



## Finding myself as a cervical cancer survivor: A qualitative study

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### ABSTRACT

**Purpose:** To determine the process and meaning of the experience of women with cervical cancer who had completed treatment within less than 5 years.

**Methods:** Qualitative study that included 13 women with cervical cancer, who participated after receiving a year of treatment. The data was collected by conducting 16 in-depth interviews that took place in participants' domiciles. Grounded theory procedures were used to conduct the analysis.

**Results:** "Finding myself as a cervical cancer survivor" was identified as the central dimension on the present study, confirmed by 5 subcategories: entering an unknown path, facing what no one can imagine, living with the disease, moving on regardless of the tiredness, and stop suffering for a new opportunity.

**Conclusion:** Gaining an understanding of the reality that women with cervical cancer face reveals their strength and capacity to deal with difficulties and late side effects that need to be recognized by health professionals in the face of a disease categorized as deadly and dangerous.

### 1. Introduction

Cervical cancer is a malignant disease of the cervix. It is caused by the human papillomavirus (HPV) in 90% of cases. Globally, this disease has caused 8.2 million of deaths, representing an alarming situation in developing countries, where the resources for prevention and early diagnosis are limited (WHO, 2014). In Colombia, this type of cancer represents the second cause of death due to neoplasia among women in the country, with 1986 cases that represent 10.4% (International Agency for Research on Cancer, 2012).

Both the side effects and treatment of the disease influence the physical, psychological, social, and spiritual well-being of the cervical cancer survivors (Seol et al., 2014; Greenwald et al., 2008; Ljuca and Marošević, 2011) despite the fact that there have been significant advances in education, prevention, and screening of this neoplasia, as well as the treatment procedures, such as surgery, brachytherapy, and chemo-radiation concurrent therapy (NCCN, 2016).

The quality of life of cancer survivors has been explored before, and alterations in the physical, psychological, social, and spiritual domains have been reported (Parra and Carrillo, 2011; Montes et al., 2006; Torres et al., 2010). Also, qualitative studies have explored other features of the lives of women with cervical cancer, such as quality of life, side effects, changes in sexual activity and couple relationships, and the

psychosocial and familial consequences (Maree et al., 2013).

Despite those findings, the recent evidence does not include studies aimed to describe the process and meaning of women with cervical cancer. Therefore, a deeper understanding of the experience of these patients is needed in order to create care strategies for survivors that consider the complexity of the situation to improve the well-being of these women.

The main objective of this study was to propose a theoretical approach to describe the process and meaning of dealing with cervical cancer.

### 2. Methods

This was a qualitative grounded theory study, based on the methodology of Corbin and Strauss (Strauss & Corbin, 2002) to discover the experiences of women with cervical cancer and identify the meaning that is attributed from the diagnosis to the end of treatment. It was considered an appropriate method considering that the available literature suggests that the experience of survivors is a dynamic process.

#### 2.1. Sample and recruitment

Women aged 18 and older with a diagnosis of cervical cancer from 1

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**Table 1**  
Participant overview.

Name <sup>a</sup>	Age	Occupancy	Marital status	Stage of the disease	Treatment received
Luisa	62	Independent worker	Single	IIIB	Surgery + Concurrent Radiotherapy + Brachytherapy
Andrea	54	Stay-at-home	Single	IIA	Surgery + Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Natalia	39	Employee	Cohabiting	I	Surgery
Manuela <sup>b</sup>	55	Stay-at-home	Cohabiting	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Sara	45	Employee	Single	IIA	Cirugía + Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Juana <sup>b</sup>	46	Employee	Single	I	Surgery
Liliana	61	Retired	Divorced	IIIB	Chimotherapy + Concurrent Radiotherapy + brachytherapy
Olga <sup>b</sup>	45	Independent worker	Single	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Rosa	34	Employee	Cohabiting	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Martha <sup>b</sup>	68	Stay-at-home	Single	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Isabel	64	Stay-at-home	Divorced	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Elizabeth <sup>b</sup>	53	Employee	Married	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy
Carol	36	Employee	Single	IIIB	Chimotherapy + Concurrent Radiotherapy + Brachytherapy

<sup>a</sup> The participants were give fictitious names.

