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ARTICLE

Getting Sick and Living with Cancer: Narratives Found in Blogs

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ABSTRACT

This study, of data collection with documentative, descriptive, exploratory and interpretative basis, anchored in Paul Ricoeur's hermeneutics-phenomenology, aimed at analyzing, from the point of view of the patient, how it is to live with osteossarcoma in Brazil. Personal narratives were investigated in 259 posts in eight blogs. In this article we present three emerging categorical themes: difficulties in accessing treatment, physical barriers and attitude barriers. The posts pointed indicated that being affected by osteosarcoma implies: facing barriers that involve geographical distance, transportation, and accommodation; dealing with failures in the health service related to delays in diagnosis, test results, and procedures; physical, including architectural obstacles; and stigmatization. Emotional concerns, especially related to relationships with family, friends, and feelings about society´s reactions toward the person with the disease were mentioned as important as the concrete barriers they faced on an everyday basis.

Keywords: osteosarcoma; cancer; health services; health policies; stigma.

Introduction

Osteosarcoma (OS) is a rare type of bone cancer, which usually affects growing bones. Despite its rarity, it is the most prevalent malignant primary tumor in children, adolescents, and young adults and the fifth among adolescents aged 15 to 19 years. Any bone can be affected but the most common are those in the arms and legs, particularly around the knee joint. Each year, about 1,000 new cases of osteosarcoma are diagnosed in the United States and about half of these in children and teens (ACS, 2020). In Brazil it is estimated that there are 350 new cases per year (INCA, 2018).

Disease-free survival for non metastatic cases has reached 70% in five years (Picci et al, 2010). In case of recurrence this survival rate is around 20% in one year, reaching 40% in five years when complete removal of lung metastasis is possible and aggressive chemotherapy administered. For patients who already have metastases at the time of diagnosis, a less than 20% survival rate is estimated (Hoffman, McCarthy, Recklitis, & Ng, 2009). From a public health perspective, the earlier the disease is detected, the less costly the treatment will be including for public administration.

Early diagnosis offers more chances of success in treatment, leading to better opportunities for survival and quality of life. In Brazil, 30% of OS patients already present detectable metastasis at diagnosis, decreasing their survival expectations and quality of life (Sizínio, Barros, Xavier, & Pardini Junior, 2009).

Individual and contextual conditions make the experience of living and coping with OS very complex and painful for both patients and their families. Families are particularly distressed due to continuous care for a person becoming gradually dependant. Physical and psychological suffering requires the patient to develop different coping strategies that go beyond killing pain and trying to perform everyday tasks. The patient faces a reality of becoming more conscious and feels threatened by death. Many try to escape this reality by denying and avoid talking about it with family and friends. Others, at the contrary, find a way of coping by reflecting, communicating, and speaking about their situation.

Blogs have been used by some patients as tools for coping with the emotions brought about by OS in Brazil. This study aimed to better understand this phenomenon, guided by a research question: what is like to be an adolescent or young adult living with OS in Brazil? We were interested in how adolescents and young adults affected by this disease use blogs to help them to find new meanings in life.

The international, as well as the Brazilian literature available about this rare type of cancer is scarce and when we searched about the use of blogs related to Os we found even less research studies or publications. We hope that this study can open new avenues for better understanding OS and also how people feel about having a disease that represents a real life threat, and how, even in these circumstances, they find creative ways of coping.

Method

Human science research investigates phenomena affecting human behavior and the contexts in which these phenomena take place. Meticulous work and sound interpretation regarding language, time, relationships, culture, social conditions, and history are frameworks for understanding the investigated phenomena, Based on Ricoeur's (1981) hermeneutic phenomenology and triangulation interpretive methods (Carter et al, 2014) this study looked at documentary, descriptive and exploratory data in order to shed light on the experience of OS patients who shared their stories on *blogs*.

We included in the study personal blogs publicly accessible without requiring login or password and managed by Brazilians over 14 years of age with narratives posted by them in Brazilian Portuguese. The posts were published between June 2017 and March 2018, not co-authored with third parties and with no inserts such as lyrics, poems, and messages from others than the blogger. Even though the blogs were constituted of freely accessible materials on the Internet, and thus considered archival content, the study was submitted and approved by the Brazilian Ethics Committee on Research with Human Beings.

