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Information provision for patients by breast cancer teams about the side-effects of hormone treatments

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ABSTRACT

The choice of adjuvant hormone treatments in post-menopausal women with breast cancer increasingly includes anastrozole as an alternative to tamoxifen. Clearly there may be overlapping side-effects, but other important differences may have serious implications for health and quality of life. Patients consequently require information regarding the side-effects of recommended treatments and their comparisons. This study evaluates the extent of information provision about the side-effects of adjuvant anastrozole and tamoxifen by respective breast cancer professionals within 16 different breast care teams in the United Kingdom (UK). The study used interviews with individual members of breast cancer multidisciplinary teams (surgeons, oncologists and breast care nurses) from 11 cancer centres and 3 district general hospitals, to examine the information they give to patients relating to the side-effects of tamoxifen and anastrozole. The results show that vasomotor symptoms were the most frequently mentioned side-effect for both treatments. All teams, in large part addressed the adverse effects of both treatments (endometrial cancer and thromboembolic events for tamoxifen and anastrozole-associated loss of bone density). There was variation between the different professionals as to how frequently side-effects were mentioned. The greatest discrepancies occurred between the information given by team members and that included in patient information leaflets. In some cases, important information pertaining to side-effects was omitted from leaflets. This study suggests the need to standardise information-provision nationally in the UK and within breast cancer teams regarding the evidence-based side-effects of tamoxifen and anastrozole.

1. Introduction

In recent years the delivery of cancer services has changed. Care in many countries is now provided by multi-disciplinary teams and treatment recommendations are intended to be more evidence-based. Patients are encouraged to ask for more information and there are a plethora of websites, support groups and other information sources available to patients. For the majority of patients, however, the most credible information will be that supplied by their specialist cancer care teams.[1] The integrity, continuity and congruence between team members of the information provided is important. The recently published National Institute of Clinical Excellence (NICE) guidance on Cancer Services (Improving Supportive and Palliative Care for Adults with Cancer) stated that patients should 'have access to high-quality information materials to aid decision making.[2] It is imperative that this is of high quality in particular evidence-based, balanced and

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regularly updated'. Such information is likely to be derived from multicentre randomised clinical trials and meta-analyses. Some multidisciplinary teams (MDTs) have experienced difficulties working in optimally functional ways and many are unaware of the informational roles of their colleagues.[3]

Many options are available for women with hormone-receptor-positive breast cancer. Arguably where there is choice and so many options, it is even more important that teams provide consistent information not just among themselves, but also in the information leaflets, brochures or websites to which they direct patients. This study examined the information provided by a randomly selected group of breast cancer teams in the United Kingdom (UK).

Comparisons of anastrozole with tamoxifen, with the latter an established adjuvant treatment for breast cancer, have shown that anastrozole significantly prolongs disease-free survival after 33 months and that this is sustained at a median follow-up of 68 months (Arimidex, Tamoxifen, Alone or in Combination (ATAC) Trialists' Group, 2002, 2003, 2005).[4–6] Furthermore, a reduction in contralateral breast cancer was found in the anastrozole group, with a risk reduction of 53% in hormone receptor positive tumours, compared with tamoxifen. Longer term follow-up results will ascertain whether this difference is maintained and whether it translates into a difference in overall survival (ATAC Trialists' Group, 2005).[6] At the time of the study (January-May 2004), the UK licence for anastrozole use was related to a contraindication for using tamoxifen. A recent amendment of the licence now includes the approved use of anastrozole in the adjuvant treatment of post-menopausal women.[6,7] Since the publication of the first results from the ATAC trial, however, anastrozole has received considerable media attention. This has consolidated patient pressure to prescribe anastrozole and incited wider-ranging discussions regarding treatment options with consultants. In this context, there is an increasing scope for patients to exert their preferences, underlining the importance of well-informed discussions regarding side-effect profiles of different hormone treatments.

