

# Storying Illness Across Disciplines

Jornada – 14 de Março de 2014

Programa

One-day Meeting – 14<sup>th</sup> March 2014

Programme

MESA-REDONDA / ROUNDTABLE

09:30 am – 11:00 am

**Isabel Fernandes** – The Narrative & Medicine Project: Past, Present and Future

For the benefit of our guest speakers and general audience, the purpose of my brief talk will be to summarize the stages of the Narrative & Medicine project, from its inception in 2009 to the present moment, by highlighting its main events and achievements. I also wish to draw attention to the need of preparing the future, by strengthening and extending our national and international partnerships and devising a new multidisciplinary fundraising project/s.

**Maria Antónia Rebelo Botelho** – Exploring Lived Experience through Narrative Research

“If you want to know me then you must know my story... my story defines who I am.” (McAdams, 1993)

Narratives cross the discipline and practice of nursing. Since Florence Nightingale (1859) that sick people's narratives are a source of knowledge and a foundation for clinical practice. Disease is a biographical event and to understand it nurses need to give voice to the sick person and hear what he/she has to say.

What epistemological status should be attributed to the narrative? How do narratives turn into knowledge? These are the questions that will guide my presentation.

I will try to find comprehensive answers grounded in a conception of person-centered nursing.

**Teresa Casal** – Listening to the First Person in the Clinical Encounter

Presumably the discomfort pinpointed by Havi Carel is precisely what has drawn many of us to Narrative Medicine, just as it has led Carel to explore a phenomenological approach to illness: the realisation that, much as we trust medicine's science-based knowledge, an “objective (and objectifying), neutral and third-personal” (Carel 2008, 8) description of illness neither fully accounts for the experience of illness, nor is it sufficient for good clinical practice, which requires “both the scientific or hypothetico-deductive and the practical or interpretive” reasoning (Montgomery 2006, 45).

Whose first-person do we talk about when we talk about the clinical encounter? Carel's claim, and the current proliferation of illness narratives, would suggest that it is the patient's first-person experience that needs to be acknowledged within the therapeutic relationship. Narrative medicine, however, argues that for this to happen, healthcare practitioners need to “achieve first the subject position and then, with luck, the intersubjective bond between ourselves and others, thereby inaugurating and framing the therapeutic relationship” (Charon 2008, 236). Listening to the patient's first-person experience thus seemingly needs to start at home, in acknowledging the practitioner's own first-person experience. This involves a conceptual and cultural shift.

Having become involved in Narrative Medicine by bearing witness to the vital need to listen to the patient, I have come to listen to practitioners' narratives, which testify to the need for this shift to occur.

**Cecilia Beecher Martins** – Stories of Self through Film Analysis

In my practical research with free associative film analysis, I have seen the potential for acceptance and change that writing personal narratives relating responses to external stimuli, in this case films, can exercise on individuals' lives. One of techniques I used to stimulate these narratives was free associative film analysis as developed by psychoanalytical literary critic Norman Holland and presented in Meeting Movies (2006). When volunteers with high levels of anxiety (measured using Charles Spielberger's State and Trait Anxiety Inventories) wrote free associative analysis about films with simple narratives and positive if alternative endings (my choice), they were able to develop coping strategies, based on their writings, for dealing with this situation. Other volunteers became aware and accepting of unique identity principles when

they wrote free associative analysis to film scenes in movies they had connected with free associatively. Identity principles were defined according to Heinz Lichtenstein's unique identity theme defined in the essay "Identity and Sexuality—A Study of their Interrelationship in Man." (1961).

Writing these narratives was often difficult, especially if the film has been the volunteer's free associative choice, as this often required the revisiting of past events. Nevertheless, strong personal narratives were produced that allowed the writer to look at his/her personal story outside of social constraints. I wonder if or how this technique could be used within a clinical or educational context.

### **Diana V. Almeida – The Physical and Energetic Bodies**

Last June, I taught with Maria de Jesus Cabral a Summer Course at ULICES, entitled "Reading: The Text of the Body, the Body of the Text." During a week, we explored the interactive process between multiple dimensions of corporality, from the material to the discursive, through the more subtle energetic fields. I now aim to reflect on that teaching experience, presenting a holistic concept of the body that expands our scientific perception of its limits. My corpus will be Rumi's poem "Body Intelligence" and Rafael Campo's "What the Body Told," and I will try to reflect on some of the body's mysteries.

### **Alda Correia Correia – Imaginary, Science and Emotion, a Shared Journey**

I came across Narrative Medicine when I was looking for connections between art and science, imaginary and body; it came up as one of the most interesting and important forms of relating these two areas, incorporating also a third fundamental element – empathy. David Bohm in his text *On Creativity* suggests, for example, that the process that is in question in artistic creativity is the same that works in the formation of a scientific theory.

In my perception there are two distinguishable areas, implied in Rita Charon's approach and that is clear in *Narrative Medicine – Honouring the Stories of Illness*: one that has to do with "predicament" and "catharsis", interrelated with narrative psychology and another that emphasizes the aesthetic, artistic and plastic (creative) side of literature (art). The potential of Narrative Medicine is immense but I believe that if we do not pull things apart some inconsistencies may arise. We could, for instance fall in the simple exploitation of illness stories, forgetting the creative perspective and the capacity of art in relation to welfare. But we can also find extremely captivating ways to stimulate life.

Moderadora / Chair **Marijke Boucherie**

**11:00 a.m. – 11:30 a.m. Discussion**

**11:30 a.m. – 12:00 Coffee break**

**12:00 – 1:00 p.m. PLENARY SESSION**

### **Brian Hurwitz – Urban Observation and Sentiment in James Parkinson's *An Essay on the Shaking Palsy* (1817)**

This talk examines how James Parkinson came to recognize a complex disorder of trembling, posture and gait through observations – some repeated over a 10-year period – in his apothecary's shop and on London streets. Although his *Essay on the Shaking Palsy* was quickly acknowledged to be an important description of a progressive, disabling condition, Parkinson himself believed its claims to be tentative: he was unsure of the cause, had little to offer by way of treatment, and could find only indirect evidence of the seat of the condition in the nervous system.

