




REHPA

Danish Centre on
Rehabilitation and
Palliative Care

WRITING, NARRATIVES AND MEDICINE

Workshop | 3 October 2017 | 13:00 - 16:00 | REHPA, Vestergade 17, 5800 Nyborg

Programme

- 
- 13:00 Welcome and introduction
Ann-Dorthe Zwisler, Head of Centre and Professor, introduces REHPA and the exploratory motivation for carrying out writing workshops at REHPA.
- 13:15 The power and significance of narratives: Why writing and reading narratives are important in health and severe illness
Rita Charon, Professor, Columbia University, author of the book "Narrative medicine. Honoring the stories of illness" (2006), gives a lecture on this topic based on her extensive knowledge and experience in this field.
- 14:15 Break
- 14:30 The affective meeting
Merete Mazzearella, Professor, University of Helsinki, author of the book "Den goda beröringen: Om kropp, hälsa, vård och litteratur" [The good touch: on the body, health, care and literature] (2006), introduces her work on narratives in medicine, focusing on literature and creative writing.
- 15:00 An anthropological evaluation of a Writing Workshop at REHPA
Helle Ploug Hansen, Professor, Research unit of General Practice, Department of Public Health, University of Southern Denmark, presents the preliminary results from the first Writing Workshop held at REHPA focusing on the participants' experience based on participant-observation and ethnographic interviews.
- 15:30 Panel discussion and closing remarks
Narrative medicine: finding the way ahead in rehabilitation and palliative care, chaired by Helle Timm, Professor, REHPA.
- 16:00 End

Overall aim of the Center

Background

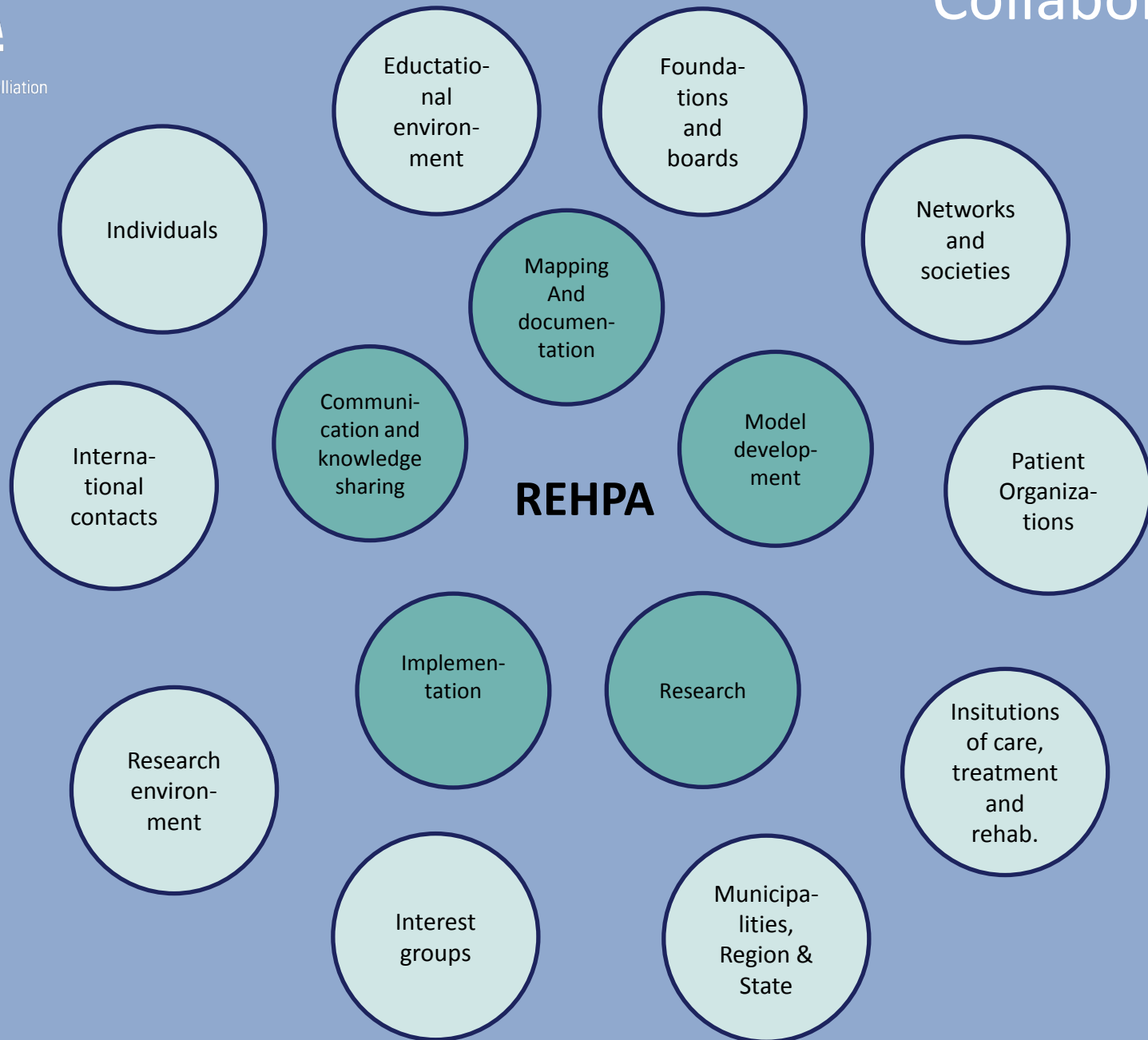
The Danish Knowledge Centre for Rehabilitation and Palliative Care was established in 2012 as part of the national health budget to achieve a greater coherency between rehabilitation and palliative care

