# Subjective Experience with Medications of Patients living with Breast Cancer: a **Photovoice**

DOI doi: https://doi.org/10.32635/2176-9745.RBC.2018v64n2.75

Experiência Subjetiva com Medicamentos de Pacientes convivendo com o Câncer de Mama: um Fotovoz Experiencia Subjetiva con Medicamentos de Pacientes conviviendo con el Cáncer de Mama: un Fotovoz

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#### Abstract

Introduction: The subjective experience with medication must be understood and explored in the day-to-day clinical practice. Objective: To understand the subjective experience with the medications of women living with breast cancer. Method: Qualitative study with the theoretical and methodological orientation of the Subjective Experience with Medications proposed by Ramalho de Oliveira & Shoemaker and Photovoice from the perspective of Wang and Burris from a cancer hospital in Minas Gerais between August and November 2017. The sample of three participants was established at the time when the inclusion of new participants did not add anything new to the research and the objectives were achieved. The inclusion criterion was intentional among women accompanied by the Medication Therapy Management services and who accepted to participate in the study. Participants used photographs to portray their experiences with the use of medications. These photographs were discussed and interpreted in photodialogue; these were recorded and transcribed whose data were interpreted by the inductive data analysis. Results: The experience with the use of medications was defined in four thematic units: 1. Chemotherapy and the idea of hair loss; 2. Implications of subjective experience with medications in family and work relationships; 3. Valuing the use of endocrine therapy: adherence to treatment. 4. The body's response to chemotherapy reactions! Conclusion: The themes of the study validated the importance of Pharmaceutical Care operationalized by the Medication Therapy Management in the context of women with breast cancer.

Key words: Drug Effects; Breast Neoplasms; Drug Therapy; Photography.

### Resumo

Introdução: A experiência subjetiva com medicamentos deve ser compreendida e explorada no dia a dia da prática clínica. Objetivo: Compreender a experiência subjetiva com medicamentos de mulheres convivendo com o câncer de mama. Método: Estudo qualitativo com orientação teórico-metodológica da Experiência Subjetiva com Medicamentos, proposta por Ramalho de Oliveira & Shoemaker, e do fotovoz na perspectiva de Wang & Burris, de um hospital oncológico em Minas Gerais, entre agosto e novembro de 2017. A amostra com três participantes foi estabelecida no momento em que a inclusão de novos participantes não acrescentava nada de novo à pesquisa e os objetivos foram alcançados. O critério de inclusão foi intencional entre mulheres acompanhadas pelo serviço de Gerenciamento da Terapia Medicamentosa e que aceitaram participar da pesquisa. As participantes utilizaram fotografias para retratar as suas experiências com o uso de medicamentos. Essas fotografias foram discutidas e interpretadas nos fotodiálogos, que foram gravados e transcritos, e cujos dados foram interpretados pela análise indutiva dos dados. Resultados: A experiência com o uso de medicamentos foi definida em quatro unidades temáticas: 1. Quimioterapia e a ideia de perda de cabelo; 2. Implicações da experiência subjetiva com medicamentos nas relações familiares e de trabalho; 3. Valorizando o uso da terapia endócrina: adesão ao tratamento. 4. Resposta do corpo às reações da quimioterapia! Conclusão: Os temas do estudo validaram a importância da atenção farmacêutica operacionalizada pelo gerenciamento da terapia medicamentosa no contexto da mulher com câncer de mama.

Palavras-chave: Efeitos dos Fármacos; Neoplasias da Mama; Tratamento Farmacológico; Fotografia.

