



ESPEN Congress Glasgow 2002

Intestinal Failure

Too Little or Too Much?

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*TOO LITTLE OR
TOO MUCH ?*

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Home parenteral nutrition - disabilities

Aims of the Presentation

- To describe the disabilities arising from intestinal failure
- To explain some of the reasons why care and treatment planning may not result in the most suitable treatment for the individual
- To demonstrate the need for an integrated model of assessment

Core Disabilities

From intestinal failure

- Electrolyte and nutritional deficits
- High output stoma/fistula
- Faecal incontinence
- Distressing wounds
- Pain
- Exhaustion
- Psychosocial distress

Core Disabilities

From home parenteral nutrition (HPN)

- Disturbed sleep - micturition, noisy pump
- Impaired mobility - pump, stand
- Fluctuating feelings of well being
- Impaired spontaneity
- Need for daily planning

BANS 1997

Barriers to Patients' Understanding

- Intrinsic: Fluid, electrolyte imbalance, malnutrition
Anxiety
Lack of trust
Misinterpretation of symptoms
Unrealistic expectations
- Extrinsic: Attitudes/values/competency of
professionals
Means of communication

What do HPN Patients Want?

- Clearer lines of communication
- More trained HPN nurses
- Improved emergency support
- More and better services closer to home
- More knowledgeable professionals
- Modern equipment
- Explicit standards
- To be heard

Helpful Humanizing Factors

- Small unit
- Being listened to
- Sustained affirmation by caregivers
- Non clinical discussions with professionals
- Participation



Hagren (2001)

Conclusions from the Available Evidence

- Physiological care alone will not meet patients expectations for improved well being
- Patients with mild to moderate intestinal failure may not be identified
- The autonomy of patients with intestinal failure is fragile and requires fostering

References

- Carlsson J WOCN 28;2:96-105, 2001
- Greenfield The Union Institute 1996 PH.D (169 p)
- Hagren, B et al J Advanced Nursing 34;2:196-202, 2002