Tamoxifen (T) and anastrozole (A) overlap in their side-effect profiles, with some important differences.[4–6] The updated ATAC trial highlights significantly greater hot flushes following tamoxifen compared with anastrozole (T = 40.9% versus A = 35.7%; $P < 0.0001$), with an increased risk in venous thrombo-embolic and cerebrovascular events in favour of anastrozole (T = 4.5% versus A = 2.8% ($P < 0.0004$) and T = 2.8% versus A = 2.0% ($P = 0.03$), respectively).[5,6] A small tamoxifen-associated increased risk of endometrial cancer (T = 0.5% versus A = 0.2%; $P = 0.02$) was also observed.[6] Anastrozole-associated additional events related to a higher risk of arthralgia and fractures compared with tamoxifen (T = 29.4% versus A = 35.6% ($P < 0.0001$) and T = 7.7% versus A = 11.0% ($P < 0.0001$), respectively).[6] Significantly ($P < 0.05$) fewer patients in the anastrozole group reported problems with vaginal bleeding (A = 5.4%, T = 10.2%; $P < 0.0001$) or vaginal discharge (A = 3.5%, T = 13.2%; $P < 0.0001$) at 68 months.[6,8–10] Similarly, in the quality of life (QoL) sub-protocol evaluating 1021 women, vaginal itching favoured anastrozole (A = 3.4%, T = 5.0%; odds ratio (OR) 0.7) at 5 years, whereas the opposite was true for vaginal dryness (A = 18.5%, T = 9.1%; OR 2.0), dyspareunia (A = 17.3%, T = 8.1%; OR 2.5) and loss of libido (A = 34%, T = 26.1%; OR 1.5).[8–10] Extended tamoxifen use (over 5 years) has been associated with an increased risk of developing cataracts.[11], with no differences between the treatment groups in the ATAC trial.[4–6]

A number of other less frequent and/or less serious side-effects relate to tiredness, mood disturbances and gastrointestinal problems, including nausea/vomiting, with similar frequencies for women in both groups of the ATAC trial.[8,9]

The present study focuses on the content, extent and frequency that side-effect profiles of these two treatments are communicated to patients by breast cancer teams. Each treatment is associated with its own set of potentially serious side-effects, as well as less serious, but persistent ones. Against a background of increased treatment choices, there is evidence that patients' value being fully informed.[12], despite others preferring to take the consultant's advice and participate less in decision-making.[13] We specifically report the information that breast care teams 'believe' they give to patients concerning the side-effects of tamoxifen and anastrozole and discuss how this may affect patients' perceptions of how the side-effect profiles compare. We also look at the consistency of information-giving between team members.

2. Participants and methods

2.1. *Participants*

Letters were written to 29 surgeons inviting them to participate in the study. The surgeons were chosen randomly from 11 cancer centres and 3 district general hospitals in the UK (see Acknowledgements) so as to be representative of multidisciplinary working. Twenty-three positive replies were received and six surgeons did not reply. Of those who agreed to participate, six surgeons were unable to be interviewed during the time frame of the study. Dates were arranged to see all remaining surgeons and at least one breast cancer nurse who worked with them. An oncologist from each team was identified and invited to participate in the study. All oncologists agreed to participate, however one oncologist was unable to be seen during the course of the data collection period.

With respect to two of the teams, we were able to interview two surgeons and two breast care nurses. Two of the interviewed teams shared the same surgeon, but were assessed separately because they were based at different hospitals and used a different oncologist and breast care nurse. In total 16 teams, comprising 50 health professionals (17 surgeons, 15 oncologists and 18 breast care nurses), participated in the study.

2.2. *Procedure*

The interviews were conducted by a researcher (RMcG) at the hospitals where the teams were based. Participants were seen individually and permission was sought to audiotape the interview. The researcher explained that the study was evaluating how the side-effects of tamoxifen and anastrozole were explained to patients. The reason given for carrying out this research was that we were interested in the information that patients may potentially use to form a treatment preference.

It was clarified that the questions should emulate those discussed at the initial patient consultation relating to the commencement of adjuvant hormone treatments. The researcher then used an interview protocol to guide the rest of the interview. The question from the interview protocol that elicited the information used in this study was: 'Can you tell me the side-effects that you always mention to women when talking about adjuvant treatment with tamoxifen?' A prompt list was used after the interviewee had given a free recall response. Items included on the prompt list were generated from data from the main ATAC study and the quality of life sub-protocol.[4–6,8–10] The interviews usually lasted no more than half an hour.

3. Results

Summarised in Figs. 1–3 are the results on the main side-effects that were mentioned for each treatment, grouped by discipline. For each side-effect, the interviewee was classified as either consistently mentioning that side-effect or not mentioning it. Therefore, if the interviewee said that they sometimes mentioned that side-effect or would mention it only if asked, then this was categorised as not being consistently mentioned.

