Compliance with growth hormone treatment—are they getting it?

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Abstract

A study was undertaken to investigate compliance in patients receiving growth hormone treatment. Two hundred patients completed a questionnaire designed to establish understanding about and compliance with treatment; 50% of our patients failed to comply with all aspects of their treatment. Failure to respond to treatment seems to be associated with poor compliance.

(Arch Dis Child 1993;68:91-3)

Embarking on a course of recombinant human growth hormone (rhGH) treatment is a major commitment not only for the child and parents but also for the health care team. rhGH is administered by subcutaneous injection on a daily basis, often for a period of time stretching over many years. The initial perception about the treatment may effect subsequent compliance with the treatment regimen.

We had suspected for some time that some of our patients for whom we had prescribed rhGH were not complying fully with their therapeutic regimen. To investigate this we designed a questionnaire to assess the level of understanding about and compliance with treatment.

Methods and results

Consecutive patients attending the paediatric endocrinology clinic of the Middlesex Hospital were asked if they were receiving rhGH and, if they were, whether the person responsible for administering the hormone would complete our questionnaire (appendix). We studied understanding of the treatment regimen and compliance with the treatment by combining answers from several of the questions that were designed to obtain the information in different ways.

Two hundred patients accepted the questionnaire and none refused. Of the patients who accepted only 188 were on rhGH; the remainder were receiving an assortment of other treatments including somatostatin and testosterone (Sustanon, Organon). Of the 188 patients on rhGH, 179 had been on treatment for longer than a year, nine had started treatment during 1991.

Before 1991 there had been no set policy for the training and education of patients requiring rhGH treatment. As a result, a number of different health care professionals had been involved in the training of patients. Sixty had been taught by a hospital nurse, 26 by a hospital doctor, 18 by a general practitioner, 41 by their practice nurse, and 43 by a community nurse.

The variety of personnel involved ranged from those with knowledge of administering injections but with no knowledge about rhGH to those with considerable knowledge of rhGH but little about the intricacies of administration.

To assess the level of understanding about their treatment, questions were designed to elicit the number of units administered daily. Fewer than 20% of the patients were able to identify the number of units contained in each vial of rhGH. At the time of the study most of our patients were on 12 IU vials of rhGH. Seventy six (40.4%) patients had an adequate understanding about their treatment, 55 (29.3%) had limited understanding, and the remaining 57 (30.3%) had no clear idea what they were doing. There was major confusion about the dosage of rhGH required and the amount to inject each day. Errors in dilution and mixing of the rhGH were the major contributory factor to poor understanding.

Compliance with treatment was assessed by questions designed to uncover the number of missed injections, the policy regarding injecting while on holiday, and the level of difficulty experienced in performing the injections. Ninety

Relation between knowledge and compliance.

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two (48.9%) patients were classified as being good compliers, that is, they consistently adhered to the prescribed treatment (had missed fewer than five injections since the last clinic visit). Sixty one (32.4%) complied intermittently (had missed fewer than 10 injections since the last clinic visit) and 35 (18.6%) failed to comply in that they rarely, if ever, administered all the injections prescribed; of these patients some admitted to missing up to 30 injections since the last clinic visit.

The level of compliance was related to the level of understanding (figure) in that the better the understanding about treatment the more likely the patients were to comply. Patients in the group with a good understanding about their treatment had a significantly better compliance score than those with average or poor knowledge (one way analysis of variance $F=21.6$, $p<0.001$; Duncan's multiple range test: good v average $p<0.01$; good v poor $p<0.01$; average v poor $p<0.01$).

Discussion

The way in which questions pertaining to compliance are asked in the clinical situation may elicit the response that we wish to hear. Careful and detailed questioning is necessary to discover the real level of compliance in children who are prescribed growth hormone.

We were disturbed to discover from this survey that more than 50% of our patients failed to comply with some aspects of their treatment regimen. The method for mixing the rhGH certainly caused problems to many of our patients and their families, thus confirming previous suspicions.¹ The advent of convenience preparations may well circumvent this problem. A more important factor may well be the involvement of a specific member of the health care team experienced in the administration of growth hormone and in the methods necessary to gain the cooperation and confidence of children.

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¹ Smith PJ, Hindmarsh PC, Brook CGD. Contribution of dose and frequency of administration to the therapeutic effect of growth hormone. *Arch Dis Child* 1988;63:491-4.

