



Narrative critical care: A literary analysis of first-person critical illness pathographies

Ingrid Egerod, RN, PhD^{a,*}, Benjamin Olivares Bøgeskov, PhD^b, Janet F. Jensen, RN, PhD^{c,d}, Lisa Dahlager, PhD^e, Dorthe Overgaard, RN, PhD^b

^a Intensive Care Unit, University of Copenhagen Rigshospitalet, Blegdamsvej 9, 2100 Copenhagen O, Denmark

^b Faculty of Health, Department of Nursing and Nutrition, University College Copenhagen, Copenhagen N, Denmark

^c Department of Anesthesiology, Holbæk Hospital, Holbæk, Denmark

^d Department of Regional Health Research, University of Southern Denmark, Odense, Denmark

^e Dep. of Management, Organisation and Administration, R&D University College Copenhagen, Copenhagen, Denmark



ARTICLE INFO

Available online xxxx

Keywords:

Intensive care unit
Literature
Narrative medicine
Nursing
Personal narratives
Qualitative research

ABSTRACT

Background: Life-threatening illness can be devastating for patients as they experience shifting levels of consciousness, recurrent delirium, and repeated setbacks. Narrative Medicine and its sub-discipline Narrative Critical Care increase healthcare professionals' understanding of the patient perspective, and interpretation of their stories is a means to improving practice.

Purpose: We aimed to investigate book length first-person accounts of critical illness to gain a deeper understanding of universal and individual patient responses and to provide an example of Narrative Critical Care.

Method: We performed a comparative literary analysis of five books supported by the Biographical Narrative Interpretive Method (BNIM) that moves through stages of structural analysis, thematic analysis, and cross-case theoretisation.

Findings: Universal patient responses evolved through five existential dichotomies of life/death, sanity/madness, before/after, gain/loss and inner strength/external support. Individual patient responses were expressed as turning points along the illness trajectory, and biographical continuity was restored by integration of new self and old self.

Conclusion: We uncovered commonalities and differences in storied accounts of critical illness and survival. New insights might enable healthcare professionals to personalize patient care. More consistency is needed during transitions and rehabilitation of intensive care survivors.

© 2020 Elsevier Inc. All rights reserved.

1. Introduction

Critical illness and treatment in the intensive care unit (ICU) can be a devastating and life-changing experience. Patients are plagued with shifting levels of consciousness, fluctuating bouts of delirium, and harrowing life-threatening setbacks [1–3]. These experiences take their toll on ICU survivors as they struggle with the aftermath of critical illness, known as the post-intensive care syndrome [4]. Cardinal events along the critical illness trajectory are highlighted as regaining awareness, transitioning from ICU, and returning home after recovery [5]. Each of these transitional events is characterized by ambivalence: relief of survival vs. distress of serious illness, relief of independence vs. distress of feeling abandoned, and relief of coming home vs. distress of

continued dependence on others. Some survivors are unable to recall their ICU stay, and others experience flashbacks and recognize bodily sensations of the ICU stay even after 10 years [6]. During the ICU-stay, some patients escape the extreme discomforts of life-saving technology by mentally 'being somewhere else' [7]. Strange and frightening memories surface as the indeterminate border between fact and fiction dissolves [8,9]. Memory of critical illness is chaotic. Efforts have been made to help patients put their experiences in order by providing a diary written by nurses or family, to help them create structure and chronology to events during the ICU-stay [1,10–12].

1.1. Narrative description

Personal narratives are empowering when the illness experience is put into a temporal sequence of events [13–15]. To help people make sense of their experiences, Arthur Frank (1995) proposed three fundamental illness narratives: 1) Restitution narrative: I was healthy, I got sick, I got healthy again, 2) Quest narrative: I was healthy, I got sick, I

* Corresponding author.

E-mail addresses: ingrid.egerod@regionh.dk (I. Egerod), BOS3@KP.dk (B.O. Bøgeskov), jffe@regionsjaelland.dk (J.F. Jensen), LISA@KP.dk (L. Dahlager), DOOV@KP.dk (D. Overgaard).

learned from my sickness, and 3) Chaos narrative: I was healthy, I got sick, life won't get any better [16]. In the first illness is transitory, in the second illness is accepted, and in the third the story is unresolved. Illness narratives represent a genre of storytelling that are referred to as pathographies, automythologies, or medical confessionals [16,17]. Pathographies can be categorized as testimonials or tales of anger, rebirth, or altruism [18]. Book length pathographies are composed with motives of coming to terms with illness, helping others, obtaining catharsis, educating or criticizing doctors, or making money [17]. Serious illness severs the life continuum in a 'before and after' leading to biographical disruption, i.e. disruption of taken-for-granted assumptions and behaviors, fundamental re-thinking of one's biography and self-concept, and mobilizing resources to face the new situation [19].

1.2. Application of narrative description

First-person accounts of critical illness provide a window through which healthcare professionals can view and vicariously follow the patient perspective. Some narrators have double authority as patient and scholar, providing reflective, rehearsed and analytical accounts of their experiences [2,20]. They publish in professional journals, providing an academicized account of the illness experience [21]. First-person illness narratives told by lay persons and published as books speak to a broader audience. Narrativity has many applications. Narrative Medicine was introduced as a discipline to help doctors to understand and increase their compassion for their patients [22]. Later, Narrative Critical Care was presented as an interdisciplinary practice to understand suffering in life-threatening illness as a means to help future patients [23–26]. While third-person narratives are more common [27], there is a lack of first-person critical care narratives [25]. We believe there is much to learn from contemporary literature written by ICU survivors. The aim of our study was to investigate book length first-person accounts of critical illness to gain a deeper understanding of universal and individual patient responses and to provide an example of Narrative Critical Care.

