# Treatment decision-making in breast cancer: the patient-doctor relationship

L. J. Fallowfield

Received: 19 March 2008/Accepted: 19 May 2008/Published online: 11 June 2008 © Springer Science+Business Media, LLC. 2008

**Abstract** A diagnosis of breast cancer, whether the disease is early or advanced, can be devastating. With this in mind, constructive patient-physician relationships are essential to minimizing disease-related stress and anxiety, as patients undergo treatment and learn to cope with their diagnosis. Good communication skills are vital, and achieve measurable benefits, yet doctors receive very little training in communication. Patients may find it difficult to process large amounts of information, may not understand medical terminology, and can become confused or scared during discussions. They may need time to absorb information, and discuss it with friends and family, before treatment decisions are made. Patient awareness of treatment options is greater than ever, largely because of media exposure and the internet. Consequently, patients' expectations and desire to be involved in treatment choice are increasing, although some patients still prefer to leave decision-making to their doctor. Information about potential side-effects and other treatment burdens is vital, if patients are to make truly informed choices. Knowing in advance what side effects may be encountered, and how to manage them, can also help to improve adherence to treatment, which is necessary for patients to gain the maximum benefit. Side effects that patients find most problematic often differ from those that most concern doctors. Individual patients have different needs and expectations that must be respected, but ensuring that they understand their diagnosis, and the expected benefits and potential risks of treatment, is the key to establishing a good therapeutic relationship and providing the best possible care.

**Keywords** Decision making · Breast cancer · Doctor–Patient relationship

#### Introduction

Effective communication between doctor and patient is essential to best practice in the management of breast cancer [1]. Good communication results in measurable benefits, including shorter hospital stays, fewer complications, better adherence to treatment, increased patient satisfaction and understanding, and decreased anxiety, uncertainty and likelihood of litigation.

Despite these benefits, doctors still receive inadequate training in communication skills. It is often assumed that such skills will be learned through practice, but in reality, senior doctors report the same communication difficulties as their more junior colleagues [2]. Burnout, a combination of emotional exhaustion, perceived lack of accomplishment, and low job satisfaction, is highest among doctors who feel they have not received adequate training in communication and management skills [3]. As hospital doctors may perform up to 200,000 patient interviews during their career [4], communication is clearly an area requiring urgent attention.

Following a diagnosis of breast cancer, good communication is essential, to ensure that patients do not leave the consultation confused about what their diagnosis means and what their options are. Many patients want more information about their disease and potential treatments, and physicians should ensure that adequate time is allocated to discussing treatment options and available sources of additional information. Delivering this in an appropriately paced manner is an advanced but worthwhile skill that helps avoid information overload, particularly in

L. J. Fallowfield ( $\boxtimes$ )

CRUK Psychosocial Oncology Group, University of Sussex,

Falmer, Brighton BN1 9QG, UK e-mail: l.j.fallowfield@sussex.ac.uk



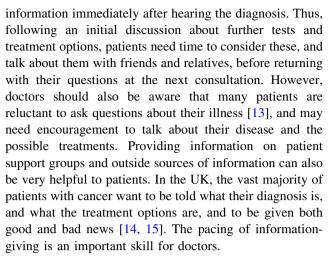
distressed patients who have just received their diagnosis. Research shows that patients who know more about their treatment and care options worry less, and have better outcomes, than those who are less well informed [5].

Many treatment options are available for both early and advanced breast cancer, consideration of which can be quite daunting for patients. Inviting women to take part in the decision-making process, but not imposing it on them, can increase both acceptance of therapy and consequent adherence. All treatments (surgery, radiotherapy, chemotherapy and endocrine therapy) have side effects, and individual patients may have strong aversions to some of them, which will influence treatment choices [6]. Doctors should be aware that the side effects that concern patients the most (e.g. alopecia, loss of libido, fatigue, and hot flashes) are not necessarily the same ones that doctors consider most problematic. Although not life-threatening, these symptoms can have a detrimental impact on patients' quality of life (QoL), which can ultimately affect their willingness to continue with treatment. Symptoms that have the greatest impact on QoL are often underestimated or unrecognized by clinicians [7, 8]. Although many large clinical trial protocols now include a QoL substudy, where standardized questionnaires probe aspects of disease and treatment that affect QoL, these areas are rarely discussed in routine clinical assessments, hence the discrepancies.

The use of newer, more effective anticancer agents can significantly reduce disease recurrence. Their follow-up period is still rather short, however, thus their long-term safety and true impact on QoL may not become evident for many years. For example, the side effects of tamoxifen were not apparent until it had been in use for some time. This creates a problem, as patients need to be clear about potential benefits and risks before deciding on and starting any medical intervention. In this article, the impact of anticancer therapy on the patient is discussed, with a particular focus on the importance of effective doctor–patient communication, and the involvement of patients in the treatment decision-making process.

