

## **The Cost of Medical Care for the Acromegalic Patient**

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*Author's Note: The Pituitary Network Association's mission is to support, pursue, encourage, promote, and, where possible, fund research on pituitary tumors in a sustained and full-time effort to find a cure for these illnesses. The PNA disseminates information helpful to the medical community, the public, pituitary patients and their families on matters regarding early detection, symptoms, treatments and resources available to patients with pituitary tumors.*

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## **Introduction**

The subject of health care costs for patients with acromegaly is a difficult puzzle to solve. This is mostly because the disease has no clear limits with many permutations related to its complications. Thus, we feel obligated to emphasize at the outset that patients with acromegaly do not simply suffer from a tumorous disorder. They sustain a disorder characterized by insidious, seemingly “unrelated” symptoms and complaints, overlaid with severe hidden complications before the true diagnosis is established. Up until now, there has been no consensus on a standardized scientific approach to calculate the economic burden of the disease and all of its complications. The scientific community needs to devise a system to accurately separate the cost of care for osteoporosis, colorectal polyps, diabetes mellitus, visual impairment, mental and emotional disorders, carpal tunnel syndrome, reproductive and sexual disorders, dental disorders and many others problems from the recognized costs of treating high IGF-I and GH levels. Until then, they will all be categorized under “separate umbrellas” and not be recognized as part of the overall cost of treating an acromegalic patient. They must be related to the disease at a much earlier date than is possible under the current standard, thereby accelerating initial diagnosis and “core” acromegaly/adenoma treatment.

Clearly, it is not possible to define and segregate the cost of caring for an acromegalic patient and the insurance issues in the United States. There are too many variables, and in a country like the United States, the cost of care varies with the timeliness of the diagnosis, the quality and experience of endocrinologists, neurosurgeons, and pathologists alike. Most importantly, an accelerated diagnosis is almost directly in proportion to the insistence of the patient to find answers to a constellation of “unrelated problems.” Nevertheless, we will attempt here to define some of the sources of the problem and some of the emerging patterns that contribute to the costly care of patients with acromegaly.

## **Acromegalic Patients’ perspective**

Of major concern to patients with acromegaly is the number of times procedures such as hysterectomies are performed on patients without a specific underlying diagnosis. We have the same concern with expensive and cumbersome treatments for sleep apnea and carpal tunnel syndrome. It appears that only pituitary endocrinologists see the relationship between these common conditions and the underlying diagnosis of acromegaly. This relationship is often conveyed with great reluctance to patients. Surprisingly, there has been no consensus on the design or implementation of prospective screening programs to diagnose acromegaly among populations at risk. Acromegalic patients often cannot make clear judgments about underlying causes and categorization of the treatments they have received prior to their diagnosis. This is particularly true if the treating physicians have not offered a clear relationship between the multitude of disease complications and the unifying diagnosis.

### **The Pituitary Network Associations' perspective**

An overview of the prevalence of pituitary adenomas offers a reasonable basis to examine the emerging patterns behind the care of acromegalic patients. One of few meta-analyses examining the prevalence of pituitary adenomas was published in the journal *Cancer* by the American Cancer Society in June 2004 (1). In that systematic review of 14 studies, 16.7 % of the population was estimated to harbor a pituitary tumor. The relative percentages of hormonal production in adenomas identified by immunohistochemistry included 43% for PRL, 2.8% for GH, 4.9% for ACTH, 1.4% for LH, and 0.7% for those producing TSH. These findings indicate that GH-producing pituitary tumors represent a significant proportion of all pituitary tumors. Given that pituitary adenomas in general are clinically under diagnosed, it is no surprise that acromegalic patients represent a significant population that is often missed.

But the symptoms, in retrospect, are clear, unmistakable, irrefutable and obvious. Growing feet and hands are unmistakable and measurable. Sleep apnea is unmistakable and measurable. Bilateral carpal

tunnel syndrome, heavy sweating, (hyperhidrosis) and unpleasant body odor, are all unmistakable and noticeable. These are but a few of the symptoms anyone can recognize. There are another five to ten symptoms, from cardiovascular dysfunction to high blood pressure to dental malocclusion, which are easily measured, and a simple blood test will determine the presence of excessive GH levels and lead to a strong suspicion of acromegaly. And, most cannot be confused with any other disorders. How many other disorders manifest with increased shoe size, growing hands or bilateral carpal tunnel syndrome?