### Resumen

Introducción: La experiencia subjetiva con medicamentos debe ser comprendida y explotada en el día a día de la práctica clínica. Objetivo: Comprender la experiencia subjetiva con medicamentos de mujeres conviviendo con el cáncer de mama. Método: Estudio cualitativo, con orientación teórico-metodológica de la Experiencia Subjetiva con Medicamentos propuesta por Ramalho de Oliveira & Shoemaker y del Fotovoz en la perspectiva de Wang y Burris de un hospital oncológico en Minas Gerais entre agosto y noviembre de 2017. La muestra de tres participantes se estableció en el momento en que la inclusión de nuevos participantes no añadía nada nuevo a la investigación y los objetivos se alcanzaron. El criterio de inclusión fue intencional entre mujeres acompañadas por el servicio de Gestión de la Terapia Medicamentosa y que aceptaron participar en la investigación. Las participantes utilizaron fotografías para retratar sus experiencias con el uso de medicamentos. Estas fotografías fueron discutidas e interpretadas en los fotodiálogos; estos fueron grabados y transcritos cuyos datos fueron interpretados por el análisis inductivo de los datos. Resultados: La experiencia con el uso de medicamentos fue definida en cuatro unidades temáticas: 1. Quimioterapia y la idea de pérdida de cabello; 2. Implicaciones de la experiencia subjetiva con medicamentos en las relaciones familiares y de trabajo; 3. Valorizando el uso de la terapia endocrina: adhesión al tratamiento. 4. Respuesta del cuerpo a las reacciones de la quimioterapia! Conclusión: Los temas del estudio validaron la importancia de la Atención Farmacéutica operacionalizada por la Gestión Gestión Integral de la Farmacoterapia en el contexto de la mujer con cáncer de mama.

Palabras clave: Efectos de los Fármacos; Neoplasias de Mama; Tratamiento Farmacológico; Fotografía.

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### INTRODUCTION

Breast cancer treatment consists of various stages and modalities, including surgery, radiotherapy, and chemotherapy<sup>1</sup>, targeted therapies, immunobiologicals<sup>2</sup>, and hormone therapy as prevention against relapses1. Hormone therapy has a well-documented positive impact, since it provides overall and progressionfree survival of 15 to 20 years<sup>3</sup>. However, patients are susceptible to drug-related problems (DRPs) that can compromise treatment efficacy and pose risks to their health, leading to morbidity and mortality related to their pharmacotherapy<sup>4,5,6</sup>. This a major social problem that requires permanent attention<sup>6</sup>.

The patients' encounter with chronic-use medication starts their subjective experience with the use of medication. This encounter entails a range of meanings for the patient, many of which are established before the actual encounter occurs<sup>8,9</sup>. The experiences of family and friends, the woman's own experiences prior to her cancer treatment, and the meaning society assigns to various types of drug therapy comprise a mosaic of concepts and preconceived ideas that influence the patient at the moment of deciding whether or not to use the prescribed treatment, or even whether to believe in the expected result when the treatment is administered in the hospital setting. In addition to these individual and social meanings assigned to medication, each drug therapy has intrinsic characteristics that lead to real changes in the patient's body. However, these transformations in the individual's body and behavior are perceived in certain ways and become part of the subjective experience. Individuals on chronic medication sometimes question the need for it. Over time and with experience, the individual may exercise control over the medication, altering the dosage or even suspending its use<sup>10</sup>.

Each patient's experience is unique. Even though the treatment may be very similar, not all patients necessarily assign the same meanings and cope with the adverse reactions to the medication in the same way. Cultural, social, and psychological aspects are determinant for the process of coping with the diagnosis, living with the treatment, and ensuring the appropriate care for achieving cure<sup>8,9,10</sup>. Understanding patients' subjective experience with their medication informs their degree of involvement in the treatment process and provides input for decisions by health professionals involved in the drug therapy, including physicians, nurses, and pharmacists 10,11.