## Communicating diagnosis and prognosis

Each year, approximately 1.2 million women are diagnosed with breast cancer worldwide [9], making it the most common cancer in women. A woman's lifetime risk of developing breast cancer has been estimated at 1 in 8 [10]. Breast cancer has been reported to be the disease that many women fear the most [11], although they are actually nine times more likely to die of heart disease [12]. As the diagnosis of breast cancer can be devastating, doctors should be aware that patients may not be able to understand the implications fully, or absorb large amounts of



Following a diagnosis of breast cancer, patients may experience many feelings, including anger, grief, distress and guilt. These emotions can be overwhelming, adversely affecting patients' QoL. However, responses to the diagnosis differ greatly: some patients may view it as a challenge and invest their energy in fighting the disease, whereas others may feel helpless and hopeless, or develop depression or anxiety disorders. Psychological assessments—and, where necessary, appropriate therapy—can help patients come to terms with their situation, and improve treatment acceptance and disease outcomes [16].

#### Treatment decision-making in early breast cancer

Over the last 20 years or so, several studies have investigated the role of the patient in the selection of breast cancer therapy, and found that most patients prefer to have some degree of involvement during the decision-making process. Three main styles of patient decision-making have been identified. Passive involvement, as the name suggests, means that the patient prefers to leave the treatment decision to others, usually their doctor. Shared decision-making involves collaboration between patient and physician, while active decision-making indicates that the patient prefers to make the choice of therapy alone [17]. The preferred role of patients in treatment selection varies between studies, and is often influenced by patient characteristics, such as age and education. Older and less educated patients, for example, are more likely to prefer a passive or collaborative role [18, 19], whereas an active role is generally preferred by younger and better educated patients [20].

Involving patients in treatment decision-making can be empowering at any stage of the disease. Active participation can help patients to feel that they have some control over their future, and may reduce the psychological morbidity associated with cancer. However, while several



recent studies have reported a trend towards an increase in the number of women who prefer to take an active role in treatment decision-making [21–24], it is important to recognize that some patients find being involved in the process too great a responsibility, and prefer their doctor to make the decision. In a recent study of decision-making preferences in patients with gynecologic cancers, a substantial proportion preferred to either share the decision or delegate the choice to their doctor [25].

Whatever a patient's preferred role in treatment decision-making, a match between the preferred level of participation and the actual level of involvement is a strong predictor of satisfaction with treatment outcomes [21, 22]. Furthermore, the key to achieving the right degree of involvement for the individual patient is adequate access to information about the disease, the available treatment options and the associated risks and benefits [26]. Women with access to such information are more likely to be satisfied with their decision-making than those without [23, 27].

Therapy for breast cancer can include several approaches, with different considerations at each stage and for each type of treatment. The important issues, and potential benefits of involving patients, at each stage are discussed below.

## Breast surgery and radiotherapy

For women with operable breast cancer, mastectomy, breast-conserving surgery (BCS), wide local excision (WLE) or lumpectomy may be available. Following lumpectomy, radiotherapy to the surrounding breast tissue may also be considered, to reduce locoregional recurrence. Neoadjuvant (or primary systemic) therapy may also be offered, to shrink or down-stage a tumor to reduce the extent of surgery required, to improve the cosmetic outcome or, for women with inoperable tumors, to render the tumor operable.

Women facing surgery for early breast cancer are increasingly taking a more active approach to treatment decision-making [21, 22, 24]. Evidence suggests that women who prefer to take an active role in the choice of surgery are more likely to achieve their desired level of participation in the decision-making process [24]. Moreover, patients who achieve their desired role in decisionmaking are more likely to be satisfied with their surgery choice, although reported concordance rates between desired and actual roles range between 49% and 61% [24, 28]. Concordance between patient perspectives and physician views on treatment decision-making is also limited; in a 2004 study by Janz and colleagues, only 38% of patients agreed with their doctor's assessment of how the treatment decision was made [21], indicating a need for better patient-physician communication.

The psychological effects of being offered a choice of mastectomy or lumpectomy have been investigated, but many studies had short follow-up periods and small sample sizes. More recent studies are retrospective, with no contemporaneous evidence to support what actually happened during an interview. It might be predicted that, given a choice, most women would prefer BCS and would benefit psychologically from being offered the choice, but in fact, there is little evidence for either claim [29]. Several studies have shown that providing patients with greater autonomy in surgical treatment selection does not necessarily result in a reduced rate of mastectomy [22, 24, 28].

In a 3-year prospective study of 269 women aged <75 years with stage I or II breast cancer, semi-structured psychiatric interviews and standardized questionnaire assessments were performed before surgery and at 2 weeks and 3, 12, 24 and 36 months thereafter [30]. Psychological outcomes were assessed in women treated by surgeons who favored mastectomy (n = 30), those who favored lump-ectomy where possible (n = 121), and those who offered a choice of treatment where possible (n = 118).

At 3 years, data were available for 216 (80%) women. Anxiety and depression that warranted intervention were found in a significant minority of patients. The risks of anxiety and depression were significantly reduced in women who were given a choice, compared with women who were treated by surgeons favoring mastectomy (P < 0.05). However, psychological morbidity was not affected by being offered a choice regarding surgery. Of the 118 women treated by the 'choice' surgeons, 56 were not actually given a choice, because of technical considerations such as a large central lump in a small breast. Anxiety and depression were not different in these 56 women compared to the 62 who were offered a choice: merely being treated by a 'choice' surgeon had psychological benefits.

