

Preferred identity as phoenix epiphanies for people immersed in their illness experiences. A qualitative study on autobiographies

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Submitted: October 26, 2020 – Accepted: January 14, 2021 – Published: March 31, 2021

Identità narrativa come epifania di una fenice per le persone immerse nelle loro condizioni di malattia. Una ricerca qualitativa su autobiografie

The illness immersion condition prevents patients from enjoying everything worth living life for. In any case, according to Frank, this condition could represent one of the most insightful experiences towards understanding the meaning of life. Using the metaphor of phoenix (as a symbol of rebirth) taken from May (1991), Frank identified four kinds of embodiments through which the phoenix can reveal itself in a patient after an illness immersion experience: the phoenix that could ever be and the phoenix that might have been; the recurrent and cumulative phoenix and the reluctant phoenix. Based on these considerations, a qualitative study was conducted in order to give voice to the different phoenix embodiments focusing on several autobiographies of patients afflicted with severe or terminal illness. The analysis highlights several similarities that the different phoenixes shared (i.e. the ability to use words and experiential learning skill); however, a deep difference emerged in their worldview which proves able to lead them towards different epiphanies. These evidences reveal that every sick person should be understood, stimulated and accompanied throughout his lived experience of illness by an expressly designed and dedicated care.

La condizione di *immersion in illness* impedisce ai pazienti di godere di tutto ciò che può rendere la vita degna di essere vissuta. Tuttavia, secondo Frank, questa stessa condizione rappresenta una delle esperienze più fruttuose per comprendere il senso della vita. Tratta da May (1991) la metafora della fenice (come simbolo di rinascita), Frank ha potuto identificare quattro modalità attraverso le quali una fenice può rivelarsi nella persona dopo un'esperienza di immersione nella malattia. Sulla base di queste considerazioni è stato condotto uno studio qualitativo per dare parola alle diverse fenici identificate da Frank, prendendo in considerazione alcune autobiografie di pazienti colpiti da patologie croniche. Pur se identificate alcune somiglianze tra le diverse fenici, tuttavia sono molti di più gli elementi che attengono all'unicità delle persone che possono spiegare le loro capacità di fronteggiare la loro condizione di malattia e che possono essere compresi solo mediante un'intenzionalità di cura dedicata.

Keywords: Narrative medicine; Chronic patients; Illness lived experience; Education; Medical education.

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1. Introduction

The majority of healthy people go through their lives without realizing that every day numerous persons live immersed in their illness: patients afflicted with chronic heart disease, Aids, dialysis or neurodegenerative pathologies live, silently and often alone, their sufferance (Charmaz, 1997, p. 135) which can prevent them from enjoying many ordinary things, such as working, traveling, caring for their children, playing sports, reading, playing an instrument, and everything else that can make life worth living. The pain that afflicts them emerges, indeed, from many unbearable losses: the first of which concerns their body integrity. Symptoms such as pain, asthenia, nausea and vomit, breathlessness, muscle stiffness, hypotension force people to pass from a state of normal bodily disappearance or unawareness to a state in which their body is the object of worried attention because it cries out its limits (William, 1984) and the immediacy of being-in-the world is ruptured by its incapacity (Becker, 1997, p. 81). Gradually, individuals understand it is impossible to make or to achieve any life projects, thus they lose their freedom and become conscious of another loss they have to bear: the loss of control. The sense of mastery is one of the vital human needs, and its loss leads people to perceive themselves as confused and defenseless against the assaults of life and that of disease (Frank, 1991). This condition makes people become aware of another loss that concerns the linearity of their life, taken for granted until that moment. There is a loss of innocence about the normal expectation of life (Frank, 1991, p. 39) because illness makes sick persons know that order cannot ever prevail in the organization of the world along some defined cultural lines (Becker, 1997, p. 38).

