

Women's perceptions and experience of adjuvant tamoxifen therapy account for their adherence: breast cancer patients' point of view

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Abstract

Objective: The aim of this study on primary breast cancer patients undergoing adjuvant tamoxifen treatment was to determine how their perceptions of the treatment and their experience of side-effects contributed to their adherence to the treatment.

Methods: A consecutive series of primary breast cancer patients eligible for tamoxifen therapy were studied qualitatively by conducting semi-structured in-depth interviews at two French cancer centres.

Results: The women aged 35–65 ($N = 34$) were struggling with several issues involving their understanding and experience of the treatment, which have not been documented so far. These issues included confusion about the 'hormonal' nature and activity of tamoxifen and the etiology of the changes in their menopausal status, as well as the symbolic associations formed by patients about the paradox of taking a treatment that has aging effects but saves lives.

Conclusions: This study shows the great physical burden often associated with tamoxifen treatment and brings to light women's own complex representations of the treatment and their interpretation of the side-effects. Better communication between health-care providers and patients should ultimately help to prevent refusal or discontinuation of tamoxifen treatment. Copyright © 2009 John Wiley & Sons, Ltd.

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Introduction

In breast cancer patients with oestrogen receptor positive tumours, a five-year course of adjuvant tamoxifen reduces the risk of recurrence by 46% and that of death from breast cancer by 26% [1]. Comparisons between treatment durations have indicated that women taking tamoxifen for less than five years have significantly higher rates of breast cancer recurrence and mortality [2]. Non-adherence to tamoxifen or early discontinuation of the treatment is therefore likely to result in significantly less favourable outcomes among patients.

Tamoxifen is a selective oestrogen receptor antagonist with a weak agonist activity [3]. Side-effects of the treatment include slightly increased risks of thrombosis and endometrial cancer, and lesser effects such as the development or worsening of menopausal symptoms [4]. Its use, which is generally combined with adjuvant chemotherapy, results in premature menopause and the loss of

childbearing capacity in the increasingly large numbers of young women who are surviving for long periods after breast cancer diagnosis [5].

The recent increase in patient autonomy has led to the term 'adherence' being preferred to 'compliance' in the literature. The most commonly cited definition of adherence is 'the extent to which a patient's behaviour coincides with medical health or advice' [6]. Depending on the population surveyed and the methods of measurement used, the rates of adherence to tamoxifen have been found to range from 45 to 88% [7–13]. It was recently established that adherence to tamoxifen cannot always be taken for granted during the five years required to obtain maximum benefits [14–18]. Adherence tends to decrease with time, with most discontinuations occurring during the first year of follow-up [18]. This pattern is not limited to patients taking tamoxifen [19,20].

Adherence to medical advice, prescribed medication and medical treatment is known to depend on

many factors. The reasons for non-adherence to tamoxifen have not been closely documented to date. There is little evidence available on the effects of demographic factors, but extremes of age (under 45 and over 75) have been found to be associated with less adherence [12,16–18,21]. Severe side-effects are certainly likely to cause women to discontinue the treatment [10,13,15,16,18].

Values and beliefs about health and medicine have also been found to impact patients' use of medication [22–24]. In the case of tamoxifen, patients' belief that the pros of the medication outweigh the cons (giving a positive balance score) was found to be another key predictor of their adherence [14,15]. Negative or neutral beliefs about the value of tamoxifen were found to be associated with discontinuation of the treatment [13].

The exact reasons for negative beliefs about tamoxifen treatment have not yet been established, however. The aim of the present study was therefore to document the representations underlying these women's beliefs and their experience of tamoxifen treatment, and to obtain a comprehensive picture of how these factors affect their adherence to the treatment.

Methods

Study design

This study was based on the qualitative methodological tradition of Grounded theory [25]. Grounded theory generates concepts and relationships between concepts that account for the variations in the area investigated and bring to light the chief concerns of those involved. One advantage of this inductive, discovery-orientated approach is that it generates new hypotheses, perspectives and meanings about complex behaviour, attitudes and interactions, which quantitative methods cannot do [26]. In order to investigate the complex issue of adherence and non-adherence with tamoxifen treatment, this approach was therefore used here to encourage breast cancer patients to discuss their perception and experience of the treatment [27] during individual open-ended in-depth interviews.

