

ORIGINAL ARTICLE**Nutrition**

An innovative educational program for adolescents on home parenteral nutrition for the “transition” to adulthood

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Abstract

Facing with an increasing demand for transition to adult care management, our home parenteral nutrition (HPN) team designed an adolescent therapeutic educational program (ATEP) specifically intended for adolescents on long-term HPN. The aim of this study was to report on the first sessions of this program. **Methods:** The ATEP is designed in three sessions of five consecutive days, during school holidays over the year. It includes group sessions on catheter handling, disconnecting and connecting the PN and catheter dressing, dealing with unforeseen events (e.g., fever or catheter injury), but also sessions with psychologist, social worker, sports teacher, fashion specialist, meeting with adults who received HPN since childhood. Specific course for the accompanying parents were also provided. Six months after the last session, a 3-day trip to the attraction park “le Futuroscope,” Poitiers, France, was organized without any parental presence. **Results:** After 3 ATEP courses, a total of 16 adolescents have been enrolled. They were aged between 13 and 17 years (median 14 IQR: 14–16.25). All were on long term HPN started during the neonatal period

Abbreviations: ATEP, adolescent therapeutic educational program; CE, congenital enteropathy; CIF, chronic intestinal failure; CIPOS, chronic intestinal pseudo-obstruction syndrome; CRBSI, catheter related blood stream infections; CVC, central venous catheter; HPN, home parenteral nutrition; IED, intestinal epithelial dysplasia; LSHD, long segment Hirschsprung disease; MD, medical doctor; MVID, microvillous inclusion disease; NHA, National Health Agency; PN, parenteral nutrition; PNDI, parenteral nutrition dependency index; QoL, quality of life; REE, resting energy expenditure; RN, registered nurse; SBS, short bowel syndrome; THES, tricho-hepato-enteric syndrome; TLP, Tauroldine lock procedure.

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except for four who started PN at a median age of 10 years old (IQR: 1–10). At the time of the ATEP, their median PNDI was 105% (IQR: 95.5–120.8) while receiving a median of six infusions per week (IQR: 5–7). Thirteen received Taurolidine lock procedure. After the ATEP, 11 adolescents could be considered as fully autonomous, 4 as partially autonomous and one failed to gain any autonomy. Course evaluation by adolescents or parents was good to excellent.

Conclusion: Through the holistic and multiprofessional approach of this training and the group cohesion, the adolescents were not only able to handle catheter care and PN connections but were able to understand and accept better their illness and project themselves into their own future.

KEYWORDS

adolescence, intestinal failure, parenteral nutrition, quality of life, self care management

1 | INTRODUCTION

Intestinal failure (IF) is the inability of the intestinal tract, being reduced, absent or nonfunctional, to cover the nutritional needs necessary for survival and for growth.^{1,2}

IF requires parenteral nutrition (PN) for a variable duration of time, by replacing or completing oral feeding.^{3–5} In Europe, the Necker-Enfants Malades University Hospital (NEM-UH) is one of the pioneer centers for pediatric IF, where pediatric PN was developed in the late sixties. In the early eighties, home PN (HPN) was considered as the only option allowing the “long-term” PN dependent hospitalized children, to live in a family environment and to attend regular school.⁶ An educational program for HPN, certified by the National Health Agency, was designed to train the parents to PN and central venous catheter (CVC) care for a safe return home. To date, over 800 children have been discharged on HPN from our center^{7–10} while HPN developed all around the world.^{11–18}

The CVC care is carried out morning and evening including three main procedures: connection of the infusion line in the evening, disconnection in the morning and CVC dressing, representing around 2 h/day, excluding unforeseen events or complications for example, fever, catheter related infection or mechanical problems, increased fluid losses, water-electrolytes imbalance and over care such as stoma care.

