

**Narratives of Suffering
A Look on Disease in Medical Anthropology
– A case study* –**

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Abstract. This paper aims at presenting the way in which the subjective experience of an illness is transposed and renegotiated within the illness narrative. Our case study reveals the hermeneutical travail through which a woman suffering of breast cancer tries to give meaning to the experience of her illness. In the first part of the article I present the main conceptual instruments regarding the relationship between illness and narrativity, as it was theoreticized by specialists in the domain. The second part of the study focuses on the process of deconstructing the life narrative – prior to the disease – and on the attempt to reconfigure the narrative into one that is able to restore the order that was destroyed by the disease.

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Introduction

The appearance of the disease in human life is a critical moment that often requires special strategies in order to handle this event. In most cases the illness signifies a disruption of the daily natural flow, a disturbance of work, activities, relationships and the current meanings of the surrounding world. Considering that human individuality fundamentally depends on the body, an attack on the physical integrity of the individual causes a profound dislocation of the underlying fundamentals of life. The restriction of physical skills leads to the impossibility of fulfilling one's social roles, to a deterioration in relations with others and to a significant transformation of everyday life details.

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Faced with these changes, the person raises the inevitable question “Why me?”, that implies questioning their own life, the meanings of illness, its causality, and eventually its purpose. Causing a sudden aggression against existence, the disease calls for a restructuring effort, based on new coordinates. The present, the past and the future must be re-evaluated and reconfigured, which requires reflecting the place the individual occupies within society and in his/her own family. In other words, the disease, eventually, has to get a clear, definite place in the patient’s life.

In this process of regaining a new sense of existential coherence, the narrative of personal experience is probably the first and most available human resource. Through narrative, the disease is explained and related to other personal experiences, and its meaning is negotiated in a way that should be appropriate to the personal expectations as well as to the context of the social and cultural norms shared by the community.

Starting from a broader research on the narratives of patients affected by cancer, this paper focuses on the presentation and analysis of a single illness narrative, performed by a woman affected by breast cancer. Through this case study we try to grasp both the way the narrative of life prior to the disease enters a process of deconstruction at the moment the diagnosis is pronounced, as well as the process of reconfiguration of a new narrative with the aim of restoring the order that the appearance of the disease has destroyed. We will also try to identify the main cultural representations of illness in contemporary society which contributes and guides the patient in choosing the right attitude towards their own disease.

In the first part of this paper we will briefly present the main theoretical issues related to the relationship between disease and narrativity in order to be able to provide a proper analysis of the chosen narrative.

Theoretical background: Illness and narrativity

During the last decades, narrativity has become a major topic of interest in the social sciences concerned with health, illness and medicine. The first studies of narrativity in the medical field were mainly focused on the process of narration as part of clinical practice and doctors’ experiences, while the patients’ narratives of suffering were paid less attention. The skeptical attitude of the doctors concerning the way the patient presents his/her own disease has been taken over by social scientists in their studies about the social reality of biomedicine and disease.¹ Later, when the disease/illness distinction² became a representative analytical framework in social sciences, the narratives of patients’ personal experiences became the focus point of interest for researchers.³

¹ Lars-Christer Hyden, “Illness and narrative,” *Sociology of Health and Illness* 1 (1997): 48–69, 48.

² Disease lesion represents an anatomical or psychological dysfunction that can be identified by means of biomedicine. Illness includes a subjective experience of illness, reflected in its individual life plan. While the disease is rooted in the biological side of the human, illness is culturally structured, comprising the entire experience of suffering.

³ Hyden, “Illness and narrative,” 49.

The moment when personal narratives of illness have gained researchers' attention in particular, coincides with the loss of authority of the great narratives in medical sciences,¹ a characteristic of postmodernity. On the other hand, the decreased risk of infectious diseases and the increased impact of chronic diseases have made the biomedical narrative model based on searching for a final organic healing lose relevance in terms of personal experience of suffering. Managing this suffering requires now a different semantic framework in which disease-related events can be integrated into the individual's personal history. The most suitable medium for information on how patients give significance to their disease and manage their perpetual condition of 'patient' is considered to be the personal narrative of illness.

Analyzing the evolution of illness narratives from a historical perspective, Arthur Frank makes a distinction between the modern and postmodern experience of illness. In his view, the modern experience of illness begins with the acceptance of biomedicine as the official and general health care support. In this context, illness narratives performed by patients are actually versions of what the doctor told them about their illness, and the medical story now becomes a criterion according to which all other things are judged as true or false.²

The postmodern experience of illness begins when people realize that their experience cannot be entirely captured by medical narratives, since they do not include the subjective aspects of living with the disease and do not even stalk the process of accommodation to the new condition.³ At this point, patients feel the need to find a new voice in order to express themselves, a voice they will be able recognize as their own voice that is different and detached from biomedical narratives and traditional norms of society.⁴

Illness narratives have become a recognized chapter in medical anthropology since the publication of Arthur Kleinman's book, *Illness Narrative*, in 1988. Unlike biomedical case studies, where the patient is only given reference points to some standardized criteria, Kleinman puts a greater emphasis on the patient's subjective experience, on the way he perceives his own disease and the socio-cultural elements that contribute to the interpretation of the events related to the disease. In the author's view, narratives of illness act as a way of giving meaning and coherence to all the events related to the disease. Narrative threads of these stories, as well as the metaphors and rhetorical processes used in their shaping are based on both personal patterns and cultural narrative patterns shared across the entire community, patterns that contribute to a significant structuring of the events of illness, and to the transmission of the meanings they carry.⁵

¹ Michael Bury, "Chronic illness as biographical disruption," *Sociology of Health and Illness* 2 (1982): 167–82, 265.

² Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago, London: The University of Chicago Press, 1995), 5.

³ *Ibid.*, 6.

⁴ *Ibid.*, 6.

⁵ Arthur Kleinman, *Illness Narratives* (New York: Basic Books Inc. Publishers, 1988), 49.

Researchers were primarily concerned with the stories of patients affected by severe illnesses or various chronic diseases. All types of diseases affect the individuals' daily lives, but chronic or severe diseases determine with predilection a major intrusion into one's personal history. Disease, particularly chronic disease, is a major experience that more or less undermines the structures of everyday life, our knowledge about the world, or values that guide our existence.