2. Materials and methods

The study was a collaborative investigation conducted by an interdisciplinary team of experienced qualitative researchers: three female nurses, a female sociologist and a male philosopher.

2.1. Design

We applied a qualitative comparative design using literary analysis to investigate illness narratives of ICU survivors. We did not differentiate between story and narrative, but we did distinguish between author, protagonist and narrator [28].

2.2. Material

An experienced librarian helped us identify published illness narratives using the following criteria: book length first-person accounts of critical illness, intensive care and mechanical ventilation experienced in Denmark in 1999–2019. Books with co-authors were accepted,

while poetry, short-stories and professional accounts were excluded. Five books met our criteria, Table 1.

2.3. Strategy of analysis

Analysis was supported by the Biographical Narrative Interpretive Method (BNIM) moving through stages of structural analysis, thematic analysis, and cross-case theoretisation [29]. Structural analysis placed the 'lived events' in chronological order and thematic analysis provided the 'told story' by identifying the main dichotomies permeating the five narratives. The investigators performed interpretive panel analysis at each stage. The final step was cross-case theoretisation, where the stories were compared, contrasted and jointly analyzed.

2.4. Ethical considerations

The books were all published and, as such, did not require ethical approval. Nonetheless, we attempted to be as fair as possible to the authors to avoid misrepresentation and harm. We refrained from using the names of spouses or other persons involved and we assume the authors obtained necessary permission from co-narrators to publish their input, including email correspondence and letters. Throughout the text we use the first names of the authors as given in the books.

3. Findings

3.1. Characteristics of the survivors

The authors of the five books investigated were not typical ICU patients. They were relatively young, with a mean age of 37 (range 29–48), compared to the average ICU patient twice their age [30], Table 2. Jason Watt [31], Anne Meiniche [32], Sabine Varming Cheyne [33] and Michelle Hviid [34] were treated at the University Hospital in Copenhagen, and Rikke Schmidt Kjærgaard [35] was treated at the University Hospital in Aarhus, the second largest city in Denmark.

The books offered some biographical information and photographs to provide a context for the illness narrative, Table 3. Jason's book was closer to an autobiography, providing a life story, while Anne's book was more autopathography, adhering to the illness narrative.

3.2. Structural analysis: lived life patterns

The structural analysis and events forming the lived life patterns are presented in Tables 4 and 5.

3.2.1. Author, protagonist and narrator

All five books were, according to their cover, authored by the survivor, the protagonist in the illness narrative. At second glance, more authors and narrators emerged. Jason's book was co-authored by a journalist, who preferred anonymity. Jason was the main narrator, but co-narrators joined in, such as his fiancé, a friend, the trauma surgeon, the intensivist, and several nurses. Anne's husband was part of the 'story' as they shared the same accident. He co-narrated when Anne was unable to recall being in ICU. Sabine authored, narrated and published her own book. After a closer look, Sabine's story included other voices, i.e. eight Facebook posts with friends, a loving letter from her mother, two emails with her doctor, two songs and two poems to enrich her text. Rikke was aided by her husband's diary: "His notes were what enabled me to piece this time together" [35] p. 13. At the end of her narrative, Rikke offered advice to caregivers: "A Caregiver's Checklist" p. 216. Michelle was the sole author and narrator, but she availed herself of information from family and friends: "The next long passage is pieced together from what I have later been told" [34] p. 119.

Table 1

Books included in the study.

- | |
|---|
| 1. Jason Watt. Because I'm determined. The race car driver that would not give up* [31]. |
| 2. Anne Meiniche. Two coffees and a spelling board. The story of an accident* [32]. |
| 3. Sabine Varming Cheyne. The dance of life* [33]. |
| 4. Rikke Smidt Kjærgaard. The blink of an eye. A memoir of dying - and learning how to live again** [35]. |
| 5. Michelle Hviid. Raw strength. When life turned a #tumor-summersault* [34]. |

*Titles translated by the authors of this paper; **we refer to the English version of the book.

Table 2
Demographic overview.

Survivor	Illness year/ Book year (span)	Gender Illness age	Insult: Illness	Resulting disability	Primary caregiver	Married/ Children	Pre-illness career
Jason	1999/2001 (2 years)	Male 29	Accident: Spinal fracture	Paraplegic	Fiancé	Engaged 0	Race car driver
Anne	2000/2003 (3 years)	Female 35	Accident: Multi trauma	Gait impairment	Husband	Married 4	Journalist
Sabine	2012/2016 (4 years)	Female 35	Disease: Acute lymphocytic leukemia	Cognitive impairment, temporary paralysis	Mother	Partner 0	Freight forwarding agent
Rikke	2013/2018 (5 years)	Female 38	Disease: Systemic lupus erythematosus	Blind one eye, loss of fingertips	Husband	Married 3	Scientist
Michelle	2014/2015 (1 year)	Female 48	Disease: Brain tumor	Blind and deaf on right side	Mother	Single 2	Independent public speaker and writer

3.3. Thematic analysis: the told story

In the following, the stories are investigated through the main dichotomies we identified during analysis and interpretive panel discussions.

3.3.1. Life vs. death

The most pronounced dichotomy permeating the narratives was the pivotal point balancing life and death. A close call with death is the

hallmark of acute and critical illness, feeding well into our five stories. Narratives as a genre allude to non-actualized possibilities and their consequences [36]. As such, the stories all referred to the possibility of death that by virtue of the narrator living to tell the story was not actualized.

“Life is dangerous”, Jason’s chapter 10. It provides a reflective look at his illness and fate: “*Death comes to us all, but until it does, life should be lived*” [31] p. 145, referring to his passion for life in the fast lane. Jason alluded to the possibility of death or suicide several times in his narrative but then his killer instinct took over p. 36, 191.

