Internet Informs Parents about Growth Hormone

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Key Words

Growth hormone · Internet · Risk · Benefit · Parents

Abstract

Background: Parents' knowledge influences decisions regarding medical care for their children. **Methods:** Parents of pediatric primary care patients aged 9–14 years, irrespective of height, participated in open focus groups (OFGs). Moderators asked the question, 'How do people find out about growth hormone (GH)?' Because many parents cited the Internet, the top 10 results from the Google searches of 'growth hormone children' and 'parents of children who take growth hormone' were examined. Three investigators independently performed content analysis and then reached a consensus. The results were tabulated via summary statistics. **Results:** Eighteen websites were reviewed, most with the purpose of education (56%) and many funded by commercial sources (44%). GH treatment information varied, with 33% of the sites containing content only about US FDA-approved indications. Fifty-six percent of the sites included information about psychosocial benefits from treatment, with 44% acknowledging them as controversial. Although important to OFG participants, risks and costs were each omitted from 39% of the websites. **Conclusion:** Parents often turn to the Internet for GH-related information for their children, although its content may be incomplete and/or biased. Clinicians may want to pro-

vide parents with tools for critically evaluating Internet-based information, a list of prereviewed websites, or their own educational materials.

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Introduction

Short stature is a common concern in pediatrics, as growth is an important indicator of child health [1]. Concerns about a child's poor growth may be raised by their parents, their primary care provider (PCP), or both. Many factors, including a child's physical health, quality of life, and psychological well-being, contribute to a parent's decision to seek evaluation and treatment for a child's short stature [2–5]. Ultimately, the PCP must identify children with abnormal growth patterns and decide whether to investigate further with diagnostic tests and/or referral to a specialist. Parental concern and psychosocial issues can influence the medical decision-making process, irrespective of objective measures of the child's growth. Family concern increases both PCP referrals to specialists [6] and the prescribing of growth hormone (GH) by endocrinologists [7, 8]. Parental perceptions of the benefits of GH treatment also affect their acceptance of physician treatment recommendations [9].

Due to the influence of parental concern on the medical decision-making process, we sought to understand how parents learn about GH treatment and the information that is readily available.

Methods

Open Focus Groups

The study was granted exemption by the institutional review board of the Children's Hospital of Philadelphia. To explore parent knowledge about short stature and its treatment, 13 open focus groups (OFGs) were held with a total of 71 (40 African American, 31 Caucasian) parents of children aged 9–14 years randomly selected from five primary care pediatric practices affiliated with a tertiary care pediatric hospital. They were stratified by race, but child height was not a factor in participant selection. Two trained researchers moderated each OFG and prompted the participants with open-ended questions, including 'How do people find out about GH?' OFG sessions were audio recorded, transcribed, and then analyzed to identify themes (NVivo 8; QSR International, Melbourne, Vic., Australia).

Website Content Analysis

On November 8, 2011, two searches were conducted (Google, Mountain View, Calif., USA) using the phrases, 'growth hormone children' and 'parents of children who take growth hormone'. The resulting top ten sites from each phrase were examined. Sponsored sites – those that paid a premium to be listed on the results page of a search engine – were excluded from analysis. These sites were considered advertisements, which may have the greatest potential for bias and skew results when included in summary statistics. Consumers may already be thinking about caveat emptor when looking at these sites as opposed to sites 'naturally' listed by the Google search, potentially rendering them less critical readers of the nonsponsored sites.

Each search was replicated monthly (December 8, 2011 and January 6, 2012) to evaluate temporal consistency among the results. The first ten sites from all six searches were tabulated and duplicates deleted. Three members of the research team independently scored the resulting 18 unique websites (Appendix A) using a novel coding rubric. Because people browse the Internet expeditiously, we focused on content found within three clicks of the homepage of each site. Further, only static text (not reader comments) on the webpage was reviewed. Each rater chose the single best classification for each of twelve categories. After all websites were scored, discrepancies were discussed and resolved as a group to reach consensus. Results were analyzed via descriptive statistics (Microsoft 2007; Redmond, Wash., USA).

