Miss Maria Latchia (Cyprus)

Caring for the families of patients receiving palliative care for traumatic brain injury
Caring for the family of patients receiving palliative care for traumatic brain injury (TBI)

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Palliative care definition (WHO, 2004)

- Improves patients and families QoL facing life-threatening illness, through prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems such as physical, psychosocial and spiritual

- Provides relief from pain and other distressing symptoms,
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until their death
- Offers a support system to help the family cope during the patients’ illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance QoL, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications
Research problem

- Family members of ICU patients have certain needs that are generated when a loved one is hospitalized in an ICU. The satisfaction of those needs is crucial, because it affects their coping mechanisms. Which are the most important family member’s needs? How are family member’s needs satisfied and how does this affect their coping mechanisms?
Traumatic brain injury (TBI)

- It is a result from a violent blow or a jolt to the head, or a penetrating object.
- Moderate and Severe types: bruising of the brain, torn tissues, bleeding and other physical damage. Symptoms as above, more severe long term complications or even death.
- Several complications may occur immediately or soon after the event and it includes altered consciousness, physical complications, intellectual problems, communication problems, behavioral changes, emotional changes and sensory problems.
Traumatic Brain Injury statistics

- It accounts for 5% of all deaths in developed countries
- 4 of 5 patients have one or more injuries
- Increase of severity -> worse prognosis.
- Severe TBI -> permanent 100% disability
- Severe TBI when GCS is below 9 within 48h of the injury
- High risk populations: young people, men, low income persons, unmarried, substance abuse, previous TBI.
Significance of the problem

- Serious Public Health Problem. Large number of deaths and disability.
- No exact number of cases due to lack of case registration from several countries.
- Worldwide > 1 billion People live with disabilities
- ¼ of disabilities caused by accidents and violence.
- Reduced accessibility to health and rehabilitation services, education, work
- Increase hospital care costs
- Non-participating in society

Eurostat 2012

~57,000 deaths in EU
82,000 deaths in Europe
(post) Intensive care unit syndrome family (PICS –F)

- Increased demands during patient’s hospitalization
- Altered sleep and eating patterns
- Displacement from home
- Disrupted work routines
- High stress levels from ICU environment

Suggested by Netzer and Sullivan, 2014, to recognise Family Intensive Care Unit Syndrome

Anxiety
Depression
Complicated grief
PTSD
Family – patient centred care

- Helps family’s adaption to the demanding ICU environment
- Helps adapt with loved one’s condition
- Recognises the patient as part of his/her family system
- Inclusion of both family and patient in care → Fundamental to the delivered care

- 4 Core Concepts
  - Dignity and respect to family and patient
  - Information sharing → participation in DM
  - Participation in care
  - Collaboration of all parties of interest → develop policies
Systematic review

– Conducted in November – December of 2019
PsychInfo, Pubmed, EBSCOHost, CINAHL Plus, MedLine
Publication date 2009 – 2019

**Key words:** “Patient’s family”, “Family needs”, “Family satisfaction”, “ICU”, “Family coping”, “Family needs”, “ICU patients”, “NOT cancer patients”, “NOT reviews”, “NOT pediatric”, “NOT end of Life”.
Retrieved results for ICU Family members needs, coping, satisfaction

- Total of 1281 results yielded
- 220 titles of which 78 abstracts were left
- 29 articles left of which:
  - Coping: 4 quantitative and 2 qualitative
  - Needs: 8 quantitative, 1 mixed methods, 3 qualitative
  - Satisfaction: 3 interventional quantitative, 6 qualitative, 2 mixed methods
Retrieved results for ICU family needs

- Mostly family members place needs for assurance and information about patient’s condition as first needs to be fulfilled
- First ranked needs: Assurance of best possible care provided and Knowing specific facts of patient’s progress and expected outcome= less personal distress and anxiety
- Few studies: need to have directions at patient’s bed side, expected to provide care to their loved one= help decrease feelings of powerlessness
- Need for hope and need to be called at home at any time patient’s condition changes, access social services
- Least ranked needs: proximity, support and comfort
- Need consistent, honest and understandable information of patient’s condition= helps cope and increase satisfaction.
Neuroscience patients family members