The severity of the illness conditions, the presence of many intrusive symptoms and the necessity to attend to the routines of therapies take away a significant amount of time — often all the available time that a person can spend in a day (Charmaz, 1997, p. 44) — but, moreover, they could make people feel ashamed and guilty about what they no longer are and what they couldn't be anymore (Frank, 1991, p. 103). This, in turn, often, induces ill persons to refuse any social contacts and to give up their work positions or opportunities, which are other losses to bear. "... physical conditions imposed restricted social life and, hence, can limit the sense of self" (Charmaz, 1997, p. 84) and this is the last, but worst loss: the loss of the self. In their illness immersion condition, people learn that all the positive identifications by which they have formed their precedent identity are swept or ripped away by illness and now all that is left seems to be the necessity to accept the identification imposed by others, often conditioned by their disease, or to be overwhelmed by their illness (Charmaz, 1997, p. 102). Even within their own family, the sick persons understand that many things have changed due to their illness: their incapacity to work or to take care of the family needs, joint with their growing necessity to be helped and supported in every daily activity, make them feel increasingly dependent on others and guilty for the burden these needs of assistance place on the latter. Frustration, anger and sadness are feelings they soon become familiar with.

Nevertheless, persons immersed in their own illness can find in their condition an opportunity to live, to accept their limits and losses and to assign significance to all events of their life. Particularly, according to Frank, in our time, culture and society, a sort of *change rhetoric* has spread: in the author's words, the belief (perhaps the hope) that "certain events or experiences are understood as occasions to change the self" (Frank, 1993, p. 39). In this sense, the condition of illness immersion is one of the most fruitful experiences towards understanding the meaning of life, removing the veil of trite daily normality. Frank underlines that in our times the ill persons not only can write about their case history (allowing many people to read it), but they can also survive their disease for a long time and, finally, can feel the need to react to the clinical and scientific tendency to integrate their individual history in specific and restricted categories (defined by chemistry, biology or physiopathology).

In order to help patients to understand themselves and the opportunities illness gives them to change their viewpoint on life and the world, it is necessary to allow them to reflect on themselves and their story and, even more, to allow them to tell it in their own words. Telling stories is an ancient way through which men and women have tried — and are still trying — to make plans about their lives, share their thoughts with others and, above all, give meaning to life, to themselves and to the world in which they live and would like to live in the future (Polkinghorne, 1991).

Throughout historical times and across different cultures, people have always felt the need to contrast the fatigue of living by inventing some positive illusions of control that often took shape through

the narration of a different self and a different world they lived. This new *self* people tell themselves and others about is a *preferred identity* in which plans, hope and desire are summarized (Charmaz, 1987). Ricoeur calls it *narrative identity* and underlines that, taken for granted the necessity of an internal coherence of the plot, this is the scene where the harmony and order line is reconciled with the chaos line of life, desires are reconciled with needs, what people hope is reconciled with what people have to live: it's the scene where people understand that what happened *happened* so that people could become what they were or what they could have been (Ricoeur, 2001, p. 239). Beyond the necessity for an internal coherence of the plot, people could create a better identity than that they perceive because they need to be accepted and appreciated by others (Ricoeur, 2001, p. 240).

Taken from May (1991) the metaphor of phoenix (as a symbol of rebirth), Frank identified four kinds of embodiments through which the phoenix (that is Ricoeur's narrative identity) can reveal itself after an illness immersion experience. These are:

1. *the phoenix that ever could be*: when pain and discomfort overwhelm life and people live only to attend to their illness, they can understand that the old self "already possessed the resources to deal with the epiphanal crisis" (Frank, 1993, p. 42);
2. *the phoenix that might have been*: in this case, people who were overwhelmed by the disease understand that precisely this experience has given them the right resources to deal with it; the same resources that they did not possess before and that they could never have possessed without that experience;
3. *the recurrent and cumulative phoenix*: there are some ill persons that have to live with their illness throughout all their life, shifting from waiting times of quiet and peace and the awaited time of crisis. For these people, for whom disease is an unpleasant life companion, it is impossible to define a precise moment of revelation of the self: they are, rather precisely the fruit of their ever-present condition, or better said "whatever they have become has been formed in and through" (Frank, 1993, p. 46) their condition;
4. *the reluctant phoenix*: last, there are some people who cannot accept the evidence that the illness has changed both their life as well as their own selves and prefer to remain in a condition of ambivalence.

Because of these considerations, a qualitative study was conducted in order to describe these four different ways of giving shape to a narrative identity by people living in an illness immersion condition. By selecting several autobiographies written by sick authors over the last ten years in Italy, this study attempts to provide both physicians and nurses with an opportunity to better understand the different ways people immersed in their illness perceive themselves and the life they live.

