

## Case Report

# Illness and Object Relations: Narratives From Women With Pulmonary Hypertension



Andrea Caputo<sup>1</sup>

1. Department of Dynamic and Clinical Psychology, Sapienza University of Rome, Rome, Italy.



**Citation** Caputo A. Illness and Object Relations: Narratives From Women With Pulmonary Hypertension. Iranian Journal of Psychiatry and Clinical Psychology. 2020; 26(1):130-141. <http://dx.doi.org/10.32598/ijpcp.26.1.3124.1>

<http://dx.doi.org/10.32598/ijpcp.26.1.3124.1>



**Received:** 12 Jun 2019  
**Accepted:** 12 Mar 2020  
**Available Online:** 01 Apr 2020

### Key words:

Pulmonary hypertension, Self-perception, Personal narrative, Qualitative research, Psychoanalysis

## ABSTRACT

**Objectives** The current research study aims at investigating the illness experience of people affected by Pulmonary Hypertension (PH), as a particularly challenging rare disease that is paradigmatic for the understanding of regulatory processes.

**Methods** The study used Giorgi's method to analyze the illness narratives of 11 adult Italian women affected by PH according to a qualitative phenomenological approach. An object relations perspective looking at chronic illness as an internal object was adopted for result interpretation.

**Results** Four general themes were identified that characterize illness narratives of people with PH and illustrate the progressive stages of the disease. They respectively deal with the body/mind disruption at symptom onset, the protagonization of illness in the search for a diagnosis, the complicated grief at the time of diagnosis, and the anaclitic strategies to face the future.

**Conclusion** Findings make a significant contribution to the exploration of the subjective experience of people with PH in managing illness-related challenges from symptom onset to after diagnosis.

## Extended Abstract

### 1. Introduction

**P**ulmonary Hypertension (PH) refers to a group of rare and chronic disorders characterized by increased blood pressure (hypertension) within the arteries of the lungs (pulmonary artery) for no apparent reason [1]. It is featured by unclear causes, with pulmonary arterial hypertension (as the major form) affecting about 15 individuals per million annually (women in 80% of cases). Because of unspecific and covert initial symptoms (e.g. dyspnea, syncope, edema, ascites, cyanosis, abnormal heart rhythm), the disease is not so "visible" and affected people

feel isolated because they appear as exaggerating their sick status [2, 3]. Accordingly, diagnosis is generally delayed and this contributes to a mortality rate of 61% at 5 years [4]. Besides this, as symptoms mostly include breathlessness, fatigue, and lack of energy, affected people need frequent resting and progressively restrict the completion of everyday tasks, with consequent limitations on physical activities, employment/work, social opportunities, and relational adjustment [3, 5]. Then, there is not decisive treatment (with lung transplant as a potential option) but only multiple medications slowing the progression of the disease, which may be difficult to incorporate into everyday life because of invasive and painful side-effects of some routes of drug administration (e.g. intravenous and subcutaneous delivery) [6, 7]. Therefore, as a consequence of illness experience,

#### \* Corresponding Author:

Andrea Caputo, PhD.

Address: Department of Dynamic and Clinical Psychology, Sapienza University of Rome, Rome, Italy.

Tel: +39 (347) 8297064

E-mail: andrea.caputo@uniroma1.it

psychological issues are frequently reported by patients with PH, such as anxiety, panic attacks and depressive symptoms, with a concomitant psychiatric disorder in more than one-third of cases [8-11].

Psychodynamic research has highlighted that people living with chronic or disabling conditions experience profound narcissistic injuries resulting in a sense of self-defectiveness, perceived as a bad internal object at a symbolic level [12, 13]. Indeed, according to object relations theory, body functions represent significant means to put into effect drives in a primitive grammar of physical expression, so to secure a sense of vitality and connection with the outside world [14, 15]. Accordingly, earlier bodily experiences progressively ensure the building of a stable and cohesive self-representation, intended as the introjection of a good object that can serve as the basis for all mental processes from childhood to adult life [12]. However, when the individual experiences some threats to physical integrity, the increasing awareness of the loss of bodily intactness may cause a body-psyche disruption [16-18]. Indeed, in chronic somatic diseases, illness often represents a sort of personified enemy (personification) that becomes the protagonist in the narrative when making sense of one's condition (protagonization) [19, 20], replacing the taken-for-granted mood of a lived body with the disturbing unfamiliarity of a broken body [21].

