

## Cancer in times of COVID-19: repercussions in the lives of women undergoing oncological treatment

*Câncer em tempos de COVID-19: repercussões na vida de mulheres em tratamento oncológico*

*Cáncer en los tiempos de COVID-19: repercusiones en la vida de las mujeres sometidas a tratamiento oncológico*

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### ABSTRACT

**Objective:** to understand the experience of coping with COVID-19, as perceived by women undergoing cancer treatment. **Method:** qualitative, participatory action research based on the three phases of Paulo Freire's Research Itinerary: Thematic Investigation; Coding and Decoding; and Critical Unveiling. A Culture Circle was held online with 12 women from different places in Brazil undergoing breast cancer treatment. **Results:** in the virtual Culture Circle, they discussed two themes: challenges in coping with cancer and COVID-19; and learning generated in that experience, with a view to rebirth from their own ashes. **Final considerations:** the pandemic has prompted thinking about living. Accordingly, women undergoing cancer treatment and also under social restrictions were able to express their feelings, and in discovering and rediscovering weaknesses and strengths, to resignify themselves and to grow in a society that can and should deploy strategies for health promotion.

**Descriptors:** Medical Oncology; Breast Neoplasms; Quarantine; Coronavirus Infections.

### RESUMO

**Objetivo:** compreender a vivência do enfrentamento e repercussões da COVID-19, na percepção de mulheres em tratamento oncológico. **Método:** estudo qualitativo, do tipo ação-participante, fundamentado no Itinerário de Pesquisa de Paulo Freire, que possui três fases: Investigação Temática; Codificação e Descodificação; Desvelamento Crítico. Foi realizado Círculo de Cultura virtual, com a participação de 12 mulheres em tratamento do câncer de mama, de diferentes localidades do Brasil.

**Resultados:** no Círculo de Cultura virtual discutiram dois temas: desafios no enfrentamento do câncer e da COVID-19; aprendizados gerados nessa vivência, considerando um renascimento das próprias cinzas. **Considerações finais:** o momento pandêmico tem instigado reflexões sobre o viver. Assim, as mulheres em tratamento oncológico e também em restrição social puderam expressar seus sentimentos, descobrindo e redescobrando fragilidades e fortalezas para ressignificar e crescer como seres, em uma sociedade, que pode e deve articular estratégias para promoção da saúde.

**Descritores:** Oncologia; Neoplasias da Mama; Quarentena; Infecções por Coronavírus.

### RESUMEN

**Objetivo:** comprender la experiencia de afrontamiento del COVID-19, según la perciben las mujeres en tratamiento oncológico.

**Método:** investigación-acción cualitativa y participativa basada en las tres fases del Itinerario de Investigación de Paulo Freire: Investigación Temática; Codificación y decodificación; y revelación crítica. Se realizó un Círculo Cultural en línea con 12 mujeres de diferentes lugares de Brasil sometidas a tratamiento contra el cáncer de mama. **Resultados:** en el Círculo de Cultura virtual se discutieron dos temas: desafíos en el afrontamiento del cáncer y COVID-19; y el aprendizaje generado en esa experiencia, con miras a renacer de sus propias cenizas. **Consideraciones finales:** la pandemia ha llevado a pensar en vivir. En consecuencia, las mujeres en tratamiento oncológico y también bajo restricciones sociales pudieron expresar sus sentimientos, y al descubrir y redescubrir debilidades y fortalezas, resignificarse y crecer en una sociedad que puede y debe desplegar estrategias de promoción de la salud.

**Descritores:** Oncología Médica; Neoplasias de la Mama; Cuarentena; Infecciones por Coronavírus.

## INTRODUCTION

In December 2019, recurrent cases of severe pneumonia were identified in the Chinese population, which alerted authorities to the possible spread of a microorganism identified as the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), the virus causing the Coronavirus Disease 2019 (COVID-19). It was transmitted communally with worldwide dissemination, thus reaching the status of a pandemic<sup>1</sup>. As a result, the abrupt population contagion required that health authorities employ measures to control its spread, namely isolation, quarantine, social distancing and community containment<sup>2</sup>.

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At first, according to the epidemiological survey of individuals infected with SARS-CoV-2, it was found that the majority of cases occurred to elderly persons with comorbidities or to health care workers<sup>3</sup>. Thus, individuals undergoing cancer treatment add to the risk group, as the natural history of neoplastic disease and its treatments tend to weaken cancer patients' immune response, making them susceptible to respiratory infections<sup>4</sup>. Therefore, the maintenance of measures against the spread of COVID-19 is reinforced to this group. In this context, the following question emerged: how is coping with and the repercussions of COVID-19 experienced, according to the perception of women undergoing cancer treatment?