It can be seen that for both treatments, vasomotor symptoms were the most frequently mentioned side-effect (94% of surgeons (S) and 100% of nurses (N) and oncologists (O)

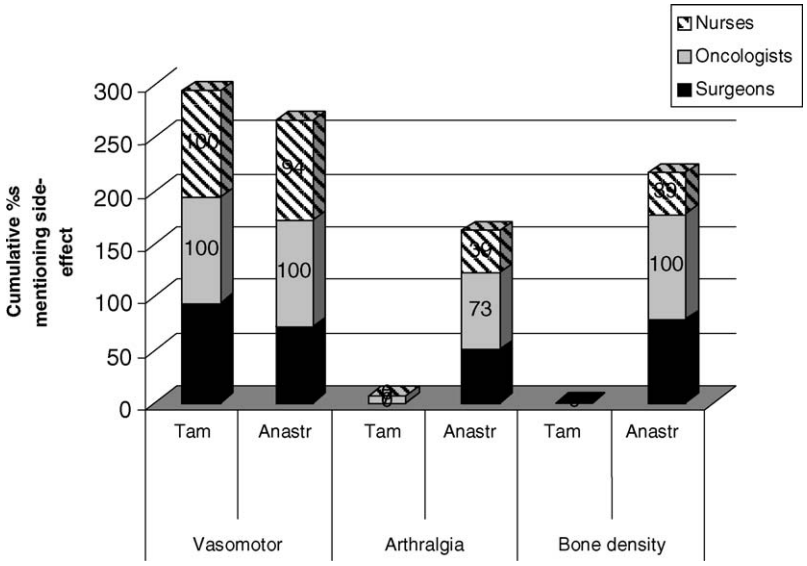

Fig. 1 – Reporting of side-effects of tamoxifen and anastrozole grouped by professional role. Tam, Tamoxifen; Anastr, Anastrozole.

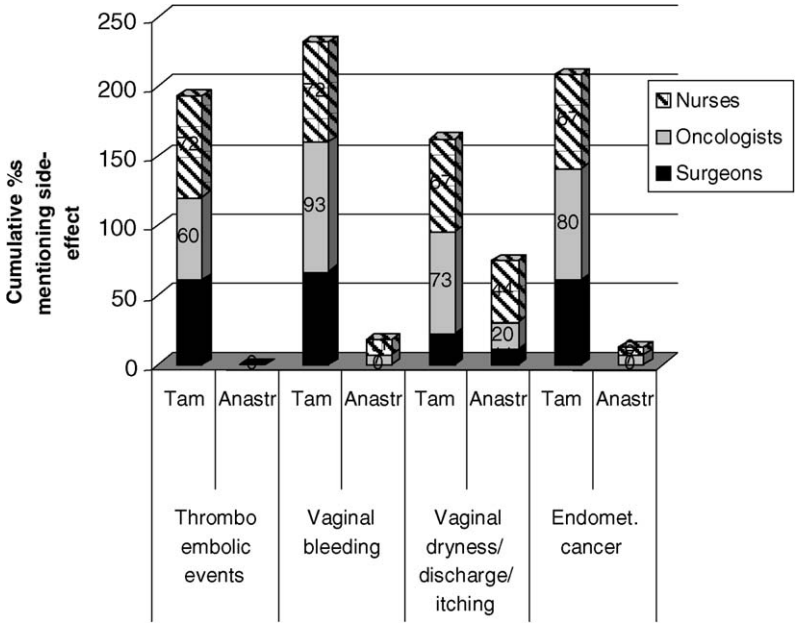

Fig. 2 – Reporting of side-effects of tamoxifen and anastrozole grouped by professional role. Tam, Tamoxifen; Anastr, Anastrozole.

