

The Psychosocial and Economic Burden of Pituitary Adenomas: Implications for Community Health and Healthcare Systems

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ABSTRACT

Background: Pituitary adenomas are among the most frequently encountered intracranial tumors, yet their psychosocial and economic consequences remain under-recognized; clinically recognized adenomas must also be distinguished from incidental lesions identified at autopsy or imaging. **Objective:** This narrative review synthesizes evidence concerning the psychosocial burden, quality of life, healthcare utilization, economic impact, and community-health implications of pituitary adenomas, with particular attention to resource-constrained settings. **Methods:** A narrative review with a structured literature search was conducted. Peer-reviewed literature published between January 2004 and December 2020 was identified through searches of PubMed, Scopus, Google Scholar, and the Directory of Open Access Journals, and evidence was synthesized narratively and thematically. **Results:** Included studies consistently reported substantial psychosocial distress, reduced health-related quality of life, work impairment, caregiver burden, and high healthcare utilization; however, reported magnitude varied by tumor type, disease activity, treatment status, measurement instruments, and study setting, with the highest psychosocial burden observed in Cushing disease and acromegaly. Most formal economic estimates were derived from high-income healthcare systems and should not be directly extrapolated to low- and middle-income countries, where the literature more often describes contextual burdens such as delayed diagnosis, out-of-pocket expenditure, and limited access to specialist care. **Conclusion:** The available evidence supports improved clinical awareness, timely recognition of suggestive symptoms, targeted hormonal evaluation, appropriate referral pathways, and improved access to specialist endocrine and neurosurgical services. Such integrated, multidisciplinary care may reduce avoidable morbidity and potentially lessen long-term health-system burden, although context-specific economic and community-health research from low- and middle-income countries is needed.

Keywords: Pituitary Neoplasms; Quality of Life; Mental Health; Health Care Costs; Community Health Services

INTRODUCTION

Benign neoplasms arising from the anterior pituitary gland, pituitary adenomas affect an estimated 76 to 116 per 100,000 individuals, ranking among the most frequently encountered intracranial tumors.[1, 2] Despite this relatively high prevalence, these lesions are often characterized as a "hidden threat" within human populations because their initial presentation typically involves non-specific symptoms or complete asymptomaticity, resulting in delayed detection and progressive cumulative morbidity over time.[3] In line with the 2022 World Health Organization classification, these lesions may also be termed pituitary neuroendocrine tumors (PitNETs); however, the term pituitary adenoma is retained in this review for consistency with the clinical literature and the manuscript title. [4, 5]

The clinical consequences of pituitary adenomas reach well beyond the confines of the sella turcica. Functionally active adenomas—those characterized by excessive hormone secretion—produce distinct clinical

syndromes: prolactinomas induce hypogonadism and infertility; growth hormone-secreting tumors generate acromegaly with its hallmark disfigurement and cardiovascular complications; and corticotropin-secreting lesions produce Cushing disease, marked by central obesity, hypertension, diabetes mellitus, and osteoporosis.[6, 7] Non-functioning adenomas, while hormonally inactive, can compress adjacent anatomical structures, leading to hypopituitarism, visual field defects, and persistent headaches.[8] Each of these clinical trajectories carries profound implications for patients' psychological well-being, social engagement, and econ-

omic productivity. Affected individuals frequently report chronic fatigue, depressive symptoms, anxiety, and cognitive difficulties that severely disrupt daily functioning and interpersonal relationships.[9] The persistent nature of these symptoms often precipitates long-term disability, reduced work output, and increased healthcare resource consumption, collectively amplifying the socioeconomic burden on communities and families.[10]

From a public health standpoint, the insidious nature of pituitary adenomas demands a reconceptualization of how these tumors are perceived and managed within healthcare systems. Enhanced awareness and education among both healthcare professionals and the general public regarding early warning signs and symptoms could facilitate earlier detection and more effective intervention, potentially attenuating the long-term complications associated with these neoplasms.[11] Furthermore, the development of clear clinical care pathways and management guidelines for patients in whom pituitary disease is suspected could help reduce the overall burden on both individuals and healthcare infrastructure.[12] Given the rarity and heterogeneity of clinically significant pituitary adenomas, the available evidence supports strengthening clinical awareness, early recognition of suggestive presentations, targeted diagnostic assessment, and referral pathways rather than advocating unselected population-based screening.[13, 14]

This study did not use AI and/or LLM tools during the preparation of this manuscript. The anatomical relationships of the pituitary gland within the sella turcica are shown in Figure 1.

