

Counseling for Growth Hormone Therapy

Sanjay Kalra¹, Sameer Aggarwal², Ashok Kumar³ 

¹Consultant Endocrinologist, BRIDE Hospital, Karnal, Haryana, India

²Consultant Endocrinologist, Apex Plus Super Speciality Hospital, Rohtak, Haryana, India

³Consultant Endocrinologist, CEDAR Clinic and Park Hospital, Panipat, Haryana, India

ABSTRACT

Growth hormone (GH) therapy is an integral part of the treatment of short stature. Over the period of the last few decades, due to the better availability of recombinant human growth hormone (rhGH), we have more clinical data on the uses of GH in various diseases. The list of approved uses of the GH apart from the classical growth hormone deficiency (GHD) is increasing and is much longer than before but still, adherence to therapy is poor as seen in other chronic diseases also. In this review, we plan to discuss the means of better communication and counseling of the patient to ensure adequate adherence to therapy for optimal clinical outcome.

Keywords: Recombinant human growth hormone (rhGH), growth hormone deficiency (GHD), short stature, adherence, counseling

INTRODUCTION

Growth hormone (GH) is an integral part of the management of short stature. Its list of indications has grown gradually and so is its availability from the use of limited supply human pituitary tissue-derived human growth hormone (hGH) in mid-1980s to the development of a recombinant, 22 kDa recombinant human growth hormone (rhGH), which is widely available currently. It is indicated not only in growth hormone deficiency (GHD) but also in short stature due to small for gestational age (SGA), Turner syndrome, chronic kidney disease (CKD), and in adult GHD.² Currently, the US Food and Drug Administration approved indications of GH therapy include GHD, CKD, Turner syndrome, SHOX gene haploinsufficiency, Noonan syndrome, SGA with failure to show catch-up growth, Prader-Willi syndrome (PWS), and idiopathic short stature (ISS).² GH therapy is effective, safe, well-tolerated, and beneficial from a health economics perspective.²

In spite of this, only a few patients are able to avail themselves of the benefits of GH therapy. This leads to a considerable burden of disease, which could easily have been prevented with timely therapy in the period of a therapeutically beneficial time window. Most of the reasons for this are well documented, such as late presentation due to lack of awareness and suboptimal adherence due to cost restraints, apprehension about efficacy and safety, and inappropriate use of the drug. These challenges can be overcome by ensuring adequate therapeutic patient education (TPE) or counseling. Patient involvement is essential to optimize outcomes with GH therapy, and this can be achieved by adequate counseling, education, and support. It is necessary to involve family members as well, to ensure comprehensive and optimal health outcome for the child.

Though there is ample literature on TPE and patient education in diabetes³ and other endocrine conditions, no guidance is available to explain counseling for GH therapy to health care professionals. In this review, we describe GH counseling in 3 parts: the style of communication, the content of communication, and communication to facilitate adherence.

Corresponding author:

Ashok Kumar

✉ashoka08@gmail.com

Received: April 17, 2021

Accepted: May 5, 2021

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Cite this article as: Kalra S, Aggarwal S, Kumar A. Counseling for growth hormone therapy. *Turk Arch Pediatr.* 2021; 56(5): 411-414.

Table 1. Ideal Style of Communication of the Health Care Professional Can Be Remembered by the Mnemonic of CARES⁴

Domain	Approach
Confident	Physician should have confidence in his/her own skills and knowledge.
Competence	Competence is of utmost importance in right decision making can be achieved by continuing medical education.
Authentic accessibility	Approachability and accessibility are important in period of initiation and intensification of therapy.
Reciprocal respect	For communication to be effective and fruitful, respect for each other is very important.
Expressive empathy	Empathetic attitude rather than a sympathetic one should be adopted.
Straightforward simplicity	A simple and straightforward approach of communication should be adopted.

Table 2. Process of Motivational Interviewing Is Important to Ensure Adequate Adherence and Acceptance of Therapy and Can Be Achieved by the WATER Approach⁵

Domain	Approach
Welcome warmly	Meeting patient with warmth to establish a rapport for further communication
Ask and assess	Detailed interview with the patient to ask and assess the social aspects, beliefs, and comorbidities associated
Tell the truth	Communication should always be truthful from both sides
Explain with empathy	Things should be explained in an empathetic manner rather than a sympathetic manner
Reassure and return	Reassurance in further follow-ups