Results

Open Focus Groups

Parents in 5 of the 13 OFGs (38%) cited the Internet as a resource to learn about GH treatment, while participants in 10 OFGs (77%) identified physicians as a source.

Magazines, television, and movies (31%), and friends and family members (54%) were also cited.

Participant comments clustered into three themes: the Internet was a ready source of GH-related information, Internet-based information could be useful before and after medical evaluation, and relying on Internet-based information warranted caution. For example, one OFG participant stated, 'The Internet. You can get anything off the Internet'. Another specified, 'Internet, it's the Google', to which others agreed. Some participants, possibly experienced with GH treatment or evaluation, reported seeking information on the Internet before or after medical evaluation. One mother explained, 'Just been working with his endocrinologist and just trying to get more inform – and I read up a lot, you know, I got on the Internet, I read about it'. A father said, 'If a doctor tells you, oh, this would benefit your son, but he hasn't given you a script, you go on the Internet, bam, this is the name of it, this is how we get it'. However, some participants acknowledged negative aspects of Internet information. Two participants commented, 'you know, sometimes the Internet's a really dangerous thing' and '...unfortunately you can get way too many things over the Internet'.

Website Content Analysis

A Google search (November 8, 2011) of 'growth hormone children' yielded about 6,620,000 results and 'parents of children who take growth hormone' yielded about 5,530,000 results. By December 8, 2011 those search term results increased to 11,700,000 and 6,120,000, respectively. A third search (January 6, 2012) yielded 8,740,000 and 6,750,000 results, respectively. However, the top 10 sites for each search term remained consistent.

Website Characteristics

The website's purpose and sponsor were analyzed to understand the aims of the site and who is responsible for webpage maintenance. Educational sites were identified as those trying to provide information, such as The MAGIC Foundation and Wikipedia. There are also advocacy sites aimed at reversing discrimination against short people, such as Short Persons Support. Most of the websites (56%) aimed at educating their reader, 33% presented news stories, 6% were pharmaceutical based product information, and 6% were advocacy sites. Of the sites, 44% had commercial funding (supported by advertisements or sales) such as WebMD or pharmaceutical companies. Thirty-three percent were sponsored by foundations, 22% belonged to hospitals or academic institutions, and none was funded by government or parent groups.

While commercial sources like pharmaceutical companies often provide financial support to foundations, hospitals, or academic institutions, the relative contribution of this indirect funding to the website authors is not transparent or quantifiable and so categorization was limited to the direct funding source only. Thirty-nine percent referred to GH in the generic, while 33% named three or more commercial brands of GH, 11% named two brands, and 17% cited only one brand name. This included mention of a pharmaceutical company or specific GH product.

The audience and potential population for GH treatment were also analyzed to determine the site’s focus. Two thirds of the websites dealt with pediatric GH use, while the remainder discussed both pediatric and adult indications for GH in general. None focused solely on GH use in adults, which was expected given that both search phrases contained the term ‘children’. The content of 61% of the websites referred to GH treatment in the broadest context, while 11% were limited to GH deficiency and other diseases, and 28% to idiopathic short stature (ISS) specifically. None of the websites included illicit uses of GH treatment, such as for sports performance enhancement or antiaging purposes. Accessibility to potential readers was evaluated along two parameters: readability and complexity. Readability divided the content into above or at/below a seventh-grade reading level, based on the density of polysyllabic words, sentence structure and length, and the amount of medical jargon. Complexity referred to the site’s structure, with ‘simple’ describing straightforward websites and ‘complex’ sites containing multiple sections. Half of the websites were considered simple with content at or below a seventh-grade reading level, and 33% were considered simple with a higher reading level. Only 17% of the sites were complex, 11% at the lower reading level and 6% above.