A response saturation criterion was used to determine the sample size for both blogs and posts which means that the material was sampled up to the point where no new information was obtained and redundancy was reached (Fontanella, Ricas, & Turato, 2008). A number of posts were excluded for not offering a suitable linguistic significance for the purpose of analytical work. The shortest blog narrative, thus selected, had 3,937, almost four times more than the minimum found in the existent literature (Biber, Conrad, & Reppen, 1998). After converting posts into file format, words or phrases were marked (underlined or highlighted) and divided into units of meaning that provided thematic categories.

Thematic categorization constituted the hermeneutical exercise that allowed understanding the narratives collected from the blog posts. In addition to exhaustive readings, the analysis was anchored in the following steps, based upon Ricouer´s (1981) method: a) formulation and annotation of an immediate understanding, from an initial reading; b) division of texts into Units of Meaning (words, phrases or sentences found significant); c) agglutination of Units of Meaning to form themes and subthemes; d) validation of themes by comparison with the initial understanding; e) reflection on the themes and initial understanding, contrasting them with the literature on the meaning of lived experience; and f) formulation of a comprehensive understanding admitting new textual possibilities.

Results and discussion

Two hundred and fifty-nine (259) posts were selected from eight blogs identified by codes (B1, B2 … B*) and published in five different states located on four of the five different Brazilian geopolitical regions, predominantly in those considered more developed (South East and South). Bloggers had been diagnosed with OS 14 to 48 months prior to the study, being therefore in different stages in terms of needs of hospitalization and treatments. Seven bloggers identified themselves as females, with only one male and their ages ranged between 14 and 32 years. Five bloggers had university degrees, two of them in health professions (medicine and physical therapy). One had earned a master´s degree and two had completed fundamental education (1st to 9th grade, in Brazil) (Table 1).

Table 1 - Themes and Units of Meaning related to barriers faced by OS patients

THEMES	SUBTHEMES	UNITS OF MEANING
THEME I **Access**	**Subtopic 1** Barriers to treatment	Being affected by OS implies logistical barriers that involve distance, transportation and accommodation.
	Subtopic 2 Health services failure	Getting OS means dealing with health service failures, such as delayed diagnosis and test results.
THEME II Physical Barriers	**Subtheme** Physical Barriers	Having OS demands dealing with physical barriers related to architectural barriers and uneven roads.
THEME III Attitudinal Barriers	**Subtheme** Stigma	Individuals with OS suffers with stigmatization

Source: Authors

Socioeconomic and cultural contexts determine, to a great extent, how individuals cope with serious illnesses (Wünsch Filho, Antunes, Boing, Lorenzi, 2008). Table 1, above, give us a springboard to explore the themes, sub-themes, subtopics, and units of meaning that emerged from the blog narratives.

Theme 1: Access

Subtopic 1: Barriers to treatment

Access to health services is an essential element for prevention, diagnosis, and treatment of cancer. Access differs in the different Brazilian cities and states and only people who live near capitals or metropolitan areas in the most economically developed states or have enough financial resources may benefit from the existent specialized services (Martins & Perez, 2012).

Delay in OS diagnosis may happen due to factors that involve distance to specialized centers, transportation, accommodation conditions, and availability of needed exams (Ambroggia, Biasinia, Del Giovanec, Fornarib, & Cavanna, 2015). In this study, only three of the eight bloggers were residents of state capitals with specialized cancer services.

Although cancer treatment (hospitalization and pharmacotherapy) is offered by the national public health system, indirect costs, such as those related to longer trips, are usually paid for by the individual patient, a burden for those in the lower economic strata. The disease impact is heightened for many who already struggle to satisfy even basic needs.

In this scenario, barriers related to mobility were considered by the bloggers as a main obstacle to adequate health care, especially in the case of a severe and chronic disease as OS. Syed, Gerber, & Sharp (2013) have pointed out that such kinds of barriers, for those who live in remote, rural or smaller urban centers, are not only of a geographical but also of a financial nature. And, even though city halls may support trips in the "hit and run" style, costs for families can still be too high and circumstances may turn it to worse:

"I arrived earlier today (...) the health department's ambulance broke and it would only be possible to come on Saturday. But for everyone's relief, mom got a driver who brought us; but I thought it was absurd for him to charge us 200 *reais*" (B7).
OBS: 200 reais, equivalent, at the time, to about USD$ 50. Minimum salary, in Brazil, at the time, was close to USD$250.