Moderador / Chair: **João Almeida Flor**

**1:00 p.m. – 3:00 p.m. Pausa para almoço  
Lunch break**

**COMUNICAÇÕES / PAPERS**

**3:00 p.m. – 4:00 p.m. PLENARY SESSION**

**Christian Hervé – Trois entreprises d'intégration des sciences humaines et sociales dans le cursus des études médicales: l'enseignement 'EM2R' avec les patients comme enseignants, le DIU 'Médecine et Humanités' et les 'Rencontres d'Hippocrate'**

Moderadora / Chair: **Maria de Jesus Cabral**

**PAINEL EM FRANCÊS / FRENCH PANEL:**

**4:00 p.m. Maria de Jesus Cabral & Gerard Danou – Maladies d'Alzheimer et sida à l'épreuve de la littérature**

Lutter contre la perte des mots, contre la perte de la mémoire des langues en maintenant du lien affectif, tel est le combat que l'écrivain Pierre Pachet a mené près

de sa mère atteinte d'une maladie d'Alzheimer (Devant ma mère, Paris, Gallimard, 2007). Cet essai de "philosophie fiction" selon l'expression de l'auteur, traduit une connaissance subjective de la maladie de l'autre mais laisse intacte l'énigme de l'épreuve intime du mal.

Dans Cytomegalovirus, Journal d'hospitalisation, (Paris, Seuil, 1992) ouvrage posthume d'Hervé Guibert (atteint par le virus du sida) le texte fragmentaire, troué, traduit l'épreuve intime de son corps épuisé, épuisement contre lequel le rempart tissé par les mots écrits et lus offre malgré tout encore une ultime lumière, une illusion d'éternité.

Le rapprochement de ces deux textes porteurs d'un savoir anthropologique de la maladie vise à cerner les enjeux de l'écriture de deux grands maux d'actualité, afin d'interroger, de manière interdisciplinaire, les images et la poétique du corps malade, vécu ou fictionnalisé.

#### **4:20 p.m. Nuno Proença – Quelques difficultés de la compassion**

Dans un article intitulé «Compassion in the care of patients», Rita Charon soutient que la compassion - entendue comme capacité pour établir une communication avec un autre être humain et pour reconnaître le malheur d'autrui - peut être apprise, renforcée et utilisée afin d'améliorer la pratique médicale. Elle permettrait, notamment, de dépasser des situations de «souffrance parallèle» où médecins et patients sont simultanément renfermés dans une souffrance non communiquée. La compassion rendrait aussi possible à chacun de ceux qui sont impliqués dans les soins de mieux y participer, non pas en faisant disparaître la charge affective rattachée à la maladie, mais en lui permettant de trouver un sens par le biais de moyens narratifs.

Nous aimerions reprendre les arguments de R. Charon en faveur d'une éducation de la compassion médicale tout en leur ajoutant une réflexion sur les difficultés de la compassion dans les institutions de soins, notamment pour comprendre quelques unes des raisons qui mènent le personnel soignant à s'écarter de la souffrance d'autrui, à vouloir y devenir indifférent ou à essayer de se réfugier derrière une routine qui neutraliserait en eux tout bouleversement possible. Bien qu'en étant capables, souhaitons-nous vraiment apprendre la compassion, si celle-ci nous demande aussi d'accepter les limites d'une condition humaine et l'appartenance à une communauté vivante qui n'a cure ni des différences institutionnalisées par le cadre hospitalier ni des exigences de son organisation ?

Moderador / Chair: **António Barbosa**

**4:40 p.m. – 5:00 p.m. Discussion**

**5:00 p.m. – 5:30 p.m. Coffee break**

**PAINEL EM INGLÊS / ENGLISH PANEL:**

#### **5:30 p.m. Zuzanna Sanches – Healing with Stories: Deirdre Madden and the Encounter with the Other**

This paper deals with Deirdre Madden's representations of selfhood and otherness as depicting the deepest levels of identity in their most authentic revelation. These processes are constructed and performed in dialogue and in relation to the other so that one can be healed of suffering and physical pain resulting from a somatization of anxieties and memories that contain the unexorcised past. When encountering the other, one has the sense of entering into something of a great significance both in a general sense of cultural codes and in a particular sense of personal growth towards overcoming psychological traumas one carries since childhood.

This essay will provide an overview of Madden's fiction as representative of the generation of Irish women writers born in the 1960's. It will also serve as an analysis of some chosen fragments from the following novels: Hidden Symptoms, Remembering Light and Stone and Authenticity.

#### **5:50 p.m. Marijke Boucherie – Literature and the Solitude of Illness**

In my very short intervention I would like to make an addendum to my reflections of the 8th of January 2013 (open seminar) in order to stress the healing dimensions of literature. I want to say that, in my opinion, the activity of reading strengthens the capacity to listen to words (rather than to people) and that in this sense the many forms of literature may serve as dwelling places for those who, because of illness or disability, live in other places than those not affected by illness. I want to emphasize that for the ill and their carers, literature may acquire a dimension that is an integral part of life.

I will quote two stories of Alice Munro ("Dance of the Happy Shades" and "Child Play"), a novel by Jane Urquhart (A Map of Glass) and text by Emily Urquhart about children with albinism ("The Meaning of White").

Moderadora / Chair: **Luísa Leal de Faria**

**6:10 p.m. – 6:30 p.m. Debate e encerramento / Discussion and closing session**