Ministry of Health, Note 2012

Overall aim:

- To strengthen development and research within clinical rehabilitation and palliative care
- To ensure that knowledge is translated into interdisciplinary and intersectoral clinical practice

= = > > to the benefit of people suffering



Residential stay aiming at people with life-threatening diseases



Focus on further development of rehabilitation and palliative care
to the benefit of the people suffering

Bringing medicine and humanities together through rehabilitation and palliative care



Anne-Marie Mai
Professor
Department for the Study of culture
University of Southern Denmark



“It is not a bunch of symptoms seeking the doctor,
It is a whole story, a whole person”

Kim Brixen, CEO, University Hospital Odense, SDU



Anders Juhl Rasmussen
PostDoc, PhD

REHPA

Videncenter for
Rehabilitering og Palliation

SKRIVEVÆRKSTED

*Skrivning som innovativ indsats i
rehabilitering og palliation*

REHPA | NOTAT NR. 6 | SEPTEMBER 2017

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Praksis (SDU) og REHPA



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There is no seminar fee, but registration no later than 19 September is required, as seats are limited. Please register at <http://webpay.sdu.dk/system/narratives>.

SDU



Professor Rita Charon
Columbia University, New York, USA

“The power and significance of narratives:
Why writing and reading narratives are
important in health and severe illness”



