

# Breast Cancer Patients' Experiences and Reflections Regarding Information about Adjuvant Endocrine Therapy and its Side-Effects - A Focus Group Study

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## Abstract

**Objective:** Adjuvant endocrine therapy is essential for women diagnosed with a hormone receptor-positive breast tumour. However, not all women adhere to the therapy. The purpose of the study is to identify representations, experiences and beliefs of women undergoing adjuvant endocrine breast cancer therapy regarding information and communication about the therapy and its side effects.

**Methods:** In this socio-anthropological survey study altogether 46 women with breast cancer participated, 33 from Stockholm County and 13 from Norrbotten County in Sweden. Eight focus group interviews were conducted. The recorded interviews were analysed using qualitative content analysis with an inductive approach.

**Results:** In Stockholm County the most reported sources of information were the patient organization, health care providers, the Internet and other media, and friends. In Norrbotten County, health care providers were by far the most frequently reported source of information. Most of the women trusted their physician and understood that it was important to take the therapy. Still, some women had misconceptions as to why they had been prescribed adjuvant endocrine therapy in the first place. Many women reported that when they were put on the therapy they had a mental block or were unreceptive for a variety of reasons. Some reported that they had heard or read tasks on Internet or in other media that made them question the therapy. The information the women had received about the side effects of the therapy differed between the regions regarding how and when they had received information. In both regions, however, the women reported information gaps.

**Conclusions:** The key finding in this study is that most of the women trusted their physicians and understood that the therapy was essential, but many women reported that when the therapy was offered they were unreceptive for a variety of reasons. Another finding is that patient organization, friends, Internet and other media have a significant role in how women perceive the endocrine breast cancer therapy.

**Keywords:** Breast Cancer; Adjuvant Therapy; Endocrine Therapy; Information; Adherence; Media

## Introduction

Breast cancer constitutes 30% of all female cancers in Sweden. The median age for diagnosis is approximately 60 years [1,2]. Breast cancer is often hormone receptor-positive, i.e. the cancer is stimulated to grow by the woman's own sex hormones. Therefore, women who have undergone breast cancer surgery and have a hormone receptor-positive tumour are offered adjuvant endocrine therapy for 5 or 10 years to reduce the risk of recurrence. Treatment with tamoxifen for 5 years can reduce the recurrence rate by up to 39% during the first 10 years after surgery [3] and if Aromatase Inhibitor (AI) is included during some point in the therapy, this further reduces the risk [4]. Endocrine therapy with tamoxifen or AI can, however, produce side effects, for example menopausal symptoms, that can negatively affect the woman's daily life [5,6]. Other side effects can be joint symptoms/arthritis syndrome [7,8] and up to 46% of the women treated with AI will have one or more symptoms of osteoarthritis, bursitis, carpal tunnel syndrome or tendinitis [9].

For breast cancer treatment to be successful, adherence to the therapy is a requirement. However, not all women adhere to adjuvant endocrine therapy and discontinuation measured in different studies varies between 31% and 73% at the end of a 5-year therapy [10]. In a Swedish study the level of adherence after 3 years was 69% [11]. Many studies report how demographic, socio-economic, psychosocial, and health and treatment-related factors seem to affect the patient's adherence to treatment [12-17]. A French study has shown that socio-economic conditions also influence the information seeking behavior [18]. Non-adherence to treatment can occur because the benefits of treatment are not obviously apparent [19]. To achieve long-term adherence it is important to educate the patients regarding endocrine therapy and involve them in the treatment decision [20-22] that, endocrine-treated breast cancer patient may benefit

additional information to ordinary care and that this can improve adherence has been demonstrated in a recently published study [23]. Although there are several studies that highlight the need for information regarding adjuvant endocrine cancer treatments and the importance of good communication between the health care providers and the patients, the low compliance degree indicates that the topic needs to be further researched.

### **Purpose of the study**

The purpose of the study is to identify representations, experiences and beliefs of women undergoing adjuvant endocrine breast cancer therapy regarding information and communication about the therapy and its side effects.