Shoemaker and Ramalho de Oliveira<sup>8,9</sup>, researchers who developed the concept of subjective experience with the use of medication in collaboration with other researchers 8-11, demonstrated the importance of incorporating research on this concept as an approach for the identification, prevention, and solution of DRPs. In this process, health professionals should share their decisions with the patient based on the best available scientific evidence and in balance with each patient's particular context<sup>10,11</sup>. Together with the patient, the pharmacist can solve problems related to the treatment's indication, effectiveness, and safety, as well as adherence to it. The latter is a source of major concern for health professionals, but to encourage treatment adherence without first knowing the patient's subjective experience with the medication can be interpreted as a risky professional approach. For example, the patient may fail to adhere to a treatment which is not safe or is not even the most appropriate for that individual case. Considering the patients' real experiences involves a set of strategies<sup>8-11</sup> used by providers of Drug Therapy Management (DTM) to break with what has been called the "pharmacist's take-it-for-granted attitude", focusing exclusively on pharmacological knowledge and the monitoring of proper use of the prescribed drugs, without critically assessing the daily use of the medication and the patient's real-life experiences with it. Capturing the patient's subjectivity in the use of medication means stepping down from the "pharmacological pedestal" and valuing the patient's own experiences. This movement favors the openness needed for person-centered practice and allows the patient to assess the treatment 12, and based on this analysis, to deliberate on how to use it. As Cipolle<sup>13</sup> said: "Drugs don't have doses; people have doses" (p.47). This quote shows that despite validation of efficacy and safety in controlled clinical trials, the drugs' effects are also assessed by patients according to their reactions to them<sup>8-13</sup>. These experiences are submerged in the patient's words, which requires retrieving them during the patient-provider encounter<sup>14</sup>. They can be found in the patient's narratives and are usually not revealed in a single encounter, but are unveiled during a series of encounters, emerging more spontaneously when the therapeutic bond has been established between pharmacist and patient<sup>11,12</sup>. Given the epidemiological relevance of breast cancer in Brazil<sup>7</sup>, the scarcity of studies that explore breast cancer patients' subjective experiences with medication, and the need for interventions to reduce drug-related morbidity and mortality, this study aimed to shed light on the subjective experience with medication for women living with breast cancer.

### **METHOD**

This was a qualitative study using as the theoretical and methodological references the "subjective experience with medications" method proposed by Ramalho de Oliveira and Shoemaker<sup>8,9</sup> and the photovoice technique proposed by Wang and Burris<sup>15</sup>. In photovoice, individuals discuss photographs which they themselves have produced on their experiences with a given phenomenon and as members of a group. The photographs provide the possibility of elaborating photo dialogues with the researchers15.

Participants in the current study used photographs to portray their experiences with the use of medication in breast cancer treatment. The study was conducted in the oncology department of a tertiary referral hospital in the Triângulo Mineiro region of Minas Gerais State, Brazil, from August to November 2017. Three women participated in the study. Their data allowed meeting the study's objectives, and it was thus unnecessary to include more participants<sup>15</sup>. The inclusion criteria were established intentionally and included: patients in treatment for breast cancer, followed at that hospital's DTM service, and who agreed to participate in the study. The DTM service adopts the theoretical, philosophical, and methodological framework of pharmaceutical care practice<sup>12,13</sup>.

This professional practice was proposed and developed to meet the demand to reduce the morbidity and mortality associated with the use of medications<sup>16</sup>. The philosophy of this practice orients attitudes and values for the pharmacist to assume shared responsibility for the patient's pharmacotherapeutic needs in a holistic and personcentered way. This professional's main role in caring for the patient is to identify, prevent, and solve DRPs. For this purpose, the pharmacist assesses whether all the drugs used by the patient are actually indicated, effective, and safe, and then encourages the patient to adhere to the respective products. By following these stages, the pharmacist determines whether the patient presents any DRP, prepares plans to solve the problem in collaboration with the patient and healthcare team, and subsequently assesses the results of his or her recommendations<sup>6,11,12,13,16</sup>.

The data collection was organized via photovoice, photo dialogues, and participant observation with annotations in field diaries. The data collection techniques, photovoice, and photo dialogues were presented and explained to participants during a training meeting in the preparatory phase, along with an explanation of the study's objectives and training on the ethical principles involved in a study with photographs<sup>17</sup>. The action phase involved the photo dialogues, a technique that employs a "guiding topic" script to promote a critical dialogue on the photographs chosen by participants<sup>17</sup>. The script for this study was elaborated according to preestablished criteria and based on themes identified through a systematic review and meta-synthesis of qualitative studies<sup>18</sup>, and the

following topics were used: 1. Tell me what you see in this photograph. 2. Tell me what each object or person in this photograph means. 3. Is there some relationship between this photograph and your chemotherapy? and with your medication? 4. Please cite the positive and negative points in your chemotherapy. 5. Tell me a little more about the side effects that you experienced during your treatment. In this approach, the photographs taken by participants were used as the point of departure for the dialogue, interpretation, and reflection on the phenomenon.