“Life or Death”, Anne’s chapter 3. The first brush with death was during the accident, where Anne said to her husband: “*I’m dying, take care of my girls*” [32] p. 11. The second crisis came 11 days later in ICU, when an unexpected spike of fever put her once more into the “*throes of death*” p. 39. Her sudden setback left her husband unprepared and devastated.

Table 3
Short biography and description of photographs.

Jason	Jason was born in London to a Jamaican father and a Danish mother. At three, his parents divorced, and he moved to Denmark, never to see his father again. He had a happy childhood, growing up in a suburb near Copenhagen with his mother and stepfather. From an early age, Jason had a passion for fast cars, putting racing before everything else. Jason became a celebrity. Photographs: At the end of his book are 26 pictures of his life; on the back cover is his wedding picture.
Anne	Anne did not offer much background information, but it can be inferred that her childhood was without major incident. Her father was a businessman, her mother a homemaker, and she had a brother, but they were not close. Her family remained in rural western Denmark, but Anne relocated to Copenhagen and worked as a journalist. Photographs: The cover of her book shows an x-ray of her reconstructed pelvis with various hardware. The back flap shows a family photo with four beautiful little girls.
Sabine	Sabine grew up on the west coast near a major commercial fishing harbor. At nine months, her parents divorced, and she lost contact with her German father. Her mother eventually remarried and had a son. Sabine was close to her family, but was independent from an early age, making enough money to do what she wanted. Photographs: At the end of her book are five pictures showing her baldness during illness, her wedding, her husband, her new look, and the five canine family members.
Rikke	Rikke was born on Funen, the middle of Denmark, to a teenage mother and young father working odd jobs. They later divorced. Her grandparents helped raise her and she had a happy childhood. At twenty, she was diagnosed with systemic lupus erythematosus (SLE). She was the first in her family to get a high school diploma and go to the university. After having three children, she completed her phd-degree in science communication in a single year. Photographs: On the back flap of her book is a portrait of Rikke.
Michelle	Michelle and her brother were born in Australia. Her mother, alone with two children, moved back to Denmark and remarried. Michelle was raised in a supportive family, but never succeeded in having a conventional family herself. She had two children with different fathers, and they formed a happy family. She made a living by writing, speaking and consultancy. She was working from home with few savings when she was diagnosed. Michelle was a public figure before her illness. Photographs: The front cover of the book shows a portrait of Michelle where the affected side of her face is blocked off. The front flap shows an x-ray of her tumor behind the right eye. The back flap shows the complete portrait of Michelle with an enlarged right eye.

Table 4
Structural analysis: Lived life patterns.

Jason	Jason was a winning race car driver that experienced a sudden and serious motorcycle accident on a quiet road. He was immediately paralyzed from the waist down and spent five weeks in ICU and three months in rehabilitation. Although he made a speedy recovery, he became 80% disabled. He married his fiancé and partially regained his ability to drive race cars.
Anne	Anne was involved in a serious car accident with her husband and their four daughters. Anne was most severely injured and immediately spent 28 h in surgery and five weeks in ICU. She transferred from ICU to a step-down unit and later to her local hospital. She was placed in the geriatric ward that offered little rehabilitation. Three months after the accident she went home and continued rehabilitation as an out-patient at the Polio, Traffic and accident Union (PTU). She had reconstructive surgery after five months and recovered as 65% disabled. She continued to write, speak, and assist aspiring writers.
Sabine	Sabine developed acute lymphocytic leukemia (ALL) with a rapidly growing inoperable sub-sternal tumor. The tumor erupted during emergency surgery and she was taken to ICU in critical condition. After more than three years of high dose chemotherapy and temporary paralysis she eventually recovered and married her boyfriend.
Rikke	Rikke unexpectedly came down with flu-like symptoms and rapidly deteriorated. She suffered a cardiac arrest and was taken to ICU where she was diagnosed with bacterial meningitis. This was related to her underlying disease, systemic lupus erythematosus (SLE), diagnosed when she was twenty. She woke up from coma with locked-in syndrome. After a couple of weeks, she able to communicate by blinking. Recovery was slow and arduous; she lost part of her eyesight and the tips of her fingers. After recovery she gradually resumed her job at the university but later made a career change, to focus on helping others.
Michelle	Michelle developed a brain tumor. Surgery was initially a success but was followed by internal hemorrhaging that brought her to the neuro-ICU. She had partial paralysis and was transferred to the ward for rehabilitation. Training was inadequate and Michelle decided to pay for private rehabilitation. With assiduous training, her paralysis subsided, but her eyesight and hearing were lost on the right side.

Table 5
Events in the illness narratives.

Survivor	ICU	MV	Delirium	Ward	Rehab	First visit home	Finally, home	Further treatment	Other events
Jason	1 week	1 week	Yes	4 weeks	3 months	–	After 4 months	–	Wedding
Anne	5 weeks	5 weeks	Yes	1 month	1 month	At 2 months	After 3 months	Corrective surgery	Trip to Paris
Sabine	3 days	2 days	Yes	14 months	Out-patient	At 6 months	After 14 months	3.3 years of chemo	Wedding
Rikke	1 month	3 weeks	Yes	6 weeks	3 months	At 3 months	After 5 months	Fingertip amputation	Trip to Norway New job
Michelle	1 week	1 week	No recall	1 week	3 weeks	At 4 weeks	After 2 months	Final brain scan	New love

MV = mechanical ventilation.

A doctor reassured him: “a 35-year old mother of four makes everyone do their utmost” p. 52, but it was touch-and-go.

“The day I died”, Sabine’s chapter 6. “I died late that morning ... I was in a coma, kept artificially alive, and danced with death for two days” [33] p. 31. Nurses and doctors fought for her life, but Sabine resisted: “I had to die in order to face life” p. 34. Four months later, she started to hope for survival: “I asked Death to dance with me on the Titanic and the band was still playing ‘Nearer my God to Thee’ on the deck. But perhaps there was a lifeboat for me?” p. 73.

