ORIGINAL ARTICLE

EXPERIENCES OF THE MOTHERS OF CHILDREN WITH CANCER IN PALLIATIVE CARE

EXPERIÊNCIAS DE MÃES DE CRIANÇAS COM CÂNCER EM CUIDADOS PALIATIVOS

Márcia Angélica Dantas Jesuíno da Costa¹, Glenda Agra², Nathanielly Cristina Carvalho de Brito Santos³, Cecília Daniele Bezerra Oliveira⁴, Maria Eliane Moreira Freire⁵, Marta Miriam Lopes Costa⁶

ABSTRACT

Objective: to understand the experiences of the mothers of children with cancer in palliative care. Method: qualitative, exploratory-descriptive study, guided by the methodological framework of Theory Based on Data. It was carried out in a public hospital and 20 mothers attended the treatment of children with cancer. Data was collected from a semi-structured interview. Results: the results allowed the construction of the theoretical model "Facing difficulties and limitations in the process of caring for the child" with the subcategories "suffering before the diagnosis of the child", "perceiving changes in daily life", "perceiving a distancing from family relationships", "perceiving the detachment of social life" and "experiencing difficulties during the treatment of the child." Conclusion: the results achieved enabled us to discover the meanings of the mothers' experiences and to understand their way of being in the face of the palliative treatment of their children. Descritores: Mothers; Child. Diagnosis; Neoplasms; Therapeutics; Palliative Care.

RESUMO

Objetivo: compreender experiências de mães de crianças com câncer em cuidados paliativos. Método: estudo qualitativo, exploratório-descritivo, guiado pelo referencial metodológico da Teoria Fundamentada nos Dados. Foi realizado em hospital público e participaram 20 mães que acompanhavam o tratamento dos filhos com câncer. Os dados foram coletados a partir de entrevista semiestruturada. Resultados: os resultados possibilitaram a construção do modelo teórico “Enfrentando dificuldades e limitações no processo de cuidar do filho” com as subcategorias “sofrendo diante do diagnóstico do filho”, “percebendo mudanças na vida cotidiana”, “percebendo um distanciamento das relações familiares”, “percebendo o distanciamento da vida social” e “vivenciando dificuldades durante o tratamento do filho”. Conclusão: os resultados alcançados possibilitaram desvendar sentidos das vivências de mães e compreender o seu modo de estar diante do tratamento paliativo de seus filhos. Descritores: Mães; Crianças; Diagnóstico; Neoplasia; Terapêutica; Cuidados paliativos.

Nurse (egress), Federal University of Campina Grande / UFCG. Cuité (PB), Brazil. E-mail: marcia.dantas.jhs@hotmail.com ORCID iD: http://orcid.org/0000-0001-5844-4462;¹ Master (Doctorate student), Postgraduate Program in Nursing, Federal University of Paraíba / UFPB. João Pessoa (PB), Brazil. E-mail: s.gara@yahoo.com.br ORCID iD: http://orcid.org/0000-0002-7628-9029;² PhD, Bachelor's Degree in Nursing, Federal University of Campina Grande / UFCG. Cuité (PB), Brazil. E-mail: nathaniellycristina@gmail.com ORCID iD: http://orcid.org/0000-0001-5844-4462;³ Master (Doctorate student), Associate Program of Nursing Post-Graduation UPE / UEPB, Recife (PE), Brazil. Email: cecilia.dbo@gmail.com ORCID iD: http://orcid.org/0000-0002-4989-678x;⁴ PhD, Undergraduate Nursing Course, Federal University of Paraíba / UFPB. João Pessoa (PB), Brazil. Email: cecilia.dbo@gmail.com ORCID iD: http://orcid.org/0000-0002-0305-4843;⁵ PhD, Undergraduate and Postgraduate Course in Nursing, Federal University of Paraíba / UFPB. João Pessoa (PB), Brazil. Email: marthamiyam@hotmail.com ORCID iD: http://orcid.org/0000-0002-2119-3935

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INTRODUCTION

Child cancer accounts for 2% to 3% of all tumors in Brazil and, in Latin America, accounts for 0.5% to 3% of all malignancies.1 Estimates of the National Cancer Institute José Alencar Gomes da Silva (INCA) report the occurrence of 11,530 new cases of cancer in children and adolescents in the country, with the exception of non-melanoma skin tumors in the period between 2012 and 2013. In 2010, cancer caused 2,740 deaths among children and adolescents of zero to 19 years in all regions of the country. As in developed countries, in Brazil, cancer is already the leading cause of death due to illness among children and adolescents from one to 19 years of age.1