2. Research approach and methods

The qualitative study was conducted via a hermeneutic phenomenological approach wherein the lecture of the selected books offered the possibility of attempting an interpretation of the subjective world the authors described (Reinharz, 1983). This kind of approach identifies in the narrative a tool by which people can transform their lived experience in a story, making it listenable, knowable and therefore scientifically analyzable by others (Van Manen, 1990; Ricoeur, 1990), on the basis of a structural identity between action and text (Ricoeur, 1983; Gadamer, 1975). In the pages written by the authors of autobiographies, the interaction between concrete reality, the memories deformed by time and the need of coherence produces a narrative identity (Ricoeur, 1993) which can be more significant than the real identity, because it can express the true experience as it was lived by the subject (Good, 1999).

In order to identify and describe these different phoenixes, the choice was made to analyze some of the novels recently published in Italy, focusing on illness experiences. Initially 25 novels were identified because their titles appeared to be consistent with the survey theme. Upon reading their abstract on

the back cover, only 12 were selected because of their relevance. These 12 novels were thoroughly read. They are:

1. M. Cunningham (1998/1999), *The hours* (dealing with Aids)
2. P. Pera (2016), *Al giardino non l'ho ancora detto (I haven't told my garden yet)* (dealing with motor neuron disease)
3. E. Silvestri (2009), *Presente infinito (Present Ever)* (on organ transplantation)
4. A. Sartori (2010), *Scompenso (Deficit)* (dealing with psychosis)
5. L. Genova (2010/2015), *Still Alice* (dealing with Alzheimer)
6. L. Genova (2011), *Left neglected* (focusing on post-traumatic disability)
7. S. Bonino (2006), *Mille fili mi legano qui (A thousand threads tie me here)* (dealing with unknown)
8. L. Allnutt (2018), *Il cielo è tutto nostro (We own the sky)* (death after a diagnosis of cancer)
9. G. Alongi (2010), *Alla fine un paio di scarpe (At last, a pair of shoes)* (dealing with organ transplantation)
10. C. Ronco (2015), *Carpe diem* (focusing on dialysis)
11. C. Vighy (2006), *L'ultima estate (The last summer)* (focusing on SLA)
12. J. Bazzi (2019), *Febbre (Fever)* (dealing with HIV seropositivity).

This research then was oriented towards identifying approximately four novels able to represent each of the four kinds of phoenix defined by Frank. Moreover, three other exclusion parameters have been identified as follows:

- the genuineness of the plot: many of the works published within the last ten years are written by authors who have never been sick, hence what they describe is only the result of research, more or less seriously and scientifically conducted; but many others are, instead, the fruit of a genuinely lived experience of illness; thus, given the target of the study, it was necessary to choose only authentic autobiographical novels, eliminating all the rest from our research;
- the coincidence of the main character (as well as of the author) with the person afflicted with illness;
- age of the main character: there is a well-known and significant difference between experiencing illness during childhood or during adulthood; given the quality of this research targets, only autobiographical novels of adult men or women, aged between 18 and 60 were chosen to be analyzed.

After applying the aforementioned parameters, it became clear that the novels of Allnutt and Ronco had to be excluded given the age of the main character (in both novels, a child) and because the narrators were respectively the father of the ill child in the former, and his physician in the latter. Cunningham's novel was excluded for the same reason (the narrator was a friend of the ill person). Sartori's book and the novels of Genova were excluded because they were not true autobiographies, but only fictional accounts written by healthy writers; Alongi's work was not included in the analysis as it recounts the experiences of more than one patient. Last, Bonino's work was excluded because it is an essay and not an autobiography.

Since the aforementioned novels were all hard copy books (the e-book version not being available for all), a *chart and paper* test analysis has been conducted. The four kinds of phoenix embodiments have been chosen as main categories of analysis.

3. Results

Four genuine autobiographies were analyzed, namely the works of Pera, Vighy, Silvestri and Bazzi. Each of them reflects in their plot the epiphany of one kind of phoenix embodiment, particularly: Pera focuses on a *phoenix that ever could be*; Bazzi recounts the experience of a *phoenix that might have been*; the story told by Silvestri is the story of *cumulative epiphanies*; last, Vighy describes a *reluctant phoenix*.