Pressed by the need of routine journeys, expenses with meals as well as other expenses are paid by the families, encapsulated in the complex, continuous, and long-term treatment process.

As a strategy to reduce treatment withdrawal cancer patients, specially low-income patients and their families living far from specialized centers can be helped by Support Homes, run by the volunteer sector. Bloggers also registered friends, relatives, and volunteers´ hospitality for which they expressed much gratitude:

"We were very *thankful for having people welcoming us in their homes (...) during such a difficult period. There were three months coming to Conquista and for approximately one year and a half we alternated between my house, theirs, and Stª Izabel*" (B4).

"After all the distressing and tiring trips to São Paulo, I wanted to thank those who gave us (...) the necessary support (...) in the denotative and connotative sense, since it prevented us from having to stay at the support house, giving us assistance worthy of a five-star hotel (B6).

And despite the offer of solidary hospitality, numerous situations get out of control, causing discomfort, insecurity, and anxiety:

"I had no idea how long I would stay in my aunt´s house (...) in the Metropolitan area, almost an hour from Salvador. (...) when I returned, she had appendicitis surgery, so I went to Joana's apartment, a great friend of ours who helped us (B4).

In this case above, the aunt´s house was still far from the capital, where the treatment was taking place, creating additional burdens for the patient's family and interfering in her friends and close relatives´ routine.

The fact is, from the patient´s viewpoint, having excellent treatment centers means little if it is too hard to reach it. Anything interference in the logistics of transportation or accommodation may increase their preoccupation with missing an appointment, usually difficult to schedule, or affecting their finances. The sensation of being a burden to their families or to occasional hosts may add to an already damaged self-esteem. Feeling humiliated is not uncommon as someone sense that another person is obligated to become their daily companion. No wonder, for most of the bloggers, traveling to receive treatment meant more than just a logistical problem. It was perceived as a heavy obstacle, of an existential nature, and even a frightening prospect for some.

Other situations were identified as barriers to treatment and pointed out as sources of anxiety and frustration. As is not uncommon for patients and their family members to have to travel to specialized treatment centers without returning home for weeks and even months, they are forced to make alternative arrangements with their employers. Mandatory absence may turn into fear of being replaced at work, increasing anxiety, frustration, and even a self perception of uselessness. These feelings can fuel a perception, on the part of the patient, of being gradually separated from friends and family, and make them sense feelings of compassion from their part:

"My cousins B. and I. took me to the ambulance with eyes full of tears, That made me feel very sad" (B7).

The experience of living with OS highlights the role of family.

"Warriors are the mothers who manage to care for a sick child and, still, take care of those who are healthy, but also in need of care" (B2).

The economic burden of cancer is substantial and was very much present in this discussion. For most of the bloggers families had to cut back on care due to financial constraints, which placed additional strains on them. It was noted that parents who care for a child with cancer are particularly vulnerable to financial ruin at the time of treatment, when expenses resulting from the disease lead to severe negative financial effects. In situations of constant aggravation, as usually is the case of OS, the purchasing power of families can be even more compromised when the patient and / or their caregiver is the family provider:

"*My co-workers (...) were collecting money to send to me, worried since we had to be in the capital, with constant costs with medicines and travel*" (B4).

There are virtually no government programs to support families that care for people with catastrophic diseases such as OS. Bloggers are conscious of that and some recognize the families as heroic and resent the Government, perceived as not efficient and constantly creating red tapes:

"Strong families are those who, despite few financial resources, abandon their homes and take shelter in pensions, hotels or support homes, without privacy and comfort. Courageous are the parents who resign from their jobs and depend on government assistance projects. And let the truth be told: to achieve any benefit, the procedures are so bureaucratic that many give up halfway. In addition, what the government offers is so insignificant that it is embarrassing to mention the value" (B2).

In this study, most caregivers were mothers. They are usually the ones who reduce their workload or leave work to be a full-time caregiver, regardless of the family's purchasing power. This confirms, in practice, what is pointed out by Gutiérrez & Minayo (2008), the responsibility of women for the care and well-being of family members.