Child cancer is a situation that generates suffering and changes in family dynamics since the family assumes and plays an important role in caring for the child and experiences with it the whole process of coping with the disease, in addition to the daily challenges of caring for a child undergoing various physical, physiological, psychological, social and spiritual transformations.2-3

The diagnosis of childhood cancer leads to profound changes in the structure and organization of the family. Having a child diagnosed with cancer equals the imminence of the loss and causes an immense pain with the sense of collapse of a built and dream world. Then, as a perspective of the future, the imminent approach of death remains.4

One of the challenges in the course of treatment is facing the hospital environment, which may be perceived by the child and their parents as an impersonal place surrounded by unknown people where they will undergo invasive and painful procedures and experience a frustrating experience. Children surviving cancer experience the hospital routine and aspects of this pathology, feelings of uncertainty regarding the evolution of treatment, pain and losses that impair their interpersonal and social development.5

When participating in treatment, the family should receive support not only to care for the child, but to face, understand and share the existing situation so that it can deal with their own problems, conflicts and fears. The impact with the disease causes family members to develop new skills and tasks in the family routine, generating crises that affect the emotional, social and economic aspects, since, often, the mother will have to stop exercising her work activities to accompany the child being treated, since, in most cases, it is the mother who takes on the routine of hospital visits, hospitalizations, care, medication schedules, among other intercurrences.6-8

In this context, it is up to nurses to promote care centered on the child in a living / dying situation, in addition to establishing an effective communication with the parents, since the family is the essential component in promoting health and caring for the child in its completeness (biopsychosocial, economic, spiritual and cultural). It is a fact that the mother of a child with cancer experiences all the disease trajectory, which begins with the diagnosis, accompanying every moment of the treatment. In cases of incurable cancer, he witnesses the finitude of the child, with a high burden of physical, emotional and spiritual suffering. In this phase, palliative care is indicated, which is directed to patients not for the purpose of healing them, since the disease is already at a progressive stage, irreversible and not responsive to the curative treatment, but to provide them a good quality of life in its final moments.9 Therefore, it is urgent to understand the meaning of the mother to be with a child with cancer under palliative care so that the multidisciplinary attention extends also to the family represented, most of the time, by the mother. Under this premise, this study aimed to find answers to the following question: What are the experiences of mothers of children with cancer in palliative care?

OBJECTIVE

- Understanding experiences of the mothers of children with cancer in palliative care.

METHOD

A qualitative, exploratory-descriptive study that adopted, as a theoretical reference, Symbolic Interactionism, whose premise consists of analyzing the meanings of the experiences that human beings can attribute to the social interaction established between them.10-11 In consonance with this theoretical presupposition, the Data Based Theory (DBT) was adopted as a methodological reference, which tries to discover and develop theories and concepts that emerge in the process of data analysis during the course of the research.12

The study was carried out in February and March of 2013, in a public school hospital located in Campina Grande (PB), with the authorization of the management and approval of the research project by the Research Ethics Committee of the respective
The study included 20 mothers who met the following inclusion criteria: being the mother of a child with cancer undergoing treatment at the selected hospital; have an age of 18 years or more; be accompanying your child at the time of collection; agree to participate in the survey.

Data collection was performed in a room located at the pediatric oncology unit where palliative care actions are offered to children with advanced cancer. Initially, the researcher presented to the nurses responsible for the sector, the objectives of the study. It was then conducted and presented to the mothers. At that moment, there was the initial interaction and the clarifications about the study.

Regarding the ethical aspects, the researcher also requested permission to record the interview, clarified the voluntary nature, the anonymity of the participation and the possibility of the participant to dissociate himself from the research without personal injury. Afterwards, the research participants were invited to read the Term of Free and Informed Consent (FICT) and sign it. Thus, he began the interview.

Data was obtained through semi-structured interviews, recorded using Sony branded MP3 equipment and carried out at the time of the visits or when the child was sleeping. The interview began with the question: “Tell me about your experience as the mother of a child with cancer receiving palliative care?” In the following, another question emerged to specify and explore the investigated reality: “What changes occurred in your personal and social life after the diagnosis?” Subsequently, the data were transcribed in full. To guarantee the secrecy of the participants, they were randomly assigned flower names as codenames.