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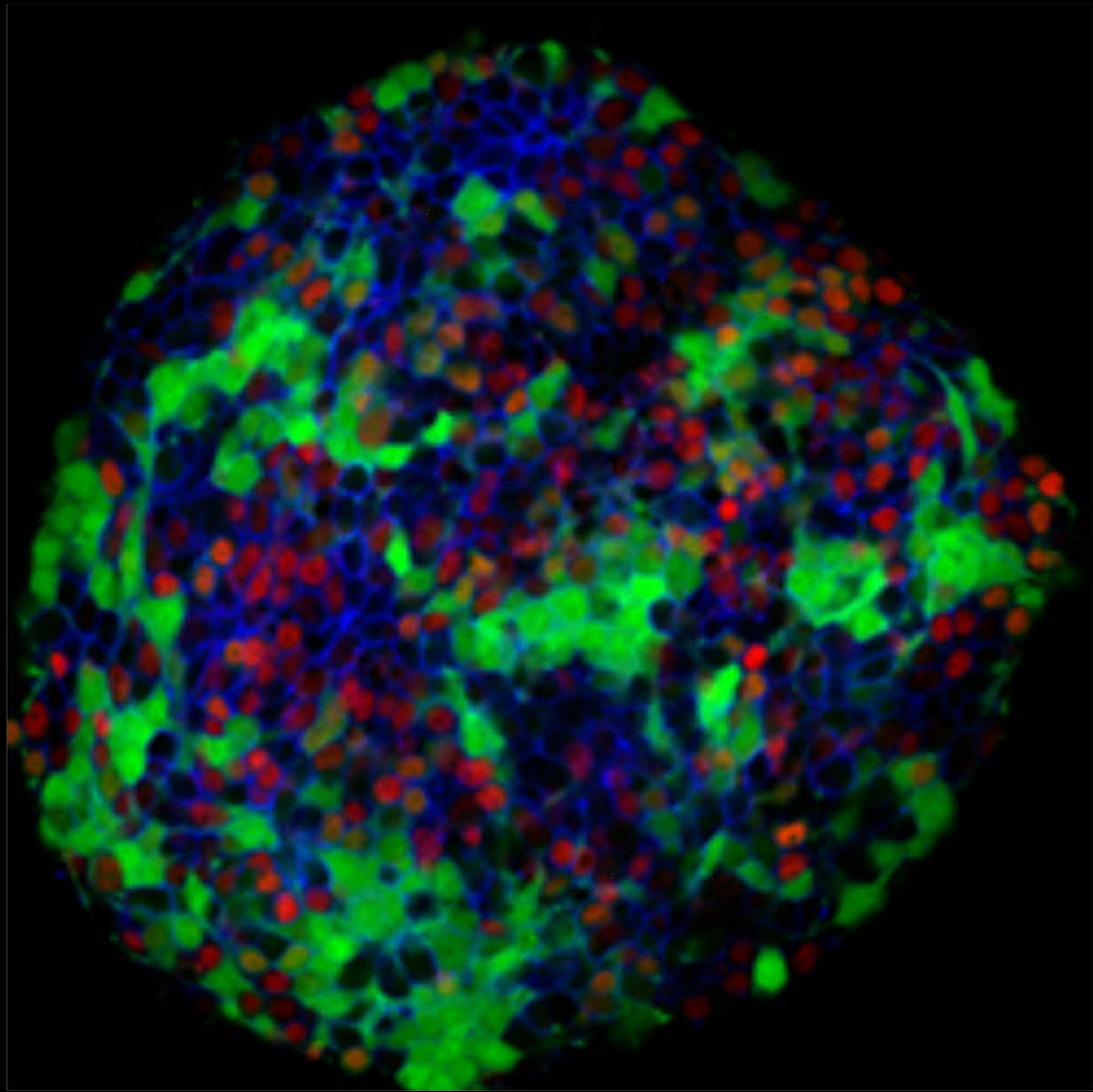
*College of Physicians
and Surgeons*

