



Sumak Mama, life stories: Portrait photography to raise awareness about the culture of post-chemo rehabilitation in women who have suffered from breast cancer

Sumak Mama, historias de vida: Fotografía de retrato para concientizar sobre la cultura de la rehabilitación postquimio en mujeres que han padecido cáncer de mama

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Abstract

The present research focuses on the analysis of breast cancer and its relationship with the physical and psychological sequelae that affect the female identity and self-concept of survivors, causing emotional exhaustion and a possible identity crisis in them. In Peru, during 2019, 6,985 new cases of breast cancer were reported, of which 1,858 were fatal and 5,127 managed to recover (National Institute of Neoplastic Diseases [INEN], 2020). Accordingly, the following question is asked: What happens after having won the battle against breast cancer?

In response to this situation, Sumak Mama, life stories, was born, a design and photography project that seeks to raise awareness about the physical and psychological consequences of breast cancer treatment based on the testimonies of patients and survivors of the disease. Using photographic portraits, the project aims to communicate to survivors the importance of undergoing psychological therapy to accompany their physical recovery; and promote the prevention of the disease, as well as respect for patients, making their experience known.

In this framework, the project highlighted the need to create spaces dedicated to exposing problems related to women's health that encourage dialogue and expose aspects that could improve the quality of life of those affected. Likewise, the importance of support from the family environment and the community was demonstrated to achieve comprehensive rehabilitation in breast cancer survivors and patients.

Keywords: graphic design, photography, exhibition, cancer

Resumen

La presente investigación se enfoca en el análisis del cáncer de mama y su relación con las secuelas físicas y psicológicas que afectan la identidad femenina y el autoconcepto de las sobrevivientes, originando en ellas un desgaste emocional y una posible crisis de identidad. En Perú, durante 2019, se reportaron 6 985 casos nuevos de cáncer de mama, de los cuales 1 858 fueron letales y 5 127 lograron recuperarse (Instituto Nacional de Enfermedades Neoplásicas [INEN], 2020). De acuerdo con esto, se formula la siguiente pregunta: ¿Qué sucede después de haber vencido la batalla contra el cáncer de mama?

En respuesta a esta situación nace Sumak Mama, historias de vida, un proyecto de diseño y fotografía que busca concientizar sobre las secuelas físicas y psicológicas del tratamiento oncológico mamario con base en los testimonios de las pacientes y sobrevivientes de la enfermedad. Utilizando el retrato fotográfico, el proyecto tiene como objetivos comunicar a las sobrevivientes la importancia de llevar una terapia psicológica que acompañe su recuperación física; y promover la prevención de la enfermedad, así como el respeto a las pacientes, dando a conocer su experiencia.

En ese marco, el proyecto evidenció la necesidad de crear espacios dedicados a exponer problemáticas relacionadas con la salud de la mujer que fomenten el diálogo y expongan aspectos que podrían mejorar la calidad de vida de las afectadas. Asimismo, se demostró la importancia del apoyo del entorno familiar y de la comunidad para lograr una rehabilitación integral en las sobrevivientes y pacientes de cáncer de mama.

Palabras clave: diseño gráfico, fotografía, exposición, cáncer

◆ Introduction

The project analyzes the physical and psychological effects on women who have suffered from breast cancer; consequences that affect their self-perception and result in emotional exhaustion and a potential identity crisis. It is important to emphasize that, currently, oncological treatments have been perfected, so the survival rate is 99% in early diagnosis and 27% in advanced stages (Sausa, 2019). In this sense, to combat the consequences of this disease, we seek to reinforce a culture of comprehensive rehabilitation from diagnosis to the recovery process.

