Multi-stakeholder Round Table on Home Parenteral Nutrition: Summary Report

22 October 2018 - Munich, Germany

Background

The Medical Nutrition International Industry (MNI) is the association representing companies developing nutritional solutions such as oral nutritional supplements, enteral tube feeding and parenteral nutrition. MNI wishes to launch a campaign to inform patients, carers, healthcare professionals, homecare providers, pharmacists and payers on the use of home parenteral nutrition.

Home parenteral nutrition (HPN) – i.e. parenteral nutrition administered outside the hospital, either at home or in a nursing home – may be a life-saving therapy for patients leaving with different illness conditions. HPN may improve patients' quality of life and support their ability to perform daily activities. Nevertheless, concerns regarding the risk-benefit profile of HPN and its safe use are widespread: would HPN work for me? who could help to ensure I do it right? what support can I get? how shall I handle the devices? is HPN reimbursed? what are the basic safety measures?

The objective of the initiative is to answer these questions and to raise awareness on the feasibility, safety and practical aspects of home parenteral nutrition.

In this process, MNI is engaging with relevant stakeholders - representing patients, carers, healthcare professionals and clinical societies - to share views and experiences on HPN, to ensure that this initiative addresses all questions related to HPN and builds on real-life situations of patients on home parenteral nutrition.

With this in mind, MNI proposed a two-step approach to stakeholders:

1. Input to informative materials, such as frequently asked questions (FAQs).
2. Participation in a round table gathering relevant stakeholders to address in particular:
   a. HPN benefits and concerns
   b. Practical issues related to HPN
   c. Potential areas for future cooperation

Summary Report of the Round Table on Home Parenteral Nutrition

A multi-stakeholder round table on HPN was organised by MNI in collaboration with the European Oncology Nursing Society (EONS) on 22 October 2018 in Munich, Germany,
within the framework of the EONS track at the 2018 Congress of the European Society for Medical Oncology (ESMO).

The European Oncology Nursing Society (EONS) is a pan-European society of cancer nurse providing leadership in all areas of cancer nursing, research, practice, continuing education, communications and advocacy for better recognition of cancer nursing across Europe.

EONS Director, Emma Woodford, welcomed the participants, whose expectations for the day varied from getting more information on the initiative; learning what others are doing, exchanging experiences to improve patients quality of life, improving access to HPN, and discussing opportunities for collaboration.

MNI introduced the rational of the initiative and objectives of the round table:

- To gather for the first time all relevant stakeholders with an interest on home parenteral nutrition;
- To build a comprehensive list of questions and concerns linked to the feasibility and safety of HPN from various stakeholders’ perspectives;
- To understand what needs to be done to address pending concerns and to propose solutions for the future;
- To the frequently asked questions on HPN as currently developed by MNI;
- To discuss next steps and interest for further cooperation.

MNI clarified there is no intention to duplicate existing activities, but rather to complement existing initiatives and working together to improve the status quo on HPN.

**Barriers and Solutions**

Participants shared their experiences and current activities, and listed anumber of topics that can be clustered in three blocks.

1. **Education of patients, carers, and healthcare professionals**
   - Lack of patient’s education, especially in elderly, and need for medically-based information
   - Lack of knowledge and competence by personnel in the hospitals
   - Lack or poor training of healthcare professionals
   - Knowledge gaps in the role of nutrition in medical curricula in general

Earlier this year the European Cancer Patient Coalition (ECPC) published the patient nutrition booklet ‘Living well with cancer treatment’ addressing patient concerns on cancer-related nutritional issues. The booklet is based on a survey of 907 people with cancer about the importance of nutrition and physical activity, which is showing a substantial gap in terms of need for information and practical management of cancer-related nutritional problems for people with cancer. The booklet includes a charter of
cancer patient’s rights for appropriate and prompt nutritional support. Other patients associations showed interest for developing similar publications.

The European Society for Clinical Nutrition and Metabolism (ESPEN) publishes Clinical Nutrition guidelines aim at preventing, managing and treating different chronic diseases and improve patient outcomes. These guidelines are intended for health care professionals and should be used as guidance for taking decisions about a patients’ nutritional care. The ESPEN guideline on Home Parenteral Nutrition is expected to be published in 2019. ESPEN also hosts a special interest group on home artificial nutrition (HAN SIG).

The European Patient Forum and ESPEN are currently developing a partnership to involve patients in the development of ESPEN guidelines, and to develop lay versions of ESPEN guidelines for patients.

