

# Craniopharyngiomas

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**Abstract:** Craniopharyngiomas are rare, benign, suprasellar brain tumors that account for 1%–3% of all intracranial tumors. Pituitary gland involvement causes loss of pituitary function, which makes endocrine evaluation necessary before and after surgery. Symptoms of intracranial mass effect, including visual field loss, obstructive hydrocephalus, and extraocular palsy of the cranial nerves, may occur. Lifelong follow-up is crucial because of the risk of recurrence and the need for ongoing hormone replacement therapy. Surgical resection is the primary therapy. However, radiotherapy may be indicated. Nurses play a major role in caring for patients with a craniopharyngioma by preventing and identifying complications, educating patients and families about the importance of long-term follow-up, and collaborating with multidisciplinary teams.

Craniopharyngiomas are rare brain tumors that originate in the anterior superior margin of the pituitary gland. They account for 1%–3% of all intracranial tumors and have a calculated incidence of 338 cases per year in the United States (Bunin, et al., 1998). Although they are histologically benign, the overall treatment regimen for craniopharyngiomas is a challenge. Craniopharyngiomas have a tendency to adhere to vital brain structures, primarily the hypothalamus and pituitary gland; this factor makes total resection or cure difficult (Chakrabarti, Amar, Couldwell, & Weiss, 2005). Craniopharyngiomas often recur because they cannot be totally resected.

Effective treatment for patients with a craniopharyngioma requires communication and coordination among the multidisciplinary team (Vance, 2003). Nurses play a major role on the multidisciplinary team. This article reviews the pathophysiology, diagnosis, and treatment as well as the nursing implications of craniopharyngiomas. The emphasis is on effective communication and coordination of care.

## Anatomy

The pituitary gland is a pea-size organ below the hypothalamus and within the sella turcica. It is divided into the anterior lobe and the posterior lobe. The sella turcica is in close proximity to delicate vascular and neurologic structures, including the optic chiasm and cavernous sinus, as well as the third, fourth, and sixth cranial nerves and the ophthalmic and maxillary

division of the fifth cranial nerve (Fig. 1). An enlarging pituitary mass, such as a craniopharyngioma, can affect any of these structures (Martin, 2005).

The pituitary stalk, or infundibulum, connects the pituitary gland to the hypothalamus. It contains important nerve fibers (the hypothalamo-hypophysial tract) and small blood vessels (the hypothalamo-pituitary portal vessels) that carry hormones into the posterior and anterior pituitary lobes respectively (Vander, Sherman, & Luciano, 1994). Compression of the pituitary stalk by a craniopharyngioma can affect these nerve fibers and blood vessels and produce endocrine abnormalities.

## Background

Craniopharyngiomas are embryonic remnants of Rathke's pouch. They grow slowly from birth. Tumors can vary in size from a small, solid, well-circumscribed mass to a huge multilocular cyst. Most tumor cysts are filled with cholesterol crystals (Greenberg, 2001). A craniopharyngioma can develop in the pituitary stalk in the suprasellar region, next to the optic chiasm (Recht, 2005), and invade the sella turcica, shifting important neurologic structures around it. A craniopharyngioma can extend along the path of least resistance, laterally, medially, superiorly, or toward the base of the brain, shifting the third ventricle superiorly.

The molecular and biological bases of craniopharyngiomas are poorly understood. Remnant cells may lie dormant for decades before forming into a tumor (Ullrich, Scott, & Pomeroy, 2005).

Craniopharyngiomas occur equally among males and females. The common age groups for craniopharyngiomas are children 5–14 years of age and adults 50–74 years of age, but they can occur at any age (Bunin et al., 1998).

## Signs and Symptoms

The hallmarks of a patient with a craniopharyngioma are vision loss, endocrinologic disturbances, and headache (Ullrich et al., 2005). Most craniopharyngioma patients seek treatment because they are experiencing visual deficits (Chakrabarti et al., 2005; Fahlbusch, Honegger, Werner, Huk, & Buchfelder, 1999; Van Effenterre & Boch, 2002). Optic chiasm compression can result in bitemporal hemianopia. Extraocular palsies may also occur as a result of tumor extension into the cavernous sinus. Headaches can result from distension of the diaphragma sellae or cerebrospinal fluid (CSF) obstruction, leading to hydrocephalus.

Signs and symptoms of endocrine dysfunction or panhypopituitarism may be manifested at the time of