The probable explanations for this seemingly strange finding all related to communication. More of the women treated by 'choice' surgeons were satisfied with the information and communication when the diagnosis was discussed, than in the other two groups (P < 0.01). In the sample as a whole, women who perceived their information as good were less likely to be anxious and/or depressed than those who perceived it as bad at 12, 24 and 36 months post-diagnosis (P = 0.005). These findings suggest that, although there may be little direct psychological benefit in involving patients in treatment decision-making, providing clear and accurate information is important for the patient's long-term acceptance of breast cancer treatment.

The psychosocial impact of mastectomy or lumpectomy may be influenced by the cosmetic outcome of surgery, and breast reconstruction can be offered to help patients overcome the trauma of surgery. Several studies have



investigated whether lumpectomy has psychological benefits over mastectomy, and how breast reconstruction reduces the negative impact of surgery on patients' mental health.

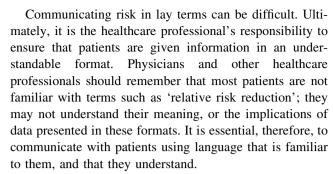
A retrospective analysis of 577 patients with primary breast cancer revealed a significant benefit in favor of lumpectomy plus reconstruction compared with mastectomy or lumpectomy alone, when assessed using self-evaluation questionnaires. Mastectomy was associated with the greatest psychosocial morbidity (anxiety, depression, body image and sexuality) [31].

In a separate study, good cosmetic outcome after lumpectomy correlated with levels of anxiety and depression, body image, sexuality and self-esteem [32], suggesting that the cosmetic result has a marked impact on future psychosocial wellbeing. The timing of reconstructive surgery also affects psychological morbidity: prompt reconstruction is associated with less anxiety and depression, and improved self-esteem and perceptions of personal attractiveness, compared with delayed reconstruction [33]. These findings support the use of neoadjuvant therapy to increase eligibility for lumpectomy, and reduce the number of women undergoing mastectomy. Expeditious breast reconstruction could reduce the psychological burden of breast cancer and surgical intervention.

## Systemic adjuvant therapy

Systemic adjuvant therapy reduces the risk of the patient developing metastatic breast cancer, by targeting undetectable micrometastases at distant sites. Patients may receive adjuvant endocrine therapy (for hormone-receptorpositive [HR +] disease), chemotherapy, or both, with the choice of treatment depending largely on the estimated risk of relapse. Patient acceptance of the need for adjuvant therapy (and therefore their willingness to start treatment) depends on the information they are given about treatment options; the potential benefits, possible side effects and convenience of treatment; patients' prior knowledge and expectations of treatment; and the advice they receive from others. While patients are receiving treatment, adherence to therapy is influenced by the actual burden experienced, and its impact on the patient's daily functioning and QoL [34, 35].

Effective communication of the risk of recurrence, and the potential benefits of adjuvant therapy in reducing that risk, is essential for patients to understand what the future may hold for them, and how adjuvant therapy can improve outcomes. Only then can patients make informed choices about their treatment. All information given and recommendations made to patients should be based on accurate and credible evidence from robust clinical trials.



The adverse effects of a treatment have a significant impact on its acceptability to patients. In general, the acute toxicities of chemotherapy (e.g. nausea and vomiting, stomatitis, alopecia) are generally far less tolerable than the side effects of endocrine therapy, which are generally similar to the symptoms of menopause. Chemotherapy may not, therefore, be considered acceptable therapy for patients with small, low-grade, strongly HR+ tumors, who would probably benefit more from endocrine therapy [35], or for elderly or frail patients with other comorbidities. Patients' wishes must also be taken into consideration: chemotherapy-associated alopecia can be very distressing, particularly for women who are struggling with body image issues after breast surgery.

Tamoxifen has been the standard adjuvant endocrine therapy for HR+ breast cancer for several decades. The current recommended duration of tamoxifen treatment is limited to 5 years, although recent data suggest that 10 years of treatment reduces disease recurrence [36]. However, longer-term use of tamoxifen is also associated with an unfavorable risk-benefit ratio, due to a persistent excess of potentially life-threatening adverse events (thromboembolic disease, stroke and endometrial cancer). Even among patients who do not experience these serious adverse events, less severe toxicities, especially hot flashes, can have a detrimental effect on QoL and reduce adherence [37, 38].

The route of administration of adjuvant therapy may also affect patient acceptability and adherence. Many patients develop a phobia of needles during or after intravenous (IV) chemotherapy, and will refuse further therapy via this route [39]; however, it may be possible to alleviate or prevent such problems if psychosocial support is provided. On the other hand, providing IV therapy in the hospital does remove the problems of adherence associated with oral medications taken in the home. Non-adherence is common with oral adjuvant therapy [40], and is likely to reduce the expected efficacy of treatment. Patients must be educated about the importance of adhering to their treatment regimen, and urged to contact their doctor if adverse effects occur and result in non-adherence. It is also important that patients understand that options are available to manage side effects, should they occur.