The photo dialogues were conducted with each participant as they showed the photographs to the researchers. The dialogues were thus held at different moments in the study, in a place chosen by the participant to guarantee her privacy.

The encounters in which the photo dialogues took place lasted an average of 64 minutes, and participants showed 11 photographs for analysis. The researchers also recorded their impressions in field diaries. The photo dialogues were recorded with a smartphone and transcribed in full, cyclically and continuously, and interpreted with inductive thematic data analysis as follows: (a) familiarization with the raw data by listening to the recordings, verification of the transcriptions' precision, underlining key ideas and recurrent themes; the data transcribed from the recorded photo dialogues were read several times and coded lineby-line, creating thematic units that emerged from the text. This coding was done by comparing the data within the same photo dialogue, between the photo dialogues, and between the field diaries and the photo dialogues; (b) elaboration of analytical categories by breaking the description down into structural elements of the speech acts; and (c) interpretation of the themes attributed by the participants<sup>19</sup>.

As the analyses progressed, the initial codes were reexamined and renamed to adjust them to the data from the photo dialogues and allow a higher level of abstraction. The analysis initially identified 14 themes that were later rearranged in four major themes that will be presented in the results and discussed: 1. chemotherapy and the idea of hair loss; 2. implications of the subjective experience with medication for family and workplace relations; 3. valuing the use of endocrine therapy; treatment adherence; and 4. the body's response to reactions to chemotherapy.

The article is intentionally refraining from showing the participants' photographs, as agreed in the free and informed consent form. The study was approved by the Institutional Review Board of the Federal University of Uberlândia under protocol CAAE: 64779716.4.0000.5152. In order to maintain confidentiality, participants chose their own pseudonyms, which were used throughout the study and article.

### **RESULTS AND DISCUSSION**

The study included three participants, whose sociodemographic characteristics are shown in Table 1. Their experience with the use of medication was a dynamic process, permeated by fear, worries, and frightening ideas, followed by a search for adaptation, family support, beliefs, and equilibrium. The introduction of drug treatment in the person's life elicits feelings and issues even before the treatment itself happens<sup>8-10</sup>. When these drugs are chemotherapy, patients experience feelings that are typical of the subjective experience with medication. Hair loss (alopecia) is the experience most feared by women with breast cancer<sup>20</sup>. Hair loss usually occurs one to two weeks after the start of chemotherapy and is due to the lack of production or thinning of hair caused by the abrupt interruption of mitotic activity in the hair matrix, leading to weakening of the hair shaft and resulting in hair loss when combing, brushing, shampooing, or even smoothing one's hair. Hair loss peaks about one to two months after the start of chemotherapy, and repeated cycles can lead to total alopecia<sup>20</sup>.

### 1. CHEMOTHERAPY AND THE IDEA OF HAIR LOSS

The first photograph shows several scribbles, balls, and diamonds drawn on paper by a physician. The drawings depict the diagnosis, the moment in which the physician explained the disease staging with the presence of sentinel lymph nodes, and information on the start of chemotherapy. The participant reported that discussing chemotherapy as a treatment option was extremely frightening for her. She did not understand clearly what was about to happen. This participant's photo dialogue included the following quote:

> The photo reminds me a lot of that. What was I going to do with chemotherapy?! My hair was going to fall out, and all those symptoms you see in others, or that you hear about, and that really scared me! I was desperate, already imagining myself with my

hair falling out! All weak! Or very thin, or I don't know what all! (Anna)

Another participant also emphasized the alopecia:

I was going to take the strongest [chemotherapy]. They told me my hair was going to fall out. It was the red medication. That really scared me! And my eyebrows fell out, and my eyelashes, too. Later I took the white medication, too. It was four reds and four whites! (Patricia)

