Did that really happen? Delusional memories and the impact of an ICU Diary

October 16, 2011
Gwynne MacDonald, Kara Livy and Allan Shustack
Post Traumatic Stress Disorder

• Complex anxiety disorder
• Changes in DSM-IV:
  – No longer necessary for the afflicted person to be the direct victim of the traumatic event
  – No longer necessary to have a catastrophic event such as combat, torture or rape – now includes the victim’s perception of any event that leads to feelings of intense fear, helplessness or horror
Post Traumatic Stress Disorder (PTSD)

Criterion A

TRAUMATIC EVENT or series of events [directly experienced] or [subjectively observed]

Subjective Response
- fear
- helplessness
- horror

Cluster B
- flashbacks
- re-experiencing

Cluster C
- avoidance & numbing

Cluster D
- hyperarousal
- irritability

Criterion E
- Symptoms in clusters B, C, D exist ≥1 month

Criterion F
- Functional impairment

PTSD
Incidences of PTSD in ICU

- 15 studies
- PTSD symptoms (questionnaire) 22%
- PTSD diagnosed by clinician 19%
- Predictors:
  - Prior psychotherapy
  - > ICU benzodiazepine administration
  - Post-ICU memories frightening and/or psychotic experiences “delusional memories”
Incidence of PTSD in ICU

- Patients were eligible if received mechanical ventilation for 21 days and had been weaned for 3 days
- Psychologist diagnosed PTSD in 12% three months after ventilator weaning
- Tool to measure PTSD symptoms at one week reliably predicted PTSD at 3 months
Incidence of PTSD in ICU

- 150 trauma patients in ICU > 24 hours
- Assessed at discharge, 3 months and 12 months
- PTSD symptoms 18% at 1 year
- Predictors:
  - Factual memories
  - Low educational level
  - Not having care of children
  - Female gender
Risk Factors PTSD General Population

- Risk factors in general PTSD literature
  - Female gender
  - Younger age
  - Pre-existing psychiatric history
  - Greater number of traumatic memories/frightening recollections
  - Presence of delusional memories
PTSD Risk Factors in ICU Survivors

- Known risk factors for PTSD or PTSD symptoms
  - ICU LOS (longer duration)
  - Hospital LOS (longer duration)
  - Length of mechanical ventilation
  - Greater levels of sedation
Memory and PTSD
Physiological Effects of PTSD

- Decreased volume of the hippocampus, left amygdala and anterior cingulate cortex
- Elevated levels of epinephrine and Norepinephrine, with Norepinephrine hyperactivity
- Alterations in HPA system
  - Decreased cortisol levels
PTSD Effects on Emotion and Memory

- Amygdala: fear conditioning
- Hippocampus: short-term memories to long-term memories
- Hemispheric lateralization with failure of left hemispheric function: possibly accounting for confusion related to time sequence of traumatic events
PTSD and Memory

• Critical illness and treatment “dampen” memory
  – Profound amnesia during delirium
  – Slow wave sleep reduced in ICU patients
    • reducing consolidation of episodic memories
  – Treatment effects on memory
    • Opiates  Benzodiazepines
    • Propofol  Epinephrine
    • Corticosteroids
Delirium

- Acute and potentially reversible impairment of consciousness and cognitive function that fluctuates in severity
- Delirious patients have impaired short-term memory, abnormal perception, and intermittent disorientation, which is usually worse at night.
PTSD and Memory

- Memory negatively affected for external events but enhanced for internal events such as hallucinations
  - Physical restraints, social isolation and life threatening nature of illness may increase hypnagogic hallucinations (between waking and sleeping)
    - Vivid, detailed, frightening memories
    - Replay of flashbulb-like memories
PTSD Risk Factors

• There are two significant risk factors for ICU-related PTSD:
  – The absence of factual recall of day-to-day experiences while in an ICU unit
  – The presence of vivid delusional memories of events that, in reality, did not take place while in an ICU unit.
Causes of Delusional and Fragmentary Memories