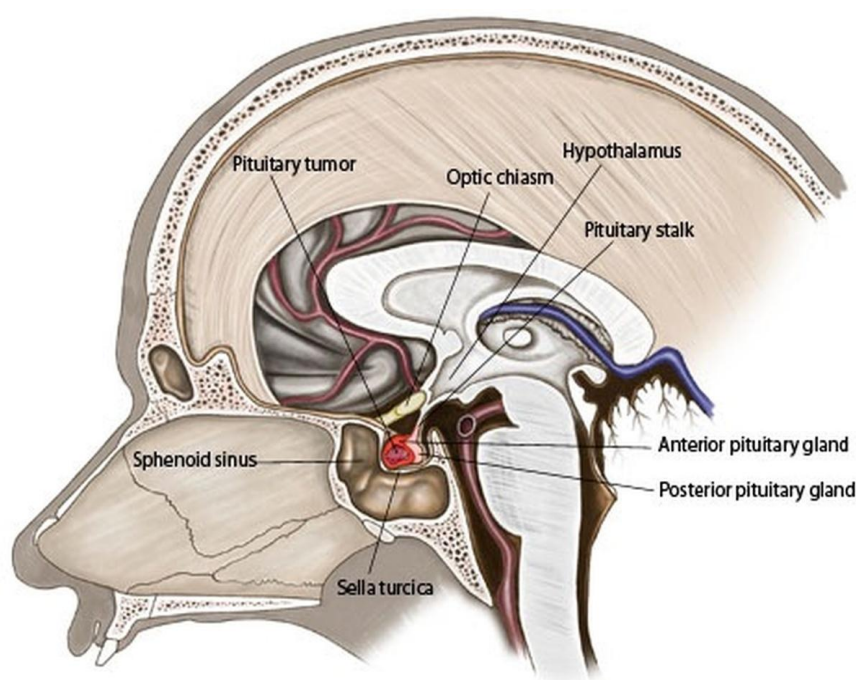


Figure 1. Anatomical diagram of the pituitary gland showing the relationship between the pituitary gland, sphenoid sinuses, sella turcica, and the location of a pituitary tumor. Original figure created by the authors.

METHODS

Study Design

This study was a narrative review with a structured literature-search approach. It was designed to summarize and critically contextualize evidence on the psychosocial, quality-of-life, healthcare-utilization, and economic

consequences of pituitary adenomas, with particular consideration of implications for community health and resource-constrained settings. The review was reported with attention to the SANRA domains for narrative reviews; it was not conducted as a systematic review and did not include protocol registration, duplicate independent screening, formal risk-of-bias assessment, or quantitative meta-analysis. [15]

Information Sources and Search Period

The literature search covered publications from January 2004 through December 2020 and included searches of PubMed, Scopus, Google Scholar, and the Directory of Open Access Journals (DOAJ).

Search Strategy

Search concepts combined terms for pituitary adenoma or pituitary neuroendocrine tumor with terms related to psychosocial burden, mental health, quality of life, healthcare utilization, costs, productivity, caregiver burden, community health, health systems, low- and middle-income countries, diagnosis, referral, and access to care. Reference lists of key reviews, guidelines, and eligible studies were also examined to identify additional relevant literature.