Impact of adjuvant treatment on quality of life

Patients are clinically cancer-free when adjuvant therapy is started and, therefore, they will not gain perceptible benefits from treatment. On the other hand, adverse effects may negatively affect patients' daily functioning. Side effects that have the greatest impact on patients' QoL are not usually life-threatening, and therefore often differ from those that most concern physicians. Consequently, such side effects may be dismissed or not even considered when discussing treatment (planned and ongoing) with patients [41].

In recent years, the third-generation aromatase inhibitors (AIs; letrozole, anastrozole and exemestane) have become available, and have challenged the supremacy of tamoxifen in the adjuvant setting. A number of large, randomized controlled trials have assessed the overall value of AIs; these trials have had three main designs:

- 5 years' tamoxifen therapy versus 5 years' treatment with an AI.
- 5 years' tamoxifen versus a protocol consisting of tamoxifen for 2–3 years, followed by a switch to an AI for the remainder of the 5-year period.
- Placebo versus AI in patients who have already completed 5 years' treatment with tamoxifen ('extended adjuvant' therapy).

The impact of AI therapy on QoL has been investigated in three of these trials: ATAC, IES and MA.17 (Table 1) [42–44]. The findings of the MA.17 trial are discussed separately, as it deals with extended adjuvant therapy.

In the ATAC (Arimidex, Tamoxifen, Alone or in Combination) Adjuvant Breast Cancer Trial [45, 46], 5 years'

treatment with anastrozole monotherapy was associated with a lower risk of disease recurrence (P=0.015) and contralateral breast cancer than with tamoxifen monotherapy. Combination therapy with anastrozole and tamoxifen did not confer any benefit over tamoxifen alone; this regimen is thus not recommended for use in clinical practice, and will not be discussed further here.

As part of the ATAC trial, 1021 patients took part in a substudy to assess the impact of long-term adjuvant therapy on QoL, 682 of whom received either anastrozole or tamoxifen alone (Table 1) [42]. QoL was assessed at baseline and again at predetermined intervals for 5 years, using the FACT-B (Functional Assessment of Cancer Therapy-Breast) questionnaire (version 3) in conjunction with an 18-item endocrine subscale (ES). The primary outcome was the Trial Outcome Index (TOI), which combines scores from two of the domains from the FACT-B (physical and functional) with the score from the ES for each patient; the maximum score for the 23 items in this index is 92. Higher TOI (and FACT-B) scores correlate with better QoL; a change in TOI of  $\pm$  5 points is considered clinically significant.

At 2 years' follow-up, both anastrozole and tamoxifen were associated with increases in TOI (i.e. improvements in QoL) from baseline to 2 years (means +4.16 vs. +3.49, respectively; not statistically significant). Additionally, most patients in both treatment arms had clinically significant improvements in QoL during the same period (i.e. an increase in TOI of  $\geq 5$  points): 60.0% for anastrozole, and 61.9% for tamoxifen [47].

The final 5-year data from the monotherapy arms of the ATAC health-related QoL substudy confirmed the initial findings. There was no statistically significant difference in

Table 1 Quality-of-life (QoL) subanalyses of large randomized, multicenter trials of aromatase inhibitors as adjuvant [42, 43] or extended adjuvant [44] therapy in early breast cancer

Study	Design	QoL substudy			
		n	Duration (years)	Instrument(s)	Primary endpoint
ATAC [42] Adjuvant therapy	5 years ANA vs	335	5	FACT-B + ES	TOI
	5 years TAM <sup>a</sup>	347			
IES [43] Adjuvant therapy	5 years TAM $\rightarrow$ EXE vs	289	2	FACT-B + ES	TOI
	5 years $TAM \rightarrow TAM^b$	293			
MA.17 [44] Extended adjuvant therapy	5 years LET vs	1813	3	SF-36	Not stated
	5 years PLA <sup>c</sup>	1799		MENQOL	

<sup>&</sup>lt;sup>a</sup> In patients who had completed primary therapy (surgery, radiotherapy and chemotherapy) for operable breast cancer. A third intervention (ANA + TAM) was studied in the trial, but not listed here; it had no clinical benefit over TAM alone, and is not recommended in the adjuvant setting

<sup>&</sup>lt;sup>c</sup> In patients who had completed approximately 5 years of TAM. ANA anastrozole, ATAC Arimidex, Tamoxifen, Alone or in Combination, ES endocrine subscale, EXE exemestane, FACT-B Functional Assessment of Breast Cancer–Breast, IES Intergroup Exemestane Study, LET letrozole, SF-36 36-item Short-Form Health Survey, TAM tamoxifen, TOI trial outcome index (sum of scores from physical and functional well-being and breast cancer subscales of FACT-B)



b Patients were randomized after 2-3 years of TAM to switch to EXE or remain on TAM until the total length of adjuvant therapy was 5 years

TOI between the two treatment groups (median score change from baseline +2.9 for both anastrozole and tamoxifen; P=0.65). Consistent with the 2-year analysis, QoL was maintained, or slightly improved, during the treatment period for both anastrozole- and tamoxifentreated patients [42].