Data analysis followed the following steps recommended by the DBT: open coding, where the researcher makes a careful reading of the responses by assigning expressions or words and forming the preliminary coding; codification, in which the preliminary codes are regrouped with more abstraction giving rise to subcategories that must explain facts of the social scene and selective codification, which consists of ascertaining and integrating categories from which the category considered central, that constitutes the theory of the study can emerge.13-14

RESULTS

♦ Characterization of participants

Twenty mothers of children with cancer who were receiving palliative care participated in this study. Among the participants, nine (45%) were between 31 and 40 years of age; seven (35%), between 21 and 30 years; three (15%), between 41 and 50 years, and only one (5%) mother was less than 20 years old. It is noteworthy that 11 (55%) mothers were not developing work activity at the time because they gave up their professional life to care for their sick children. The number of families with only one minimum wage was ten (50%), followed by four (20%) receiving a minimum wage of one-half and one (5%), with four minimum wages.

♦ Data related to the study objectives

The analysis of the data obtained from the interviews of mothers with children with cancer who were receiving palliative care enabled the construction of the theoretical model “Facing difficulties and limitations in the child care process” (Figure 1), which emerged from the interpretation of the grouping of categories that represented the essence of the meanings attributed by the mothers interviewed. The theoretical model aims to make explicit these meanings and to make the participants’ experience understandable in the face of the process of confrontations and feelings experienced in the course of the children’s illness.

Next, the subcategories that make up the theoretical model presented in figure 1 will be presented and analyzed.
Suffering due to the child's diagnosis

When asked to speak about the experiences of being with a child with cancer receiving palliative care, the participants of the research began their reports from the moment of the diagnosis, which was described as a painful experience, very difficult, expressed by feelings of anguish, sadness, fear, anger and despair.

It is a very difficult situation [...] a family shock [...] was very painful [...] I felt a lot of anguish [...] it is a desperation [...] when I first learned, At the beginning, the doctor called me into the room, I did not want to hear it [...] I left desperately [...] I wanted to take him and hold him in the arm. (Lily)

At the time, I felt insecurity, uncertainty, a responsibility. (Fleur de lis)

When a family receives the diagnosis of an incurable and progressive cancer with imminent death, it immediately begins to question why this is happening to their loved one, especially when it comes to a child. Therefore, it seeks an explanation for the occurrence, a justification.

It is a feeling that generates only sadness in our lives. Then comes the question: why does my daughter have cancer? (Belladonna)

I felt desperation. I was afraid. At the time, I did not feel anger, but we ask: why? (Iris)

Anguish, fear, pain, revolt, very sad feeling, sadness. I rebelled with everything! With the disease [...] because it is unacceptable. (Gardenia)

It's the worst thing! It seems the world is over at the moment! (Lavender)

Any disease that has strong clinical repercussions on children leads parents to experience feelings of distress that may intensify with uncertainties about the child's survival in the near future. Often they verbalize that they do not believe in the diagnosis of cancer, and the fear of losing their child appears almost immediately accompanied by emotional distress, despair, revolt, among other negative and painful feelings, which requires coping strategies for the situation in force.

I felt a huge pain that has no explanation [...] it was anguish, it seemed that it had ripped off a piece of me [...] I thought she was not going to take it, then my despair was very great thinking that I was going to lose her. (Dahlia)

I felt a tightness in my heart. I thought she was going to die. I was upset, disgusted! (Sunflower)

I felt no floor, no hope of anything! Sensation of loss, indeed! (Pansy)

Perceiving changes in everyday life

The mothers participating in the research had the opportunity to report the changes that occurred in their personal lives after the child's illness. Some of them had to quit their jobs, others had to stop studying and interrupt their daily activities, because they would be more willing to give up everything for their child and follow the various stages of treatment. They take on the routine of care, going to the doctor, hospitalizations, medications and home care such as food and hygiene.