Pia Pera was an Italian novelist, essayist and translator, a professor of Russian Literature. She mainly wrote about nature and landscape but, above all, she loved to take care of her garden in the family plot of land on the Tuscan hills. She became aware of her illness (a motor neuronal syndrome) in a strange way:

One day a man who said he loved me told me, reproachfully, I was limping (p. 17).

Everything started this way, without the need of a physician presence: she understood it was true as soon as the illness took control of her life.

I felt like my right leg was drying out, as it sometimes happens when a branch dries on a tree. I was withering. Dying was no longer an intellectual speculation, it was really happening. Very slowly and ahead of schedule. Leaving me the time, perhaps, to write about a gardener facing death alive (p. 17).

The illness experienced by Pia was traumatic: frustrations and anguish for the painful death she was waiting for were emotions that sometimes overwhelmed her.

Metaphysically, not to be anymore. To disappear. To leave. Nothingness. [...] Physically: the body gets weaker. Legs don't bear, I wobble, I risk falling. The ability to breathe may decrease, death by suffocation. It is impossible for me to think of the throat that closes, the lungs that cannot fill up with oxygen, as nothingness. Nothingness shouldn't be able to tighten in anguish. The nothingness should be harmless, nothingness (p. 37).

Nevertheless, she has the strength to face this situation because she had three kinds of abilities, which serve as the reason why her epiphany was that of a phoenix that could be. These abilities were her familiarity with words by which she can give voice, reality and sense to her feelings. Secondly, she had a large social support network that did not abandon her when she could no longer leave her home. The last one, but not the least, she was a gardener, and as such since her infancy she learned to take care of plants, of a single plant or flower, to have a thought for every small presence of nature that lived on her land.

All is amazing, beautiful, full of grace and harmony [...] it is strange that when I doubt, I don't take it for granted (to live and see another spring), now the world seems to me incredibly rich in wonders (p. 204).

She learned the virtue of patience and perseverance that are essential to gardening; but, above all, she learned the ability to accept death as a necessary duty to enjoy a new birth, even the smallest. These abilities made her able to perceive herself as a part of nature, to take care of her own fragility, to enjoy every small thing her illness did not prevent: when she felt sick, even if slowly and gradually, she was able to understand that now her duty was to accept the end and find a place to wait for it in peace: her garden, even if only seen through a window.

... this inner lightness was born perhaps because I feel free from the terrible ballast of the future, indifferent to the anguish of the past. Immersed in the present, as before it had never happened to me, I am finally part of the garden, of that floating world of continuous transformations (p. 20).

The recurrent metaphor, which is sprinkled throughout the pages, proved useful even to summarize Pia's epiphany, as the outcome of a meaning-making process focused on her illness and her life. She understood two things: first, that life is too filled with frills:

Perhaps this is what we should do in the time we have: do not consume it in futile attempts, but we should concentrate on pruning, more than ever on pruning. To accept, serenely, the end (p. 40).

Secondly, towards the end, like a plant, nobody can avoid their own destiny.

A tiger mosquito settles on my foot. I am not able to chase it away. I can't escape, like a plant (p. 209).

Johnathan Bazzi was born near Milano; after receiving a degree in philosophy, he collaborated with several journals writing about gender issues. In 2016 he chose to reveal his HIV seropositivity writing a post on Facebook. Some months later he wrote *Fever*. This choice is the origin and the core of the story he tells and it holds his epiphany because it originated with three elements: first, his need to sow and then reap; secondly, to protect himself and his life, even if it can seem inconsistent; thirdly, to do something about the virus with which he is afflicted. These three elements, even if they can be distinguished, are all joint together and linked with his past and his family's story. He writes:

I was bred by substitutes, raised, managed by others. Facing their broken love, my parents restarted: another man, many other women. Another son, to restart. Dreams, to stay alive. Remediating the failed plan. They must leave me behind: how much cumbersome a three-year-old boy can be? (p. 271).

And few words after:

I have a desperately social nature. My egocentrism is radical, that is imploring. Help me to be in the world, help me not to vanish (p. 271).