“Dying”, Rikke’s chapter 1. Being a scientist, Rikke expressed herself in literal terms; her cardiac arrest held no magic: “There was nothing. No light at the end of the tunnel, no angels, no harps. No Heaven’s Gate and no Hell. Nothing” [35] p. 9. Contrary to the prosaic portrayal of death, illness and recovery were infernal: “I had been through hell and it wasn’t pretty ... and [friends] made me see the light at the end of the tunnel” p. 192.

“I Disappear”, Michelle’s chapter 6. Michelle suffered short-term memory loss. As her memory came back, her mother sensed the transition: “Saturday was a turning point. My mother could see in my eyes that I was returning” [34] p. 132. Later Michelle said: “In a way it was a gift to be able to look death in the eye ... It brings things to life; things taste better and look better” p. 13.

3.3.2. Sanity vs. madness

ICU delirium is a common complication of critical illness. The condition was narrated by Misak (2005), who “stepped over the fuzzy line that separates sanity from madness” [8]. She described a Christmas party (in April) where “the physicians drank copious quantities of alcohol and proceeded to parade, ridicule, and humiliate the most pathetic patients”. Party nightmares are common in ICU delirium because of the constant cacophony of voices and noises surrounding the patients [9]. The authors in our study experienced their initial awakening as a smooth transition to delirium. One of the hallmarks of ICU delirium is fluctuating consciousness [3]. A second awakening entailed a confrontation with reality and a fight against sedatives.

Jason awoke to distortion: “I floated without a sense of time or place” [31] p. 33, and later: “My brain didn’t work normally because of all the medications ... I saw many weird twisted faces coming out of the walls and moving their lips like they were talking. If I closed my eyes the faces changed from grey to red” p. 61.

Anne had a nightmare involving Jason, who had been to the same ICU the previous year, Table 4. Although Anne did not know Jason personally, he suddenly appeared in a delirious nightmare with his driving mates: “They poured motor oil in my mouth, it tasted terrible” [32] p. 61. Anne also had delirious experiences involving her husband. In one nightmare her husband appeared with a new wife. In another, her husband conspired with a nurse about turning off her ventilator. Anne’s deepest fears were abandonment and rejection, while she was in “the fluid state between coma and consciousness” p. 58. Waking up was like being caught under water, unable to reach the surface. At the same time, she nearly went insane from thirst.

Sabine had a vivid out-of-body experience, in which she viewed her lifeless body from above. She “traveled to another place”, where she had an encounter with Christ: “It was neither a dream nor an unreal experience” [33] p. 32. When she awoke, she was disappointed to realize

that she had been resurrected in her old ravaged body. During her divine experience, she was suffering severe internal hemorrhage and was transferred to ICU p. 33. She felt strangely elated during her illness: “I was never scared. But I was brimming with morphine and steroids” p. 37. Her condition continued to be critical long after she transferred from ICU: “I dropped in and out of consciousness ... when I lost consciousness I was back to the place where I spoke with Christ” p. 69–70.

Rikke came out of coma paralyzed, unable to speak, and not knowing why: “It was like the most horrifying claustrophobic nightmare; except I was awake” [35] p. 48. She drifted uncontrollably in and out of consciousness: “Waking up is a process, a fragmented jumble of impressions ... you drift in and out of consciousness and you can’t control it” p. 49. Her mind “moved constantly between a conscious and illusory state” p. 57. Holding on to sanity was a challenge: “Apart from staying alive, my main job was to keep myself sane” p. 64. “At night the demons came” p. 92.

Michelle had no memory of ICU: “I slept in a morphine fog” [34] p. 126. Being a neurological patient, she suffered posttraumatic amnesia and was heavily sedated: “My brain doesn’t work as it should. I’m doped by medications” p. 125. As a comedienne, Michelle wanted to write something humorous, but there was nothing funny to say p. 129.

3.3.3. Before vs. after

The authors offered glimpses of their former lives to set the stage for their illness narrative, Table 3. Life as they knew it was abruptly severed by their illness, and they had to learn or re-learn activities of daily living to regain their independence, Tables 4 and 5. All authors experienced memory loss. Even Anne’s husband who helped her reconstruct her story was unsure of the chronology. Rikke was grateful for her ICU diary and her husband’s notes that helped her understand what had happened. As the authors reflected on their recovery, they decided that many things had changed, but they were still the same person.

After the accident, Jason became aware of his ‘fate line’, the vertical line used in palm reading that predicts career, fortune and fate: “On the other side of my fate line the world was a different place” [31] p. 12. His fate was his disability, but his fortune and career were not lost. His turning point was the day he left rehabilitation with his sweetheart: “Now life began” p. 107. In the last chapter of his book, Jason tried to unite his before and after persona. He revisited the location of the accident to honor the person that disappeared a year ago: “Who am I? The guy that lay there last year, the guy who woke up at the hospital a week later, or someone else? I’m not sure” p. 191. On the last page he states: “I am still Jason Watt” p. 192.

Anne was content with life before the accident, but afterwards her values shifted: “Having been at the end of the Tunnel puts a new perspective on life ... things I wanted to experience when I got older, I no longer want to postpone” [32] p. 206. She experienced her first turning point when she awoke in ICU and realized that she had survived. Her pre-illness identity was tied to her role as a mother of four. To her regret, her husband now filled the void created by her absence. Anne slowly regained her children’s confidence and mused: “I have a new life now ... but I have not become a different person” p. 206.