The treatment of this disease and its recovery is debilitating, it is physically reflected with the loss of hair and breasts, which, according to Amayra, Etxeberria and Valdosedá (2001), generate in those affected a feeling of emptiness, self-mutilation and decay. of body image which, in turn, in the emotional aspect, is expressed in feelings related to sadness, loneliness, hopelessness, helplessness, low self-esteem and depression (Amayra et al., 2001). What is described negatively affects the patients, because they face the demands and beauty stereotypes marked by society. Breasts are features that define the female body, whose social representation is related to sexuality and the experience of motherhood, aspects that are highly valued by women (Figueroa-Varela, Rivera-Heredia and Navarro-Hernández, 2016). The identity crisis and emotional instability are perceived in almost all patients, due to the lack of a treatment that comprehensively addresses the effects of the disease from diagnosis to the rehabilitation process. The immediate environment—family, friends—as well as society in general, need to be informed and aware of the problem to help cancer survivors in their recovery process.

In Peru, most campaigns are focused on the prevention of the disease, so it is necessary to reinforce the importance of emotional and psychological support for patients for their recovery and reintegration into society. According to the Ministry of Health (Minsa, 2021), this condition represents the second most common neoplasia in the country, with women aged 35 years and older being the most affected. Likewise, according to the National Center for Epidemiology, Prevention and Disease Control

of Peru (CDC, 2022), its incidence exceeds uterine and colorectal cancer (Breast cancer: if detected in time, it has a 90% chance of healing, 2022).

Given this situation, the Sumak Mama project seeks to help patients overcome the psychological and emotional consequences related to breast cancer, using photography as a visual communication tool. Through a photographic exhibition, a space is designed with the fundamental interest of reinforcing the culture of rehabilitation regarding this disease and raising awareness about the psychological effects on women who suffered from it.

Theoretical foundation *Breast cancer*

It is a type of cancer that arises from the uncontrolled growth of breast cells. Regularly, cells grow and divide to generate new ones, in some cases this process becomes disordered and the body does not discard old or damaged cells, allowing tissue masses commonly diagnosed as tumors to form (American Cancer Society, 2019; INEN, 2020).

According to a study carried out by the World Health Organization (WHO), in 2018, breast cancer had 25.2% incidence and 15.1% mortality in all cases collected in America. Two years later, 2.3 million women were diagnosed with this disease, of which 685,000 lost their lives. However, it was recorded that 7.8 million women diagnosed with breast cancer during the previous five years survived, making the incidence level of this type of cancer the highest in the world. Likewise, it is estimated that by 2030 diagnoses will increase by 572,000, with a rate of 130,000 deaths in Latin America and the Caribbean (Pan American Health Organization [PAHO], 2023).

Breast cancer affects both men and women; However, for the former it is a rare disease, less than 1% of all cases presented occur in this part of the population. Women are at greater risk of suffering from this disease due to factors related to age, heredity, among other physiological aspects. On the other hand, the recovery process is complicated and does not stop once the disease is defeated, but requires treatment that addresses the psychological and emotional trauma resulting from the physical changes experienced.

In this sense, this project focuses on women who survive breast cancer, as well as on the physical and psychological consequences that affect their self-perception and that converge in emotional deterioration and a virtual identity crisis. The main objective is to raise awareness—both in women who have suffered from breast cancer and in their families—of the importance of rehabilitation after cancer treatment.

The image of women and their relationship with breast cancer

Breast cancer presents physical consequences that affect a woman's body image and confront her with the physical stereotype of beauty imposed by society. This can generate negative feelings in the affected person, such as a perception of loss of femininity and bodily integrity due to not feeling attractive, demonstrating difficulty seeing themselves in the mirror naked (Sebastián, Bueno & Mateos, 2002).

Several specialists recommend that patients diagnosed with cancer undergo psychological therapy from the beginning of their treatment, since with this they can face the changes that their body will show throughout the disease (Greer, 1992). Those who suffer from cancer experience a significant impact on a psychological level, because they associate it with death, disability, fear of physical disfigurement, isolation and loneliness (Juárez and Almanza, 2011). Even a large number of those affected endure the five phases of grief in the Kübler Ross model (1992): denial, anger, negotiation, depression and acceptance. Some fundamental aspects to be able to manage this treatment are based on socio-family support, a fighting and optimistic attitude, and maintaining a good relationship with doctors (Barón, Ruiz, Alba, Saiz, Enguita and Bazaco, 2022).