- Hallucinations and altered perceptions by ICU medications
- Initial insult stresses the brain and body causing shifts in consciousness
- Delirium: perceptual disturbances, misinterpretations, illusions, delusions or hallucinations “slamming of a door misinterpreted for a gunshot” “fold in bed clothes mistaken for animate objects”
Delusional Memories


- Effects of An ICU Diary on Post Traumatic Stress Disorder Symptoms in Intensive Care Unit Survivors and Family Members (2010 – Present) Gwynne MacDonald, P.I., CNS; Jim Kutsogiannis, Intensivist; Allan Shustack, Intensivist; Kara Livy, NP; Donalda Dyjur, Program Manager; Pamela Thompson, Psychologist; Carolyn Lord, Psychologist and Joanne Fugina, Psychologist. Funded by Royal Alexandra Nursing Research Fund and Canadian Nurses Foundation.
ICU Memory Tool

- Two weeks and two months after discharge from ICU
- Recall of ICU events
- Factual events (cues such as “tube in my nose”), memories of feelings (cues such as “pain”, “panic”, or “feeling confused”), and delusional memories (cues such as “thinking people were trying to hurt them”, “hallucinations” or “nightmares”)
Memories

- "Nighttime was bad - I hated nights, I felt like someone was after me. They were doing things to me and I would feel the pain and the anxiety"

- "There was this black type of tubing tangled in my face - I was trying to get untangled and people came running at me to untangle me"

- "I once thought I was in Mexico hiding from gorillas."
"When I was in the 4 bed ward - I thought they were filming a production - there were cameras - if actually was kind of scary - there was a lady on fire running past me - I couldn't understand why they would put a show like this on for patients. The room felt very dark." "There was another night where it was nurses 'party' night - they were all walking around in fancy dresses with their drinks in their hands."
Memories

• “I felt someone come in, I told them to get out. They were trying to kill my husband and my mother. They would bring out plates of hamburger, steaks and beef and tell me it was them”.

Memories

“I kept thinking my doctors were trying to hurt me - twice I dreamt that they were trying to drown me - I think that is when I pulled things out of my mouth and nose.”
Memories

• “I felt like I had done something wrong and they were punishing me.”

• “I felt like I was being gagged and choked – I think it was the breathing tube.”

• “I kept wanting to get my glasses and someone was stirring cement and someone splashed the glasses with cement and the glasses were stuck on the hoses in my nose; then they tied my arms.”
Delusional Memory Themes

- Restraints: “trapped”, “persecuted” “victimized”
- Thirst: “deprived”
- Unsafe situation: lights, sounds, noises, lots of people, masks, gowns, gloves, “threat”
- Traumatized: “overwhelming”
- Dream states mixed with reality: “hovering”, “seeing things”, “hearing gunshots”
Background

- Interventions which help build a coherent story from fragmented and distorted memories and nightmares may decrease the development of PTSD
- A simple therapeutic intervention such as an ICU Diary may be beneficial
- Backmann & Walther (2001) used diaries as a debriefing tool post critical illness.
- Beneficial for patients with little or no recall of their ICU stay
ICU Diary Literature

- Prospective diaries (n=35) implemented and trialed with follow-up at 2, 6 and 12 months post discharge
- Benefits:
  - Better understanding of the events of critical illness
  - More realistic goal setting during the recovery period
  - Improved communication within families through discussion of the diary
  - Source of comfort for the bereaved

ICU Diary Literature

• Content analysis of 8 diaries
• Themes:
  – Narration of daily events
  – Perceived presence of health professionals and family at the patient’s bedside and the patient as a person through the diary entries
  – Expression of feelings as written throughout the text
  – Commitment and care of the contributors to the patients’ welfare

ICU Diary Literature

- Qualitative personal interviews and analysis (n=9)
- Narrate experiences of their personal diary written
- One theme emerged “touching a tender wound”
  - Being afraid and deeply touched
  - Appreciating close relatives’ notes
  - A feeling of unreality
  - Gaining coherence

ICU Diary Literature

- Qualitative analysis of interviews at 6 months (n=8) and 18 months (n=8) of “lived experience” of patient diaries, post-ICU conversations and visits back to the ICU.
- Findings:
  - Diary as text and photos induced post-experience reflections.
  - Conversation provided an opening to the patient’s willingness to talk about experiences.
  - Return visit by “feeling” the room that “things” fell into place.