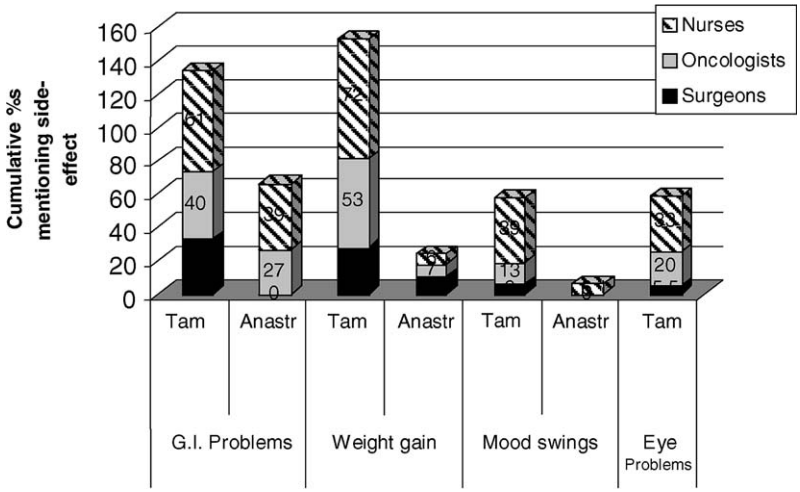

Fig. 3 – Reporting of side-effects of tamoxifen and anastrozole grouped by professional role. Tam, Tamoxifen; Anastr, Anastrozole.

always mentioned these with tamoxifen, and 72% of S, 100% of O and 94% of N always mentioned these with anastrozole) (Fig. 1). Many of the interviewees said that they told patients that hot flushes and other vasomotor symptoms may be less of a problem with anastrozole than with tamoxifen. Vaginal bleeding (S = 67%, O = 93%, N = 72%), endometrial cancer (S = 61%, O = 80%, N = 67%) and thrombo-embolic events (S = 61%, O = 60%, N = 72%) were, after hot flushes, the next most frequently mentioned side-effects for tamoxifen (Fig. 2). Arthralgia (S = 50%, O = 73%, N = 39%) and loss of bone density/fractures (S = 78%, O = 100%, N = 39%) were the next most commonly mentioned side-effects for anastrozole after hot flushes. Of all three professions, nurses were the least reliable source of information about loss of bone density or arthralgia (Fig. 1).

Vaginal dryness/discharge/itching were consistently mentioned more often when discussing tamoxifen versus anastrozole (S = 22% versus 11%, O = 73% versus 20%, N = 67% versus 44%, respectively) (Fig. 2). Sexual problems were rarely mentioned for either treatment (tamoxifen: S = 6%, O = 7%, N = 6%, anastrozole: S = 0%, O = 13%, N = 6%). Gastrointestinal side-effects (e.g. nausea, vomiting, diarrhoea, constipation, bloating) were addressed more frequently in relation to tamoxifen compared with anastrozole (S = 33% versus 0%, O = 40% versus 27%, N = 61% versus 39%, respectively) (Fig. 3). Similarly, professionals from all disciplines mentioned weight gain and mood swings more consistently when talking about tamoxifen compared with anastrozole (Fig. 3).

Occasionally, there was a marked variation between professions regarding the frequency that certain side-effects are discussed; in particular, the possibility of tamoxifen-associated weight-gain as mentioned by significantly fewer surgeons (28%) compared with others (O = 53% and N = 72%) (Fig. 3). Figs. 1–3 illustrate a consistent tendency by oncologists (O) and nurses (N) to discuss any particular side-effect compared with surgeons (S), with a further example relating to tamoxifen-associated effects on the eye.

A number of perceived lesser side-effects were rarely mentioned and included skin rash, headaches, dizziness/lightheadedness, hair thinning, tiredness/weakness; with others exclusively mentioned in relation to tamoxifen (memory/concentration issues, sleep disturbances, hirsutism, voice changes and fluid retention/bloating).

3.1. *Adjuvant hormone information leaflets*

Table 1 depicts the range of information leaflets pertaining to tamoxifen and anastrozole currently being used by the participating teams in this study, with some teams using more than one source of leaflet, whilst Breast Cancer Care (BCC)-derived leaflets were mostly used. Notably 'older' versions of anastrozole leaflets were also in use. Tables 2 and 3 show the side-effects listed in the information leaflets for each treatment. There were some additional side-effects and issues mentioned in leaflets for tamoxifen:

- the potential for tamoxifen to provide benefits for bone health was stated in all but one leaflet (in-house team 15) and similarly in all but two leaflets (in-house teams 5 and 15), there was information regarding its potential cardioprotective effects; in addition to its established 'chemoprevention' effects with respect to contralateral breast cancers (omitted in four leaflets; in-house teams 9a, 9b and 10, plus Tenovus);

Table 1 – Types of currently utilised information leaflets on hormone treatment side-effects

Leaflet[a]	Tamoxifen	Anastrozole
Breast Cancer Care (2001)	11	6
Breast Cancer Care (2003)	–	8
AstraZeneca leaflet (1999)	–	1
AstraZeneca leaflet (2000)	2	2
AstraZeneca leaflet (2003)	–	1
In-house leaflet	5	2
Tenovus leaflet	1	–

a Some teams used more than one leaflet.

