2.1 Access to Medical Care: Medical Insurance and Suffering at Life's End

Key Points

1. Medical insurance or the lack thereof has a major impact on the type of medical care a patient may receive.

   Insurance coverage, rather than patient or family preference, often determines location of care.

2. Many families deplete their savings caring for loved ones at the end-of-life.

   Terminal illness impoverishes 40% of patients and families. Many patients worry about being a financial burden on their families.

3. Private insurance is often contingent on employment. Persons who become ill and unable to work often lose insurance coverage. Private insurance frequently does not cover hospice or home care.

   Payment schedules and covered services vary greatly from policy to policy. Patients who are unable to pay insurance premiums due to illness and loss of income lose their coverage.

4. Medicaid is a federal program administered by the state.

   Patients must apply for Social Security disability to apply for Medicaid.

5. Honorably discharged veterans are eligible for medical services through the Veterans Administration.

   Services and co-payment may vary based on factors such as income and service-connection status.

6. The Medicare hospice benefit covers hospice care.

   A physician certifies an individual as eligible for hospice care based on criteria that reflect the severity of the illness, primarily limited life expectancy. Patients or their representatives sign a form to elect hospice care that is primarily symptom focused and supportive and usually delivered in the home or a nursing home setting.

Access to Medical Care at Life's End

The Palliative Response

Impact of Medical Insurance

- Coverage, or lack thereof, determines

  Type of medical care a patient may receive

  Location of care

- Patients often use several different sources of payment during the course of an illness

Impact of Life's End on Family Finances

- Expenses not covered by insurance
- Loss of income
- Loss of insurance
- Loss of savings
- Loss of assets

Financial Burden

Many additional expenses at Life's End are not covered by insurance

- Transportation
- Medications
- Durable medical supplies
- Nondurable medical supplies
- Co-payments

Loss of Income

- Patient loses job and income due to inability to work
- Family members must leave work or limit hours to care for patient

Loss of Insurance

- Patient loses insurance when unable to maintain employment
- Patient is unable to pay COBRA

  The Consolidated Omnibus Budget Reconciliation Act of 1985 is a law that allows individuals to maintain their insurance if they leave their job. Most are unable to afford the cost if unemployed.

Loss of Savings

- Many families deplete their savings while caring for loved ones at Life's End

Loss of Assets

- Patient often loses home or other assets to qualify for long-term care

Impoverishment

- Terminal illness impoverishes 40% of patients and families

Emotional Burden

- Many patients worry about being a burden on family finances

Forms of Medical Insurance

Medicare

- Part A
- Part B
- Purchase supplements for co-pay
- Medicare HMO

Medicare Hospice
Benefit

- Type of care
  Primarily symptom management
  Usually delivered in home or nursing home
- Eligibility
  Must have Medicare A
  Physician certifies person as terminally ill and eligible for hospice care
  Patient elects hospice care
  - *Certifies understanding of terminal status*
  - *Requests care as defined by hospice*

Medicaid

- Administration
  Federal program administered by each state
  Differs from state to state
  Funds are a State-Federal match
- Eligibility
  Must first apply for Social Security Disability
- Primarily covers (e.g., Alabama)
  Nursing home care
  Prenatal and obstetrics care
  Pediatric care for children without private insurance

Veterans Administration

- Eligibility
  Honorably discharged veterans
- Coverage
  Services and co-payment may vary
- Factors determining coverage
  Income
  Service-connection status

Private Insurance

- Policies vary greatly
  Payment schedules
  Covered services
- Limitations for care at Life's End
  Hospice or home care frequently not covered
  Patient must continue to pay premiums to maintain coverage

Medically Indigent

Example: Jefferson Health System

- Eligibility
  Medically indigent resident of Jefferson County
- Coverage
  Primary ambulatory and acute hospital care
  Some prescriptions
  Some durable medical supplies
  HOSPICE CARE through County Health Department
- Co-pay determination
  Income
  Size of household

Access to Medical Care
The Palliative Response

- Be aware of realities of healthcare financing
- Be informed about resources available for patients
- Be sensitive to the economic burdens and realities of a life-threatening illness on patients and their families

Case 1

When Charlie was 40 years old, he began to have severe pain in his left hip that prevented him from working as a construction laborer. Thinking that he had injured himself on the job, he went to see a doctor to explore a worker's compensation claim.

The x-rays revealed that Charlie's problems were much more serious than first believed. He was referred to the oncology clinic, where it was discovered that he had metastatic cancer to the bones from an asymptotic lung cancer in his left lung.

