of those surveyed were between 51-70 years of age. 13% were 71 or over. Nearly half of respondents were retired (43%), 39% were educated to a higher level and 44% had Internet access. A similar proportion of women surveyed were taking one of the available aromatase inhibitors (49%) as were taking anti-oestrogen tamoxifen (51%). The participants had been taking treatment for an average of 2.6 years.

Figure 1: Survey Respondent Demographics

Survey Respondent Demographics						
Age	50 or younger	51-60	61-70	71 or over	Not Stated	
	16%	36%	35%	13%	*	
Working Status	Employed**	Retired	Disabled/LT sick	Homemaker	Unemployed	Not stated
	31%	43%	4%	18%	3%	1%
	Internet Access					
	Yes		No			
	44%		56%			
	Highest Education Level	Primary/Secondary	Higher Education**	Not stated		
60%		39%	1%			
Current AET						
Aromatase inhibitor		Tamoxifen				
49%		51%				

* <0.5%
 ** Full -time, part -time, self -employed
 *** College + graduate + post graduate

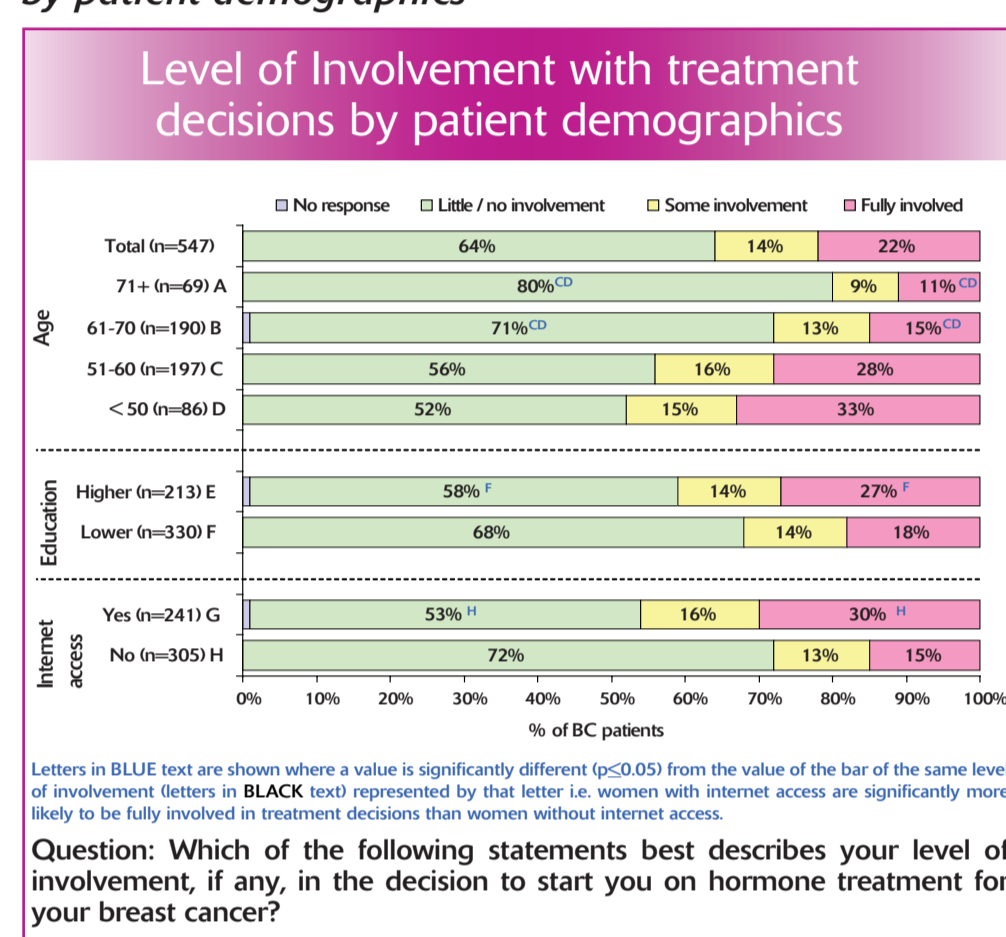
Awareness of treatment options

Younger women were much more likely to be told about treatment options than their older counterparts. The survey showed that 33% of women aged 71 years or over were made aware of treatment options whereas 55% of women 60 years or younger were told about different treatment options.

Involvement in treatment decision making

Most of the women surveyed were not at all involved in the decision to start adjuvant endocrine therapy (41%; n=231). Only 22% (n=107) of patients were fully or highly involved in treatment decision making. Older women were much less likely to be involved in treatment decision making. 57% of women who were 71 years or over were not at all involved in the decision to start on adjuvant endocrine therapy (average of 41%). In stark contrast only 22% of women aged 50 years or younger were not at all involved in decision making. Overall younger women, women with a higher level of education and those with internet access were more likely to have been more actively involved in decision making. Those who were not involved in decision making were much less likely to be satisfied with their level of involvement.