The Shock of Attention: Discoveries of Narrative Medicine

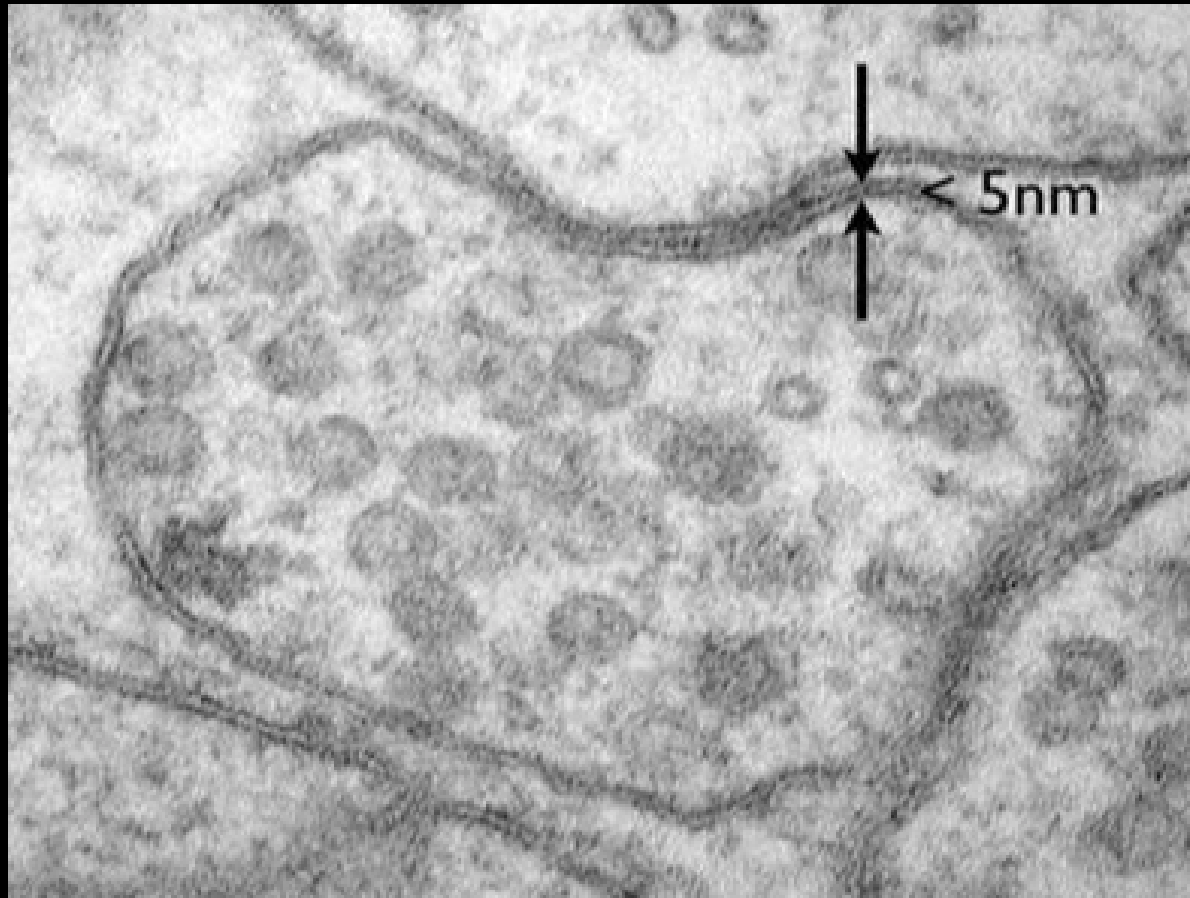
Rita Charon, MD, PhD

Columbia University















Narrative Medicine Principles

- To recognize, absorb, interpret, and be moved to action by stories of illness
- Sources in primary care, narrative studies
- Relational, embodied, creative
- Co-construction of illness narratives
- Commitment to social justice



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The PRINCIPLES
and PRACTICE *of*
NARRATIVE MEDICINE



Rita Charon, Sayantani DasGupta, Nellie Hermann,
Craig Irvine, Eric R. Marcus, Edgar Rivera Colón,
Danielle Spencer, Maura Spiegel

OXFORD





Movements of Narrative Medicine

Attention—reception, fine perception, use of the self

Representation—capturing the perceived in words or images, use of the imagination

Affiliation—with patients, colleagues, partners toward social justice, self



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Merleau-Ponty, “Cézanne’s Doubt”

“The artist is the one who arrests the spectacle in which most men take part without really seeing it and who makes it visible to the most ‘human’ among them.”



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Philip Larkin, “Days”

What are days for?

Days are where we live.

They come, they wake us

Time and time over.

They are to be happy in:

Where can we live but days?