Charlie was informed that:

1. the cancer was incurable because it had spread beyond the lung;
2. his life expectancy was estimated at less than a year (and that patients rarely live more than two years);
3. he would never be able to work again; and
4. he needed to start radiation treatment to reduce the pain in his hip and the risk of fracture, a treatment that would cost approximately $10,000.

Charlie is married with three young children. His employer offered no health insurance benefits.

What would you do?

Options

- Apply for Social Security Disability
  Charlie could wait 3–6 months for a determination.

- Apply for Medicare
  Since Charlie is only 40 years old, he must wait for two years after being deemed disable to apply for Medicare.

- Apply for Medicaid
  Charlie must apply for disability first.

- Apply for Assistance from Local Charities
  Such assistance is usually limited to a one-time benefit of a few hundred dollars.

Charlie is sponsored for the radiation by the local charity hospital. His pain improves, but within three months he develops progressive disease.

Charlie is a candidate for a chemotherapy study for a new experimental drug being compared to standard chemotherapy. Chemotherapy would cost more than $1000 a month. He enrolls in the study, which provides free chemotherapy. One month later, Social Security Disability and Medicaid are granted. Six months later, the lung cancer is stable but the chemotherapy study is completed.

One year after the initial diagnosis, several brain metastases are discovered, and Charlie begins another course of radiation therapy. Charlie enrolls in a hospice program using his Medicaid benefit. Charlie dies 20 months after the original diagnosis and four months before his Medicare benefits were to begin.

Questions

• What are the problems that Charlie had in accessing medical care?

• What are some possible changes in our health-care funding and delivery systems that would have improved Charlie's access to care and the quality of his care?

Case 2

Brenda, a 35-year-old self-employed cosmetics saleswoman, noticed that she had acquired a pot belly and that, over the last few weeks, she had developed small red spots on her legs. She decided to stop in at a local walk-in emergent care clinic between sales calls. She was told that her platelet count was dangerously low, which might cause her to bleed. Since she had no private insurance, she was referred to the local charity hospital.

Brenda was diagnosed with advanced cirrhosis of the liver brought on by an asymptotic infection with the hepatitis C virus and worsened by daily consumption of 2–3 alcoholic drinks. Further evaluation revealed ascites and an enlarged spleen causing the low platelet count. Brenda also has enlarged veins in her esophagus, called varicies.

Brenda stops drinking any alcohol and begins taking medications to reduce the fluid collection and the chance of a bleeding episode from the varicies. Despite this, she is admitted to the intensive-care unit for a life-threatening bleeding episode that requires more than 8 units of blood.

Brenda and her husband are informed that:

1. the cirrhosis of the liver is irreversible and progressive;
2. only one-third of patients with a bleeding episode survive for one year;
3. a liver transplant might help her condition, but she must have some form of insurance and be abstinent from alcohol for one year before she can be evaluated.

What would you do?

Options

- Apply for Social Security disability
  Brenda could wait 3–6 months for a determination

- Apply for Medicare
  Since Brenda is only 35 years old, she must wait for two years after being deemed disabled to apply for Medicare.

- Apply for Medicaid
  Since Brenda's husband is employed and they have some assets, such as a home and a car of modest value, their income is above the minimum allowed to qualify for Medicaid.

Brenda was awarded Social Security disability three months after the original diagnosis. She has been abstinent for one year but has had two more life-threatening episodes of bleeding and has declining hepatic function. It will be 10 more months before she is eligible for Medicare.

Questions

• What are the problems Brenda had in accessing medical care?

• What are some possible changes in our health-care funding and delivery systems that would have improved Brenda's access to care and the quality of her care?

Case 3

Despite David'd weight of nearly 325 pounds, his family has managed to bring him to the ER for the third time this month. Each time he received a shot of IV medicine to make him urinate some of the nearly 30 pounds of water weight that had collected since the previous visit and was causing him to gasp for breath.

David had developed severe heart disease secondary to morbid obesity and emphysema from smoking. The ejection fraction of his heart was less than 20% (normal is 60%). David had been intubated in the past when he was severely short of breath and had informed his family and doctor that he wanted no aggressive life support in the future. In light of this and his frequent visits to the ER, David was referred to home hospice.

Having been disabled for more than two years, David qualified for Medicare; but it did not help pay for the expensive medicines required for his heart and lung conditions. The hospice team developed a plan to help David and his family to manage his illness. The plan included setting up David's medications in a pill box, helping the family budget for medicines not covered under the Medicare Hospice Benefit, and daily weighing to adjust David's water pill dose.

