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# Transitional Care Model for Patients with Acromegaly

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## Abstract

The long-term care of acromegaly patients is associated with numerous challenges, including frequent monitoring, parenteral drug administration, chronic comorbidities, treatment-related adverse events and limited specialty care centers. Improving health-related outcomes can be hindered by gaps in collaboration across various health care settings. An Acromegaly Nurse Consensus Panel comprising highly experienced endocrine nurses to review this problem. Close collaboration between specialty care centers with community care settings may improve the overall quality of care received by acromegaly patients. Carefully transitioning care for patients with chronic illnesses may improve their physical functioning, quality of life, and treatment satisfaction among patients and caregivers.

**Keywords:** Acromegaly, Transitional care model, Nursing, Health-related outcomes, Quality of life

## Introduction

Patients with rare diseases have complex medical needs, often requiring a multi disciplinary approach to their care; however, improving health-related outcomes in chronic rare conditions can be challenging if there are gaps in the collaborative communication plan across various health care settings. Recently, greater emphasis has been placed on developing transitional care models for several disease states with the goal of improving the quality of care and treatment satisfaction among patients and caregivers. These models include the elderly [1] and specific disease states such as diabetes [2] and heart disease [3]. To date, little has been published regarding the use of transitional care models in chronic rare diseases, such as acromegaly [4]. The goal of this article is to review current treatment practices in acromegaly and explore the use of a transitional care model in this patient population.

## Acromegaly

Acromegaly is caused by the overproduction of growth hormone (GH), usually the result of a benign pituitary tumor [5]. Subsequently, excess GH results in overproduction of insulin-like growth hormone-1 (IGF-1). Together, GH and IGF-1 are responsible for the clinical manifestations of the disease [6]. Acromegaly has an estimated prevalence of 40 to 125 cases per million and an incidence of 3 to 4 new cases per million annually[6], generally affecting men and women in equal numbers [7]. The diagnosis of acromegaly requires specific biochemical assessments [8] and imaging techniques. Subsequent treatment is usually multimodal, consisting of surgical, pharmacological and sometimes radiologic treatments to suppress GH hypersecretion, reduce IGF-1 levels, and control tumor growth to achieve symptom control [9].

Acromegaly is a clinical syndrome that may not present with clear diagnostic or phenotypic features. The diverse range of possible co-morbidities includes

diabetes, hypertension, arthralgias, cardiac disease, fatigue, headaches, carpal tunnel syndrome, sleep apnea syndrome, diaphoresis, vision loss, colon polyps and characteristic changes in facial features [5,10,11]. These patients may also show evidence of cognitive and neurophysiological impairment [12,13]. Due to the slow onset of symptoms, diagnosis may not occur until the fifth decade of life at a mean age of 44 years [5] during which time the patient may accrue progressive dysfunctions.

## Current care model

As patients diagnosed with acromegaly are often seen by many different healthcare providers in a variety of practice settings [8], identifying and characterizing these healthcare settings may be useful for understanding the role of each provider in the overall care of acromegaly patients. To this end, a Acromegaly Nurse Consensus Panel[1] was convened comprising highly experienced endocrine nurses that are actively involved in the care of this patient population. The purpose was to categorize current health care settings in the United States (U.S.) in order to better understand how the transfer of care is managed as patients move from one provider to another. The primary goal was to identify what aspects of care may overlap between various providers and to determine if there could be improvements in the transition of care.

The Acromegaly Nurse Consensus Panel[1] categorized clinical practice settings based on four characteristics:

- location
- team members
- primary focus, and
- number of acromegaly patients

As shown in table 1, practices within large academic centers are reported to consist of multidisciplinary providers including physicians, nurses and support staff working as a multi disciplinary team and whose primary focus is endocrinology.

Depending upon the center, endocrine care may even be further specialized into subspecialties, narrowing the focus to care of just thyroid problems, diabetes or, in the case of acromegaly, pituitary conditions. The team specialists at these centers may include endocrinologists, neurosurgeons, neurologists, radiation oncologists, neuro-ophthalmologists, neuro-radiologists, psychologists, nurse practitioners, physician assistants and specialty nurses. Drawing on their experience from these various specialties, they have the ability to provide a comprehensive care plan for patients with acromegaly. In addition to providing patient care, they are also more likely to have the resources and be involved in basic and clinical research, clinical trials and access to teaching/ educational opportunities. In the U.S., these centers often serve as referral centers.