We are increasingly concerned that some continue to deny the obvious. Why the persistent delay in diagnosis when so many tools and yardsticks are available to the thoughtful Physician? Screening for high GH/IGF-I levels immediately comes to mind as a tool before any elaborate and costly procedures for sleep apnea, tongue reduction, or bilateral carpal tunnel syndrome, for instance.

One of the authors (RK) is an acromegalic patient and can relate to the prolonged course of treatment for kidney stones, migraine headaches, weight gain, sexual and emotional disorders, sleep apnea, plus innumerable developing skin tags and cysts for many years before the recognition of acromegalic status. Knowing that there is a strong thread among all of these issues leads us again to the dilemma: how to separate these issues? How do we “cost categorize” each series or types of treatments?

On June 26<sup>th</sup> 2003, the University of Michigan and Rand Corporation released a joint study on health care in the United States (2). Researchers noted that, “The deficiencies in health care pose serious threats to the health of the American public.” In reality, the study found that many people are *not* receiving appropriate treatment. The study, which examined preventive care as well as the management of 30 common health problems such as diabetes mellitus, asthma, hypertension and heart disease, was published in the New England Journal of Medicine. Most other studies have assessed a single condition, focused on a small number of indicators of quality, looked at care in one geographic area or assessed people with a single type of insurance coverage. This study looked at how health care across the nation is being provided and

cuts across all geographic areas, insurance types and a wide range of conditions. Quality of care varied substantially according to medical condition, ranging from 79% of recommended care for cataracts among older people to 11% of recommended care for people with alcohol dependence. But it also points out that the proportion of care for patients with chronic conditions is 56.1%.

Among the key findings, there were some particular areas of great concern to patients with acromegaly: patients with diabetes mellitus received only 45 % of the care they need. People with coronary artery disease received 68 % of recommended care, but only 45 % of heart attack patients received medications that could reduce their risk of death by more than 20 %. Patients with colorectal cancer received 54 % of recommended care, but just 38 % of adults were *screened* for colorectal cancer. Routine tests and follow-up could prevent 9,600 deaths a year. Patients with high blood pressure received less than 65 % of recommended care. Poor blood pressure control is associated with increased risk for heart disease, stroke and death. In fact, poor blood pressure control contributes to more than 68,000 preventable deaths annually. The study seems to echo an observation made recently by a Surgeon board member of the Pituitary Network Association:

“I just saw a patient with acromegaly yesterday one month following pituitary surgery. Although he appeared to have been “cured” this was achieved only after he had had 3 carpal tunnel releases, 1 colonic surgery and at least 3 lithotripsies for kidney stones. Your additional calculation of these costs seems appropriate.”

A recent article from the University of Virginia is particularly interesting in supporting the above observations (3). Again, it deals with issues related to - but not necessarily part of - the pituitary tumor. The authors noted that “The most common presenting complaints of patients with a sellar mass are headache and, in patients with macroadenoma, visual loss (classically temporal or bitemporal hemianopsia) (from compression of optic chiasm). Cardiac disease is a major cause of morbidity and mortality in acromegalic

patients. Indeed, the most frequent cause of death in untreated acromegaly is cardiovascular with 50% of patients dying before the age of 50. Hypertension occurs in approximately 40% of acromegalic patients. Left ventricular hypertrophy can occur in the presence of systemic hypertension, but also occurs in at least 50% of normotensive acromegalic patients.”