### **Subjects and Methods**

In this socio-anthropological survey study the sampling frames comprised women living in Stockholm County or Norrbotten County who had started adjuvant endocrine breast cancer therapy within the past 7 years and were reported to adhere to the therapy, and were able to understand Swedish. Exclusion criteria were prior endocrine therapy and/or prior breast cancer disease. All women had to have completed chemotherapy at least one year before the participation in the focus interview. The time frame for the interviews in relation to chemotherapy was chosen to ensure that the women had recovered from the sequel from the chemotherapy. The study was initiated in Stockholm County, which is the most densely populated area in Sweden. To acquire a wider experience in relation to the adjuvant endocrine therapy, and through this increase credibility, women from Norrbotten County, which is the most sparsely populated area in Sweden, were recruited as well. The two counties differ both in terms of socio-demographic issues and the organization of the cancer care system.

The interviews were based on an interview guide developed on the basis of the literature and discussions in the project group, covering perceptions and experience related to information and communication about endocrine breast cancer treatment. The same guide was used in all interviews. The interview guide addressed the following issues:

1. What explanations perceive the women they have been given by the attending physician as to why they should take the endocrine treatment?
2. What side effects perceive the women they have been told by the attending physician that the treatment might cause?
3. How important do the women think it is to complete the treatment? What do they base this opinion on?
4. Which sources of information have been significant for the women's understanding of the importance of the treatment and the side effects the treatment might cause?

Participants were recruited in the waiting areas of oncology clinics in two hospitals in Stockholm County and one hospital in the north of Sweden, where we put out notices informing patients of the study. The Breast Cancer Association in Stockholm and

Norrbotten Counties also helped with recruitment via email to their members. The Association is a patient organization that raises breast cancer awareness in society and promotes and safeguards the interests of breast cancer patients regarding treatment, care and rehabilitation.

The notices at the clinics and the emails sent out described the study and its purpose. Interested persons were invited to contact the project leader/last author (A.J.). Those who did contact then received additional information about the study, its voluntary nature, and confidentiality. Meanwhile demographic and treatment-related data were obtained.

In total 46 women participated in the study, 33 from Stockholm County, and 13 from Norrbotten County. In Stockholm County the women were invited to specific occasions, matching their type of treatment (chemotherapy: yes/no) and age. The matching was done in order to increase homogeneity and facilitate discussion, as suggested by Kreuger [24]. Eight focus groups were organized containing four to nine women each (median 5). In Norrbotten County there was no distinction between treatment and age groups when the number of participants was too small to allow such a division. After eight focus group interview we felt that the issue was saturated, no attempt to form new focus groups composed of women who had not attend at the specific interview sessions was made.

Six of the interviews were held in a hospital in Stockholm County and two in a hospital in Norrbotten County. The interviews in Stockholm County were conducted from 9 October 2013 to 22 January 2014 and the interviews in Norrbotten County 21 October 2013. The principal investigator (A.J.) moderated all the interviews and the second author (A.W) was present at six of the interviews. The fifth author (J.Å.) was observer at two of the interviews. The interviews lasted 90 minutes with a 15-minute break after 60 minutes. Focus group interviews were carried out as described by Krueger [24] Chrzanowska [25]. The interviews were tape-recorded and by transcribed verbatim.

All participants signed an informed consent. The ethical procedures followed in the study are in accordance with the ethical principles stipulated in the Helsinki Declaration. The study was approved by the Regional Ethical Review Board in Stockholm County in 2013, reference number (2013/453-31/3).

### **Data Analysis**

The recorded interviews were analysed using qualitative content analysis with an inductive approach as described by Patton [26]. The recordings were transcribed and analysed by the first (J.S.) and last author (A.J.). The interviews were read several times to form an idea of the content as a whole. Words and sentences that were connected through their content and context were then combined into meaningful units. After this, the meaningful units were condensed. The condensed text was provided with codes. The codes were then combined into subcategories and categories. Finally, themes were formulated to indicate the underlying meaning in the interviews. All members of the project team had access to the printed interviews and

contributed valuable comments. All members participated in the final analysis. The project team consisted of representatives from several professions, physicians, a nurse, a social worker, and a specialist in human rights. This multidisciplinary approach should enhance the credibility of the analysis.