More common are those practices with a broader view of endocrinology and which tend to focus on all conditions affecting the endocrine system. Practices in this category may also be found in academic centers or in a group or solo practice within a community setting. As there may be a broad spectrum of practice types found within this care setting, the medical professionals, the availability of resources and the primary focus of these practices may also be highly varied. These centers may choose to refer to subspecialists in larger centers to co-manage care or for access to more specialized diagnostic capacity, surgical care or access to treatment through clinical drug trials.

Finally, there are primary cares practices located in community settings that may be internal medicine or family medicine who may be the initial referral source for one or two patients or may provide ongoing chronic disease management or may include the care of endocrine diseases care as part of their patient population.

## Special needs of acromegaly patients

**Multiple physicians for diagnosis, treatment, and long-term care:** Patients with acromegaly often present to a primary care physician with a diverse range of nonspecific symptoms that are common complaints raised by many patients seen in the same setting. In fact, data gathered from an informal survey of U.S.-based acromegaly patients (*N* = 162) noted that it was often a primary care physician or other health care professional such a neurologist or gynecologist that first suspected a diagnosis of acromegaly [14]. According to this survey, patients stated that the disease was most likely to be confirmed by a general, non-specialty endocrinologist that possessed the resources to conduct the requiring diagnostic testing. Since the first line therapy for acromegaly is often surgical removal of the tumor, patients with a confirmed (biochemical) diagnosis and evidence of a pituitary tumor were often referred to a

[1]Fourteen endocrinology nurse clinicians convened in Chicago, IL in July, 2015. Members of the Nurse Consensus Panel were: Chris Yedinak, Daphne Adelman, Dawn Shaver, Denise Humphries, Jayme Ewanichak, Jennifer Mercado, Karen Liebert, Kelley Moloney, Lisa Mitchell, Michele Charles, Michelle Gurel, Monica Chiu, Vivian Hwe, Yelena Lalzar.

**Table 1:** Current Care Model for Acromegaly.

| Specialty/Interest | Location | Team Members | Physician Focus | Acromegaly Patients (N) |
|---|---|---|---|---|
| Endocrinologist, Pituitary Focus | Academic Center | •Neurosurgeon | | 10s-100s |
| | | •Endocrinologist | • Basic Research | |
| | | •Pituitary specialist | • Clinical Trials | |
| | | •Specialist nurses | • Teaching | |
| | | •Radiologists | • Patient care | |
| | | •Psychologists | | |
| | | •Radiation oncologist | | |
| Endocrinologist, Broad Focus | Academic Center | •Neurosurgeon | •Patient care | Low 10s |
| | | •Endocrinologist | •Clinical trials | |
| | | | •Teaching | |
| | Community | •Endocrinologist | • Patient care | 0-Low 10s |
| | • Group practice | | | |
| | Community | •Endocrinologist | • Patient care | 0-Low 10s |
| | • Solo practice | | | |
| Internal Medicine, Family Practice | Community | •Internal Medicine | • Patient care | 0-5 |
| | •Group practice | •Family Practice | | |
| | Community | •Internal Medicine | • Patient care | 0-5 |
| | •Solo practice | •Family Practice | | |

neurosurgeon. Based on published findings, patients should be encouraged to seek out a neurosurgeon with substantial experience removing pituitary tumors to increase the chance of success and minimize the risk of surgical complications [15]. Most often, these experienced neurosurgeons were associated with larger healthcare settings, such as academic centers that provide more opportunities for surgical sub-specialization. Post-surgically, patients are likely to be initially treated by an endocrinologist or in some cases a neurosurgeon; however, the literature suggests that the long-term management plan may often be carried out by other health care providers, such as a primary care provider. It is evident from this informal survey and the published literature that confirming the diagnosis of and long term management of acromegaly patients in the U.S. often involves health care professionals from various healthcare settings.

**Need for long-term monitoring:** Approximately 50% of all treated acromegaly patients will still require life-long care after non-curative surgery to reduce disease morbidity and normalize mortality rates [16]. Others may experience tumor recurrence and return of symptoms following initial disease control [17] or experience delayed adverse effects if radiation therapy is required for tumor control [18]. Therefore, patients with a history of acromegaly often require long-term monitoring to maintain biochemical control of their disease, manage co-morbidities and prevent the possible consequences of disease recurrence [19].