Born and bred in a broken family, having discovered himself different from his peers in sexual preferences and even for this reason exposed to many refusals, he spent his infancy and youth missing attention. So, he tried and tried again to keep the love and interest of someone who could give him a sign of appreciation. Neither his mother, nor his father gave him the appreciation he needed to understand himself and to assess his own abilities. Even his grandmother concurred in damaging his self-esteem, making him afraid of the world. He spent his life, before the diagnosis, desperately searching for himself, trying to understand what he could do with his life. Many interests, many meetings, much research, many loves, none of these could give him the peace an identity could. Everything, every target pursued with all the strength he possessed: the degree in philosophy with the highest grade, yoga exercises done as nobody could do, all at the best, because he needed to be admired, to be appreciated, he needed to be loved for what he could do. And indeed, he writes:

... it isn't skill, someone tells it: it is fear to lose everything again (p. 274).

When he realized his condition, all changed because HIV gave him an identity, even if not chosen nor wanted. A diagnosis searched desperately throughout months of inexplicable fever that debilitated and disoriented him and, above all, terrified him:

I discover in myself a hole that hypnotizes me, a space in which thought can't do anything else. My self, now suddenly, completely embodied: my self is a body that can get sick, no longer an almighty, theoretical abstraction (p. 114).

Fear, anguish and guilt enabled him to perceive his illness more than symptoms could.

I cry because I know I have no way out, I'm losing control of my body and my will, I cry, and crying doesn't make me feel better; it isn't liberating. Anguish is a giant insect that spews its stickiness ...in waves, taking advantage of the spasms, I try to go back up, but every movement makes things worse (p. 222).

The first turning point is given to him by his mother who came to take care of him starting by feeding him, not only physically.

My mother comes above all to make me eat. She cooks, I can't: she brings pasta and fresh vegetables from her home. [...] my mother wakes me up, feeds me (pp. 281–282).

She feeds his need of love and care, and so she allows him to become aware of his own strength and of the opportunity his illness provides him with. Illness becomes the tool that makes him able to let people know, really, what he is, what he thinks and feels and, above all, what he can be: a writer. The writing is his skill, but nobody knew it (it is only after he published a revelatory post on Facebook that a journal calls him to collaborate). He chose to write to sow and then reap because he knows that:

Everyone returns what he or she received (p. 132).

So, he understands that in order to claim his choices, remove guilt and, accordingly, protect himself from stigma he must tell his story.

Refusing the imperative of silence, I make myself transparent, my skin is made of air, if necessary, I disappear; words, kind and ferocious, don't stay in me. They come in and out, in me only the path stays. I can expose them, show them. I offer them, I return them to the world (p. 316).

Writing that post offered him the chance to shape his own self and show it to the world because illness makes him realize that only by letting people listen to or read his story, he can reap all the appreciation and esteem he had never perceived, or perhaps he had never allowed himself to perceive:

I was always afraid [...] I'm trying to avoid a bigger corruption; I protect other parts of me I didn't want to get ruined (pp. 115–116).

This is another turning point: the illness permits him to understand his gift (writing) and use it to give meaning to his life

I don't know who I'm, I have never known it all my life, still now. [...] Now I'm satisfied. I have a permanent skill to show to the world [...] My degree is a medical report, the outcome of a blood sample. [...] HIV positivity: an identity chosen by my body (pp. 308–309).

The lived experience of illness allows him to understand that his life is under his control and he possesses the ability to make something for himself and for the others.

I want to do something of the virus, make something about it, change it, without staying armless, without suffering it. I'm interested in things from which I can learn. Writing about it, for example, taking advantage of my condition of favored, infected who isn't ashamed. Giving a new name to my experience, appropriating it by words, to learn, to see more: using diagnosis to explore what it is kept silent. Giving it an aim, not leaving it mold in the drawer of the wrong things (p. 310).

He is a phoenix that might have been; illness gave him the opportunity to finally be.

Emilia Silvestri is a pen name, but as she wrote at the beginning of her autobiography:

My name isn't relevant, what is relevant is my story (p. 7).

Emilia was born afflicted with a congenital heart disease that made her a fragile child.

This is the reason why I was weak, thin; my lips were blue, and my physical development was slowed down. This is the reason why I was different from all my peers, and consequently, I always played alone, with my loved dolls because I couldn't run; I never frequented kindergarten, because I couldn't get sick or get cold. This is the reason why I had no friends (p. 7).