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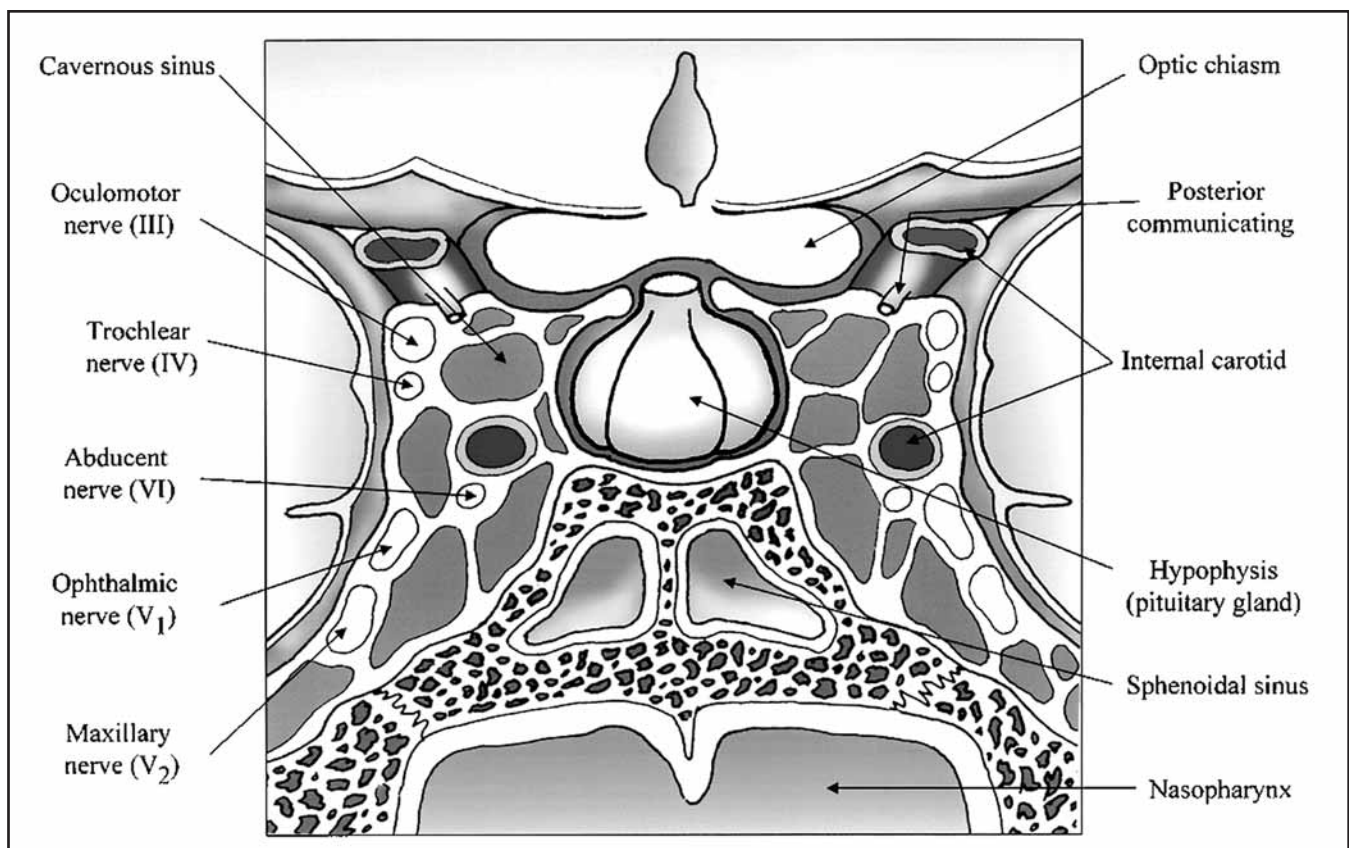


Fig 1. Coronal view of pituitary gland and surrounding structures

diagnosis. They include diabetes insipidus (DI), weight gain, menstrual irregularity or amenorrhea, hypothyroidism, growth failure (in children), and delayed or precocious puberty. These symptoms can also be related to hypothalamic or pituitary damage.

Craniopharyngioma patients are more likely to present with psychiatric symptoms, which may be characterized by loss of short-term memory, personality changes, dementia, and depression, compared with those diagnosed with other pituitary lesions (e.g., Rathke's cleft cyst, arachnoid cyst; Shin, Asa, Woodhouse, Smyth, & Ezzat, 1999). It is important to recognize that psychiatric symptoms are usually accompanied by neurological symptoms, such as headaches and visual deficits.

### Diagnosis

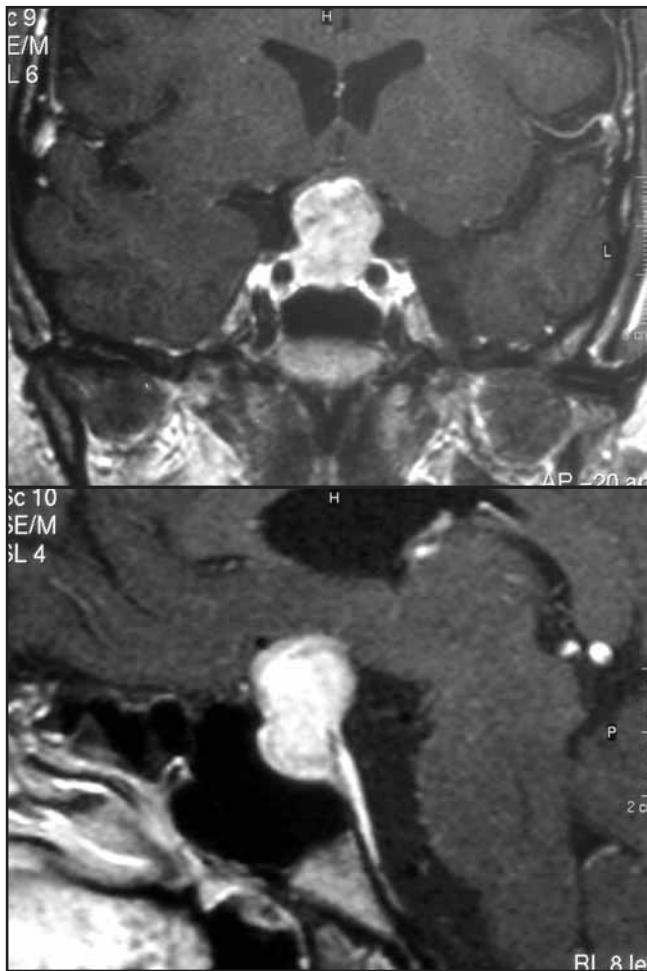
MRI (with and without contrast) and CT scanning are the prime neurological imaging techniques for diagnosing craniopharyngiomas. MRIs identify the extent of a craniopharyngioma and approximation to the third ventricle, but CT scans are best for identifying calcification (Freda & Post, 1999). MRIs also show whether the lesion has invaded the sella turcica, whether the lesion displaces the chiasm, and whether it invades the hypothalamus, as well as the location of adjacent major blood vessels.

The MRI appearance of craniopharyngiomas can vary depending on the proportion of solid versus cystic components, the amount of calcification, and the cystic fluid contents of the tumor. The solid components typically appear isointense or hypointense on T1-weighted images (Fig. 2) while hyperintense on T2-weighted images. Cystic components usually demonstrate a high signal on T1-weighted images due to high protein content (Freda & Post, 1999).