FACT-B in combination with ES was also used to assess QoL in a substudy of the IES [43]. In IES, relapse-free patients (n=4724) were randomized, after 2–3 years' treatment with tamoxifen, either to continue their existing regimen or to switch to exemestane. In both arms, the total duration of adjuvant therapy was 5 years. Switching to exemestane was associated with a significant 24% reduction in the combined endpoint of disease recurrence, contralateral breast cancer and death, compared with tamoxifen continuation. Switching to exemestane also achieved a borderline 17% survival benefit in the subgroup of patients with ER +/ER-unknown disease (P=0.05), but no significant survival benefit in the exemestane group as a whole [48].

The 2-year QoL substudy recruited 582 patients from the IES trial. As in the ATAC trial, treatment with either tamoxifen or AI was not associated with a clinically important mean change in TOI from baseline to 2 years. Additionally, there were no statistically significant between-group differences in the change in TOI versus baseline at any time point beyond 6 months. Thus, neither treatment had a clinically meaningful effect overall (positive or negative) on QoL over 2 years, suggesting that the clinical benefits of switching to exemestane are achieved without sacrificing QoL.

Thus, evidence from large randomized trials suggests that the clinical benefits of AIs, in terms of reduced disease recurrence and incidence of contralateral breast cancer, are achieved without any significant reduction in overall QoL. The results from maturing clinical trials can enable much more positive conversations with patients about the benefits of adjuvant treatment.

#### The GAEA initiative

Patients' attitudes to, and knowledge and understanding of, endocrine adjuvant therapy were investigated recently in a pan-European survey of 547 postmenopausal women, all of whom were receiving tamoxifen or an AI—the GAEA (*G*athering information on *A*djuvant *E*ndocrine ther*A*py) Initiative [49].

In this survey, <30% of the women received information pertaining to the side effects of adjuvant therapy, or on the risks of disease recurrence, either during or after completing therapy. Additionally, less than half recalled being informed of the available treatment options, and only 36% had any involvement in the decision to start adjuvant

therapy [49]. Women aged ≤60 years, those with a higher level of education and those with internet access were more likely to have received information, or to have been involved in the decision-making process. Interestingly, women indicated that their most important sources of information and support were doctors and breast cancer support groups; printed, patient-oriented materials such as leaflets and brochures were considered much less valuable.

These results suggest that women with breast cancer are often neither given sufficient information about adjuvant endocrine treatment, nor told what to expect in terms of outcomes and side effects. Fewer still are involved in the decision to start treatment. These results are particularly interesting in the context of a randomized clinical trial conducted by Whelan and colleagues [27], which showed that women who received detailed information about their disease, adjuvant treatment options and likely outcomes were significantly more knowledgeable, and more satisfied with the decision-making process, than those who did not receive such information.

### Extended adjuvant therapy

At the present time, letrozole is the only AI licensed for use in patients who remain disease-free after 5 years' treatment with tamoxifen. At this point in their treatment, women may be reluctant to continue with adjuvant therapy because of concerns about short- and long-term toxicities, inconvenience, cost and perceived lack of need. Recalling such women to discuss extended adjuvant therapy may, in itself, generate anxiety, and sensitivity is necessary to avoid causing distress. Perhaps more than at any other stage in their treatment history so far, patients will need to balance the potential benefits and risks of continued adjuvant therapy, and decide for themselves whether or not to proceed. Uppermost in many patients' minds will be the potential effects of extended adjuvant therapy on their QoL, particularly in relation to menopausal symptoms.

MA.17 was a large (n=5187) clinical trial in which postmenopausal women who were free from disease after approximately 5 years of tamoxifen therapy were randomized to receive either placebo or letrozole for an additional 5 years [50]. After a median of 2.4 years' follow-up, letrozole was associated with a significantly reduced risk of disease recurrence or contralateral breast cancer, compared with placebo (hazard ratio 0.57; P=0.00008). Additionally, the estimated 4-year disease-free survival rate was significantly higher for those receiving letrozole than for placebo recipients (93% vs. 87%, respectively;  $P \le 0.001$ ).

Thus, extended therapy with letrozole significantly improves disease-free survival and reduces disease recurrence; but are these benefits achieved at the expense of



QoL? To answer this question, the impact of extended letrozole treatment on QoL was studied in 3612 of the women in MA.17, using the 36-item Short Form Health Survey (SF-36) and the Menopause-Specific Quality of Life (MENQOL) questionnaire [44].

The 36 items in the SF-36 are divided into eight domains: physical function, role-physical, bodily pain, general health, vitality, social function, role-emotional and mental health. The results are used to generate two scores, the Physical Component Summary (PCS) and the Mental Component Summary (MCS), changes in which can be used to gauge the impact of an intervention on QoL. The MENQOL questionnaire is designed to assess the severity of symptoms related to the menopause or estrogen deprivation, and is divided into four domains: vasomotor, physical, psychosocial, and sexual. Increases in MENQOL questionnaire scores indicate a worsening of symptoms and/or QoL; in contrast, higher SF-36 scores indicate an improvement in QoL.