STYLE OF COMMUNICATION

The ideal style of communication is encapsulated in the CARES⁴ mnemonic (Table 1). Confidence means a belief in one’s own skill and knowledge. It is necessary to convey this to the child and family to foster a sense of trust. Confidence should also be accompanied by competence, which can be maintained by regular continuing medical education.⁸ It is important to be accessible during the period of initiation and intensification of therapy. A good chronic disease care provider explains to the patient how and when to contact the health care team and what to do in case of an emergency. Reciprocal respect is mandatory for effective communication. The family’s needs, preferences, wishes, and financial condition must be respected while discussing the plan of treatment with them. One should be able to empathize with them and express this, as opposed to demonstrating sympathy.⁹ The easiest way to do all this is to be simple and straightforward and make GH therapy simple and straightforward as well. The CARES rubric can be presented in a simpler, HOT manner, which suggests that communication should always be hot, open, and 2-way to nurture the trust between the stakeholders in decision making. A GH prescription alone is usually not adequate to ensure acceptance and adherence to therapy. A process of motivational interviewing, designed to create information equipoise, helps facilitate shared decision making and implementation of decisions. The WATER approach (Table 2) enjoins building a good rapport with the patient, understand his or her concerns, suggest appropriate therapy, explain its pros and cons, and agree upon a plan of action.⁵ One should not force a decision for GH initiation in the first clinical encounter and should be a good listener with a positive attitude, and the approach should be patient-centered rather than physician-centered. The 3I approach (Table 3)—inform, incubate, and initiate—based upon Prochaska’s model of behavioral change should be utilized. This gives the family adequate time for contemplation, which is necessary to ensure persistence with therapy.


CONTENT OF COMMUNICATION

A 360° approach to history taking and clinical evaluation should be followed. This includes assessment of symptoms and signs, psychological and social issues, and screening for comorbid conditions and concomitant medication use. A 360° style also means that the parents and siblings should be involved in the discussion, along with the child. Financial issues should be discussed only with the parents, to avoid burdening the child with guilt.

We use the mnemonic BLACK to list the basics of GH counseling in black and white (Table 4). This includes the benefits of GH, its limitations, potential adverse effects, expected costs, and the knowledge and skills that are necessary to use GH effectively. GH counseling should include a comprehensive overview of the manner of GH administration, expected benefits, potential risks, and possible limitations. The responsibilities of the child and his/her family should also be clarified. It should be reinforced that optimal height achievement requires good nutrition, physical activity, and emotional health as well. The 3C model—contraindications, caveats (ifs and buts), and checkpoints (need for monitoring, red flag symptoms, signs, and

Table 3. Flow to Adherence to Therapy

Information: inform the patient in detail about the therapy.
Incubation: give sufficient time to take a decision after the first discussion.
Imbibition: let the patient imbibe the knowledge given by the doctor.
Initiation: initiate the GHT as early as possible for optimal outcome.
Adherence: motivate to continue medication and to have adherence to therapy.
Persistence: adherence is necessary for the persistence of the therapy.



Domain	Approach
B-Benefits of GH	Discuss clearly the uses and advantages of GHT.
L-Limitations	Discuss limitations of therapy so as to avoid giving any unrealistic expectations to the patient.
A-Adverse effects	Discuss the safety profile and possible adverse effects before starting therapy and counseling about the routine early adverse drug reactions.
C-Cost	The price and financial aspect must be discussed as it is chronic long-term therapy causing recurring monthly expenses.
K-Knowledge and skills	A sound knowledge is necessary to execute all the above-mentioned parts of the counseling.

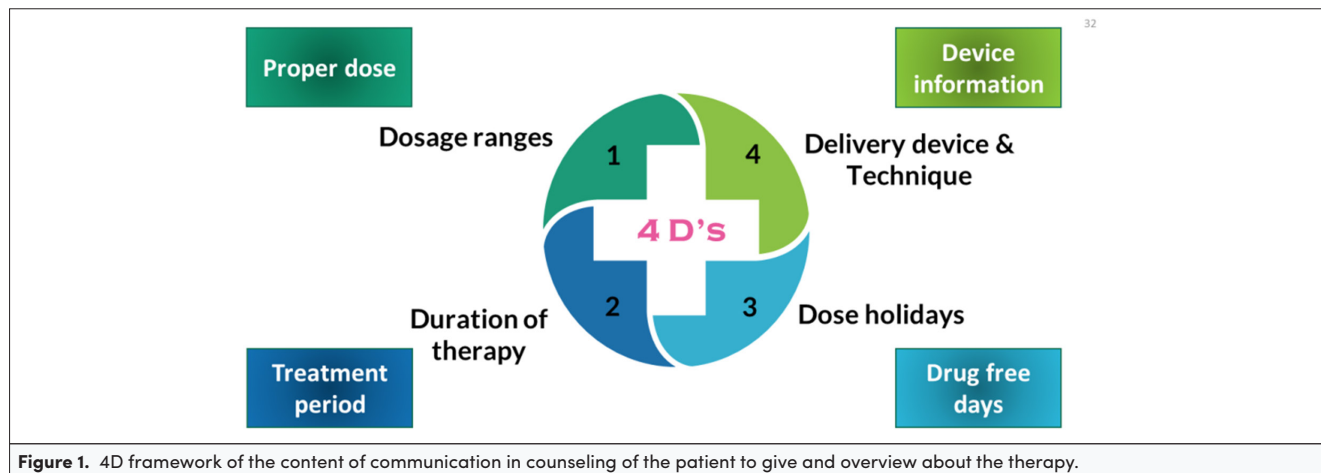


Figure 1. 4D framework of the content of communication in counseling of the patient to give and overview about the therapy.

laboratory values)—is a useful checklist to help ensure completeness of counseling.