<sup>b</sup> Participants who where re-interviewed.

to 4 years post-treatment, without cognitive alteration and good verbal expression comprehension were included in the study. Women with synchronous cancer of the cervix, ovary, and endometrium were excluded due to the specific considerations that these type of diseases require. Consistent with grounded theory, patients were recruited using purposeful and theoretical sampling.

An initial review of the dataset and medical records of women with cervical cancer made at the institution in which the study was conducted, phone calls for participants' recruitment and home visits for the depth interviews were implemented.

Thirteen women took part in the study. These participants are residents of Bogota and were included in the study through the oncological gynecology consult of the Hospital Clinical Los Nogales. The participants' ages ranged from 34 to 68 years. Nine participants were at stage IIB of the disease, 2 were at the stage IIA, and 2 were at stage I.

Standard treatments were surgery, concurrent chemo-radiation, and brachytherapy. External beam and brachytherapy were given sequentially. (Table 1).

## 2.2. Data collection

Data was collected by in-depth interviews conducted during the second semester of 2017.

The first author performed all interviews, using a theme guide to record the thoughts, emotions, feelings, and opinions that participants had in response to their experience (Polit and Hungler, 2000). The theme guide contained questions about the experience, including diagnosis, treatment, and factors the participants stated as important. The opening question was, "Can you tell me how has the process been from the moment you were diagnosed with cancer to the present?" The interviews lasted between 16 and 50 min for a total of 575 min of recording.

All the interviews were recorded, transcribed textually, and transferred to Atlas. ti software. Thirteen participants took part in the study, 31 meetings occurred, and 31 sets of field notes were written by the research team.

## 2.3. Data analyses

The interviews, audio, and field notes were transcribed and analyzed by the constant comparative method proposed by Corbin and Strauss, in which data is analyzed, organized and compared to find similar characteristics (Strauss & Corbin, 2002). During the open and axial coding, important processes and sub-processes were identified and relationships were established between them. These processes were those that were selected for a more detailed analysis and were considered as the most important for the development of the theory. These

were determinants for the study and occurred with frequency in the data (in vivo codes). The processes were integrated and helped to formulate the theory during selective coding. This was complemented by the notes of the researchers who recorded their analysis, thoughts, interpretations, questions and instructions to obtain additional data. The constant compilation and comparison, through which emerging ideas and processes were continually omitted, was used to guide research. (Strauss & Corbin, 2002).

Axial, open and selective coding processes were conducted, and 444 in-vivo codes with similar features were identified and transformed into 24 nominal codes. From these last 5 subcategories were obtained that allowed to determine a major category.

## 2.4. Ethical considerations

Approval of the ethical and research institutional committees of the Los Nogales Hospital and National University of Colombia was obtained. An informed consent that described the study purposes was used, the participation was voluntary, the information was confidential, and the results were shared with the participants at the end of the study.

Four criteria for research rigorousness were followed: credibility, transferability, confirmability, and dependability, evidenced in the recording and transcription of the interviews, the description of the work in a way that eases the transference of the results to other contexts, and in the construction of theory based on the narratives as well as the interpretation of results.

## 3. Results

"Finding myself as a cervical cancer survivor" was identified as the central dimension of the present study, confirmed by 5 subcategories: entering an unknown path, facing what no one can imagine, living with the disease, moving on regardless of the tiredness, and stop suffering for a new opportunity (Table 2).

This process is part of the constant reflection of women on what they have experienced and what they have learned during this situation. The symptoms are present in the process, although these change in frequency and severity. On the other hand, women emphasized family support as a fundamental contribution in overcoming the disease and maintaining the optimism needed to continue in their struggle. Likewise, they expressed their faith in their spiritual beliefs as a refuge of hope in the face of adversity (Fig. 1).

Subcategory 1: Entering an unknown path.