Ah, solving that question

Brings the priest and the doctor

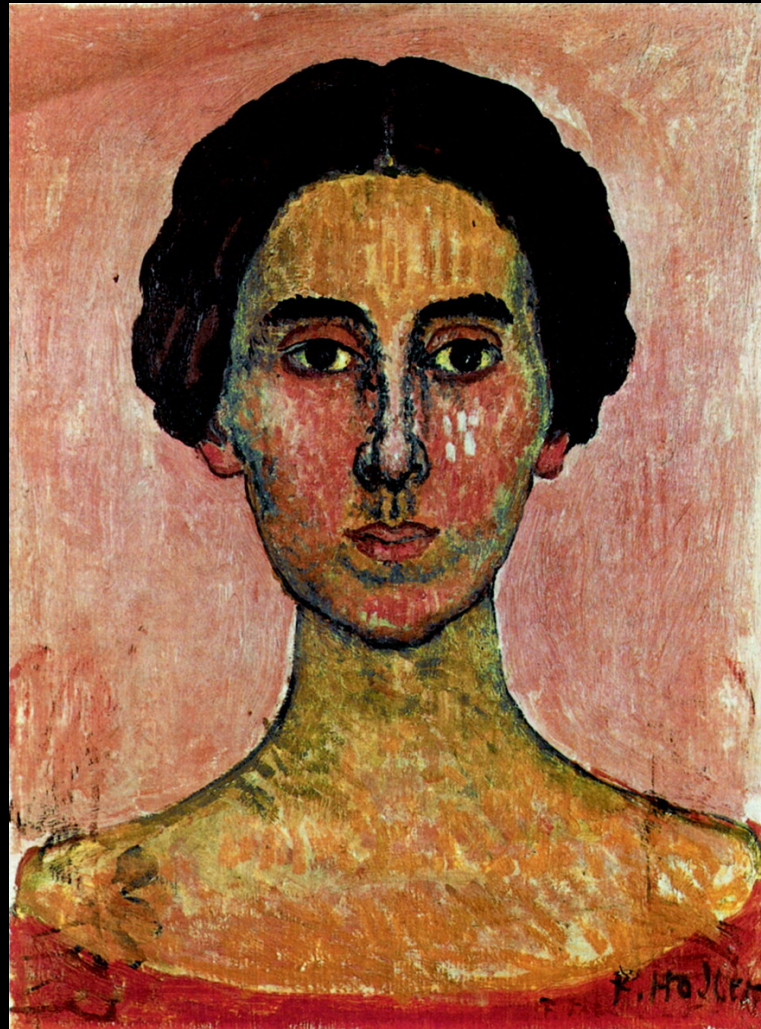
In their long coats

Running over the fields.