## Results

In Stockholm County a total of 69 women reported interest in participating, of these 4 women were no longer interested at the time of the interviews, and 3 women did not meet the inclusion criteria because they had previously been treated for a breast cancer disease and, finally 15 were unable to attend the meeting they were invited to. In Norrbotten County all interested women participated in the study. During the focus group interview emerged that one of the women previously had been treated for breast cancer. The included women from Stockholm County were between 36 and 77 years of age. In Norrbotten County the women's age varied between 52 and 78 years. Almost all the women from Stockholm County (76%) had a higher education diploma or university degree. Among the participants from Norrbotten County about one-third (38 %) had equivalent education. Among the women from Stockholm County two-thirds (61%) had completed chemotherapy before undergoing adjuvant endocrine therapy, compared with a quarter (23 %) in Norrbotten County. Of the participants from Stockholm County 14 had been offered tamoxifen solely, while 12 had been offered AI solely. Six of the women had switched endocrine treatment after consulting their physician. Of these women one was also treated with goserelin. Information is lacking from one of the women. Four of the women from Norrbotten County had been offered and were still being treated with tamoxifen and one with AI. More than half of the group, 8 women switched endocrine therapy according to the recommendations from their physician.

Socio demographic and treatment-related data are presented in Table 1.

The analysis of the results resulted in six themes:

1. The most important sources of information
2. The women's perceptions of the reason why they had been prescribed endocrine therapy; and
3. Their reasons for continuing the therapy
4. The women's reasons for being sceptical about the therapy
5. How the women experienced the physician's way of communicating about the therapy; and
6. How they experienced the information provided by healthcare providers about side effects.

The women from the two counties of Sweden had somewhat different experiences. For this reason, we present their results separately. When it comes to the treatment and age matched groups no obvious differences were observed. The women are referred to in the quotations by assigning a confidential code. Each woman was given a group number and an individual number. Statements from participant from Stockholm were signified by letter S and from Norrbotten by letter N.

### The most important sources of information

(The results are based on all 46 participated women)

In Stockholm County reported sources of information were the patient organization, healthcare providers who also gave out patient information leaflets, the Internet and other media, and friends. The most cited information source was the patient organization. The information from this organization came partly in the form of a member magazine from the central organization,

**Table 1: Sociodemographic and clinical characteristics among 33 women from Stockholm County and 13 from Norrbotten County offered endocrine therapy.**

Characteristics	Stockholm County	Norrbotten County
<b>Number</b>	<b>33</b>	<b>13</b>
<b>Age</b>		
Mean (range)	59 (36-77)	65(52-78)
SD	9.75	7.77
<b>University degree</b>		
Yes	25	5
No	8	8
<b>Total</b>	<b>33</b>	<b>13</b>
<b>Chemotherapy</b>		
Yes	20	3
No	13	10
<b>Total</b>	<b>33</b>	<b>13</b>
<b>Prescribed endocrine therapy</b>		
Tamoxifen solely	14	4
AI solely	12	1
Switched therapy	6	8
Unknown	1	
<b>Total</b>	<b>33</b>	<b>13</b>
<b>Years with therapy</b>		
Mean (range)	3.2 (1-6)	2.4 (0.5- 5)
SD	1.31	1.57

and partly from local information meetings with healthcare providers that the local group was organized. Among healthcare providers, it was primarily oncologists and breast cancer nurses that were reported as the most important sources of information, but surgeons and other nurses were also mentioned. The Internet and other media were important resource. The women from Stockholm County browsed freely; only one woman mentioned one of the websites recommended by healthcare providers, the website of the Swedish Cancer Society ([www.cancerfonden.se](http://www.cancerfonden.se)). No-one mentioned 1177, Sweden's national website for healthcare providers information. Friends and women acquaintances as well as women whom the participants had met at different rehabilitation sessions were another important source of information. The patient information leaflets were mentioned but to a lesser extent.

In Norrbotten County, health care providers were by far the most frequently reported source of information. In comparison, the other sources of information were mentioned only marginally. Another difference between Stockholm County and Norrbotten County was that in Norrbotten County two of the women mentioned 1177 as a source of information. None of the women in Norrbotten County mentioned the patient organization as a source of information.