Eligibility Criteria

Studies were eligible if they were peer-reviewed primary studies, systematic reviews and meta-analyses, clinical practice guidelines, or health-economic evaluations addressing psychosocial outcomes, quality of life, disability, work productivity, caregiver burden, healthcare utilization, access to care, or costs in pituitary adenomas, and were published in English with available full text. Conference abstracts without full reports, opinion pieces without empirical evidence, studies with insufficiently described methods, and case reports or very small case series were excluded unless specifically used to illustrate a rare issue and clearly identified as such.

Study Selection and Synthesis

Titles and abstracts were screened for relevance, followed by full-text assessment of potentially eligible publications. Selection was purposive rather than exhaustive, consistent with a narrative review design. Evidence was synthesized thematically across psychosocial outcomes, quality of life, healthcare and economic burden, caregiver and occupational effects, and community-health implications. Where evidence was heterogeneous, findings were described narratively rather than statistically pooled.

Quality Appraisal

No formal study-level risk-of-bias assessment was undertaken because the aim was a narrative synthesis rather than a systematic review. Priority was given to clinical guidelines, systematic reviews, population-based studies, and well-described primary research. This limitation is acknowledged in the interpretation of findings.

Mental Health Impacts of Pituitary Adenomas

Reported estimates varied substantially across studies because of differences in pituitary tumor subtype, hormonal disease activity, treatment phase, country income level, outcome definitions, and measurement instruments. Therefore, the figures presented below should be interpreted as study-specific estimates rather than pooled prevalence values.[16, 17, 18]

The psychiatric burden associated with pituitary adenomas is considerable and arises from multiple interacting factors, including direct neuroendocrine effects of hormone excess, the psychological stress of chronic illness, physical disfigurement, and complications related to treatment. Depression represents the most extensively studied psychiatric comorbidity in this population, with study-specific prevalence estimates ranging from 40% to 60% across adenoma subtypes, though rates reach particularly elevated levels in Cushing disease.[9, 10, 19] The underlying pathophysiology is complex, involving direct cortisol-mediated effects on the hippocampus and prefrontal cortex, alongside psychosocial stressors related to altered body image, sexual dysfunction, and diminished occupational identity.

Anxiety disorders are also prevalent, affecting approximately 35% to 50% of patients with pituitary adenomas in the studies reviewed. In acromegaly, the progressive physical disfigurement—manifested by coarsening of facial features, prognathism, and enlargement of the hands and feet—can precipitate social anxiety and avoidance behaviors.[20, 17] Patients with prolactinoma frequently report anxiety stemming from infertility, galactorrhea, and sexual dysfunction, which can strain marital relationships and reduce social participation.[16] Cognitive dysfunction, encompassing deficits in attention, executive function, and memory, has been documented in a substantial proportion of patients, particularly those with long-standing disease or a history of radiation therapy.[9] These cognitive impairments can limit patients' capacity to perform occupational tasks, manage personal finances, and maintain independence in daily living.

Sleep disturbances constitute another frequently underrecognized mental health complication. Patients with Cushing disease commonly report insomnia and fragmented sleep, potentially mediated by hypercortisolism-induced alterations in circadian rhythm.[7] In acromegaly, sleep apnea affects a large proportion of patients and is associated with daytime somnolence, impaired concentration, and increased cardiovascular risk.[20] The combined impact of depression, anxiety, cognitive dysfunction, and sleep disturbance generates a pervasive mental health burden that can persist even after biochemical remission, underscoring the necessity for long-term psychiatric surveillance and intervention (Table 1).

Table 1. Selected study-specific estimates of psychosocial and quality-of-life burden in pituitary adenoma

Adenoma Subtype	Depression (%)	Anxiety (%)	Cognitive Dysfunction (%)	Key Psychosocial Challenges	Reference(s)
Prolactinoma	40–50	35–45	20–30	Infertility, sexual dysfunction, galactorrhea, relationship strain	[9, 16]
Acromegaly	45–55	40–50	30–40	Body disfigurement, joint pain, social anxiety, occupational disability	[17, 18, 19]
Cushing disease	55–65	45–55	35–45	Central obesity, mood lability, cognitive decline, osteoporosis-related disability	[7, 9]
Non-functional adenoma	35–45	30–40	25–35	Hypopituitarism, visual loss, chronic fatigue, uncertainty about tumor progression	[9, 10]

Values are study-specific and should not be interpreted as pooled prevalence estimates. Differences in tumor subtype, hormonal control, treatment status, study setting, and measurement tools limit direct comparison.

