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VIDEO ARTICLE

Resisting the 'Patient' Body: A Phenomenological Account

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According to the biomedical model of medicine, the subject of the illness event is the pathology rather than the person diagnosed with the disease. In this view, a body-self becomes a 'patient' body-object that can be enrolled in a therapeutic protocol, investigated, assessed, and transformed.

How can it be possible for cancer patients to make sense of the opposite dimensions of their body-self and their body-diseased-object? Could a creative embodied approach enable the coping with trauma tied to the experience of illness?

By applying a phenomenological approach and auto-ethnographic analysis to the experience of cancer, this visual exploration provides support for rethinking the cancer event through a performative perspective. This work previews images and video material collected over ten years of onco-haematological treatments, video dance performances and physical explorations.

This work displays how processes of healing can be set in motion by creative embodied practices, physical explorations and unexpected journeys. By resisting the biomedical model and allowing the emergence of new meanings, it illustrates how dance and performative practices offer ground for transformation.

Keywords: Phenomenology of the Body; Dance; Embodied Practices; Autoethnography; Cancer Treatments; Illness Narrative

VIDEO ARTICLE

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STILLS FROM THE VIDEO ARTICLE





VIDEO ARTICLE TRANSCRIPT

[00:13]

Resisting the 'patient' body: a phenomenological account

By Sarah and Ruggero Pini

[00:46]

[Sarah Pini:]

Phenomenology considers the body our perceptual horizon, the background mode of our consciousness, “a necessary support of all that we perceive and experience” (Ram and Houston 2015, 12). Sometimes the body emerges from this background and reclaims our attention in ways that can be unfairly brutal, and merciless. When the body does that, we cannot longer ignore its centrality in shaping how we think and who we are. “In illness, in disability, in the awareness of death, in pain, we find that ‘bodily events become the events of the day’”

[01:25]

“In illness, in disability, in the awareness of death, in pain, we find that ‘bodily events become the events of the day’”

(Merleau-Ponty 1986, 85 in Ram and Houston, 2015, 12).

[01:46]

In November 2006, aged 22, I was diagnosed with Hodgkin Lymphoma. From that moment a long transformative journey started for me. I suddenly had to interrupt my dance career to undergo a first-line chemotherapy regimen. Unfortunately, the results were ineffective, so I went through what is called second-line therapy, in my case an even stronger chemotherapy regimen, an autologous stem-cells transplant and a cycle of radiotherapy. After a year of strenuous treatments, I finally thought that my problem was solved, but in fact, it was not. After the failure of all standard protocols, it was the time for scientific testing. In the following six years I was enrolled in several clinical trials including monoclonal antibodies and immunotherapy, and in between trials, I received different salvage chemotherapies.

[03:55]

In 2010, four years later having received my diagnosis, I began my studies in Cultural Anthropology at the University of Bologna, in Italy. For my degree I carried out a research based on my dual experience of haematological patient and medical ethnographer, collecting and analysing the narratives of several cancer patients as well as reflecting on my own. The aim of my research was to gain a deeper understanding of this illness by engaging with different contexts and professionals, observing the practices of different clinicians, biologists, nurses and psychologists in various hospitals across Europe. In doing so, I acknowledged my privileged position of being part of a world where I could have free access to treatments and the right to cure. This privileged standpoint didn't excuse me from questioning the common metaphors and mystifications bound to cancer within our Western culture, from its etiological explanations to its relative moral implications. I addressed the meanings of alterity that this disease seems to carry with it, the stigmatization, the feeling of otherness, the unpredictability, the fear of the unknown.

[05:25]

Susan Sontag defined cancer as "the disease of the Other" (Sontag 1977), while Deborah Gordon stated that cancer experience is entirely informed by a dimension of alterity. She pointed out that "the illness itself is often lived as 'other'. Both medical and popular accounts present a battle between the 'good' and the 'bad', the 'benign' and the 'malign', reasserting the dichotomous understanding of the world that cancer in fact defies."

[05:40]

"the illness itself is often lived as 'other'. Both medical and popular accounts present a battle between the 'good' and the 'bad', the 'benign' and the 'malign', reasserting the dichotomous understanding of the world that cancer in fact defies"

(Gordon 1990, 276).

[06:08]

One of the challenges I faced along my journey was to find a sustainable balance between these two polarities. From a biomedical point of view in fact, the subject of the illness event is the pathology. In order to be treated and possibly cured, the ill person has to subject herself to a specific regime and control, the biomedical one, where a body-self is made a "patient" body-object that can be enrolled in a therapeutic protocol, investigated, cut, scrutinized, assessed, and transformed. But from the narrative perspective the subject is the person diagnosed with the disease (Mattingly 1994, 817). How can it be possible for cancer patients to comprehend and to hold together these two opposite dimensions, their body-self and their body-diseased-object? When the body becomes uninhabitable, where the exiled occupier of this body can go?

[08:00]

During this path, I embarked on several journeys, I visited hospitals in four different countries, and collected images and video material of my healing journey. I also travelled and visited meaningful places across five continents. In these places, with the help of my brother, a professional video maker, I recorded video dance performances, undertaking improvised explorations of my inner and external landscape. The performances we captured were often spatiotemporally distant to each other but deeply related to the unfolding of my life narrative. The locations where I performed my illness were not just the scenarios where I emplotted my story, they were physical manifestations, situational metaphors of my feelings and thoughts. The resonance of my lived experience with the meanings embodied in these places, enabled me to make sense of the inextricable, incomprehensible events that, all of a sudden, became my path.