I quit working and stopped studying. Before, I was walking, now, I do not do it anymore, I was struggling to lose weight, now, I am won because I do not have time to take care of myself. I started smoking a lot. (Carnation)
Ah, of course, it has changed, because we leave everything to abdicate, to live the life of the son, I left my job. I barely have time for my other daughter. (Rose)

Attention to the child with progressive disease and with a perspective of finitude is a priority for the parents, especially for the mothers, who take care to provide the child with more comfort, relief from suffering, affection, among others. Thus, the life of these women changes considerably, because their personal needs are put in second place, they undergo changes in their emotional, in the appearance, in the affective life and in their daily life.

Changed the will to live, the will to get ready, the will of everything! I just live for her, I do not want to do anything anymore. (Lily)

It totally changed! We do not go out anymore, we do not have contact with the outside world, we live alone in the hospital. I live for him twenty-four hours; I relaxed everything about myself. (Narcissus)

My mood has changed: I get more stressed, more uptight, more worried. (Rose)

♦ Perceiving distancing of family relationships

The alteration in family relationships was also evident in the reports of the mothers participating in the research, who, together with the other family members, had to adapt to new habits and the routine of hospitalization. Due to this new routine, some of them started to live less with the family and this affected the routine and the relationships with the other children, who received less attention and demonstrated, through complaints or changes in behavior, their dissatisfaction.

I got a little distant from my own family. My children get stuck because I can not pay attention to them[...] they complain[...] it’s so much that my son is giving a lot of work at school [...] I can not go out to school meetings his. (Anise)

We used to go to the pizzeria, go out for the weekend, go to the children’s park! (Begonia)

The estrangement of the spouse is also evident in the reports of some mothers. The lack of time to dedicate oneself to the spouse due to devotion to the care of the child, changing the daily routine of the family and the process of sickness of a child contribute to the estrangement of the couple and promote the increase of the stress between the spouses.

My relationship with my husband is a little troubled because we are not having time for each other. (Azalea)

♦ Perceiving distancing of social life

When questioned about the changes in social relationships, the mothers participating in the research revealed that the moment the family lived was also characterized by changes in social life that meant the discomfort associated with the commitment to quantity and quality of activities related to family leisure. These changes occurred due to the routine hospitalization, treatment and care of sick children.

We left to travel, to go to the beach, to the pool, we would go out to these songs! We stopped doing everything, practically closed the world, not even in a restaurant; It’s just at home. (Hydrangea)

When we went out to a place, I could take him; now it can not; have to have privacy, can not be where there are many people. (Daisy)

I received a lot of people in my house, gave a lot of dinner, a lot of lunch; I brought my family home a lot, nowadays, I do not bring any more. (Camellia)

We do not go out anymore, we do not have contact with the outside world, we live alone in the hospital. (Lily)

♦ Experiencing difficulty during the child’s treatment

In relation to the treatment of the child with cancer, the mothers’ statements highlight the difficulties regarding management with the clinical conditions of the disease from the diet and the risk of infections, to the emotional aspects and physical exhaustion to which they are exposed. By taking care of their children, they experience the need to change their habits and often stress and wear out.

It’s looking after a crystal for fear of breaking. Hygiene in everything; what you have to wash has to be sterilized; have to take such care. I wake up very early, I’m going to sleep very late cleaning the house. (Carnation)

In the beginning, it is hospitalization. He can not get close to people who have the flu [...] The food part was a difficulty because the things he could eat before today, he can not, then he asks for too much, he cries wanting to eat. (Daisy)

You have to wear a mask so you do not give anything to him because the immunity gets too low. You have to be careful not to catch any hospital illness. (Narcissus)

I had to talk to her, play with her, I was the child who played with her, had to explain why so much bored. (Gardenia)
Very laborious! A lot of dedication and enough care! (Dahlia)

She does not go to school, I can not take her to the swimming pool, she does not take a hose bath that she loves, she does not play on the ground, she does not go out in the sun, she does not go out in the serene. (Lily)

The lack of knowledge about the disease and its clinical signs and symptoms, as well as the possible reactions and complications presented by children in face of the imposed treatment, also presents as a difficulty imposed to the mothers participating in the study.

I had difficulty with the symptoms because, at first, I did not know what it was. She had [...] strabismus, headache, vomiting. (Iris)

The difficulty I encountered was after she started taking the drug because she got very aggressive. Then I found it difficult to take care of her. (Lavender)

The chemo is very stressful because she already had a catheter, she took a catheter because the body rejected it and put it back on. (Fleur de lis)

Rising costs linked to all the nuances of treatment, such as transportation, medication, food, among others, require the family to lease extra resources, not foreseen in the family budget. For this reason, it mobilizes to ensure continuity of treatment and this has a significant impact on household finances.

