

## How Breast Care Nurses Alleviate Suffering among Breast Cancer Patients – A Qualitative Analysis

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**Submitted:** 15 Mar 2019; **Accepted:** 23 Mar 2019; **Published:** 02 Apr 2019

### Abstract

*Alleviation of suffering is a key characteristic of breast care nurses' (BCNs). This study proposes a conceptual framework based on statements of women diagnosed with breast cancer. Responses' answers underwent textual content analysis, which identifies three dimensions of content relevant to the women's suffering: Physical, perceived as a "war" on cancer; cognitive, focusing as chaotic and emotional, reflecting the women's sense fragility. Professional intervention was shown to respond to all three dimensions. The coping methods that patients practiced after experiencing professional intervention address these dimensions as well: Physical—the women claimed to have "fought" the illness successfully and have even accepted and reconciled with the "foreign invader"; cognitive—achieving clarity and restoring order; emotional—displaying optimism, confidence and hope. The findings show that BCNs address women's physical, cognitive and emotional suffering holistically. Bearing this observation in mind, the present study maintains that BCNs manifest the optimal approach to patients' suffering.*

**Keywords:** Cognitive-suffering, Emotional-suffering, Physical-suffering, Breast care nursing

### Introduction

Alleviation of suffering is among the most important objectives of oncological nurses, especially those specializing in breast cancer. Prof. Eric Cassell [1], a contemporary pioneer and leader in the treatment of human suffering, differentiates between suffering and

pain, noting that even slight pain can cause suffering if it entails dread (such as pain originating in a malignant tumor). By contrast, even intense pain need not cause suffering if it is perceived as temporary and controllable and its origin poses no threat. Similarly, Charmaz (2002) contends that one may experience pain without suffering and suffering without pain [2]. Cassell (1983) explains that suffering is the result of a perceived threat to one's integrity and consequently may be expressed in all aspects of the human ethos: Family relations,

work, body image, other social functions, perception of the future, etc. Suffering is alleviated when the perceived threat is neutralized [1]. In a later work [3], he indicated that each patient's subjective perception of this multidimensional conception of suffering demands all due attention and discussion. Subjective experiences are essential to our understanding of patient suffering that is perceived differentially even when physiological symptoms appear identical. Failure to diagnose and consequently treat suffering suitably and adequately originates in the therapists' inclination towards a dichotomous view of body and soul that focuses on physical aspects only. We tend to overvalue data concerning physiological symptoms and to minimize the importance of information on the patient's characteristics, values and needs as a human being, based on the assumption that subjective information is less "authentic." Remaining aspects—emotional, social and spiritual—are thus underestimated and even ignored, despite their centrality in the experience of suffering.

This study examines Cassell's (1999) claim as it applies to breast care nurses (BCNs) in Israel, with attention to the following themes that were derived from patients' remarks concerning their suffering: (1) Dimensions of suffering after diagnosis of breast cancer; (2) How BCNs help such women cope with their suffering; (3) Coping results following BCN intervention [3].

**The aim:** To report on how breast care nurses alleviate suffering among breast cancer patients in a qualitative manner according to the women's perception.

### Method Sample

321 non-metastatic breast cancer patients aged 28 to 84 (average age: 55.2; average age at time of diagnosis: 52.8) with 0-13 children.

Inclusion criteria: Native speakers of Hebrew or Arabic, who completed surgery, chemotherapy and/or radiation therapy during the two years preceding the study and visited outpatient clinics at one of seven designated medical centers, all of whom met with a BCN at least once at any time of treatment- surgery and/or oncology treatment.

Exclusion criteria: Metastatic disease or some diagnosed mental illness.

**Table 1: Socio-demographic Characteristics (n=321)**

Characteristic	Number	Percent
<b>Continent/ Country of Birth</b>		
Israel	211	65.7
Africa	34	10.6
Europe	27	8.4
CIS	23	7.2
Asia	12	3.7
South America	7	2.2
U.S.A.	3	0.9
South Africa	1	0.3
Response not provided	3	0.9
Total	321	99.9*
<b>Marital Status</b>		

