

Financial Burdens for People with MS, their Families, and Society

Overview of Costs

- The average annual costs for someone with MS in the U.S., including both direct and indirect costs (i.e. lost wages), is approximately \$69,000. Of this, approximately \$39,000 consists of health care costs. Total costs for all people with MS in the U.S. is approximately \$28 billion annually.
- Among people with MS, 5% of family incomes and 25% of individual incomes fall below the federal poverty level. (Minden et al, 2006)
- Compared to those with relapsing-remitting MS, people with primary progressive MS are more likely to be unemployed (82% vs 42%) and have lower family income. (Sonya Sifika Study, 2006)
- The costs associated with MS increase with greater disability. Costs for severely disabled individuals are more than twice those for persons with relatively mild disease. (Kobelt, et al, 2004)
- Compared to an individual with an EDSS score of 2, costs for an individual with an EDSS score of 8 are almost three times as high. (Lipsy et al, 2009)

Medical Care

- The two most frequent reasons cited for stopping disease-modifying therapy are perceived lack of efficacy (24%) and cost (13%). (Minden et al, 2008)
- Among people with MS, the most frequently cited reason for difficulty in access to prescription medication, MS medical care, and mental health care was cost. (Minden et al, 2007).
- People with MS living in rural areas, especially those areas most distant from large population centers are more likely to have difficulty getting MS care due to a lack of money. (Buchanan et al, 2006)
- Although the vast majority (90+%) of people with MS have some form of health insurance, 70% report at least some difficulty paying for health care and 16.4% reported a lot of difficulty. 21% reported that they had spent less on food, heat, and other necessities in order to meet health care expenses. Many also reported putting off seeking health care (30%) because of costs, delaying filling prescriptions, skipping doses of medications, or splitting pills (20%) due to costs. (Iezzoni & Ngo, 2007)

- People with MS who are employed and/or have higher incomes are up to 50% more likely to be taking a disease modifying drug. (Minden et al, 2008)
- Among people with MS, factors associated with not seeing a neurologist for a year or more include being unemployed, lacking health insurance, being older, and having a lower income. (Buchanan et al, 2008)
- A study of the cost-effectiveness of the MS DMT's found that over a two-year period, the costs for both drugs and medical care in order to prevent a single exacerbation ranged from around \$80,000 to \$140,000, depending on which MS DMT was utilized. The largest proportion of these costs was attributable to the cost of the DMT's. (Goldberg et al, 2009)

### Out of Pocket Costs and Their Impact

- A recent study of medical bankruptcy (Himmelstein et al, 2009) found that 62.1% of all personal bankruptcies in the U.S. were related to medical costs. The authors reported that:

Among common diagnoses, nonstroke neurologic illnesses such as multiple sclerosis were associated with the highest out-of-pocket expenditures (mean \$34,167), followed by diabetes (\$26,971), injuries (\$25,096), stroke (\$23,380), mental illnesses (\$23,178), and heart disease (\$21,955). (p. 4)

- Gleason et al (2009) investigated the impact of the out of pocket costs associated with filling a prescription for an MS disease modifying drug for the first time. Subjects of the study were individuals with MS residing in the U.S. and enrolled in a number of private health plans. The out of pocket costs could be either co-payments or co-insurance associated with the individual's pharmacy benefits. The average out of pocket cost was \$112.75 and 84% had costs of \$100 or less. However, the investigators found that the higher the out of pocket costs, the less likely the individual was to actually fill the prescription. When out of pocket costs were \$100 or less, only 3.5% did not fill the prescription. This percentage rose to 19.7% when these costs were between \$251-\$500 and 30.8% when costs were over \$1,000.
- Among persons with MS taking one of the disease modifying drugs, those paying more than \$150 out of pocket for each prescription were 19% less persistent (a measure of adherence to therapy) than those paying less than \$20. (Express Scripts, Inc., 2006)
- Median out of pocket costs for health care among people with MS (excluding insurance premiums) was almost twice as much as the general population (Minden et al, 2007).
- In over a third of cases, people with MS and their families paid 100% of the cost of mobility aids such as canes, crutches, walkers, and wheelchairs. (Iezzoni, 2006)