Table 2 – Side-effects listed in leaflets about tamoxifen

	Breast Cancer Care (2001) $n = 11$	AstraZeneca (2000) $n = 2$	In-house team 5 $n = 1$	In-house team 9a $n = 2$	In-house team 9b $n = 1$	In-house team 10 $n = 1$	In-house team 15 $n = 1$	Tenovus $n = 1$
Hot flushes	√	√	√	√	√	√	√	√
Thrombo-embolic events	√			√	√			√
Vaginal bleeding	√	√		√	√			√
Vaginal dryness/discharge/itching	√	√		√	√	√	√	√
Endometrial abnormalities	√			√				√
Endometrial cancer	√	√	√	√	√	√	√	√
Weight gain	√			√		√	√	√
Gastrointestinal problems	√	√		√		√		√
Eye problems	√		√	√				√
Hair thinning				√		√		√

Table 3 – Side-effects listed in leaflets about anastrozole

	Breast Cancer Care (2003) $n = 8$	Breast Cancer Care (2001) $n = 6$	AstraZeneca (1999) $n = 1$	AstraZeneca (2000/2003) $n = 3$	In-house team 5 $n = 1$	In-house team 15 $n = 1$
Hot flushes/sweats	√	√	√	√	√	√
Vaginal bleeding	√	√	√	√	√	
Vaginal dryness/discharge/itching	√	√	√	√	√	√
Musculoskeletal discomfort/joint pain	√	√		√	√	
Loss of bone density	√				√	
Skin rash/sensitivity	√	√	√	√	√	
Hair thinning	√	√	√	√	√	
Gastrointestinal problems	√	√	√	√	√	√
Headaches	√	√	√	√	√	
Tiredness/weakness	√		√	√	√	

- the following side-effects were each listed in two leaflets: sexual problems (in-house teams 9a & b), brittle nails (in-house teams 9a & 10), skin rash (in-house team 9a & Tenovus), changes to singing voice (Breast Cancer Care & in-house team 9a), liver cancer in rats (Breast Cancer Care and Tenovus), dizziness/light-headedness (in-house team 9a & Tenovus) and fluid retention/bloating (in-house team 9a & Tenovus);
- the following side-effects were each listed in one leaflet only: mood swings (Tenovus), tiredness (in-house team 9b), headache (Breast Cancer Care), leg cramps at night (Breast Cancer Care), increase in downy facial hair (Breast Cancer Care), liver problems (Tenovus), tendency to bruise more easily (Tenovus).

All leaflets for both treatments listed hot flushes as a possible side-effect. All but one of the leaflets for tamoxifen referred to vaginal dryness/discharge or itching, and all leaflets for anastrozole referred to vaginal dryness as a possible side-effect. Potential gastrointestinal problems were listed in five of the eight leaflets for tamoxifen, and in all seven leaflets for anastrozole.

All of the leaflets for tamoxifen referred to the small risk of endometrial cancer, whereas vaginal bleeding was listed in only five of the eight leaflets. The three leaflets that did not refer to vaginal bleeding were in-house produced. Only half of the leaflets for tamoxifen listed thrombo-embolic events as a potential side-effect, with most of these (three out of four) being in-house produced. Five out of the eight leaflets for tamoxifen referred to weight gain. Half of the tamoxifen leaflets listed eye problems as a possible side-effect.

Arthralgia was listed in five out of the seven leaflets used for anastrozole, however potential loss of bone density was only listed in two leaflets. Loss of bone density is only listed in the more recent version of the Breast Cancer Care leaflets for anastrozole. Six out of the seven leaflets used for anastrozole referred to skin rash/sensitivity, hair thinning, headaches and vaginal bleeding, and five listed tiredness/weakness as a potential side-effect.