One difficulty was the transportation from my city to bring her to the hospitals in the intercurrences. (Pansy)

The financial part was a difficulty because I had to buy medication and it is very expensive. (Dahlia)

DISCUSSION

Faced with the diagnosis of child cancer, the mother experiences various feelings that cause her to plunge into a phase of suffering, uncertainty, hopelessness and revolt, as the sickness of this loved one presents them with the possibility of interrupting the maternal bond.

These feelings are also shared by family members and this period is characterized as a rather painful and stressful phase and that not infrequently leads some parents to blame themselves for their child's illness. Added to these feelings are the possibility of losing the child and impotence, which lead these families to experience an emotional imbalance11, a behavior due to the anguish of realizing that cancer can lead to death, regardless of efforts, which more evident according to the severity of the disease, the length of hospital stay or the possibility of relapse.17

Faced with the diagnosis of cancer, the mother is faced with a duality: the cure or the death of the child. It is in this argument that the maternal expectation is placed, because, although she hopes for the effectiveness of the treatment, she is always fearful of the risk of death. The sadness, usually associated with the dualities of healing / illness, life / death, hope / hopelessness to which the mother is subjected, reflects both the child's positive expectation of healing and the negative expectation of losing it, painfully in remembrance.15

The mother develops the feeling that the child is part of her body, that is, it has been part of her forever, inserted in her existence.15-6 Therefore, receiving the diagnosis of cancer causes her to immerse herself in a state of existential crisis in the face of the possibility of losing part of itself, as it is emphasized in the following speech: "It looked like it had torn a piece of me!" (Gardenia)

In this context, the impact of the diagnosis can lead the family to experience the stages of mourning described as shock, denial, sadness and detachment, that is, the adaptation stages people pass through when they miss something very significant, or when, instead of the dreamed child, a child with his or her own needs and care.18

Once a diagnosis of the disease is made, hospitalization and the routine of treatment also become present in the lives of mothers who need to accompany their children in search of healing or a better quality of life. In this new context, they begin to focus on the follow-up of the child's consultations and hospitalizations, which requires them to abandon their jobs and studies19 and start to live according to the child, primarily for the child's needs.

Therefore, maternal care, provided to the child with some chronic condition, presents itself as a complex experience that demands permanent attention in daily activities of care. To this reality, we add the repercussions on the social and financial life of the family20. The routine imposed by the treatment causes the mother to experience a stress condition permeated by situations of anxiety and depressive mood expressed by reactions of fear, irritability, sadness and apathy.15-21

This change in their daily life, after receiving the news that the child has cancer, has an impact on the life of the mothers and
disrupts the family, which causes conflicting situations and the distancing of their members because, by having their activities of daily living modified, the family experiences moments of distress caused by restricted coexistence with other family members, both by the health conditions in which the child is and by the conditions imposed by the hospitalization. In this way, changes occur in the family functioning that lead to changes in the roles developed by its members and overload some, usually the mother.22

This new phase brings effects that transcend the disease and alter the family structure, as the illness of a family member affects their other members and this often generates tension, stress and fatigue, especially among those responsible for care. The disintegration of the family world is triggered in the struggle for the maintenance of the child’s life, generating conflicts, disagreements and ruptures, sometimes irreversible. And the mother, in addition to feeling the need to have the child hospitalized, worries about the other children who stayed at home, who may feel jealous of the differentiated attention offered to the sick brother and, consequently, may even feel abandoned.17,23

In addition to distancing herself from the other children, the mother still faces the estrangement of the spouse and this contributes to increase the stress between the couple because, for the parents, the children are fundamental parts in the search for family happiness.74 The condition of deprivation, of hospitalization, accentuates the distance between the spouses who are deprived of their affective-sexual motivation. This deprivation is permeated by a feeling of impotence and guilt.15,9

Another relevant aspect concerns the changes related to leisure activities, because, faced with the demand imposed by the activities focused on child care, mothers cannot enjoy pleasurable activities as they used to. Therefore, leisure or any activity that is not directly or indirectly related to the care of the hospitalized child is not considered a priority.21

In the meantime, the mothers participating in the research reveal signs of a high level of tiredness, mental and physical exhaustion in their speeches, as they are permeated with attributions, with constant preoccupations with the sick child and with household chores. Favors the installation of some physiological changes that have been highlighted the commitment of sleep and feeding, as well as changes in behavior such as the incorporation of cigarette use.

