

Therapeutic Education Dedicated to Patients Followed for Growth Retardation Treated with Somatropin

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Abstract

Original Research Article

Growth retardation is a frequent reason for consultation. Its causes are numerous and their respective frequencies differ somewhat depending on whether one is in endocrinology or paediatrics. Therapeutic education (TE) represents a cornerstone in the management of various chronic diseases in children and adults, nevertheless, it remains less common and less developed in certain diseases such as growth retardation (GR). The objective of our work is to report the attitude of multidisciplinary management of this serious pathology within the service of Endocrinology, Diabetology, Metabolic Diseases and Nutrition of the University Hospital Center (UHC) Mohammed VI of Marrakech, which is based on a global approach centred on the patient and his family: medical, psychological and dietetic approaches, which make it possible to expose the difficulties encountered, to develop a project to optimise the "patient pathway", to develop hospital and outpatient care and to strengthen the role of the UHC as a recourse and expert.

Keywords: Therapeutic education-growth retardation-Somatotropin.

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INTRODUCTION

GR is a frequent reason for consultation in endocrinology and paediatrics. Its etiologies are multiple and their clinical presentations are variable. The diagnosis is often made late, this delay is often due to the lack of knowledge of the pathology, and the absence of regular anthropometric monitoring in our patients. The management of RSP requires a multidisciplinary approach and close collaboration between several specialists: endocrinologist, paediatrician, biologist, radiologist, geneticist, gastroenterologist, paramedical staff, psychotherapist, dietician, etc. The treatment depends on the cause of the GR: in our study treatment with synthetic growth hormone was indicated. Somatropin produced by genetic engineering is an expensive hormone, and requires a well codified use and a good therapeutic observance in order to reach a satisfying height before the welding of the growth cartilages and to avoid the psychological and social repercussion which results from it. This requires a good therapeutic education of the patient and a structured clinico-biological-radiological follow-up.

MATERIELS AND METHODS

We conducted a prospective cross-sectional study in the therapeutic education unit (TEU) of the endocrinology, metabolic diseases and nutrition department of the Mohamed VI UHC in Marrakech, Morocco, over a period of 16 months, from February 2019 to June 2020, including children followed for RSP requiring treatment with growth hormone (GH).

In the framework of this work, our study aims on the one hand to report the experience of the service concerning the therapeutic education of these children; and on the other hand to try to optimize the management of the patient at the various stages of its course, to propose ideas to improve the modalities of ambulatory and hospital management of this affection.

However, the difficulties encountered during this study were patients who were lost to follow-up after the start of treatment; the cessation of treatment due to a shortage of GH in the case of Ramedist patients; and patients who missed their appointments

due to the state of health emergency caused by Covid19.

Outcome

Forty-five patients were included, 24 of whom were ramedists and 21 mutualists, with an average age

of 13 years and 4 months, with extremes ranging from 5 to 21; with a clear male predominance of 73%. The average height gain was 16.70 cm, with a maximum value of 38 cm in 4 years.

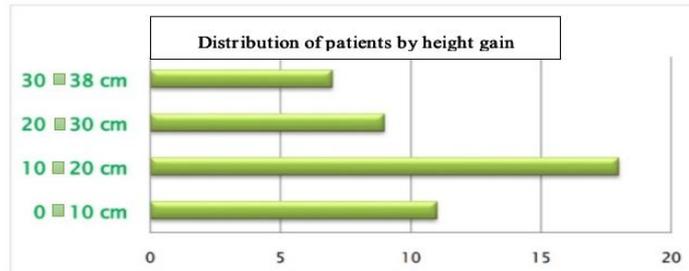


Fig-1: Distribution of patients by height gain

The GH used in all our patients was Norditropine® (100%). However, we report the occurrence of an intracranial hypertension syndrome in one of our patients as a side effect, which imposed

substitution by genotropin®. The average consumption of our patients was 6.95 pens/month, i.e. an average of 17.37 clicks/day.