Affecting the natural flow of everyday life, the disease causes a crisis within the individual's personal biography, threatening "one of the fundamental aspects of life – its extension in time, its temporality. The experience of continuity and inner coherence is called into question, perhaps becoming invalid altogether."¹ In this context, the person affected by the disease is sometimes forced to reassess their entire life, preceding a careful examination of the present and especially of the past, thus the narrative becomes an ideal opportunity to establish a link between past, present and future.²

Re-evaluating present and past events through the lens of the present, and re-organizing their perception of the future according to the current situation, a person can regain a lost existential order. By reinterpreting the narrative of events and establishing relationships between them, the patient manages to recreate a new context in which disease events have a natural place, or, in other words, the disease is "positioned within the time and the space of one's personal biography."³

In the case of people affected by serious diseases, one of the central – functions of narrativity, and perhaps the most important one, is that of the re-affirmation in a positive sense of the self and that of restructuring a personal identity threatened by the disease or its consequences. In an excellent study on the consequences that chronic disease may involve in the individual's life, Kathy Charmaz argues that one of the main sources of suffering for those affected by disease is the continuous process of losing the sense of self integrity. As a result of disease suffering, patients experience a restricted life (mainly due to equipment deficiencies), some degree of social isolation and the loss of independence, being forced to rely on others, while all these facts lead to the overburdening of their family, friends, etc. and to the disintegration of the positive self-image prior to the disease.⁴ Given the theoretical framework of symbolic interactionism, which states that "the self is developed and maintained by social relations", the dependence on others (in the case of chronic disability) the impossibility of fulfilling social roles, and the loss of control over their own lives and future make patients' self-esteem decrease significantly, a fact that leads, most of the times, to a de-construction of their identity.⁵

¹ Hyden, "Illness and narrative," 52–3.

² Elinor Ochs and Lisa Capps, "Narrating the self," *Annual Review of Anthropology* 25 (1996): 19–43, 24.

³ Hyden, "Illness and narrative," 53.

⁴ Kathy Charmaz, "Loss of self: A fundamental form of suffering in the chronically ill," *Sociology of Health and Illness* 2 (1983): 168–95, 168–9.

⁵ Ibid.

Starting from the story of a man affected by multiple sclerosis, divorced and unemployed, Catherine K. Riessman analyzes step by step how this person uses different narrative strategies to assert a positive self. A key aspect of this narrative is “bewitching” the listener, completely capturing the listener in the narrator’s story.¹ Through the reinterpretation of tragic events in his life, the individual is undertaking a process of selection, of re-organization and reinterpretation of these events until he appears as a competent person in the audience’s eyes, who has control over his life and whose failures are always caused by his disease, in spite of which he may perceive himself as having an integral, valuable and socially competent identity.

In a survey on people affected by cancer in Mexico, Linda M. Hunt shows how patients use illness narratives as a tool, as a form of reaction to the previous identity disintegration by reaffirming a narrative of a new place in their social and family life. Representing a legitimacy of certain incapacities of fulfilling culturally valued social functions, the disease gives the individual the opportunity to negotiate, through narrative, a new identity in which earlier social roles are modified in the favour of the patient.²

Another representative author in narrative studies is B. Good, whose research on epileptic patients and their families in Turkey constitutes a milestone in medical anthropology. Trying to overcome previous studies on narratives of disease – focussing on structural features of illness narratives, on various types of knowledge and interpretation of disease patterns suggested in these narratives, and on the consequences of disease on people’s lives³ – Good brings new elements in this line of study. Based on studies of literary theorists (as Iser and Ricoeur), Good highlights what is called “reader response”, a theory based on the temporal and intersubjective qualities of the narratives. This perspective especially reveals the central role that the “reader” plays in the process of giving sense to a narrative. Far from being a passive recipient of the message conveyed by the narrator, the reader is – by contrast – an equal partner in building the significations of the text, while the production of meaning is the result of the interaction between reader and text.⁴

Applying this theory to narratives of illness, Good transfers the reader’s role from literary theory to the narrators of the disease. Thus, the narrator (in this case the suffering person) behaves as a “reader” of his own life and the events related to the disease. Because the “story” is never complete, story-tellers resemble the readers of a text, stories having the potential to constantly change as events

¹ Catherine Kohler Riessman, “Strategic Uses of Narrative in the Presentation of Self and Illness: A Research Note,” *Social Science & Medicine* 2 (1990): 1195–200, 1197.

² Linda M. Hunt, “Strategic Suffering. Illness Narrative as Social Empowerment among Mexican Cancer Patients,” in *Narrative and the Cultural Construction of Illness and Healing*, eds. Cheryl Mattingly and Linda C. Garro (Berkeley, Los Angeles, London: University of California Press, 2000), 88–102.

³ Byron Good, *Medicine, Rationality, and Experience* (Cambridge: Cambridge University Press, 1994), 142.

⁴ *Ibid.*, 143.

unfold, opening ways to interpretations and alternatives.¹ Good highlights how the narrative makes reality subjective, inviting the reader-narrator to bring together the multiple readings of his own story, in an effort to identify the various causes of disease, different sources of efficacy in treatment, or alternative story endings, etc.²

Regarding the intersubjective nature of narratives, Good identifies the main elements of intersubjectivity: first of all, the bases of each disease are some stories shared by the entire community and by cultural patterns that shape the way in which experience is structured into the narrative; secondly, stories are dialogically constructed, sometimes made into a conversation between two or more people; thirdly, the narratives are always somewhere between the authors, narrators and audience.³

The intersubjective character of the narrative has been noted in various studies that focused on stories of personal experience. As Elinor Ochs and Lisa Capps remarked, narratives constitute a medium of socialization,⁴ a space where different voices contribute to the co-construction of the entire narrative. In the process of description and interpretation of events related to health and illness, the individual resorts to a framework of pre-established values and attitudes in the culture and society to which he belongs. It is generally accepted by social researchers that the very definition of health and disease is variable in terms of socio-cultural and historical narratives and that patients' narratives are always based on a frame of reference that is supported by the entire community. The narration of their personal disease takes place according to certain formal narrative structures that they acquired in the family or among friends, according to stories of popular culture or other patients, using certain standard metaphors and images related to what is allowed to be said.⁵ The narrative convention "determines what is considered [to be] a credible, coherent, comprehensive, interesting, moving and morally sound story."⁶

From the simple description of symptoms to the evaluation of the consequences of a disease, each narrative is driven by the dominant discourses in the context in which the patient is positioned. In other words, stories of illness are generated within the contexts of social interactions and use images and ideas that are socially available.⁷ In modern societies today, each illness story is based, more

¹ Ibid., 145–6.

² Ibid., 153–6.

³ Ibid., 158.

⁴ Ochs and Capps, "Narrating the self," 31.

⁵ Arthur Frank, *The Wounded Storyteller*, 3.

⁶ Laurence J. Kirmayer, "Broken Narratives. Clinical Encounters and the Poetics of Illness Experience," in *Narrative and the Cultural Construction of Illness and Healing*, eds. Cheryl Mattingly and Linda C. Garro (Berkeley, Los Angeles, London: University of California Press, 2000), 154.