These restrictions related to the new routine, which end up depriving family members of their families, are a significant factor affecting not only family relationships but also social relations.25 The overload of activities, the changes in family relationships, and the circle of friends and the lack of a sufficient support network favor the isolation of friends and the lack of leisure and pleasure activities.

Living the disease is a disturbing aspect for the family, since the child needs almost exclusive dedication and becomes the focus of attention of his caregivers26. In this sense, the fragility of the child is always a frightening situation for parents and family members who signal their fear of making mistakes, show insecurity in care and tend to overprotect them due to the need to reduce their suffering. This is a cultural issue strongly instituted in Brazilian society. The mother suffers from not knowing what can happen to the child, feels powerless in the face of illness / hospitalization and criticizes herself for judging herself as an overprotective mother.18,27

Home care involves, in addition to activities related to body care, feeding, elimination, administration of medication, dressing, care and sheltering. These factors significantly influence the treatment and rehabilitation of the patient.28

The costs of childcare are also a difficulty faced by the mothers, since these expenses increase the expenses of the family. Among the difficulties associated with the process of illness are the risk of losing employment, increased expenses with medical expenses, medication, transportation and travel, food and the need to constantly monitor the state of health of the child.29

Therefore, the frequent hospitalizations that the cancer causes and its confrontation require from the family, availability of time, dedication and reorganization of the finances since the parents can not bear, for a long time, the dedication imposed by the disease and its treatment. Thus, financial difficulties become more of an aggravating factor in the family’s suffering towards the child with cancer19. For this reason, the caregiver experiences several stressful family situations such as the lack of financial resources, the exercise of multiple functions, feelings of helplessness, loss of control, lack of support network, exclusion and overload.18 This can cause stress in the mother and in the other members closer to the family as a response to
the fundamental requirements for the care of children who experience advanced cancer and without therapeutic possibilities of cure.

CONCLUSION

The illness of a child generates severe physical and emotional exhaustion and, over time, affects the relations between the other members of the family due to the vicissitudes in the face of illness and the treatment. Childhood cancer is a chronic disease and the revelation of its diagnosis promotes significant changes in the family structure and the life of the child. In this sense, the study allowed to know the experience of mothers of children with cancer under palliative care.

The mothers participating in the research expressed that the moment of their child's cancer diagnosis is a singular, shocking, painful and desperate experience in their lives, as it represents the possibility of the death of their child. Negative feelings such as anguish, sadness, anger and fear are cited by mothers when they encounter the diagnosis they have mentioned as the most difficult moment of their lives.

The study showed that, in the face of a child's illness, cancer, for example, mothers dedicate themselves almost exclusively to caring for them. Thus, there are several changes in his professional, family and personal life, such as: abandonment of employment; removal from home and their domestic duties, leaving spouse and other children in the care of others; withdrawal from social life, as well as the detachment of their personal desires and needs. These situations contribute to intensify the physical and emotional exhaustion of these women.

In relation to the care directed to the child with cancer, it was possible to verify that many difficulties occur in the process of adaptation to the new reality that include not only its gradual process of acceptance but also operational problems such as hygiene, feeding, medication administration, besides increased expenditure.

This study led the authors to unveil important meanings of mothers' experiences and to understand their way of being in the face of the palliative treatment of their children.

It is worth mentioning that, taking into account the scarcity of material in the literature focused on the experience and understanding of the role of the mother in relation to the child's illness, it is believed that this research contributed to the construction of a new view of its authors about the the experience of the mothers of children with cancer and can also serve as a premise for new studies on the subject, as well as instigating reflections among the pediatric oncology health professionals for a humanized reception to the family nucleus and the implementation of a pervasive care of understanding, solidarity, sensitivity, with the support of technical and scientific knowledge.

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Corresponding Address
Nathanielly Cristina Carvalho de Brito Santos
Universidade Federal de Campina Grande – Campus Cuité (CES)
Sítio Olho d’água da Bica, s/n
Bairro Centro
CEP: 58175-000 – Cuité (PB), Brazil