It is important to emphasize that falling ill with cancer has repercussions in several dimensions of daily life, such as work, social and marital relationships, body image, sexuality and leisure. In times of a pandemic, it can be said that a cancer patient limits his/her relationship with the social world a little more than he/she has already experienced. In a systematic review of the repercussions of cancer among health professionals, patients and family members, the "communication" element was evidenced for facilitating the translation of information between people and reducing various barriers created during the illness process<sup>5</sup>, such as the social barrier.

In order to overcome the communication barrier and the physical distancing necessary to prevent the spread of SARS-CoV-2, the use of communication technologies can be considered, such as the use of software that makes video calls, allowing an affectionate approach in social restriction<sup>6</sup>. In this scenario, experienced researchers in the development and mediation of the Culture Circle, proposed by Paulo Freire, opted to perform it in a virtual fashion with women undergoing cancer treatment. Thus, this study emerged with the objective of understanding the experience of coping with and the repercussions of COVID-19, according to the perceptions of women undergoing cancer treatment.

The study is justified by the fact that, in the face of COVID-19, this is a vulnerable group of individuals that require attentive care from nurses and other health care professionals. Moreover, through the study, it is possible to establish connections and overcome boundaries in the fight against fear, anxiety and other repercussions that influence the health-disease process of women experiencing cancer and the current pandemic moment.

## **THEORETICAL FRAMEWORK**

The study was based on Paulo Freire's theoretical approach, which seeks to transform subjects by creating relations founded on care and affection through ethical and humanized relationships, with respect for human beings, their values and beliefs by means of dialogical praxis. In addition, it is understood that every subject has his/her own knowledge and that it should be taken into account in order to establish loving connections and the exchange of experiences so as to empower such subjects by encouraging autonomy in search of freedom for those who are oppressed<sup>7</sup>. Thus, possibilities are created for health professionals and researchers to establish a relationship with women coping with cancer and COVID-19.

## **METHOD**

This is a qualitative, participatory-action study<sup>8</sup>, carried out by means of the Culture Circle, in which Paulo Freire's Research Itinerary was traveled. The trajectory of the research itinerary systemically unfolds in three phases that are interconnected: 1) Thematic Investigation: it consists of the initial dialogue that leads to the identification of the generating themes, thus allowing the contradictions imbricated with human life in society, in the dynamics of each and every reality, to be revealed; 2) Encoding and Decoding: critical reflection on the themes using codes. Such themes are characterized by being cognizable objects and will later allow the dialectical analysis of the situation experienced, with a view to overcoming limit situations; 3) Critical Unveiling: when participants allow themselves to remove the veil that limits them in order to view the analysis and veracity of facts, unveiling the inside of their ideas so as to leverage transformation through knowledge<sup>7</sup>.

However, given the situation of social restriction imposed by COVID-19, the Culture Circle was conducted in a virtual fashion, thus being somewhat innovative. To that end, the Zoom® application was used by means of electronic devices (a computer or a cell phone), which enabled interactive and simultaneous participation, although the participants were geographically distant.

In order to organize the Virtual Culture Circle (VCC), three women undergoing cancer treatment at a public hospital in Santa Catarina were initially invited. Through the Snowball<sup>9</sup> sampling method, these women invited other friends, who were also going through the cancer process, to compose the Circle, thus leading to the total participation of 12 women from different locations in Brazil. As inclusion criteria, women undergoing breast cancer treatment (radiotherapy and chemotherapy) and who were socially restricted during the VCC period were considered. Regarding the exclusion criteria, women under 18 years of age and without access to the internet or electronic devices at the time of VCC were considered.

VCC was developed in a single meeting held in June 2020. It lasted approximately two and a half hours and was mediated by an experienced nurse in conducting Culture Circles, namely the first author of this paper, who used a field diary as support for information recording.

To start VCC, an analogy was made concerning the use of a headscarf, an object that has been naturalized by the participants as a symbol of their resistance, since, just as the headscarf needs fabric and sewing for its making as well as wisdom for its tying up, so that its use can be efficient, it is understood that nursing care also needs to be fixed on the particularities of the reflections of those who experience the challenges from cancer and the constant threats imposed by COVID-19. From this perspective, the Research Itinerary was conducted with lightness, creativity, dialogicity and depth in the stages that support it, which were interconnected during VCC, as exemplified in Figure 1.