During her adolescence she underwent three non-resolving open-heart surgeries, until at 22 she faced a heart transplantation. When she wrote *Ever Present* she is a 35-year old woman. Twelve years of light-heartedness had passed, until a problem caused by the drugs she took threw her into a new nightmare. Her book starts when she enters in the ICU (Intensive Coronary Unit), after a worsening of her heart condition. She came out from that unit 235 days later, when another heart became available for transplantation. Although she was facing one of the most challenging experiences of her life, she chose to write a diary. The diary is the space of her umpteenth epiphany, one of the epiphanies she cumulated in her life and made it possible for her to face this new nightmare in which she lost everything, sometimes even her hope.

I was screaming like a wounded beast. My screams came out without anything I could do to control them. I needed them, I needed to scream with all the strength I possessed. I didn't scream for the endless and useless punctures made trying to replace the jugular catheter, but for the despair that was slaughtering my life, my hopes to come back to live as others do. [...] a deep and deaf pain that screams when all the other defenses have fallen. And in that moment, it takes the sound of a groan, the death rattle of a wounded beast (p. 91).

The recurrent metaphor she used is that of a captive bird in a cage:

My body is now a rusty cage that is giving way under the physical and psychological weight necessary to resist everything: my pain, my fear and the time that passes away (p. 139).

I can't grasp life anymore, I can't. All I have left is to envy those few birds that I see hovering in flight in the piece of sky that my window shows me. Birds that, in their dreamless life, are almost free to fly away (p. 51).

During her childhood and adolescence, experience after experience, she learned to manage the challenges of her destiny: she learned to survive her sick body.

First, she learned how to relate to nurses and physicians preventing them from making her feel powerless.

Today it happened again...I risked suffocating...in that moment she came (the physician) and she said: "You aren't so bad; it is all due to your fear." I thought what she could know about my fear, about my feeling of dying suffocated at every dinner, about the feeling of rotting muscles I perceived?...I took away the oxygen mask to speak with her, to tell her: "If I'm so well as you say, I don't need your help. Please, go away" (p. 79).

Secondly, she learned to take care of the relationships she built with her family members, her lover and her friends, and she learned to ask for help when necessary.

These are people for whom it is worth fighting to stay alive [...] if someone loves you so much to bear to see you die, without turning his gaze, then for that same gaze it is worth fighting to stay alive (p. 52).

Thirdly, she learned how to fill her waiting days with drawing, embroidery and crochet.

It is fine to draw. To reproduce the beauty of nature with my own hands... to draw makes this never-ending time less anguishing and painful, it is enchanting because it is deceptive. It deceives this passing of hours and days, filling them with creativity, with life. [...] It makes me alive (p. 47).

Moreover, she learned not to be ashamed of her condition:

There is a lady, near us [...] she is staring at me. She doesn't take her gaze away from me, insistent, curious, inappropriate [...] I look at her, smiling. The shame makes her to take her gaze away. There isn't shame in my gaze. I was never ashamed of what I am. Of my pain. I don't search for it. Although I have always tried to prevent it, avoiding any risk, it did what it wanted of me. Pain is an inopportune mate for many persons, for me it is only painful. And people must love me even more for this (p. 75).

Fourth, she learned to voice her pain, to tell her story, to create meaning from her experiences. This diary is precisely this: a place and a time of peace, in which she could voice her inner torments and thus prevent them from devouring her. However, this new and extreme experience lets her learn something new (that could be her umpteenth epiphanies) because she must face the real possibility of her end, touching with her hand the coldness of death.

Panic. Death on my face, like a cold slap that takes your breath away. And after only the void, no chances, I can only stay here to look at the slap that is coming to me and resist, beyond any desire for despair (p. 117).

In those days she became aware of another thing she didn't understand before: the precariousness of any representation. She understands that everything is more complex than expressible, even thinkable.

She can't, they can't understand. It is not understandable. I did everything wrong in my books... It is not understandable, it is only imaginable, in the distance looking through a glass dirty with our prejudices. Beyond, a shaded form that is interpreted but not clearly seen. She, he, they are beyond that glass. I am that form, which for me is not nuanced. Its contours are as sharp as knife blades, sharp edges that cut and break my days, my dreams. She, he, they can't understand (p. 80).