### Treatment

As with other pituitary-region tumors, ophthalmological and endocrine testing is required. Ophthalmological testing documents the extent of visual dysfunction and serves as a baseline for comparison after surgery. The visual examination includes evaluation of the visual field, visual acuity, and extraocular movements. Visual field testing ascertains whether the optic pathways are compressed.

Endocrine testing is crucial because most craniopharyngioma patients have hypopituitarism. Panhypopituitarism may include hypothyroidism, adrenal insufficiency, hypogonadism, growth hormone deficiency, and DI. Endocrine function should be evaluated to lessen complications during and after surgery (Vance, 2003). The patient should be referred for an endocrinology consultation before surgery for appropriate clinical



**Fig 2.** MRI of brain, T1-weighted images. (Top) Coronal view shows an enhancing enlarged pituitary mass that extends outside the confines of the sella turcica and compresses the optic chiasm. (Bottom) Sagittal view shows an enhancing pituitary lesion that compresses the optic chiasm.

testing and treatment. The endocrine blood tests include analysis of prolactin with dilution, insulin-like growth factor-I, adrenocorticotrophic hormone, 8 am cortisol level, free thyroxine (FT4), thyroid-stimulating hormone, luteinizing hormone, follicle stimulating hormone, and testosterone level (for male patients; Vance, 2003).

Surgery is the primary treatment option for symptomatic craniopharyngioma patients. Surgery confirms the diagnosis and removes as much of the tumor as possible. Surgical goals include improving visual function and minimizing the worsening of endocrine function and neuropsychological impairment (Chakrabarti et al., 2005; Van Effentere & Boch, 2002).

Yasargil et al. (1990) described several approaches for the surgical treatment of craniopharyngioma: transsphenoidal, pterional, transcallosal, combined pterional-transcallosal, and combined pterional-transsphenoidal. The surgical approach chosen should

be based on the patient's age and medical condition; the preference of the surgeon and patient; the experience of the surgeon; the tumor size, location, and extension; and the postoperative radiotherapy options available (Chakrabarti et al., 2005).

Greenberg (2001) recommended a transsphenoidal approach as the optimal surgical procedure because it has several advantages: no external scarring, no brain retraction, and, most likely, a shorter hospital stay. A transcranial approach or a craniotomy is indicated when the tumor extends beyond the boundaries of the sella turcica, when an unrelated pathology such as a parasellar aneurysm is suspected, or when the neurosurgeon suspects a fibrous tumor that cannot be completely removed by the transsphenoidal approach. Modern neuroimaging with CT or MRI allows the neurosurgeon to choose the precise surgical approach.

Unlike most benign tumors, craniopharyngiomas tend to recur and behave in a malignant manner. Complete resection may not be achieved for several possible reasons: the tumor's firm adherence to the hypothalamus, an obstructed view of the tumor, calcification, the tumor's adherence to perforating vessels, severe bradycardia during dissection, older age, significant blood loss when an aneurysm is present, or the tumor's very thin capsule. Even when complete tumor removal appears to have been achieved, a residual tumor may appear on an MRI after surgery (Fahlbusch et al., 1999).

Fractionated stereotactic radiotherapy (FSRT) is usually recommended when complete resection is not achieved during surgery or when the tumor recurs. Stereotactic radiosurgery (SRS) or FSRT increasingly is being utilized for both adult and pediatric brain tumors, including craniopharyngiomas (Kalapurakal, 2005). Both SRS and FSRT utilize the principle of stereotaxis, which allows precise target or tumor localization and accurate delivery of radiation to the tumor, either with a single session (SRS) or a series of sessions (FSRT), while reducing radiation dose to critical nearby structures (Kalapurakal, 2005). Both SRS and FSRT are noninvasive and can be performed on an outpatient basis without general anesthesia. However, SRS or FSRT should be used only after surgery to prevent or treat a recurrence (Laws & Vance, 1999).

Radioisotopes or chemotherapeutic agents, such as bleomycin, may be instilled, especially when treating residual or recurrent craniopharyngiomas (Amendola, Wolf, Coy, & Amendola, 2003). Bleomycin is an antineoplastic agent that stops the production of cystic fluid, causing tumor cells in the craniopharyngioma to shrink. Intracystic administration of bleomycin via an Ommaya reservoir, followed by radiation, is an alternative method for eradicating cystic craniopharyngiomas.

### Prognosis and Outcomes

The survival rate for craniopharyngioma patients is excellent; 90% of all patients are still living 10 years after

diagnosis (Ullrich et al., 2005). However, functional outcomes, quality of life, and community reintegration are of more concern for craniopharyngioma patients.

In a retrospective study performed by Duff et al. (2000), 73 of the 121 patients evaluated had a *good outcome*, with a mean follow-up period of 10 years. Good outcomes were associated with survival at the follow-up examination; the absence of major motor deficits related to treatment or tumor progression; functional vision; a Katz grade of A, which denotes independence and not requiring any supervision in feeding, continence, transferring, using the toilet, dressing, or bathing; school status at no more than 1 year behind the expected grade or employability for an adult of working age; the absence of incapacitating psychological or emotional problems; and a Karnofsky Performance Scale (KPS) score of at least 80. The KPS is an assessment tool for evaluating functional status or impairment that is widely used by clinicians. It consists of an 11-item rating scale, with scores that range from 100 (*normal function*) to 0 (*nonfunctional or dead*; Hickey, 2003).

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Of the 73 patients who had a good outcome, 48 patients had a gross total resection of the tumor, and 25 patients had a subtotal tumor resection. Duff et al. (2000) concluded that gross total resection was associated with better clinical outcomes, compared with subtotal resection. Partial or subtotal resection was associated with tumor recurrence at 12.8% in the first year after surgery and 23.4% in the fifth year after surgery. Tumors located primarily in the sella turcica and tumors initially treated by the transsphenoidal approach were associated with good outcomes. Patients who were lethargic; exhibited visual deterioration, hemianopia or papilledema, tumor calcification or hydrocephalus, and tumor adhesiveness to surrounding neurovascular structures; and had been treated with a transcranial surgical approach were more likely to have poor outcomes (Duff et al.).