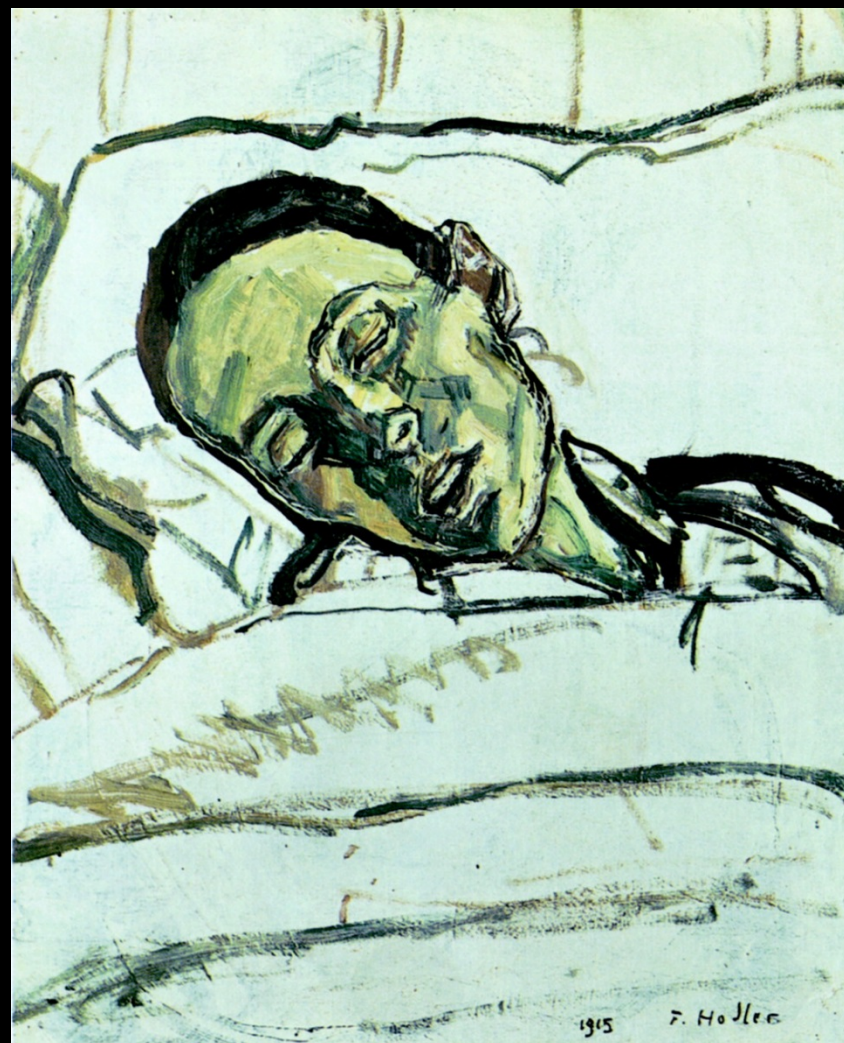


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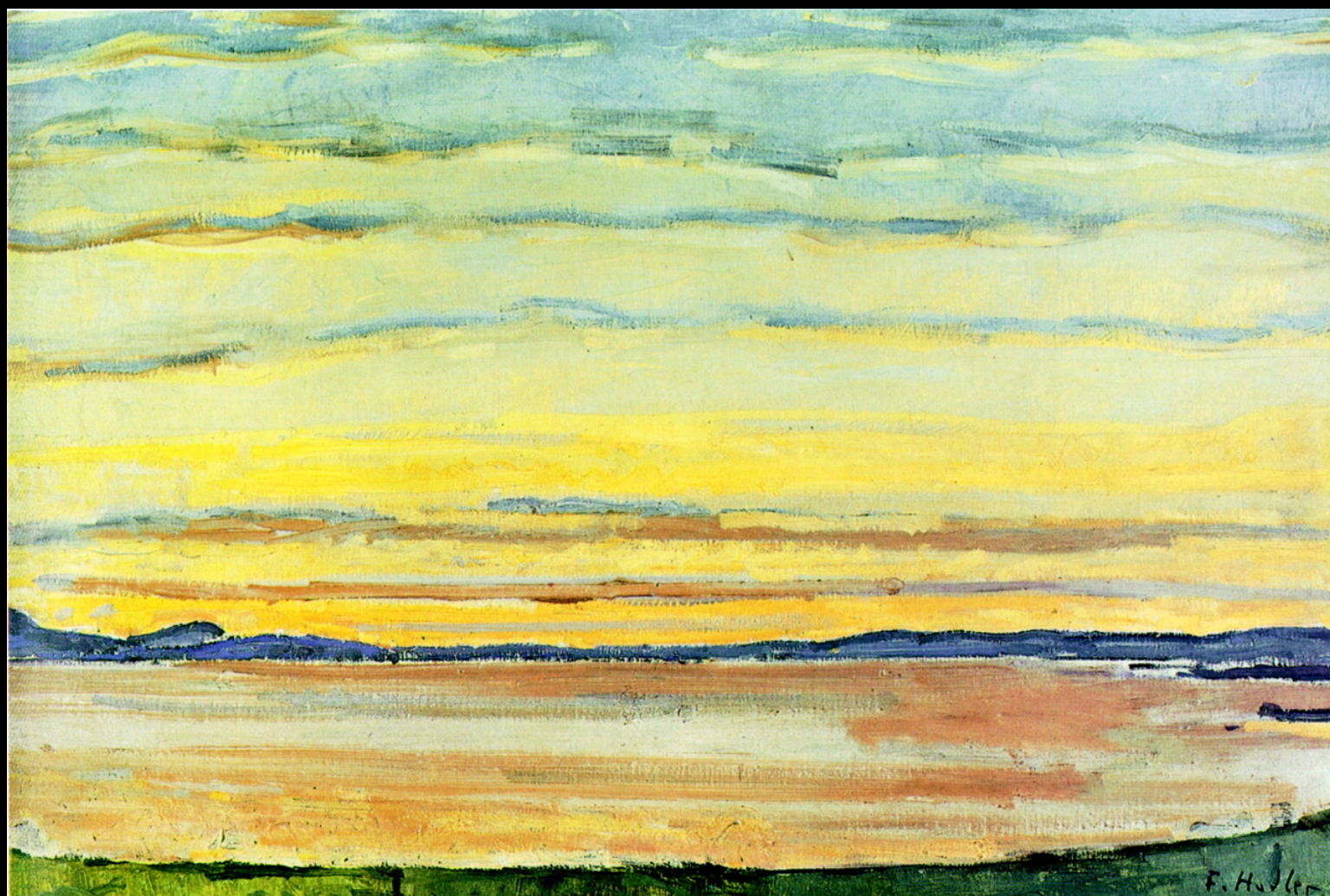














Professor Helle Plough Hansen
University of Southern Denmark, Odense

“ An anthropological evaluation of a
Writing Workshop at REHPA ”

Preliminary results from

the first creative writing workshop for people with cancer in Denmark



Helle Ploug Hansen

Department of Public Health, University of Southern
Denmark, hphansen@health.sdu.dk



