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Complex Home Care: Part II – Family Annual Income, Insurance Premium, And Out-of-Pocket Expenses

Executive Summary

- Annual costs paid by families for intravenous infusion of home parenteral nutrition (HPN) health insurance premiums, deductibles, co-payments for health services, and the wide range of out-of-pocket home health care expenses are significant.
- The costs of managing complex chronic care at home cannot be completely understood until all out-of-pocket costs have been defined, described, and tabulated.
- Non-reimbursed and out-of-pocket costs paid by families over years for complex chronic care negatively impact the financial stability of families.
- National health care reform must take into account the long-term financial burdens of families caring for those with complex home care.
- Any changes that may increase the out-of-pocket costs or health insurance costs to these families can also have a negative long-term impact on society when greater numbers of patients declare bankruptcy or qualify for medical disability.

THE OUT-OF-POCKET HEALTH care costs paid by families managing complex technology-based home health care are often absent or underreported (Clabaugh & Ward, 2008; Stanton & Rutherford, 2005) and have yet to be systematically tabulated or estimated (National Association for Home Care and Hospice, 2008). Annual costs paid by families for intravenous infusion of home parenteral nutrition (HPN) health insurance premiums, deductibles, co-payments for health services, and the wide range of out-of-pocket home health care expenses are presented. Subsequently, the economic impact of these non-reimbursed expenses on family quality of life and patient's clinical outcomes are analyzed.

Background

The definition of out-of-pocket costs varies and may include any one or a combination of expenditures paid by families for insurance premiums, deductibles, co-payments for health services, or items not covered by insurance such as home health personnel needed to assist with patient care and home care supplies, transportation, and costs to obtain services (Hwang, Weller, Ireys, & Anderson, 2001; Naessens et al., 2008).

For this study, out-of-pocket costs were defined as medically related expenses for HPN care and

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services not reimbursed by insurance. Insurance premiums were defined as the premiums families paid annually for the HPN patient's health insurance. This average does not include any premium portion paid by employers or government payers. The deductible costs were defined as the amount paid each year for various patient services before insurance coverage of these expenses begins (Mosby, 2008). Co-payments were defined as the fixed amount paid at the time of receiving health services, often $10-$50 for each doctor's appointment or $500 for emergency room visits.

Most plans require co-payments for annual physicals and other specifically identified health services (Lightbulb Press, 2008). Deductible payments for emergency room and other out-of-pocket costs were tabulated on an annual basis. Premiums, deductibles, and co-payments for physicians and prescriptions were reported by patients on a monthly basis. The use of these clear and comprehensive definitions for what constitutes out-of-pocket costs enhances the clarity of data collected in this study (Health Insurance Information, 2009).

Study Design and Methods

Data were collected for this institutional review board approved study from patients who provided signed consent forms to participate. The 80 families were recruited through home care infusion agencies and the Oley Foundation, a 501(c)(3) non-profit organization for families managing HPN. Data collection methods included the completion of a health services/out-of-pocket expense questionnaire and semi-structured interview questions about health insurance coverage. This use of prospective expense questionnaires for collecting the wide range of out-of-pocket expenses has been validated in several studies (Goossens, Rutten-van Mölken, Vlaeyen, & van der Linden, 2000; Hoogendoorn, van Wetering, Schols, & Rutten-van Mölken, 2009; Ritter et al., 2001; Saba & Arnold, 2004; Stark, König, & Leidl, 2006), including the national survey by the U.S. Medical Expenditure Panel Survey collected across decades by the Agency for Healthcare Research and Quality (AHRQ, 2009a; Cohen, Howard, & Smith, 2003).

Family income adequacy was also measured using the Family Economic Stability Survey (Fillenbaum & Smyer, 1981). Using this income adequacy survey, patients rated their ability to pay monthly bills as "can't make ends meet," "have just enough no more," "have a little extra sometimes," or "always have money left over." As in other studies these survey results were found reliable with rating of patients and caregivers living in the same household highly correlated (Smith, 1999; Smith et al., 2003; Smith, Fernengel, Werkowitch, & Holcroft, 1992). In prior studies, health care economists have judged the Family Economic Stability Survey to be valid and reliable for obtaining information on health services use and family income adequacy (R.E. Lee, personal communication, 2002; Smith, Kleinbeck, Fernengel, & Mayer, 1997; Spaniol, 2002; A. Williams, personal communication, 2008).

Sample

The sample for this study included patients requiring lifelong HPN for nonmalignant bowel diseases and their family caregivers, mean age 50 years and 49 years respectively. One-third (33%) of the patients and 42% of the caregivers were male. All patients selected White as their race except one African-American. Caucasians are disproportionately affected by Crohn's disease resulting in 97% of HPN (Crohn's/Colitis Foundation, 20xx). The caregivers were 89.7% (n=70) White, 5.1% (n=4) Hispanic, one caregiver was American Indian/ Alaskan Native, and one Asian while two reported their race as "other." Patients in this sample had required lifesaving HPN care for an average of 8 years (SD=8 years). The majority of subjects (88%) had some college education.