Therefore, the ill person needs to learn to manage challenging situations and inhabit a new world in the ongoing adaption to illness [21], through regulatory processes aimed at repairing a defective self [22-24]. The presence of a chronic disease is thus intended in terms of an object loss that needs to be recognized, accepted and worked through [13, 25]. Otherwise, individuals with pathological grief reactions may fail to adequately adjust to or integrate the changes in their body image as a result of their chronic disease [26]. For instance, when this mourning process is not successful, several strategies may be enacted as alternatives to reparation (that is integral to a depressive position), such as becoming trapped in frustration, maniacally denying one's condition, or experiencing destructive urges towards the self and resentment towards healthy others [13].

The present study aims at investigating the illness experience of PH, which can be considered as a paradigmatic disease in dealing with a defective body [27] due to unclear causes, diagnosis delay and lack of decisive treatment. To this purpose, illness narratives consisting of unstructured subject-derived data represent relevant source of information [28-30] to show how patients seek 'the repair and restoring of meanings when they are threatened' [31, p. 264].

## 2. Method

### Study participants

The illness narratives written by 11 adult Italian female patients with PH were used for the present study, which were retrieved through the Internet-based database of the Italian National Centre for Rare Diseases. The database was part of a community-based participatory project promoted by the Medical Ethics Committee of the Italian National Health Service in the field of narrative medicine, for sharing illness experiences of people affected by rare diseases. Specifically, patients were asked to freely provide subjective accounts of the disease and of its perceived impact on their life. All participants gave their written informed consent to be included in the study before participation. In detail, textual data from the collected illness narratives were overall composed of 19 pages and included 5,453 word occurrences, with a mean of 496 words per narrative.

### Narrative analysis

Consistently with an object relations informed narrative research on chronic diseases [19], Giorgi's method [32] for qualitative phenomenological analysis of illness narratives was used. Such a method consists in a four step procedure relying on: Getting a general impression of the whole (from chaos to themes); identifying meaning units (from themes to codes); providing a systematic abstraction of meaning units through condensation (from code to meaning); and synthesizing the contents of the condensates (from condensation to descriptions and concepts). This method requires only a small number of participants and allows the researcher to access individuals' lived experiences within the context in which such experiences take place, through a thematic cross-case analysis. The result of this procedure consists in general themes that are described giving voice to participants through direct quotations from their accounts, according to a clinical case approach [33]. Such themes are then discussed and interpreted according to an object relations framework [22, 23], which consents the deepening of meanings related to the different identified themes (and sub-themes), beyond the explicit statements, so to provide further insights about participants' repairing processes to ensure self-regulation in coping with the somatic experience of a defective body. To this purpose, we relied on the coding scheme developed by Mitchell and Helson [34] for describing object relations in short stories, including dimensions related to mutuality of autonomy and conceptual level of object representation. These dimensions are conceived along a developmental continuum from the paranoid schizoid position to the depression position. Mutuality of autonomy refers to the degree to which self-object

relationships are perceived as destructive, dangerous, and overwhelming, as opposed to relationships represented as mutually enriching, safe, and well-balanced. Whereas, conceptual level of object representations deals with moving from the need-gratifying or need-frustrating properties of the object to more internal representations allowing complexity, contradiction, and change.

### 3. Results

The analysis has detected four main themes that characterize illness narratives of people with PH and illustrate the progressive stages of the disease. They respectively deal with the body/mind disruption at symptom onset, the protagonization of illness in the search for a diagnosis, the complicated grief at the time of diagnosis, and the anaclitic strategies to face the future. Each theme is presented focusing on the overarching concept emerging from textual data, based on an object relations interpretative framework, and describing its relative sub-themes. The number of participants reporting each sub-theme and some examples of direct quotations are presented as well.

