New Strategies for Managing Parenteral Nutrition

HPN: Care of the Patient in the Home Setting: Focusing on Short Bowel Syndrome

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HPN
Care of the patient in the Home setting focusing on Short Bowel Syndrome

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Home TPN - quality of life
Differences

Cancer patients
- Old
- Retired
- Assistance with HPN
- Terminal disease
- High mortality

SBS patients caused by Crohn’s disease
- Young
- Working
- HPN mainly self administered
- Chronic disease
- Low mortality
Results from an interview study

- Inability to act spontaneously - planning
- Fatigue hampers social and leisure activities
- Fistulas are the most trying part
- Some have never accepted the stoma
- Job is important for Quality of life
- Handling the stoma, nutrition, medicines and planning the day = Half-time occupation

Results from an interview study cont.

- Disease negatively influences sexlife
- Satisfied with medical care and information
- Staff continuity is important
- Dominate family life
- Fear of being a burden
### Worries and concerns - SBS patients

The most intense concerns (RFIPC-Drossman et al.1991)

<table>
<thead>
<tr>
<th>Item</th>
<th>HPN n=8</th>
<th>Non-HPN n=19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beeing a burden</td>
<td>1 80</td>
<td>1 81</td>
</tr>
<tr>
<td>Energy level</td>
<td>2 60</td>
<td>3 49</td>
</tr>
<tr>
<td>Having surgery</td>
<td>3.5 58</td>
<td>2 60</td>
</tr>
<tr>
<td>Feeling alone</td>
<td>3.5 58</td>
<td>12 27</td>
</tr>
<tr>
<td>Loss of sexual drive</td>
<td>5.5 49</td>
<td>21 12</td>
</tr>
<tr>
<td>Achieve full potential</td>
<td>5.5 49</td>
<td>11 28</td>
</tr>
<tr>
<td>Loss of bowel control</td>
<td>17 12</td>
<td>4 45</td>
</tr>
</tbody>
</table>

Carlsson, E et al. 2002. to be published.
... living with HPN

Positive aspects

• Increased well-being, strength and ability to undertake activities
• Gain in weight - improved body image
• Reduction in hospital admissions

Negative aspects

• Artificial way of living
• Fear of complications
• Inability to act spontaneously - travelling
• Disturbed sleep
Important for successful HPN-patient-related

- Patients participate in decisions on management - included in the team
- Enough time to learn HPN technique
- Evaluate home situation
- Is assistance with HPN needed?
- Legal aspects must be considered

What the patient needs to know before going home

- What to do when complications occur
- Whom to contact
- Open return to the ward
- Special contact person at the pharmacy
- Meeting with home care team
- Follow-up
References

8. Carlsson E et al. What are the Concerns, Quality of life and Coping in subjects with Short Bowel Syndrome.2002, to be published