In this sense, to combat the consequences of breast cancer on a psychological and emotional level, it is important to inform and raise awareness in society about the problem, to achieve comprehensive rehabilitation that has community acceptance as its starting point, and with this achieve that patients and their close environment collectively manage to reintegrate into society by building a positive perception of the female body, a type of beauty that shows struggle and courage. In this aspect, photography is a determining tool, because, as Múnera (2020) states, we tell our story with images, whose strength comes from the fact that they are material realities with the ability to transform what surrounds us.

Photography as a visual communication tool

Photography, considered one of the greatest inventions of the 19th century, has gone through a long evolution as part of the technological and communicational development of humanity. In this way, it has become one of the active elements of history, due to its contribution as a means of visual representation and its narrative and persuasive capacity (Newhall, 1983).

As Dubois (1986) states: "If there is an irresistible living force in photography, if there is something in it that seems to have absolute gravity, it is because, with photography, it is impossible for us to think of the image outside of the act that makes it possible." " (p. 36). This gives us to understand that the act of taking a photograph is not only reduced to the moment in which the shutter release is pressed, but that the context

of the moment captured and the preparation and intention behind it intervene in the result. De las Heras (2011), in his book *The Testimony of Images*, mentions: "While making a history 'of' photography, turns it into the very object of research, making a story 'from' or 'through' of photography, implies that it becomes an instrument of research, analysis and interpretation of History" (p. 22).

Both authors emphasize the use of photography as an applied method and its usefulness as an instrument to reveal stories that last over time with a purpose. In this framework, this research uses social portraiture and visual storytelling, because they are techniques that allow reinforcing the participation and commitment of the people involved, by facilitating the emotional connection with the problem being addressed. According to Molinet (2016), the photographic portrait is a tool that, in addition to recording or distorting reality, allows us to study identity from a visual dimension. It indicates that photographic representations, in addition to describing the person portrayed, reflect an identity and a defined context, which is why they surpass reality and motivate reflection on what is observed.

◆ Methodology used

The main actors of the project are women survivors of breast cancer, supported by their families, oncologists, surgeons and psychologists. Regarding the tools, testimonies, interviews with the actors, collection of information and visual material such as photographs and videos were used.

During the research, we sought to address the identified problem using photography as a communication and social awareness tool. The process began with the call for potential project participants. For this, a publication was made on Instagram and surveys were applied through Google Forms.

The project was limited due to the pandemic caused by COVID-19, therefore, three female breast cancer survivors were selected virtually and the sessions with them were held in open spaces and under biosafety protocols. First, interviews were conducted with the aim of knowing their history and personal experiences with the disease. Then the photo sessions were held to convey resilience and improvement from a personal approach, with a warm and human style. Subsequently, the editing and post-production process began. At the end, the graphic pieces were designed for the identity of the project and its application on social networks such as Instagram and Facebook.

Additionally, as part of the research process, two interviews were conducted with specialists in Oncological Psychology and Gynecology. Likewise, to measure the acceptance of the project, a survey was conducted

with 64 people related to the study problem. Finally, the result of the proposal was validated by experts in Visual Communication.

Project Sumak Mama

The Sumak Mama project aims to raise awareness about the physical and psychological consequences of oncological treatment in breast cancer patients to promote body acceptance, transcending current beauty standards. Through a photographic exhibition, the improvement and adaptation of breast cancer patients in the city of Lima is reflected. The concept of the project is identity and motivation, with the purpose of being an incentive for hope that allows one to cope with oncological treatment. In this way, we seek to help women who are struggling to accept their new physical appearance and overcome the emotional consequences of the disease.

In Peru, campaigns have been carried out such as Mama Knows, which, through interviews with female survivors, raises awareness in society and promotes carrying out preventive actions regarding breast cancer. The League against Cancer also carried out an advertising campaign called #TITS WITH PURPOSE to encourage the prevention of the disease. These initiatives are important, but they focus on promoting disease prevention and do not expose the need for post-chemo psychological rehabilitation to promote self-acceptance on a physical and emotional level.