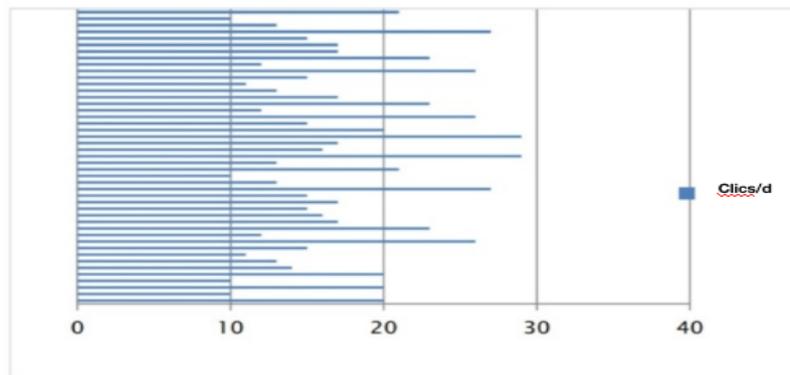


Fig-2: The average GH consumption of our patients in number of clicks per day

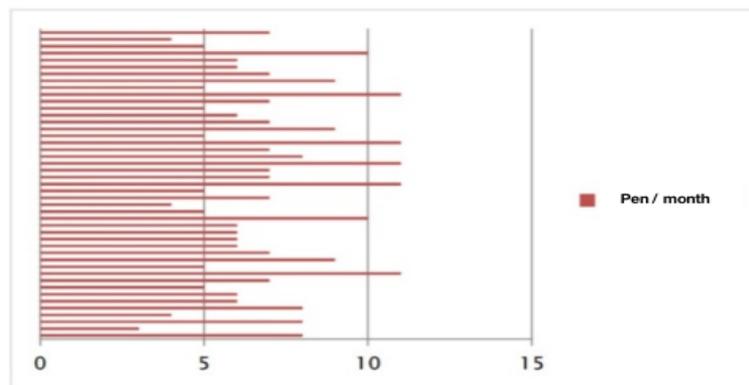


Fig-3: Average GH consumption in our patients in number of consumed pens

In our series, 25 patients injected themselves while 20 were injected by their parents, a percentage of 56% versus 44%. The needles used by our patients were

4, 6 and 8 mm in diameter. The frequency of needle change was as follows: 69% every day, 29% every 2 days, 2% every 3 days.

Table 1: Number and percentage of patients injecting themselves and those injected by their parents

Injection done by	Number of cases	Percentage
Patient	25	56%
Their parents	20	44%

Table 2: Number and percentage of patients by frequency of needle change

Frequency	Number of cases	Percentage
Everyday	31	69 %
Every 2 days	13	29 %
Every 3 days	1	2 %

All our patients varied their injection site, however we found an area of lipodystrophy in the left arm of a 12 years old patient. The rules of GH conservation were respected in 98% of our patients. We report the notion of non-compliance with storage rules

in only one of our patients (no refrigerator). The average number of missed injections per month was 1.14. However, we report the notion of treatment discontinuation in 8 of our patients.

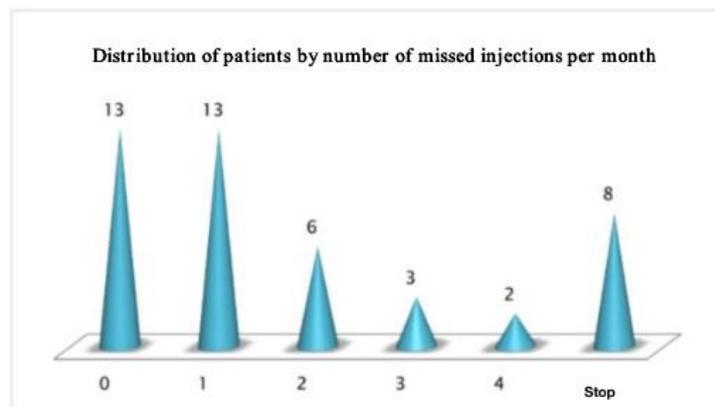


Fig-4: Distribution of patients by number of missed injections per month

All our patients have received an educational diagnosis with a summary of educational objectives.