### **The women's perceptions of the reason why they had been prescribed endocrine therapy**

(The results are based on all 46 participated women)

This theme is about how the women understood and perceived the information they had received from their health care provider. There were different perceptions among the women as to why they had been prescribed endocrine therapy, as outlined below:

**Oestrogen/hormone receptor-positive tumour:** In Stockholm County only a few women reported that their physician had informed them that they had a hormone receptor-positive tumour and therefore needed endocrine therapy. One woman stated:

*"Yes, my oncologist said, 'That's great, your tumour is hormone-sensitive so therefore we can use another weapon in our war.'" - S3:4*

By contrast, the majority of the women from Norrbotten County knew that they had a hormone-receptive tumour and this was why they had been prescribed the therapy. Several of them described that their tumour was dependent on oestrogen, as can be seen in this quote:

*"Yes, someone explained ... that you produce oestrogen your whole life and if you take this tamoxifen it results in that the cancer can't get any food, because the cancer wants oestrogen." - N2:1*

**Other perceptions as to why they had been prescribed the therapy:** Some women in Stockholm County believed that they had been prescribed adjuvant endocrine therapy for reasons other than the tumour being oestrogen/hormone receptor-positive. One participant said that she had been prescribed the

therapy because she had dense breasts rich in fibroglandular tissue:

*"Since they say I have dense breasts ... I understood, that I just had to eat this so I won't get anything back [a recurrence]." - S7:3*

Another woman thought the reason was to avoid chemotherapy:

*"... I think it was much about that I could get around having chemotherapy." - S7:1*

In Norrbotten County none of the women had any misunderstandings about why they had been prescribed anti-hormonal therapy.

### **The women's explanations for not understanding why they had been prescribed endocrine therapy:**

In both counties several women reported that when they received information about their different treatments they were not receptive. They were confused and in shock. They did not have enough energy to take information. Afterwards they had problems to remember what the health care providers said. They were not very adaptive. One woman in Norrbotten County described the time when she got her diagnosis as a movie:

*"It's like you're in some movie, but then when you look at yourself in the mirror: I'm actually sick! ..." - N1:6*

Other explanations for not understanding the reasons for being prescribed endocrine therapy in both groups of women included insufficient information from health care providers, as mentioned by a woman from Stockholm County:

*"I feel that you should be even more explicit when you inform [patients] about a medicine. Because one is still in a phase where one can't really grasp everything" - S8:6*

There were other factors in the women's lives that affected how receptive they were for information. For example, one woman in Norrbotten County had a husband who had recently been diagnosed with cancer:

*"... But when my own [cancer] came I didn't have the energy to take it in." - N2:3*

### **The women's reasons for continuing the therapy**

(The results are based on all 46 participated women)

In both study groups the women's reasons for continuing the therapy were primarily that they experienced the therapy as essential for their survival and that they trusted the physician and/or the health care providers.

**Essential for their survival:** Several of the women from both counties described that they continued the therapy out of fear that the cancer would come back otherwise:

*"I was scared to death to get it back. I think that it was the fear and horror that it would come back, and therefore I thought that if I took it [i.e. the therapy] ..." - N1:5*

Women in both counties reported that they perceived the therapy so important that they wanted to continue it for a longer

time period than prescribed:

*"I would like to get treatment for longer, but I'm going to my doctor in a month or two and then I will fight for it."* – S7:6

#### **Trust in the physician and/or health care providers:**

Both in Stockholm County and in Norrbotten County, women reported that they trusted the recommendation from the health care provider and followed the physician's prescription without questioning it. One woman in Stockholm County said:

*"Yes, it's not like I think anything about it but it's because I believe that the doctors know and then I do as they say."* – S3:2

#### **The women's reasons for being sceptical about the therapy**

(The results are based on all 46 participated women)

Not all women were convinced of the therapy's importance. Some of the women had the perception that the therapy does not always help. One woman in Stockholm County stated:

*"But you've heard some rumours that this anti-oestrogen only helps some."* – S3:5.