The current project is inspired by the portraits taken by David Jay in 2011, The Scar Project, breast cancer is not a pink ribbon. These photographs show the harsh reality of the physical and psychological consequences of breast cancer patients and former patients. The style used by Jay highlights the high contrast in black and white on a uniform background, thus expressing the problem from a dramatic approach. For its part, Sumak Mamma reflects this from a vibrant and hopeful context, to this end, photographs of the survivors are exhibited in a private and personal environment, like their home; a space in which they feel comfortable and with which they have an emotional connection. The proposed format is a portrait framing, applying everything from detail shots to the American shot. As for the editing, the photograph is kept as close to the original as possible, using natural light and making some necessary adjustments to define a somewhat saturated style with little contrast.

In this framework, the portraits reflect different emotions and tell unique stories that seek to sensitize the viewer when they are exhibited, not only in the physical environment of an exhibition, but also in a virtual gallery and on the project's social networks, to amplify their impact. In the general public. Likewise, these platforms facilitate the participation of those involved because they allow comments related to the images and content published, which promotes interaction between the target audience with

other survivors at a national and international level, favoring dialogue and open communication. and, with this, building a community.

Relationship of the project with the target audience

The project is aimed at female breast cancer survivors over 30 years of age and residents of metropolitan Lima, who have experienced the rehabilitation process and can serve as inspiration for patients undergoing active cancer treatment. Likewise, the relatives of those affected and the medical personnel in charge are considered as secondary audiences, due to the contact that these patients maintain and their presence at each emotional and physical peak of the treatment.

Taking these points into account, interviews were carried out that demonstrated the problem stated. Many of the participants indicated that they initially resumed their lives with fear due to the uncertainty of a relapse. However, they stated that, with time and proper rehabilitation, they gradually managed to resume their normal activities. Many of them consider that this episode allowed them to rethink various aspects of their lives, such as their relationships, work environment, and even gave them the opportunity to identify harmful habits.

In this sense, the project visualizes the testimonies of survivors and how they face breast cancer from personal contexts. Each survivor reflects a unique and inspiring story that promotes the culture of post-chemo rehabilitation and raises awareness in society about the physical and psychological consequences of cancer treatment.

Project concept

As mentioned in previous lines, the concept of the project focuses on two ideas: identity and motivation. According to the analysis carried out, it was evident that the process of this disease for its healing and rehabilitation generates personal growth in the patients, since learning to live with it and follow a daily routine become admirable actions not only due to the physical consequences that are difficult to overcome, but also considering the psychological effects that must be faced. Overcoming these challenges requires constant motivation and resilience that is inspiring to other people with the same diagnosis.

From that perspective, identity as a key idea refers to not losing personal essence. Even though an individual experiences a mutilation process, he or she must find the mental and emotional strength to not lose his or her individuality and personal recognition. Through photography, the aim is for breast cancer survivors to identify with themselves and strengthen the idea that being a woman is more than physical appearance, that beauty is expressed in freedom, health, happiness, empathy, intelligence and strength. , among other positive aspects that are nourished and formed within the person.

For its part, motivation is the engine that allows them to move forward and goes hand in hand with identity, because cancer survivors must overcome pain and strengthen themselves by accepting the reality of the disease. Finding that inner strength, enriched with the support of doctors, loved ones and society, is decisive in overcoming the different stages of this condition.

Project's name

For the selection of the name, various criteria were considered such as phonetics, sound and the use of a native language of Peru, taking into account the origins of the project and the target audience.

In that sense, in accordance with the concepts identity and motivation, the name of the project is defined using the following terms in Quechua: SUMAK, adapted from the original version SUMAQ: suyu, adjective referring to the beautiful, good, pleasant, exquisite, sympathetic (for example: nice person, “beautiful persona”; beautiful girl, “beautiful girl”); and BREAST, an expression that has a direct relationship to the analyzed topic, breast cancer.

The visual image of the project is a logo, composed of typography and pictography. The isotype was inspired by circumferences that refer to the breast and nipple. The thick line symbolizes the strength of the woman for her admirable recovery, while the concentric links depict emotional support, representing union and community. Regarding the color palette, dark blue and earthy pink were used, associated with the feminine, the elegant and the sober, which in turn express strength, delicacy, naturalness and seriousness.