### **More than Dollars and Cents**

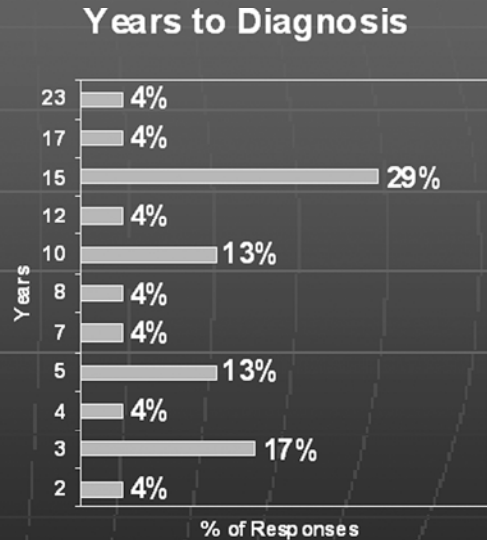
For many years the Pituitary Network Association has been conducting ongoing surveys of patients to determine a variety of information, hopefully to be useful in future research. The broader pituitary patient survey included 2,524 responses, which included 266 acromegalics. More than 200 (216) patients with acromegaly from the United States alone gave us information on where and by whom they had been treated. We can only verify 49 patients who were treated by a Physician or at a medical facility considered to represent a “Centre of Excellence”. Most patients are treated on a hit-and-miss basis, too often by well-meaning, but untrained and inexperienced physicians and surgeons who, sadly, often do more harm than good. In fact, only about 30% of acromegalic patients are treated by experts in the field of pituitary medicine including neurosurgeons or endocrinologists.

No wonder, then, that so many are treated for what are perceived as non-endocrine-related issues, often for many years before they are diagnosed. But, when eventually diagnosed they may also learn they have been treated for acromegaly-related disorders for many years. And no one knew: least of all, the patient.

Further examination of our data revealed that on average there is an almost ten year’ time lag between onset of recognized symptoms and diagnosis as depicted in Figure 1.

# Acromegaly: The Road to Diagnosis

- 24 Responses
- Range: 2 to 23 years
- Average: 9.79 years from onset of symptoms to actual diagnosis.
- 54% of patients go 10 or more years before diagnosis.
- 37% go 15 years or more.



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This realization is *very* important to our understanding of acromegaly and it probably applies to other Pituitary tumors and related disorders. The fact that patients spend so many years “in the wilderness” without proper diagnosis or treatment greatly increases the cost of their care and makes it almost impossible to calculate the full financial burden.

We at the PNA clearly have no way of calculating these patients’ cost, in time, effort and money, over the many years they were looking for an answer. It is a common problem. For example:

“I have no idea of the many thousands of dollars I spent on treatments for back pain over at least 20 years before my diagnosis. Or headaches, or minor Dermatological surgery or Therapists time! I finally had back surgery two years ago to remove some bony growths in my lower back, 13 years after my transphenoidal surgery for acromegaly. That cost about \$7,000.00. I am still a frequent patient of chiropractors and I am assuming that my bone and joint pain will increase over the years and that hip and

knee or elbow replacement may be in my future. At what cost I can not yet determine. So far, in 10 years I have had 52 colorectal polyps' removes, albeit at a decreasing rate. I also recently had two teeth implanted at a fine dental school. They had been loose for many years, pushed out of their socket when my jaw grew. Also, I had the acromegalic patients' typical acid reflux, so the teeth finally had to be removed before I swallowed them. That, alone, cost \$3,600. Agreed, I could have gone toothless, but I decided I wanted it treated.”

Thousands of acromegalic patients have provided similar accounts to the PNA over the years.

We next refer you to a previously published study by Wilson and colleagues (4). The objective was clear. To determine the cost of caring for an acromegalic patient - in this case in Canada. The costs are reported in 1998 Canadian dollars, which I suppose could be updated for inflation, increases in cost, and exchanged into U.S. dollars. However, for our purposes today it would have no value. Of the 53 patients studied, 47% had microadenomas at time of admission for treatment. 53% obviously had macroadenomas. Patients were treated either by transphenoidal surgery (N=27) or in conjunction with medical therapy (N=26). Outcomes were analyzed as person-months spent in various health state outcomes, which were defined on the basis of growth hormone and insulin-like growth factor-1 levels. The mean duration of follow-up was 49 months. Patients spent as much as 65 % of the time in “un-cured” health states. Patients with less extensive disease had better outcomes (within the 49 months). The mean actual cost per patient was (1998) \$8,111. Medications were the largest contributor to the overall cost (38%). Although the per-patient surgical costs themselves were high, (ranging from approximately \$2,800 to \$9,200) when averaged over the 4 years, the mean annual cost was approximately \$2,400 less than the cost of medication. Treatment of macroadenomas cost more than the treatment of microadenomas (\$11,425 versus \$4,442 annually).

It is a clear snapshot over 49 months of a patient's life. It sadly, however, does not account for the costs incurred during the total acromegalic patients' health state, which as we now realize, is a **lifetime** from the onset of the first symptoms.

