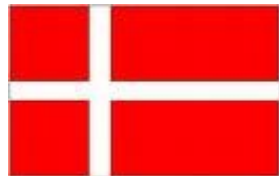


Analysis of patient diaries – a narrative approach

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Background

- More patients are surviving critical illness
- ICU-survivors often experience
 - memory loss
 - vivid dreams and nightmares
 - unreal experiences
 - posttraumatic stress

Patient diaries

- Have existed since 1980s
- Are written by nurses and family
- Help patients understand their illness experience

Aim of the study

- To describe the structure and content of intensive care patient diaries

Material

- 25 patient diaries written for patients at a general ICU in Denmark in 2007 were analyzed

Theoretical framework

- Narratives are chronological
 - beginning, middle and end
- Stories have a plot
 - predicament, conflict, or struggle
- Communication
 - authors and readers

Illness narratives

- Restitution narrative
 - from health, to sickness, and back to health
- Chaos narrative
 - life will never get better
- Quest narrative
 - illness as impetus for change

Stages of analysis

- Familiarization
 - Read and develop coding scheme
- Organization
 - Single-case sequential coding
- Verification
 - Internal consistency and saturation
- Comparison
 - Cross-case comparisons
- Documentation
 - Narrative excerpts

Findings

- All 25 diaries in the sample had a similar structure
- Saturation was obtained

Integrated structure of diary

Extra-case level: SAMPLE	Case-level: DIARY	Sub-case level: ENTRY	SUB-ENTRY	Embedded level
Characteristics – patients – trajectories – diaries	Summary (first entry) – Reason for admission	Greeting Narrator status (relationship)	Patient status – Neuro – Resp. – Circ. – Abd. – Kidney – Mobility – Emotion	Neuro status – Sedated (not awake) – Waking (not sedated) – Awake (confused) – Awake (oriented)
	Entries (daily entry) – Daily events	Patient status Family status Contextual cues		
	End-note (final entry) – Status at discharge	Sign-off Encouragement		

Findings

- The narrative structure was:
 - Crisis
 - Turning-point
 - Normalization

Stages of the narrative

Stages of narrative	Parallel plots		
	Nurse's storyline	Patient's storyline	Family's storyline
Crisis	Active, focus on technology	Passive, depersonalized	Spectator, worried
Turning Point	Shifting focus to caring interventions	Emerging, repersonalized	Engaging, relief and gratitude
Normalization	Converging plots		
	Relating, participating, connecting, letting go		

Restitution narrative

- Relative health
- Illness
 - Crisis
 - Turning-point
 - Normalization
- Relative health

ICU narrative

- Crisis
 - Crisis and rescue include insertion of tubes, equipment hook-up, organ failure
- Turning-point
 - Patient is waking up, resuming breathing, contact, confusion, and communication
- Normalization
 - Patient can eat, sit, stand, walk, talk

Crisis

“Dear Henry. I took care of you ... when you ran out of steam and we had to ventilate you . . . You got a plastic tube in your throat and we connected it to a ventilator that breathes for you. You also had a plastic catheter inserted in your neck ... We put a small plastic needle in your wrist ... You have also got a plastic tube through the nose and down into the stomach ... Finally we have put a catheter in your bladder, so urine can accumulate in a bag ...”

Turning-point

“Things are looking up ... we are considering taking the tube out of your throat, so you can breathe on your own. You are still sleeping too deeply, so it will have to wait till you are more awake and I think this will happen within the next day or so, because I have turned off your sleeping medication and you are already wrinkling your brows, you are trying to open your eyes and move your arms a little ... “

Normalization

“I have taken care of you this weekend ... You get better each day, as everyone writes ... and you are mostly oriented. When you get tired you start talking nonsense ... You have been up in a chair several times a day ... Last night we changed from daylight saving time, so we have joked about how tired we all are because we have lost an hour of sleep. We watched the boxing match on TV ... You still get a bit of nasal oxygen, but your cough is stronger and you are keeping your lungs clear ... You ... started to eat some yoghurt and take sips with a straw ... I wish you well”.

Discussion

- Nurses and patients are front stage characters
- Doctors and other staff are back stage characters

Discussion

- Family and visitors are described in the diary; should they be permitted to read and write in the diaries?
- Diaries are spontaneous and voluntary; should nurses write diaries according to guidelines?

Discussion

- Diaries expose information, e.g. most patient are confused upon extubation
- Diaries conceal information, e.g. due to the unsystematic nature of writing some visitors are mentioned more than others

Discussion

- The diary text focuses on nurses' actions more than patients' reactions
 - I have turned down your oxygen, rather than: you are breathing better
 - I have reduced your sedation, rather than: you are more awake.

Discussion

- Each diary entry ends on a positive note:
 - Hope: I hope you are better tomorrow
 - Well-wishing: Get better soon
 - Encouragement: You are so brave
 - Empathy: You want to go home

Conclusion

- The patient diary gives the patient an account from which he can construct his own illness narrative
- The positive and personal tone in the narrative shows that the patient was never alone and that someone was always there for him

Thank you