Composed by six nominal codes, clarifying beliefs about the disease, looking for answers about the disease, sharing experiences with others, lack of acknowledgement of the disease, experiencing manifestations of

**Table 2**  
Description and nominal codes of the categories.

Category	Nominal codes
Entering an unknown path	Clarifying beliefs about the disease Looking for answers about the disease Sharing experiences with others Lack of acknowledgement of the disease Experiencing manifestations of cancer Imagining the types of treatment
Facing what no one can imagine	Changing my work routines Living with financial burden Dealing with burden of access to health services Receiving financial support
Living with the disease	Living with a cancer diagnosis Feeling treatment related side effects Suffering brachytherapy
Moving on regardless of the tiredness	Trusting in spiritual comfort Avoiding compassion Missing others' support Thinking about death Thinking about surrender Finding strength to continue Feeling family support
Stop suffering for a new opportunity	Living late treatment effects Overcoming the disease Thinking about avoid relapse Living another opportunity

cancer, and imagining the types of treatment, this subdomain is reflected in the reality of women who do not have an understanding of the disease and find guidance in other's knowledge. Women also found support in the guidance of health professionals initiating their treatment.

*“Because that does not cause pain, I swore that it was like menopause, I was changing the cycles, I thought that was it. I was worried, I said that bleeding cannot be anything else, why the bleeding? I started to show that I had hemorrhage, that I came out again, I started to stain again”.* (Andrea)

*“As I was about to start the chemotherapy, they told me to take a blanket and I imagined it as one ... that they would put me on a stretcher and leave me there for a while, they told me, and she will be alone all the time. They had told me that they put me there in a machine, they take it*

*there and put it in a machine and leave it for more than half an hour.”* (Liliana)

Subcategory 2: Facing what no one can imagine.

This subdomain is related to unexpected conditions and is composed of the nominal codes changing work routines, living with financial burden, dealing with burden of access to health services, and receiving financial support. Although the financial burden represents an issue, it is not perceived as extreme by women who work. However, changing work routines and dealing with the burden of access to health services are not understood until the situation is already happening.

*“I work, have a job, sell beauty products, visit pharmacies and I am outside on the streets most of the times. Then, when I was incapacitated the company respected that, and I was incapacitated by 3 months”.* (Elizabeth)

*“I know it is difficult to try to overcome things by yourself. I thought about finances, because, well ... I work in sales and have a basic salary, but my earnings depend on commissions for sales”* (Sara).

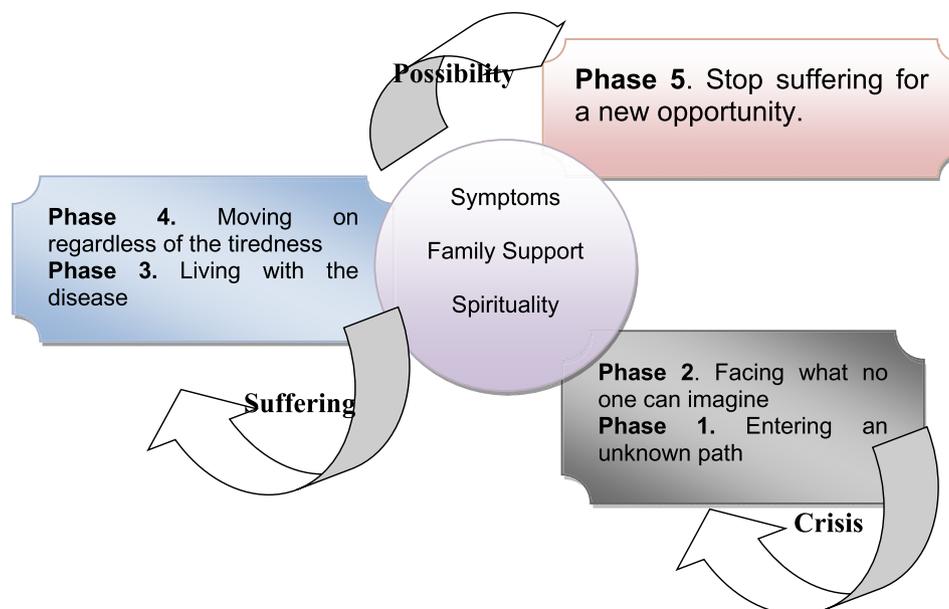
Subcategory 3: Living with the disease.