#### Theme 1: Body/mind disruption at symptom onset

The first theme includes the meaning units overall reflecting the ongoing disruption at the time of disease onset before receiving an accurate diagnosis, when patients are faced with early symptoms. Patients experience an impaired object constancy with regard to their physical integrity, which progressively leads to depersonalization as the feeling of being out of control of their bodily sensations.

In this regard, lack of meaning (reported by eight participants) refers to the perception of a sudden somatic disruption, that signals the rupture of a cohesive self. This leads to the consequent difficulty to make sense of and find explanation for one's physical condition, leaving room for feelings of confusion and anguish.

I suddenly started feeling a growing weakness and experiencing fainting for the first time, without being able to explain what was happening to me [...] That's actually how my adventure started in absolute confusion [story 1].

My life changed in a moment, I felt something strange in my chest [...] suddenly I began to no longer understand what was happening to me [story 6].

Denial (reported by four participants) seems to represent a potential strategy to handle such a body/mind disconnection, by minimizing the importance of one's perceptual experience. In such a way, the individual may maniacally

triumph over symptoms, thus avoiding to acknowledge illness and continuing to lead a normal life.

I tried by all means to lead a seemingly normal life, trivializing some situations or ignoring some symptoms that, however, affected my relational and work life, but this has probably worsened the evolution of the disease itself [story 9].

I did not pay much attention to this episode and my life went on, despite the recent shortness of breath under stress [story 11].

#### Theme 2: Protagonization of illness in the search for a diagnosis

The second theme includes the meaning units regarding the protagonization of illness during the long and stressful search for an accurate diagnosis, as a sort of hidden enemy to contrast. Splitting processes are reinforced, with the need-frustrating properties of illness progressively increasing and self-themes becoming more relevant in terms of needs for achievement and understanding.

In this regard, frustration (reported by eight participants) refers to a helpless position in facing illness as a persecutor that is assigned the role of protagonist in the narrative. Patients express feelings of concern, distress and burden for not achieving accurate, timely and definitive explanations about one's illness and for passing from doctor to doctor.

I went round several hospitals and consulted different medical specialists to try to obtain a confirmed diagnosis [story 9].

My tribulations started when I travelled to visit all the hospitals in my region, because health facilities are almost non-existent in my city [story 11].

As well, mistrust (reported by four participants) emerges as perception of being dismissed, doubted and scarcely considered by doctors, due to the poor awareness on such a rare disease by healthcare providers. This contributes to increase persecutory feelings, leading patients to progressively displace their frustration on doctors to some extent and refuse further medical advice.

I was sure I was sick even though no doctor seemed to take me seriously, as if I was hysterical [...] About two years had passed since the first symptoms and I was too discouraged [story 1].

I was always sleepy and tired, the neurologist said that I was suffering from depression caused by my environmen-

tal situation [...] I sought other medical opinions and all the consulted doctors replied that a check-up of my immune system was not necessary and that I was surely affected by psychological stress [story 2].

### Theme 3: Complicated grief at the time of diagnosis

The third theme includes the meaning units regarding the complicated grief experienced at the time of diagnosis communication, deemed as a traumatic event. Mixed feelings of anger, pain, and resignation emerge in discovering one is affected by a chronic and incurable disease, that is perceived as an overwhelming external oppressor.

In this regard, death anxiety (reported by nine participants) seems to signal the strong sense of fragmentation and the lack of autonomy in ego functioning. Diagnosis is experienced as a death sentence, accompanied by feelings of anger about not deserving the disease and despair about acknowledging that there is absolutely nothing to do, as other potential solutions are equally risky and ominous.