Chakrabarti et al. (2005) and Fahlbusch et al. (1999) agreed with Duff et al. (2000). Patients treated with a transsphenoidal approach had better visual outcomes compared with those who were treated transcranially. Chakrabarti et al. attributed this to the superior capability of rapidly decompressing the visual apparatus when employing the transsphenoidal approach.

Endocrinological outcomes may be unclear when endocrinological evaluations are not performed before surgery, as can occur when emergency surgery is required. In a study performed by Honegger, Buchfelder, and Fahlbusch (1999), 143 patients underwent endocrinological testing before and after surgery. Ninety-two patients had a transcranial approach, while 35 patients had a

transsphenoidal approach. (The remaining 16 patients underwent limited procedures such as stereotactic-guided cyst puncture or CSF shunt placement.) Panhypopituitarism increased from 10.9% before surgery to 34.8% after surgery for those treated transcranially; the increase was 40%–42.9% for those treated via the transsphenoidal approach. Honegger et al. concluded that there was no significant difference in the DI occurrence between the two groups. Regardless of the surgical approach, DI is an expected consequence of craniopharyngioma resection.

## Nursing Implications

### Panhypopituitarism

Craniopharyngioma patients may require hormone replacement before and after surgery as a result of injury to the hypothalamus or the pituitary stalk from the tumor or surgery. An endocrine service consultation is imperative both before and after surgery, to evaluate patients who may need lifelong hormone replacement therapy. Patients who are hormone deficient must have hormones replaced to physiological levels.

Adrenal insufficiency is treated with hydrocortisone (20 mg in the morning and 10 mg no later than 4 pm to replicate diurnal rhythms). A stress dose of glucocorticoid (usually a doubling of the current dose, for several days) is recommended during periods of acute infection, surgery, or physiological or psychological stress. Nurses and other healthcare providers must emphasize the need for stress-dose steroids. A patient's failure to receive adequate amounts of cortisone during stress can cause devastating metabolic complications, including circulatory collapse and death.

Patients receiving cortisone replacement therapy should be observed for signs of both undermedication (addisonian crisis), and overmedication (cushingoid symptoms). Signs and symptoms of addisonian crisis are weakness, dizziness, orthostatic hypotension, abdominal pain and cramping, and sodium and water retention. Cushingoid signs and symptoms include moon face, fat pads, a buffalo hump, acne, hirsutism, weight gain, psychic disturbances, peptic ulcers, and headache. Nurses should immediately report any of these symptoms to the primary care provider.

Patients undergoing cortisone replacement therapy should be observed for gastric irritation and tarry stools. Gastric irritation can be avoided by ingesting an antacid or a proton pump inhibitor with each medication. Nurses should warn their patients to not abruptly stop cortisone replacement therapy and tell their patients that gastric irritation or tarry stools must be reported immediately to their healthcare provider.

Hypothyroidism is treated with thyroid hormone replacement therapy, such as levothyroxine sodium (Synthroid). The dose should be adjusted in accordance with the free thyroxine (FT4) level. Serum thyroid-stimulating hormone usually is in the normal

range in the setting of secondary hypothyroidism (Vance, 2003).

The need for sex hormones should also be evaluated after surgery. Women who are premenopausal should resume their menstrual cycles within a few months after surgery. If menstruation does not occur, cyclical estrogen and progesterone are recommended until menopause is reached. Testosterone replacement is indicated for men who report a decreased libido or erectile dysfunction and have a low testosterone level. Men older than 40 years of age should have a prostate-specific antigen test before starting testosterone replacement. Both men and women dealing with fertility issues should be referred to a fertility center for possible gonadotropin treatment (Levy, 2004).

Craniopharyngioma patients should be evaluated for growth hormone deficiency. Growth hormone replacement therapy may be helpful in improving body composition by increasing muscle mass and reducing adipose mass. It may also help to improve muscle strength, exercise endurance, and serum lipid levels (Vance, 2003).

### After Surgery

Central DI is the inability of the pituitary gland to secrete adequate amounts of antidiuretic hormone (ADH). This inability could result from injury to the hypothalamus, the supraoptic hypophyseal tract, or the posterior pituitary gland (Hickey, 2003). Nurses should be vigilant in watching for early DI signs and symptoms including polyuria, a urine output of 4–10 liters per day or an hourly output more than 200 cc for 2 consecutive hours or more than 3 cc per kg per hour in pediatric patients; extreme thirst in conscious patients; low urine-specific gravity (1.001–1.005); high serum osmolality; hypovolemia; signs of dehydration; and hypernatremia.

The management of patients at risk for DI include recording intake and output every hour; observing for signs of dehydration, such as tachycardia, hypotension, or orthostasis; performing neurological assessment, with particular attention to lethargy or change in mental status; and checking urine-specific gravity, serum osmolality, and electrolytes, as ordered. Any abnormalities should be reported immediately.

Depending on the degree of damage to the pituitary stalk, hypothalamus, or posterior pituitary gland, DI may be transient or permanent. Transient DI occurs in approximately 12% of patients who undergo pituitary surgery; 3% may have permanent DI after pituitary surgery (Vance, 2003). Craniopharyngioma patients have a very high risk of developing permanent DI.

Patients with transient DI may not require medical treatment. Patients who have an intact thirst mechanism and no functional impairment are usually capable of maintaining an adequate fluid intake. On the other hand, patients who are lethargic, are functionally impaired (e.g., unable to hold a glass or a cup), or have dysphagia may require intravenous fluid replacement to correct fluid imbalances.