Sabine had an exciting career abroad but after settling down with her boyfriend and a mediocre job, life became trivial and meaningless:

"If my life is going to be like this, then I don't want to live!" [33] p. 19. Her first turning point came after four months: "I began to fight for myself" p. 70. A second turning point came a year later, when she out of exhaustion demanded the doctor to stop her treatment: "Then the doctor received a miraculous sign from above" p. 116. Her medications were changed, and she improved. A turn in the wrong direction was learning that she could not have children. She gradually came to terms with this and eventually accepted her dogs as her children: "I'm sure the encounter between myself and my dogs was planned at a higher level long ago, before we chose to descend to earth together" p. 159. Sabine's outlook changed, as she found her spirituality and finally learned to love herself p. 71.

Rikke's first turning point was the initial contact with her husband in ICU: "I had re-entered my life. The gradual process of putting myself together had begun" [35] p. 57. This was not easy: "I could use my memories as building blocks; by placing them carefully in the right order" p. 211. A second turning point was when her kidneys started working. This was cause for celebration. The third was after surgical removal of her fingertips: "This was the first day in my new life" p. 171. After recovery Rikke said: "I am still me, but I have changed. My priorities are different" p. 213.

Michelle was initially devastated by the information: "You have a tumor" [34] p. 39. After recovery she stated: "My whole life is now separated in before and after that information" p. 40. In her chapter "Who am I now?" Michelle said: "I am the same person in an impossible body" p. 223.

3.3.4. Gain vs. loss

The five stories started to present themselves as versions of the quest narrative. The authors recovered with dramatically changed bodies and disabilities, and they needed to tell their story. According to Frank (1998), storytelling can change a person's life [37]. The audience might wish to hear that what was lost in one aspect of life was gained in another, but the quest story refuses this fantasy. The quest story is not a restitution story; it is testimony of the reality of illness and what can be reclaimed of life.

When Jason regained consciousness, the doctor told him: "We saved your life, but you lost your ability to walk" [31] p. 34. Jason immediately realized that everything he had lived for was gone: "During those seconds I was in freefall through every layer of horror of the soul" p. 35. Although he quickly regained his equilibrium, he always regretted his loss. But he reclaimed his identity as a racecar driver.

Anne's gains were negative in the form of disfigurement, anxiety and nightmares. Her prognosis is uncertain: "Ten years ago I wouldn't have had a chance of survival" [32] p. 204. But the love and gratitude for her four girls was, if possible, amplified by her misfortune: "It looks like nothing in writing, but it's a big feeling" p. 207. She reclaimed her identity as a mother.

Sabine experienced the most remarkable transformation; probably because she had hit rock bottom before her illness. After cancer survival: "My brain was completely fried after chemotherapy ... I had memory loss, social phobia and anxiety" [33] p. 141. But she rejoiced: "The woman that died came to life, danced again between life and death, was destined to a life in a wheelchair, is now dancing freely, authentic and happier than ever" p. 182. After recovery she became author, public speaker, divine channel, intuitive healer and helper. Sabine found her calling.

Rikke lost much of her eyesight and dexterity. When she broke down, grieving her loss, her young son complimented her hands: "I realized I had gained so much more. I had added another layer to what it means to be human ... that day I healed" [35] p. 207. After recovery, life took on a new meaning: "I am trying to see my unexpected survival and recovery as a gift that can help others, too" p. 215. Even after the psychologist diagnosed her with cognitive impairment, Rikke reclaimed her role as a scientist.

Michelle suffered partial loss of eyesight and hearing but survived a brain tumor: "The tumor was a huge gift of about five centimeters reminding all my people that they should live according to their values each day" [34] p. 269. She boldly stated: "I recovered so well that I

wouldn't have missed the experience" p. 183. She reclaimed her role as mother and head of the family.

3.3.5. Inner strength vs. external support

In her book, *Illness as Metaphor*, Sontag (1991) described fighter/killer/crusade metaphors in cancer 'victims' combatting disease [38] p. 59: "Widely believed psychological theories of disease assign to the luckless ill the ultimate responsibility both for falling ill and for getting well". All authors described themselves as fighters. They did not blame themselves for their misfortune, but some blame was allotted elsewhere. Our authors used two types of armament in their fight: extraordinary inner strength and support from unusually dedicated caregivers. The fight was bi-directional, fighting both for and against something. The five authors let us to build an image of the fundamental differences in their understanding of their fight.

"I had everything. In a split second I lost it all ... I continued to fight, and I still fight every single day" [31] p. 9. Jason struggled to overcome his disability and to recover his position as a professional racecar driver, while nurturing his blossoming relationship with his sweetheart. She gladly managed their relationship, but success in his career hinged upon his extraordinary willpower. This was both the means and goal of his success; loss of his willpower would be the ultimate failure. When Jason quickly completed rehabilitation, the nurse stated: "He's a ceaseless fighter" p. 88. As Jason put it: "The greater the challenge, the greater the satisfaction" p. 191.

Anne's fight was often against some external factor, such as the healthcare system, the insurance company, the car manufactures, or the judicial system. Her fight was directed toward obtaining the support she needed and deserved. Her goal was to uphold her standard of living and the barriers were moral wrongs, such as incompetence or greed. But she worshipped her doctor: "Dr. [x] is God in my life" [32] p. 205. Although Anne was grateful for her survival, anger was her primary emotion and blame was never far away. It is worth noting that Anne's misfortune was the only one caused by the fault of others.