Having known about the disease was like entering a nightmare. What else could happen worse? You get angry, as well as terrified: why me? I am too young, it is not yet my time, I still have too many things to do, too much responsibility, I do not have time to die! [story 4].

You feel detached from reality, like you're at the center of the world but you're alone, you cannot accept to suffer from a rare disease especially when you do not find the cause, you continuously ask yourself "Why me? What did I do wrong?". But you are not allowed to have an answer [story 11].

As well, acceptance of limitations (reported by six participants) refers to reconciling oneself to the irreversible impairments and activity limitations imposed by the disease. This perspective involves more relational themes such as mourning one's body image, recognizing the reality as it is, and moving to a depression position in order to learn to live with altered circumstances.

Now begins the phase of hope, the process of mourning, the awareness of your illness and your new limits. You learn to accept them, you learn to understand the precise point where you need to know to stop yourself [story 4].

Sometimes, I felt very sad because I wanted to do everything I did better, instead of having to stop to catch my breath and regain my strength [story 5].

### Theme 4: Anaclitic strategies to face the future

The fourth theme includes the meaning units regarding the anaclitic strategies that ill people rely on to restore internal goodness, highlighting a desire for rapprochement with their body and ego vitality. Despite different, such strategies are based on the search for external sources of help, alleviating negative feelings associated with the sick status and allowing to face the future and continue to live with PH.

In this regard, medication (reported by four participants) refers to the perceived usefulness of medical treatment and equipment for PH management that can help slow the progression of disease and overall improve quality of life. In such a way, medication symbolically represents a substitute the patient may identify him/herself with and allowing the maintenance of a narcissistic investment on the body.

I have discovered that there are treatments: thanks to the portable pump that infuses precious medications 24 hours a day, not only I have been allowed to survive for so long, but I have had a fully acceptable quality of life I still enjoy [story 8].

Religious beliefs (reported by five participants) deals with reframing the meanings of one's illness as part of a broader purpose and dependent on external superior forces. Trusting God represents a way to maintain hope for the future as a magical form of restoration by taking refuge in a good external object and relying on idealization processes.

I understood that my suffering could have a purpose of great value, if lived in the light of faith and in abandonment to God. Since then I have a great inner serenity of mind and, although trusting the progress of medicine, I have faith much more in the good God, absolute arbiter of life and death [story 9].

Then, social support (reported by six participants) refers to the search for validation, help and guidance from patients' associations to reduce loneliness feelings. Trusting damaged others in the same condition appears as a process of mirroring, ensuring approving admiration of others and enhancing self-esteem, given the authentic understanding of what PH means.

The only people I have found really available for both listening and practical issues are those affected by my own disease and the patients' associations I have addressed in particular moments along my way and that I am very grateful to [story 2].

## 4. Discussion

The present study highlights different progressive stages that characterize illness stories of people with PH, in line with previous findings showing that the narratives of such patients reflect an ongoing adjustment process in coping with the disease-related decline and changes to therapy [35]. In this regard, other qualitative studies have identified different psychological descriptors across pre-diagnosis, diagnosis, and after diagnosis [36, 37], shedding light on the use of distinct strategies at various illness trajectory time points [38].

In the first stage patients show different responses to symptom onset, overall reflecting a body/mind disconnection caused by illness. In psychodynamic terms, such a disruption of sense-making processes is featured by a somatic depersonalization [17] and the impaired constancy of one's physical integrity as an internal object [19]. This engenders anxiety feelings and the consequent reliance on denial to downplay the relevance of symptoms as reflecting a damaged self [39]. Such feelings of uncertainty and anxiety about the subjective experience of people affected by PH have been confirmed also in previous narrative research studies [36, 37, 40]. Indeed, patients generally feel uncomfortable to talk about their illness with family and friends and tend to hide their symptoms [36]. This could depend on issues of shame and guilt due to feeling unable to effectively respond to societal and family expectations and negatively impacting on partners and children [35]. While searching for a diagnosis, ill people tend to experience illness as a hidden enemy that becomes the protagonist in their narratives [19, 20]. Frustration and helplessness feelings emerge that mostly pertain to the invisibility of their condition, as it has covert signs and is poorly known by healthcare providers [2]. Because in the early stages patients do not appear as sick, they might be disbelieved and scarcely listened to, thus making them unconfident in receiving help [3, 35], which may result in refusing medical advice as highlighted in our study.