The social life of these families is impacted by this demanding daily life, while one of the parents must remain available for the daily care and unexpected events.^{19–23} The professional activities of the parents are impacted, while the consequences for the child on his psycho-socio-emotional life may be numerous: schooling disrupted by absences, complicated meals in case of eating disorders, no sleep-over at friends in the absence of his/her parents, no summer camps, etc. As a matter of fact, on top of being attached to a line, the obligatory and permanent presence of their parents

What is Known

- Home parenteral nutrition (HPN) is the corner stone for the management of infants, children and adolescents dependent on long term PN for chronic intestinal failure (CIF).
- Long term outcome of some adolescents with severe CIF requires their transfer to adult medical care through the process of “transition.”
- The “transition” process to adulthood is very specific and requires a multiprofessional approach.

What is New

- An adolescent therapeutic educational program allowing the adolescents to become aware of their disease and their dependence, to take care of themselves, to become autonomous in the PN management, and to approach more serenely the “transition” to their adult life.
- The program in terms of organization in 3 weeks training together with specific and original meetings with parents as well as young adults themselves on HPN.
- The association of care givers and professionals for a holistic approach preparing the “transition” to adulthood.

highlights these children differences. This dependence can be particularly badly experienced during adolescence, the period preceding the “transition” to the world of adults.^{24–29}

Facing with an increasing demand for a transition process, we report on an adolescent therapeutic educational program (ATEP) aiming to allow the adolescent to become aware of his medical condition

and his dependence to PN, to take care of himself, to become autonomous in the PN management, and to approach more serenely the “transition”.

1.1 | Population and methods

1.1.1 | Population

Adolescents with chronic IF caused by a primary digestive disease, considered most-likely to remain PN-dependent in adulthood were included. Causes of CIF were: short bowel syndrome (SBS) and long segment Hirschsprung disease (LSHD); congenital enteropathy (CE), pediatric intestinal pseudo-obstruction syndrome (PIPOS).

1.1.2 | Parenteral nutrition

As previously described, all adolescents were receiving PN according to the clinical requirements and the ESPGHAN guidelines to allow optimal growth.^{10,30} Compounding was made by Baxter-Façonnage while PN bags, after control, were delivered home by a transport company. The degree of IF was assessed by using the PN dependency index (PNDI) which is the level of PN energy intake required for achieving normal growth and development.^{31–35} The PNDI is established from the ratio between non protein energy intake (NPEI) supplied by PN and resting energy expenditure (REE) calculated by using Schofield formula for age, gender, body weight and size (NPEI/REE).^{36,37} Catheter related blood stream infections were prevented by using Taurolidine lock procedure (TLP).³⁸

1.1.3 | The objectives of ATEP for achieving autonomy in HPN care, were as follows

- Explain the illness, most often a neonatal one, its treatment and the reasons for continuing long term PN.
- Identify the material necessary for PN: CVC and its dressing, infusion line, PN bag, infusion device...
- Training to carry out the care alone including connection and disconnection of the central line, CVC dressing, infusion programming, checking the medical sets and the PN bags.
- Deal with unforeseen events: fever, CVC injury, infusion device dysfunction and so forth.
- Psychological support to gain self-confidence in carrying out technical care, by identifying and managing emotions related to growing autonomy of the patient during adolescence.

2 | METHODS

To limit the impact on schooling, the ATEP was designed in three sessions of five consecutive days, during school holidays over the year, in a dedicated building at NEM-UH. The adolescents were not admitted on the ward but were offered complimentary accommodation at the hospital “Maison des Familles” with one parent. Following the three training sessions, the team organized a trip (2-night stay) at the attraction park “le Futuroscope” (Poitiers), without the parents. The aim was to put the adolescents in a “real-world” situation to evaluate their practice of care and to experience an unforgettable weekend with their peers.

The sessions were collective or individual, depending on the educational objectives. They were supervised by the home PN multidisciplinary team including registered nurses (RN) graduate in TEP. The other professionals attending were medical doctors (e.g., PedGI doctors being referring physician of the adolescents), pharmacist, anesthetist, psychologist, youth educator, occupational therapist, social worker and sports teacher. Along the three sessions, specific actions were achieved as follows.