Patients who cannot manage fluid losses with intake or have permanent DI require ADH replacement therapy. Intravenous vasopressin is recommended for patients with acute DI because of its immediate response and shorter action, which makes titration or adjustment easy. For patients who are alert enough to ingest or inhale their medications appropriately, oral or nasal desmopressin 1-deamino-8-D-arginine vasopressin (DDAVP) may also be administered. DDAVP dosing is patient-dependent; dose and frequency are individualized to a patient's needs. Patient condition is assessed by asking whether there is abnormal urinary frequency and thirst or observing for increased urinary output. Such information is helpful in properly adjusting DDAVP doses to maintain fluid balances.

### The Potential for CSF Leak

A CSF leak is a potential complication after transsphenoidal surgery. It can occur several days or weeks after surgery. The leak is caused by an opening in the dura that allows fluid to drain through the nose. According to Sudhakar, Ray, and Vafidis (2004), the incidence of CSF leak after transsphenoidal surgery is 1.5%–4.2%.

Nurses should observe the mustache dressing for clear, watery nasal drainage and look for any characteristics that may indicate the presence of a CSF leak. Patients and family members should also be instructed to immediately report any nasal drainage. Another characteristic of a CSF leak is a salty or sweet taste in the patient's mouth. Patients may develop a low-pressure headache when standing (Greenberg, 2001).

According to Kerr, Chu, and Bayles (2005), most CSF leaks heal spontaneously within 7–10 days. Conservative treatments include cautioning patients not to blow their nose and avoid sneezing, coughing, or any activities that stimulate straining (Hickey, 2003). Bed rest, with the head of bed (HOB) at 30° for several days, is also beneficial.

A lumbar drain may be inserted to allow healing at the operative site by decreasing CSF volume and pressure. A lumbar drain is usually inserted if a CSF leak persists with bed rest or if CSF is seen in the surgical field. Nurses should tell patients and families to ask for assistance in closing the lumbar drainage system before standing and before any other position change or ambulation, so as to prevent overdrainage headaches and accidental disconnection of the lumbar drain system. Assessing for changes in mentation and watching for signs and symptoms of meningitis are also indicated.

### Late Effects of Radiotherapy

Patients who undergo pituitary radiation should be followed regularly for the possible development of new pituitary deficiencies (Vance, 2005). The effects of panhypopituitarism after radiation therapy may not be immediately evident, and deficiency may not become evident for several months or years. A baseline ophthalmological test and subsequent testing are required, because pituitary radiation can cause visual deterioration.

Complications such as radiation necrosis, cognitive decline, and the development of secondary malignancies occur in 2% of patients (Schulz-Ertner et al., 2002). Radiation-induced vasculopathy, such as *moya moya* disease, can occur as much as 6–12 years after radiation therapy (Kalapurakal, 2005).

### **Pathologic Obesity**

Craniopharyngioma patients may develop pathologic obesity. It is more common among children diagnosed with a craniopharyngioma and occurs as a result of injury to the ventromedial hypothalamus, which is the area responsible for regulation of appetite and satiety. Patients tend to gain a profound amount of weight, which predisposes them to develop cardiovascular risks, such as diabetes mellitus and metabolic syndrome. Nurses and other multidisciplinary teams should refer patients to their primary care provider for early recognition and treatment of these cardiovascular risks, which can affect survival and the quality of life. Unfortunately, diet and exercise may be insufficient to control the pathologic obesity associated with craniopharyngioma. Further studies are needed to determine the most effective treatment.

### **Knowledge Deficit**

Nurses and all team members have an important responsibility in educating craniopharyngioma patients and their families. The malignant nature of this tumor is often misunderstood. Patients and families who are well-educated about the importance of rigorous long-term follow-up tend to be more compliant and supportive of the care required. The need for serial MRIs, because of the high incidence of recurrence, should be emphasized. Patients and families must understand the importance of following up with several healthcare specialists in addition to the primary care provider. Often, patients and their families find the multitude of specialist appointments to be overwhelming. The side effects of medications, the importance of taking hormone replacement therapy and not stopping it unless instructed by the endocrinologist, the need for adjusting hormone replacement in case of any acute illness, and the need for periodic visual examinations are critical subjects to discuss with patients and families.

### **Case Study**

G. A., a high school senior, is a 17-year-old Hispanic male who was in his usual state of good health until 2 months before seeking medical attention from his primary care physician. At that time, G. A. noted decreased vision in his left eye; his vision seemed blurry when he looked to the left. He described trouble seeing things toward his left side. Although he had been wearing eyeglasses for 5 years, there had been a recent and acute decrease in his visual acuity. This complaint prompted a referral to an optometrist, who subsequently referred him to an ophthalmologist. Visual testing was performed, and a bitemporal hemianopia was identified. His left visual acuity

was 20/200, while his right visual acuity was 20/20. The ophthalmologist suspected a pituitary tumor. An MRI with and without gadolinium was ordered; it revealed a pituitary mass hyperintense to the brain on T1-weighted images (Fig. 2) and isointense to the brain on T2-weighted images. The mass had a dumbbell shape and was centered in the sella turcica but extended into the suprasellar cistern and compressed the optic chiasm. G. A. was referred to a neurosurgery clinic for further evaluation.

After visiting the neurosurgeon, G. A. was referred to the endocrinology clinic for baseline endocrinological testing. On further history review, G. A.'s energy level was adequate and his bowel movements were regular. G. A. had gained about 50 lb (22.68 kg) during the last 3–4 months. He complained of headaches, which occurred primarily in the morning. He was urinating 2–3 times per night. His initial endocrine workup results were normal, however, including his sodium level.

His physical examination was normal except for his weight and visual deficits. No extraocular palsies were noted, but he had decreased visual fields with bitemporal homonymous hemianopia.