The care pathway of our patients in the therapeutic education unit is as follows:



Fig-5: Department of Endocrinology, Diabetology, Metabolic Diseases and Nutrition, Mohammed VI University Hospital, Marrakech

- Ambulatory approach: which consists of recruiting patients at the day hospital for an initial clinical, biological and radiological assessment, and if necessary a complementary conventional hospitalization is performed. Patients GH treatment are gathered in a homogeneous group of six patients according to age groups and are informed by phone call about the hospitalization appointment in the education unit.
- Hospitalization approach: consisting of an interdisciplinary approach, which includes 4 parts: the medical part; a thorough interview and clinical

examination are carried out and finally the educational diagnosis of this patient is made before starting the presentation of the programme. The therapeutic education of the patient begins on the first day of hospitalization with educational workshops in groups. At the end of the hospitalization, this therapeutic education program allows our patient to acquire several skills (understanding the origins of GR, the principle of treatment, awareness of misconceptions about GH, recognition of the psychosocial impact of this condition). The dietetic aspect; the dietician carries out a dietary survey and gives the first dietary

advice to the patients. The psychological aspect; psychological care is initially individual and then takes the form of discussion groups. And the paramedical aspect; the nurse, although his or her activity is not sufficiently valued, plays a central role in the assessment and monitoring of patients with GR.

- Follow-up: The subsequent follow-up of each group is carried out according to a well-established schedule with fixed dates and hospitalization in the education unit.



Fig-6: Patients during Hospitalization in the education unit

DISCUSSION

Therapeutic education of the patient is a practice that is rooted in medicine, health pedagogy and the human and social sciences. It is an educational process based on a structured approach to improve the health care relationship and to give the patient a leading role as an actor in his or her own health.

According to the WHO, therapeutic patient education includes awareness, information, learning, psychosocial support, all related to the disease and treatment. Therapeutic education is a personalized, constructive and continuous process. It is tailored to the child and his/her parents, and depends on the quality of the relationship between caregivers, the child and the parents [1].

The Educational Diagnosis

The educational diagnosis is a process of identifying the patient's needs. It is a personalized educational step that facilitates the elaboration of the educational contract. Making an educational diagnosis means gathering relevant and useful information to help the patient acquire new skills. The educational diagnosis reiterates the principle of meeting the patient, whether or not he or she is "known" to the careers [2].

It has 5 dimensions: biomedical, socio-professional, cognitive, psycho-affective and motivational. It is neither definitive nor exhaustive: it is evolving.

- Biomedical dimension: What is the matter with him [2]? This question investigates the bio-clinical dimension. It approaches the evolution of the disease and the medical and health history.

- Socio-professional dimension: What does he/she do [2]? By being interested in the patient's profession, hobbies, activities and family environment.
- Cognitive dimension: What does he or she know [2]? This involves assessing the patient's knowledge of his or her illness, the perception he or she has of the illness.
- Psycho-affective dimension: Who is he, what does he feel [2]? This psycho-affective dimension identifies the psychological characteristics of the patient, and how they affect his behaviour.
- Motivational dimension: What are his plans [2]? The plan is a source of motivation, the patient feels that he is taken into account as a whole.

Carrying out an educational diagnosis means asking questions, which is a way of involving the patient; in particular, open-ended questions while avoiding closed ones, but also listening: Listening, which is an active approach, is the seizure of the intellectual and emotional content of what has just been said. Also in the educational diagnosis, it is necessary to persuade and not to manipulate. All this is done in the context of group and individual educational sessions [3]. The evaluation of the skills acquired by the patient is also an important step to reinforce learning [4].