2.1 | Personal interviews

Personal interviews were dedicated to the adolescents to establish “their past history” by telling their medical and personal story from the beginning with the help of their parents, the referring MD and the psychologist. This was a space for questions where different aspects, versions and views of life and personal history could be discussed. During these sessions the patient's identity could be affirmed independently of health issues, but also taking into account the impact of the illness. The goal was to involve the adolescent in the whole process of communication and that he/she could elaborate on ways to a more independent future by building up on his/her past. These interviews were started on the second session of the ATEP program so did not include all patients.

2.2 | Parents counseling group

The referent psychologist had a regular follow-up of families during the HPN years and the period of growing independency and autonomy of their children. During the ATEP, it was an opportunity to share fears and difficulties while changes are ongoing in the relationship between growing children and parents.

2.3 | Specific support for adolescents

The teenagers were stressed by the session of individual training with the nurses for teaching PN care. Therefore, support was organized by the HPN team youth educator and occupational therapist to channel their emotions and anxiety. Relaxation methods were offered such as dance and yoga associated with games and creativity workshops. These collective sessions of relaxation allowed the teenagers to get to know each other, contributing to group cohesion.

2.4 | Meeting HPN adult patients

A 4-h meeting with three or four HPN dependent adults aged 35–40 years old was organized from the second session. All adults had been on HPN during childhood and were still on HPN at the time of the course. These participating adults were all self-managing their PN care, professionally committed, and living, most often, as a couple with children of their own. In the last part of the meeting, the parents were invited to meet with these adult patients.

2.5 | Invitation to travel

We wanted to make adolescents aware of the possibility to travel and to the specific requirements supported by the HPN team and the parents. It is up to them to convince their parents to make these dreams come true. In the form of a card game, teenagers learnt about all the logistical and medical aspects of a trip, whatever the duration and destination: manufacture-transport-delivery of PN bags, PN equipment, including when traveling by plane, what to do in case of problem, local contacts and so forth.

2.6 | Specific course for the accompanying parents

From the second course, parents were invited to spend time in visiting the Necker-IMAGINE Research Institute and participating at meditation, Shiatsu and Yoga course.

2.7 | Evaluation of the training course

- The level of the teenager autonomy was assessed by the specialized TEP nurses and scored as: total, partial or absent according to the ability for connection and disconnection of the central line, CVC dressing, infusion programming, checking the medical sets and the PN bags, dealing with unforeseen

events: fever, CVC injury, infusion device dysfunction and so forth.

- The patients and their parents evaluated the course according to the following items: communication and training with the ATEP nurses, meetings with PedGI, anesthetist, pharmacist, psychologist, youth educator, occupational therapist, social worker and sports teacher. The personal interview, the meeting with adults, and the traveling invitation were also evaluated as were the parents course and the trip to “le Futuroscope.” A four levels notation was used: A: great, B: good; C: might be better, and D: not good.

2.8 | Organization and financial support

Several partners supported all financial expenses to avoid any charge for the parents. The first session was supported by the association “La vie par un fil” and FIMATHO (French consortium for rare abdomino-thoracic diseases). The other sessions were fully supported by the Mécénat Necker and the Pièces Jaunes Foundation including the weekend at “le Futuroscope.” The design, organization and logistics of “le Futuroscope” weekend, were managed by the Necker HPN-team: hotel reservation, railway ticketing, delivery of refrigerators on site, equipment and nutrition bags including a rescue PN bag.

2.9 | Ethical issues and validation

This program is supported by the Unité Transversale d'Education Thérapeutique and validated by the Agence Régionale de Santé. It was presented at the International Congress on Intestinal Rehabilitation (Paris July 2019), at the meeting of the French speaking Society of Clinical Nutrition and Metabolism in 2021. This program was awarded in 2022 as first prize in the contest organized by Assistance Publique-Hôpitaux de Paris for innovation in therapeutic education. It was presented as an oral presentation at the ESPGHAN 2023 annual meeting.