Doxorubicin, part of the drug therapy protocol used by participants in this study, is known to patients as the "red" chemotherapy, and all the patients experienced this adverse reaction. The participant's reference to "white" chemotherapy is paclitaxel. Although alopecia is not considered a clinically important event, it affects the woman's body image, causes suffering, alters interpersonal relations and social life, and can lead to depression and decreased immunity. Hair is an intrinsic symbol of selfesteem for women. Although patients are aware that alopecia can occur after the start of chemotherapy, since the healthcare team has prepared them for it, they refer to the strategies they have used to disguise or hide the hair loss, citing accessories such as headscarves, wigs, and caps. The choice was related to the type of access and the woman's adaptation, and their reports showed that their use of such accessories was necessary to hide the alopecia from society and family. One participant reported:

> The hair loss, when it happened, my hair started falling out for a week more or less, falling, falling, and I thought all that was terrible. I went and had my hair cut right away, really short. And it didn't look right, because it was really thin, and it started falling out in front first, and it looked really ugly! I said, 'I'm going to shave it right away, so I don't have to look like that.' So, I had my head shaved. When the day came for the second chemo, I was already wearing a headscarf! (Marcia)

Table 1. Patients' sociodemographic profile and clinical characteristics (N=3)

	Patricia	Marcia	Ana
Age	65 years	46 years	50 years
Schooling	Secondary	Secondary	University
Marital status	Married	Divorced	Widow
Occupation	Housewife	Administrative Assistant	Administrator
Surgery	Mastectomy	Quadrantectomy	Quadrantectomy
Radiotherapy	No	Yes	Yes
Chemotherapy	ACTH	ACTH	ACT
Hormone therapy	Exemestane	No	Tamoxifen

ACTH = A: Doxorubicin C: Cyclophosphamide T: Taxol\*ou Taxotere\* /Paclitaxel ou Docetaxel H: Herceptin\*/Trastuzumab

## Patricia continues her photo dialogue:

I didn't have the courage to shave my head, no way! I cut it really short, but I wasn't about to shave it! I felt bad just thinking of the hair clippers shaving my head, and to this day I still don't feel the spirit for it, understand? So, today, I don't worry about my hair, and this makes me a little uptight, because I used to love my hair! But I got used to it little by little, because the important thing is to live! In this photo here, I was in treatment, and the wig was a gift from my brother [a hairdresser], and it even looked like my own hair. My hair was straight, and I had dyed it blonde. (Patricia)

Another photo shows a relaxed moment with the patient among family and friends. She was in chemotherapy and wearing a wig. Anna reported that she needed a shield to hide her hair loss.

> The hair loss was hard, you know why? Because it's not just the hair loss itself. It's vanity! We all have our vanity, and losing your hair, eyebrows, and eyelashes, you know? You look at yourself in the mirror, and it shows you have that disease! It really messes with you! That's really hard! It really messes with your vanity! With the exposure and self-esteem, the wig was a shield for me. (Anna)

Hair loss was the subjective experience with chemotherapy that women feared the most. Although it is a debilitating experience, the results after this phase offer prospects of cure from the tumor and the patient's recovery. Patients experience mixed feelings. Although they feared alopecia, affecting their self-esteem and causing feelings of anxiety, Anna and Patricia acknowledged that the most important thing was to achieve their cure and continue living.

## 2. IMPLICATIONS OF SUBJECTIVE EXPERIENCE WITH MEDICATION FOR FAMILY AND WORKPLACE RELATIONS

When they referred to family relations, women in different social contexts expressed their meanings related to the family, such as: their need for the family's presence, concern for family members, and gratitude for their love and affection, considered determinants for performance during chemotherapy.

> When they told me that I had to have chemo, I kept thinking to myself about what kind of image I would show to my daughter, because it's sad, you know, to see your mother weak like that. (Anna)

> The love you receive from your family is very gratifying. This kind of love is different. You even

forget that you're nauseous, that you're bald. It's very important, you know, for your recovery. I was treated like a queen. (Patricia)

Family support plays a fundamental role for breast cancer patients coping with chemotherapy. A woman who enjoys support from her loved ones is able to turn this love into strength for her struggle. Meanwhile, women that lack this support report that when they seek other resources, it is impossible to fill that gap<sup>21</sup>. In light of this importance, the healthcare team should include the family in the woman's process of care. Such family participation is important to be able to offer both emotional and practical support, for everyone to be strengthened emotionally and psychologically, and to be informed as to the patient's needs22.