Setting and sample

Eligible women were defined as primary breast cancer patients to whom tamoxifen had been prescribed, who were willing to discuss this issue and share their experience. Twenty participants were initially recruited consecutively from the consultations of two oncologists and one radiotherapist working at two regional cancer centres in South Eastern France (in Marseille and Nice). In keeping with Grounded theory, a further purposive sample of 14 women was recruited from the same

physicians' active consultation files using the same criteria as previously, but maximizing the variations in dimensions relevant to the emerging analysis: age, duration of treatment, menopausal status at diagnosis, discontinuation of treatment and refusal. Any patients showing acute distress, cognitive impairments or insufficient mastery of French were excluded from the study.

This study therefore included 34 women, who were asked to choose where they would feel most comfortable while being interviewed (16 at home, 18 at the hospital). Our project was in line with the French national and local ethical requirements and regulations (informed written consent, authorisation from the local hospital administration and the medical staff).

Data collection and analysis

Data were collected at in-depth interviews designed to facilitate free expression of thoughts and feelings in a non-judgemental environment with each patient at a single point in time after tamoxifen had been prescribed. The interviews were carried out by the first two authors, who both had prior experience of conducting qualitative interviews with cancer patients and kept a reflexive diary. An interview prompt guide was used to plan the interview. Topics covered included the onset and history of the disease, women's experience of previous treatments, the side-effects experienced, relationships with the clinic and/or staff, their understanding and expectations of the treatment, and their views about their future health. Since Grounded theory involves an iterative process, the first participants' responses shaped the content of subsequent interviews, and the guide was adapted accordingly to emerging issues (mode of action of the treatment, previous use of hormonal treatments and associated meanings, etc). Each interview lasted 40–60 min. The interviews were audiotaped, transcribed verbatim, and checked for accuracy.

The first four interviews were reviewed to check the reliability of the interview technique. Data on the patients of greatest interest (treatment refusal or discontinuation) were examined at an early stage. A systematic iterative method of analysis based on the constant comparative method [25] was subsequently applied to gradually review all 34 interview transcripts in their entirety. In the data analysis, open codes indicating the significance of various sections of the text were first generated in order to classify the data. These sections were then arranged incrementally and coded in terms of themes and coding categories. Using a systematic method of reviewing transcripts line by line, the texts were coded and compared across cases by the two authors, who performed the analysis independently to maximize rigour. As new transcripts were analysed, the themes were refined, focused,

or altered. Some themes relating to tamoxifen (such as severity of side-effects) were immediately obvious and were coded at an early stage in the analysis. Others (such as the higher-order themes of 'ambivalence', 'representations of menopause' and 'coping with loss') emerged only after further analysis. Once a theme had emerged from some interviews, the data were re-analysed to establish whether other respondents referred to this theme explicitly or implicitly and to look for deviant cases. Data collection and analysis were iterative, and new data were used to assess the reliability of the ongoing analysis. Periodic discussions were held with other members of the research group to check the plausibility and relevance of the themes and patterns observed. The study ended when the findings were no longer improved by further interviews or analysis (when the data saturation point was reached).

Results

Sample characteristics

Thirty-four women (median age 49, range 35–64) diagnosed during the previous five years with early-stage breast cancer who were eligible for tamoxifen treatment participated in this study. Their demographic and medical characteristics are presented in Table 1. At the time of the interview, 28 women were taking tamoxifen (mean duration of treatment 20 months, SD 18 months), 2 had discontinued the treatment (after 3 and 14 months), and 4 had refused the treatment at the start. Eight women reported that they were taking hormone replacement therapy when the breast cancer was

diagnosed, and that the treatment had been stopped at that point.

Findings

Conflicting representations about the hormonal/anti-hormonal effects of tamoxifen

One of the most striking aspects of these women's accounts was the fact that they used many different terms to designate tamoxifen. Approximately one-third of the women referred to tamoxifen as 'hormone therapy', 'hormonal treatment', or even 'hormone'. Many of them spontaneously mentioned their past experience with contraceptive pills and HRT when explaining what they thought about tamoxifen because of the common hormonal basis ascribed to all these treatments.

