The Nutrition Patient At Home

HOW TO TRAIN THE PERFECT PATIENT

T. Tas (NL)
How to train the “perfect” patient
(depending on parenteral nutrition at home)

TPN & intestinal failure (IF) team
Amsterdam UMC

Tirzah Tas, RN, MSc
September 1st 2019
15:00 - 15:30
Conflicts of interest

Nothing to declare
One of two expertise centers in the Netherlands

1. Education
   • Training patient to selfcare
   • Nurses, dietitians, physicians, pharmacists, pharmacy staff

2. Monitoring patients, 24/7 back up, Optimize logistics

3. Research
   • Improving patients care, prevent complications

4. Participate in (inter)national working groups

5. Working together with other HPN teams/ If teams for optimal care for IF patients (UMC Nijmegen, Rotterdam, Maastricht, Groningen)
Location of patients and the Two expertise centers

\( P \) = pediatric IF (type 2 & 3)  
\( A \) = acute IF (type 2)  
\( C \) = chronic IF (type 3)

(P/A/C) Training patients

Nijmegen (P/C) Training patients
TPN & intestinal failure team

IF type 1
- Short term - weeks, in hospital; Perioperative, after surgery
- Clinical, clinical staff takes care (physician, dietitian)
- advice from IF team

IF type 2
- Mid long - 3 - 12 months, complex care, bridging to surgery, part clinical, part at home, Referral to specialized team: care at home
- Team approach: surgeon, internal medicine, PA, nurse consultant, dietitian

IF type 3
- Long term - chronical patients, outpatient clinic
- Team: internal medicine, GE, MCs specialized nurse, nurse consultant, dietitian

Children with IF
- Mostly type 3, long term chronical patients
- Team: paediatric GE (physician, fellow), MCs specialized nurse, nurse consultant, dietitian /case manager

Nummers of patients and team members

2001

- Type 2 -> 0 patients
- Type 3 -> 25 patients
- Children -> 2 patients

Total -> 27 patients

5 team members
- Prof. Dr. Sauerwein (internal medicine/endocrinology),
- Cora Jonkers, dietitian
- Tirzah Tas, RN, MSc
- Pharmacist and Social worker

2019

- Type 2 -> 83 patients
- Type 3 -> 110 patients
- Children -> 44 patients

Total -> +/- 237 patients

13 team members
- See members next slight...
Team members 2019

• Physicians:
  • Prof. Dr. Mireille Serlie (internal medicine/ endocrinology),
  • Prof. Dr. Marja Boermeester (surgeon)
  • Dr. Merit Tabbers (pediatric GE)

• Nurse specialist: Tirzah Tas, RN, MSc

• Physician assistent (i.t.): Irene van Arum, RN

• Nurse consulent: Titus Vink, RN
  Lisette Lievense, RN

• Dietitians: Cora Jonkers, Natascha van Rijssen,
  Miriam van de Werf

• Pharmacist: Anne-Loes Gerards

• Social worker: Jacinth Jennekens

• Secretary: Birgit Ensing
Train the “perfect” patients to go home with home parenteral nutrition
The patient with PN at home and his aid worker contacts:

- **Physicians**
  - Prof. Dr. M. Serlie, internist
  - Prof. Dr. M Boermeester, surgeon
  - Dr. M Tabbers, children gastroentrologist

- **Physicians of the ward**

- **Nurses of the TPN team**
  - Tirzah Tas RN, MSc
  - Irene van Arum, RN, PA (i.t)
  - Titus Vink, RN
  - Lisette Lievens, RN

- **Stoma & woundcare nurse**

- **Nurses of the training ward**

- **Nurses of the childerns ward**

- **Home care nurses**

- **Nurses of the transfer ward**

- **Secretary of the team**
  - Birgit Ensing

- **Dietitians of the team**
  - Cora Jonkers
  - Miriam van de werf
  - Natascha van Rijssen

- **Dietitians of the ward**

- **Social worker**
  - Jachintha Jenniskens

- **Doctor assistent of the out patiënts clinic**

- **Pharmacist who makes the TPN**

- **Pharmacist assistant**

- **Facility company**

- **Psychologist / psychiatrist**

- **Courier service**

- **Home farmacist**

+-/-19 professionals
In other words....

The patient with home PN is in terms of organization and logistics a very complicated patient!
How do we try to achieve those goals?
Multi disciplinary team approach!
Aims of TPN & intestinal failure team:

- Improve or maintain nutritional status
- Ensure growth in children, sufficient growth (height, weight and bone)
- Ensure good condition of the patient for:
  1. bridging to surgery
  2. possible intestine transplantation when necessary
- Decrease admission duration
- Provide good IV access (prevent complications (infections/trombosis)
- Prevent (PN) complications
- Save costs
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- Nurses of the childrens ward

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\[ +/-19 \] professionals

- CASE MANAGER => PN & intestinal failure team
Aims of TPN & intestinal failure team

Optimize quality of life:

- Make and keep patient independent as much as possible
- Pediatric:
  - training parents
  - training child from 16 years (when possible)
  - if necessary specialized home care to help parents
- Adults:
  - Training patient, not partner (should remain partner)
  - If necessary specialized home care to help

110 patients Total >200 since 1986
How to Optimize quality of life?