In MA.17, letrozole did not adversely affect overall QoL. Although PCS and MCS scores decreased between baseline and 36 months for patients receiving letrozole, scores decreased by a similar amount among patients receiving placebo. With respect to the individual domains of the SF-36, there were statistically significant betweengroup differences in the mean score change versus baseline for 3 of the 8 domains, but the differences were small, and did not occur at all time points (bodily pain at 6 months; physical function at 12 months; and vitality at 6 and 12 months).

MENQOL questionnaire results showed improvement in vasomotor symptoms in both treatment groups from baseline, with no significant difference between the groups at 36 months. Changes from baseline in the physical and psychosocial domains were similar for letrozole and placebo (scores increased in both groups); sexual function did not change in patients receiving placebo, whereas scores decreased significantly among those receiving letrozole (P < 0.0001).

The investigators also conducted a response analysis, with the aim of determining the proportions of patients with improved, stabilized, or worsened QoL on treatment, compared with baseline. Most women in both treatment groups had either improved or stabilized physical and mental functioning (SF-36) during the study, with no statistically significant differences between the groups (Table 2).

In summary, these data suggest that extended adjuvant therapy with letrozole does not affect overall QoL, although there may be small changes in some areas such as sexual functioning; any negative effects need to be weighed against the benefits of therapy in preventing disease recurrence and increasing the probability of disease-free survival.

**Table 2** Results of the response analysis (SF-36; PCS and MCS) in the MA.17 study [44]

Treatment	Placebo (%)	Letrozole (%)	
PCS			
Improved	21	21	
Stabilized	41	39	
Worsened	38	40	
MCS			
Improved	24	23	
Stabilized	43	41	
Worsened	33	36	

MCS, Mental Component Summary; PCS, Physical Component Summary

#### Treatment decision-making in advanced breast cancer

Receiving a diagnosis of metastatic breast cancer is often devastating for patients, as it signals the development of incurable disease. Maintaining QoL is of the utmost importance; the expected toxicities of aggressive treatment dictate that such an approach may be neither appropriate nor desirable, and the care team must take the wishes of the patient and her significant others into account when making treatment decisions. Emotionally, patients will experience fluctuations in mood and significant distress following their diagnosis, and may find it difficult to maintain a sense of dignity and control; they may also feel isolated as a result of their disease. On top of this, disease-related symptoms may compromise patients' QoL, and limit their ability to perform everyday activities.

Soon after diagnosis, physicians should discuss the implications of metastatic disease, taking time to explain the available therapeutic options (which are not limited to cytotoxic chemotherapy, see Table 3), the aims of these options (e.g. symptom control, survival prolongation, maintenance of QoL), and their expected benefits and adverse effects.

Preferences for involvement in decision-making in patients with advanced cancer appear variable, though in general approximately two-thirds of patients would like to have some degree of active participation [51]. A study of decision-making for palliative chemotherapy suggested that a patient's involvement in treatment choice was influenced by the stage of their disease progression. Patients who were offered first-line chemotherapy were more likely to have had a passive role in the decision-making process, despite seeking more information, compared with patients who were offered second-line chemotherapy [52].

Typically, the information needs of patients with breast cancer fall into five categories: (i) the nature of the disease, its natural history and prognosis; (ii) treatment; (iii) diagnostic and investigative tests; (iv) preventive, restorative



Table 3 Current (non-chemotherapeutic) treatment options for metastatic breast cancer

Treatment option	Benefits		
Palliative			
Radiotherapy	↓ Bone pain		
	↓ Neurologic complications from spinal cord compression		
Radioisotopes	↓ Bone pain		
Surgery	↑ Healing of pathologic fracture		
	↓ Neurologic complications from spinal cord compression		
Cementoplasty	↑ Stability		
Analgesia	↓ Bone pain		
Preventive			
Bisphosphonates	↓ Bone pain		
	↓ Incidence of skeletal-related events		
	Potential antitumor activity		

and maintenance physical care; and (v) psychosocial [53]. The first question patients with metastatic breast cancer often have is: 'how long will I live?' Clearly, this is difficult to predict with accuracy, and not all women will die from their cancer; however, it is important to be honest with the patient about the seriousness of their condition. Emphasis should be on maximizing the quality of the remaining time, ensuring that the patient is treated with dignity and respect at all stages, and ensuring that the patient and her significant others are kept fully informed at each decision point as the disease progresses, and are as involved as they wish to be in decision-making at each juncture. Major choices that need to be made include the type of treatment (active versus supportive) and its location (home, hospice or treatment center). It must be remembered, however, that the need for information, and the desire for participation in the decision-making process, varies greatly between patients. The needs and wishes of patients, and of their families, should be respected at all times.