I'm a woman, I know what hormones are. I've been taking hormones since the birth of my daughter: I first took contraceptive pills, then hormonal treatment for menopause. Now I am on hormone therapy, so I have been taking hormonal treatment for 35 years. I must have beaten all the records in terms of taking hormones. (El., aged 61, 5 years of treatment)

This analogy was also made when speaking about their drug-taking habits, which were similar to those they had previously adopted with the contraceptive pill.

I tell myself that instead of the pill I am taking tamoxifen. It's a hormonal treatment, and it is one pill a day. I take it in the same way as I took my pill in the evening, before I go to sleep. I usually put it on my bedside table, so I will not forget to take it. (I., aged 36, two years of treatment)

Conversely, some women expected tamoxifen to have adverse side-effects because this had occurred with contraceptive pills.

'I've never taken the pill, because I have never been able to bear hormonal treatment, it made me sick. With tamoxifen, I was expecting it to be disastrous because I thought it would be like taking the pill, vomiting all the time, bleeding problems, etc. But for the moment it seems to be OK. (P., aged 37, 3 months of treatment)

A large number of respondents expressed some dislike of drugs. Many expressed concern about hormonal treatments because they interfere with natural processes (the monthly cycle, the body, life, etc.).

I heard the word hormone, and I was shocked. I do not like this word. It frightens me a little, hormonal treatment, I wonder whether we are not

Table 1. Summary of women's characteristics (n = 34)

Category	Type	Number of women
Median age (range)	49 (35–64)	
Marital status	Married	25
	Single	9
Menopausal status at diagnosis	Nonmenopausal ^a	20
	Perimenopausal ^b	7
	Menopausal ^c	7
Tamoxifen treatment duration at interview	0 (initial refusal)	4
	1–6 months	8 (including one discontinuation)
	6–12 months	6
	12–24 months	5 (including one discontinuation)
	25–36 months	3
	37–48 months	4
	48–60 months	4

^aRegular menses.

^bIrregular menses, but at least one period had occurred during the previous 12 months.

^cMenstrual periods for at least 12 consecutive months.

over-medicated...‘I am not sure it is really necessary...’ (P., aged 37, 3 months of treatment)

The increased risk of uterine cancer known to be associated with tamoxifen and the fear of cancer associated with hormonal treatments in general were reasons often given by respondents to explain why they were reluctant to take tamoxifen. It is worth noting that the recent controversial debate about HRT and cancer was found to have had a strongly negative impact on many women.

Most importantly, I read that tamoxifen causes cancer of the uterus. The contraceptive pill? I never took it because it was said to be carcinogenic. The hormone treatment for menopause? I did not agree to taking it either, for the same reason. Cancer I already had it once, and that was enough, so I refused to take tamoxifen! (C., aged 56, refused tamoxifen)

Tamoxifen was referred to as an ‘anti-hormonal treatment’, an ‘anti-estrogen’, or an ‘anti-hormone’ by about one-third of the respondents. These terms were generally used when describing the purpose or the mode of action of the treatment. The women mostly declared that it prevents the recurrence of cancer and in some cases, the trade-off between the risks and benefits seemed perfectly obvious to them.

It is an anti-hormone, which prevents cancer recurrence. I think it removes hormones from women, right? When you’ve had this disease, it is terrifying to think that it may happen again! Sometimes I woke up at night and I thought: ‘I’m not going to die, damn!’ So when I was told that my cancer was hormone-sensitive, I just took tamoxifen. That’s it. (B., aged 48, 30 months of treatment)

On the other hand, the terms ‘hormone’ and ‘anti-hormone’ were often both used to designate tamoxifen at the same interview. In these cases, the decision-making process was more complex: many women admitted to lacking knowledge about the mode of action and doubting whether the treatment was really indicated.

The doctor told me: ‘After radiotherapy you will have a hormone..., an anti-hormonal treatment, since your cancer is hormone-dependent’. It must be the same system as the pill, but I do not really know how it works. I think it blocks hormones which are targeted to the breast at certain times of the cycle, it puts me in a state of menopause. I wonder whether they just do things by thinking ‘if... (P., aged 37, 3 months of treatment)

The need for clarification about the causes of the perceived menopausal symptoms

When asked about the symptoms experienced, women reported having hot flushes and/or night

sweats. Other problems, such as becoming less attractive, weight gain, tiredness, menstrual changes, decreased sexual drive, vaginal dryness, and mood swings were also mentioned. The first year of treatment was characterized by a feeling of loss of control over their body.