Composed by 3 nominal codes living with a cancer diagnosis, feeling treatment-related side effects, and suffering brachytherapy, this category reflects the feelings of women during treatment and describes the events since diagnosis, the diverse side effects, and their impact on the women's lives. It is unpredictable whether receiving a cancer diagnosis results in total sadness or total peace. However, peace turns into anguish when the reality of the diagnosis is acknowledged.

Treatment by chemotherapy produces effects, such as nausea, vomiting, loss of appetite, tiredness, and fatigue that may lead patients to take bed rest. Moreover, radiotherapy generated unpleasant symptoms, such as diarrhea and radiodermatitis that causes pain, cystitis, and inconvenience to use underwear and remain seated.

During surgery, symptoms, such as pain, sensation of internal body organ loss, and infections are common. However, those symptoms are resolved in a short period of time. Brachytherapy generates side effects described as traumatic, such as pain, discomfort, and burning sensation.

*“It took away my appetite, I had no appetite. I felt nauseous and wanted to vomit, but I vomited nothing. It was nausea. And, with the radiotherapy was the pain and the pain here, in this side that they use to burn on me. It did hurt a lot”.* (Liliana)



**Fig. 1.** The process of finding myself as a cervical cancer survivor.

“Burning of the colon and vagina by the rays, diarrhea, but hard hard, the burning of the colon and the vagina with radiations” (Elizabeth).

“Brachytherapy is awful. I mean I do not recommend this to no one. To me, it is the worst medical procedure that I have received in my life” (Olga).

After the radiotherapy, it was worse, diarrhea and everything, I felt very bad. I was burned, and the cystitis was terrible. I urinated and that seemed to be burning inside. They did the surgery. I got very well from the surgery. The recovery was a bit hard because she touched me alone and gave me a urinary infection, which sent me back to the emergency room (Sara).

Subcategory 4: Moving on regardless of the tiredness.

Seven nominal codes constitute this category that is related to the exhaustion that both the disease and its treatment represent for women. This is reflected in both emotional and physical matters. Women do not wish to continue receiving the treatment and want to finish soon and avoid everything that can cause more pain. They enhance their spiritual domain as a way to cope and relieve the suffering. During this phase of the disease, women tend to attribute value to life meaning, which enables them to continue in treatment. This, for women, means to be filled with strength, courage, and grace to defeat the disease and survive the most terrifying experience of their lives.

“I have been always a woman of God all my life, but in these moments, it was mostly my relationship with him, because I always talked to him and told him, God you know what my life has been. Who other than him was the one in who I found haven and support?” (Elizabeth)

“Always, I left with discomfort and tired and did not want to like, come back”

I said whether it's bald or hairy I'm not going to stay locked in my house, I'm not going to be locked up, and I told my friends if I feel good with the treatment, I still work the same, and I'm not going to stay in my house locked because I do not want anyone to look at me with pity and I do not want anyone to visit me either at home. (Luisa)

Subcategory 5: Stop suffering for a new opportunity.

This subcategory describes the experience of women with cervical cancer after treatment, who are in the process of overcoming the disease and its most acute symptoms. Feelings that were demonstrated in this category are fear of relapse and experience again other treatment effects or deciding to wait for death and anguish toward living with late side effects of the treatment. Given that life will not be the same, these women are aware of the changes in their bodies and have to learn to live with the effects of treatments. Re-engaging in work constitutes a good opportunity to develop daily activities again, which creates a feeling of satisfaction. New opportunities make them think over the meaning of life and value more sharing time with their families. It represents an opportunity to be better people.