3.2. *Reporting consistency of side-effects within teams*

Consistency within each team revealed a mixed pattern of results, with internal consistency being high for reporting of some side-effects and low for others. Examples showing the greatest disparity are discussed as follows: the only side-effect for which internal consistency was strong across every team was hot flushes. Nearly everyone in each team talked about hot flushes with tamoxifen and, to a slightly lesser extent, with anastrozole. Discrepancies in reporting tamoxifen-associated endometrial cancer were evident, with this being consistently mentioned by all professionals within seven out of 16 teams and similarly for associated thrombo-embolic events that were reported conscientiously by all team members in five out of 16 teams (data not shown). For both of these side-effects, the number of people in each team who mentioned them ranged from everybody to no-one, although in the majority of teams these side-effects were mentioned by

more than one person. Notably in one team, all professionals omitted to mention endometrial cancer and likewise this phenomenon was repeated with respect to thrombo-embolic events in two teams (data not shown). Anastrozole-associated loss of bone density was uniformly reported by all professionals in only six out of 16 teams evaluated (data not shown). A similar pattern was evident with a wide variation in the number of team members discussing this side-effect. There were no teams where internal consistency was high for every side-effect. In the teams where more than one nurse or surgeon was interviewed, it was apparent that even within a professional discipline, there was a large degree of individual variation in the content and spectrum of side-effect profiles that are discussed.

4. Discussion

When starting patients on adjuvant treatment with either tamoxifen or anastrozole certain side-effects were usually mentioned by the teams we interviewed. Patients would always be told about hot flushes/sweats for both treatments. If patients were taking tamoxifen they would also be told about vaginal bleeding and vaginal dryness/discharge/itching, and at least one person in almost every team discussed the risk of thrombo-embolic events, endometrial cancer and weight gain. Gastrointestinal symptoms were also frequently mentioned for tamoxifen, and mood swings and eye problems were addressed by at least one person in about half the teams. For patients starting anastrozole, bone density loss was mentioned in every team, and someone in all teams except one mentioned arthralgia. Vaginal dryness/discharge/itching and gastrointestinal symptoms were mooted by at least one person in about half the teams with regard to anastrozole. Other side-effects were also mentioned for both treatments, but with less frequency. These findings highlight the reported breadth of side-effects discussed as opposed to their potential significance determined from ATAC.

Within all teams therefore, the serious side-effects of each treatment were usually addressed. However there were instances where no-one in the team mentioned thrombo-embolic events and/or endometrial cancer when talking about tamoxifen, and this is a cause for concern. Usually a higher proportion of oncologists and breast care nurses talked about any given side-effect than did surgeons. This may reflect complementary working by teams and delegation of adjuvant discussions by clinicians. The exception to this pattern occurred with bone density loss and arthralgia. It was noticeable that, out of all team members, nurses were the least likely to mention these two side-effects. This is a point of issue, as it is often the nurse who spends most time talking with patients. Therefore it is important that nurses are well informed about the risk of bone density loss and arthralgia, and that teams ensure these issues are discussed with patients.

Most of the leaflets given to patients for anastrozole did not list the potential effect on bone density. This problem was compounded by older versions of leaflets being used. There were also serious omissions in some of the patient information leaflets, e.g. leaflets for tamoxifen not referring to vaginal bleeding and thrombo-embolic events (Table 2). This was particularly prevalent for many of the in-house produced leaflets. Even if members of the team mention these side-effects, they should be substantiated with written information, based on prior studies suggesting that patients do not always retain the information they receive in consultations.[13] Contrary to this, many of the information leaflets used for tamoxifen listed rare and unusual side-effects, such as a tendency to bruise more easily, or a tamoxifen-associated increase in liver cancer in rats, with a questionable validity of such patient information. Overall the consistency between the information given by teams and that in leaflets was low. There were many side-effects that were frequently mentioned in leaflets, but rarely, if ever, mentioned by the breast care team. A particular example of this was vaginal bleeding with anastrozole; all but one of the leaflets referred to this, but only 3 out of 51 health professionals mentioned it to patients, in all likelihood due to its significantly lower frequency following anastrozole.[4,6] The ATAC trial data showed that vaginal bleeding occurred in 5.4% of patients taking anastrozole compared with 10.2% of patients taking tamoxifen.[6,8–10] However, given the significance of post-menopausal vaginal bleeding as a possible indicator of endometrial cancer, it remains important that patients are informed of the possible relevance of timely reporting of vaginal bleeding.