The logo represents the union and support that must exist in the patients' environment, the constant concern and involvement in oncological treatment and the close relationships between the patient, family, friends and medical staff, necessary for good treatment, and survival from this disease.



Figure 1. Isotype creation process.
Source: self-made.



Figure 2. Logo Sumak Mama.
Source: self-made.

Description of the design project

Based on the analysis carried out on the benefits of rehabilitation after oncological treatment, this project seeks to generate motivation and raise awareness in society about the problem being treated, using photography as a medium. By creating photographic portraits, the aim is to reinforce the positive self-perception of those affected and normalize some standards of beauty related to women so that socially beauty transcends physical perception and reflects the resilience and courage of the survivors.

Considering these criteria, a photographic exhibition was designed to show the portraits and through them the stories of women who survived breast cancer. For its planning, the process was divided into four different stages: launch and call, photographic and audiovisual production, installation, and maintenance.

First stage: Launch and call

To promote Sumak Mama, life stories, accounts were created on social networks such as Facebook and Instagram, to share information regarding breast cancer, as well as to publicize the purpose and objectives of the project.

Additionally, through these means, a call was opened to capture the attention of people interested in joining the project. Then the necessary coordination was made to define the dates of the photo sessions and interviews.

Second stage: Photographic and audiovisual production

In the first instance, based on the theoretical analysis of the research and the information collected, photographic and audiovisual material references were sought in order to form a moodboard that reflected

the concept of the project and with that support begin to produce the material. At the same time, a list was created to organize the contents of the videos and a script with the basic questions posed for the interviews.



Figure 3. Portraits of the survivors Silvia Diaz and Carla Saavedra. Source: self-made.

Third stage: Installation

The third stage of the project focuses on exhibition, design and realization. This experiential, photographic and audiovisual space is divided into four segments: The entrance of the installation, the first stop with the hanging books, the second stop with the large-scale projections and the closing with the photographs displayed on the walls and totems.

At the entrance to the installation, uneven sheets of fabric are displayed with projections of warm light in pink and orange tones. The texture and colors reflect the feminine side and the skin, while the folds of the fabric and the sinuous path express the experiences and scars of breast cancer patients and survivors.



Figure 4. Render of the photographic installation. Source: self-made.

At the first stop, books are displayed hanging with the participants' testimonies printed on them. Each book has as its title the name of the interviewees, who were asked to propose the title of their life. This seeks to reflect the personal process of each survivor. This stage closes with an invitation hanging on the wall: "tell your story", so attendees and other survivors have the opportunity to share their experiences with the disease. This is because many patients compile the process of their disease in notepads or agendas.

HISTORIAS DE VIDA



Figure 5. Books with testimonies.
Source: self-made.

In the second part, large-scale audiovisual projections showing the testimonies and photographs of the participants are displayed on the walls of the room. The video lasts six minutes and is programmed as an endless tape, in this way the people who interact with this installation will be able to see all the recorded testimonies without a time limit.



Figure 6. Video testimonies.
Source: self-made.

The last part and centerpiece is the photography exhibition. The images are printed on totems with a short description of each person portrayed on a booklet. The large-scale exhibition aims to achieve the greatest impact on visitors and generate conversation on the topic.



Figure 7. Render of the photographic installation. Source: self-made.

Fourth stage: Maintenance

This stage focuses on maintaining the project through social networks, where publications designed in relation to the topic are shared and photographs accompanied by testimonial videos (portraits and behind the scenes) of more cancer survivors and patients are uploaded. These media allow us to know the opinions and comments of the followers to achieve objective feedback on the project.