I feel very ambivalent about this treatment at the moment. I have put on 5kg since I started, it worries me a lot. Then I had a check-up with the gynaecologist which showed that tamoxifen has caused a cyst on an ovary. So tamoxifen wants to stop my hormonal system from working, but the cyst has made the system want to work. I found myself 10 days ago with my body really upside-down. My belly looked as if I was 5 months pregnant, inflated, hard, horrible. At the same time, the blood tests showed that my hormones are a little upside-down... Since I started taking this medication, I have also had a pain that I did not have before in the breast, and very poor circulation in the legs. I have been having a lot of hot flushes too. That’s horrible, it’s like a wave, all the points on your body you can imagine are sweating. When that happens, it is uncontrollable, and you feel terribly unclean... (W., aged 50, 9 months of treatment)

The lack of appropriate treatment for managing hot flushes was a recurrent concern and women were actively seeking a suitable alternative method.

The hot flushes, that’s what made me suffer most. It is the most difficult thing to cope with. I know there is no solution: I am not allowed to take any of the effective ones: oestrogen I can’t take, and soya products I can’t take either. The only thing that I am allowed to take is abufene, but it makes absolutely no difference. It’s the same with homeopathy. (G., aged 52, 10 months of treatment)

Many women were unclear about their menopausal status, and looked to physicians for assistance and explanations about the exact etiology of their symptoms. The fact that they could not say whether tamoxifen, chemotherapy, premenopause, or HRT withdrawal was obviously responsible for the side-effects often increased their uncertainty and anxiety.

One month after undergoing chemotherapy, my periods stopped. And since then, things have not been back in working order. The question is therefore: is it the tamoxifen which goes on stopping the periods? Or the pre-menopause, as the doctor said? I was taking hormones. But as the hormones were stopped and I was given tamoxifen, the hot flushes started to occur again. Was that due to stopping the hormone treatment? Was it due to tamoxifen? That is the big question. I don’t know.

Breast cancer patients' point of view

I really don't know. (M., aged 49, two years of treatment)

The women explained that they sought information by consulting multiple sources, such as their oncologist, other patients, and internet. Definite answers were not easy to find and some women ultimately blamed the symptoms on external stressors, such as changes in their environment, work, family life and/or habits.

I put on weight, but maybe it was because I stopped smoking? As far as hot flushes are concerned, I had some before, but right now I am having more and more. Every hour, suddenly I'm in a sweat! Does tamoxifen increase them? I wondered whether stopping smoking did not increase my hot flushes two-fold, as well. Or going back to work. In addition, the weather is so hot right now... (R., aged 46, 6 months of treatment)

Making sense of a paradoxical situation

Many women mentioned the paradox inherent to the treatment, which 'saves life' and at the same time 'has aging effects'.

It is a treatment which is tiring, aging, and at the same time, you say: Well, it saves your life. [Silence] It is a very peculiar situation. Paradoxical. (E., aged 54, 4 years of treatment)

The dilemma with which they were faced because they had to choose between survival and preserving their youthful looks and femininity was hinted at in most accounts.

I put on 20 pounds, I had hair on my chin, it was unbearable... As for the libido, there was nothing left at all. I'm young, my husband too, it was not easy! I lost interest in clothes. Suits, heels, I left everything drop... yes, it was an attack on my femininity. (J., aged 39, discontinued the treatment after one year)

Other concerns included the various forms of psychosocial discrimination that women with early menopause might have to face due to the deterioration of their body image, impaired occupational efficiency (because of hot flushes and tiredness), the need to find a life partner and the fear of being abandoned. The way each woman faced this situation and coped with the treatment reflected her picture of her femininity and the menopause and her own beliefs about the life stage she had reached.

Among the women approaching menopause at diagnosis, premature menopause was hardly ever described as just another phase in life and easily accepted. It was generally described rather as being a further burden which added to the threat to their

femininity already caused by breast cancer and surgery.