G. A. was admitted for a transsphenoidal hypophysectomy and tolerated the surgery well. After surgery, he was transferred to the intensive care unit. He then began to void more than 250 ml of diluted urine per hour for several consecutive hours. His sodium levels began to rise, and he was quickly placed on a 0.45% hypotonic fluid regimen with close monitoring of his sodium levels. Intravenous DDAVP was added because his sodium levels and urine output continued to be high despite the hypotonic fluid replacement. An endocrinology consultation was obtained for further recommendations on vasopressin and fluid replacement. Serum osmolality, urine-specific gravity, and sodium levels continued to be drawn and monitored every 6–8 hours. Accurate recordings of intake and output were reinforced.

On day 5, G. A.'s urine output slowly began to taper, until replacement fluids and DDAVP were no longer necessary. G. A. was able to sustain normal and stable sodium levels simply by drinking adequate amounts of fluids.

Immediately after surgery, G. A. had developed some lightheadedness, a salty taste in the back of his throat, and CSF rhinorrhea. A lumbar drain was inserted for 2 days to drain the CSF. The lumbar drain was then clamped for 24 hours and then removed because no further CSF rhinorrhea was noted.

On day 8, G. A. was neurologically stable and discharged to home. Hydrocortisone, DDAVP, and thyroid hormone replacement therapy were not considered necessary because his cortisol, sodium, and FT4 levels were adequate. G. A. and his family were educated throughout his hospital stay. They were scheduled for follow-up appointments with the endocrinology clinic; the neurosurgeon; and with the ear, nose, and throat specialist. G. A.'s vision had improved, but he was given a follow-up appointment with an ophthalmologist for a

formal visual-field exam. A follow-up MRI was scheduled during his appointment with the neurosurgeon. The need to attend all appointments was reiterated.

Two months after surgery, an MRI showed an enhancing residual tumor in the sella turcica but no chiasmatic compression. G. A.'s endocrine lab results, including his sodium level, remained normal. He was referred to a radiation oncologist for possible radiation therapy. G. A. underwent FSRT for more than a month. He tolerated the entire radiation course well. He did not have any visual changes during the course of radiation treatment.

## Summary

Treating patients with craniopharyngioma is a medical challenge for healthcare providers. Nurses are closest to the patient and are responsible for gathering and recognizing the subtle signs and symptoms associated with recurrence or possible complications of treatment. Overwhelming reactions can sometimes be observed among patients and families because long-term follow-up with several healthcare providers is required. Patient and family education plays a major role in adherence to craniopharyngioma treatment. The role of nurses in educating patients and families about the treatment for craniopharyngioma, and its complications, should not be underestimated.

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# Top 10 Needs of People with Multiple Sclerosis and Their Significant Others

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**Abstract:** The purpose of this study was to identify the needs of patients with multiple sclerosis (MS) and their significant others. A quantitative questionnaire, developed from focus groups and consisting of 75 needs statements, was administered to 353 MS patients and 240 significant others. Analysis produced rankings of the 10 most important needs of both groups. Rankings by the MS patients and significant others were similar. Three themes emerged. Psychosocial and other personal needs (relationship with physicians, the MS healthcare team, family, and friends) were ranked with high frequency. Information needs (information regarding MS or available support) and financial security were also ranked as important. The data validate the importance of interdisciplinary care for the MS population.

Multiple sclerosis (MS) is a chronic neurological disease with no known cure. Various symptom-management strategies are available to people living with MS; treatment with interferons or copolymer acetate shows modest results. MS does not significantly affect mortality, but the disease can have a significant impact on quality of life (Ford, Gerry, Johnson, and Tennant, 2001). As people with MS and their significant others negotiate life with a chronic, unpredictable illness, they often turn to hospital- and community-based services for assistance.

The MS Clinic in London, ON, Canada, is an interdisciplinary outpatient clinic based in an acute-care, university-affiliated, hospital setting. A needs-assessment survey was conducted by the MS Clinic to develop an effective and efficient plan of care for MS patients and their significant others through better understanding their needs.

The purpose of this study was to identify the needs of individuals with MS and their significant others by using a patient-derived needs-assessment questionnaire. The study was set in the framework of patient-centered care (Gerteis, Edgman-Levitan, Daley, and Delbanco, 1993). The information obtained was used to examine

and enhance clinic-based care. This article focuses on the 10 most important needs identified by individuals living with MS who attended the MS Clinic and by their significant others. The psychosocial needs of this study population are published in a separate journal article (Benbow & Koopman, 2003).

## Background

Physical, health, psychological, accessibility, financial, employment or leisure, and information needs and MS were searched independently in the databases. These needs were identified as key issues in a previous study (Koopman, 2003). This search identified several studies that focused on the needs of people with MS and their significant others. In the first study, Black, Grant, Lapsley, and Rawson (1994) examined the service needs of 1,143 MS patients. The service needs the patients identified were respite care, family support, support from others with MS and education, and counseling about MS for the family. In a second study, Sato, Ricks, and Watkins (1996) looked at MS caregivers. The caregivers reported needs related to role function, practical needs (e.g., meal preparation, finances, assistance with child care, household duties), learning about the disease process, and receiving practical training in caregiving. An opportunity to be heard and understood was also deemed important in this study. In an Australian study, researchers noted that caregivers requested practical support (such as respite and home support services) rather than information to help reduce their burden (Wollin, Reiher, Spencer, Madl, & Nutter, 1999). In a study by Wollin et al. (1999), researchers concluded that care should be carefully planned and structured on the basis of these identified needs. Finally, a systematic review of the study of needs in MS caregivers ( $N = 24$ ) was performed by McKeown, Porter-Armstrong, and Baxter (2003). This review recommended further studies in the area of caregiver needs, in particular the development of reliable and valid disease-specific caregiver assessment instruments.

A Canadian study surveyed MS patients ( $N = 697$ ) and their caregivers ( $N = 345$ ) in Ontario by using self-completed mailed questionnaires (Aronson, Clegghorn, & Goldenberg, 1996). Respondents ranked the services of a doctor, physical and occupational therapists, home modification, and nursing care as important. This study recommended awareness of the use of services and the assistance available to the population served. Although patients and significant others who attended the MS Clinic may have participated in

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this research study, it was not possible to extrapolate these data.