3 | RESULTS

A total of three courses have been organized with the first one in 2018–2019. In 2019–2020, because of an insufficient number of candidates, the course was postponed. The two others were held during the school years 2020–2021 and 2021–2022. Along the three training courses, a total of 16 adolescents were enrolled in the ATEP (Table 1). Median age was 14 years (IQR: 14–16.25). The underlying rare digestive disease was: SBS ($n=8$; including three LSHD), CE ($n=5$), and PIPOS ($n=3$). Six adolescents had a

TABLE 1 Patients characteristics at inclusion in the program.

Patients	Age; (years)	Age at PN start (years)	Course year	Home	Parents status	Siblings	Disease	PNDI %	Infusion per week	Taurolidine lock procedure
1	14	Birth	2018–2019	R	Stable	1	MVID	157	7	O
2	14	Birth	2018–2019	R	Stable	2	LSHD	77	4	O
3	13	6.5	2018–2019	R	Divorced	1	PIPOS	84	6	O
4	14	Birth	2018–2019	IdF	Stable	2	SBS	100	5	O
5	16	Birth	2018–2019	R	Stable	1	IED	148	7	N
6	15	10	2020–2021	IdF	Stable	1	PIPOS	105	7	O
7	18	12	2020–2021	R	Widow	1	SBS	117	7	O
8	14	Birth	2020–2021	IdF	Divorced	2	LSHD	98	4	O
9	18	Birth	2020–2021	R	Stable	2	IED	136	7	O
10	14	Birth	2020–2021	R	Stable	2	LSHD	105	7	O
11	17	1	2020–2021	R	Divorced	1	PIPOS	103	5	N
12	17	Birth	2020–2021	R	Divorced	0	IED	88	4	O
13	13	Birth	2021–2022	R	Divorced	2	SBS	109	7	N
14	15	Birth	2021–2022	R	Stable	1	WNT2B	81	5	O
15	14	Birth	2021–2022	R	Stable	3	SBS	129	7	O
16	13	Birth	2021–2022	IdF	Stable	2	SBS	118	6	O

Abbreviations: IdF, Ile de France (Paris and surrounding); IED, intestinal epithelial dysplasia; LSHD, long segment Hirschspung disease; MVID, microvillous inclusion disease; PIPOS, pediatric intestinal pseudoobstruction syndrome; PNDI, parenteral nutrition dependency index; R, region; SBS, short bowel syndrome; WNT2B, Wint 2B mutation.

jejunostomy ($n=3$ LSHD) or an ileostomy ($n=3$ PIPOS). Twelve were on long term HPN started during the neonatal period because of congenital illness or malformation, and four others (three PIPOS and one SBS after late mid gut volvulus) started PN at a median age of 10 years (IQR: 1–10) (Table 1). At the time of the course, their median PNDI was 105% (IQR: 95.5–120.8) while receiving a median number of six infusions per week (IQR: 5–7). All but three adolescents were receiving TLP.

All teenagers followed the entire course without dropping out. At the end of the 3 sessions, 11 adolescents could be considered as fully autonomous fulfilling all criteria, 4 as partially autonomous, 3 for disconnection of the central line in the morning and for CVC dressing, 1 for disconnection of the central line only and one failed to gain any autonomy.

Evaluation of the ATEP by adolescents and parents is reported in Table 2. Overall evaluation of the course was excellent or good. Scores for meetings and teaching sessions with the health care providers ranged between 62.5 for the physicians to 100% for the pharmacist. The core of the ATEP was globally very well quoted (87.5% great). The psychological approach, as reflected by the score of the sessions with psychologist, educator and occupational therapist,





achieved a good score (81%) while personal interviews were appreciated by only 55% and declined by 26% of the adolescents. Meeting with social worker was great (50%) or good (50%), with sport teacher was great for 94%. Releasing tension with body relaxation, dancing and yoga was great (72%) or good (18%). Without a doubt, the meeting with adults on HPN, organized from the second course, was a great success for all adolescents (100%).

Sessions for parents organized only from the second and third courses were greatly appreciated for meditation and Shiatsu (100%) while the visit of the IMAGINE Research Institute was a bit less appreciated by parents (great 55% and good 45%).