Married	240	74.8
Divorced	30	9.3
Widowed	31	9.7
Single	16	5.0
Living Together	1	0.3
Response not provided	3	0.9
Total	321	100.0
<b>Education</b>		
Informal	13	4.0
Elementary School	35	10.9
High School	130	40.5
Academic	140	43.6
Response not provided	3	0.9
Total	321	99.9*
<b>Religion</b>		
Jewish	273	85.0
Moslem	27	8.4
Christian	15	4.7
Response not provided	6	1.9
Total	321	100.0
<b>Level of Religiosity</b>		
Secular	136	42.4
Traditional	128	39.9
Religious	43	13.4
Ultra-orthodox	7	2.2
Response not provided	7	2.2
Total	321	100.1*
*round-off error		

### Research type and tools

We conducted mixed-method, both quantitative and a qualitative analysis. In addition to the qualitative study, we report here on the qualitative analysis of one open question: "Please describe—in your own words—the experiences resulting from your contact with the breast care nurse, specifying the significance of such contact in coping with your illness and with the attendant treatment(s)." The present study focuses on the women's responses to the open question, while the quantitative findings were summed up in a separate study [4].

### Data Collection

Data collection took place in each of the seven institutions. In every center where the research was conducted, a research assistant was employed, preferably a nurse and one who had not taken care of the study participants at any stage during their treatment. Prior to the initiation of the study, a meeting was held with the research assistants. Contact by the head nurse or the secretary in each clinic/ward was made with women who came for routine follow up and met the study's inclusion criteria.

**Credibility:** Giving the qualitative data analysis to peer colleagues, who totally supported the analysis and to another expert in qualitative research.

## Ethical Aspects

The study received ethical approval from all seven medical institutions involved before the BCNs have started to collect the data.

## Analysis of findings

In the first step of analyzing the data, few of the researchers read by themselves the responded answers on the open question. All of them agreed that the issue of “suffering” is the fundamental one. Textual content analysis was applied to identify words, expressions and metaphors that responded to the research questions. The dimensions thus defined were assigned to appropriate categories and themes, thereby structuring a conceptual framework comprising themes and relationships among them. A thematic analysis of the findings was conducted with regard to the theoretical framework of suffering [3]. The women’s remarks regarding suffering reflected feelings of nonetheless. Rendering analysis of their responses and interpretations is useful in constructing a conceptual framework centered on suffering (see Table 2). Moreover, categorization of the various dimensions of suffering, types of nursing intervention and the results thereof was accomplished solely for analytical purposes and applied in the development of a conceptual schema. The intertwined and often overlapping dimensions of the women’s subjective experiences cannot be separated from one another.

## Findings

### Dimensions of suffering expressed by women diagnosed with breast cancer

#### SUFFERING

**Physical: Subversion.** Analysis of women’s remarks regarding physical symptoms reveals widespread use of war related terminology in describing their illness as a surprise invasion by an enemy or alien body and the need to halt and fight it. Examples include:

- “I tried to understand how suddenly, in the middle of my life, cancer **invaded** my body. I spoke about this with the nurse, who gave me the motivation I needed to overcome it”.
- “This illness fell on me **suddenly** and I had to **fight it**”.
- “I wanted to **halt** the disease as quickly as possible while it’s still small, before it **spreads** in every direction”.

**Cognitive: Fogged, Flustered.** The findings indicate unequivocally that most women perceived their situation as chaotic, disordered, unclear and amorphous. The women felt threatened by the sudden diversion from their life routine, the flood of new information, the need to make rapid decisions about an unfamiliar phenomenon with a language all its own and the uncertainty entailed by the new course their lives were taking against their will, not to mention the greatest threat of all—discovery of a life-threatening illness.

- “This is a very **confusing** and difficult situation”.
- “I was hesitant and had difficulty making decisions. I could not determine what the right thing to do was. I was unfamiliar with the new concepts. This is a highly **amorphous** situation”.
- “All this new and unfamiliar information made my **head spin**. All at once, my entire life was turned **upside-down**. Everything looked like one big **mess** to me. I had to learn a new language. It drove me crazy!”
- “Suddenly, your life looks like it’s in total **chaos**. Everything stops. **Your path is diverted** and you don’t know where the new path leads. It’s no simple matter”.