The 4D framework (Figure 1) lists dosage ranges for initiation and titration, delivery devices and injection techniques, drug holiday management, and expected duration of therapy as essential points to be covered. The dosage is decided by the treating endocrinologist, based upon the indication and weight of the child. GH injection technique is similar to that of insulin, and standard guidance of insulin technique can be followed.⁶ Various delivery devices are available for GH administration, including pre-filled pens and vials which need reconstitution of powder. Research suggests that patients and physicians prefer to use pre-filled pens. An informed and shared decision should be made regarding the choice of the delivery device, based upon individual needs and preferences. Drug holidays should be discussed in advance. The treating team should explain the disadvantages of drug holidays while keeping a flexible attitude and respecting the child’s priorities and family’s limitations. Duration of therapy is a challenging issue; the doctor should use open-ended statements which allow one to modify opinion as per the results of therapy. Common complaints, such as pain at the injection site, bruising, or bleeding, can be minimized by reinforcing injection technique, especially site rotation and daily change of needles. Fear of complications can be addressed by acknowledging genuine concerns and sharing a roadmap for regular monitoring.

COMMUNICATION TO IMPROVE ADHERENCE

Adherence to GH therapy, after having initiated it successfully, can be a major challenge. Adherence is a multifaceted

phenomenon, which can be influenced by socioeconomic factors, the health care system, the natural history of the disease, the nature of therapy, and the patient’s attitudes. Suboptimal adherence should not be handled in a judgmental way rather an empathic approach must be followed to assess the challenges leading to lack of adherence and to overcome them. One should try to search for means of mitigating the financial impact of GH deficiency, making the health care system GH friendly, pre-empting possible comorbid conditions and complications, and preventing therapy-related adverse events.

Children, and their parents, often get frustrated with the apparently slow pace of growth so the height gains should be explained according to the etiology and age of presentation, for example, height velocity will be very good in a very young patient with classical GHD but it will be slower in Turner syndrome and ISS and also dose requirement will also be higher than classical GHD so a rough idea of per centimeter height gain to money spend should be given to the patient.⁷ Accurate height charting, along with growth velocity measurement, prior to and after therapy, helps in overcoming this. A simple, yet comprehensive, explanation of the child’s current health status, coupled with a realistic expectation setting is important. Bone age velocity can also be used as a means of explaining improvement in health status.

Adherence may be improved with injection pen devices which increase the convenience of GH administration, simplify GH administration, are more child and user-friendly, decrease pain associated with injection, and also offer storage flexibility.

Analogies can be used to describe the importance of GH and its expected benefits. GH can be termed as a fertilizer that is essential for plant growth, a fuel that is required for a vehicle, or a RAM upgrade needed for a computer. In all these analogies, the person with GH deficiency is compared to a plant, vehicle, or computer, and GH therapy is depicted as an essential necessity. To be effective, analogies should be relevant to the family's sociocultural and educational background.

Similes and proverbs can be used to explain the effects of GH therapy as well. "Rome was not built in a day," and "we are running a marathon, not a 100-meter sprint" are examples of ways to explain the slow and steady improvement seen with GH therapy. "One step at a time" and "we will cross the bridge when we come to it" help calm parents who are apprehensive about future health. Metaphors like "fountain of youth" and "fountain for the future" are useful in motivating children and families to persist with treatment.

Regular investigations are a part of GH therapy monitoring. However, it is not mandatory to perform all investigations in one go. While the absolutely essential tests cannot be missed, others can be staggered to reduce the financial burden on the family. Such decisions should be based on the clinical status of the child, keeping his or her well-being as the foremost priority. The cost of investigations should also be judged vis-à-vis the economic impact of traveling to consult the doctor and the possible loss of daily income that this entails for the parents.

SUMMARY

In the case of chronic diseases, for a treatment to be successful, adherence is of utmost importance, which can only be achieved by a multifaceted approach. The physician should be confident and competent in the subject and should explain all the aspects of the therapy in a respectful manner considering the social background of the patient following the WATER approach. The treating physician should consider not only the disease and the drugs but should also understand the patient and the society to

which the patient belongs by the means of bidirectional communication to ensure an optimal outcome.

Peer-review: Externally peer-reviewed.

Author Contribution: Concept - S.K., A.K., S.A.; Design - S.K., A.K., S.A.; Supervision - S.K., A.K., S.A.; Resource - S.K., A.K., S.A.; Materials - S.K., A.K., S.A.; Data Collection and/or Processing - S.K., A.K.; Analysis and/or Interpretation - S.K., A.K., S.A.; Literature Search - S.K., A.K.; Writing - S.K., A.K., S.A.; Critical Reviews - S.K., A.K., S.A.

Conflict of Interest: The authors have no conflict of interest to declare.

Financial Disclosure: The authors declared that this study has received no financial support.

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