Content about Benefits and Risks of GH Treatment

In the OFGs, parents reported they would consider benefits and risks when deciding whether to seek treatment for a short child. Website content analysis regarding benefits and risks of GH treatment is summarized in table 1 and figure 1, respectively. Current controversies surrounding potential benefits of GH treatment include off-label use for nonapproved indications, height enhancement in healthy short children solely for psychosocial benefits (such as career and dating success as an adult, or a decrease in emotional distress, bullying, and teasing as a child [10]), and promoting expanded use by relaxing the terms of the FDA-approved definition of ISS (height

Fig. 1. Website content about potential risks of GH treatment. One website directly stated GH ‘does not have any significant side effects’.

Table 1. Content analysis of potential benefits of GH treatment

<i>Non-FDA-approved indications</i>	
No mention (limited to FDA-approved indications only)	33
FDA approval mechanism mentioned	
GH beneficial for nonapproved indications	11
GH controversial/needs studies for nonapproved indications	50
No mention of FDA approval mechanism	
GH beneficial for nonapproved indications	0
GH controversial	6
<i>ISS (or non-GHD short stature)</i>	
Use FDA criteria for ISS	67
Other personal definition	11
Vague/no definition of how short is too short	11
No mention of GH to treat ISS at all	11
<i>Psychosocial benefits</i>	
No mention at all	44
Beneficial for specific populations (boys, athletes, etc.)	6
Beneficial for all	6
Controversial	44

Results show the percent of websites classified for each of the three categories. GHD = GH deficiency.

more than 2.25 SD below the mean (1.2 percentile) for age and gender, growth velocity that will not lead to a normal adult height, and identifiable causes of growth failure have been ruled out [11]). For example, 11% of the websites gave a vague or no definition of how short is too short, while another 11% used their own definition of ISS, such as ‘the cutoff point to be considered eligible for treat-

ment is under age 14' [12]. Similar to the overstated benefits, underreported risks can bias parents towards wanting GH treatment for their child. For example, one website [13] stated 'growth hormone does not have any significant side effects when used as a replacement therapy for growth hormone inadequacy or deficiency' and three sites [14–16] identified the most common side effects as 'mild, including ear infections and joint and muscle pain'.

Content about Acquiring GH

Parents may also seek information related to getting and paying for GH treatment. All of the reviewed websites recommended seeking the opinion of a medical professional to obtain GH treatment, while only half cited an endocrinologist specifically. Specific information about cost varied, with half providing an annual cost of GH treatment between USD 10,000 and 30,000. Thirty-nine percent did not discuss cost. Cost was mentioned without stating who was responsible for payment on 22% of the sites. Twenty-two percent acknowledged expensive out-of-pocket costs, even with insurance, while 11% reassured that insurance covered GH, with no information about personal costs. Assistance with payment, such as coupons, copay support, or other promotions, was offered on 6% of the websites.

Discussion

In summary, we found that parents are likely to talk with their medical professional and/or turn to the Internet to obtain information if concerned about their children's stature. This was true for parents with limited GH awareness and for those who had already sought the assistance of a medical professional but still had some unanswered questions. Our content analysis found that pertinent websites are more likely to be commercially funded and although most are aimed at educating the public, important information such as possible side effects and costs of treatment may be minimized or lacking.

Internet use has been increasing as a convenient, anonymous, and cost-efficient method of obtaining information, and health information is one of the main types specifically sought. Seventy-four percent of US adults used the Internet in 2010 [17], and 56% of Europeans reported using the Internet daily or almost daily in 2011 [18]; 80% of the former and 54% of the latter looked online for health information [17, 18]. Patients commonly search the Internet to investigate drug side effects or complications of a

medical therapy [19]. Reasons cited in a children's hospital study included wanting to know more (97%), reducing anxiety (75%), because more information was available than had been provided by the doctor (53%), and the doctor had not been able to adequately answer all of their questions (53%) [20]. Parents used Google as their search engine (75%) with their children's condition (90%) or symptoms (21%) as the keyword(s) [21].