- Wean PN when possible (think in days, not in mL)
- Efficient delivery of TPN bags, lines, pumps etc.
- Good QOL (school, work, holidays, sports, hobby’s)
- Acceptance of the situation
- Provide future ......
Give the patients tools to live their lives as independent of medical care as possible.
Ways of care at home:

“Short” Term
- Bad condition (Wound, fistula and/or stoma)
- Home care nurse

Chronic
- Self dependence
- Training patient

Pediatrics
- Unable to perform self
- Training Parents

Focus
Routing of the **chronic** patient

1. Patient referred by own specialist via website, mail or phone
Before Admission:

(When possible)

1. Informing patient before admission by giving a brochure, protocols, and DVD
2. Patient is seen in outpatient clinic
3. Parenteral access: inform patient and make a choice of central venous catheter (most tunneled single lumen CVC, sometimes port or a shunt. Preferably no PICC except for hospitalized and or short term patients
   1. Nurse visiting patient in (referring) hospital
   2. Nurse gives referring physician advise
   3. Dietitian gives referring physician or referring dietitian advise
Routing of the **chronic** patient

1. Admission / training
2. Discharge
3. Follow up via phone and mail (working on video consulting)
4. See the patient in the outpatient clinic
TPN prepared by patient

- TPN/ fluids / Taurosept order
- Pump & medical supplies
- Home pharmacy information
- Insurance company authorization
- Delivery at home by Facility company

Chronic patient
- Self Dependence
- Training patient
Facility company

- TPN
  - Prepared
  - Unprepared
- Insurance company
- Contact home pharmacy
- Delivery
  - Prepared 2 x pw prepared TPN
  - Unprepared on demand
- Qualified nurses
Tailor made TPN by hospital pharmacy

TPN order

Pump & medical supplies by Mediq

Insurance company authorisation

Weekly PN delivery by AMC pharmacy

Chronic patient

Self Dependence

Training patient
Pro and cons PN tailor made versus ready to use all-in-one bags:

Tailor made by pharm AMC:
- Delivery once a week
- Vitamins and minerals have been added
- Shelf life 1 week
- Holiday in own country, or only 1 week abroad
- Need a refrigerator, need to store the prepared bag in a refrigerator

Ready to use all-in-one bags by facility company:
- Delivery every other week or longer
- Patient or caretakers prepare bags themselves
- Shelf life one year or longer
- Possible to go on holiday abroad for more than 1 week
- You do not need a refrigerator
Procedure of training:

1. The nurse of the TPN & IF team and the nurses at the ward will make a trainings schedule
2. Patient is admitted (aprox. 3-5 days)

Training includes

1. Connect and disconnect catheter for TPN, fluids, electrolytes, medication
2. Care of CVC / PAC/ PICC/ shunt
3. Use of infusion pump (facility company)
4. Preparation of TPN standard bags / fluids bags with medication and or electrolytes (pharmacy)
5. When needed home care involvement
Informing the patient by giving a brochure

Adults

Children
(strict) Protocols and instruction DVD: “How to take care of the central line and TPN”
Practice on a dummy and themselves
When discharge?

1. Patient is totally and well trained
2. Patient is self confident about going home
3. Patient is medically ready
4. Resources (PN, pump, lines etc.) delivered at home
5. Follow up visit to out-patient clinic is planned
Follow up outpatient visit after 2 - 4 weeks

1. Weight / fluid balance
2. Venous access
3. Goals for home TPN, adjustment of TPN prescription due to change needs (growth, weight, electrolyte losses, IFALD)
4. Quality of life, open for questions, psychosocial accompaniment
5. Blood control (Electrolytes vitamins, minerals (Fe, vitm D) liver function kidney function
6. Follow up depends on stability -> 4 weeks - 6 months
7. When needed (before next outpatient clinic visit) -> blood controle via general practitioner
Every week out patients clinic

• Monday: type 2 patients -> Multi disciplinary (physician, nurse, dietitian)

• Tuesday: Type 3 patients -> Multidiciplinary

• Friday: Type 3 patients -> Specialist nurse
• Friday: type 2 patients -> Physician assistent

• Every other Monday: Children -> Multi disciplinary
Prevent complications:

Follow up outpatient clinic:
- DEXA scan -> Osteoporosis
- Ultrasound veins, anticoagulation
- Anthropometry (growth, weight)
- Lab:
  - Liver, kidney, electrolytes, vitamins, trace elements, iron, Hb, essential fatty acids, oxalic acid,

General complications
- Psychosocial due to chronic illness
- Fatigue
- Feeling cold during the day

TPN related complications
- Liver
- Micronutrient deficiencies
- Electrolytes
- Fluid balance
- Osteoporosis
- Hyper- en hypoglycemia

CVL related complications
- Infection
- Occlusion
- Trombosis
- Dislocation
Backup 24 / 7 !!!

Weekdays 8.30 - 18 uur:
  • TPN & IF team: by mail or phone for complications like: fever, problems with CVC, not feeling well

Weekends, holiday’s, evening and night:
  • direct contact with physician on call
  • or via the (training) ward
PN at home...
But also abroad....
Recommendations

Provide safety!

• 24 hr back up service without delay
• Training in-hospital
• Training at home in collaboration with well-trained home care organizations and own strict protocols -> after training check proceedings in hospital
• Frequent evaluation through experienced team in out-patient clinic
• Good co-operation with home physician, home care nursus, farmacy and facility company
• Good communication channels (phone, mail, video consultans)
"Do you want the regular I.V. or fat-free?"