For the acromegalic patient the term *perioperative* takes on a whole new meaning. It includes the time before, during and after treatment – and for how long a time period? What is counted, what is not? How much could be saved if a diagnosis was certain BEFORE seemingly unrelated symptoms were treated as if they were de-novo happenings and diseases?

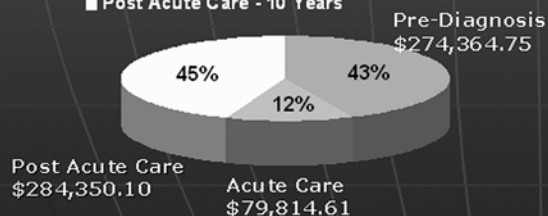
At the PNA we have decided to break down the average pituitary patient's medical life into three separate stages, each incurring its own set of costs, yet inseparable from the main underlying disease. Acromegaly clearly is no exception (Figure 2). The two longest stages, and perhaps the most costly, are pre-diagnosis years and rest-of-life care. The shortest, usually, is the acute treatment stage, but we can all agree that some “acute care stages” take an inordinately long time, often a series of surgeries, medical treatments and interminable long and unhappy stages of waiting, in order to find out what works. The last obviously depends a great deal on the first two stages (early or late diagnosis, micro or macro adenoma, the skill and success of treatment methods and the patient's response to medication and treatment).

# Annual and Acute Care Costs

- Annual average cost of care prior to diagnosis: \$28,025.00
- Average number of years prior to diagnosis: 9.79 Years
- Total average cost pre-diagnosis: \$274,364.75
- Average cost, achieving diagnosis/pre-acute care: \$12,844.45
- Average cost, acute care: \$44,400.11
- Annual costs during first year post acute care: \$22,570.05
- Total average cost diagnosis and acute care: \$79,814.61
- Estimated annual costs of care after first year: \$28,435.01

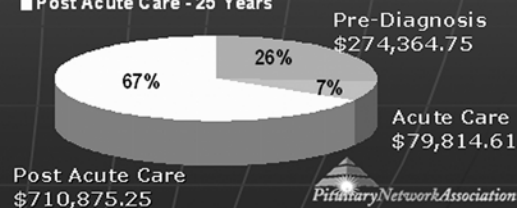
## Patient Costs Including 10 Years Post Acute Care

- Cost of Care Prior to Diagnosis
- Diagnosis, Pre & Acute Care, First Year Care
- Post Acute Care - 10 Years



## Patient Costs Including 25 Years Post Acute Care

- Cost of Care Prior to Diagnosis
- Diagnosis, Pre & Acute Care, First Year Care
- Post Acute Care - 25 Years



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## Measuring Quality of Life

In a clinical study from Erasmus Medical Centre, University Hospital of Rotterdam titled “The bio-assay quality of life might be a better marker of disease activity in acromegalic patients than serum total IGF-1 concentrations,” Dr. van der Lely and his colleagues succinctly summarized the situation (5). Their objective was to investigate the quality of life (QOL) in acromegalic patients in relation to biochemical parameters. Their study indicated that currently used biochemical criteria for disease control in acromegaly might be sufficient in assessing long-term mortality and morbidity. However, they are “*insufficient in addressing the most important parameter from the patient’s perspective – quality of life*” (5).

We believe at this stage that the findings and observations from the Netherlands, the USA, and Canada point in the same direction. The quality of life, not the treatment of the adenoma or medical control of hypersecretion, is what matters the most to the patient. Quality of life is paramount.

There is no possible way, at this time, to segregate and classify the time span and cost of care for an acromegalic patient. It may be that *perioperative* is a permanent state for acromegalic patients. It has no clear beginning, like flu, or a broken leg. Instead it is a continuum, requiring expert medical and surgical care. Sadly, in many cases it only appears to end at death, however many years that may take.

Far too many physicians and surgeons, (plus insurance companies and society in general), treat pituitary tumors and hormonal disorders with diffidence, disinterest, and disdain. We believe that the endocrine community and health leaders in most cases have not been able to convey the potential seriousness of the issues at hand either to their medical colleagues or to the health authorities and public. Sometimes, sadly, not even to themselves or to the patients.

And there, in a nutshell is the crux of the matter: *The other things* acromegalic patients have to deal with!

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