On the topic of work, study participants referred to their frustration. Several conditions limited their work activities, for example, their appearance and the lack of disposition to perform their work activities.

> I was selling make-up. Mary Kay! Selling beauty products! Can you imagine that? (Anna)

### And another participant:

I'm a sales representative! I don't have the appearance to be a good sales person any more. If I take this 'headscarf' off, I only have a few strands of hair. I used to make good sales, but now I can't attract people, and I don't sell anything! Because there's this fear, you know? People don't understand. A few people approach you, but I suppose it's out of pity. (Patricia)

A study with women participating in a support group also identified an intense fear of rejection by the husband or boyfriend, children, family, and friends<sup>23</sup>. Participants also reflected on the limitations for routine activities at home and at work.

> I used to work hard. I would get off work at six or seven PM and arrive home and fix dinner to be able to get up early the next day. And I was happy like that. I never felt tired. I had it all covered! But I don't today. I wish I did, so I feel this huge frustration! (Patricia)

### Another participant added:

I do everything at home, but I feel tired in my legs. I have to stop and lie down. I feel tired when I iron clothes, and I have to stop. Working away from home can't be like that, because they don't wait for you.

You can't stop, because nobody would understand! You can't tell others about your problem, because it raises suspicion. You have to look healthy, always smiling. It's not easy! (Marcia)

The fatigue caused by chemotherapy is also present in the subjective experience with medication. It is defined as tiredness, malaise, apathy, and the inability to perform routine activities, whether at home or at work. It persists for a long time after the end of cancer treatment and occurs in 80% of patients that receive chemotherapy and is sometimes prolonged during hormone therapy<sup>24</sup>. Based on the evidence, the causes of fatigue include metabolic and immune system disorders and increased levels of tumor necrosis factor alpha (TNF- $\alpha$ )<sup>25</sup>. The women in this study defined their fatigue as persistent discomfort, especially physical and emotional tiredness and limitations. These reports resemble those of other studies in oncology: the fatigue is considered a subjective and persistent feeling of tiredness, related to the chemotherapy, prone to affecting work activities. Patients, describe it as a different kind of tiredness from that of work or other activities they have experienced<sup>24,25</sup>.

## 3. VALUING THE USE OF ENDOCRINE THERAPY: TREATMENT **ADHFRENCE**

There is a major concern among healthcare professionals regarding adherence to endocrine therapy in breast cancer patients. Several quantitative and qualitative studies have reported low adherence<sup>26,27,28</sup>. Participants in one study emphasized the burden of adverse reactions<sup>27</sup>. A previous study identified three different behaviors regarding treatment adherence in women with breast cancer. Some women understood the need for the medication to avoid relapse and attributed the possibility of cure to it, and they showed good adherence and persistence. Women who understood the need for the treatment but who struggled with adverse reactions were identified as ambivalent and tended to abandon the medication or alter the dosage. Women who were unable to interpret the treatment as necessary did not use the medication, resulting in low treatment responses<sup>28</sup>.

One patient in the current study assigned a special connotation to tamoxifen, treating it as her "friend", where someone's friend is somebody (or something) who can help you, who you can count on, in whom you can confide, or who represents something good (affection, love). This patient adhered regularly to her hormone therapy.

> I think that as I matured throughout the process and with help from the entire service, especially the

pharmacist, during the chemo, during everything, I was calmer. And when I'm about to take the medication, I joke, "Be my friend! Not my enemy!" [laughter]. So, I haven't had any problems. (Anna)

Another participant assigned a sense of "protection" to exemestane:

> I understood here at the follow-up [with DTM] that I had to take [exemestane] to fight off the cancer, and the cancer hasn't come back so far. Why hasn't it come back? Because of this medication, which I can't forget to take even one day. (Patricia)

The participant was attributing her cure and the prevention of relapses to the medication. When women receive support from health services with information on their medication and potential adverse reactions, as well as how to manage them, valuing their subjective experience with the drugs, the treatment tends to be continuous and results in better adherence.