## Treatment-related issues

Challenges associated with the long-term care of this patient population are multifaceted and include monitoring and management of the disease which may also be confounded by both access to care and communication gaps between the various healthcare providers taking care of a single patient. Although many health care environments have access to electronic medical records, platforms vary and often do not communicate with each other. Likewise, fax communications are not available in all practices necessitating slower postal deliveries of medical records between facilities. Access to care may be limited by patient physical, economic or psychological issues.

Disease management for acromegaly patients is complex and can be complicated and time consuming for some healthcare professionals as it may require the need for regularly-scheduled monitoring GH and IGF-1 levels, parenteral drug administration, management of chronic

comorbidities and minimizing treatment-related adverse events. Injections are highly technique-dependent [20] and may cause apprehension for both staff and patient. The incidence of injection site pain associated with intramuscular injections is high [5] and the anticipation of injection pain can be a source of patient anxiety [21]. Due to the overall demands associated with treatment, the rate of noncompliance has been reported to be about 20% [22] and as many as 18-20% of patients are lost to follow-up and likely to experience active disease [16,23]. Factors that may prevent patients from seeking routine disease monitoring include travel expenses and lost productivity and income while often travelling to distant specialty care practices.

The chronicity and complexity of acromegaly often requires managing patients by many different healthcare professionals and can result in fragmented care. In one report, nearly 80% of patients received most of their long-term care from non-endocrinologists [24] while another report suggests only about 30% of acromegaly patients are treated by specialists such as neurosurgeons or endocrinologists [25]. Some centers with many acromegaly patients may be too busy to provide chronic care while others see too few patients to achieve disease specific expertise. Patients report some endocrinologists are much less familiar with the nuances of acromegaly care than others [26]. Thus, patient confidence in their care can be diminished. Based on patient interviews, the endocrinologist who is caring, knowledgeable, informed, and proactive and positive can make acromegaly a very manageable disease. A key recommendation from patients is to find an endocrinologist or other healthcare provider who is experienced with acromegaly, open to collaborative discussions and shared decision making [26]. Since pituitary specialty centers may have the most experience managing patients with acromegaly, collaboration between specialty care centers with community care settings may improve the overall quality of care received by acromegaly patients and ultimate outcomes.

## The transitional care model

As previously mentioned, specialty endocrinology centers generally use a multidisciplinary approach to patient care involving many specialized healthcare providers. It is usually here where the long-term management plan for the acromegaly patient is established. Some patients may begin their treatment at these centers prior to being referred back to their local physician, while treatment for others is initiated by their primary care provider. Still others may receive most of their treatment from a primary care physician while maintaining communication with a specialty center. The complexity of these transitions may allow for significant communication gaps where information and/or patient follow-up can be lost.

The results of research conducted by the University of Pennsylvania show that carefully transitioning care for patients with chronic illnesses can improve the quality of care, physical functioning, quality of life, and treatment satisfaction among patients and caregivers. Designed and implemented by nurse specialists, discharge planning and home care intervention can reduce readmissions and re-hospitalization days and decrease the overall cost of providing health care [27,28].

The Transitional Care Model proposed by Naylor and associates [29] defines a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location [30]. Although the emphasis was originally placed on elderly patients [1,31-33], the Transitional Care Model has since been implemented for a range of chronic illness including heart disease [28,34,35], stroke [36], diabetes [2] and cancer [37]. This model is reviewed here for possible use with acromegaly patients.

In the Transitional Care Model, a transitional care nurse (TCN) with advanced training in the care of patients with complex, chronic illnesses acts as the primary care coordinator. Using an evidence-based care plan, the TCN provides comprehensive assessment and treatment preparation that begins at the time of hospital admission. The TCN continues to provide patient support for an average of 2 months following discharge by regular telephone contact and home visits whenever possible. It is the responsibility of the TCN to work closely with family caregivers, physicians, nurses, social workers and any other healthcare professionals involved in the care of the patient. A comprehensive review of the Transitional Care Model and evidence for its effectiveness are available from the Coalition for Evidence-Based Policy [38].