[10:05]

I considered these performances a form of immanent rituals to link together my broken self with my surroundings. During my medical journey I could also observe how the practices related to cancer therapeutic treatments are intrinsically linked to the rites of passage, intended as the ones in which “a person leaves one world behind her and enters a new one” [Van Gennep (1909) 1969, 19]. I'm referring to cancer diagnostic procedures, like entering the positron emission tomography scanner for example. It is the passage through the diagnostic device that ratify the access to the new role of cancer patient.

Another example is the cutting of the hair or shaving the head, a common practice for those who undergo chemotherapy treatments. To these binding rituals of passage – as they were happening – I juxtaposed my personal story, re-enacting these rituals instilled with my own meaning. As Sondra Fraleigh said, “my purposes project me into action, not my contingency. Likewise, I create and define my body as I enact my purposes. I am not moved by superior energies, I move myself.”

[11:34]

“my purposes project me into action, not my contingency. Likewise, I create and define my body as I enact my purposes. I am not moved by superior energies, I move myself.”

(Fraleigh 1987, 18).

These performances became a magnification of the rites of passage and separation that I underwent, and they played a crucial role alongside the unfolding of my history with the disease. They acted as practices of resistance to counteract the dispossession of my body and to restore a form of agency, necessary to navigate what became a disrupted alien world.

[12:35]

These performances became my coping strategy to simply find a hospitable locus after having been cast out from what once was a familiar habitat. They also testify the struggle to reshape the therapeutic trajectory of my illness. By re-enacting my way towards-the-world I sought to shape my identity in other and more endurable terms than the ones provided by the biomedical model and cancer's common rhetoric. The practice of performing my illness helped the construction of sense-making and sustained the process of elaboration of my own narrative.

[13:53]

After eight years of recurring cancer treatments, I was confronted with the necessity of receiving a bone marrow transplant. A profound fear was gripping my soul, along with the increasing awareness that the transplant might have been the last chance to cure my disease. I was feeling like I was stuck in a separate dimension, where I couldn't breathe. In December 2014, I decided to enact this feeling and filmed an underwater dance in Tenerife. This dance became a visual metaphor of my inner landscape at this phase of my medical journey. With my brother we later framed this performance into a short film named ABISSO. As a performative act, ABISSO marks the acknowledgment of my deepest fears and the courage to embrace my fate. ABISSO also portrays the last dance I performed with my original blood. Several months later I underwent a stem cells transplant from an unknown unrelated donor that radically transformed my blood and my body.

[15:35]

My long medical trajectory finally culminated with the success of the most transformational of all treatments. The allogeneic stem cell transplant completely morphed my blood, not only by equipping me with a different

blood type than the one I was born with, but it also gave me a radically new immune system. The entire biology of my body was changed, hybridised, to the point of allowing the co-existence of two different genomes. I finally became a Chimaera.

[16:27]

By performing and recording such biographical events, and by staging my illness in affective and significant scenarios, I aimed to rewrite my medical and life history. The act of creatively re-modelling my illness narrative in meaningful environments was supported by a hidden belief, the hope that by enacting my illness, it would have not only allowed me to construct a different meaning, but also to exercise an effect on the biology of my body, and so to transform my fate.

To conclude this journey, I borrow the words of Rosi Braidotti, who said that "what sustains the entire process of becoming-subject is the will to know, the desire to say, the desire to speak; it is a founding, primary, vital, necessary and therefore original desire to become."

[17:26]

"What sustains the entire process of becoming-subject is the will to know, the desire to say, the desire to speak; it is a founding, primary, vital, necessary and therefore original desire to become"

(Braidotti 2003, 22)

Through this work I aim to display how processes of healing can be set in motion by creative embodied practices, physical explorations and unexpected journeys. Through the lens of embodied research, the experience of illness can be transformed and become a powerful ground for reconsidering our relational and affective positionality towards both our emotional landscape and our social and outer environment.

[18:34]

Written, Performed and Narrated by
Sarah Pini

Filmed and Edited by
Ruggero Pini

List of dance performances
(in order of appearance)

SEGNO

Dance and Choreography Sarah Pini
Videography Ruggero Pini
Filmed in 2011 in Marzabotto, Municipal Theatre, Italy

SOGNO

Dance and Choreography Sarah Pini
Videography Gianmarco Gaviani
Filmed in 2007 in S. M. Codifiume, Ferrara, Italy

DESERTO

Dance and Choreography Sarah Pini
Videography Ruggero Pini
Filmed in 2009 in Avdat, Negev, Israel

SPETTRO

Dance and Choreography Sarah Pini
Videography Ruggero Pini
Filmed in 2007 in Marzabotto, Villa Aria Park, Italy

RISVEGLIO

Dance and Choreography Sarah Pini
Videography Ruggero Pini
Costume Design Beatrice Zannini
Production Assistant Paolo Carraro
Filmed in 2016 in Sirano, Setta River, Bologna, Italy

INCUBO

Dance and Choreography Sarah Pini

Videography Ruggero Pini

Filmed in 2007 in Sirano, Bologna, Italy

ABISSO

Dance and Choreography Sarah Pini

Videography Ruggero Pini

Filmed in 2014 in El Puertito, Tenerife, Spain

RICORDO

Dance and Choreography Sarah Pini

Videography Ruggero Pini

Filmed in 2008 in Monte Sole Historical Park and in Sasso Marconi, Italy

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[19:33]

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Competing Interests

The authors have no competing interests to declare.

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