## Conclusion

Treatment decision-making in breast cancer has traditionally been seen as the sole preserve of the medical or clinical oncologist. Reflecting consumer trends in general, cancer patients are becoming ever-more adept at retrieving and assimilating information on diseases and their treatment, and are increasingly likely to expect consultation and active participation in their care. The ability to accommodate this paradigm shift will become an essential part of the provision of services for women with breast cancer in the future.

#### References

- Fallowfield L, Jenkins V (1999) Effective communication skills are the key to good cancer care. Eur J Cancer 35:1592–1597
- Fallowfield L, Lipkin M, Hall A (1998) Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom. J Clin Oncol 16:1961–1968
- Taylor C, Graham J, Potts HW et al (2005) Changes in mental health of UK hospital consultants since the mid-1990s. Lancet 366:742-744
- Fallowfield LJ (1995) Communication skills of oncologists. Trends Exper Med 5:99–103
- Siminoff LA (1992) Improving communication with cancer patients. Oncology 6:83–87
- Fallowfield L, McGurk R, Dixon M (2004) Same pain, less gain: potential patient preferences for adjuvant treatment in premenopausal women with early breast cancer. Eur J Cancer 40: 2403–2410
- Butler L, Bacon M, Carey M, Zee B, Tu D, Bezjak A (2004) Determining the relationship between toxicity and quality of life in an ovarian cancer chemotherapy clinical trial. J Clin Oncol 22:2461–2468
- Fromme EK, Eilers KM, Mori M, Hsieh YC, Beer TM (2004) How accurate is clinician reporting of chemotherapy adverse effects? A comparison with patient-reported symptoms from the Quality-of-Life Questionnaire C30. J Clin Oncol 22(17):3485– 3490
- http://www.imaginis.com/breasthealth/statistics.asp. Cited 30 May 2007
- Ries LAG, Melbert D, Krapcho M et al (2006). SEER Cancer Statistics Review, 1975–2004. National Cancer Institute, Bethesda, MD. Available via: http://seer.cancer.gov/csr/1975\_ 2004. Cited 30 May 2007
- Tracy GE (2004) Breast cancer–the disease many women fear the most. SDJ Med 57(4):148
- Schenck-Gustafsson K (2007) Diagnosis of cardiovascular disease in women. Menopause Int 13:9–22
- 13. Wen KY, Gustafson DH (2004) Needs assessment for cancer patients and their families. Health Qual Life Outcomes 2:11
- Cox A, Jenkins V, Catt S et al (2006) Information needs and experiences: an audit of UK cancer patients. Eur J Oncol Nurs 10:263–272
- Jenkins V, Fallowfield L, Saul J (2001) Information needs of patients with cancer: results from a large study in UK cancer centres. Br J Cancer 84:48–51
- Perry S, Kowalski TL, Chang CH (2007) Quality of life assessment in women with breast cancer: benefits, acceptability and utilization. Health Qual Life Outcomes 5:24–37
- Degner LF, Kristjanson LJ, Bowman D et al (1997) Information need and decisional preferences in women with breast cancer. JAMA 277:1485–1492
- Mandelblatt J, Kreling B, Figeuriedo M, Feng S (2006) What is the impact of shared decision making on treatment and outcomes for older women with breast cancer? J Clin Oncol 24:4908–4913
- Deber RB, Kraetschmer N, Urowitz S, Sharpe N (2007) Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. Health Expect 10:248–258
- Wallberg B, Michelson H, Nystedt M et al (2000) Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. Acta Oncol 39:467–476
- Janz NK, Wren PA, Copeland LA et al (2004) Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. J Clin Oncol 22:3091–3098



- Lantz PM, Janz NK, Fagerlin A et al (2005) Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. Health Serv Res 40: 745–767
- Sabo B, St-Jacques N, Rayson D (2007) The decision-making experience among women diagnosed with stage I and II breast cancer. Breast Cancer Res Treat 102:51–59
- Caldon LJM, Walters SJ, Reed MWR (2007) Changing trends in the decision-making preferences of women with early breast cancer. Br J Surg (in press). doi: 10.1002/bjs.5964
- Beaver K, Booth K (2002) Information needs and decisionmaking preferences: comparing findings for gynecological, breast and colorectal cancer. Eur J Oncol Nursing 11:409–416
- Katz SJ, Hawley ST (2007) From policy to patients and back: surgical decision-making for patients with breast cancer. Health Aff (Millwood) 26:761–769
- 27. Whelan T, Sawka C, Levine M et al (2003) Helping patients make informed choices: a randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. J Natl Cancer Inst 95:581–587
- Keating NL, Guadagnoli E, Landrum MB et al (2002) Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? J Clin Oncol 20:1473–1479
- Fallowfield L (1997) Offering choice of surgical treatment to women with breast cancer. Patient Educ Couns 30(3):209–214
- Fallowfield LJ, Hall A, Maguire P, Baum M, A'Hern RP (1994) Psychological effects of being offered choice of surgery for breast cancer. Br Med J 309:448–454
- Al-Ghazal SK, Fallowfield L, Blamey RW (2000) Comparison of psychological aspects and patient satisfaction following breast conserving surgery, simple mastectomy and breast reconstruction. Eur J Cancer 36:1938–1943
- 32. Al-Ghazal SK, Fallowfield L, Blamey RW (1999) Does cosmetic outcome from treatment of primary breast cancer influence psychosocial morbidity? Eur J Surg Oncol 25:571–573
- Al-Ghazal SK, Sully L, Fallowfield L, Blamey RW (2000) The psychological impact of immediate rather than delayed breast reconstruction. Eur J Surg Oncol 26:17–19
- Atkins L, Fallowfield L (2006) Intentional and non-intentional non-adherence to medication amongst breast cancer patients. Eur J Cancer 42:2271–2276
- Fallowfield L (2005) Acceptance of adjuvant therapy and quality of life issues. Breast 14:612–616
- 36. Peto R, Davies C, on behalf of the ATLAS Collaboration (2007) ATLAS (Adjuvant Tamoxifen, Longer Against Shorter): international randomized trial of 10 versus 5 years of adjuvant tamoxifen among 11500 women—preliminary results. Breast Cancer Res Treat 106 (suppl 1):abstract 48
- Fallowfield L, Fleissig A, Edwards R, West A, Powles TJ, Howell A, Cuzick J (2001) Tamoxifen for the prevention of breast cancer: psychosocial impact on women participating in two randomized controlled trials. J Clin Oncol 19:1885–1892
- Partridge AH, Wang PS, Winer EP, Avorn J (2003) Nonadherence to adjuvant tamoxifen therapy in women with primary breast cancer. J Clin Oncol 21:602–606