## Applying the transitional care model to acromegaly

Fully implementing the Transitional Care Model described above for acromegaly patients may not be feasible in all situations; however, it may be relatively easy to implement some principles of this model. Firstly,

the designation of a TCN at specialty centers to be the primary care coordinator with responsible for organizing resources to be transitioned to the community or primary care facility with the patient. Early involvement of the TCN begins at the point of diagnosis and/or hospitalization. Instead of a typical in-hospital patient assessment, the TCN would compile documents outlining the patient history, diagnostic studies, current clinical summary including pathology report (if available) and recommended care plan or ensure this information is relayed to referring provider and/or provider(s) who will be involved in patient's long term management. If technology at both sending and receiving facilities allows, this type of information may be shared more easily using electronic medical records, lessening the burden of transitioning information between practices. If not, this data can be designed to travel with the patient to the prospective treatment center, faxed or mailed. As technology becomes more sophisticated with greater availability in rural areas, the ability to provide telemedical care may soon become routine.

Immediate post-operative care needs can be coordinated by phone contact with the patient including symptoms of surgical complications to be vigilant for, and coordination of post-operative laboratory and other required and recommended assessments such as echocardiogram, colonoscopy, abdominal/gallbladder ultrasound, spinal x-rays, sleep studies, imaging, and ophthalmologic review. These can be directed using approved treatment protocols.

Contact with the long term management providers can be further established by phone and information provided as requested by the local management team such as updated disease and treatment related materials, recommendations for long term treatment monitoring and staff training regarding the proposed treatment protocol. If injection training is indicated, video conferencing and other media applications may be utilized. Although still in early stages of development, video conferencing or telemedicine can also be used for providing direct face-to-face assessment and instructions to patients in some circumstances.

Frequent follow-up communication with the new treatment center would be the responsibility of the TCN, becoming less frequent as the transition becomes more established. The frequency may be limited to an as-needed basis or may be restricted according to the resources of the principle care/pituitary center. Teaming with the patient's local physician and providers can be an aid to early identification of changes in the patient health, make adjustments in therapy or identify the need for further evaluation at the principle care center or potential telemedicine review. There are no recommendations in current guidelines for long-term follow-up which are recommended to be patient-specific, such as a schedule for checking IGF-1 levels, liver function testing, pituitary hormonal testing, imaging studies or mechanisms for providing the treatment site with information about new therapeutic options or educational materials, such as updates in treatment guidelines [6,11,39].

Other beneficial functions of the TCN might include providing links to online acromegaly education resources for newly-diagnosed patients and family members [40,41] and healthcare providers [42] including patient support groups [43] The TCN might also arrange for counseling for emotional and psychological issues, and 24-hour availability of a TCN or pharmacist to respond to questions about drug therapy and possible treatment-related adverse events. In addition to providing education to help patients better understand their disease; the TCN may be ideally situated to connect newly diagnosed patients with other local acromegaly patients who can also act as source for educational and psychosocial support.

In summary, the overall goal of the Transitional Care Model is to ensure continuity of care between hospital and community or primary care facility, provide education and support for the patient and their family, include the patient and family caregivers as part of the healthcare team, rapidly identify and respond to disease-related changes and treatment-related adverse events to achieve beneficial long-term outcomes, and ensure open communication among the patient, family caregivers and health care providers.

It is noteworthy that the Endocrine Society is currently establishing similar Transitional Care Models for other endocrine disorders, such as growth hormone deficiency and Turner syndrome and for providing a smooth transition from a pediatric practice to an adult practice within the same specialty [44]. Tools have been developed by the Endocrine Society to help the healthcare team prepare for and successfully manage the transition of patients with growth hormone deficiency include an Assessment of Patient Skills; Patient Self-assessment of Worries, Concerns, and Burdens; Clinical Summary; Recommended Approach to Receiving a New Patient;

and Dosing Guide. It may be possible to adapt these tools to meet the goals of a transitional care model for acromegaly.

## Conclusion

Approximately one-half of all acromegaly patients require life-long care to reduce morbidity and normalize mortality rates. Many of these patients have complex medical needs, often requiring a multidisciplinary approach to their care. Pituitary specialty centers may have the most experience managing patients with acromegaly. Close collaboration between specialty care centers with community care settings may improve the overall quality of care received by acromegaly patients. Carefully transitioning the care for patients with chronic illnesses may improve their physical functioning, quality of life, and treatment satisfaction among patients and caregivers. Nurse clinicians with advanced training in the care of acromegaly patients are well-suited for managing the transition of care of acromegaly patients from specialty care centers to local community care centers.

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