TE within the context of the GR

GR requires long-term care, so building ongoing partnerships with families is a fundamental part of the pediatric endocrinology educator's role.

Being tall is seen as a positive characteristic, while being short is seen as less desirable. Social stereotypes related to height are established from an early age and are considered to lead to social stigma [5]. However, although shortness does not always translate into negative psychosocial experiences for children and young people [6], it is an anxiety frequently expressed

by parents. To develop a helping relationship with parents, the educator-caregiver needs an empathetic approach.

The initiation of GH treatment is a central point in the development of long-term relationships between the parents, the child, and the education team. Initially, parents may seek reassurance that their decision to start therapy is correct. They are consenting to long-term replacement therapy for their child and may be concerned about side effects. Information can reassure them; for example, the available evidence indicates that GH therapy is considered safe and side effects are rare.

Children and parents may have different opinions about the consequences of shortness and the need for daily subcutaneous injections of growth hormone for many years [7, 8]. Children aged two to seven years may not perceive themselves to be short and comparison with their peers is not as important to them as it is to older children [9]; adolescents may feel that once growth has stopped there is no point in continuing with GH therapy. These perceptions may affect cooperation with treatment. Parents seek to discuss developmentally appropriate strategies for managing these situations, which reinforces the importance of maintaining supportive, non-judgmental and long-term relationships with families.

Adherence to treatment is fundamental for a child who is receiving years of GH treatment and refers to the patient's behaviour in relation to their treatment. Acerini *et al.*, [10] describe three steps for involving families at the start of treatment:

- Education about GH therapy.
- Selection of injection device.
- Follow-up after device selection.

Table 3: Factors of poor compliance according to Fisher and Acerini [11]

Types of problems	Factors
Development understanding	Age of the patient Absence of symptoms Developmental behaviour at different stages Pain Perceived slow growth
Cognitive and emotional problems	Omission Perceived ineffectiveness of treatment Needle phobia Lack of understanding of GH deficiency Complexity Misunderstanding of benefits and consequences
Psychosocial problems	Poverty Insufficient literacy Limited social networks Cultural beliefs Low family support
Additional obstacles	Discomfort Difficulties with the daily treatment schedule Long-term commitment

Realistic goals and treatment times are considered, as well as information on how responses to therapy will be monitored. Improved cognitive skills enable children to better understand their bodies and their disease. Therefore, teaching children about GH therapy and its management requires a developmentally sensitive approach to meet their changing needs.



Fig-7: Child receiving growth hormone [12]

It is necessary to actively participate in the development of the patient's pathway and to ensure the adaptation of the care offer by improving the care modalities of the GR based on educational, medical, dietetic and psychological approaches in order to ensure the best possible physical, mental and social condition of the patients as well as a better quality of life.

Access to care within the unit

To facilitate this and to establish direct links between the patient, his family and the medical team; we propose several methods:

- Setting up a website specifically for TE patients and possibly making appointments online.
- The provision of a telephone line which will allow us to maintain personal coaching throughout the week following the implementation of treatment.

Pre-Hospital Service

For this, we propose to collect all the administrative documents necessary for hospitalization formalities and delegate them to a member of the patient's family to handle. In the meantime, a structured administrative mini-circuit should be created and specially prepared for these patients.

Reception of Patients

To make things easier, we offer a welcome booklet to help patients and their families get to know the care offered during their stay.

Carrying out the various biological and radiological tests:

In order to obtain a good paraclinical follow-up and to avoid any delay, we wish to obtain quotas of complementary examinations specially intended for patients followed for growth retardation outside the usual quotas of the patients of the classic hospitalization.

Comfort during the hospital stay:

The following are some proposals:

- The provision of a suggestion box and a box for collecting questionnaires so as to preserve anonymity and encourage interaction with the team.
- The installation of a fixed telephone in the rooms to facilitate communication with the nurse at any time. Access to an internet connection would also be desirable.

CONCLUSION

Normal growth is a reflection of the child's overall health, genetic potential and living conditions.