To kill off the female hormones that I produce is unacceptable to me. It is an additional mutilation after the mastectomy, a loss of my female image. I was born a woman and I want to remain a woman. With this treatment, we have to make up our minds to take it every single day for five years. Five years is a long time, and these five years are important when you are not far from the menopause like me, because there's no turning back. We are pushed into the menopause without being able to go back. It also means that we will not have access to alternative treatments for menopause. So we will age more quickly. (I., aged 50, 15 months of treatment)

However, the changes in the respondents' identities and lives induced by the treatment were found to be neither uniformly nor permanently distressing. A number of women gradually made up their minds while undergoing the treatment and advancing in age, and eventually accepted what seemed to them to be inevitable, however unpleasant.

I have many circulation problems and I have gained weight, that's true. But maybe these things cannot all be attributed to the treatment. We know there are phases in life, physical changes that occur at menopause, and well, we have to accept it... You have to tell yourself: 'you are not 20 any more!' I will be 50 years old in a few days, that's not easy to accept. With the disease that has added on 2 or 3 years, it's even more difficult. But in the end, the side effects, I guess once you have accepted them, you feel better! I feel the way you cope with this treatment is part of the treatment. (E., aged 49, 2 years of treatment)

Among the younger women who had no children and those who had family plans at the time of diagnosis, preserving their fertility was a particularly crucial issue. Two participants who had refused or discontinued the treatment mentioned their plans to have children when explaining their decision. They regarded having a child not only as an investment in the future but also as symbolic means of counteracting the life-threatening disease.

I had a girlfriend, who helped me during the disease. She had kidney cancer 4 years ago while she was pregnant. She had a splendid baby, and no longer had cancer. It's a bit mysterious, cancer, isn't? After the disease, my husband and I had to go ahead. We thought: 'If that is the case, there's no point in taking tamoxifen and wasting five years. Tamoxifen did not seem vital to me, nor very reliable. Our wish to have a child was very strong,

we did not agree with waiting.' (C., aged 35, pregnant, refused tamoxifen treatment 3 years ago)

Several other women under the age of 40 also mentioned this issue spontaneously. Lastly, some women also described having difficulty in forgetting about the disease and getting on with their lives, since they were being reminded of it every day by having to take the tamoxifen pill.

Discussion and conclusion

Discussion

During the past two decades, several studies carried out in various settings have shown that up to half of the women to whom adjuvant tamoxifen treatment has been prescribed stop taking the treatment before the end of the recommended period of five years [14–18]. The qualitative approach used in the present study made it possible to closely examine women's interrelated feelings and opinions about the use of tamoxifen, as well as the differences between various women's experiences of the treatment. Although tamoxifen treatment seemed to have little impact on the lives of a few respondents, most of the women's accounts showed that it was associated with distress, ambivalence and tensions. Some of the findings, such as their negative or neutral beliefs about the value of tamoxifen and the severe side-effects they experienced, are in keeping with the conclusions reached about non-adherence in previous quantitative biomedical and psychosocial studies [10,13–16,18]. A number of other concerns emerged from these interviews, which help to explain the beliefs and problems associated with the treatment. These concerns relate to (1) the complexity of women's representations about tamoxifen and (2) the symbolic meanings associated with the menopausal side-effects of tamoxifen.

First, women often had confused representations of the drug (hormonal, and/or anti-hormonal?), which affected their understanding of the treatment. They were wrestling with complex issues involving 'hormones' as relating to their femininity and 'hormones' as increasing the risk of cancer. Although these representations may have partly resulted from what they had heard about the effects of tamoxifen (tamoxifen has both anti-oestrogen and oestrogen-like activity, depending on the target tissues), confusions about the mode of action frequently occurred, leading to ambivalence or perplexity about the value of the treatment. Some women mentioned the potentially harmful effects on their bodies of taking 'hormones' and voiced concerns about disrupting the natural physical rhythm. These beliefs are similar to those previously expressed in patients' 'unorthodox' accounts about medication in general [22] and HRT

in particular [28]. More specifically, women expressed reluctance to take hormonal medication because they had heard about the slightly increased risk of endometrial cancer associated with the use of tamoxifen and about the recent controversial debate about HRT and cancer. However, in many cases, previous use of contraceptive pills or HRT tended to favour adherence to the treatment. Beliefs about the effects of tamoxifen are therefore not hard and fast, but depend on women's own representations of hormonal medication and their previous experience with HRT or contraceptive pills.