⁷ Jan Robinson, "Personal narratives, social careers and medical courses: analysing life trajectories in autobiographies of people with multiple sclerosis," *Social Science and Medicine* 2 (1990): 1173–86, 1184.

or less (depending on the person's social status), on the bio-medical explanatory model, without being reduced to it. Within the same narrative, voices of doctors, medical press, religious courts, or other patients who have undergone similar experiences, family etc. are interwoven. Moreover, the same events can be presented differently as the patient comes into contact with other people and other types of discourse.

Research context and methodology

As stated at the beginning of this article, the present study is an analysis of the way the subjective experience of illness is transposed into the narrative of a woman affected by breast cancer. The main objectives of this analysis are: a) presenting the process of deconstruction of life narrative prior to the disease and the reconfiguration of a new narrative aimed to restore the order that the disease has destroyed; b) identifying ways in which the meaning of illness and the attitude towards it is based on cultural representations in contemporary society.

The narrative I will refer to was collected during a qualitative research carried out on cancer-patients. The survey started in April 2010, in a surgery clinic in Cluj-Napoca (Romania), where I held several interviews with cancer patients. In addition to the research conducted in the clinic, several interviews were taken in private places (patients' home or other locations in the city).

The participants in my study suffered from various types of cancer and came from diverse backgrounds (workers, intellectuals, farmers, etc). They were of different genders and aged between 30 and 76.

The qualitative research methodology used is mainly based on in-depth and semistructured interviews. The first part of the interview was centred on the initial narrative of the disease, where my role was to encourage the patient to report the main stages of the disease as much detailed as possible and to talk about the issues that he considers relevant in connection with this experience. This first story aimed to place the events of the illness in a broader context of the patient's life, and to get as much information as possible about his life before and after the diagnosis. The second part of the interviews aimed at deepening certain aspects of the experience of illness, while the patient was guided by certain key questions in the pre-interview.

Focusing on a single narrative of illness, this article is justified by the wish to provide a coherent and detailed vision regarding the process of deconstruction involved in the experience of illness. The presentation of a single case enables a detailed analysis of the biographical context in which the disease occurred, facilitating the establishment of relationships between certain elements of personal biography and the representation and attitudes towards illness. Moreover, focusing on a single narrative gives the opportunity to reveal extended excerpts of the interview, giving the narrator the chance to re-present himself/herself to the reader.

Case study: Cancer narrative

The protagonist of our narrative is Mary (a pseudonym), a 46 years old engineer. She is married and her daughter graduated from university.

The appearance of the disease was sudden, as it is in almost all breast

cancer cases. One morning, Mary discovered a nodule in one breast. Initially, her reaction was one of denial, postponing medical consultation for a month. Eventually, medical tests confirmed a cancer diagnosis. She attended the first surgery and radiotherapy. Although initially her case appeared to be a simple one with no complications, after less than a year, her disease relapsed, and the result was losing one of her breasts.

“Hey, without any symptoms. [...] I told them I am an engineer...an extremely active life, from morning...till evenings ...and [...] sports style. I’m in a continuous motion. I never had health problems of any kind. Appendix, that’s all. And one morning, in the shower, I found a nodule. Painless, not at all. I thought it’s only in my mind, I postponed medical control for one month, and after a month I said...well, however, I should not [...] run away from it. And then I went across the street, I had a mammogram, and to my surprise there were two, not one ... Two nodules, a well-defined one (that I’ve found on the surface), and a hidden one, under the nipple. “None of them will create problems”, I’m quoting doctors ... so, “they will not create problems...” Ok, I said, two nodules, it’ll be all right, radiotherapy ...” [...] So, finally, I had them taken out, everything was ok ... I had radiation therapy, and now, after less than a year, I have found another one ... This time I had my breast removed, and I started chemotherapy. As you can see, I am waiting to collapse.”¹

The period following the diagnosis is characterized by an attempt to exclude the disease from their daily life and continue the lifestyle prior to the disease. Continuing their professional activity represents the maintenance of social validity, and at the same time the maintenance of a coherent sense of identity. The initial denial of disease is a sign of resistance to the breaking-down of the life story. The disease is not excluded from consciousness, but there are efforts to place it in the background.

“What can I say ... now, you know, I blame myself because, during that period of time, last year [...] there were a lot of projects I was involved in, and although I was undertaking medical treatment, whenever I was needed, I went to

¹ -Mai, fără niciun simptom. [...] Ți-am zis că sunt constructor, o viață extrem de activă, de dimineața [...] până seara, și [...] genu sportiv, genu în mișcare continuă. N-am avut niciodată probleme de sănătate, de nici un fel. Apendicele, atât. ,i, într-o dimineață, la duș, am găsit un nodul. Nedureros, ne nimica. Am zis ca mi se pare, am amânat o luna, după o lună am zis că totuși, hai să nu mă [...] ascund după degete. ,i-atuncea am trecut peste drum, mi-am făcut o mamografie, și spre surprinderea mea nu erau unul, că erau doi...Doi noduli, unul bine definit, așa, pe ăla l-am și gasit la suprafață, și unul ascuns sub mamelon. « Nici unul dintre ei n-o sa creeze probleme », citez din medicii care...asa, « n-o sa creeze probleme...Ok, am făcut un sector, doi noduli, axila, cu tot, o să fie totul în regulă, radioterapie... » [...] Așa, în fine, i-am scos, totul o fost ok...Am făcut radioterapie, și acuma ,după mai puțin de un an, o recidivat, mi-a apărut un alt nodul, tot așa, l-a gasit...De data asta mi-a scos sânul, și-am început chimioterapia. După cum mă vezi, is în așteptarea căderii.

work. And this means that I worked almost 8 hours every day [...] As a chief engineer, you know? And honestly ... I never realized how tired I was... or how sick. After all, ... I had no symptoms whatsoever. And after the surgery I just had a nasty feeling in my arm [...] Okay, I used to put pads in my bra... so, [...] I went on. [...] I had to behave normally. And [...] I never noticed, as I was moving forward and doing a great job ... [...] Well, I went on ... you know, about 5 months in this rhythm. Of course with the fear I have to keep my job. You know, thinking that if I do this it'll be ok, that complications will not arise, and everything will be fine [...]

– And did the fact that you were going to work help ...?

- It helped a lot, you realize that ... I was ok. Sometimes it happened that someone looked at me and said: "I know that ..." Well, so what? Look at me, I am very well...¹

This initial attitude towards Mary's illness falls in what A. Frank called "restitution narrative", a theory based on a contemporary cultural model that considers health a value and the normal human condition; this type of narration reflects the desire and belief in recovery. The story follows a simple scheme: "Yesterday I was healthy, today I am sick, tomorrow I'll be healthy again."² Specific to the initial phases of the disease, these narratives are shaped by contemporary institutional discourses about disease, stories that present different materials containing stories of people who have recovered,³ or advice about the benefits and effects of the desire for recovery. This narrative pattern comes from the biomedical sphere, obsessed with complete healing, certainly the most desirable cultural model of disease,⁴ but which, unfortunately, proves to be non-efficient for people suffering from chronic or extremely severe diseases.

