Psychological adaptation to the progression of the handicap

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Plan

DISEASE IMPACT

QUALITY OF LIFE

RESPIRATORY DYSFUNCTION : NIV AND TRACHEOSTOMY
DISEASE IMPACT
Facing different losses

- Announcement:
  - Psychological stress; will never be forgotten. Great variability of adaptations
  - After: new self-representations, fear concerning future and eventual handicap

- Loss of walking ability: 2\textsuperscript{nd} major stress
  - Transition from “disease to handicap”
  - Dealing with the necessity of technical devices that evoke disease severity and progression
  - Child: awareness of his/her illness

- Loss of upper limbs abilities: loss of autonomy

- Reduction of ventilatory capacities: « another step to
Psychological Impact

- Chronic disease – a particular affective dimension (C. Réveillère, 1984)
- Anxiety and disease evolution may determine different personal strategies:
  - Priority to “imaginary world”
  - Deny reality
  - Suppression of affective reactions
  - Looking for sense: culpability may emerge

- Major familial impact
Impact on the others

- Paradoxical position: becoming expert vs keeping personal "normal" relationship

- Special emotional impact in parents: either a constructive development or a feeling of being wounded

- To be physically dependant is **NOT** synonym of being psychologically dependent → psychological autonomy can be preserved
QUALITY OF LIFE
Duchenne Disease and Ventilation (Bach et al., 1991)

- 2 groups: 273 health care professionals / 82 ventilator-assisted DMD patients

- 2 questionnaires:
  - QoL
  - Evaluation of 3 aspects of handicap: functionality of upper limbs / functionality of lower limbs / respiratory functioning

- Results:
  - QoL attributed by health care professionals < QoL reported by patients
  - Greater impact of hands dysfunction (patients) ≠ need of ventilator support (predicted by health care professionals)

- Health care professionals’ perception is very different from patients’ perception → we can’t put in patient’s shoes.
QoL, teenagers and NMD (Vuillerot et al., 2009)

- Similar scores for NMD and control concerning:
  - vitality
  - body image
  - relationships
  - physical and psychological well-being.
- Higher scores concerning school performance and relationships with teachers
- Lower scores concerning pleasure activities
- No significant differences between ventilated NMD patients and non-ventilated
- Conclusion: NMD teenagers should benefit from less compassion and more boldness and dynamism
Life process and QoL (Rabheek et al., 2005)

- 65 DMD patients (18 to 42 yrs): semi-structured questionnaire
- Results: description of life process and satisfaction
  - Primary and secondary school.
  - Around 24 years: live alone assisted by a personal care assistant 24/24h.
  - Average: 4h/day watching TV, 3h on the computer, time with family once a week
  - Satisfaction expressed concerning housing, income, home help and social activities.
- As a whole, very good QoL but worried not to have a love and sexual life. This frustration decreases with age at the cost of a significant resignation.
RESPIRATORY DYSFUNCTION: NIV AND TRACHEOSTOMY
Non Invasive Ventilation

Mrs D. : Pompe Disease, under treatment. Indication of NVI

- Patient’s refusal: « I want to stand up and without NIV to the end. »
- She judges she’s asymptomatic and NVI will be a sharp increase in the medicalization of her life.
- NIV is experienced as intrusive and stigmatizing
- An intrusion into her marriage, her bed, her femininity.
- « As long as I will be under treatment I can’t accept it »

Importance of narrativity → to keep the dialogue
Tracheostomy (Gargiulo et al. 2008)

- Like the loss of walking ability, tracheostomy marks a no return point.
- Not an organ nor a limb withdrawal but a new body orifice, an appearance of a hole
- This physical modification comes with different fantasies: rape, penetration, intrusion, cutting the throat.
- The patient is afraid that his physical appearance is changed permanently and therefore he can never claim to be loved, desired.
Tracheostomy

- Negative symptoms expressed by DMD patients who are not psychologically prepared to tracheostomy (Bénony et al., 1996):
  - Hypersensitivity to the noise of the breathing apparatus
  - Occurrence of nightmares.
  - More emotional sensitivity (tears)
  - Less sleep
  - Less dream and less taste for life

- 2/3 of the subjects experience a difference between before and after the ventilation in a positive or a negative way.

- The regression of somatic symptoms (headache, sleep, congestion, fatigue, appetite, breathing, muscle relaxation) is experienced very positively.
Tracheostomy

- Changes in the experience of the body and its image, confronting the subject of strangeness phenomena or dissociation impressions.

- Mechanical ventilation / Ventilator assistance marks an evolutionary step and needs various psychological adaptations sometimes exhausting. When it’s not prepared it might be traumatic.

- No psychological preparation becomes a risk factor.

- This study underlines the great need of these patients to communicate their fear and to be supported.
Objective: to investigate traumatic aspects of the Intensive Care Unit (ICU) hospitalization experience.

Population: following an episode of respiratory failure
- 20 patients required invasive mechanical ventilation (V Group)
- 20 treated with NIV (N Group)

Proportion of subjects who met criteria for a likely diagnosis of PTSD: 35% (V Group) / 10% (N Group)

High prevalence of psychopathology, specifically posttraumatic, in UCI patients who are subjects to invasive ventilation as a consequence of acute respiratory distress.

Experience of intubation and mechanical ventilation may be an additive risk factor for the development of PTSD. It may be associated with fears about survival and experiences of feeling out of control at the same time as the individual is not able to communicate his or her sense of distress.
In conclusion...

Adaption is a continuous process that differs depending on characteristics of patients and their family. Disease can be a major event in one’s life, but it does not change personal characteristics (H. Paré, 2003).

Illness can render patients progressively dependent. Successive losses of physical abilities oblige them to mourn a previously autonomous condition.

Dialogue between patient and medical staff are essential to live with the disease.

Psychologists: essential tool especially in the moments of questioning. It allows a better comprehension of emotional aspects, beyond medical aspects.
Deep Breath –
Mélanie WEIDNER
Bibliographie


