

## Self-management Strategies Adopted by Breast Cancer Survivors to Improve their Adherence to Tamoxifen

To the Editor:

With increasing use of oral anticancer agents, concerns about adherence to prescribed regimens become an important issue in oncology (1). Adjuvant tamoxifen treatment, which is delivered to women with breast cancer after surgery, chemotherapy and radiotherapy, is a good example. Rates of adherence to tamoxifen have been found to range from 45% to 100%, with adherence gradually decreasing with each passing year in the course of 5 years and most of discontinuations occurring during the first year of follow-up (2). Previous studies have focused mainly on the factors contributing to nonadherence to the treatment. Discontinuation of the treatment was found, for example, to be associated with extremes of age, negative or neutral beliefs about the value of the treatment, and experiencing burdensome side-effects (1,3,4). The aim of the present qualitative patient-focused study was to document how women deal with their drug-taking on a daily basis, and what self-management strategies they adopt to improve their adherence to the treatment in the long run. As far as we know, this issue has not been investigated so far.

In-depth interviews ( $N = 34$ ), 40–60 minutes length, were conducted with women recruited consecutively from the consultations at two regional cancer centers, defined as primary breast cancer patients to whom tamoxifen had been prescribed (average age: 49 range: 35–64). At the time of the interview, 28 women were taking tamoxifen, 2 had discontinued the treatment, and 4 had refused it. The interview covered: onset and history of the disease; women's experience of previous treatments; side-effects experienced; relationships with the clinic and/or staff; women's understanding and expectations of the treatment; their views about their future health; and their medication practices, with

special emphasis on the self-management strategies adopted to remind themselves to take their daily tamoxifen. The interviews were audiotaped and transcribed verbatim. Analysis was based on the constant comparative method. Initial coding frame was generated from the text, and all themes were subsequently examined in the context of each woman's interview, as well as across the whole data set.

Self-management strategies for not forgetting to take the drug were analyzed. Women described how they tried to integrate the treatment into their everyday lives, so that they would take their tablets routinely. This goal was achieved by associating them with a daily activity, or with other daily medications, or by keeping the tablets in specific places. Those who were already taking other medication tended to associate their tamoxifen tablets with their other daily drugs. This finding confirms previous reports that women taking multiple drugs apply their prescriptions more regularly than those taking only tamoxifen tablets (5). The present results also indicate that the routines women adopted with tamoxifen were based upon those previously set up with other "hormonal" treatments, such as oral contraceptives or hormonal replacement therapy. Previous use of the contraceptive pill or hormone replacement therapy therefore tends to improve adherence to tamoxifen. When tamoxifen was their sole medication, the self-management strategies adopted to prevent women from forgetting to take their daily tablet resulted in integrating it into their everyday lives like an ordinary thing, ingesting them just like ordinary food, and keeping the tablets in a specific place just like other everyday goods. This process of appropriation made it possible for women to avoid thinking about their cancer every time they took their tamoxifen. Therefore, with tamoxifen as with other long-term treatments (6), integrating the drug-taking habit into patients' everyday life promotes long-term adherence.

The places where medicines are kept correspond to various modes of perception of these drug-objects and to the importance attached to them (7). Keeping tamoxifen

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in the kitchen, the main social space serves a practical purpose, as seeing them several times a day reminds patients to take them, and also reflects the close relationship felt to exist between food and drugs. Drugs kept in the kitchen are also openly exposed to the view of the patient's partner and the other members of the household therefore signaling the patient's social identity as a person in poor health.

Keeping the tablets in a place associated with the patient's private life, such as bathroom/bedside table was another practical strategy described by the women. Keeping tamoxifen out of sight of the other members of the household may reflect the constant conflict experienced by women between wanting to forget about the disease and the need to reduce the risk of recurrence. Although they are being urged at both medical and societal levels to go on leading normal lives and not to behave as if they are ill, they nevertheless have to take the treatment prescribed. To overcome this "double bind", they sometimes hide one of the stigmas (the tablets) associated with the status of a sick person by masking the social visibility of their treatment (their drug-taking). Our finding that women do not seek much support or participation from their partner or the close family circle—except one, who reported that her husband took an active part in reminding her to take her tablets—with the everyday management of their treatment is also in line with this idea.

Once the habit of taking a pill has been acquired, the gesture seems quite banal and becomes habitual. However, the least incident upsetting the sequence of automatic everyday gestures can lead to the drug being involuntarily overlooked. Drug packages then serves as an essential reminder. Some women kept the tablets in the original packet, on which they noted the days of the week, whereas other women transferred the tablets to pill-boxes, weekly dose-boxes, or special boxes in which they kept only tamoxifen.

Women also described self-management strategies intended to reduce the undesirable treatment side-effects. Many women adapted time of tamoxifen intake to eating. Apart from the fact that they found it helpful to associate taking the tablet with an everyday event, they also felt that taking it at mealtimes would make it easier to "assimilate". For women, the term "assimilate" referred not only to the physical process of drug digestion but also to the symbolic process, whereby the drug becomes identified with ordinary food. Adapting time of tamoxifen intake to sleeping for a better action of the drug was also described. Lastly, two participants

reported that they changed the timing of their drug-taking to coincide with their morning or evening shower in the hope of combating hot flushes. Therefore, women coped better with hot flushes and night sweats by relating their ongoing symptoms to their perceptions of the mode of action or assimilation of drug. In this sense, patients' representations of treatment triggered behavioral response leading to improved self-management of their symptoms.

Altogether these results contribute to fill the lack of knowledge about how cancer survivors manage their treatments outside of the hospital setting. During initial phases of breast cancer care, treatments are traditionally administered at the hospital, and patients have regular contacts with their health care team who provide them with support. As they move from the acute to more chronic level of care, women develop self-management strategies intended at facilitating adherence to the drug. By appropriating the treatment, by integrating the drug into the realm of everyday objects, and by assimilating the constraints inherent to the treatment, they develop drug-taking automatisms which promote long-term continuation of the treatment.

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