"I called my mother, crying in pain, she left the city at dawn; she didn't even sleep that night (...). Thankfully, because J., poor thing, was already in need of rest since my aunt had been operated ... and nothing like a mother's lap to ease the suffering" (B4).

STOP STOP STOP

In this scenario, the drop in family income imposes more vulnerability in the face of life's unforeseen events, as in the case of OS. What is highly suggested is that inequities have an impact on people's health condition, contributing to hinder the management of serious diseases. That is why the treatment, before, during, and after the clinical course of the disease, should not focus only on such clinical development, but also on the patients and families quality of life. It is increasingly important, and necessary, to develop long-term follow-up strategies for cancer survivors (Skinner, Wallace, & Levitt, 2006).

Social exclusion is one of the complications of the post-treatment period, and geographical distance is not the only problem for accessing appropriate and integral health care (Martins & Perez, 2012). Evidence suggests that patients are more likely to miss an appointment, the farther they are from the place of care (Schain, 1994). Also, repeated trips and long distances are potential physical and psychological stressors, affecting coping behaviors and stress levels, therefore considered as barriers to adequate health care. These factors may cause low adherence or withdrawal and psychological suffering (Costain & Hewison, 1999).

What the bloggers have told us is that transportation barriers constitute a great problem in coping with the disease, partly reflecting the relationship between poverty and mobility (Syed, Gerber, & Sharp, 2013). Understanding the relationship between transportation, mobility, and access to health care can be of importance when addressing OS in more vulnerable populations.

Subtopic 2: Health services failures

Early on, OS symptoms can mimic sprains, strains, bruises and common swelling generating inaccuracies in outpatient analysis and for weeks and even months patients can be mistakenly treated (Kim et al, 2009): Late diagnosis is associated to higher risks in terms of morbidity and mortality. It is thus important for doctors to correct correct information and to have timely access to quality tests.

"He examined my knee. He lightly touched the protruding mass in a first analysis. Then he squeezed it tightly. I saw the stars. (...) He asked me to send to the health plan, shook my hand and said that we would see each other after 10 initial physical therapy sessions" (B3).

The delay in reaching a conclusive diagnosis proves to be a difficult stage for those already suffering constant pain. In many cases, people need to go to the doctor several times before satisfactory treatment starts. Blogger B8 considered takes this as irresponsible and negligent behavior, causing weariness, dissatisfaction, and revolt, pointing out that *"the delay in diagnosis heightens all kinds of distress"* It is important to note that complaints regarding delay in diagnosis and medical care, found in the *blogs*, rule out oncologists.

A common complaint, in the narratives, was about the difficulties encountered in the search for a health service:

"*Whenever the pain appeared (...) I was (...) looking for an orthopedist, but it was mild pain and … the X-rays did not show anything, They gave me anti-inflammatory drugs, which masked the pain and postponed the discovery*""(B4).

In no narrative did patients mention the use of self-medication, a frequent practice in Brazil. Most blogs were written by university students who are usually aware that self-medication can mask symptoms favoring delay in seeking a health care service and, consequently, accurate diagnosis (Bennadi, 2013). The most common initial symptoms and signs reported by the bloggers included trinomial pain, edema, and limited mobility. The distress of these patients in view of waiting for a conclusive diagnosis was visible (Table 2).

Table 2 - Bloggers complaints

Blogger	Complaints in the search for conclusive diagnosis
4	"The fourth doctor was the one who requested my first MRI scan ... very rude ... the right word might be irresponsible! 'This may be an inflammation or even a tumor, but you can return to your usual activities and return in three months'. At that time I was limping constantly and pain was my companion. Amazing! How does someone say that you may have a tumor and that you should return three months later?"
3	"I then went back to see the same doctor for new referrals. By this time, my knee had already a slight increase in volume. After the exam, the doctor maintained the diagnosis, stated that tendinitis is common in winters ... initially, 10 physiotherapy sessions"
1	"the months went by and the pain didn't go away ... appointment scheduled! 'You are in a growth phase and your nerves are not following your bones ... I will give you a referral to make an appointment'. Diagnosis: 'Oh for sure you hit that knee (and me saying no) I'm going to put a splint without a cast and give you a medicine for muscle pain'. Since nobody solved my case and the pain only increased, I looked for a trauma emergency service. Diagnosis: 'Patella! You have a congenital malformation in the patella! I will leave you a week of plaster splint with pain medication and then you will come back here for us to analyze'. One week later, diagnosis: 'It's very swollen, I'm going for another week of splint (then I went crazy) ... it can only be resolved with physical therapy and if it doesn't work ... surgery ... after ten sessions you come back here for me to evaluate you".