Quality of Life and Disability

Individuals living with pituitary adenomas consistently report diminished health-related quality of life relative to population norms, and this impairment frequently endures even after successful biochemical or surgical intervention.[10] Generic health-related quality-of-life instruments, such as the 36-Item Short Form Health Survey (SF-36), demonstrate consistent reductions in physical functioning, role limitations attributable to physical health, bodily pain, and general health perceptions.[10] Disease-specific instruments, including the Acromegaly Quality of Life Questionnaire (AcroQoL) and the Cushing Quality of Life Questionnaire (CushingQoL), reveal even more pronounced deficits in domains such as physical appearance, energy levels, and emotional well-being, and contemporary systematic reviews have confirmed that patient-reported outcomes frequently remain impaired despite biochemical control.[21, 22, 23]

The physical disability associated with pituitary adenomas is considerable. In acromegaly, arthropathy affects the majority of patients and may necessitate joint replacement surgery, while carpal tunnel syndrome and spinal stenosis further restrict mobility.[20] In Cushing disease, osteoporosis-related fractures, proximal myopathy, and cardiovascular complications can produce significant functional limitation and reduced life

expectancy.[7] Patients with large non-functional adenomas may experience visual field defects that preclude driving, operating machinery, or performing tasks requiring fine visual acuity. These physical limitations, combined with chronic fatigue and persistent pain, frequently lead to early retirement or extended periods of sick leave.

Social disability is equally significant. The altered physical appearance characteristic of acromegaly can lead to social stigma, diminished romantic prospects, and withdrawal from public engagement.[17] Infertility and sexual dysfunction in prolactinoma and Cushing disease can disrupt family formation and marital stability.[16] Cognitive dysfunction and mood disorders across all adenoma subtypes can strain interpersonal relationships and reduce participation in community activities. The cumulative effect is a progressive narrowing of the patient's social environment, with profound implications for community integration and the availability of social support networks.

Healthcare Costs and Utilization

Direct medical expenditures for pituitary adenoma management accumulate across multiple service categories: diagnostic imaging, laboratory testing, pharmacotherapy, surgical intervention, radiation therapy, and long-term endocrine surveillance.[10] Formal cost estimates are available mainly from high-income healthcare systems; for example, cross-sectional and claims-based analyses in prolactinoma and acromegaly have documented substantial healthcare utilization and costs related to imaging, pharmacotherapy, surgery, and comorbidity management.[24, 25] Magnetic resonance imaging (MRI), the gold standard for pituitary imaging, is expensive and typically requires repeated studies to monitor tumor progression and treatment response. Transsphenoidal surgery, the primary treatment for most symptomatic adenomas, carries significant costs related to hospitalization, neurosurgical care, and postoperative intensive monitoring.

Pharmacotherapy costs are particularly notable for prolactinoma and acromegaly. Dopamine agonists (cabergoline and bromocriptine) are first-line treatments for prolactinoma and may be required for many years, while somatostatin analogues (octreotide, lanreotide) and growth hormone receptor antagonists (pegvisomant) used in acromegaly are among the most expensive chronic medications in endocrinology.[26] Radiation therapy, whether conventional fractionated radiotherapy or stereotactic radiosurgery, adds further costs and requires lifelong surveillance for hypopituitarism and secondary malignancies. Hormone replacement therapy for post-treatment hypopituitarism—including hydrocortisone, levothyroxine, testosterone, estrogen, and growth hormone—represents a lifelong cost burden that is often underestimated in economic analyses.