Growth retardation is a frequent reason for consultation in paediatrics and endocrinology. Its seriousness is linked to the pathology in question, to the prognosis of the status and to the psychological repercussions that it has on the life of the patient and his family. Its management must be early, and requires a multidisciplinary approach and close collaboration between several specialists: endocrinologist, paediatrician, biologist, radiologist, geneticist, child psychiatrist, gastroenterologist, psychotherapist, dietician and the paramedical team.

Its treatment depends on the etiology, the indications for somatropin treatment are well established, this imposes a good therapeutic education provided by the medical team specialised in TE, in order to guarantee its good use at home and subsequently an ideal statural response in optimal time.

This work exposes the circuit and the course of the patients followed for growth retardation requiring a treatment by GH within the unit of therapeutic education of the Endocrinology, Diabetology, Metabolic diseases and Nutrition Department of the UHC Mohammed VI of Marrakech adopted since 5 years; and proposes new tracks with an aim of optimizing and of improving the assumption of responsibility of this heavy pathology in ambulatory and in hospital while being based on a multi-field approach centered on the patient.

REFERENCES

1. World Health Organization. (1998). *Therapeutic patient education: continuing education programmes for health care providers in the field of prevention of chronic diseases: report of a WHO*

- working group* (No. EUR/ICP/QCPH 01 01 03 Rev. 2). World Health Organization. Regional Office for Europe.
2. Iguenane, J. A. C. Q. U. E. L. I. N. E., & Gagnayre, R. (2004). L'éducation thérapeutique du patient: le diagnostic éducatif. *Les cahiers de kinésithérapie*, 2, 58-64.
 3. De Santé, H. A. (2007). Éducation thérapeutique du patient. Comment la proposer et la réaliser? Saint-Denis, France: HAS, Recommandation.
 4. Wémeau, J. L., Schlienger, J. L., & Vialettes, B. (2014). *Endocrinologie, diabète, métabolisme et nutrition pour le praticien*. Elsevier Masson.
 5. Voss, L. D., & Sandberg, D. E. (2004). The psychological burden of short stature: evidence against. *European journal of endocrinology*, 151(Suppl_1), S29-S33.
 6. Erling, A. (2004). Why do some children of short stature develop psychologically well while others have problems?. *European Journal of Endocrinology*, 151(Suppl_1), S35-S39.
 7. Kremidas, D., Wisniewski, T., Divino, V. M., Bala, K., Olsen, M., Germak, J., ... & Lee, W. C. (2013). Administration burden associated with recombinant human growth hormone treatment: perspectives of patients and caregivers. *Journal of pediatric nursing*, 28(1), 55-63.
 8. Otero, S. C., Eiser, C., Wright, N. P., & Butler, G. (2013). Implications of parent and child quality of life assessments for decisions about growth hormone treatment in eligible children. *Child: Care, Health and Development*, 39(6), 782-788.
 9. Lagrou, K., Xhrouet-Heinrichs, D., Heinrichs, C., Craen, M., Chanoine, J. P., Malvaux, P., & Bourguignon, J. P. (1998). Age-related perception of stature, acceptance of therapy, and psychosocial functioning in human growth hormone-treated girls with Turner's syndrome. *The Journal of Clinical Endocrinology & Metabolism*, 83(5), 1494-1501.
 10. Acerini, C., Albanese, A., Casey, A., Denvir, L., Jones, J., Mathew, V., ... & Sparrow, S. (2012). Initiating growth hormone therapy for children and adolescents. *British Journal of Nursing*, 21(18), 1091-1097.
 11. Fisher, B. G., & Acerini, C. L. (2013). Understanding the growth hormone therapy adherence paradigm: a systematic review. *Hormone Research in Paediatrics*, 79(4), 189-196.
 12. Collin, J., Whitehead, A., & Walker, J. (2016). Educating children and families about growth hormone deficiency and its management: part 2. *Nursing children and young people*, 28(2).