ICU Diary Literature

- 352 patients from 12 hospitals in 6 different European countries
- ICU patients with ICU stay > 72 hours
- Intervention patients received their ICU dairy at one month post-ICU discharge
- Assessment of development of acute PTSD at 3 months
- Results:
  - Incidence of new cases of PTSD was reduced in the intervention group compared to the control patients (5% versus 13%. P=0.02)

ICU Diary

- An ICU diary providing day-to-day accounts of the patient’s ICU stay may help restore memories and decrease PTSD symptoms
- Pilot study at RAH revealed that 25% of ICU survivors and families scored high on measures of PTSD, suggesting high risk of PTSD
- 8% had clinically diagnosed PTSD
Effects of ICU Diary

• ICU patients may be haunted by delusional memories
• May try to suppress memories, but leads to greater physiological arousal
• Cognitive Behavioral Therapy is recommended treatment of PTSD
• ICU Diary may offer similar mechanism by helping patients to change how they think about their illness as they reread the story and build autobiographical memory
What is an ICU Diary?

- Day-to-day account of patient’s ICU stay
- Includes initial entry of why patient was admitted to ICU, date of admission and patient’s name
- Can include photographs; however, photographs cannot be posted in diary until consent is received from patient
What is the nurse’s role?

- Record significant events or milestones
- Examples:
  - Admission into ICU
  - Extubation
  - Tracheostomy tube insertion
  - Sitting in chair for 1st time
- If progress is slow, make regular entries
- Encourage families and other disciplines to write in diary
ICU Diary

- Writing in diary is encouraged
- Entries need not be made every shift
- Avoid information of sensitive nature (Malignancy, HIV status, substance abuse)
- Write only what you would be comfortable disclosing verbally to the patient or relative at the bedside
- Writing should be relevant and professional
ICU Diary

- Use laymen terms
- Avoid jargon or abbreviations
- Date and sign all entries
- Do not write on hard cover of diary
- Use black ink
ICU Diary

• Include relatives.
• Encourage them to write and say they have been visiting (they can include what has happened at home or anything the patient has a particular interest in)
Who can write in the ICU Diary?

• ANYONE!

• Encourage multidisciplinary involvement
  – A diary with contributions from nurses, doctors, PT/OT, NPs, relatives, etc. is likely to hold more meaning than from one person alone
ICU Diary Review

• At 6 weeks post- ICU discharge, an ICU nurse will meet the patient to discuss her/his ICU experience, using the diary to fill in any missing memories. The family member will be present.

• A tour of the ICU will be offered.
How to improve outcome?

• Use light sedation: helps form factual memories
• Introduce patient diaries: come to terms with traumatic event and delusional memories
• Routine monitoring of delirium
• Appropriate management of delirium
• Early mobility
• Least restraint policy
• Follow-up of patients with delirium: risk of cognitive impairment increases nine times

https://sites.google.com/site/jvcicu/icu-delirium---an-overview/discharge-post-icu-follow-up
Acknowledgements

• Donalda Dyjur, Program Manager, ICU
• Candace Kercher, Acting Unit Manager, ICU
• Royal Alexandra Hospital Critical Care Research Group
  – Patricia Thompson
  – Kirby Scott
  – Reagan Bartel
  – Norine Whalen
Questions?

- Gwynne.macdonald@albertahealthservices.ca
Questions?