

promotoren: prof.dr. T.A. Abma
prof.dr. G.A.M. Widdershoven

Contents

1. Introduction	11
<i>Focus & scope • humanization • research question • settings • hermeneutic philosophy • personal & plural accounts • practices of narration • research methodology • qualitative and responsive evaluation approach • datacollection- and analysis • quality procedures • ethical considerations • overview of chapters • reading guide</i>	
Part A Experiencing health care practices	
2. Perceptions of people with cystic fibrosis on hospital admissions	35
<i>Qualitative study • hospital admission of people with CF • in-depth interviews • patient perspectives • importance of technical performances by health care practitioners • normative expectations • being acknowledged as a person • consistent segregation policies • flexibility and autonomy • challenging school and work activities</i>	
3. What cardiovascular patients have to say about psychosocial support	51
<i>Qualitative study • experiences with and expectations of psychosocial support • patient perspectives • in-depth interviews & focusgroups • patient researchpartners • importance of support on a daily basis, in addition to interventions • having a say in treatment & care • being seen as a human being • solution-oriented and empowering support</i>	
4. 'Why Me?' Phases of understanding in chronic illness: learning from a narrative account	67
<i>On the process of understanding chronic illness and the phases of understanding • narrative analysis • three phases of understanding • understanding as meaning making process • understanding to gain knowledge • dialogical understanding • being understood as validation of one's authority</i>	
5. Patient issues in health research and quality of care: an inventory and data synthesis	83
<i>Data synthesis • patient criteria to appraise quality of care and research • importance of information, empowerment, health system and safety • connection between scientific research community and patient lay networks</i>	
<i>Intermezzo: To be or not to be listed for a double lung transplant: a patient's and clinician's perspective, by Yvonne Prins and Ed van de Graaf</i>	105

Part B Care practices that aim to support humanization

6. Towards shared responsibilities in COPD practice	111
<i>Responsive evaluation of multidisciplinary approach for people with COPD • in-depth interviews with patients, pulmonologist and physiotherapists • dialogical communication • responsibilities for recovery • co-ownership • entanglement of mind-body • articulation of lifeworld through life story</i>	
7. Moral learning in an integrated service network	129
<i>Responsive evaluation of multidisciplinary approach • in-depth interviews, focusgroups, case study and questionnaire • narrative analysis • relational, hermeneutical stance • responsibilities • challenges of instrumental thinking • moral learning processes • moral competence</i>	
8. Relational responsibilities in responsive evaluation	147
<i>Moral responsibilities of the responsive evaluator • responsive evaluation of multidisciplinary approach • narrative analysis • interpretation of guidelines and quality criteria • awareness of over- and under-identification • interpretive grid to reflect upon responsibilities of the researcher</i>	
9. General discussion: openings for humanization	167
Summary	189
Samenvatting	197
Acknowledgements	

Cover image

Field of Sparks (fragment)
Ink and watercolor on paper
Donald Wijsenbek, 1982

The idea of the gathering of sparks and ‘uplifting’ them to a *Field of Sparks* at the Cosmic Beginning is a central element in the mystical thinking of Isaac Luria, who lived in Safed in the 16th century.

At this Cosmic Beginning, the One had created three perfect vessels, then withdrew and left the further creation of another seven vessels to the first three. In the overenthusiasm and excitement that ensued, the next step of creation was not faultless. Vessels cracked, some broke, some overflowed and their content (conceived as sparks) scattered.

Our world is through a cascade of stages connected to this Cosmic Beginning and hence not perfect (it is a relief to notice here that overenthusiasm and not sin is connected to the imperfections of the world).

According to Luria, the mystic’s goal is to collect the hidden sparks in everyday life, to kindle them into glowing by taking responsibility and being fully human. As we kindle those sparks, we ‘uplift’ them and our intention carries them to the Cosmic Beginning where they are collected in the *Field of Sparks* and a new cycle.

Luria’s thinking greatly influenced the Hasidic movement in 18th century Russia and Poland with its emphasis on inspired humanity and social responsibility.