But, above all, she learned, another time, to love life, as it is. And this kept her alive for eight months connected to a continuous dialysis machine and stuck in a bed invaded by venous catheters. It allowed her not to lose her hope.

A day, perhaps, this never-ending present will end. A phone call and a smiling physician will make it end (p. 66).

The last novel chosen is written by Cesarina Vighy, the reluctant phoenix. She calls herself (and the disease with which she is afflicted) simply Zeta, the last letter of alphabet, because it is a signal of her imminent end. Cesarina starts her novel with a few pages dealing with her illness, but immediately leaves this subject in order to recount the story of her troubled life, before her diagnosis. For most of the book, it doesn't look like an autobiography of an ill person but of a healthy woman. Only on page 139 (two thirds into the book) does she actually start to describe her illness experiences. It is interesting to note this choice that seems to be originated from a difficulty to speak about her condition. A condition that has a troubled diagnostic itinerary:

I met seven neurologists, one at time, not all together as Snow White's dwarfs appeared. But always seven they were (p. 139).

This phrase appears to identify the caustic humor she uses to dampen the potentially devastating meaning of the experiences she is living.

I should have paid more attention to the term degenerative but thinking of the degenerates who enjoy being whipped I immediately laughed (p. 147).

With her sarcastic prose she destroys every positive aspect that the disease could offer her.

...it is a triumphalist phase, that in which you think you earned as much as you lost and to have been chosen for something unclear but important. The feeling, often justified, to understand better than others, to comprehend their thoughts, joint with the certainty of the control of your brain, makes you overestimate your intellect, at the expense of more poor bodily expressions that will take their revenge at the end, destroying you (p. 148).

Even the process of adjustment in her words acquires a strange meaning, almost an undignified meaning.

Homo sapiens is the more adjustable animal that ever appeared, without disappearing, on the face of the earth. Go dinosaurs, go mammoth, but the human being is already here. Because he bends himself, without prejudices but not without disgust, to eat meat or glass according to famines. ...even when he thought to be civil, he ate potatoes peels, trash, boiled leather. Other different men sold their sons to live. At the end everything is accepted, believe me (p. 151).

Even if humor can be a good cognitive strategy of adjustment, in this case it seems to be only the last sign of a life lived in trouble through which she learned to defend herself from the assaults of existence by attacking them. Given the multiple devastating experiences she had (the most significant of which was an abortion during her adolescence), she learned to protect herself from frustration by discrediting everything, even the most important things of life, as the sentimental bonds (with her husband, her mother or her daughter) or any ethical reference. However, in this way, she deprived herself of the opportunity to welcome those good things life could have offered her. Even when she got sick, she chose to defend herself by attacking, and in this way, she remained a reluctant phoenix that could not appreciate what illness could have given her.

In the end of her writing, she tries to think and speak about her death. Her words are these:

If you believe in any god, hold him tight. It is possible that he is useful, at the beginning or at the end [...] if you don't believe in anything, better: you will have fewer thoughts (p. 175).

Moreover, she even employs sarcasm about the wording that she imagines will be placed on her death certificate:

Cardiovascular collapse is right for all the elderly, but it is inconvenient for my blood- pump [...] it would be better, and more exact, to take something from popular simple humor: "Tizio (so and so) is dead because he forgot to breath" (p. 189).

4. Discussion

Four kinds of phoenix were described in the chosen novels, in which each main character was suffering of an illness: Johnathan and Emilia survived their disease, Pia and Cesarina died. Illness came in the life of Pia, Johnathan and Cesarina as an unexpected accident, only for Emilia the illness had been a life companion since her birth. Pia, Emilia and Cesarina were afflicted by a degenerative disease that could destroy, even if slowly, their body integrity. Only Johnathan could attribute the origin of his condition to contagion. The pathology that afflicted Pia and Cesarina seems to have originated from the same kind of degenerative process; what is suffered by Johnathan (during the years he covers in the pages of *Fever*) is not a true pathology, because only an HIV-positivity had been diagnosed, not a full-blown disease. There is nothing that connects their illness conditions, which are very different from one another. Nevertheless, each of them decided to write his or her story, to tell it to the world, not only for the others who could have read them, but above all for themselves. They needed to tell their story to achieve a sort of ontological passage, to clarify the plot they must face living in (Marroni, 2014, p. 120).