Second, the results of this study show the powerful impact of the side-effects of tamoxifen on women's sense of identity and the efforts required to make sense of these effects. Throughout this quest, women looked to their physicians for assistance. The need to understand the changes in their bodies and the exact origin of their problems was central to the way they coped with the treatment. The menopausal symptoms associated with tamoxifen treatment are known to increase up to three months after the start of treatment before improving gradually with time [7,8]. As with other drugs prescribed to treat chronic diseases [29], women who stop taking tamoxifen tend to do so within the first year [14,18]. In agreement with these findings, our results show the existence of considerable tensions associated with the side-effects experienced during this period, which add to the psychological distress resulting from breast cancer itself and the psychological adjustments women have to make to resume their normal lives after being treated for cancer. In the context of tamoxifen, several studies have shown that the information with which women are provided about the side-effects of the treatment and what to expect is insufficient [30–32]. Our results confirm and extend these results by showing that during the first few months after the start of the treatment, women need medical explanations about the side-effects, and that gathering information is thought to be a positive way of overcoming these problems and regaining some control.

Cancer is strongly equated with death in most people's minds, and several women spoke of their need for tamoxifen treatment and sometimes explicitly for 'survival'. However, at the same time, they also worried about its aging effects. For women who are struggling to recover their sense of social and sexual identity, which has been undermined by breast cancer, apart from the unpleasant side-effects and discomfort experienced in their everyday lives, the deeper meanings associated with the side-effects of the treatment mainly involved symbolic issues of life and death and the theme of loss (of youth, femininity, fertility, etc.). Women's narratives were often reminiscent of the 'grieving process' that accompanies menopause and what it signifies [33]. For some women, tamoxifen may

restore the sense of identity threatened by cancer, but also may constitute a threat to that sense of identity.

Poor communication is commonly cited to explain why patients behave unexpectedly, by not complying with treatment or expressing unfounded anxiety, for example [34,35]. A recent survey on health-care professionals and their patients with advanced breast cancer showed that doctors and nurses underrated both the prevalence of the side-effects of tamoxifen therapy and the resulting distress, in comparison with patients' own accounts of their experience [36]. In the present study, the side-effects of tamoxifen were strongly equated with premature menopause in women's accounts. Women do not necessarily approach menopause via the biomedical model, however. A woman's experience of menopause is inevitably shaped by her own subjective perception of her bodily changes as well as by the currently circulating ideas about menopause, which are influenced by social and cultural practices and traditions [37]. This is particularly relevant in the case of younger women. Early menopause and/or the counter-indication of pregnancy associated with the use of tamoxifen were found to be of great importance to the younger women, for whom preserving fertility and femininity was a vital issue, not only in terms of childbearing opportunities, but also as a symbolic barrier against the life-threatening disease. As reported by Thewes *et al.* [31], younger women with breast cancer have unmet needs for fertility- and menopause-related information. The present results show that some younger women who have a strong desire to become pregnant at diagnosis are prepared to trade off some survival benefits for the preservation of their fertility and childbearing potential. This point is worth mentioning, as hormone therapy is being increasingly advocated in the case of younger and premenopausal women as part of their program of adjuvant treatment and even for 'high risk' women not affected with breast cancer [38].

Conclusion and practice implications

The interviews conducted with women about tamoxifen in this study give a complex picture of their opinions and experience of the treatment. They gave voice here to fluid, variable, and often conflicting representations of this drug and the multiple meanings they attached to the changes in their bodies and lives resulting from tamoxifen treatment. However, the changes and problems caused by the treatment were found to be neither uniformly nor permanently distressing.

In the context of taking the relative costs and benefits of a treatment for each individual into account, this study confirms the need to promote women's individual understanding and discuss

their concerns on an ongoing basis. It also suggests what kinds of information and clarification women may need, both at the start of treatment and during the following months. In addition, the patients' main priorities were identified. The present findings should help health-care providers to communicate with their breast cancer patients in a way that meets their needs and expectations. This should ultimately contribute to preventing refusal or discontinuation of the treatment.

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