Another reason could be that the women did not fully believe that the decision to prescribe the therapy was particularly well founded:

*"I think that, it's a little bit standardized. Or that I'm in a research project without knowing it."* – S7:2

Some women in Norrbotten County also questioned the therapy. One said that she started questioning the therapy after she had independently obtained information about the medicine:

*"I have read and heard something about what these pills do and so I thought, should I really take them then?"* – N2:3

#### **How the women experienced the physician's way of communicating about the therapy**

(The results are based on all 46 participated women)

Only one woman in Stockholm County reflected on how the physicians communicated about the therapy:

*"We suggest, '... I thought it was so respectful to me as a person. This is what we suggest and it is still your choice.' So I liked that formulation."* – S5:2

Several women in Norrbotten County described their physician's way of presenting endocrine therapy as necessary. They said their physician informed them about the therapy in a serious and thoughtful manner and told them that they wanted them to undergo the therapy.

#### **How the women experienced the information provided by health care providers about side effects**

(The results are based on all 46 participated women)

**What information did they receive?** Most of the women in Stockholm County reported that they had received both oral and written information about possible side effects, and that

they were satisfied with the information. Some women did not remember whether they had received this information or not.

Most of the women in Norrbotten County stated that they did not receive information from the health care provider about possible side effects, when the medicine was prescribed. However, the information regarding side effects which they described during the interviews was more detailed compared with that described by the women from Stockholm County.

The women in Stockholm County had more comments about the information they had received about the side effects from the health care providers than the women in Norrbotten County, who did not review this at all. Whether it was positive or negative and those who have not received information about side effects differed among the women in Stockholm County. Many of them were dissatisfied with the lack of information. One said,

*"... I think that the doctors should be much clearer when they prescribe medicine. At least personally I would prefer to be more prepared, rather than to find out afterwards..."* – S7:1

Others had the opposite opinion. They felt it was positive not knowing in advance what side effects they might experience:

*"Why should they say anything at all? Then you'll wait for it [the side effects]: when will this [side effect] come, and when will that come, and now I feel this."* – S5:5

One woman in Stockholm County believed that health care providers had deliberately avoided informing her about the side effects:

*"I think they're afraid that you'll imagine that you feel pain. It can happen, if you know, that it's like that."* – S6:3

**How the women reacted to experienced lack of information about side effects:** The women in Stockholm County reported that they primarily searched for information online or went to lectures arranged by the local breast cancer organization. When searching the web they were not using the web pages recommended by the health care providers. Instead they searched freely.

In Norrbotten County the common trend was that when the women had side effects symptoms or needed information they turned to the health care providers for advice. There were several instances where women who had obtained information about the therapy from other sources then talked to their physician about the information they had heard.

**Difficulties the women experienced in contacting the health care providers about side effects:** In general, the women from Stockholm County were more negative to the health care providers compared with the women in Norrbotten County. For example, women in Stockholm County reported that they had met different physicians during their appointments and that they used to have a breast cancer nurse who was no longer available when they tried to contact her. However, both in Stockholm County and Norrbotten County there were women who experienced difficulties to contact the health care providers about side effects. Women in both counties reported that they did

not want to bother health care providers too much. One woman in Stockholm County told:

*"You don't want to be seen as a person making a fuss." – S7:6*

A participant from Norrbotten County likewise expressed the idea of bothering the health care providers when she said,

*"... When you feel that you have a severe problem, when you call and bother ..." – N1:5*

Another difficulty some women in Stockholm County reported was that they felt rejected and that health care providers did not have time for them:

*"Yes, I was a bit disappointed when I called and was told, 'Yes, but you are an old patient of ours. We have so many new patients.'" – S5:2*

One woman in Norrbotten County said that she did not know how to meet health care providers:

*"But how do you meet health care providers? Are you going to see the family doctor or do you come here (to the hospital)?" – N1:4*

## Discussion

In this study, women who reported adherence to endocrine therapy were asked about their experiences and beliefs about the information and the communication regarding the therapy. The principal findings are that most of the women trusted their physicians and understood that the therapy was essential. But even so, many had misconceptions as to why they had been offered the therapy. Some said they had heard or read tasks that made them question the therapy. Many of the women reported that when they were put on the therapy they had trouble taking in information from healthcare providers as they had a mental block or were unreceptive for a variety of reasons. Several women also reported that they experienced obstacles when contacting healthcare providers about their side effects. The experience of the therapy differed somewhat between the counties regarding information, communication and level of knowledge.