In a paper about the cultural history of disease representations, Claudine Herzlich and Janine Pierret show how in our contemporary society "the duty to be

¹ *Ce să zic... Acuma, așa, știi, pe parcurs îmi reproșez că în perioada aia, anul trecut, [...] erau o gramadă de proiecte în care eram implicată, și chiar dacă făceam radioterapie și tratament, și eram în concediu medical, de câte ori m-or solicitat am fost la muncă. ,i asta înseamnă că am fost aproape program de 8 ore, în fiecare zi [...] Fiind șef de punct de lucru, știi? ,i...sincer nu mi-am dat seama cât îs de obosită...Sau cât îs de bolnavă. Că până la urmă...n-am avut nici un simptom, de niciun fel. ,i după operație era numai senzația neplăcută cu axila, cu mâna, limfa, și astea. [...] Bine, mai puneam pernițe în plus la sutien și...cam atât, [...] Am mers mai departe. [...] A trebuit să mă manifest normal, a trebuit să mă port normal. ,i [...] nici n-am bagat de seamă, fiind în mișcare și facând mai departe o treabă ...[...] No, am mers...știi eu, vreo 5 luni în timpul ăsta. Bineînțeles cu spaima că trebe să-mi țin locul de muncă. ,tii, că dacă fac asta o să fie totul ok, ca n-o să se ivească complicații, ca eu termin și o să fie în regulă[...]*

-,i faptul că mergeați la muncă vă ajută...?

-Asta m-o ajutat foarte mult, îți dai seama, că...eram ok. Mai dadea câte unul cu ochii de mine și zicea : « ,tiam ca... » No, și ce, ți se pare că-s pe moarte? Uită-te la mine ce bine arăt, sunt în formă...

² Frank, *The Wounded Storyteller*, 77.

³ Ibid., 70–80.

⁴ Ibid., 83.

healthy replaced the right to the disease.”¹ In such a context, the disease constitutes an obstacle to social and personal fulfilment, and narratives that favour recovery and the perception of disease as a simple unwanted incident are always the most sought in contemporary society.

In this first stage, Mary refuses to get too much biomedical information related to her disease. Sitting around other women with cancer who talk for hours about their illness, she chooses to ignore aspects of its organic existence, because she does not wish her preoccupations to be reduced and limited to her disease. Refusing knowledge of biological mechanisms that stand at the basis of her disease is actually an act of resistance to enter a world dominated by disease. She does not want her concerns and her whole existence to be restricted to comments related to her bodily condition.



Irina Dumitrașcu, *Self Confused 3*
Photography print, 40x40 cm, 2009
Website: www.bavardestudio.ro

¹ Claudine Herzlich and Janine Pierret, *Malades d'hier, malades d'aujourd'hui* (Paris: Payot, 1991), 284.

“I don’t want to know a lot about my illness. I just don’t want to. That, [...] you know, when you know too many things, you put them together and they grow too much. And I said no. Sir, you are my doctor, tell me it goes well or it goes wrong. And if it goes wrong, tell me what we should do, if it’s all right, tell me what we should do. I quoted what I told the surgeon”.¹

We can observe that during the healing process, doctors play the active role, while patients have a passive role, a model assigned to the functionalist perspective on doctor-patient relationship and about the obligations that each part has to play in the context of the disease. The functionalist model, theorized by Talcott Parsons, known as the “sick-role” model, affirms that patients must give up control over their body and fully comply with medical examination. According to this model, the patient is freed from social obligations for the moment, his/her only duty being to want to heal and to follow medical advice in order to achieve this goal.²

The concept of “sick-role” becomes ineffective when it comes to relate to people suffering from chronic diseases.³ Failure of healing leads to an emphasis on how to manage symptoms and adapt to the new situation. When healing does not seem possible anymore, the doctor’s role is practically annihilated, and the control over the situation is taken by the patient and often by his/her family. This is also Mary’s case. Her refusal to know detailed aspects related to her disease and her tendency to entirely rely on doctors can be observed only as long as the disease appears to be only an incidental and fleeting episode. The moment when the situation becomes complicated and the disease is seen as a permanent condition, Mary understands the need to take control over it and is actively involved in managing her disease.

After the breast operation, a period of real crisis followed. This time the disease and its effects have finally entered Mary’s consciousness, causing a collapse of all the significant structures that were the basis of her existence.

So [...] this is what I can say ... it is... [...] really [...] a life turned upside down [...] ... suddenly life no longer makes any sense.⁴

The first serious shock was the possibility of losing her job (she was told to find another job when the sick-leave period would end).

“Look, he says, go home and stay home, we’ll call you when we need you, but keep searching for some other job, because we cannot give you a job with no

¹ *Eu nu vreau să aflu foarte multe despre boala mea. Deci nu vreau. Că, [...] știi, când aflu multe lucruri le pui laolaltă, deja capătă prea mare amplitudine. ,i-am zis că nu. Domnule, tu ești doctorul meu, spune-mi că merge bine sau nu merge bine. ,i dacă merge bine, ce facem, dacă nu, ce facem. Chiar așa i-am zis și chirurgului.*

² Kathy Charmaz, “From the “Sick Role” to Stories of Self. Understanding the Self in Illness”, in *Self, Social Identity, and Physical Health*, eds. Richard J. Contrada and Richard D. Ashmore (New York, Oxford: Oxford University Press, 1999), 211.

³ Ibid., 213.

⁴ *Deci asta [...] pot să spun că...îi chiar [...] o viață dată peste cap [...] dintr-o dată nu mai are sens viața.*

stress, you know. After your sick leave ends [...] you must look for a new job, I hope it's clear. Well, I suppose this was a pretty big shock for me after a period – I told you – when I went to work for five months, from September to September, October, November, December, January, five months - I went every day to work, and ...”¹

Given the fact that we live in a society where individuals are recognized by the professional or social activity they perform, a disease leading to disability is a threat to the place the individual has within the community.

All the social rules regarding the criteria that legitimize social identity are most often deeply internalized. In Mary's case, her professional identity overlapped ninety percent over the meaning of her existence in the world. A disease that could lead to the end of her professional activity means a sudden interruption of her personal story. We are dealing in this case with what Frank A. called the "narrative wreckage",² that is a fall of all the coordinates that were once establishing a person's identity before the appearance of the disease. Profession is one of the basic elements of this identity. In Mary's case, not only financial problems may arise from losing her job, , but also the problem of losing a significant key-element of the self.