“I think that is the hardest sequel of this process, the fact of not having control and finding someone to let me use the washroom, and sometimes you have to pay. Sometimes I do not have a washroom service, and if I arrive to a shopping mall, nooo ... I have leaks that I can't control” (Sara).

“The experience is like being shaken to react that you are still alive and have a reason to fight, stop complaining that much. Well ... I learned to value a little bit more my life and the life of my son, my family, sharing more with them”. (Carol)

They say that cancer creates roots. You do not know if it comes back to you, but whatever God wants, if he comes back or gives me again, I'll continue with the treatments. (Elizabeth).

The dynamic nature of experiencing cervical cancer allows women to think over each phase. The sequence of actions initiates with a moment in which the disease is manifested by different means: bleeding,

pelvic pain, or alterations confirmed by the PAP test. However, women do not associate those symptoms with cancer and diminish the importance of the severity of the disease. When the symptoms are exacerbated, the diagnosis is confirmed, this generates worry for a woman and her family since the diagnosis is immediately associated with death. These feelings conflict the desire for live and the strength to battle (Fig. 1).

The process identified reflects an alternation between the positive and the negative, between sadness and joy, between support and loneliness, and between the desire to live and fatigue.

Undoubtedly, it implies a change in the approach of nursing care to women with cervical cancer, a rerouting of the protocols and guidelines that focus on prescribing indications about predetermined side effects versus understanding a situation that involves knowing the woman and her family, identifying the role she represents in the family, and exploring the questions of each stage of the treatment.

#### 4. Discussion

The age of women who participated in the study varied between 34 and 68 years, and this group reported cervical cancer more often, which is consistent with other studies that have approached this population (Marquez et al., 2008; Parra and Carrillo, 2011; Castillo et al., 2015). The stage of the disease observed coincides with the results of the World Health Organization (2014), which reports that stages I and IIIB are observed in more than 20% of cases.

The patients received surgery, radiotherapy, chemotherapy, and brachytherapy as treatments, as well as concurrent radiotherapy and concurrent chemotherapy. Aguiar et al. (2015) highlight the concurrent type of treatment as the most effective for advanced stages of the disease. After studying the treatment options for the initial stages, Solis (2005) concludes that surgery has the highest survival rate. Moreover, the author reported that at stage IB, when lymphovascular invasion is present, the survival probability increases if radiotherapy is added to the treatment after surgery (Solis, 2005). However, women are often diagnosed late, at stages that require concurrent treatment.

It was observed that most of the participants were single, followed by cohabitating, divorced, and once married, contrary to previous findings in which the predominant marital statuses were married and single (Parra and Carrillo, 2011), and others that have found married to be the most common marital status of participants in a sample from Cartagena, Colombia (Castillo et al., 2015). On the other hand, Campbell et al. (2015) found in a sample from South Africa that the most common marital status was single, followed by married. All of the above denote that having support from one partner grants emotional stability and courage in facing the disease.

The occupation was employed, independent workers, and other participants reported to stay at home. Campbell et al. (2015) also describes employed as the most common occupation. In contrast, Parra and Carrillo (2011) reports that 56% of women of a study conducted in Colombia are dedicated to home and 34% are employed. The change in occupational labor shows the impact that the disease has on women who are employed or have independent work as an occupation, as a source of social and familiar development.

Women with cervical cancer exhibit a dynamic process of the disease that allows them to reflect during each stage of the disease. Different questions arise, intended mostly to find the cause of the disease, but do not consider Human Papilloma Virus (HPV) as the etiology. Accordingly, the findings of Bellinger et al. (2015), confirming the lack of knowledge about the effects of HPV.

There is also a lack of knowledge about the diverse types of treatments available and their side effects. Women who are subject to surgery assume that this treatment is sufficient to be cured (NCCN, 2016). However, when women are informed about the need for radiotherapy and chemotherapy, they experience an internal conflict because these treatments denote the severity and complications of their disease.