Healthcare utilization patterns in pituitary adenoma patients are marked by elevated rates of emergency department visits, hospital admissions, and specialist consultations. In the years preceding diagnosis, patients frequently present to primary care with non-specific complaints and may undergo extensive—and expensive—diagnostic workups before the underlying pituitary pathology is identified.[3] After diagnosis, patients require coordinated care from endocrinologists, neurosurgeons, ophthalmologists, radiation oncologists, and mental health professionals. The complexity and fragmentation of this care can result in redundant testing, delayed treatment decisions, and increased costs. In resource-limited settings, where specialized endocrine and neurosurgical care is scarce, these challenges are magnified: patients may travel long distances for treatment, face prolonged diagnostic delays, and experience worse outcomes due to limited access to essential medications and monitoring.[13]

Economic Burden

The economic burden of pituitary adenomas extends beyond direct healthcare costs to encompass substantial indirect costs related to productivity loss, disability, and caregiver burden. In studies from high-income countries, indirect costs—including lost wages, reduced work productivity, and premature mortality—have been estimated to account for a substantial share of the total economic burden, and the magnitude of indirect costs is particularly high in younger patients and those with functional adenomas.[10, 27] In acromegaly, the physical and cognitive limitations associated with the disease frequently lead to occupational disability and early retirement, with studies reporting that a considerable proportion of patients are unable to work or have reduced work capacity at the time of diagnosis, with only partial recovery after treatment.[20, 25] In Cushing

disease, the metabolic and cardiovascular complications, combined with neuropsychiatric impairment, can render patients unable to perform physically demanding or cognitively complex work.[7, 14]

Most available economic estimates were generated in high-income healthcare systems and should not be directly extrapolated to low- and middle-income countries. In resource-constrained settings, the literature more often describes contextual burdens—including delayed diagnosis, travel costs, out-of-pocket expenditure, interrupted employment, limited access to magnetic resonance imaging and specialist care, and fragmented referral pathways—than comparable formal cost estimates.

Caregiver burden represents an additional, often overlooked, component of the economic burden. Partners and family members frequently assume caregiving responsibilities, including medication management, transportation to medical appointments, and assistance with activities of daily living. This informal caregiving can reduce the caregiver's own workforce participation and earning capacity, creating a secondary economic impact on the household. The emotional and physical strain of caregiving can also compromise the caregiver's health, leading to additional healthcare costs and lost productivity. In low- and middle-income countries, where formal social support systems are limited, the economic and psychosocial burden on families is particularly severe, often pushing households into poverty (Table 2).

Table 2. Estimated annual economic burden of pituitary adenomas per patient (US dollars, high-income settings)

Cost Category	Cost Range (USD)	% of Total Burden	Key Cost Drivers	Reference(s)
Direct medical costs	\$15,000–\$50,000	50–70%	Imaging, surgery, pharmacotherapy, hormone replacement, radiation	[10, 24, 25, 27]
Indirect costs (productivity loss)	\$8,000–\$25,000	20–35%	Sick leave, early retirement, reduced work capacity, unemployment	[10, 27]
Caregiver burden (informal care)	\$3,000–\$10,000	5–15%	Lost wages, transportation, home care assistance, health impact on caregiver	[10]
Total annual economic burden	\$26,000–\$85,000	100%	Combined direct and indirect costs per patient	[10, 27]

Economic estimates were largely derived from high-income settings and are not directly generalizable to low- and middle-income countries.

Community Health Implications

The community health implications of pituitary adenomas are profound and multifaceted. At the individual level, the chronic physical and mental health burden compromises patients' ability to participate in family life, education, employment, and civic activities. At the household level, the economic and caregiving burden can destabilize family finances, reduce educational opportunities for children, and increase reliance on informal social support networks. At the community level, the aggregated burden of untreated or poorly managed pituitary adenomas contributes to healthcare system strain, workforce attrition, and lost economic productivity.