- In a Harris Interactive poll conducted during the first few years in which the MS disease modifying drugs were available, 30% of those not on one of the drugs cited cost as one of the reasons for not being on therapy. (Taylor & Leitman, 2001)

#### Age as it Affects MS Costs

- People with MS who are 65 or older are more likely to be unemployed, have lower incomes, live alone, have more trouble with walking, bowel and bladder function, and need help with activities such as travel, shopping, bathing, dressing, and using a toilet. (Minden et al, 2004)
- Among persons with MS over the age of 55, one in five report unmet needs concerning wellness or health promotion services. (Finlayson, 2005)
- Compared to people with MS over 30, those 30 and younger tend to have lower incomes, are less likely to have health insurance, but are more likely to be employed. (Buchanan et al, 2009a)

#### Insurance

- Among people with MS who do have health insurance, out of pocket costs for insurance premiums are close to \$2000 per year while around a quarter of people pay over \$2000 annually. In spite of the high cost for health insurance almost one in five have coverage that pays nothing for prescription drugs. (Minden et al, 2007)
- Just over half of people with MS report that they have long-term disability insurance. (Iezzoni & Ngo, 2007)
- One-third of the MS population has no life insurance and more than half of those who apply for life insurance after being diagnosed with MS are turned down due to their MS. (Iezzoni, 2006)

#### Employment

- Although almost all people with MS have a work history and labor force participation at the time of diagnosis is comparable to that in the general population, over time the ability of people with MS to remain in the labor force declines steadily. This decline may be as much as three percentage points per year following diagnosis. At present just slightly more than 40% of the MS population is working. (Minden et al, 2006; Sonya Slifka, 2006)

#### Long-Term Care

- More than a quarter of people with MS use some form of home care but over 80 of this care is provided by unpaid caregivers, mainly family members and, in many cases, youngsters. (Whetten-Goldstein et al, 1998; Sonya Slifka, 2006)

- Almost 30% of informal caregivers reported also using a paid housekeeper and 30% reported using a paid nurse or aide. (Buchanan et al, 2009b)
- 10% of informal caregivers report that they cannot work due to their caregiving responsibilities. ( Buchanan et al, 2009b)
- In a survey of caregivers' perception of predictors of nursing home placement, aging, bowel dysfunction, poorer health, functional decline in the person with MS, and caregiver burden were associated with increased probability of future admission. Higher family income and greater satisfaction with access to MS-focused care were associated with lower risk of nursing home admission. (Buchanan et al, 2010)

### Implications

- Health insurance does not guarantee coverage for prescription drug medications, or necessarily ensure prescription drug medications are affordable for the consumer.
- Increasing medical costs, including costs for prescription drugs, correlate with a decreasing adherence to treatment and use of prescription drugs.
- Multiple sclerosis directly impacts the financial stability of the person diagnosed, and his or her family. Factors that contribute:
  - Median out-of-pocket medical expenses (Minden et al, 2007)
  - Inability to work due to disease progression (Minden et al, 2006)
  - Mobility aids (Iezzoni, 2006)
  - Paid nurse or aide (Buchanan, 2009)
- Multiple sclerosis is associated with the highest out-of-pocket expenditures among common, non-stroke neurologic illnesses. Medical costs account for more than half of all personal bankruptcies in the U.S.

### Recommendations

- Costs impede access to disease modifying therapies and adherence to prescription drug regimes. To better ensure access and treatment, advocacy to limit out-of-pocket expenses for the consumer should be undertaken.
- Costs permeate all aspects of family life and finances. To mitigate these adverse consequences, advocacy should be undertaken to enhance:
  - Employment services
  - Affordable and accessible housing
  - Home and community based services
  - Respite care resources

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*Questions or Comments?*

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