Indeed, Otero et al. (2011) attributes the obstacle to diagnose earlier to the difficulties when accessing the health services system. Colombia faces this issue as well. Women report difficulties in accessing health services for different reasons, such as the contracts with the health provider corporations, which leads them to look for solutions in other institutions when the initial manifestations of cancer appear. Another obstacle to a proper diagnosis is the remission to other agencies that carry out tests aimed to confirm the diagnosis. Initially, the symptoms are confused with symptoms of menopause, and the patients are sent to another institution. In this part of the process, there is no awareness of the disease and there are not enough reasons to be preoccupied.

Although women with cervical cancer receive information about the treatments and their side effects, they experience uncomfortable symptoms, such as vomiting and diarrhea, and describe the radio-dermatitis as traumatic. Likewise, brachytherapy is perceived as the most painful both physically and emotionally, making patients consider abandoning the treatment, as Maree et al. (2015) have pointed out. One of the possible complications for patients who are subject to surgery is postsurgical infection. Similar findings suggest that around 7.08 and 9.16% of the patients present internal and postsurgical complications after hysterectomy is performed (Xiaojian et al., 2010).

The most common urinary and gastrointestinal implications reported by women who receive concurrent chemotherapy are vomiting, diarrhea, and cystitis (Tan and Zahra, 2008). However, in the present study, no evidence was found about participants' concerns about re-initiating sexual activity since the women attributed more importance to being alive. Some studies report that although there are diverse factors that influence sexual activity, women learn to live with them (Vermeer et al., 2016; Afyanti and Milanti, 2013).

Women with cervical cancer receive family support that gives them the possibility of finding meaning in life and reasons to continue battling the disease despite the inconveniences with medical services and the side effects of the treatment. Yagmur and Duman. (2016) also points out social and family support as determinants of the fighting spirit and minimization of fatalism.

Another important factor pointed out by the women with cervical cancer was having faith in God. The spiritual strength they get in moments of hopelessness, praying and beliefs make them feel peaceful in the hardest moments and increase their confidence in being cured through treatment. Parra and Carrillo (2011) reports that the spiritual dimension constitutes a buffering component when coping with cervical cancer.

The disease trajectory of cervical cancer gives women an opportunity to improve their family life and strengthen the relationships they have as couples and with children, parents, and siblings. They appreciate the value of each breath, every night of rest, and the peace of mind that they feel as a result of being loved and supported.

One of the limitations of the study is that the participants were interviewed after being found through the gynecologic consultation. Recruiting participants in earlier moments of the disease would allow researchers to explore the reactions and feelings while they are occurring.

## 5. Implications for practice

Experiencing cervical cancer constitutes a complex process. Nurses must approach the process carried out by women with cervical cancer since the diagnosis, know the practices they are carrying out, the information they have about the different treatments, the support networks they have, and the roles they assume. With this description, nurses can establish a plan of care according to the particular situation. The implications of the theory obtained represent a different view of nursing versus the management of women with cervical cancer that goes beyond treating the symptoms and side effects of cancer. It is about guiding the patient and her family in the care at home, listening and allowing space for women to discuss the fears, anxieties, and

concerns that they often do not tell the family to avoid their concern. Finally, it is important to carry out a continuous follow-up that makes the woman feel with cervical cancer feel important, accompanied by the resolution of questions to minimize negative thoughts about the prognosis.

## 6. Conclusions

Experiencing cervical cancer constitutes a complex process, representing a woman who is immersed in a social, familiar, physical, and emotional reality that enables her to reflect on her life.

The experience of women with cervical cancer develops in five phases that represent the sequence of actions, thoughts, feelings, and events presented during the disease, which present new life purposes.

The meaning women attribute to the experience of living with cervical cancer is a traumatic and painful suffering that simultaneously allows them to encounter new opportunities in life and place more value on their family and little things that make them happy.

The theoretical assumption "Finding myself as a cervical cancer survivor" arose as a result of the interaction with the reality of a woman with cervical cancer, in which a woman is determined as a resilient person, able to deal with problems and the effects of a disease categorized as deadly and dangerous.

## Conflict of Interest

The authors have no conflicts of interest to disclose.

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