**FIGURE 1:** Freirean Itinerary: analogy to the use of the scarf. Brazil, 2020.  
Source: Adapted by the authors from <https://www.fitarosa.com.br/lenco-quimioterapia-beanie-pink>

The Thematic Investigation was woven, thread by thread, with all the participants. To this end, the mediator presented a headscarf and argued that it was necessary to carefully investigate its fabric in order to obtain information on its durability, maintenance and ideal handling until it was tied around the head. With such analogy, the women were invited to investigate their feelings in the face of coping with cancer and COVID-19, since just as the headscarf needs to be known to be used, health care professionals also need to learn about their subjectivities so as to better assist them. In order to stimulate dialogue, the question was: what are your feelings regarding the situation of experiencing cancer during the COVID-19 pandemic? After the discussion, the women chose two generative themes to tailor their experiences at VCC.

Encoding and Decoding of the themes were then mediated, in a constant process of coming and going over the issues that strengthen the fabric of their experiences and enable them to re-signify life, even in the face of cancer and COVID-19. To this end, accompanied by the sound of the song "*Peça Felicidade*" ("Ask for Happiness") by Gabriela Melim, the women recorded their perceptions on an A4 sheet of paper. Then, each participant, based on her cultural elements, told about her way of dealing with these issues, her feelings and doubts in the face of the unknown and the uncertainties about the future. At this stage, each seam stitched on the fabric was fundamental for the construction of a web of meanings present in VCC, thus allowing the creation of an environment conducive to the exchange of knowledge in a critical and reflective manner among the participants, which was typical of the Freirean methodological framework.

For the Critical Unveiling of the chosen themes, we sought to raise awareness of the collective and private aspects of each experience. Hence, the mediator symbolically put a scarf around her head, tied it up and shared, with the women, the reflection that there would be no point in acquiring good quality fabric or in knowing the different ways to tie up the headscarf, if it were not used consciously, making it meaningful in one's life. According to the problematizing effect of this action, the women reacted based on the elements that influence their culture and showed to understand their reality, reflecting on their living and unveiling their limits and potentiality to cope with cancer and COVID-19.

As a final act, the mediator invited each participant to express a sentence that represented the possible transforming action felt at that moment. Amid emotions and surrounded by feelings of empowerment, they presented their perceptions to the group. At the same time, the mediator took off her headscarf and wrote each shared phrase on it, using fabric paint, as a way of representing the VCC experience, which ended with all the women singing the chorus of the song "O que é, o que é" ("What is it?, what is it?") by Gonzaguinha.

A few days after holding VCC, a virtual meeting took place in order to validate the data with the study participants. The study complied with the ethical precepts of Resolution 466/2012, and an Informed Consent Form was sent via e-mail, signed and returned to the researchers. The participants' anonymity was preserved, by which each woman chose a star name to be named after. The study was approved by the Ethics Committee according to approval report number 4.068.387 and CAAE: 32239220.7.0000.5564.

## RESULTS AND DISCUSSION

The participants were from 34 to 56 years old and lived in different locations in Brazil: five in Santa Catarina, three in São Paulo, two in Paraná and two in Rio de Janeiro. All of them were being treated for breast cancer; ten were married; one was widowed and one was divorced. Regarding education: nine had a college degree; one had incomplete higher education, and two were high-school graduates.

During VCC, the participants defined two generating themes: 1) Challenges: cancer and COVID-19; 2) Learning: rising from one's own ashes. In the meantime, the Circle promoted dialogue and reflections, providing a dynamic space for learning to discuss the chosen themes, instigating the women's critical and reflective thinking.

At the Encoding and Decoding stage, the meanings of the generating themes were sought, in which the challenges from coping with cancer and COVID-19 were shared in order to explore such situations, thus making it clear that women recognize the legacy imposed by the experience of the pandemic and re-signify the challenges into moments of learning, so as to change the crisis into new opportunities for growth and personal maturity, as shown in Figure 2.