But, in order to understand the choice to tell their stories that unites them, it is necessary to go behind their illness condition to identify certain elements that can connect all of them. It could be conceivable that a first element that links them is their ability to use words to abstract themselves from the uncertainty and the confusion of their lived experiences (Sontag, 1977/1979, p. 35). Their precedent study experiences revealed themselves fundamental because they allowed them to learn how to use words to express even things that are not visible, such as feeling, thoughts, needs and dreams. Word is power, the power to think our thoughts and to give them to the others to create links of attachment, collaboration, comprehension and mutual support; it is the power to understand our rights to be respected as human beings (Mayo, 2007), as well as to give to the world a more understandable and acceptable appearance than it has in its rough reality (Galimberti, 2003). Pia was a woman of letters, Johnathan had a degree in philosophy, Emilia was a researcher, Cesarina was an intellectual and a free thinker, all of them had this wording ability and they chose to use it.

Another thing that could be traced to connect three of them: Pia, Emilia and Johnathan have the capacity to learn from their experiences, even from the most devastating ones. Their intellectual skills gave them the requisites to analyze their past, even if recent, and to understand what happened, to ask themselves why it happened and to search for a true, even if subjective, interpretation of what happened. This interpretation is neither dismissed nor forgotten, but it is taken as a learning opportunity which can help them in the future, when a similar situation will present itself again, and they will have the possibility to face it knowing how they must cope with it (Kolb, 1984). Pia searches for a significance of her condition by reading again the old books she loved; Emilia was able to achieve in her long experience of illness a transformative learning experience, because she understood that whoever conceives the human experience of suffering is understandable to whoever does not know pain (Mezirow, 1991), Johnathan is interested only in those things that could teach him something.

However, there is one element that distinguishes them above all: their life. Their different life experiences enable them to become four different kinds of phoenixes. But what determines the kind of phoenix a sick man or woman could become? The stories of these authors can offer us some suggestions: their worldview and their way of facing life's challenges are far from each other. Pia was a contemplative spirit who found a speck of concreteness only in her garden and it is precisely this that gave her the possibility to understand and accept the caducity of everything; Jonathan was an atypical intellectual because, despite his degree in philosophy and his passion for yoga, he was a wandering spirit that had to invent new words to understand his condition (Woolf, 1926/2006, p.11) but, above all, he learned about the roughness of life from his broken family and while fighting in school, with his mates, to affirm his homosexuality; Cesarina did not accept defeat but her ways of reacting were not always productive, because sometimes she tried to cheat and as a result hurt herself: she tried to do the same thing with her illness, not to care for it seriously, but it overwhelmed her anyway (Woolf, 1926/2006, p. 15). Emilia was a researcher, a divergent thinker, and she understood her fragility since her childhood, so she learned to appreciate the small things and know that all is passing — and has to be accepted (Marroni, 2014, p. 121) — and to demand compassion for her pain because she knew to deserve it and to need it to survive (Woolf, 1926/2006, p. 12).

5. Conclusion

The aforementioned sections can provide some indications and guidelines that could be useful for physicians, nurses, educators and all the other health professionals, in order to understand the complexity of lived illness experiences. There are some elements that could become a sort of prerequisite to produce a good adjustment to the illness experience, such as the ability to use words to voice feelings and significances, as well as a worldview that contemplates the fragility of every certainty, the consciousness of the roughness of life and the wonder of every small conquest. Nevertheless, there is something that is indecipherable in the depth of the human soul: that which can only be grasped with the certainty of its fragility. Only by attempting to know the past of patients, their life history, the quality of their social network, their way to live and to face life assaults (Bobbo, 2020), but more over by listening and remaining open to the unknown — because the invisible is more important than visible (Marroni, 2014, p. 124) —, does it become possible to understand what a sick man or woman could feel after a diagnosis that destroys the linear development of the future they expect to live (Radley, 1984; Sontag, 1977/1979, p. 39). This could be what our four phoenixes teach us: the lived experiences of patients are much more complex to understand than their pathologies.

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