4 | DISCUSSION

The current ATEP is challenging but we consider it a great success. Designing it for teenagers instead of parents required to adapt the training according to new objectives, for ensuring autonomy and safety. During this training, all but one teenagers have acquired an autonomy for their catheter-care and PN management but also have a better knowledge of themselves as well as reinforced self-esteem. They project themselves

TABLE 2 Evaluation of the ATEP training course.

Professionals	Objectives	Evaluation adolescents or parents ^a			
		Great! 	Good 	Blah... 	Not good, 
Educational program by TE nurses	Theoretical & practical sessions for learning and supporting: <ul style="list-style-type: none"> - To carry out his care. - To control and use the equipment. - To react to the unexpected settings. 	14/16; (87.5%)		2/16; (12.5%)	
PedGI MD	Explain the disease (anatomy, pathophysiology, management) and justify need for long term PN.	10/16; (62.5%)	6/16; (37.5%)		
Anesthesiologist	Presents the different CVC type and their implementation procedures.	13/16; (81%)	3/16; (19%)		
Pharmacist	PN bags process of compounding and distribution circuits.	16/16; 100%			
P psychologist	Understanding the disease and their consequences. Helping for accepting body changes (eg: CVC, stoma etc.). Emotion control.	13/16; (81%)	3/16; (19%)		
Educator/Psychomotor therapist	Understand care with complete peace of mind. Managing stress with relaxation therapy.	13/16; 81%	3/16; (19%)		
Social worker	Group's discussion & sessions for understanding and explaining the specific status of young adult: Life plan, study projects, financial support.	8/16; 50%	8/16; 50%		
Sport teacher	Help for selecting adapted physical activity and sport.	15/16; 94%	1/16; 6%		
Meeting with adults	Testimony of young adults on HPN projecting them-self as teenagers, with illness, need for care and socio-professional integration Open the field of possibilities for the adolescents.	11/11; (100%)			
Personalized interviews ^b	Discover illness through the narrative history of the parents Parents-adolescent in the presence of a psychologist and the referring doctor.	6/11; (55%)		2/11; (19%)	26% ^b
Dance and yoga	Release tension, let go; Relaxation of body and mind.	8/11; (72%)	2/11; (18%)	1/11; (10%)	
Parents counseling	A place to share fears and difficulties while changes are ongoing in the relationship between growing children and parents.	9/11; (80%)	1/11; (10%)	1/11; (10%)	
Meditation ^a	Sessions to relax the mind, channel emotions, improve well-being.	11/11; (100%)			
Shiatsu ^a	Relax body and mind.	11/11; (100%)			
Visit at IMAGINE ^a	Understand genetic research and therapeutic advances.	6/11; (55%)	5/11; (45%)		

Abbreviations: CVC, central venous catheter; HPN, home parenteral nutrition; PedGI, pediatric gastrointestinal; PN, parenteral nutrition; TE, telemetry.

^aSessions for the parents ($n = 11$) organized only during the second and third courses.^bPersonalized interviews, proposed during the second and third courses, were declined by three adolescents (26%).

independently of their parents despite their chronic illness. Benefits are also noticeable for the parents.

These holistic and multiprofessional trainings as well as the meeting with young adults brought the adolescents to better understand their illness, to know themselves better and to project themselves into their own future. Thanks to the group cohesion, teenagers freed themselves and dared to ask questions about their PN dependency, eating disorders, their future, acceptance of their body image with stoma, venous access, and even questions regarding sexual behavior. Evaluation of the ATEP by the teenagers revealed their great interest, their involvement and finally their global positive appreciation. They understood well the ATEP as the first step of transition to adult care.