Figure 2: Level of Involvement with treatment decisions by patient demographics

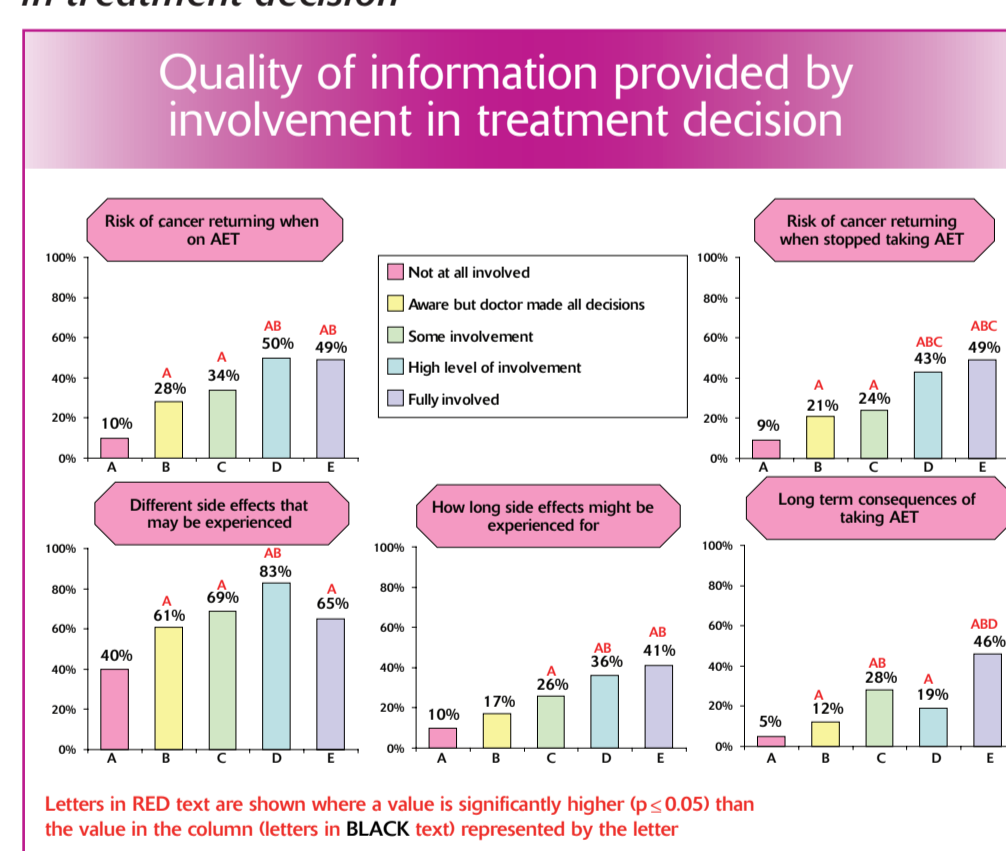


Provision of information about adjuvant endocrine therapy

Despite the fact that the women surveyed were generally satisfied with the information they received from healthcare professionals less than half (44%) received information on how the treatment works. Only 25% of patients were informed of the possible severity of side effects, 20% of the duration of side-effects and 22% of the risk of their cancer recurring at the end of adjuvant endocrine therapy. Younger women and women with Internet access were found to receive more information at the start of treatment than older or less educated patients.