Appendix

QUESTIONNAIRE

This questionnaire is about your growth hormone treatment. Please tick the answer which is correct. At the end there is a space to add any additional comments you would like to make about your treatment with growth hormone. Whoever gives the growth hormone should answer the questions.

Name

1. How long ago did you start the growth hormone injections?
 - 1 Month
 - 2 Months
 - 3 Months
 - 4 Months
 - Longer
2. Who taught you how to give the injections?
 - Hospital doctor
 - Hospital nurse
 - General practitioner
 - Practice nurse
 - Community nurse
3. Do you have a growth hormone pen device?
 - Yes
 - No
4. How many units of growth hormone are in each bottle?
 - 4
 - 12
 - 16
5. How often do you take the growth hormone?
 - 3 Times a week
 - 4 Times a week
 - 5 Times a week
 - 6 Times a week
 - 7 Times a week
6. What time of day do you normally take the injection?
 - Morning
 - Afternoon
 - Evening
7. How many times have you missed an injection since your last visit?
 - 0-5
 - 6-10
 - More than 10
8. It is important to take my growth hormone
 - To help me grow
 - Because the doctor told me to
 - Because my parents say so
9. How many units of growth hormone do you take each day?
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - Don't know
10. How much diluent (water) do you put into each vial of growth hormone?
 - 3 ml
 - 2 ml
 - 1.5 ml
 - 2.4 ml
 - None—self mixing
 - Don't know
11. Who gives the injection?
 - I do it myself
 - Parent
 - Other family member
 - Friend
 - Other
12. Do you find the injection?
 - Easy
 - Straightforward
 - Difficult
 - Impossible
13. (a) Do you use anything to clean the skin prior to the injection?
 - Yes
 - No

(b) If yes, what?

 - Soap and water
 - Mediswabs
 - Surgical spirit

<p>14. Where do you get your needles and syringes from?
The hospital
Your general practitioner
Purchased</p> <p>15. The hardest thing about the injection is
Mixing
Drawing up
Putting the needle in</p> <p>16. How often do you get a prescription from your doctor for the growth hormone?
Every week
Every 2 weeks
Every 3 weeks
Monthly
Longer</p> <p>17. Do you use a sharps bin to dispose of the needles and syringes?
Yes
No</p> | <p>18. If you were going on holiday would you?
Take the injections as normal
Have a break from the injections
Use up the vial then stop</p> <p>19. Would you like any further help or information?
Yes
No</p> <p>20. (a) Do you belong to a patient support group?
Yes
No

(b) If yes, which one?
.....</p> <p>21. How many marks on the syringe do you inject each day?
.....</p> <p>22. Would you like to make any further comments?</p> |
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NO in pyloric stenosis

Nitric oxide (NO) is clearly a very 'in' molecule in physiological circles (see Archivist 1992:934). It causes relaxation of gut muscles in animals as well as being a strong vasodilator. The relaxation of the smooth muscle of the gastrointestinal tract is brought about by the action of non-adrenergic, non-cholinergic (NANC) nerves. Until recently it was thought that the principal mediator of NANC controlled inhibition was vasoactive intestinal polypeptide (VIP) but the evidence now available makes it likely that the mediator is NO.¹

The enzyme NADPH diaphorase, which can be detected histochemically, is identical to NO synthase. Workers in Brussels (Jean-Marie Vanderwinden and colleagues, *New England Journal of Medicine* 1992;327:511-5) have used histochemical and immunohistochemical techniques to examine pyloric tissue from nine babies with hypertrophic pyloric stenosis and seven controls. Normal tissue showed NADPH diaphorase activity in the nerve fibres of both the circular and longitudinal muscle and in the nerves of the myenteric plexus. In pyloric stenosis, however, the enzyme was absent from the nerves of the circular muscle although still present in the longitudinal muscle and in the myenteric plexus. The nerves of the circular muscle were also morphologically abnormal.

Babies with pyloric stenosis, therefore, lack the enzyme (NO synthase) necessary for the production of NO in the nerves of the circular muscle of the pylorus. This may explain the inability of the pyloric muscle to relax and the work raises the possibility that an effective medical treatment for pyloric stenosis could be developed.

ARCHIVIST

1 Milla PJ. Gastric-outlet obstruction in children. *N Engl J Med* 1992;327:558-60.