1. CHALLENGES: cancer and COVID-19	2. LEARNING: rising from one's on ashes
<i>I am having difficulty completing the cancer treatment. (Sun)</i>	<i>Adversity produces learning. (Sun)</i>
<i>I am afraid of becoming infected. (Vega)</i>	<i>Experiencing moments of pain makes us stronger. (Vega)</i>
<i>I am afraid to leave quarantine for treatment. (Sirius)</i>	<i>From lemon it is possible to make lemonade. (Sirius)</i>
<i>Sometimes, I think about giving up treatment. (Atria)</i>	<i>Today, I am stronger than I was yesterday. (Atria)</i>
<i>I am anxious and concerned about my health and also about my family members'. (Hamal)</i>	<i>Cancer in the quarantine is being an opportunity to enjoy the family. (Hamal)</i>
<i>I am stressed by everything around me. (Nunki)</i>	<i>Even in those moments of sadness, I can also see joy. (Nunki)</i>
<i>I am concerned because I have to overcome the barriers in neighboring cities to follow through with my treatment. (Shaula)</i>	<i>My family is more united. (Shaula)</i>
<i>I am already stressed by such unpleasant news. (Sargas)</i>	<i>Cancer and COVID-19 are also an opportunity to draw closer to God. (Sargas)</i>
<i>I feel sad and anxious. (Polaris)</i>	<i>I hope for better days. (Polaris)</i>
<i>Why all this now? Was cancer not enough already? (Capella)</i>	<i>Life's struggles develop faith and hope. (Capella)</i>
<i>I have concerns about the future. (Castor)</i>	<i>All of this is an opportunity for growth and maturation. (Castor)</i>
<i>Will we win these fights? (Antares)</i>	<i>I am a new woman. (Antares)</i>

**FIGURE 2:** Challenges and learning in coping with cancer and COVID-19. Brazil, 2020.

**Source:** Designed by the authors.

Certainly, in view of the challenges unveiled, it is possible to show that the COVID-19 pandemic establishes barriers for the continuity of cancer treatment, as it fosters a non-harmonious environment in the women's lives. In addition, it can generate conflicts that will result in care omission in case the women are not adequately assisted by the nursing team. On the other hand, feelings like fear, sadness, stress and worry are present, which can increase anxiety and uncertainty about the cure, making them more vulnerable.

In summary, cancer and its treatments promote changes in patients' lives, placing them in unwanted situations for their body maintenance, in addition to family relationships, work and social life<sup>10</sup>. This is due to its stigma, recurrence and death rates worldwide and the fact that the disease is also responsible for triggering feelings of uncertainty about the future, which makes it difficult to adhere to prolonged and aggressive treatments, such as radiotherapy and chemotherapy sessions<sup>11</sup>. Added to the natural aggravating factors imposed by the disease, the pandemic context unleashed by COVID-19 endorses this scenario by generating concerns, anxiety and social restriction due to protection control measures.

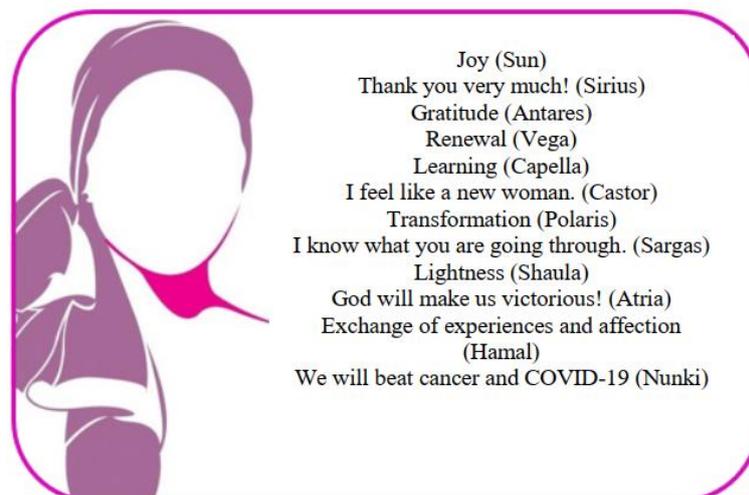
Furthermore, adherence to social distancing is related to the fear of becoming infected or suffering health damage; however, when it is not conducted in a harmonious manner, it becomes a predictor of risk for psychological issues, triggering stress, anxiety, anger, boredom, frustration and a sense of isolation from the rest of the world<sup>12</sup>. As much as social restriction in times of a pandemic is essential for taking non-pharmacological prevention measures, it is also necessary to organize strategies so as to stimulate the continuity of cancer treatment, as part of a plan to strengthen women's engagement.

In times of life threat, such as during a pandemic, peer support becomes a strategy to assist these patients. In this context, participatory-action studies are successful in articulating mutual learning at low cost, thus strengthening women's engagement and empowering them with affirmative knowledge. Oncology nurses must also fit into this context, recognizing the management of uncertainties among individuals diagnosed with cancer and encouraging healthy educational and coping measures<sup>13</sup>.