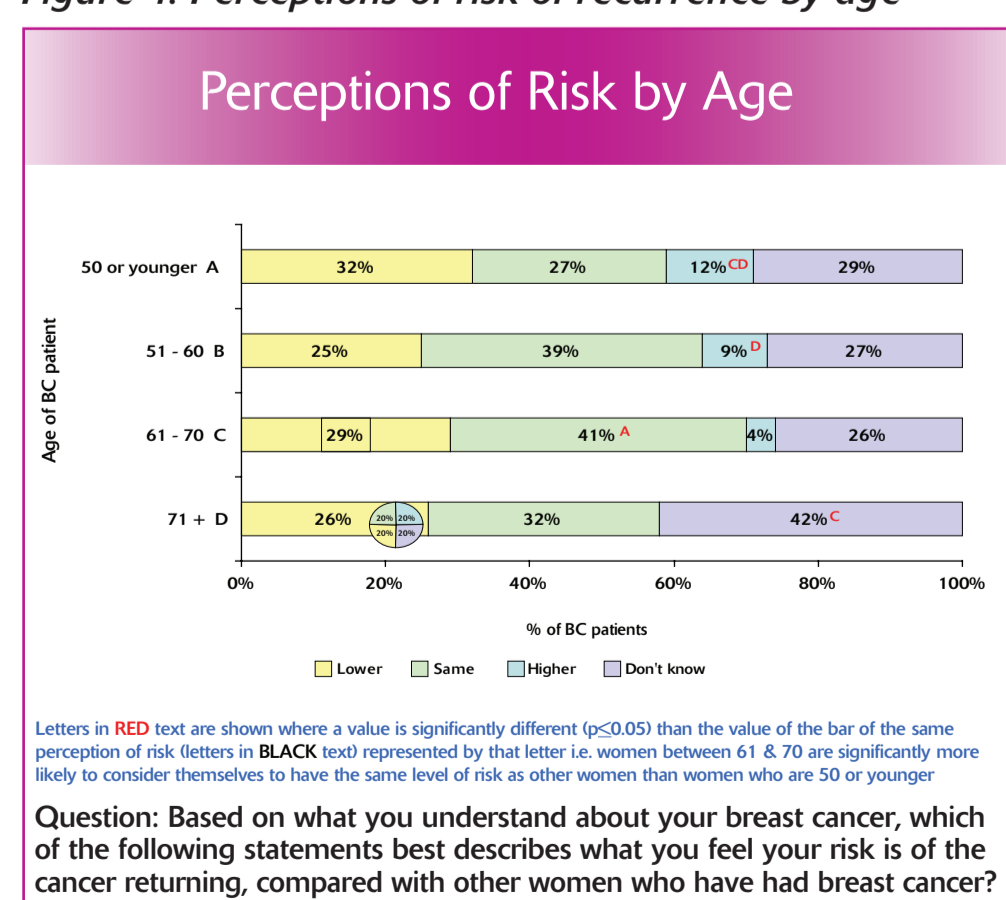
Respondents who were more actively involved in treatment decision making were significantly more likely to be told about treatment-related side-effects, long term consequences of treatment and risk of their cancer returning compared to those who had little or no involvement (p<0.05).

Figure 3: Quality of information provided by involvement in treatment decision



Given that women were provided with poor quality information at the start of their treatment, it was perhaps not surprising that many women were uncertain about their risk of cancer returning. There was a significant difference in knowledge of risk of recurrence between older and younger women. Women over 71 years of age were much more likely to indicate that they did not know their risk of cancer returning.

Figure 4: Perceptions of risk of recurrence by age



Sources of Information and Support

Doctors were the most important and useful source of information and support for the women who took part in the survey. Written materials (e.g. information accompanying the medicine, brochures etc.) were shown to be a key source of information, yet less than a third of women indicated that these informational resources were of real value to them.

34% of those surveyed stated that they were not made aware of any support services at the time of diagnosis. Even though the women surveyed that had used breast cancer support groups had found them to be a valuable source of information and support, only 44% of respondents were made aware about the existence of such groups when they were diagnosed. Women over 71 years of age used less sources of support than their younger counterparts.

Impact of Treatment on Everyday Life

When asked to what degree adjuvant endocrine therapy has had an impact on their everyday life 38% of the respondents indicated that it had no impact. However, older women had a very different perception of the impact of treatment. Most of the older women thought that treatment had had a neutral impact on their lives. In contrast most of the younger respondents indicated that treatment has had either a slight or large negative impact on their lives.

Table 1: Impact of treatment on patients everyday life by age

Impact of treatment on patients everyday life by age				
Age	50 or younger	51-60	61-70	71 or over
Large positive impact	18%	9%	4%	10%
Slight positive impact	14%	11%	14%	16%
No impact	28%	28%	49%	54%
Slight negative impact	30%	40%	28%	17%
Large negative impact	10%	12%	5%	3%

CONCLUSION:

This survey has highlighted gaps in meeting patients' informational needs and in the degree to which they are involved in treatment decision-making. Most of the women surveyed were not involved in the decision to start adjuvant endocrine therapy, nor were they made aware of different treatment options. The provision of information at the initiation of breast cancer treatment was shown to be sub-optimal. Older patients, those who are less well educated and those without Internet access were much less likely to be involved in decision making or to receive the information they need to make informed decisions.

All patients, regardless of age or educational level, should be helped to understand how adjuvant endocrine therapy works, the different treatments available, the possible side effects and their risk of recurrence so that they can make informed decisions about their treatment. Better communication between patients and professionals will facilitate this process, as will the development of high quality patient educational materials on adjuvant endocrine therapy. Special efforts are required to address the significant gaps in meeting the needs of older women, less-well educated women and those who do not have Internet access.

These findings provide initial insight into the needs of women taking adjuvant endocrine therapy and further research is required to develop greater understanding of and identify useful strategies for meeting these needs.

Note: A manuscript on the survey findings is currently being prepared and will be submitted to an international oncology publication.