**Emotional: Eclipse; Ruin.** The women’s remarks underscore the substantive emotional breakdown resulting from the diagnosis that

is characterized by feelings of despair and existential anxiety. As demonstrated below, the women often used metaphors to intensify description of their emotional suffering:

- “I was sure that the **end of the world** was upon us”.
- “I felt that I was **drowning in the sea** and did not know how to swim.”
- “I was **emotionally shattered**.”
- “I felt a **sea of darkness** enveloping me.”

## Nursing Intervention

### WHOLEness

**Physical: Partnership in fighting the disease: War.** The women’s responses not only addressed cancer in terms of invasion but also applied military terminology and metaphors to describe the nurses’ management of treatment: *A major fighting force, liaison, coordination among forces, navigation, linkage, key function, process curtailment, curtailing processes, critical significance in this war, peak power, etc.*, as in the following remarks:

- “I considered the nurse to be a highly significant **lifeline** in my battle.”
- “The nurse who treated me performed her function well. She is a key figure to me, the **most important** and central link in the chain.”
- “She serves as **liaison** among the other factors because she has to maintain contact with numerous doctors, HMOs, nurses...”
- “She helped me **coordinate** among the various bodies involved in decision making.”
- “She handled **navigation**. You need someone like that in the war against cancer.”
- “She was a **critically significant fighting force in the battle** for my recovery.”

### Cognitive:

**Instituting Order: Helping Out.** The nurses’ contribution to alleviation of the sense of uncertainty and confusion among the women, as well as the restoration of clarity and a sense of order in their lives, is expressed overtly through the metaphor of a nurse holding the despairing woman’s hand, showing her the way back and encouraging her to follow the path with confidence. Most of the women emphasize the significance of precise and repeated explanations in clear and simple language concerning what awaits them. They noted the importance of the honest and lucid descriptions that the nurses supplied regarding future stages, introducing a sense of clarity and confidence among the women, their husbands and their families. The nurses’ constant and immediate accessibility intensified these feelings and sharpened perception of things to come:

- “My meeting with the nurse is engraved permanently in my memory. My husband and I were present at the meeting. Even when my mind was in total disarray, she explained my situation clearly, detailing treatment methods and palliative care. She also backed up her explanations with written material, providing me with up to date, practical information. She was ready to answer any question we had.”
- “She took me by the hand to the treatment room and showed me everything. She simply made order out of all the confusion and uncertainty. She most certainly put me on the right path.”
- “She was my rock, for my husband and for me, a rare combination of understanding and knowledge that enabled us to obtain answers, gain understanding and follow the right path.”
- “I feel she is of key significance because her precise explanations and preparation for subsequent developments, including

possible side effects, provided us with a clear picture of what is to be expected. Knowing what's going to happen relieves your uncertainty and dispels the unorganized thoughts that overwhelm you."

- "Immediate receipt of answers boosts your confidence. Suddenly, order emerges amid all the chaos, because the nurse is always accessible by phone. Even when she's on vacation, she always answers questions precisely, willingly and pleasantly."
- "She helps us understand the situation and think things out properly. She understands my dizzy feelings and lets me ask whatever's on my mind. This puts my thoughts in order."

#### **Emotional:**

**Acceptance: Letting in.** Metaphors were used extensively, as they were in descriptions of uncertainty, emphasizing the substantive assistance provided by BCNs in alleviating women's emotional suffering. Especially prominent are metaphors confirming that the women do not feel abandoned as they undergo treatment and that the nurses accord them a sense of confidence and protection. The nurses are attentive to the women's distress, validating ("letting in") their harshest sentiments by creating a cordial and calm atmosphere, maximizing accessibility and receptivity and responding to questions at once:

- "The nurse was a true **angel**, always attentive, smiling and ready to help at all times. Her calm demeanor and her acceptance of my complex situation gave me confidence and hope."
- "On every occasion, throughout treatment and during hospitalization, I looked for the nurse. She was my **angel**."
- "She was like a **mother and sister**; very pleasant, accepting and empathetic."
- "She was my **address** for questions on issues that I could not discuss comfortably with physicians. She was like a **Big Mama** who embraces you and with whom you can talk about anything."
- "She was even **more than family**. She never forgot to contact me after each treatment. She answered the phone whenever I needed help or a kind word. She was compassionate, empathetic and concerned, accompanying it all with a smile and a wink."
- "For me, she was a **home base and supportive shoulder** throughout all stages of the disease. I cannot imagine going through the process without her accompaniment and constant presence. Knowing she was there for me was a major component of the healing process."
- "She was always a living, professional, warm and accessible person. Her behavior towards me was a **bright light** in murky waters. I encountered a sensitive, warm, understanding individual who gave me a sense of confidence, a **pearl in a sea of darkness**."
- "She was always there for me... She gave me the feeling that I was not alone because I always have someone to **listen** to me and a **shoulder** to cry on."
- "She is a **ray of light**, a source of encouragement and support, a **human angel**."
- "When anxiety struck me, at any time of day, I called her for advice and was never rejected. I felt that she was always available to me, calming me, understanding my anxieties and referring me to appropriate professionals. She also accompanied me to every professional session. Whenever I received medical information that was difficult to accept and understand, she explained it in simple terms and empathized with my responses."