In low- and middle-income countries, the community health impact is amplified by systemic barriers to care. Limited availability of specialized endocrine services, diagnostic imaging, and neurosurgical expertise means that many patients remain undiagnosed or experience prolonged diagnostic delays.[3] The cost of treatment, including expensive medications and repeated imaging, can be prohibitive for patients and families without comprehensive health insurance. The stigma associated with mental illness and physical disfigurement can further discourage patients from seeking care, particularly in communities where traditional beliefs attribute illness to supernatural causes rather than biomedical pathology.

The implications for healthcare systems are equally significant. The management of pituitary adenomas requires a multidisciplinary team that is rarely available outside tertiary referral centers in resource-limited settings.[28, 29] The need for long-term hormone replacement, surveillance imaging, and mental health support creates ongoing demands on health services that may be poorly integrated into existing primary care structures. Without dedicated pituitary clinics or hormonal health centers, patients may be lost to follow-up, experience treatment interruptions, or develop preventable complications that require emergency care and hospitalization. The establishment of hormonal and metabolism centers represents a critical infrastructure investment for reducing the community health burden of pituitary adenomas in resource-limited regions, consistent with World Health Organization (WHO) Regional Office for Africa recommendations for strengthening non-communicable disease services (Figure 2).

Practical measures to strengthen the community-health response include: (1) primary-care education to improve recognition of symptoms suggesting hormonal excess, hypopituitarism, mass effect, or visual compromise; (2) clear referral pathways from primary care to endocrinology, ophthalmology, radiology, and neurosurgery; (3) health-literacy and patient-education initiatives to reduce stigma and delayed presentation; (4) routine mental-health assessment and support within endocrine care; (5) fertility and sexual-health counselling for affected patients and partners; (6) structured assessment of caregiver needs; (7) measures to reduce financial and transport barriers, such as coordinated appointment scheduling and, where feasible, tele-endocrinology follow-up; and (8) organized long-term follow-up after treatment to detect recurrence and manage hypopituitarism. These measures are supported by consensus guidance as components of good pituitary care; however, they have not yet been proven cost-effective specifically for pituitary adenomas in low- and middle-income settings, and context-specific evaluation is needed.[28, 29, 30]

Conceptual Framework of the Psychosocial and Economic Burden of Pituitary Adenomas on Community Health

