



ESOT TRANSPLANT LIVE

ONLINE
EDUCATION

Non-adherence

A deliberative choice

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Conflict of interest

I declare I have no conflict of interest

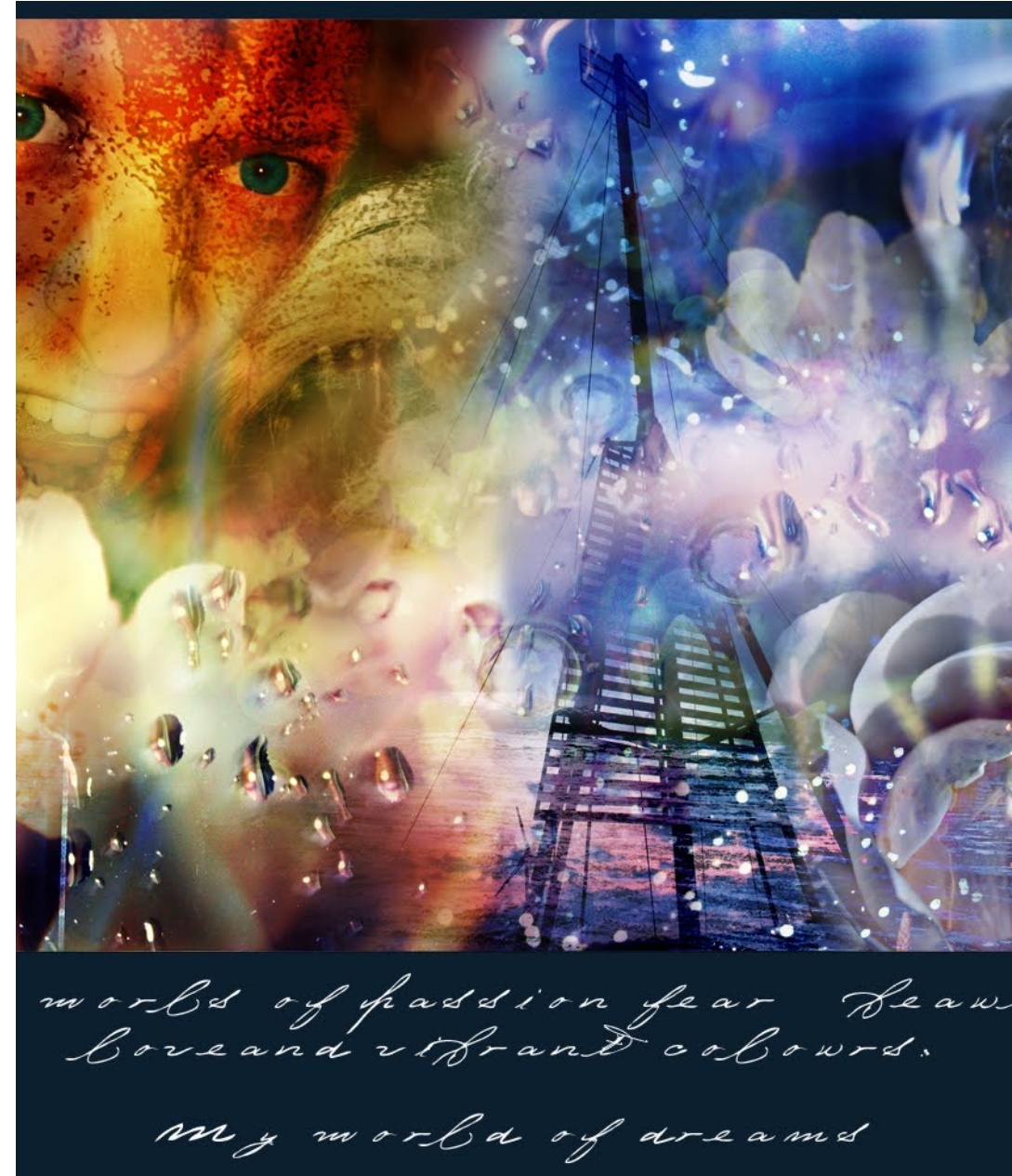
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“Let me tell you a secret”

*“Let me tell you a secret,
I only take my medication every second day”.*

*“ I have this huge problems with memory loss
and my lack of ability to concentrate on my
writing.*



*worlds of passion fear fear
love and vibrant colours.
my world of dreams*

Characteristics of the organ recipient

- Male, 58 years old
- Ulcerous colitis since he was 15 years old
- Performed his first liver biopsy at the age of 38 due to suspected “small duct” Primary Sclerosing Cholangitis (PSC).
- Elevated liver function tests (especially ALK Phs).
- Developed end-stage PSC with ascites, peritonitis and encephalopathy.
- Liver transplantation at the age of 57
- Working as a news paper journalist
- Living in the countryside
- Married with two adult children
- Plays chess in his spare time
- Interested in history

Current transplant related issues

- Visiting the out patient transplant clinic at the one-year follow up
- Slightly obese
- Still on sick leave 50 %
- Pain in his feet, probably (CIPS)
- Complaining about cognitive problems

CIPS- Calcineurin Inhibitor Pain Syndrome

Grotz W, Breitenfeldt M, Braune S, Allmann KH, Krause T, Rump J, Schollmeyer P. Calcineurin-inhibitor induced pain syndrome (CIPS): a severe disabling complication after organ transplantation. *Transpl Int* 2001; 14: 16-23.

Prommer E. Calcineurin-inhibitor pain syndrome. *Clin J Pain* 2012; 28(6): 556-59.

The vulnerability

- Seems depressed
- The transplant surgeons suggest that it might be a mental problem
- He feels frustrated
- Not feeling confirmed
- Impaired autonomy

Personal consequences

- Worried and anxious.
- Difficulties to go back to work full time
- Constantly talking to his wife about his problems making her furious
- Feels neglected by the health care professionals



Further consequences

Memory loss:

- Forgets the scope of his writing
- Can't memorize instructions from the transplant nurse
- Can't remember appointments

Difficulties to concentrate:

- Can't play chess anymore
- Feeling insecure at work meetings

The key concern

“They have performed all these test and they say that it’s nothing wrong with me. I must find my own solution.”

Personal models of explanation of illness

- He is convinced that the tacrolimus is causing his cognitive problems
- As evidenced by the fact that the days when he don't take is medicine, he feels clear in his mind and is able to write
- The day he takes his medicine his mind feels “blurred”

The clinical problem

- He is obviously non-adherent.
- He is not collaborating with the transplant professionals
- He is taking deliberate and calculated risks



Examinations and interventions

- A number of neuropsychological tests is performed
- He has been seeing a psychologist
- His physiotherapist has developed an exercise program in order to improve both his physical and his mental status
- An MRI is performed: no pathological findings

Interventions

- Being attentive and taking his concerns seriously
- Repeated educational conversations regarding his risk behaviour
- Closely monitoring his graft function
- Involve his wife



Non-adherence

“ a side-effect of the confrontation or collision between the clinical medical world and other competing worlds of work, play, friendships and family life ” (Trostle, 1988, s 1305)

Discussion

- It is the persons' meaning making that leads to his actions, not the recommendations we provide. How can we affect that?
- How can we intervene without the patient feeling questioned?
- No graft rejection yet! Should we say that his non-adherent behavior is working?

References for further studies

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Reach G. The mental mechanisms of patient adherence to long-term therapies, mind and care, forward by Pascal Engel, philosophy and medicine. Heidelberg: Springer; 2015:207.

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Thank you
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