## **Coping Results after Nursing Intervention**

### **RELIEF:**

**Physical: Survival and Reconciliation: Recovery.** Many women noted that BCNs greatly facilitated reconciliation with the disease, acceptance of undesirable realities without denial and development of appropriate coping skills. In this respect, the women effectively described a situation in which they accepted their fate but still did all they could to enable recovery.

- "I was in total denial regarding the disease. With the **nurse's help and support**, I learned to accept my illness and express my opinion about it when asked to do so."
- "Essentially, **she helped me** accept the inevitable."
- "**With her help**, I learned to accept the disease."
- "**She really helped me** take in the bitter news and accept it without denial."
- "**Thanks to her**, I succeeded in reconciling myself with my destiny. Without her, everything would have been much more difficult and incomprehensible."
- "**Thanks to her**, I returned to reality. Today, I can look within myself and say: I had cancer."

Several women noted the critical role that BCNs played in saving their lives by encouraging them to undergo tests and accept treatment despite initial refusal."

- "At first, I refused to get a mammogram. **The nurse appealed to me** several times and **encouraged me** to do it. In this respect, I can state with certainty that **she saved my life**."
- "**Her advice and encouragement were critical** to saving my life and restoring my health. Thank God for nurses like her."

### **Cognitive:**

**Clarification and Finding the Way: Lining up.** The women's responses reveal that their initial sense of confusion and disorientation was soon supplanted by a thorough, clear and confident understanding of their situation and the options they faced:

- "**She restored order** in my mind and succeeded in easing matters for me and my husband, who had doubts about the need for a mastectomy. She soon put me back on the conventional path of life."
- "She succeeded in **making order out of chaos**, as various procedures kept cropping up incessantly. It's much easier when you feel that you are not going to get lost."
- "She **put my mind in order** by detailing what to anticipate. This made life much easier for me, especially regarding fear of a vague and unknown future."

### **Emotional:**

**Alleviation and Hope: Epiphany; Flash.** In parallel to the nurses' emotional *Letting In* (see above), the women also described alleviation of distress and even manifestations of hope and strength thanks to the nurses' intervention. Despite the severity of patients' feelings when they first heard about their diagnosis—the despair, fear and helplessness described above—BCNs apparently helped institute significant change and improvement in the women's emotional ability to cope with the disease:

- "She is the one who **showed me the light**. She lowered my anxiety level."
- "It helps when someone is **treating you personally** and also **caressing you emotionally**... Suddenly, you can see the light."
- "**Thanks to her, I remained afloat** even though I do not know

how to swim.”

- “**Thanks to her**, I discovered some **optimistic** aspects of my situation.”
- “Her approach induced **emotional relaxation** after the initial storm. She spoke with me for extended periods of time, convincing me that my disease can be treated and cured.”

## Discussion

This study applied qualitative analysis to assess the role of breast care nurses in relief of suffering among women diagnosed with breast cancer, as reflected in the patients’ responses to questionnaires distributed during a quantitative study of the topic [4]. Analysis of their remarks was accomplished within a theoretical framework that addressed the issue of suffering [3], with particular attention to the *dimensions* of suffering reflected in their remarks, the nurses’ responses to those same dimensions, the results of professional intervention and the nurses’ assessment of their role and value. Analysis of the women’s remarks demonstrated that their suffering is experienced in three dimensions: **Physical**, originating in the presence of cancer (but not necessarily caused directly by physical symptoms); **cognitive**, focusing on uncertainty and on perception of the confusion and chaos of their situation and **emotional**, expressed in anxiety, mental fragility and an overall sense of helplessness originating in fear, despair, uncertainty and lack of understanding.