The Internet can empower patients and their families to proactively work with their PCP to lead a healthier lifestyle and detect potential problems earlier [22]. However, as our OFG participants cautioned, there are also pitfalls to relying on the Internet for health information. Internet content is often unregulated and for many the amount of information can be overwhelming, with good quality information difficult to find [23]. Of the 500 sites searched using Google for five common pediatric questions, 39% gave correct information, 11% were incorrect, and 49% failed to answer the question [24]. Likewise, only one link out of five using 14 of the most popular search engines led to a website with relevant information on four common diseases [25].

Consistent with comments from parents in our OFGs, studies have shown that parents are still, most often, relying on a medical professional for health information regarding their children [26, 27]. What information patients receive from medical professionals is unknown. The attitudes and beliefs of physicians themselves about short stature and its toll on emotional well-being have been shown to influence the referral patterns of PCPs [6], the prescribing practices of endocrinologists [28], and the approach to shared decision-making about GH as an elective therapy [29]. Health information retrieved from the Internet may influence the patient-family/physician shared decision-making process [30, 31].

One limitation to the current study is that OFGs are nonquantifiable, providing data on only the number of groups with pertinent comments, but not the relative proportions of people who would seek Internet information. Insofar as the focus groups were open, we did not ask about the specific search engines or search terms the participants would use. Therefore, we selected general search terms informed by our own search habits, that we believed most likely would be used by parents and hence yield representative results. This study reviewed only the first 10 websites for each search term over the course of 3 months, thereby limiting the number of sites reviewed. Because parents are often under time constraints and most try to browse expeditiously, we believed that parents/users would not read much beyond these results.

While observer bias is always possible, it was minimized by several factors. We created categories based on information from OFGs that parents use when deciding to seek evaluation and treatment for a child's stature. The coding rubric was created and finalized prior to any scoring and performed independently by three investigators of different professional backgrounds.

We learned that parents often rely on the Internet for information about GH treatment for their children. As we found, Internet content may be biased, minimizing the potential side effects and costs of treatment. Website content may also be incomplete, lacking important information critical to a parent's decision-making process. Clinician awareness of the information available to parents regarding GH treatment is important to patient care. To ensure that parents receive accurate information, clinicians may want to prepare a list of prereviewed websites, create their own educational materials, or provide tools for critically evaluating Internet-based information, such as the 'Trust It or Trash It' website [32].

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Appendix A

List of the 18 websites analyzed.

- http://www.google.com/url?q=http://www.hormone.org/Resources/upload/GHIssuesinChildrenandAdults.pdf&ei=wU41T8WqPO_q0QH6yeW4Ag&sa=X&oi=unauthorizedredirect&ct=targetlink&ust=1328895433990275&usg=AFQjCNERWCmacJjzGGFc3ZutMFATfwAW8g
- http://www.magicfoundation.org/www/docs/108/growth_hormone_deficiency_in_children
- <http://well.blogs.nytimes.com/2010/05/03/helping-short-kids-grow-up/>
- <http://www.hgfound.org/>
- http://kidshealth.org/teen/diseases_conditions/growth/growth_hormone.html
- http://en.wikipedia.org/wiki/Growth_hormone_treatment
- <http://www.cbsnews.com/stories/2003/06/11/earlyshow/health/main558240.shtml>
- <http://www.thenewatlantis.com/publications/human-growth-hormone-and-the-measure-of-man>
- <http://www.shortsupport.org/Research/Papers/growthHormoneTreatment.html>
- http://healthpsych.psy.vanderbilt.edu/HGH_kids.htm
- http://kidshealth.org/parent/medical/endocrine/growth_disorder.html
- <http://children.webmd.com/news/20081106/growth-hormone-therapy-ups-kids-height>
- <http://www.cbsnews.com/stories/2003/11/18/60II/main584265.shtml>
- http://www.emedicinehealth.com/growth_hormone_deficiency_in_children/article_em.htm
- <http://abcnews.go.com/Health/story?id=116731&page=1>
- <http://www.genotropin.com/>
- http://www.salon.com/2008/10/31/growth_hormones_kids/
- http://en.wikipedia.org/wiki/Growth_hormone

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