Sabine presented a mix of strength from within and without, as she opened the subject of faith. Unlike the others, she was the only one who experienced life as disappointing prior to her illness. Thus, she fought for a higher purpose: "I discovered that the greatest fight for me was to learn to surrender. Surrender to the love of myself" [33] p. 71. The other authors won the battle by relentless fighting, whereas Sabine learned to let go: "This (book) is about my insight that everything is possible if you dare to open your heart, let go, stop the inner and outer fight, lose your footing and find the faith to soar in the freefall of life" p. ii. She was not angry: "I was not bitter, and I did not blame others. I knew it was my own responsibility ... the doctors just did what they were destined to do" p. 34. As faith combined her inner and outer strength, she regarded her inner strength as a gift: "Through my illness I have learned that everything can be resurrected by love, that all things dead can come alive with love" p. 55.

Rikke fought to overcome the limitations of her body, and her goal was to recover her family life. Her husband understood her better than anyone else: "Feeling loved is the most potent healing power" [35] p. 54. Thus, her success was impossible without the external support from her husband; her means and goal were the same. She expressed love and gratitude, but make no mistake, Rikke was a fighter: "I have always been a fighter, never willing to give up" p. 161.

Michelle stated: "My greatest strength is my perseverance" [34] p. 21. Her inner strength was a means to a goal. Her struggle to overcome her disabilities was small compared to her fundamental struggle to remain authentic and live according to her values. To Michelle, authenticity meant to acknowledge her limitations and she boldly showed her disfigurement. The source of her strength was the pursuit of truth: "each of us is responsible for our own happiness without blaming others for our misfortunes" p. 262.

3.4. Cross case theorization

We described the five dichotomies in the order they presented themselves in the narratives as existential issues of survival, sanity, identity, values and independence. A critical feature of storytelling is an extensive and ubiquitous exercise in selection and editing [28]. As such, the five narratives were carefully edited, and each author selected the version of the story to be published. Similar storylines emerged: “*I was in good health; I suddenly became seriously ill and almost died; I fought back and survived, but my life changed*”. The quest narrative was identified, where the person does not fully recover, but accepts illness as a life-expanding event [16] p. 115. “*Quest stories of illness imply that the teller has been given something by the experience, usually some insight that must be passed on to others*” p. 118. The common traits of the authors were willpower, determination and perseverance, letting them appear as heroes in their stories. In narratives, “*mythic heroism is evidenced not by force of arms but by perseverance*” p. 119.

Quest stories appear in the form of memoir, manifesto or automythology [16] p. 119. Jason and Michelle were public figures prior to their illness and therefore applied the *memoir* format, the gentlest type of narrative, to ensure a balance between their public and private persona. Anne wrote a *manifesto*, a harsher type of narrative, fueled by her responsibility to reveal injustices during her illness trajectory. The manifesto states that “*society is suppressing a truth about suffering, and that truth must be told*” [16] p. 121. The third form, the *automythology*, was applied by Sabine, who, like the bird Phoenix, had to reinvent herself after she had crashed and burned. Rikke's narrative places itself somewhere between the memoir and the manifesto. Despite her positive outlook, her occasional dissatisfaction had to be told, but she compensated by offering advice. Anne and Rikke mustered all their resources to obtain the level of care they required and to which they were entitled. In the Danish welfare system, people feel entitled when they become ill, because a large part of their earnings go toward taxes that pay for the healthcare system. On the personal level, the authors were grateful for the care they received, but on the organizational level, they felt entitled. The stories illustrated co-existence of gratitude and entitlement in the welfare state.

Jason and Michelle received some freebies during recovery because they were publicly known. Jason's narrative could, perhaps, be viewed as an amalgamation of the restitution and chaos narratives. He recovered his ability to drive, the purpose of his life, but he would never be able to walk. As such, he was restituted but would never recover: “*I have a recurrent dream. I wake up, get out of bed and go to the bathroom. I suddenly remember that I am paralyzed*” [31] p. 178. According to Frank (1995), chaos narratives are “*chaotic in their absence of narrative order*” [16] p. 97. Events are told without sequence or discernable causality. Jason might have left some things untold in his story that surfaced by way of his recurrent dreams of being able to walk.

According to Hawkins' (1999) categorization of pathographies, Anne, Rikke, Sabine and Michelle fell into the group of altruism as they strove to help others by telling their story [18]. Anne presented an anger story, Sabine experienced rebirth, and Jason offered a testimonial to keep his followers abreast of the situation. Five dichotomies in our analysis permeated the illness narratives as each account came to a crossroads where death was a possibility, and each narrator experienced turning points as the trajectory shifted and moved (mostly) in the right direction, each with a loyal family caregiver by their side.

4. Discussion

Our analysis benefitted from Frank's narrative theory. The five stories were versions of the quest narrative placing the protagonist as the hero. The heroes demonstrated determination and perseverance and lived to tell their story. Less obvious was, perhaps, the vital role of the primary caregivers that unflinchingly remained at their side supporting their recovery. According to Frank (1998), helpers exist in

many narratives: “*The eventual defeat of the antagonist is often made possible by a helper who at first appears minor and ineffectual but eventually provides the hero with an essential resource*” [37] p. 200.

Our study identified universal responses to critical illness as all narratives evolved through similar dichotomous existential issues. The narrators described their fight through transformative illness. The cases converged toward similar descriptions of the ICU-delirium experience, adding to the analytic generalization of this phenomenon [39] p. 30. Our findings confirmed the findings of other studies increasing the qualitative evidence of lived experience [8,9,40]. As such, our study was another building block on the tower of knowledge of the critical illness experience.

Individual responses to critical illness were expressed in our study as turning points along the illness trajectory, Table 5. A key turning point was regaining short-term memory, as described by Michelle. Rikke's critical turning point was contact with the outside world, Anne's was survival. Turning points are common in pathography leading to transformation and a new set of values [18] p. 37. As in our study, turning points are described in cancer patients as biographical rupture or disjuncture dividing life into a ‘before and after’ [41].