Most MS needs-assessment studies rely on an investigator-developed self-report questionnaire format that assumes the researcher understands the needs to be investigated. Although needs-assessment tools have been developed through the use of focus-group methodology with other patient populations, similar studies could not be found in the MS literature (Buckley, Vacek, & Cooper, 1990). Therefore, a survey questionnaire was developed on the basis of patient-identified needs by using focus-group methodology.

## Methods

### Overview

A survey of individuals with MS and their significant others (SOs) was conducted at a large, university-affiliated hospital in London, ON, Canada, in 1998. A quantitative questionnaire (MS survey) was sent to 500 people who were randomly selected from the MS Clinic's database of 5,000 patients. Questionnaires were sent to another sample of 500 MS patients who were randomly selected from the same database with a request that they ask their significant other to complete the questionnaire (SO survey). All participants were selected independent of one another to ensure that data would not be biased by discussions between the MS patient and significant other. Data would then reflect the needs of the individual groups (MS and SO). The clinic nurse practitioner reviewed the randomly selected patient list to exclude those who were cognitively impaired or unable to read and comprehend English.

The needs assessment was conducted in two phases: focus-group phase (to develop a questionnaire) and survey phase.

### Survey Development

To develop a needs survey questionnaire, four focus groups, including MS patients ( $N = 10$ ) and significant others ( $N = 5$ ), were facilitated by an individual unknown to the participants, thereby reducing any bias that might occur because of the presence of the researcher (Koopman, 2003).

The investigators obtained approval for the study from the Research Ethics Board for Health Sciences Research Involving Human Subjects at the University of Western Ontario.

A needs survey questionnaire was developed from focus-group data (Koopman, 2003). Patients and interdisciplinary team members reviewed the needs statements to determine the validity of the content. A pilot test of the questionnaire with patients and significant others did not indicate the need for revisions. Words and phrases used by focus-group participants were retained in the original form to the greatest extent possible. Interdisciplinary team members, including neurologists, physiotherapists, occupational therapists, nurses, and research assistants,

did not identify any additional needs as perceived by their respective disciplines.

The needs survey questionnaire was similar for MS patients and significant others. A total of 75 needs statements were developed under seven categories (Table 1): physical (6), health (16), psychological (23), accessibility (4), financial (5), employment/leisure (9), and information (12). Respondents were asked to rank the needs statements according to level of importance on a four-point, Likert-type scale from 1 (*not important*) to 4 (*very important*) or *not applicable*. An open-ended question concluded each needs category; it asked respondents (a) "What other needs do you have?" and (b) "Is the need met with the help of spouse, friends, healthcare workers, etc.?" The purpose of this question was to identify needs that were not included in the questionnaire. This portion of the questionnaire was not consistently completed, possibly because of a flaw in the development of the questionnaire or because participants felt that all of their needs had been identified. Data from this portion of the questionnaire are not reported here. The Cronbach's alpha coefficient of the needs assessment was 0.87 for the MS patients, and 0.85 for the SOs.

On the survey, participants were also asked to complete a multiple-choice personal characteristics data form. Data from MS participants included demographic variables, type of housing, living arrangements, employment status, size of community, year of MS diagnosis, current disease course, and mobility level. Data from the SO participants included demographics, relationship, proximity to the MS patient, size of community, and employment status. Information regarding the MS patient obtained from the significant other included year of MS diagnosis, current disease course, and mobility level.

### Survey Administration

Participants were selected as described above. People who attended the focus groups may have been randomly selected to complete the needs survey. Each participant received a letter via mail that explained the study, along with the questionnaire and a stamped,

**Table 1. Sample Needs-Assessment Statements**

Needs Category	Needs Statement
Physical	To take a nap daily or sleep longer at night
Health	To have regular follow-up in the MS clinic
Psychological	To be supported in remaining positive
Accessibility	To have accessible housing
Financial	To be advised about financial planning early
Employment/leisure	To have a way to continue working after my current job becomes too much for me

addressed envelope. A reminder postcard was sent to all participants 6 weeks after the initial mailing. Consent to participate was assumed if a completed questionnaire was returned. A summary of results was sent to participants who completed a separate form that indicated they would like to receive the findings.

### Data Analysis

Differences between the needs of MS patients, and significant others were compared by using descriptive statistics for means (Student's *t* test), and proportions (chi-square test). Data were analyzed using the Statistical Package for the Social Sciences (Version 10 for Windows).

### Results

The questionnaire was returned by 353 MS patients (71%) and 240 significant others (48%). The sample was demographically representative of the general MS population (Table 2):

- 243 (70%) of the MS respondents were women ranging in age from 30 to 60 years
- 240 (70%) were married, living at home, and living with a spouse
- 190 (56%) of the MS respondents described their disease course as either stable or relapsing/remitting, with 149 (44%) describing their disease course as progressive
- 147 (62%) of the significant others were males ranging in age from 30 to 60 years
- 203 (85%) identified the person with MS as their spouse.

For data analysis, the rankings of *important* and *very important* were combined. The top 10 needs as identified by the MS patients and significant others are listed in Table 3 and Table 4, respectively. Both groups identified

the same priority of needs with few exceptions. Three themes emerged in the top 10 needs of the MS and SO respondents: psychological needs, interpersonal needs, and information needs. Seven of the top 10 needs for both the MS and SO respondents were psychosocial needs.

The psychological needs identified within the top 10 needs for both people with MS and significant others of people with MS were to maintain control in one's life, feel productive, have a sense of financial security, and plan for the future. There were no significant differences between the rankings of these needs for the MS and SO groups (Benbow & Koopman, 2003).

Needs in relationship to the MS healthcare team, community healthcare supports, and family/friends were identified in the top 10 needs statements. Both the MS and the SO groups identified these needs: to know that their doctors and individual MS team members are interested; that they have a supportive family doctor; and that they have the support of family and friends.