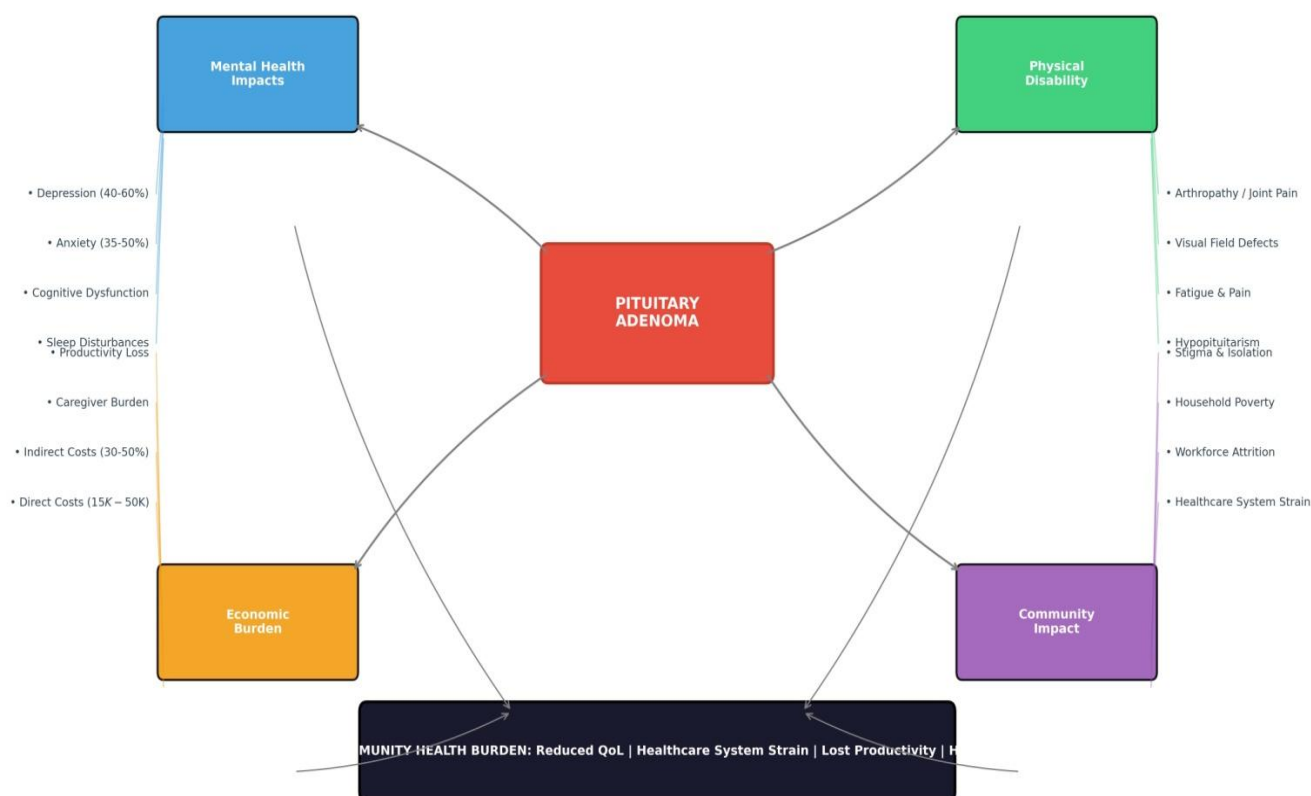


Figure 2. Conceptual framework of the psychosocial and economic burden of pituitary adenomas on community health. The central pituitary adenoma gives rise to four major burden dimensions—mental health impacts, physical disability, economic burden, and community impact—which collectively produce cumulative community health burden. Original figure created by the authors.

STRENGTHS AND LIMITATIONS

This narrative review has several limitations. The selection of evidence was purposive rather than exhaustive and did not include duplicate independent screening, formal risk-of-bias assessment, or quantitative meta-analysis. The included literature was heterogeneous with respect to pituitary tumor subtype, disease activity, treatment phase, outcome definitions, instruments, and healthcare settings. In addition, psychosocial and economic evidence from low- and middle-income countries remains limited; therefore, findings from high-income settings should not be assumed to apply directly to resource-constrained contexts.

CONCLUSION

Pituitary adenomas can be associated with substantial psychosocial, functional, and financial burden that extends beyond endocrine and neurosurgical outcomes. Available evidence supports integrated care that includes mental-health assessment, quality-of-life monitoring, fertility and sexual-health counselling, patient and caregiver education, and timely access to specialist referral pathways. In low-resource settings, priority should be given to improving clinical awareness, diagnostic access, coordinated referral, and longitudinal follow-up. More population-based and health-economic research from low- and middle-income countries is needed before the magnitude of burden and the effectiveness of specific community interventions can be determined with confidence.

Ethical Considerations

Not applicable. This study is a narrative review of published literature and did not involve human participants, animals, or primary data collection; therefore, ethical committee approval was not required.

Conflict of Interest

The authors declare that they have no conflicts of interest.

Data Availability

Data Availability Statement: No new datasets were generated or analyzed for this narrative review. All information synthesized in this article is derived from the published literature cited in the reference list.

Ethics Approval Statement

Not applicable. This study is a narrative review of published literature and did not involve human participants, animals, or primary data collection; therefore, ethical committee approval was not required.

Informed Consent

Not applicable. This narrative review did not involve human participants, and informed consent was therefore not required.

Data Availability Statement

No new datasets were generated or analyzed for this narrative review. All information synthesized in this article is derived from the published literature cited in the reference list.

Declaration of Interests

The authors declare that they have no conflicts of interest.

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Artificial Intelligence Usage Statement

This study did not use AI and/or LLM tools during the preparation of this manuscript.

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