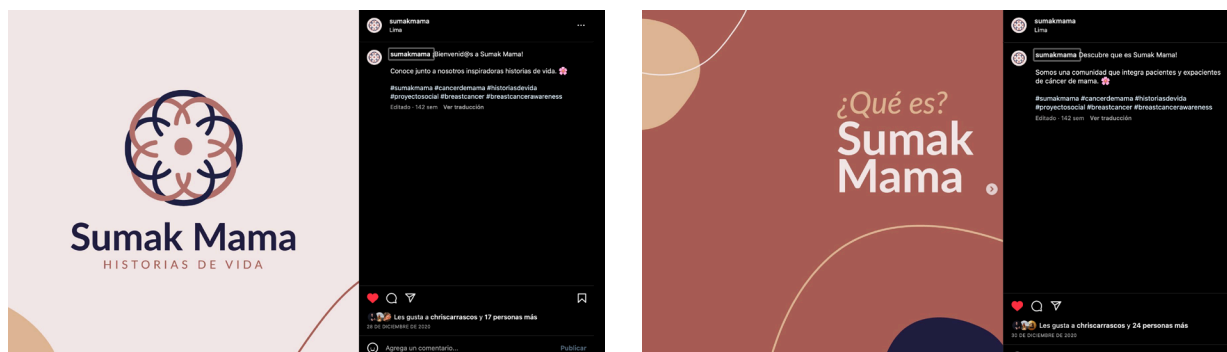


Figure 8. Instagram post introducing the page. Source: self-made.

◆ **Results** The interviews with medical personnel and the testimonies of the survivors showed the following:

- ◆ The survivors' testimonial videos showed the importance of constant emotional support during and after cancer treatment. The presence of family and friends is decisive in the recovery process of those affected.
- ◆ The photographic exhibition shows the lack of a space to expose topics related to health and contemporary social problems, since, in Peru, until now an exhibition of these characteristics had not been seen.
- ◆ The portraits of the survivors express the joy and will to live after this harsh diagnosis. They emphasize the importance of family support and psychological therapies after treatment to achieve physical and emotional stability and avoid depression or anxiety.

At the end of the launch of Sumak Mama, a photographic exhibition as a tool to raise awareness about breast cancer, a survey was carried out among 64 people that made it possible to measure the impact of the project on the target audience. This survey—based on an audience with varied profiles and age ranges—sought to gather opinions and knowledge of people interested in photographic installation. The results were the following:

- ◆ 96.8% of those surveyed have a family member who has suffered from an oncological disease and show a high interest in attending an exhibition of these characteristics, focused on the visual and audiovisual testimonies of women who survived breast cancer.
- ◆ 100% of those surveyed recognized the importance of prevention campaigns regarding breast cancer and made positive and encouraging comments about the project and the pieces carried out, concluding that there are people interested in the study addressed.
- ◆ When asked how important nonprofit organizations and projects are in benefiting society on a scale of 0 to 5—0 being not at all important and 5 being very important—89.5% of respondents indicated 5, which is which validates the importance of creating projects like the one proposed in this research.
- ◆ Only 35.9% of those surveyed stated that they had attended a photographic exhibition on some social issue, which reveals the low dissemination and rate of exhibitions related to social issues.

- ◆ 95.3% of those surveyed consider that photography is a visual tool that can generate a positive change in society's thinking, therefore, the portraits taken are interpreted as an effective awareness-raising tool.
- ◆ 95.3% of those surveyed consider that photography is a visual tool that can generate a positive change in society's thinking, therefore, the portraits taken are interpreted as an effective awareness-raising tool.
- ◆ 93.8% stated that photography is a medium that can be relevant to raise awareness about breast cancer, which validates the approach and design of the project's photographic installation.

◆ **Conclusions** The Sumak Mama project: life stories is a means to raise awareness and, thereby, normalize the consequences that breast cancer treatment can leave, motivating, informing and inspiring other cancer patients about the importance of rehabilitation after cancer treatment.

The results of the survey show the potential of the project as a means to promote prevention methods on a larger scale. In this way, preventive exams and mammograms can be promoted and help increase the number of cases of early diagnosis, which increases the chances of survival.

So that Sumak Mama can be maintained over time and have continuous growth, talks and workshops could be held with survivors and medical professionals specialized in oncology, in which topics related to the prevention and rehabilitation of breast cancer are discussed. ●

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