In Stockholm County the most frequently reported source of information was the patient organization. In Norrbotten County the most reported source was the healthcare provider. Internet and other media were especially important sources for the women from Stockholm County. When they searched the web they did not visit the websites recommended by healthcare providers but, instead, browsed freely. The finding that a source other than healthcare providers was the most important source of information for women prescribed endocrine therapy is not in accordance with earlier research, where healthcare providers was found to be by far the most important source of information [22,27]. This finding may highlight a change in attitude among women diagnosed with breast cancer. It maybe that in the future other sources of information will affect women's attitude towards the therapy as much as their physicians' words.

Most women from both counties understood that the therapy was essential for them; however, in Norrbotten County, women had a bit more confidence in the prescription and had more

knowledge about why they had been prescribed the therapy. In both counties, misconceptions, myths and/or the women's own preconceptions resulted in some women questioning why they had been prescribed the therapy. Many women in both groups reported that they were not receptive to information at the time they received information about the therapy from their health care providers and that they had a mental block for various reasons.

A patient's knowledge and understanding why a treatment is given is important in order for this person to be able to make informed decisions about the treatment [28]. According to the Cancer Research organization in the United Kingdom, there are plenty of evidence-based websites on cancer but there are also websites spreading myths. Much of the information on the web is at best inaccurate, and at worst dangerously misleading [29]. Furthermore, earlier research has shown that women's level of knowledge about cancer before their diagnosis is low [30]. Where women have little knowledge about the disease before they get their diagnosis this may be an obstacle in understanding the therapy and its benefits as well. Furthermore, breast cancer patients often do not have sufficient information about the benefits and side effects of endocrine treatment [22]. Non-adherence can occur among women diagnosed with breast cancer if they fail to psychologically accept that the therapy is important for them. If the benefits of a breast cancer treatment are not obvious to the patient, this can result in non-compliance [22]. A treatment or medicine that affects the patient's life in a negative way most likely demands greater knowledge and motivation on the part of the patient. For example, if a patient experiences pain, and takes a pain killer that relieves the pain it is motivational for the patient to continue taking the medicine. But if the patient is prescribed with a medicine that results in a worsened quality of life, the benefit from the medicine is harder to understand and the motivation to adhere may have to be much stronger [31,32]. In a meta-analysis by Zolnieriek and Dimatteo, physicians' communication was found to be significantly correlated with patient adherence. There was a 19% higher risk for non-adherence among patients whose physician communicated poorly compared with patients whose physician communicated well [33].

When we examined the information from the women about the side effects of the therapy we found that their answers differed between the regions regarding how and when they had received information. In both regions, however, the women reported information gaps. Women in both regions also reported that they experienced different kinds of obstacles when it came to contacting the health care providers about their side effects. According to Hadji, it is important that women about to start endocrine therapy receive full information about the side effects. This will enable them to manage the side effects better, and therefore lead to better conditions for adherence to therapy [28].

A limitation of this study is that this population was a selection of patients who adhered to endocrine therapy and nothing can be stated about the difference with patients who didn't adhere. Furthermore the patient's characteristics can have affected the credibility. The study population may not be representative of

women in Sweden diagnosed with a receptor-positive breast cancer because the groups consisted only of women who could understand and speak Swedish. In Stockholm women with a high level of education were over represented. Young women were under represented, especially in the focus groups conducted in Norrbotten County. The higher the level of education in Stockholm may have affected the information search behavior and explain the differences between the two counties in relationship to the Internet and other media. The circumstance that the interviews were conducted in two counties that represent extremes in terms of urbanization may also have affected the credibility. The results could have been different if parts of Sweden with other demographic structures had been included. Furthermore the focus group format may have been disagreeable for some women. Due to these biases some imported experience of the women with a receptor-positive breast cancer may have been overlooked.

## Conclusion

The key finding in this socio-anthropological survey study is that most of the women trusted their physicians and understood that the therapy was essential, but many women reported that when they were put on the therapy they had a mental block or were unreceptive for a variety of reasons. Another finding is that patient organization, friends, Internet and other media have a significant role in how women perceive the endocrine breast cancer therapy.

If the health care provider is unaware that the patient perhaps is not sufficiently receptive to information at the time it is given it may lead to misunderstanding about the benefit of the treatment. Because Internet and other media are often used sources of information, it is necessary that health care providers are aware of any misleading preconceptions and misunderstandings that are spread in media, in order to be able to counteract them.

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