Source: authors

Dissatisfaction with the initial consultations and diagnoses made blogger B3 *"to seek another orthopedist. Someone who would thoroughly investigate the problem"*. This kind of recurrent situation leave patients insecure, indignant, and exhausted:

Tired of leaving early to go to school (...) and coming back crying in pain, I went back to urgent trauma (...). I was already indignant of having scheduled the 10 physical therapies, and the doctor was only going to see me the next day and I was dying of pain there, that was going over the limits (B1).

The constant search, suffering, neglect and insecurity make people suspicious of professionals:

"Be careful when choosing your doctors, I never imagined that I had cancer, maybe that's why I was willing to be seen by the first person available (...) who instead of investigating my case gave me a diagnosis of tendonitis, anti-inflammatory drugs and requested physical therapy (...). There were four orthopedists, before the fifth, sent by God, to take my case seriously (B4).

In this study tendinitis was the most recurrent mistaken diagnosis and the average time from the onset of symptoms to the arrival at a specialized service, where the conclusive diagnosis was made, was six months. In the United States and most central European countries the average from one to three months (Guerra et al, 2006). The difference may be attributed to Brazilian general practitioners not being prepared to diagnose OS or to an excessive bureaucracy that makes patients to be sent back and forth to different health services before being referred to the right one (Malta, Schall, & Modena, 2009). Both kinds of failures may lead the patient to:

"wait ... wait ... wait ... while time was passing (...) I had already been referred to National Social Security Institute, I had to be away from work and I was already walking with the help of a crutch and no results... What is going on? It was already October !!!" B4

Problems related to accessibility also occur in the private sphere, since "*Health Plans in Brazil are a case for the police*" (B2). Four of the blogs investigated reported complaints regarding the delay in service and the authorization of procedures. According to the bloggers private health service providers put patients in long waits, even those who already have a previous history of cancer and face a possible recurrence: "*there was what I definitely didn't want to hear: it was an osteosarcoma metastasis. Nine months had passed from suspicion to diagnostic confirmation*" (B2).

Sometimes patients are surprised that their health plan do not cover all inpatient services, and for that reason the professional who was been treating the disease may not be available anymore. Even with the patient already hospitalized, there are new arrangements, transfers, and delay to proceed with the treatment: "*I was hospitalized for a few days until the pain stabilized. I warned Dr. X, but he could not do my biopsy there, as he was not affiliated with that hospital. So, we ran after it and got a transfer to the Hospital where he could do it*" (B4).

Substantial delays, as we can see, do not work only for users of the public Unified Health System (SUS): "*Unfortunately, the surgery will not be performed tomorrow. The health plan has not yet authorized the endoprosthesis (...) It is a pity that bureaucracy delays treatment … how can we measure how harmed I will be?*" (B3)

It is important to remember that non-metastatic tumors, in relatively accessible anatomical sites (knee, hip, and shoulder) have usually a good prognosis. Very large tumors in difficult regions such as the spine have less favorable prognosis, due to the difficulty of its complete removal. Once metastasis is found, the prognosis gets substantially worse (Aljubran, Griffin, Pintilie, & Blackstein, 2009).

Even with a health plan, patients are forced to face painful outpatient procedures to speed up treatment and to avoid longer waiting times:

"This procedure was performed on an outpatient basis, as it would take too long for a conventional procedure (....) to be authorized. (...) a little ointment that would only make the meat fall asleep (sigh). The cut did not hurt but they had to introduce an object in the shape of a T into the bone (...) think about the pain I felt without anesthesia (...) inside my tibia, which already hurt a lot (...) it was unbearable (B4).

Waiting for treatment seems to be a part of the daily life of Brazilians who have OS:
"*The eternal art of waiting (...) in this game of just waiting here, just waiting there, you lose hours and hours, and more hours of your life, sitting on a bench, looking at walls, ceilings, floors, and other patients*" (B6).