Biographical disruption was evident in our study, as the authors reconsidered their self-concept and mobilized resources to face their new situation [19]. Restoring biographical continuity was a process of integrating new self with old self. At a time of loss, adjustment to the loss and the new life constitute a dual process of coping that is simultaneously loss-oriented and restoration-oriented [42]. The narratives in our study demonstrated existential contemplation comparing their old and new identity. Jason confronted the scene of his accident to rethink his self-concept, Sabine used her faith to settle her life changes, and Rikke took a scientific path to understanding who she was.

Our narrow focus on contemporary Danish literature added to our understanding of recovery in the welfare state. The authors all suffered severe and costly illness, receiving state of the art life-saving treatment without financial burden, except during rehabilitation that was described as inadequate. Family caregivers were able to take care leave to support the patient. The survivors represented different types of critical illness, but at the universal level, the human response was the same, e.g. existential fear. At the diagnostic level, symptoms such as pain, had different expressions depending on the diagnosis and affected area. Finally, at the personal level, the authors responded very differently depending on their values and beliefs. Our contribution to the broader arena of patient understanding was description of three levels of patient response: universal, disease related, and personal. The levels need to be explored further to produce theory toward improving the professional response to patient suffering. Following our aim, the study increased our understanding of patient response to critical illness and presented literary analysis as an expression of narrative critical care.

4.1. Strengths and limitations

Our study was limited by uneven gender representation. This was unavoidable using our inclusion criteria of books published within our timeframe. Had we expanded to other languages; we might have identified more books at the cost of more superficial analysis. We are aware that the five authors were not representative of the typical ICU patient, but qualitative inquiry is not about generalization. It is about in-depth description promoting insight or discovery. The books were heterogeneous regarding literary style and disease. This strengthened the study as we discovered universal responses to critical illness. The credibility and trustworthiness of our findings were increased by adapting well established research methods and by investigator triangulation. We also used theoretical triangulation combining different narrative theories, where our findings converged toward the same results. Our data covered a span of almost two decades and two different sites, providing similar results and increasing the transferability of our findings. The

investigators openly discussed their predispositions to maintain objectivity during analysis and interpretation.

4.2. Conclusion

Our study uncovered commonalities and differences in storied accounts of critical illness and survival. Using the genre of pathography, the reader was invited to witness the ultimate experience of vulnerability, in suspended animation, where existential thought is provoked. New insights might enable healthcare professionals to personalize patient care. More consistency is needed during transitions and rehabilitation of intensive care survivors.

Funding

The authors received no external funding for the study.

CrediT author statement

Substantial contributions to the conceptualization, data generation, analysis and interpretation were made by all the authors: Ingrid Egerod, Benjamin Olivares Bøgeskov, Janet F Jensen, Lisa Dahlager, and Dorthe Overgaard. The first draft was written by Ingrid Egerod. Revision and important intellectual content were made by all authors, who also approved the final version to be submitted: Ingrid Egerod, Benjamin Olivares Bøgeskov, Janet F Jensen, Lisa Dahlager, and Dorthe Overgaard.

Declaration of Competing Interest

The authors have no conflicts of interest to declare.