Results

Family income adequacy. Fifty-five percent of survey respondents were on medical disability, while 27% of patients and 68% caregivers were employed. Also, 12% of patients and 16% of caregivers were retired. Patients reported annual family income ranging from $10,000 to $100,000 per year with the median between $20,000 and $30,000 per year. One patient reported family income for the year as $3,000. There was consensus on family income data reported by patients and their caregiver. There were 12 families with more than one caregiver and each of these secondary caregivers was either not employed or did not contribute to family income. And there was no significant difference in these 12 caregiver pairs on their income

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Part III, which will appear in the November/December 2010 issue of *Nursing Economic$*, will address the economic impact on family caregiver quality of life and patient's clinical outcomes.

Table 1.
Family Monthly Income Adequacy Ratings by HPN Patients in a 2002 Sample and the Current Sample

Monthly Income-to-Expense Ratings by Patients of the Family Income[1]	2002 HPN Sample (N=85)	Current HPN Sample (N=80)	Percentage and Direction of Changes between 2002 and Current Sample Ratings
Can't make ends meet	6.4%	11.35%	Increase of 4.9%
Just enough, no more	22.6%	29.6%	Increase of 7.0%
Have a little extra sometimes	64.5%	43.0%	Decrease of 21.5%**
Always have money left over	6.5%	16.2%	Increase of 9.7%*

*$p \leq 0.05$ ** $p \leq 0.01$

[1]Using this survey, patients rated their ability to pay monthly bills as "can't make ends meet," "have just enough to pay bills, no more," "have a little extra sometimes," or "always have money left over."

adequacy ratings. When patients were asked to rate the adequacy of family income compared to paying monthly expenses, 29.6% reported having "just enough" money to pay monthly bills and "no more," while 43% reported "having enough, with a little extra sometimes." On the extremes of this rating scale, 11.3% reported they "can't make ends meet," while only 16.2% "always have money left over."

Table 1 shows a comparison of family income adequacy ratings from this current sample of patients with income adequacy ratings obtained from a sample of HPN patients in an earlier study (Smith et al., 2002). As shown in the right hand column, since 2002 there has been a 4.9% increase in the proportion of patients stating they "can't make ends meet," a 7% increase in those who have "just enough money to pay bills, and no more," and 21.5% fewer who "have a little extra sometimes." In this current sample, however, the percentage reporting they "always have money left over" after paying monthly bills was 9.7% greater than in the 2002 HPN sample. Patients and caregivers in this study reported the need to keep a job to maintain health insurance coverage.

Health insurance coverage expenses paid by families. Eighty families reported on the types of insurance they had for HPN coverage. One patient was uninsured. HPN families reported a wide range of medical insurers and an assortment of plans offered by the same insurer. Overall, 55% of these 80 families had private insurance with 67% having more than one health insurance policy. Over a third (37%) had Medicare insurance.

Only 12 families were aware of the individual lifetime maximum benefit limit of their insurance policy. Three families reported no restriction on the lifetime maximum amount that would be covered by their insurance plan. Those few subjects who knew their lifetime maximum coverage allowed reported a range of $1 million to $5 million.

Subsequently, 30 families completed the expanded health insurance premium costs questionnaire that detailed information about the amounts spent for patients' insurance, premiums, co-payments, deductibles, and out-of-pocket HPN health care expenses. Though all reported their current health insurance plans covered some HPN-related expenses, 20% rated their health insurance coverage as inadequate for HPN costs, and 23% rated their coverage for other family members as inadequate.

Health insurance premiums data. The monthly range, midpoint, and estimated annual out-of-pocket costs including premiums, deductibles, co-payments, and other out-of-pocket expenses are shown in Table 2. Twenty-five families reported health insurance premium costs ranged from $100 to $1,700 per month (midpoint $350 per month or $4,200 annually). Six families paid no medical insurance premiums as the patients were covered by a state high-risk plan. One patient met low income criteria for Medicaid, and one family's employer paid their premium. Medical equipment (HPN intravenous pumps and syringes) was generally included within the medical insurance plan.

Additional premiums for prescription coverage, ranging from $10 to $87 each month (median $46), were paid by six families. One family had a medical assistance supplemental plan that paid for their annual prescription drug premium. Thus, the overall average out-of-pocket annual cost for health insurance premiums was $4,200. With additional enrollment in a separate prescription plan, the annual average insurance premiums could rise to $4,752.