One hundred ninety-five (81%) of SO respondents ranked receipt of information about services offered by the MS Clinic as number 9 among the top 10 needs (Table 4). MS respondents ranked this need as number 14, but the difference in ranking was not statistically significant ( $p = .07$ ).

Significant differences in the ranking of the top 10 needs between the MS and SO groups were found. While 283 MS respondents (80%) ranked the need to know that individual MS team members were interested as number 7 within the top 10 needs, 219 (91%) of SO respondents ranked this need as number 3 within the top 10 needs ( $p = .05$ ). The need to receive regular

Variable	MS Patients (N = 353)		Significant Others (N = 240)	
	n	%	n	%
Sex (female-to-male ratio)	2.39		0.59	
Mean age (yr)	48		48	
High-school education	326	96	220	92
Employment (full-time or part-time)	102	31	148	66
Marital status (married and living with spouse in a single dwelling)	240	70	203	85
Residence (living in urban community)	209	63	142	60
Disease course				
Stable	98	29	60	26
Relapsing-remitting	92	27	58	25
Progressive	149	44	113	49
Mobility				
No aid required	155	46	101	44
Aid required	182	54	129	56

Table 3. Top Ten Needs of MS Patients (N = 353)

Rank	Needs Statement	n	%
1	To have the support of family and friends	330	93.4
2	To know that doctors are interested	314	88.9
3	To have a supportive family doctor	312	88.3
4	To feel productive in my life	308	87.5
5	To receive regular newsletters from the MS clinic	285	80.7
6	To be encouraged to maintain control of my life	284	80.4
7	To know that the individual MS team members that I see are interested	283	80.1
8	To hear information about the future as it relates to how my condition is now	280	79.3
9	To know that concerns have been heard by the MS clinic	275	77.9

**Table 4. Top Ten Needs of Significant Others of MS Patients (N = 240)**

Rank	Needs Statement	n	%
1.	To know that doctors are interested	222	92.5
2.	To have a supportive family doctor	219	91.2
3.	To know that the individual MS team members that my significant other sees are interested	219	91.2
4.	To have the support of family and friends	217	90.4
5.	To feel productive in my life	209	87.0
6.	To receive regular newsletters from the MS Clinic	209	87.0
7.	To be reassured that when I call the clinic "I am not bothering them"	205	85.4
8.	To be encouraged to maintain control of my own life	205	85.4
9.	To receive information about the services the MS clinic offers	195	81.2
10.	To have financial security to do all I want to do to make life with MS better	193	80.4

newsletters from the MS clinic was ranked as number 5 by 285 (80%) of MS patients, whereas 209 (87%) of the SO respondents ranked this as important (number 6). The difference in the ranking of this need between the MS and the SO respondents ( $p < .0001$ ) is statistically significant.

## Discussion

Studies investigating the needs of patients and caregivers can be found in the literature. Cancer and stroke care researchers have produced several studies of patient needs (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003; Hileman, Lackey, & Hassanein, 1992; Nikoletti, Kristjanson, Tataryn, McPhee, & Burt, 2003; Pierce, Gordon, & Steiner, 2004; 2003; Silveira & Winstead-Fry, 1997). The current study is unique in relation to previous MS needs studies because the focus-group data were used to develop the needs-assessment questionnaire. Most of the previous MS studies focused on identifying the needs of the caregiver or patient, using separate and often diverse instruments, whereas this survey used the same instrument for both the MS and SO populations, which allowed for comparison of the top 10 needs between the MS and SO respondents. The results of this study suggest that people living with MS and their significant others have similar needs. This study supports care currently provided in many interdisciplinary MS clinics across Canada, and suggests that, for the most part, separate services for MS and SO populations are unnecessary. The needs identified by the MS and SO respondents in this study do not

pose a significant challenge to MS care teams and community support organizations in providing services. The key finding in this study is that psychological and psychosocial care is an essential service for the MS population.

A need of significant others of MS patients identified in this study was to have access to MS care providers (Table 4). Involving the significant other in MS care by encouraging their attendance at clinic appointments, and consistently assessing patients' and caregivers' needs, will enhance the provision of services to this population. These findings are similar to those identified by McKeown et al. (2003).

One need that differed between MS and SO respondents was about information. It would be interesting to explore this difference further in future studies. Information from such studies could impact the planning and provision of education resources in MS clinics.

This study was conducted at one university-affiliated outpatient clinic with a clinic-specific population. The results, therefore, cannot be generalized to the overall MS population. The study results are interpreted for one point in time and no follow-up studies have been performed. Unfortunately, few individuals answered the question regarding who was meeting their needs. It is not clear whether clinic services are required to meet these needs or whether these needs could be met in the community. Further research on how individuals would prefer that their needs be met is recommended. The needs that patients expect to be met by the MS Clinic team also require examination. A better knowledge of those needs and expectations could help clinic staff build on the patient-centered care they provide. On a different level, future research could study healthcare provider perceptions of needs versus MS and SO perceptions to determine if they are similar.

The survey results were not a surprise to the investigators. Rather, the resulting list of top 10 needs validated the beliefs of the investigators with respect to their identification of needs in the patient population. The prevalence of psychosocial needs within the top 10 rankings validated the current interdisciplinary approach to MS care and may be valuable data in advocating for the continuation of such care during times of cutbacks and change within the healthcare system. The needs identified as needing to be met through MS Clinic services could also be the foundation of a patient-satisfaction tool.

## Summary

In this study, self-identified needs of people with multiple sclerosis were compared to needs of significant others of people with MS, using a questionnaire developed from focus-group methodology. The top 10 needs of the MS and SO populations were similar. Highly prevalent were psychological and psychosocial needs. The needs identified in this study can be met through

interdisciplinary MS care. As MS healthcare providers and MS community support organizations partner to provide the best possible care for people living with MS and their families, a focus on program planning related to identified needs will facilitate quality care for this population.

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## Posterior Reversible Encephalopathy Syndrome *continued from page 341*

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