While being affected by OS in Brazil has its bureaucratic dilemmas both in the public and private spheres, users are aware of the expenses that this disease entails for the provider institutions: "*the expenses that the government has already had with me were much higher than the ones you had with most of you (...). Because treating cancer is expensive, very expensive*" (B6).

What has been suggested by the narratives is that health policies apparently are not efficient to cut delays and to minimize problems created by excessive or equivocated bureaucracy. It is understood that not everyone can have access to everything all the time but in the face of the enormous amount of suffering brought by OS perhaps more could be done to curtail some of the problems pointed out by the bloggers. The narratives report that there too much unnecessary waiting, for example, for health plans to authorize procedures and for public services to refer to specialized centers. Such modes of operation ignore the urgency posed by the body and mind pains of cancer. Not having access to immediate and correct treatment means, for many, prematurely losing a limb or dying.

All of this make the person living with OS to remember constantly their new social role as a patient. This means to be object of public policies, institutional bureaucracies, professional discourses, public and private consumer codes. It also means new relationships to various and different environments, in a process of social, economic, and political adaptation. The individual experiences, more than ever, subjection to the social structure, becoming conscious of the system´s rules, norms, and language that mediate life (Pêcheux, 1990). The individual character enters a new dimension, permeated and encapsulated in the very history of disease. Their autonomy is diminished and their subjective independence compromised (Foucault, 1995).

Theme II: Physical barriers

It seems simplistic to conceptualize the impact of travel on treatment adherence only in relation to the distance traveled. The nature and mode of travel are also important factors, including the availability of personal transportation and access to public transportation systems, as well as their comfort, flexibility, security and cost. Dependence on ambulances is another factor to be considered.

For a person in pain or under anxiety, traveling 20 kilometers in the city is a very different experience than traveling 20 kilometers on a highway, or on an uneven (bumpy) dirt road. These make for a difference in considering the physical or psychological condition for mobility of a sick person. A cancer treatment may cause symptoms such as general physical discomfort, nausea, fatigue, diarrhea, headaches, anxiety, and even depression.

In this study it was also found that one blogger reported the amputation of one of her lower limbs, one reported sequelae in her arms, one reported that her leg became shorter than the other and four referred stent placements.

All of these may reduce patients' tolerance for travel, resulting in various degrees of distress. We may sense the suffering in blogger B5 account:

"I was not ready for this (.. .) every ten steps I had to sit down so I wouldn't pass out. My father even wanted to give up, but I needed to go (...). I gathered all my strength and we managed to arrive"

For those with OS things are not as simple as to be reduced to the relationships of patients to medical, outpatient, and hospital care, different types of exams, and other medical procedures. Physical impairments demand convenient access in a context where architectural barriers may hinder such access:

"After a long workout with my crutches, we finally got to the elevator (...). I had never stopped to think aboout the issues of accessibility in the world (...) In my situation, this will be a practice from now on" (B3)

Living with OS means entering a new mode of living life. Details such as architectural designs, sidewalks integrity, public transportation means of accessibility, existence of places to sit in public spaces, among others, which perhaps were never thought about before, suddenly become of crucial importance. The individual perceives herself or himself differently, sees their fragility and also their power to resist, sense despair and hope, feels constant pain and much suffering but also how they can overcome and recover. It Is an everyday journey plenty of desperation and growth.

Theme III: Attitudinal barriers

Stigma

The association between cancer and death, at a time when treatment resources were scarce, made it a taboo subject, a disease that could not even be nominated. For a long time, in daily conversations in Brazil, pronouncing the word cancer was avoided, replacing it frequently with the term "that bad disease". (Aguiar, 2005). As a consequence, a cancer diagnosis meant having a death certificate in hand. But despite advances in survival rates and, for some, the cure, cancer still accounts for 12% of all causes of mortality in the world. And, even today, there is a crystallized stigma with negative representations that does not seem to disappear (Daher, 2012). 6(1988) defined as an attribute that confers profound discredit, a stereotype seen negatively by society, causing a situation where the person does not have full social acceptance. Stereotypes applied to people affected by diseases lead to prejudice and pejorative attitudes that induce fear, rejection, and distancing from them. The consequences of social stigma can be severe: reduced opportunities, low self-esteem, and sense of shame. In the case of OS stigma may induce the concealment of symptoms which may favor scarring and mutilation.

