CRUSTATIVE CARE

A new, palliative approach towards patients with a severe and persistent mental illness

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A CHALLENGING CONTEXT

Patients with a severe persistent mental illness: on the crossroads between psychiatry and palliative care

- These crossroads are a very interesting, though under-researched topic
- Several patient groups may be distinguished, e.g. people with a mental illness developing a severe somatic illness, palliative patients developing psychiatric symptoms and, e.g. in Belgium, those patients with a severe mental illness 'legally' requesting euthanasia
- SPMI patients: a specific, challenging and forgotten group

Medical assistance in Dying (MAID) based on unbearable mental suffering

- Legal framework in the BENELUX union, also for people with an incurable psychic condition and unbearable mental suffering
- The topic of active termination of life in the context of mental health care is still wildly debated among several disciplines like medicine, law, ethics, theology, philosophy, ... Authors advocate great caution and restraint regarding MAID in the context of mental health care

Recovery approach and socialization of care: possibilities, challenges and pitfalls

- brought several positive developments for many in psychiatry
 - explicitly starts from the sources of power
- YET
- there may also be significant pitfalls and a number of ethical dilemmas involved regarding to the SPMI patient group, which is by definition heavily dependent on forms of residential and chronic care

Towards a now WHO definition of palliative care?

Ongoing academic debate questions the current WHO definition of palliative care and its exclusion of SPMI patients, such as people with severe and persistent depression, schizophrenia and anorexia nervosa (1)

How can we conceptualize high-quality life-supporting care for SPMI patients?

REFERENCES

- (1) TRACHSEL, M., et al., BMC Psychiatry 16 (2016), 260.
- (2) VERFAILLIE, F., & DECORTE, I., Tijdschrift voor hulpverleners in de geestelijke gezondheidszorg 93 (2017), 10-16.
- (3) MOONEN, C., et al., Archives of Psychiatric Nursing 30 (2016), 219-225.

METHODOLOGY

- A literature review, including local vision texts and documents
- An explorative qualitative study, using in depth-interviews with caregivers in Flanders, involved in caring for SPMI patients

RESULTS

- Generally, the will to live in people with SPMI is often very high. - majority of patients with SPMI doesn't support the idea of MAID
- YET
- Caregivers and relatives are still confronted on a regular basis with the demand for termination of life because of the great suffering pressure and loss of possibilities or 'meaning' (3)

Research is needed regarding the possibilities of a palliative care approach (crustative care?) as a valid alternative for the growing number of patients with a request for MAID in psychiatry.

- For SPMI patients, the recovery approach, which has made a great contribution in mental healthcare with its focus on empowerment, is insufficient by itself.
- A radical holistic approach with a focus on quality of life and the relief of suffering, rather than continuous treatment, is paramount: this could be 'crustative care' or 'shell care'.
- crustative care aims to develop a protective, palliative framework for SPMI patients, providing structure in daily life, with high regard for existential questions, attentiveness towards (the acceptance of) loss in all its aspects and qualitative somatic treatment (2). Some challenges for holistic crustative care are:

- **Physical:** Integration and expansion of somatic accommodating the high needs of SPMI patients, e.g. comorbidity, dysphagia, detection,...
- **Social:** The care unit as a 'home' and caregivers as points of reference for those who have none of few
- **Psychic:** positive risk taking, holding and
- **Existential:** remaining present, even when powerless; addressing sources of power; care for care-givers

CONCLUSIONS

- ✓ Scientific (qualitative) research towards SPMI patients aiming at providing high-quality care is paramount
- ✓ Crustative care/Shell care as a missing link and protagonist in life supporting care for patients with SPMI
- ✓ The palliative approach both strengthens and nuances Recovery work in chronic psychiatric care
- ✓ 'Crustative care' bypasses negative connotations with end-of-life care