In the first month, David controlled his water weight gain, his depression and anxiety improved, the hospice dietician helped him lose nearly 15 pounds, and a low dose of opioid reduced his constant sense of breathlessness and improved his exercise tolerance. After six months with no ER visits, the hospice program discharged David since his prognosis seemed to have improved and was probably greater than the six months required for hospice care.

What would you do?

Outcome

The hospice program tried to prepare David and his family for discharge by establishing him with a primary doctor and seeking financial support for his medicines. David's new doctor did not approve of the use of the opioid (Lortab5™, 1 tablet four times a day) for air hunger, and David found it difficult to keep his clinic appointments.

Four months later, David had three episodes of severe shortness of breath requiring an ER visit. On the third occasion, he died in the ambulance and was coded unsuccessfully.

Questions

• What are the problems that David had in accessing medical care?

• What are some possible changes in our health-care funding and delivery systems that would have improved David's access to care and the quality of his care?

Medicare

Medicare is a national health insurance program for people ≥65 years of age, certain younger disabled people, and those with kidney failure on dialysis for greater than three months.

A U.S. citizen who is at least 65 years old is eligible for Medicare if the person or the person's spouse worked for at least ten years in Medicare-covered employment. A person under 65 can get Medicare if the person is a dialysis or kidney-transplant patient or has received Social Security disability benefits for 24 months.

Medicare is divided into Part A (Hospital Insurance) and Part B (Medical Insurance). Part A helps pay for care in a hospital, skilled nursing facility, home health and hospice care. Part B helps pay for physicians, outpatient care, and various other services not covered in Part A.

Medicare Hospice Benefit

Medicare coverage for hospice care is available only if:

1. the patient is eligible for Medicare Part A;
2. the patient's physician and hospice Medical Director certify that the patient is terminally ill with a life expectancy of six months or less;
3. the patient signs a statement choosing hospice care instead of standard medical benefits for the terminal illness; and
4. the patient receives care from a Medicare-approved hospice program.

When all requirements are met, Medicare covers physician services, nursing care, medical equipment and supplies, outpatient drugs for symptom relief and pain management, home health aides, physical and occupational therapy, speech therapy, and dietary and other counseling.

Not covered are treatment for terminal illness except for symptom management and/or pain control, care provided by another hospice not arranged by the patient's hospice, and duplication of required hospice services by another provider.

Social Security Disability

A person can receive Social Security (SS) disability benefits at any age. To qualify, a person must have contributed to Social Security long enough and recently enough through their employment. In most cases, a person needs 20 credits earned in the last ten years ending in the year of becoming disabled. However, younger persons may qualify with fewer credits:

- Before age 24 – Six credits earned in the three-year period ending when the disability began
- Age 24–31 – Must have credit for working half the time between age 21 and the time of becoming disabled
- Age 31 and up – Varies depending on the age disabled

Disability is determined by a team consisting of an MD and a Disability Evaluation Specialist. Disability is determined in a step-by-step process involving five questions:

1. Are you working? – A person earning greater than $500/month cannot be determined as disabled.
2. Is your condition severe? – The impairment must interfere with basic work-related activities for the claim to be considered.
3. Is the condition found in the list of disabling impairments? – Social Security maintains a list of major body impairments sufficiently severe to warrant automatic determination of disability. If the condition is not on the list, Social Security will determine whether it is severe enough to warrant disability.
4. Can the person do the same type of work previously performed? – If the condition is severe, but not the same or of equal severity as an impairment on the list, then Social Security must determine if it interferes with the person's ability to do the work performed in the last 15 years. If it does not, the claim can be denied.
5. Can you do any type of work?

Note: A person must receive Social Security disability for 24 months to be eligible for Medicare.

Medicaid

Generally, Medicaid is awarded if a person is eligible for Supplemental Security Income (SSI). Medicaid covers health-care costs for persons who are blind, disabled, or fall below a certain percentile of the poverty level. Unlike Medicare, Medicaid offers a perscription benefit. Most patients in nursing homes are covered by Medicaid after depleting their personal funds.

Private Insurance

Different policies pay different amounts. In general, private insurance does not pay as well as state and federal programs except in the case of Railroad Retirement, Champus, and certain pensions. Supplemental policies are almost always necessary to cover all expenses.

The Medically Indigent

Example: Jefferson County, Alabama

- Covered in Jefferson County through the Jefferson Health System.
- The patient must be a Jefferson County resident.
- The patient is assessed according to income and the number of persons in the family.
- A scale based on the federal poverty guidelines is used to determine the amount of assistance given.

Selected Readings

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Policy Recommendations

Sandy, L. G. "Homeostasis without Reserve—the Risk of Health System Collapse." *New England Journal of Medicine* 347 (2002): 1971–1975.

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