As defined by Bloom et al., “the transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centered to an adult-centered healthcare system”.²⁴ Consequently, the transition is not just a simple ‘transfer’ of patients from a pediatric center to an adult one but a slow process aiming to make adolescents or young adults independent in managing their own health and disease.^{25–27} Our dynamic multidisciplinary approach, aims to ensure continuity, coordination, flexibility and sensitivity to meet the adolescents clinical, psycho-social and educational needs as well as enhance their abilities.²⁸ Transition medicine (TM) should be adapted to specific diseases and settings and started during adolescence with pediatric specialists. Recommendations for patients with CIF on HPN from an Italian group pointed the main objectives of the transition process²⁹: (1) Motivate independent choices which are characteristics of the adult world; (2) Move towards adult goals (e.g., self-management of his pathology and sexual issues); (3) Maintain the habitual mode of care; (4) Minimize the difficulties involved in the transition process and (5) Modulate the length of the transition so as to fully share with the adult team the children peculiarities. In that view, this ATEP for HPN can be easily adapted to other HPN centers, if the size of the cohorts justifies or allows it.¹¹

The personal interview is the preparation for the future “transition” clinics with the adult HPN team. The disease story, is told in front of the adolescent, making possible to better discuss therapeutic perspectives between him and adult care givers. Moreover, during these sessions the patient's identity could be affirmed independently of health issues, but also taking into account the impact of the illness. These interviews took place with great serenity and the parents would unravel their child story from the early days.

Meeting with young adults was also highly appreciated. Adults brought testimonials of great depth, around the experience of their illness, their addictions, their family and professional background, their freedom

to act and to travel... in short, their fulfillment in their personal life despite difficulties. Their testimony raised many questions from the teenagers and contributed to an awareness of their possible future and to a major gain in confidence in it. All the participants expressed their satisfaction, and the young adults said they were ready to come back for future sessions.

HPN allows most pediatric patients to participate in age-appropriate activities. However, it may lead to significant restrictions, particularly going on holiday and traveling.³⁹ Family traveling may be perceived as impossible or at least difficult because of HPN. It can constitute an obstacle which may become a frustration for the whole family, sometimes with resentment. During the last two decades we promoted family traveling with an organization that considerably facilitates travel not only in France or Europe but as far as Thailand, North Africa, Caribbean.... with good and safe experience. However, the adolescents are not really involved in the organization and are basically unable to travel alone. Involving the future traveling teenagers through the ATEP provides a great opportunity for promoting travels to parents, adolescents, even on their own and, finally, the entire family.

Interestingly these adolescents did not know each other at the start of the ATEP sessions, the only common point being their dependence on PN with completely different pathologies, social and family structures. The weekend at “le Futuroscope” without any parents, closing the training session constitutes a great achievement for these teenagers. They establish personal relationships between each other, with the support of smartphones and social networks, while they did not know each other at the start.

The ATEP has long-term perspectives, according to the volume of the cohorts^{10,11} and the demand from teenagers and families. A 4th edition is already planned, both because of the satisfaction of the participants and their families, and in terms of results in gaining autonomy. Several months later, more than 80% of adolescents are completely autonomous for their own care. They manage to project themselves independently of their parents with study project far from the family home. No adverse events, including catheter infection, have been reported in the meantime.

5 | CONCLUSION

The acquisition of autonomy in care presupposes that the parents go through a process, sometimes difficult, of detachment and confidence in their child. The child has become an adolescent who is ready to handle the care that they have been trusted and entitled to do for years. On the other hand, the parents are relieved of a daily constraint. The benefits of ATEP for parents and family are significant with reduced anxiety and opening

up a space of freedom. For instance, parents can, for the first time after many years of “duty,” go on a romantic weekend, leaving their child behind who can now deal with his/her catheter care and safety.

All the care-givers and professionals of the ATEP are driven by the same motivation for these adolescents, who need to become autonomous. It is in line with our professional communication, during the weekly meetings dedicated to always improve the supply and safety of care, but also the quality of life on HPN. For our multiprofessional team, this is a real accomplishment in the process of accompaniment and support for children and families that has been going on for many years. We see these infants becoming children, adolescents and then young adults in a medical relationship with a major psycho-affective dimension. We have to accompany them and make them autonomous to approach together this “transition” towards the world of adults with all the skills they will need in the future.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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