The dangerousness of cancer justifies prevalent attitudes and behaviors that are still very common: being diagnosed with cancer often means *"to hear comments like 'Is she really finished? (...). Oh, poor thing'"* (B6); or "be *seen as the poor thing with their days counted* (B2)". The sick are seen, by some, no longer as the person they were before the disease; some feel uncomfortable, or even behave in a harmful or discriminatory way, in their efforts to hide or somehow exorcize the disease.

It is a fact that in our society being sick or having an illness refers to being away from work and the worse the problem, the higher is the chance for being seen as unproductive. But many times the person do not even need to come to that point. The diagnosis already makes for characterizing the sick person as useless or incapable, accentuating the stigma due to the limitations brought by the disease (Aureliano, 2007). In the particular case of OS, it is associated with mutilation, loss of bodily functions, scarring, and emotional trauma, all of which is associated with the idea of imminent risk of death.

And, although the danger offered by cancer is not related to contagion, even before of the Covid-19 pandemic OS patients used to wear a mask in hospital premises, adding to their stigmatization:

"we suffer prejudice even on the hospital premises for wearing a mask and people no longer come near you thinking they have some contagious disease and in fact, we use masks to avoid catching any disease". (B1)

The truth is that, despite technical-scientific advances, which offer the possibility of prevention, early detection and treatment, and the cure of various types of cancer, this disease is still considered one of the worst problems affecting human beings. The dread of suffering and of invasive and aggressive treatments, marks of the cancer experience, makes for people who are not a part of the daily life of cancer patients to, have difficulties in dealing with the changes brought about by the disease:

"I've lost count of how many times (...) I caught people looking at me. Curious, puzzled looks that make question marks appear. (...) I prefer that you ask what I have, kill your curiosity, take your doubt, than to look at me as if I were a strange being" (B6)

The impacts of the treatment, physically visible, raise the stigmatizing view. This plays a toxic role at a broader social level, perpetuating the cycle of fear of death (Keusch, Wilentz, & Kleinman, 2006). When related to health, stigma is usually characterized by exclusion, rejection, guilt and devaluation (Weiss & Ramakrishna, 2006). The stigma of serious illness makes one subject to prejudice; then, covering up the situation becomes part of the stigmatized person´s response. This can accentuate discouragement, even causing delay in diagnosing the disease, or in searching for a specialized service or professional.

Cultural myths and taboos provide for the social, emotional and financial devastation that often accompanies a cancer diagnosis. Combating stigma and overcoming silence can play an important role in changing this reality. There is plenty of room for educational programs aimed at raising awareness of what cancer is, where the gaps are, and what has already been done, in order to change how people perceive the disease.

Communication is critical to reducing cancer-related stigma, increasing cancer awareness and spreading cancer education. Stigma can have a silencing effect, in which efforts to raise awareness about the disease are negated. Undoubtedly, stigma needs to be challenged in order to facilitate access to services and the removal of barriers, as well as to increase health promotion.

Final remarks

Listening to patients with OS in an empathetic and non-judgmental mode made it possible to better understand the barriers that are daily faced by those who had their lives altered by a threatening disease. This study suggests that it is necessary to open our ears to their voices, in order to comprehend their suffering in the face of the severity of cancer. The disease and the inefficiency of public and private health services make OS patients to be doubly fragile, as individual human being and as citizens. Social support needs to be available and accessible.

The ethics of care, from the bloggers studied, must be focused on the dignity of the person and take into consideration their daily life needs. Equity allocating resources are not highly efficacious if not attempting to minimize the suffering caused by stigma, social exclusion, and economic difficulties. It becomes evident that inequalities stimulate suffering and OS is certainly not the only context for this phenomenon. The social determinants of health serve as a framework for fighting the negative impacts of cancer, on an individual and collective basis.

OS has also deep implications for family structures and health policies should not be limited to combat the disease at the individual level. Support for families, including in the economic aspect should be looked at as an investment from the perspective of the country´s whole economy.

Far from pretending to exhaust the themes studied, the discussions generated by this investigation may be seen as a provocation. We hope that, from a Brazilian perspective and considering the prior knowledge about OS, other studies based on personal experiences be conducted, expanding our comprehension about the nature of living with catastrophic diseases in contemporary times.

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