The **physical dimension** of suffering is characterized by militaristic rhetoric applied to the diagnosis itself, the BCNs’ role in coping with physical aspects of the disease and the results of professional intervention. The disease was described through a deep-rooted metaphor that concerns war—the sudden invasion of the body by an alien entity, requiring repulsion and elimination before it spreads. In describing the nurses’ treatment of the “alien invader,” the women used numerous military terms common in descriptions of warfare, such as *liaison*, *navigation*, *an important link in the force* and so on. The results of the *struggle* with the disease were also expressed in terms of warfare: Many women said they could resign themselves to the existence of the disease thanks to conversations with the nurses, thereby declaring that they could now appease and cope with the “enemy” until the recovery stage. Several women claimed that their lives had been saved thanks to the nurses, who encouraged them to *fight* by submitting to tests and procedures despite their initial refusal to do so.

Professionals and laymen have used military imagery to describe cancer and its treatment for some time, especially in the Western world. One outstanding example is *The Emperor of All Maladies* [5], a book by physician and cancer researcher Siddhartha Mukherjee that views twentieth-century scholarly and medical treatment of cancer as an extensive scientific *battle* aimed at instituting change by suppressing and defeating the fearsome enemy. Important discoveries, failures and successes, are described in terms such as *defeat*, *victory* and deaths in the *battle against the enemy*—cancer.

Susan Sontag’s *Illness as Metaphor* [6] also details prevailing attitudes towards cancer and their origin in military terminology: Invasive cancer cells require *radical* treatment, including *bombardment* of cells with radiation and chemotherapy to *kill* the cancer cells and *rescue* the patient. It is important to note that Sontag criticizes such terminology, imagery and metaphors, claiming that their application is erroneous and deleterious to coping techniques practiced in the West. In this context, it would be interesting to examine attitudes

to suffering originating in other cultures—including experiences, conceptions and coping methods in cultures that may perceive illness and wellness as intertwined and image-free, as Sontag proposes.

The women’s most prominent motifs in the **cognitive dimension** are uncertainty, confusion and losing one’s way, all of which constitute a major source of distress. The women also mention that the BCNs’ provision of reliable and precise information in simple and clear language was a key factor in restoring their sense of order. Their perspective is supported by research literature, confirming that clear and reliable explanations and information regarding the diagnosis, treatment options, projected course of the disease and other such issues increase the women’s satisfaction levels [7-9]. In this context as well, it would be beneficial to examine attitudes towards vagueness other than those prevailing in the West, such as the Buddhist principle declaring that tentativeness, uncertainty and disorder are the essence of everything in life. According to this view, just as the ground seems to be falling away from your feet, a new opportunity arises for someone to live a full and satisfying life (Chowdron, 2001).

Future research should concentrate on the nurses’ restoration of order to patients’ minds, examining options for reducing distress originating in lack of clarity and assessing patients’ tolerance levels with respect to uncertainty.

The **emotional implications** of breast cancer diagnosis—characterized by anxiety, fear, pressure and worry—have been studied extensively [10,11]. Fear is most likely to concern surgery, side effects of treatment, implications for quality of life, financial damage, loss of family support, treatment failure and the like [12]. The multiplicity of severe negative emotions is reflected in the wide range of metaphors and images used to conceptualize the intensity of subjective emotional suffering—a concept that is difficult to express in concrete terms. Numerous researchers have examined the difficulties entailed in conceptualizing suffering. Scarry (1985), for example, claims that no one can confirm another’s (physical) pain except the person who is actually feeling it. Consequently, one may always doubt another’s pain [13]. Keinan (2013) wonders whether one person can lead another to understand or feel his/her pain and whether it is at all possible to recognize, experience and empathize with the pain that another person feels [14].

Frank (2001), who wrote about his own experiences, claims that suffering is the fear of what lies beyond the palpable and therefore cannot be described [15].