In May 2018 EONS launched the Cancer Nursing Education Framework to address the extensive developments within cancer care, the expanding roles of cancer nurses and changes in educational structures. EONS indicated that it could be beneficial to include HPN within existing recommendations on nutrition training for oncology nurses in the future.

2. Standards of care

- No clear unified standards / use of local guidelines
- Lack of diagnosis / Screening for malnutrition
- Issues related to route accessibility (veins)
- Information on how to address potential complications at home
- Logistics / Infrastructures

In certain countries - like in Italy - the differences in practice care are extremely variable across the country and even locally within regions/provinces. Local home nutritional care guidelines are usually used. This makes measuring compliance and outcomes and developing standards more complicated.

Services related to HPN, as well as how infrastructures are organized, vary from one country to another and whether patients live in urban or suburban areas.

3. Reimbursement / costs

- Different reimbursement schemes across countries
- Fragmented overview of the different reimbursement schemes across Europe
- National nutritional policies not prioritising nutrition
- Affordability by cancer patients (or other kind of patients)
- Supplemental costs (pumps, disposable …)
The European Nutrition Health Alliance (ENHA) highlighted the importance of bringing this topic to authorities and decision-makers to improve reimbursement and standards of care where needed. The Optimal Nutritional Care for All (ONCA) campaign - launched in 2014 and facilitated by ENHA - is a multi-stakeholder initiative to facilitate greater screening for risk of disease-related malnutrition/undernutrition and nutritional care implementation across Europe. The campaign supports national professional societies, associations and patient groups in public health and health care to implement nutritional risk screening and optimal nutritional care in their country. It could act as platform of cooperation on HPN between the stakeholders present.

Participants highlighted that a consolidated overview of reimbursements across Europe would be very helpful and powerful in addressing HPN to authorities and decision-makers at European and national level. This exercise would require the commitment and coordination of several actors involved on HPN in the various countries and regions. Some information are currently available on the ESPEN database for chronic Intestinal Failure.

Communication material
MNI is developing a website and ‘frequently asked questions’ (FAQs) on HPN, with the objective to serve as a hub of information for patients and their families/carers.

Frequently Asked Questions
MNI has developed a Frequently Asked Questions Document on HPN that was shared with the participants and other relevant stakeholders in advance of the round table, in order to collect their views. Feedback from participants included:

- Importance of discussing HPN within a multi-disciplinary team
- Accessibility and reimbursement: provide for general information to contact local patient associations
- Address personal questions on living a normal life (pregnancy, raising children, working...)
- Provide for information on HPN for children
- Disclaimer on referring to a doctor to discuss HPN, to display on top

However, the Frequently Asked Questions shall be seen as a living document. Future updates shall be foreseen to address any missing information, and to make it as accurate and exhaustive as possible.

It was agreed that the MNI Secretariat will integrate the comments received as much as possible and will consolidate the document shortly. The final version will be circulated to stakeholders and published on MNI website and on HPN website when in place.

Interested stakeholders will be free to disseminate the document to their members and networks.
Website on home parenteral nutrition
MNI is planning to develop a website to serve as a hub of information on which to share communication materials on HPN, including the FAQs. The website shall address main questions related to HPN, such as: *What is it? Who shall get it and why? How does it work in practice? What’s in it for the patient?*

Infographics, videos and other visuals shall be developed to provide a general idea on how HPN works in practice. The communication material shall be freely downloadable and conceived to be user-friendly and understandable in particular for patients and their carers.

Conclusions and Next Steps
All parties present during the round table confirmed their interest on the topic of Home Parenteral Nutrition.

All showed interest in cooperation, and invited the MNI to make concrete proposals.

There was agreement that any future cooperation shall address the topics discussed:

- Developing educational material for patients and their families / carers;
- Ensuring dedicated curricula on nutrition for healthcare professionals;
- Setting-up well-designed protocols including home nutritional care to support compliance;
- Establishing a multi-disciplinary approach;
- Promoting best practice sharing;
- Developing a policy mapping to better understand how governments are currently approaching nutritional care.

Concerns for future cooperation included human and financial resources: stakeholders need to look internally whether participation to this initiative could be prioritised.

More clarifications are expected on the objectives and action plan of the initiative.

There is also the need to work to implement a better strategy to raise awareness on the use of HPN country by country. This could be done via the Optimal Nutritional Care for All (ONCA) campaign. To be confirmed.

The development of a Memorandum of Understanding was proposed as a way forward.
List of participants

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<tr>
<th>#</th>
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