### 4. THE BODY'S RESPONSE TO REACTIONS TO CHEMOTHERAPY

I still have no hair. And by now the chemotherapy phase is over. Now it's hormone therapy. So, today I don't worry about my hair. My hair made me kind of anxious, because I liked my hair. (Patricia)

Patricia is referring to the alopecia that began during the "red" chemotherapy and persisted with the use of exemestane, when she failed to recover her hair. Women generally recover their hair after chemotherapy, although some report that the regrowth hair is different, with curly or gray hair. Lack of regrowth is uncommon. The extension of treatment with exemestane is one potential cause of persistent alopecia. The drug accounts for a significant percentage of hair loss in women<sup>29</sup>. Meanwhile, the fact that the hair was not cut at the beginning of alopecia may have been a determining factor, since the hair follicles were not recovered to produce new hairs.

Another participant reported the impact of her experience with the treatment:

> I took this photo to show what happened as a result of the chemotherapy. Look what it did to my body! (Marcia)

The patient showed a photo with dark spots on her legs from the lesions that appeared during her treatment with paclitaxel. She developed adverse reactions typical of hand-foot syndrome. And she reported:

What hurt me the most was this allergy I got on my legs, from the chemo. It itched so much! When it started itching, I'd go crazy! I scratched with my fingernails and thought to myself, this is going to hurt me. It was over my whole body. I was going crazy, looking for help! And the nurse asked, 'Where did you get that allergy? I'll refer you to the pharmacist. She prepares an ointment or a cream.' I said, 'Wow! So, give me that. That's great.' And I was confident and thought to myself, now I'm going to get better. And I did, it helped me a lot! The itching stopped, and I loved the treatment! (Marcia)

Hand-foot syndrome is a toxic skin reaction that can affect a cancer patient's quality of life and cause chronic discomfort and limitations in daily activities<sup>30</sup>. It results from the high vulnerability of skin tissues to the effect of antineoplastic drugs and includes erythema, pruritis, edema, pain, and scaling on the hands, feet, and occasionally other parts of the body after the administration of certain cytotoxic drugs. It can begin in the first 24 hours of chemotherapy with drugs from the taxane class (such as paclitaxel), or up to ten months after the first infusion of such chemotherapy<sup>30</sup>.

In a qualitative study, it is not possible to determine in advance the amount of data that will be necessary and sufficient to meet the proposed objectives. The small number of participants in this study may lead the reader to consider the sample size a study limitation. This number of participants is not common in photovoice, but the fact that the objectives had been met led to the definition of this number and the interruption of the data collection. The necessary rigor was maintained throughout all the study's phases. In addition, in qualitative research, the choice of participants is intentional. It involves a purposeful search for individuals that are experiencing the target problem. The number of participants is thus small when compared to quantitative studies, since the goal is not the ultimate quantity of elements and expansion of information, but the data's representativeness, quality, and depth. In this study we did not seek generalization of the results, but their transferability to similar scenarios and contexts. The results' assessment is thus up to the article's readers. This is one of criteria for the study's rigor that is inherent to the photovoice methodology.

### CONCLUSION

Photovoice offered participants an opportunity for reflection on (and expression of) their daily realities and gave a voice to their experiences with medication during breast cancer treatment, including the chemotherapy and hormone therapy phases. The photographs oriented

a critical discussion on their experience with the context and served as a "window" on each participant's world. The situations portrayed in the photographs was consistent with the photo dialogues.

This study identified photographs whose photo dialogues between researchers and participants allowed understanding the potential of the experiences with medication for participants living with breast cancer. The themes provided important information that further validate the use of this concept in pharmaceutical care, operationalized by the drug therapy management service in relation to breast cancer treatment. We feel that the study's results are applicable to the practice of pharmacists and other healthcare professionals, valuing interdisciplinary care. The results revealed the need to better explore DTM in adherence to hormone therapy and in the care of adverse reactions, as cited by a participant in the case of hand-foot syndrome, which has received relatively little attention in adjuvant treatment of breast cancer. The results also highlight the importance of collaborative and interdisciplinary work. All these issues call for further studies involving other healthcare professionals in the chain of care.

### **CONFLICT OF INTEREST:**

None.

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Recebido em 21/6/2018 Aprovado em 27/8/2018