“Me, I worked all the time. And now what? Well I was like a lion in a cage. What do I do now? [...] If I'll have the chance to get well, I'll get sick looking for work or for ideas.”³

Mary's work performance was closely related to the role she had in the family, being, as she says, “the man in the house”, meaning that she had the responsibility for the material support of the family. Failing to accomplish this function, due to changes of circumstances caused by the disease, involves a reconfiguration of the role Mary will have in the family from now on. Appropriating some household activities previously ignored, she discovers for the first time a lifestyle that is generally associated with femininity. Although these activities often have a positive effect on her mental state, leaving her other social roles is still a constant source of suffering. Therefore, during the interviewing period, Mary was still in the process of disintegration of her old social identity, showing, at the same time, some attempts to search for future alternatives that could rebuild a different position in society.

Faced with significant changes caused by the development of the ailing process, the individual tries to find an explanation for the situation he/she is put into, thus the first question he/she asks is always a question about the origin of the

¹ *Auzi, zice, du-te acasă și stai acasa, că te mai sunam noi dacă avem nevoie de tine, dar caută-ți de lucru, pentru că noi loc de muncă fără stres nu putem să-ți dăm. Când termini cu concediul medical [...] să-ți fie clar că trebuie să-ți cauți de lucru. No, presupun că și asta a fost un șoc destul de mare pentru mine, după ce ți-am zis că din septembrie - septembrie, octombrie, noiembrie, decembrie, ianuarie, 5 luni - m-am dus în fiecare zi la servici, și...*

² Frank, *The Wounded Storyteller*.

³ Eu, eu am muncit tot timpul. Și-acuma ce fac? Păi am fost ca un leu în cușcă. Ce fac? [...] și-acuma îs la fel. Dacă o să am șansa să mă fac bine, o să mă îmbolnăvesc căutând de lucru, sau căutând idei.

disease, about the causes of its appearance. Limited to a biologist explanatory model, medicine fails to provide a satisfactory explanation, as it ignores the larger context of patients' lives. The individual is thus forced to seek throughout his/her past in order to discover the cause or significance of his misfortune. We are dealing in this case with what Gareth Williams called "narrative reconstruction" of personal experiences. In the author's view, etiological stories of patients "represent not only explanations for the onset of a given disease, but also acts of interpretation, narrative reconstructions of profound discontinuities in the social processes of their daily lives."¹

Although in Mary's case the etiological aspects of the disease do not appear as one of her major concerns, the identification of events in her personal biography that could explain the appearance of the ailing phenomenon is still an important element of her narrative. Due to the fact that biomedicine does not provide accurate data regarding cancer occurrence, etiological explanations come from outside the biomedical area, and are based on certain alternative "voices" provoking to re-evaluate their own biography in order to discover certain factors that could trigger her disease. For Mary, a possible explanation could be some conflicts in the sphere of her inter-personal relations.

But I bumped into this thing, you know, and I remembered some things...like they say that because of stress [...] your nodules appear and everything. And while searching, you know, I remembered that I had an awful experience. Awful. I was hit so ... so hard [...] by two colleagues from work. So...I was so disappointed! So... [...] we had a discussion that gave me the feeling of a cold stone on my heart. Yes, in that moment I really, really had a stone straight on my heart, you know? So, it broke my shoulders and I thought the world crashed. Okay, this was one of the things, and – in the same period of time – somewhere at the beginning of December this happened – there was another thing: I have some very good friends ... Apart from my job, I was doing a lot of stuff, you know? I used to work with these friends, [...] in my mind, I thought they cared about me. I mean our relation seemed as...I don't know how to say...an open relationship, where you can open your heart, share your ideas, they call you at midnight and say: hey, I have a problem, what am I doing? Can I...Yes, do me this favour. You know, this kind of thing. And I've discovered, to my surprise, that it wasn't like that, not at all. From my point of view, things were as I said, but from their point of view I was just the one who knows how to deal with any situation, I'm useful, that's all. I thought I am their friend, you know? Or...maybe I was, but they weren't, something like that...and this thing... upset me.

– Do you think these inter-personal conflicts, with your colleagues and with the two – so called – friends, contributed to the appearance or aggravation of your disease? Do you see it as a cause?

– I don't know...you probably heard about Hamer, and his method with the stress-factor, you know? And he says, very interesting, that breast nodules are

¹ Gareth Williams, "The genesis of chronic illness: narrative reconstruction," *Sociology of Health and Illness* 2 (1984): 175–200, 179.

*generated by social conflicts or conflicts with your partner. And [...] with my husband it's not the case. Not at all. So the social conflict. I don't know, [...] I don't want to say...I can only say precisely that that was the moment when the world crumbled.*¹

Another relevant aspect of illness narratives is the issue of social exclusion manifested in terms of disruption or change in relationship with others. Although cancer is not a contagious disease, patients often encounter feelings of social isolation and are often avoided even by their best friends. The explanation for this phenomenon can be found in the cultural dimensions of cancer, where this disease is primarily associated with death. The cancer patient is a prisoner, a living dead: “*you are deleted from the list, you don't exist anymore. Honestly ...*” concludes Mary.

*“And, it's an obvious thing, you are already out of the game ... You're out of the game [...] I have no friends anymore. My best friend... for years we worked together, we've raised children together ... [...] Well, believe me, after one year we met last week. My best friend.”*²

“And ... you know... I had very strange reactions, for example, at the bank. I went to check my [...] You know, you have to go once a year to renew your

¹ *Dar m-am bătut de lucrurile astea, știi, și în timp așa mi-am adus aminte niște chestii că cică pe bază de stres [...] îți apar nodulii și toate. Si, căutând așa, știi, mi-am adus aminte că am avut o experiență sinistă. Deci sinistă. Am fost atât de...atât de tare lovită [...] de doi colegi de la servici. Atât de...atâta de dezamăgită am putut să fiu! Așa...[...] o fost o discuție care pentru mine s-o lăsat cu senzația de piatră pe suflet. Deci în momentul ăla chiar am avut o piatră pe suflet, știi? Așa, mi s-or cocărjat umerii și parcă mi s-o sfărmat toată lumea. Bun, asta o fost una dintre chestii, și tot atunci, în perioada aia, o mai fost o altă chestie : am niște prieteni foarte buni...Pe lângă slujba de toată ziua, mai făceam în particular o grămadă de chestii, știi? Niște prieteni foarte buni cu care lucram, și eu, în [...] înfumurarea mea credeam că sunt o persoană importantă pentru ei. Adică relațiile noastre păreau de așa fel, încât...Nu știi cum să zic, știi...o relație deschisă, în care vorbești, îți spui ideile, te sună la miezul nopții : Măi, mi s-o spart țevile, ce fac? Pot să...Dă-mi, fă-mi...știi, chestii de-astea. Și-am descoperit spre surprinderea mea că nu era absolut așa, deloc nu era. Din punctul meu de vedere relația era așa, din punctul lor de vedere era: eu sunt tipa care mă descurc în orice situație, îs bună la toate, da cam atât. Eu credeam că-s și prietena lor, știi? Or eu eram, dar ei nu erau. ,i chestia asta m-o...m-o bulversat.[...]*

-Considerați că [...] aceste conflicte interpersonale, cu cei doi așa-ziși prieteni și cu colegii, au contribuit cumva la apariția acestei boli, sau la agravarea ei? O vedeți ca și o cauză?