The creative writing workshop

was

- ✓ developed from a model used in treating alcohol addiction at the Alcoholism Clinic in Odense, Denmark in 2016
- ✓ carried out in two course sessions: a 2-day stay and a 1-day follow-up session
- ✓ carried out in two groups with 9-10 participants in each group
- ✓ led by two writers of fiction



Structure and content

Participants were divided into two groups

- ✓ A short presentation of how to do creative writing
- ✓ Several 5-7 minutes non-stop writing over a given theme
- ✓ Reading aloud and comments
- ✓ Lecture about literature
- ✓ Dinner and socializing
- ✓ Reading aloud pieces of the participants work from the day



Evaluation

The course was evaluated through several approaches:

- ✓ **a descriptive approach** with baseline registration of the participants
- ✓ **a written evaluation** from the participants
- ✓ **an anthropological evaluation**
- ✓ **a verbal evaluation** from the professionals involved



The descriptive approach with baseline registration of the participants

- ✓ advertisements with short notice recruited 20 participants
- ✓ the participants were recruited from all parts of Denmark, mostly women (17/19), around 55 years of age
- ✓ the participants had substantial need for rehabilitation based on their average score of 5.6 on the 1-10 point "Dallund scale"

The written evaluation

- ✓ The participants' written evaluation was very positive
- ✓ The participants' statements included: writing memories - receiving new tools - writing about illness and daily life
- ✓ The participants' experience differed in relation to how they could link writing with their illness trajectory
- ✓ Some thought that writing fits well with the rehabilitation
- ✓ Some did not see a connection between writing and rehabilitation
- ✓ The participating professionals evaluated the REHPA model of the workshop positively and indicated the need to modify the concept slightly



Anthropological evaluation

can uncover

- ✓ different actors perspectives, experiences on a specific practice/intervention
- ✓ relations between different actors – and between actors and 'things'
- ✓ what works for who, when and under what circumstances
- ✓ how and why a specific practice looks like it does
- ✓ how a practice can be strengthened or changed in the future

Ethnographic fieldwork

Participant observation



Ethnographic interviews



Ethnographic fieldwork in a writing workshop setting

- ✓ **Participating observation** during the workshops days and evenings
- ✓ **Ethnographic interviews and observed participation** in the homes of 11 of the participants (10 women and 1 man)
- ✓ **The data-set** consisted of fieldnotes and transcribed interviews

From the fieldnotes

One theme stood out from the fieldnotes:

- enthusiasm and endurance (begejstring og ihærdighed)

Three subthemes were recurrent:

- to write
- to create community
- to be a third place

To write

Many participants said it was the theme: *Writing Workshop* that had made them sign up

One of the participants said: *“There is so much I want to write about – my illness – the thoughts I have and have had – everything that pushes into daily life”*

Another participant said: *“I want to write a little so I can get the illness and the hospitals out of my body”*

Summarizing the participants wanted to be able to:

- write memories
- get writing tools
- write about everyday life and sickness

To create community

Some of the participants knew each other from other REHPA courses

They have been in mail contact and decided to sign up together

At the arrival at REHPA they greeted each other very warmly

During breaks they talked – took a walk together – drank coffee and tea together

They talked about how writing had opened for new thoughts and ideas. One participant said: *“It is really a good thing that we are going to read aloud. We get to know each other quickly”*

To be a third place

- Several of the participants had stayed at Hotel Nyborg Strand in connection with other REHPA courses
- Some of them had made a plan of what to do at the hotel – relax – walk at the beach – take a swim in the in-door pool.
- One of the participants said: *“I never stay at a hotel. It is luxury – and dinner is served – and there is a huge breakfast buffet. It is like going on holiday. I really looked forward to this”*
- Another participant said: “I really enjoy this – only to think about myself – to get a little away

Conclusion

- ✓ Overall, the evaluation of REHPA's first writing workshop shows that this concept can be implemented in a setting in Denmark for people with cancer
- ✓ Creative writing may potentially make a difference for people with serious life-threatening illness
- ✓ The concept needs to be developed further
- ✓ A well designed research-based evaluation is needed to more deeply understand the significance of writing and determine the potential health benefits

Professor Helle Timm
REHPA, University of Southern Denmark

“ Finding the way ahead in rehabilitation and
palliative care and Narrative medicine”



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