Acknowledging of being affected by PH represents a shocking experience and diagnosis communication is perceived as a traumatic event, engendering a complicated grief. Feelings of persecution and resignation to a death sentence prevail that are typical of a paranoid schizoid position. Indeed, people fear that they are losing control on their life and recognize to be victims, differently from pre-diagnosis where achievement-themes in preserving the self were more central in illness narratives. This is consistent with previous findings about mixed feelings of relief and scare in making sense of the diagnosis [40], which may suggest patients' relief from feeling persecuted by an external hidden oppressor. As well, a state of enforced dependency following diagnosis emerges [36], which involves the acceptance of disease limitations. In order to face the future and continue to live with PH, several external sources of help are detected that

refers to different repairing strategies to cope with a defective body by relying on an anaclitic position. Acknowledging the medical benefits from treatment and equipment, despite the complexity and inconvenience of some regimens that can be difficult to incorporate into everyday life [6], can be viewed as a way to accept one's enforced dependency, elaborate on related depressive feelings and potentially restore one's body functioning. Indeed, living life with treatment and PH management are considered as central issues for adjustment to illness overtime [36, 41]. An alternative form of reparation consists in looking for social support from other patients in the same condition, as a well-known valuable help source in literature about PH [36]. Indeed, especially in the absence of a good relationship with healthcare providers, people with PH search for validation from someone with the same disease because hearing other participants' concerns may alleviate their loneliness feelings [37]. Then, religious beliefs seem to constitute a form of magical restoration where the individual attributes one's prospective survival externally to superior forces. This allows the reframing of PH-related meanings so to maintain hope for the future, as a way to refocus life and find the positive in their disease [37].

Overall, from an object relations perspective, our findings show that reparation strategies enacted by patients with PH change over the course of the disease. Whereas, denial seems to represent the main response at symptom onset to preserve the good self from the incumbent evil [17], frustration and persecutory feelings emerge during the search for a diagnosis [13]. This involves the progressive protagonization of illness, thus shifting to a paranoid-schizoid position [19, 20], with death anxiety being the primary emotional reaction to diagnosis communication. In this regard, the difficulty to elaborate on depressive feelings concerning the damaged self may lead to a complicated grief and to rely on anaclitic strategies to face the future that consent to rebuild an ego structure [38].

With regard to the study limitations, it should be acknowledged that, given its qualitative and exploratory nature, the present study provides only some clues regarding the illness experience of people with PH that need further investigation. Besides, the limited size of our sample, entirely composed by Italian women, does not consent any generalization. In this regard, future research may include male patients and explore potential gender-related differences on illness narratives. Then, because of the lack of further information about participants' characteristics, medical conditions and context-related variables, this study does not allow the identification of any causal relationship between PH and the detected themes.

This notwithstanding, this study makes a significant contribution to the exploration of people with PH's several subjective challenges in coping with a defective body from symptom onset to after diagnosis. As well, it allows a better understating about how such patients progressively shift their focus from the self to the illness as the disease progresses, enacting different repairing strategies in terms of regulatory processes. This is particularly relevant because representations that signal a health threat, such as perceived consequences, are found to relate to both adaptive and maladaptive outcomes through specific coping strategies [42]. Therefore, it should be noted the relevance of biographical continuity and self-coherence over the course of chronic illness, as well as the need to address specific priorities of patients across different stages of healthcare provision [43-45].

## **Ethical Considerations**

### **Compliance with ethical guidelines**

All study procedures were in compliance with the ethical guidelines of the Declaration of Helsinki, 2013.

### **Funding**

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

### **Conflicts of interest**

The authors declared no conflict of interest.