-Nu știu...Ai auzit...sigur ai auzit de Hamer, de metoda Hamer, asta cu factorul de stres, știi? Și ce-i ciudat că asta zice ca nodulii la sânul drept se fac pe conflicte sociale, pe conflicte cu partenerul... Ori [...] cu soțul meu nici nu se pune problema, deci nu este omul de conflict. Deci pe partea de conflict social. Nu știu, [...] nu vreau să zic...Pot să spun cu precizie că atunci s-o prăbușit lumea.

² *Și, e evidentă treaba, deja ești...ești scos din joc...Ești scos din joc [...] Nu mai am prieteni. Prietena mea cea mai bună, ani de zile am lucrat împreună, ne-am crescut copii...[...]) Ei, crede-mă că după un an de zile ne-am văzut săptămâna trecută. Prietena mea cea mai bună.*

*contract and everything. And I showed my identity card [...] and I don't know why, she looked on the back. I don't know why she did that. And there is a bar code ... for identification at the oncology hospital. She looked at me, and her attitude changed ... I got angry and said: Don't worry, it is not contagious! I took my identity card and I went to another [...] branch office, [...] I could not look at that woman anymore, I was angry. She was a woman, you know, that's even more ...*¹

*".. it is not nice at all when you see how they close the doors in front of you, it's unpleasant. And I do not know why [...] you have to lie, to hide this, because that is not [...] even a sexually transmitted disease [...]. It's not a shameful thing, you know, that's it. And then [...] I wonder... why are they so false, [...] and why ... so fearful?"*²

The perception of this disease often leads to social isolation, and contributes to the annihilation of the self, to a gradual deconstruction of personal narrative. Due to the fact that the self is developed and maintained through social relations,³ their restriction causes a dislocation of identity. In this context, a cancer diagnosis is one of the main ways of socially defining a person, and the multiple identities are, therefore, annihilated.

*You know, you're like a horse ... you have those shutters in front, you can only look forward, and everybody says: "look around, baby, look how beautiful everything is." "Where?"... Because you cannot look around, because all these people around you are some imbeciles who already put you on a dead line.*⁴

A person affected by cancer is living a time when the old order and meaning of life enters a stage of deconstruction. Life values and their meaning that used to guide their lives, as well as the significance given to the events and things that surround them, start to crush, and old priorities are losing their importance. In this sense Mary confesses:

You regret a lot of stuff, and you see very clearly your mistakes from the past [...] it no longer seems important that I sat from morning till evening at work to do [list of some projects at work] ... How many people from Cluj know that ...

¹ Și...să știi că am avut reacții foarte ciudate, de exemplu la bancă. Am fost să-mi verific [...] știi, mergi o dată pe an să-ți reînnoiești contractul și toate alea. Și i-am dat buletinul [...] și nu știi de ce l-o întors. Și este eticheta cu care...este un cod de bare cu care te identifică mai ușor la fișă. E ok, umblii mai ușor la oncologie. S-a uitat așa tipa, și-o schimbat atitudinea...M-am infuriat și-am zis: Stai liniștită că nu se ia ! Mi-am luat buletinul, mi-am luat cartea de identitate și m-am dus la altă [...] filială, [...] nu m-am mai putut uita la femeia aia, m-a scos din sârute. Era o femeie, știi, că asta-i mai...

² ...e neplăcut că ți se închid ușile în nas, e neplăcut. Și nu știi de ce [...] trebuie să minti, să ascunzi lucrul ăsta, pentru că nu e [...] nici măcar o boală cu transmisie sexuală [...]. Nu-i o chestie rușinoasă, știi, asta e. Și-atunci [...] de ce-s atâta de falși, [...] de ce-s atâta de temători...?

³ Charmaz, "Loss of self...", 170.

⁴ Știi, ești ca un cal din ala care ai clar puse obloanele alea în față, numai în față poți să te uiți, și toată lumea îți spune: "Da mai uită-te în jur, dragă, uită-te cât îi de frumos." Unde? Pentru că tu nu poți să te uiți în jur, pentru că toți ăștia care-s în jurul tău îs ca niste imbecili, care te-or băgat deja pe linia moartă.

actually was that my work from the beginning to the end? [...] Nobody knows, nobody ... And I really put all my heart into those projects, you know, I missed many other things ... I failed ... I didn't spend time with others, I rarely visited my mother and my father... he was sick ... maybe ... I did exactly the same as the others do now, [...] and now I get the same coin. I also avoided my father ... as much as I could, when he was sick. I have done my duty, but nothing more. With fear,... not from all my heart. [Pause] That's the truth ... And ... I do not know, you must put your soul [...] in everything you do. And I am watching others [...] with mercy ... those who do not know how to live their lives. Or even if they do so [...] they are fulfilling their plans, their dreams, they just make some plans, and they change their dreams, in order to be [...] trendy ... [...] I mean...it is so good to sit with your feet in the cold waters of Aries [river], whenever you want ... [...] I think it's much more OK than to go to Ibiza, you know? Because after all...all these are vices [...] you have to find fulfilment in another way, you know?¹

I enjoy the little things [...] they are so precious ... [...]. I sit in the garden and, you know, there was an ice rain in the orchard, and I go to each tree and I still find rotten apples, so I separate them from the others, while I speak with each one ... I have three bee colonies, and I speak with the bees ... Then I go under the walnut tree, where my dear dog is buried ... [...] I don't like people at all anymore. Not at all (she cries). I'm angry with them.²

Most of the time, reconsideration of personal values and beliefs is the result of the appearance of death awareness. If so far death has been a remote element, the existence of which was placed in a corner of consciousness, now it becomes a factor in relation to which life is reconsidered. Discovering new meanings, establishing new values and imposing a new order in life is but a long term process,

¹ Regreți o gramadă de chestii, și îți vezi foarte clar greșelile din urmă [...] Nu mai pare la fel de important faptul că stăteam de dimineața până seara ca să mai fac [enumera câteva proiecte de la locul de muncă] Câtă lume știe din Clujul ăsta că... practic aia o fost munca mea de la început până la sfârșit? [...] Nimeni nu știe, nimeni...și eu mi-am pus chiar tot sufletul acolo, știi, și-am ratat multe chestii...am ratat multe...N-am avut timp să stau cu ai mei, m-am dus mai rar pe la mama, pe la tata...Era bolnav...poate am făcut și eu la fel ca ceilalți, [...] și-acuma primesc aceeași monedă. Că și eu l-am evitat pe tata...cât am putut, în perioada aia în care a fost bolnav. Mi-am făcut datoria, da nu cum ar fi trebuit. Cu spaimă, nu din tot sufletul. [pauză] ăsta-i adevărul...și...nu știu, trebuie să pui suflet, [...] în tot ce faci. Și, mă uit așa [...] cu milă...la alții care nu-și trăiesc viașa asta. Sau și dacă trăiesc, [...] nu-și fac planurile lor, nu-și împlinesc visele lor, fac niște planuri, și-și schimbă visele așa, ca să fie [...] în trend...[...] Adică e atâta de bine să poți să te duci să stai cu picioarele în apă rece la Arieș, dacă ai chef...[...]Cred că-i mult mai ok decât să te duci la Ibiza, știi? Nu mai au importanță viciile, știi? Că până la urma toate chestiile astea-s vicii [...]Trebuie să-ti gasești altfel împlinirea, știi?