- Cox AC, Fallowfield LJ (2007) After going through chemotherapy I can't see another needle. Eur J Oncol Nurs 11:43–48
- 40. Chlebowski RT, Geller ML (2006) Adherence to endocrine therapy for breast cancer. Oncology 71:1-9
- 41. Fellowes D, Fallowfield LJ, Saunders CM, Houghton J (2001) Tolerability of hormone therapies for breast cancer: how informative are documented symptom profiles in medical notes for 'well-tolerated' treatments? Breast Cancer Res Treat 66:73–81
- 42. Cella D, Falowfield L, Barker P et al (2006) Quality of life of postmenopausal women in the ATAC ("Arimidex", tamoxifen, alone or in combination) trial after completion of 5 years' adjuvant treatment for early breast cancer. Breast Cancer Res Treat 100:273–284
- 43. Fallowfield L, Bliss JM, Porter LS et al (2006) Quality of life in the Intergroup Exemestane Study: a randomized trial of exemestane versus continued tamoxifen in postmenopausal women with primary breast cancer. J Clin Oncol 24:910–917
- 44. Whelan TJ, Goss PE, Ingle JN et al (2005) Assessment of quality of life in MA.17: a randomized, placebo-controlled trial of letrozole after 5 years of tamoxifen in postmenopausal women. J Clin Oncol 28:6931–6940
- 45. Trialists' Group ATAC (2002) Anastrozole alone or in combination with tamoxifen versus tamoxifen alone for adjuvant treatment of postmenopausal women with early breast cancer. First results of the ATAC randomized trial. Lancet 359: 2131–2139
- Howell A, Cuzick J, Baum M et al (2005) Results of the ATAC (Arimidex, Tamoxifen, Alone or in Combination) trial after completion of 5 years' adjuvant treatment for breast cancer. Lancet 365:60–62
- Fallowfield L, Cella D, Cuzick J et al (2004) Quality of life of postmenopausal women in the Arimidex, Tamoxifen, Alone or in Combination (ATAC) Adjuvant Breast Cancer Trial. J Clin Oncol 22:4261–4271
- 48. Coombes RC, Kilburn LS, Snowdon CF et al (2007) Survival and safety of exemestane versus tamoxifen after 2–3 years' tamoxifen treatment (Intergroup Exemestane Study): a randomised controlled trial. Lancet 369:559–570
- Wengström Y, Aapro M, Leto di Priolo S, Cannon H, Georgiou V (2007) Patients' knowledge and experience of adjuvant endocrine therapy for early breast cancer: a European study. Breast 16: 462–468
- Goss PE, Ingle JN, Martino S et al (2003) A randomized trial of letrozole in postmenopausal women after five years of tamoxifen therapy for early stage breast cancer. N Engl J Med 349: 1793–1802
- Gaston CM, Mitchell G (2005) Information giving and decisionmaking in patients with advanced cancer: a cancer systematic review. Soc Sci Med 61:2252–2264
- Grunfeld EA, Maher EJ, Browne S et al (2006) Advanced breast cancer patients' perceptions of desicion making for palliative chemotherapy. J Clin Oncol 24:1090–1098
- Graydon J, Galloway S, Palmer-Wickham S et al (1997) Information needs of women during early treatment for breast cancer.
  J Adv Nurs 26:59–64

#### Financial disclosure/conflict of interest statement

The author of this article has no commercial associations (e.g., consultancies, stock ownership, equity interests, patentlicensing arrangements, etc.) that might pose a conflict of interest in connection with the submitted article. All funding sources supporting the work and all institutional or corporate affiliations of the author are acknowledged.