References

- Egerod I, Christensen D, Schwartz-Nielsen KH, Agard AS. Constructing the illness narrative: a grounded theory exploring patients' and relatives' use of intensive care diaries. *Crit Care Med* 2011;39(8):1922–8. <https://doi.org/10.1097/CCM.0b013e31821e89c8>.
- Misak CJ. The critical care experience: a patient's view. *Am J Respir Crit Care Med* 2004;170(4):357–9. <https://doi.org/10.1164/rccm.200403-3090E>.
- Svenningsen H, Egerod I, Videbech P, Christensen D, Frydenberg M, Tonnesen EK. Fluctuations in sedation levels may contribute to delirium in ICU patients. *Acta Anaesthesiol Scand* 2013;57(3):288–93. <https://doi.org/10.1111/aas.12048>.
- Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med* 2012;40(2):502–9. <https://doi.org/10.1097/CCM.0b013e318232da75>.
- Fagerdahl AM, Knudsen VE, Egerod I, Andersson AE. Patient experience of necrotising soft-tissue infection from diagnosis to six months after intensive care unit stay: a qualitative content analysis. *Aust Crit Care* 2020;33(2):187–92. <https://doi.org/10.1016/j.aucc.2019.02.001>.
- Storli SL, Lindseth A, Asplund K. A journey in quest of meaning: a hermeneutic-phenomenological study on living with memories from intensive care. *Nurs Crit Care* 2008;13(2):86–96. <https://doi.org/10.1111/j.1478-5153.2007.00235.x>.
- Storli SL, Lindseth A, Asplund K. "Being somewhere else" – delusion or relevant experience? A phenomenological investigation into the meaning of lived experience from being in intensive care. *Int J Qual Stud Health Well Being* 2007;2:16. <https://doi.org/10.1080/17482620701436921>.
- Misak C. ICU psychosis and patient autonomy: some thoughts from the inside. *J Med Philos* 2005;30(4):411–30. <https://doi.org/10.1080/03605310591008603>.
- Svenningsen H, Egerod I, Dreyer P. Strange and scary memories of the intensive care unit: a qualitative, longitudinal study inspired by Ricoeur's interpretation theory. *J Clin Nurs* 2016;25(19–20):2807–15. <https://doi.org/10.1111/jocn.13318>.
- Barreto BB, Luz M, Rios MNO, Lopes AA, Gusmao-Flores D. The impact of intensive care unit diaries on patients' and relatives' outcomes: a systematic review and meta-analysis. *Crit Care* 2019;23(1):411. <https://doi.org/10.1186/s13054-019-2678-0>.
- Egerod I, Christensen D. Analysis of patient diaries in Danish ICUs: a narrative approach. *Intensive Crit Care Nurs* 2009;25(5):268–77. <https://doi.org/10.1016/j.iccn.2009.06.005>.
- Di Gangi S, Naretto G, Cravero N, Livigni S. A narrative-based study on communication by family members in intensive care unit. *J Crit Care* 2013;28(4):483–9. <https://doi.org/10.1016/j.jccr.2012.11.001>.
- Kleinman A. The illness narratives. Suffering, healing & the human condition. USA: Basic Books; 1988.
- Riessman CK. Strategic uses of narrative in the presentation of self and illness: a research note. *Soc Sci Med* 1990;30(11):1195–200. [https://doi.org/10.1016/0277-9536\(90\)90259-u](https://doi.org/10.1016/0277-9536(90)90259-u).
- Antonovsky A. Unraveling the mystery of health. How people manage stress and stay well. San Francisco: Jossey-Bass; 1987.
- Frank AW. The wounded storyteller. Body, illness, and ethics. Chicago: University of Chicago Press; 1995.
- Aronson JK. Autopathography: the patient's tale. *Bmj* 2000;321(7276):1599–602. <https://doi.org/10.1136/bmj.321.7276.1599>.
- Hawkins AH. Reconstructing illness. *Studies in Pathography*, 2. Edn. Indiana: Purdue Research Foundation; 1999.
- Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982;4(2):167–82. <https://doi.org/10.1111/1467-9566.ep11339939>.
- Rier DA. The missing voice of the critically ill: a medical sociologist's first-person account. *Sociol Health Illn* 2000;22(1):26. <https://doi.org/10.1111/1467-9566.00192>.
- Riessman CK. Ruptures and sutures: time, audience and identity in an illness narrative. *Sociol Health Illn* 2015;37(7):1055–71. <https://doi.org/10.1111/1467-9566.12281>.
- Charon R. Narrative reciprocity. *Hastings Cent Rep* 2014;44(1 Suppl):S21–4. <https://doi.org/10.1002/hast.264>.
- Hope AA. Principles of narrative critical care. *Am J Crit Care* 2019;28(1):5–7. <https://doi.org/10.4037/ajcc2019164>.
- Wittenberg E, Goldsmith JV, Ragan SL, Parnell TA. Connect. Communication in palliative nursing the comfort model. Oxford: UK; 2020. p. 27–9.
- Wenrich MD, Curtis JR. Narratives of critical care: the missing link. *J Crit Care* 2006;21(3):248–9. <https://doi.org/10.1016/j.jccr.2006.06.005>.
- Thurston LM, Milnes SL, Hodgson CL, Berkovic DE, Ayton DR, Iwashyna TJ, et al. Defining patient-centered recovery after critical illness – a qualitative study. *J Crit Care* 2020;57:84–90. <https://doi.org/10.1016/j.jccr.2020.01.028>.
- Guy V. Liver failure, life support, family support, and palliation: an inside story. *J Crit Care* 2006;21(3):250–2. <https://doi.org/10.1016/j.jccr.2005.10.005>.
- Paley J. Narrative Machinery Oxford Scholarship Online; 2009. <https://doi.org/10.1093/acprof:oso/9780199546695.003.0002>.
- Corbally M, O'Neill CS. An introduction to the biographical narrative interpretive method. *Nurse Res* 2014;21(5):34–9. <https://doi.org/10.7748/nr.21.5.34.e1237>.
- Olsen HT, Nedergaard HK, Strøm T, Oxlund J, Wian KA, Ytrebø LM, et al. Nonsedation or light sedation in critically ill, mechanically ventilated patients. *N Engl J Med* 2020;382(12):1103–11. <https://doi.org/10.1056/NEJMoa1906759>.
- Watt J. Fordi jeg vil. Racerkøringen, der nægtede at give op. [Because I'm determined. The race car driver that would not give up]. Denmark: MeMeMedia; 2001.
- Meiniche A. To kaffe og en stoveplade. Historien om en ulykke. [Two coffees and a spelling board. The story of an accident]. Copenhagen: People'sPress; 2003.
- Dans Cheyve SV Livets. [The dance of life]. Kaunas, Lithuania: BYHEART - Livetsdans; 2016.
- Hviid M. Råstyrke. Da livet slog en #Tumorkolbøtte. [Raw strength. When life turned a #tumor-summersault]. Copenhagen: People'sPress; 2015.
- Kjærgaard RS. The blink of an eye. A memoir of dying – and learning how to live again. New York: The Experiment; 2018.
- Beatty J. What are narratives good for? *Stud Hist Philos Biol Biomed Sci* 2016;58:33–40. <https://doi.org/10.1016/j.shpsc.2015.12.016>.
- Frank AW. Just Listening: Narrative and Deep Illness Families, Systems, & Health, 16; 1998; 16. <https://doi.org/10.1037/h0089849> (3).
- Sontag S. Illness as metaphor. AIDS and its metaphors. London: Penguin Books; 1991.
- Yin RK. Case study research. Design and methods, vol. 5, 2. Edn. Thousand Oaks: Sage; 1994.
- Malcolm D, Orme MW, Morgan MD, Sherar LB. Chronic obstructive pulmonary disease (COPD), illness narratives and Elias's sociology of knowledge. *Soc Sci Med* 2017;192:58–65. <https://doi.org/10.1016/j.socscimed.2017.09.022>.
- Sheilds L, Molzahn A, Bruce A, Schick Makaroff K, Stajduhar K, Beuthin R, et al. Contrasting stories of life-threatening illness: a narrative inquiry. *Int J Nurs Stud* 2015;52(1):207–15. <https://doi.org/10.1016/j.ijnurstu.2014.10.008>.
- Stroebe M, Schut H. The dual process model of coping with bereavement: a decade on. *Omega* 2010;61(4):273–89. <https://doi.org/10.2190/OM.61.4.b>.