² Mă bucur de lucrurile mărunte, [...] așa de mult contează...[...]. Stau în grădină și, știi, o bățut gheața în livada de poimi, și mă duc pe lângă fiecare – is mulți, meri, pruni – și mai găsesc încă mere lovite, și le iau, le separ pe alea care-s întregi, povestec cu fiecare în parte...Am 3 stupi, povestesc cu albinele...Mă duc sub nuc unde-i îngropat câțelul meu drag...[...]Nu mai îmi plac oamenii deloc. Deloc nu-mi plac (plânge). Mă enervează.

and it depends on a wide range of factors such as the physiological evolution of the disease, socio-economic status of individuals, family support, etc.

We will now continue with some aspects related to the body itself. In the case of people affected by cancer, especially in the case of breast cancer, physical modification appearing as a result of diverse medical treatments is another major factor in the process of the self-image deconstruction. For Mary, the loss of a breast was one of the hardest moments she had to survive, as the event provoked a profound alteration of her gender identity, as well as a deepening of the self isolation tendency. The impossibility of watching herself in the mirror, or the refusal to go out from her house – fearing to be seen by others – reveals a serious conflict among body, self and society.

*If I think of myself, I feel ... I am a monster ... I have no breasts, no hair, [...]... [pause, she cries]...no perspectives...*¹

*You know, when I meet someone who knows I had a surgery, you know ... I always discover their look on my breasts ... [...] trying to guess...*²

Building the image of the self takes place as a consequence of an instruction process, of interpretation and internalization of the judgements we think others make regarding our body. This process of self-configuration through the interpretation of the other's view has a "normalizing" function. The body is obliged to conform to standard rules, in such a way that it should not attract disapproval, horror, pity or any other feeling that can lead to social isolation.

In the case of a chronic disease or disability, the body's misalignment to the standards imposed by society can cause a dislocation of self-perceptions. Any damage to the body caused by the disease itself, or as a consequence of medical treatment procedures, leads to a distance between the idealized images of the actual body and its ideal image. Imagining the possible judgments of others, patients tend to depreciate themselves, a fact that leads to a sharp deterioration of personal identity, or to distance themselves from their own body trying to define themselves through other coordinates.

*And if you can believe me ... my family... they didn't see me ... not really... I couldn't let them see me. I find it difficult to wash my back, for example...but I cannot ask them to help me, you know... I secretly brought a prosthesis.*³

*Even though it looks quite good with the prosthesis, I feel... I don't know ... I'm hiding myself. I don't really go out. Only if it's really necessary, you know? And this is also complicated...*⁴

¹ *Și-acuma mă gândesc că... sunt așa, [...] un monstru, fără țâțe, fără păr, [...] (pauză, plânge)...fără perspective...*

² *Știi că mă întâlnesc cu câte cineva care știe că am fost operată, știi, nu pot să nu-i surprind privirea pe...pe săni, [...] încercând să ghicească.*

³ *Și...dacă poți să mă crezi că...ai mei nu...nu prea m-or vazut...n-am putut să-i las să mă vadă. Mi-i greu să mă spăl pe spate, de exemplu, [...]. Nu pot să-i chem să facă chestia asta. M-am dus pe furiș și mi-am cumpărat proteza.*

⁴ *Chiar dacă arată bine cu proteza și cu toate astea...mă simt [...] Nu știu, mă ascund. Nu prea ies din casă. Numai dacă-i chiar musai, știi? Și-asta...îi complicat, știi...*

So I have no mirrors at home, I'm telling you. In the bathroom... I never had mirrors, I never liked them. And I never look at myself in the mirror when I take a shower. I come out with my back, then I get dressed. Only then, I look in the mirror. Yes, I watched myself ... It's strange, can I say that I feel sorry for me? I see myself and I don't want that (she cries).¹

Facing this deconstruction, the person tries to find new foundations in order to reconfigure a new identity. We can say she is in search for a new narrative that is able to bring back the order that was destroyed by the disease. This is a long process, which implies a symbolic negotiation with the significations of the disease, and the search for an appropriate attitude towards it. Thus, most of the times, during this process, there are several dominant discourses that shape the view on the disease and on the strategies needed throughout this experience.

Mary's story reveals some of the dominant discourses on disease, characterized by the resistance towards it. We are primarily dealing with resistance to the religious discourse that calls for an individual transformation in case of a disease, a spiritual transformation that brings acceptance and reconciliation with the current situation and with the self. Accepting the fact that the disease is "God's will" is tantamount to seeking a release from the torment of other narratives that could explain and give meaning to the ailing condition.

The refusal of religious discourse is accompanied by a refusal of transformation, an attempt to maintain pre-illness identity. The need for change is today one of the moral dimensions of illness in contemporary society. Illness is perceived as the responsibility of the patient, a result of a certain lifestyle, therefore it is believed that healing requires a transformation of lifestyle and a reconfiguration of the individual ego. The refusal to change can be considered by society a lack of desire.