Regarding the challenges imposed in dealing with the ills of cancer and the countless barriers and threats that accompany the pandemic, it was shown that women learn from adversity and re-signify values to contemplate the moment as a source of new opportunities, anchoring themselves on the feeling of hope and strength that they need to survive in the face of it all.

Thus, hope is a positive link in the psychological conduction of what is not possible at that moment, but which may be one day through the projection of a promising future<sup>14</sup>. This characteristic strengthens behaviors in the present, in search of coping and resistance strategies, which are essential elements for these women's engagement in treatments by means of prevention and cure measures at this pandemic moment.

In this way, the women were able to understand their reality and reflect on their living, unveiling their limits and their potentiality to cope with cancer and COVID-19. Furthermore, the participants reported having enjoyed their participation in VCC, showing gratitude, learning, embracement and mutual transformation, as shown in Figure 3.



**Figure 3:** Experience in the Virtual Culture Circle. Brazil, 2020.

**Source:** Adapted by the authors from <https://www.fitarosa.com.br/lenco-quimioterapia-beanie-pink>

The women showed gratitude and happiness by singing together and with excitement, making it evident that, during the activity, they were transformed and left the meeting feeling different from the way they felt when it began. In addition, in the face of so many concerns about the cancer experience and the social distancing imposed by COVID-19, the use of music contributed to health promotion by providing moments of stress reduction, fun, reflection on shared messages and establishing a bond<sup>15</sup> among the participants.

Furthermore, the provision of spaces for online care was also shown to be a support tool. In the situation of social restriction and the experience of cancer, it is necessary to promote communication spaces with a view to solving questions, promoting embracement and emotional support. Online care is a strategy already known in the health care sector, but during the COVID-19 pandemic, it became popular among Brazilians, as nurses and other professionals are increasingly engaged in such modality, providing guidance through mobile devices, social networks and specific applications<sup>16</sup>.

In the current panorama of health care, we are experiencing a period in which successful care-promoting practices have gained space as compared to traditional means, with the inclusion of new health care terminologies and routine alteration<sup>17</sup>. In this case, adapting to the new becomes an invitation for survival. In this perspective, cancer care also needs to be planned, and issues such as those evidenced by the interviewees in this study become important indicators of their adherence to treatments.

In view of the necessary imposition of social restriction as a way of controlling the transmissibility of SARS-CoV-2, the human ability to reinvent was activated. Thus, with today's technological resources, it has been possible to approach people without approaching bodies. Through VCC, dialogue and knowledge exchange was made possible at a time when social restriction crossed the lives of women who experienced breast cancer, imposing greater psychological, economic and social demands on them. Thus, it was possible to promote health in an unimaginable and dialectically challenging historical context.

In this scenario, VCC is revealed as a tool for nurses to develop research and also promote health in times of COVID-19, enabling humanized and comprehensive care, even if not in person, mainly to the most vulnerable groups, as is the case of people who have comorbidities and exactly the situation of women who experience cancer.

As a limitation of the study, mention is made of the scope of women who participated, since it is a fact that an organization of this nature should not be composed of a larger group of people, so that effective participation and fluidity of ideas are not prevented. But at the same time as this limitation, which is inherent to the methodological option, is recognized, it is understood that it is feasible to replicate this proposition to other audiences, in other locations in Brazil and in the world, in order to also make space for discussion and health promotion through VCC possible, in addition to research.

## CONCLUDING REMARKS

The current pandemic moment has instigated reflections on countless aspects of human life, from everyday issues and daily practices to situations that refer to the meanings of life. Thus, it was in the midst of this scenario of intense calling to thinking that the study simultaneously allowed women experiencing cancer treatment and in restriction to express their feelings, looking at themselves and their partners in experiences, discovering and rediscovering weaknesses and strengths so that, through the exchange of knowledge, they could re-signify themselves and grow as beings in a society that can and must articulate itself to promote health.

Nevertheless, with the impossibility of face-to-face meetings due to COVID-19, the opportunity for health care professionals to perform qualified listening through VCC emerged, making exchanges and mutual learning possible. In this context, VCC based on Paulo Freire's framework emerges as a methodological and care-provision tool for nurses, enabling the development of humane, comprehensive, embracing care, as well as promoting the empowerment and autonomy of the participating subjects.

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