There were a number of side-effects that were mentioned with different frequencies for the two treatments, even though there is no suggestion in the literature that the treatments differ in these respects. In particular, team members discussed vaginal dryness/discharge and itching collectively and more frequently for tamoxifen than for anastrozole. This may reflect the ATAC trial results showing a significant tamoxifen-associated increase in vaginal discharge compared with anastrozole, however, the quality of life (QoL) sub-protocol showed an anastrozole preponderance of vaginal itching/irritation and dryness. [6,8–10] Gastrointestinal problems were mentioned more often by team members in association with tamoxifen than anastrozole, although the reverse was true in the leaflets. Data from the ATAC trial showed no difference between groups in terms of nausea/vomiting (A = 12.7%, T = 12.4%), and data from the quality of life assessment showed that there were no clear differences between patients in either group with respect to gastrointestinal side-effects such as nausea, diarrhoea, and feeling bloated.[8,9] Psychological problems and weight gain were also more frequently addressed for tamoxifen than for anastrozole, although there has been no reported difference between groups regarding these side-effects in either the main ATAC trial or the quality of life assessment. The issue of whether tamoxifen is directly linked to weight gain is controversial, in the context of no level-one evidence.[14,15] In the short-term anastrozole is not associated with weight gain; that may relate in large part to its shorter history of use as an adjuvant treatment compared with tamoxifen.[8,9] Patient information leaflets for anastrozole were more likely to refer to tiredness or headaches as a potential problem than were leaflets for tamoxifen. Again there is no suggestion in the literature that the treatments differ in terms of these side-effects.[8,9] Half the leaflets for tamoxifen referred to risk-reduction for contralateral breast cancers, though none of the leaflets for anastrozole mentioned this, despite the fact that it is significantly more effective than tamoxifen

in this respect.[4–6] These spurious differences raise the question of the rationale for mentioning/not mentioning a side-effect, or for including/excluding a side-effect or benefit of the drug in an information leaflet. If patients were to compare the side-effect profiles of tamoxifen and anastrozole on the basis of the information given by teams and leaflets in the present study, it is likely that they would have a false impression of differences in the frequency of certain side-effects.

The majority of interviewees in this study were not routinely giving patients a choice between the two treatments. It is likely that, were patients to be offered a choice between tamoxifen and anastrozole, what is said about the side-effects of each treatment and how they relate to each other would change. During this study, anastrozole was not being used frequently by many teams except in large part where tamoxifen was either contra-indicated or poorly tolerated. Further use of anastrozole may have also been recommended in high-risk HER-2 overexpressing breast cancers.[16–19] Therefore anastrozole was often being discussed in the context of not recommending tamoxifen, perhaps leading to preferential emphasis of certain side-effects and not others. Patients were often informed that they may be less likely to suffer from hot flushes with anastrozole, and that they did not have to worry about an increased risk of endometrial cancer or thrombo-embolic events. On the other hand, as discussed earlier, they were not always adequately informed regarding the possibility of developing osteoporosis and secondary fractures following treatment with anastrozole.

Importantly, a number of factors may have influenced the data collection. Of relevance is that interviewees were asked which side-effects they mentioned to patients when starting adjuvant treatment. Some side-effects may be discussed more frequently in follow-up meetings, including sexual problems or those that occur with longer term use of treatment. However, from the point of view of decision-making, it is not helpful if patients are told about potential longer term side-effects after treatment has commenced. Also some interviewees responded that the information they gave to patients about side-effects could vary for a number of reasons; for example the patient's age may influence what information is given to them about bone thinning, menopausal symptoms and sexual problems. In the present study, if the interviewee only talked about a side-effect occasionally, they were classified as not talking about it consistently, and this may have lead to under-reporting of the frequency with which some side-effects were mentioned.

The overall conclusion from this study is that there are areas where both the consistency and the quality of information about the side-effects of anastrozole and tamoxifen could be improved. It is not crucial that all professionals in a team consistently reiterate the same thing, but it is important to ensure that the key side-effects are covered by at least one person in each team and that standardised written information is provided to substantiate these. Individual team members should be aware of the current literature relating to side-effects and their potential influence on QoL, to justify why they are mentioning certain side-effects and not others.[4–6,8–10] The content of information leaflets needs to be appraised to ensure that serious side-effects are included and that there is a clear rationale for including/excluding side-effects. Ideally leaflets should be a reliable tool for use during consultations to avoid omissions and inaccurate reporting of side-effects. It would be advisable to have a uniform consensus agreement, nationally, regarding the standardised reporting of key side-effects derived from amended pharmaceutical updates. Although these conclusions suggest a UK phenomenon, we propose that many of these findings merit a future international study.

Conflict of interest statements

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