I wish [...] I was more pious or religious ... [...] [...] ... I wanted to, yes ... But I'm not! I am not [...] I do not want to change myself completely. If I do there will be nothing left of me [...] Because...you need to change everything, to give up all the things you were doing before, because that lifestyle made you sick. OK, I agree that because of my old way of living I became ill, but why? Are you convinced that my old way brought me breast cancer?²

Another dominant discourse that shapes the attitude towards illness in contemporary society is positive thinking discourse. It is a rhetoric that requires

¹ *Deci n-am oglinzi în casă, îți spun eu. La baie. N-am avut oglinzi în casă, nu mi-or plăcut niciodată oglinzile în mod special. [...],i acuma, când fac duș, nu mă privesc în oglindă, niciodată. Ies cu spatele, mă șterg, mă îmbrac, și pe urmă mă uit în oglindă. M-am uitat la mine, da [...] E ciudat, pot să zic că mi-e milă de mine? Mă văd, și nu vreau (plânge).*

² *Aș vrea [...] să fiu mai credincioasă, [...]...sau mai bisericoasă, [...]...aș vrea, da...nu-s! Nu sunt, și [...] nu vreau să mă schimb de tot. Ca atunci chiar nu mai rămâne nimic din mine [...] Că trebuie să te schimbi total, să renunți la tot felul tău de a fi pentru ca ăla te-o îmbolnăvit. Bun, sunt de acord, felul ăla al meu de a fi vechi m-a îmbolnăvit, dar de ce? Sunteți convinși că felul meu de a fi vechi m-a îmbolnăvit?*

patients to focus their attention on the possibility of healing through personal will.¹ Constantly being in the middle of an avalanche of media information and other various support campaigns “against cancer”, the patient inevitably takes the role of the heroic protagonist against his own disease, and sometimes manages to win. In these circumstances, those who do not live up to the expectation of “fighting” the disease may be socially sanctioned.²

*You know, it's like everyone would blame you because you don't want to heal. That you're the one who [...] does not strive to think positive. But how?... Show me how to think.*³

Avoiding the dominant discourses regarding the attitudes towards disease, Mary tries to understand the deeper significance of this event, to discover the meaning the disease has in her life. This “discovery” or “understanding” of the meaning of the disease is the first step towards restoring the lost coherence of the self – the search for a new scheme to guide her existence. In Mary's case, the process of searching for a meaning is a path towards self-knowledge. Facing an extreme situation, when the social determinations of her identity begin to fall apart, she starts a journey of self re-discovery. In this context, the disease represents an initiation test preceding a redefinition of a new identity.

*Well, sooner or later...I'll understand, you know ... For the moment I still don't understand, you know... I am confused, really confused. There's something I just don't get. [...] And when I'll catch the idea and understand why it happens ... well, I won't understand why exactly this thing happens, but at least the mechanism, [...] then ... then it will be ok. [...] Yeah, well, like any other problem, [...] if you know how to put it, normally you can solve it. When you miss some aspects of the problem, you cannot solve it. I still do not have all the data, but I collect them. I collect them, but not information about the disease. I don't want to know anything about it, nothing. But I am collecting data...my own. About myself ...because this is what I missed, data about myself... [...] You have to know that there are a lot of things I didn't know about myself (she laughs). It's ... clear.*⁴

¹ Francine Saillant, *Cancer et culture* (Montréal: Les Éditions Saint-Martin, 1988).

² Robinson, “Personal narratives, social careers and medical courses...,” 1179.

³ Știi, parcă toata lumea ți-ar arunca ție că parcă tu nu vrei să te vindeci. Că tu ești ala care [...] nu faci eforturi să gândești pozitiv. Cum, arătă-mi cum să gândesc...

⁴ No, o să fie undeva momentul în care să...să mi se aprindă becul, să înțeleg, știi...Că deocamdată nu înțeleg, sunt confuză, chiar confuză. E ceva ce nu prind [...] ,i-n momentul în care o să prind ideea și-o să înțeleg de ce se-ntamplă...n-o să-nțeleg de ce se-ntamplă lucrul ăsta, da să-nțeleg care-i mecanismul, [...] atunci...atunci o să fie ok. [...] Da, păi ca orice problemă, [...] dacă-i bine pusă problema, normal că poți s-o și rezolvi. Îți lipsesc datele problemei, n-o poți rezolva. Eu încă nu le am toate datele, dar mi le strâng. Mi le strâng, fără să mă informez de boală, pentru că nu vreau să știu nimic de boala asta, nimic. Dar mi le strâng eu datele...Date despre mine, că date despre mine îmi lipsesc. [...] Să știi că sunt multe lucruri care nu le știam despre mine (râde) E...clar.

Even though a configuration of the complete and final sense of the disease is not possible, this experience proves to have, after all, some positive consequences on Mary's life. The fact that her disease brought her a degree of freedom from social constraints and responsibilities led to an urge to think and helped her uncover other aspects of existence that could fulfil her personal life. Considered at first to be only a contingent and temporary issue, now the disease takes a special place in the context of her personal biography.

I'm still not convinced about the meaning of this experience in my life. I do not know if it's a punishment, or a warning, or maybe a gift. Seriously. Somehow... I start thinking that it might be a good thing ... eventually. [...] I got very close to my family. With all that quarrel that I've told you about ... and it was natural. I was scared, you know, I was furious, but ... I am much more closer to them now. I mean ... before I never had time to have a walk with my husband for example. Just for a stroll, for a little talk, for doing nothing, you know? But we do it now.¹

Final considerations

As we mentioned at the beginning of this article, the aim of our study was to illustrate through a concrete case the deconstruction of the life narrative prior to disease, and the attempt to reconfigure a new narrative to restore the order the disease has destroyed. Mary's story proved to be particularly rich in this regard, highlighting how the disease, by its destructive consequences, threatened her life order and balance, leading to a disintegration of her old social and personal identities. In this context, the narrative has served as a basis for re-evaluating the biographical context in which the disease appeared, for the experience of the disease itself and for Mary's future perspectives.

The process of deconstructing her life story and her social identity previous to the disease manifested itself in Mary's case on several levels and through several stages. Ceasing professional activity and the inability to fulfil her social role has determined a violent interruption of the personal narrative and a collapse of all the settings that maintained her identity prior to the disease. This invalidation of the person as a social actor has been strengthened by the sense of social isolation, a phenomenon manifested by interruption or changes in the relationship with others.

Due to the fact that corporality has a fundamental role in the construction of identity, mutilations caused by intrusive treatments and operations led to a deterioration of Mary's deep personal identity, especially of her gender identity, causing at the same time a profound alienation from her own body.

¹Încă nu m-am convins experiența asta ce rol a avut pentru mine. Nu știu dacă e o pedeapsă, sau e o atenționare, sau poate chiar un dar. Serios. Pe undeva încep să mă gândesc ca s-ar putea sa fie un lucru bun...până la urmă. [...] M-am apropiat foarte mult de ai mei. Cu toată partea aia de ceartă care ți-am zis c-o fost...și-o fost firească. M-am speriat iar foarte rau, știi, și m-am înfuriat și asta, dar...M-am apropiat mult. Adică...înainte n-am avut foarte mult timp în care să stau să mă plimb cu al meu, de exemplu. Să ne plimbăm amândoi, să povestim, să nu facem nimic, știi? Dar acum facem asta.

Being aware of the urge to re-construct her own life narrative, both through reinterpretation of past and future and re-evaluation, Mary partly rejects the options provided by the dominant discourses of our society. In order to maintain a minimal dose of coherence between her past and current identity (altered by the disease), she opts to search for her particular meaning of the disease by integrating this experience into the context of her personal biography.