It appears that the women in this study exerted all possible efforts to put the abstract and indescribable into words and to express the intensity of the emotional suffering they experienced. Metaphors and expressions such as *the end of the world*, *an emotional breakdown*, *drowning* and *darkness* attest to the centrality of the emotional dimension in experiencing the disease and to the critical significance of responding to such emotional distress. Besides underscoring the key role played by emotional suffering, the women described distress originating in uncertainty, but tended to avoid mention of the physical dimension, that generally focuses on the healthcare system. Furthermore, attention to the disease itself reflects conceptions and emotions but not concrete physical suffering or physical pain. The findings thus corroborate Cassell’s (1999) claim that suffering cannot be reduced to physiological dimensions alone, but constitutes harm

to the whole person, to all the various aspects of the human ethos [3]. His study describes various cases of emotional suffering that originate in both emotional and cognitive sources and are expressed as fear, confusion, lack of understanding, anxiety and the like.

Breast care nurses recognize the above range of situations as sources of authentic distress. They respond to a variety of suffering dimensions and serve as a source of clear and reliable medical information and emotional support, according high value to subjective information originating in the patients themselves, as well as to the objective information that concerns their physical situation. According to Cassell (1999), this is precisely the combination required for precise diagnosis and relief of suffering [3]. It appears that BCNs actually carry out the approach he proposes. Such abilities, claims Cassell, are contingent on the treatment staff's personal involvement, their proximity to the patients and acquaintance with their characteristics and subjective needs. The women's remarks confirm that the nurses' success in responding to the various types of distress is indeed dependent on close personal relations and knowledge of their unique needs. This conclusion is supported by various metaphors and images expressing a high level of trust, friendship and the sense of protection that the nurses provide. The most prominent imagery is derived from the family sphere: *Big Mama, mother and sister, more than family* and so on, alongside metaphors that perceive the nurse as an *angel*. In response to researchers' questions regarding whether one can describe or understand another's suffering, our findings attest that BCNs succeed in doing so, alleviating suffering by reassuring patients and their families that they are not alone as they undergo these intimidating experiences. The transition from negative metaphors and imagery on receipt of the diagnosis—those that express emotional breakdown, losing one's way, fear and despair—to those that express a sense of protection and possible hope attest to improvement in the women's emotional state as a result of the nurses' professional intervention.

Charmaz (2002) and Chowdron (2001) expressed similar approaches, focusing on the person rather than the illness and on the emotional aspects of suffering [2]. They call for a holistic approach to treatment of suffering that demands attention to the individual, rejecting differentiation between body and soul, that are considered inseparable parts of the total human ethos. Professional therapists are thus required to commit themselves to personal involvement and to process various types of information (both subjective and objective) that enhances comprehension of their patients' suffering and enables provision of appropriate responses. The women's remarks attest that BCNs apply these approaches and thus carry out Cassell's recommendations, thereby providing a basis for research analysis. As the women in this study were treated at several different medical centers, came from different cultural backgrounds and became ill at different ages and stages of their lives, the holistic approach and alleviation of suffering do not appear to be incidental or anecdotal. Rather, they constitute a built-in component of BCN training and practice and elucidate the critical significance of their function.

This study presented a rudimentary conceptual framework addressing the issue of suffering. Considering its limited nature, we recommend conducting additional studies will examine and possibly expand the original structure, applying qualitative methods such as in depth interviews to determine the women's conceptions of their suffering and their coping experiences, addressing the involvement of the nursing staff in general and breast care nurses in particular. Similarly,

we ought to study and examine additional cultural implications concerning life and death, health, illness and suffering—even those that are contrary to the principles on which we were raised—thereby expanding our knowledge, assessing new means of treatment and determining their value in coping with suffering.

### Limitations of research

In the present study, the limited information obtained refers to only a few of the dimensions of suffering, omitting others that may well constitute part of the overall experience, as addressed in the relevant theoretical literature.

In addition, if there were more than one open question on the BCN support, so the information about suffering could be more reach.

**Table 2: Dimensions of women's Suffering, Nursing intervention and Results**

RELIEF (Results)	WHOLEness (Nursing Intervention)	SUFFERing	Dimensions
Recovery	War	Subversion	Physical
Lining up	Helping Out	Fogged, Flustered	Cognitive
Epiphany, Flash	Letting in	Eclipse, Ruin	Emotional

### Acknowledgment

The authors would like to thank all the women that participated in the study, who shared with us their feelings. We also would like to thank the Israel Cancer Association for the financial support of the whole study and the ongoing support for the interest group of the Breast Care Nurses in Israel, Which initiated and established it.

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