- Need to protect the patient’s life, by being with the patient since the first moment of the hospitalization
- Try to protect other family members from unnecessary suffering
- Maintain balance and some kind of normality, especially if there are young children involved
- Protect what remains to rebuilt their lives and
- Joy of the patient’s awakening soon becomes a realization of the hard recovery that is ahead
Retrieved results for family satisfaction

- Intervention studies = total satisfaction scores improved
- Aspects of information, need improvement in studies with no intervention.
- Satisfaction in non survivors family members: slightly higher overall than survivors
- Foreigners = statistically less satisfied in decision making
- Studies showed high satisfaction to medical staff
- Room for improvement: respect and compassion for family members, completeness and consistency of information
- Most negative comments= waiting room area
- Highest scores: amount of time to make decisions and care provided by ICU staff
- Parents of patient= felt very supported and very included in decision making
Retrieved results for Family coping in ICU

- Family members anxiety levels at admission may reach psychiatric patients levels.
- Levels of anxiety and depression are severe in small percentages of Family members.
- Anxiety declines at follow up.
- Lower levels of anxiety and depression = higher levels of hope, optimism.
- Active coping, increases significantly from discharge to follow up = high levels of optimism.
  - Optimism = lower levels of anxiety, depression, and Post Traumatic Stress.
  - More problem focused coping strategies are used than emotion focused coping strategies and significantly increases over time.
  - Extended use of both strategies early = family adjustment.
- Problem focused coping strategies are decreased when anxiety increases.
- Use of spiritual connections help to maintain hope.
Aim and research questions

1. Are family member’s needs met in ICU?
2. How do family member’s satisfaction of needs affect their coping strategies?
Applications in GHN ICU for family members

- Clinical psychologist appointed to help family members of ICU patients.
- Visitation hours 2 hours daily 2 pm – 3 pm and 5 pm – 6 pm
- Every day 2 – 3 pm intensivists inform family members of patient’s condition.
- Need for decision making, family meetings held
- Calling family members at home when patient’s condition change
- ICU brochure given to family members in plain language, ward’s conduct number
- Specially modified room just outside the ICU, which renovated recently, includes recliners, a toilet and a shower, as well as some amenities.
Methodology and Sampling

- Exploratory descriptive study
- One or 2 family members of patients with moderate or severe TBI, 24 – 48 hours after patient’s admission at GHN in ICU.
- The inclusion criteria: visit patients often and be involved in family meetings over 18 years old and voluntary participation.
Questionnaire of needs satisfaction

**Critical Care Family Needs Inventory (CCFNI):**
- Created by Molter and Revised by Leske
- 45 need statements.
- 2 open ended questions
- 4-point Likert scale 1= not important to 4= very important.
- Five areas assessment: support, comfort, information, proximity, assurance.
- Cronbach’s a= 0.74 – 0.88
Coping questionnaire

**Ways of coping checklist**

- Created by Lazarus and Folkman
- 38 statements short version
- 4 – point Likert scale (0 – 3)
- Translated and culturally adapted in Greek by Karadimas et al., 1998
- Evaluates 5 factors: positive approach, seeking social support, wishing well/ daydreaming, avoidance/ escape and problem solving.
- Cronbach’s alpha of five factors range 0.60 and 0.79.
Health care professionals sampling

– Concurrently, the questionnaire of family satisfaction will be given to the nurses in order to gain an insight on their perception surrounding family satisfaction. How does this affect family member’s coping?
Importance

– Family members the most important aspect of Health care systems= responsible for caring for individuals with a chronic or acute conditions without salary
– Family members undertake a lot of tasks, to take care of their patients in need
– Result hazardous caregiving, being “hidden patients” themselves because they reduce the attention to own health, to care for their ill patient, resulting in serious adverse physical and mental health problems
– Ongoing research for more than three decades surrounding the family member’s potential hazards in caregiving = a serious gap between Health Professionals attention and family members
Thank you

Questions