Deductibles cost data. Two types of deductibles were reported by families: (a) an annual amount for all services covered under the

Table 2.
Monthly Midpoint and Annual Estimated Out-of-Pocket Expenses Related to HPN

Reported Family Expenditure for the HPN Patient	Monthly Range of Expenses Reported	Monthly Midpoint of Expenses	Annual Estimated Out-of-Pocket Expenses
Insurance Premiums			
Medical ± Prescription	$100 - $1,700	$350	$4,200
Supplemental prescription	$10 - $87	$46	$552
Insurance deductible for various health services	0 - $3,000	$250	$3,000
Co-Payments/Co-Insurance			
Physician visits[1]	$10 - $40	$25	$300
Prescriptions related to HPN[2]	0 - $100	$6.4	$77
Emergency room visits	Not applicable	Not applicable	$250
Other Out-of-Pocket Costs			
OTC medications			$240
OTC supplies			$60
Equipment			$279
Furniture to store HPN supplies			$490
Long distance telephone			$360
Housekeeping			$1,616
Travel for medical care			$570
Home care assistance			$900
Family members' HPN medical education conference			$1,581
Child care during HPN services[3]			$4,000
Total Annually			$17,923[4]

[1] Provider visits for HPN only, not the underlying or concomitant medical conditions; also excludes laboratory/radiology charges. These co-payments for physician visits were similar for private ($10-50) or public insurance ($25-$40).

[2] Prescription costs other than infusion pharmacy costs. Because these bowel disorder patients cannot absorb oral medications, they have few pharmacy medication bills.

[3] Not all families reported child care costs.

[4] Total does not include cost of a supplemental prescription or health insurance plan premium, or if any hospital admission out-of-pocket costs which can be up to $12,000, for an intravenous line infection hospitalization total charge of $60,000.

insurance plan, and (b) additional deductible amounts to be paid for specific health services such as emergency room visits or outpatient surgery admissions. Deductible amounts for the same service often differed among families. If families used providers in the insurance company's network, the amount of the deductible was reported to be less than if they used the services of out-of-network providers.

Fourteen of the 30 families reported annual out-of-pocket health insurance plan deductibles (in-network). Five families did not have any out-of-pocket deductible costs that year, and three reported their deductibles were paid by their state high-risk insurance pool. Ten patients listed the amount of the medical plan deductibles as ranging from $1,000 to $3,000 (mode $3,000).

Among these families, the annual deductible for in-network health care services was $1,500, whereas non-network services required a $3,000 deductible to be met before insurance benefits would be applied. Deductible rates for emergency room visits were reported by three families. Two were expected to pay a $50 deductible, and the third family would expect to pay a $500 deductible for each emergency room visit.

Co-payments cost data. Most health plans also required the insured to share the costs of health services in the form of co-payments. These co-payments were often due at the time of service. Twenty of the families provided information regarding the HPN consumer's co-payments, and 10 of those reported the amount charged varied based on the specific health service utilized. These charges might be fixed amounts or a percentage of the allowed charge (with 20% the most frequently reported). Whether based upon a fixed amount or a percentage, the most common co-payment for a physician appointment ranged from $10 to $40. Twenty-seven percent of these patients had public insurance only; they reported

MD office co-payments ranging from $25 to $40 while patients with private insurance only had office visit co-payments between $10 to $50.

Deductibles for emergency room and other out-of-pocket costs were estimated on an annual basis and incurred at time of utilization. Deductibles and co-payments for physicians and prescriptions were collected monthly. Four families did not pay any co-payments. For three families, co-payments were paid by the state high-risk insurance pools, and the fourth family's insurer paid 100% of medical costs after the $3,000 deductible was paid by the family.

Nineteen families also reported rates for prescription drug co-payments. Eleven of the 19 families reported charges based on a tiered prescription payment system with smaller co-payments for generic and formulary drugs and larger co-payments for non-formulary or brand-name prescriptions. The most common co-payment for generic drug prescriptions was 20% of the cost, reported as ranging from $2.25 to $20 (mode $20). Also reported were high co-payments of up to 50% (a four-fold increase) for non-formulary drugs with those costs ranging from $5.60 to $100 (median $39). Mail order prescriptions had a different set of co-payments. Two families paid fixed rates for all drugs, one family paid $5.00 per prescription, and the other paid $1.00 for each drug. For these families the annual average co-payments for physician visits were $300 and for prescriptions were $77.

Other out-of-pocket health expenses related to HPN. All families reported out-of-pocket HPN-related expenses covered by insurance. These costs were for over-the-counter (OTC) medications, supplies, furniture/transport devices, travel, long distance telephone costs for health services, child care, housekeeping, and home care assistance. Families reported spending 0 to $200 a month (median = $240 per year) on OTC medications, and 0 to $125 per month (median = $60 per year) on OTC supplies. The midpoint out-of-pocket expense for items such as furniture to organize HPN supplies and/or wheelchairs was $490 per year.

Five of these families had children under 18 in the household indicating legal and financial responsibilities. However, there was no significant difference between the ratings of family income adequacy for families with or without children (χ^2=2.54, p=0.469). Other out-of-pocket expenses reported by these families included a median of $279 for equipment (e.g., bags, pump, etc.) and $360 per year for long distance telephone calls to their health care providers. Eleven families required housekeeping assistance, and the median costs were $1,616 per year. The median travel cost for gas and highway tolls for HPN clinic visits was $570, while $900 per year was spent for home care assistance. Ten families reported they attended the Oley Foundation or a similar HPN education conference. The reported conference costs ranged from $479 to $3,500 (median = $1,581 per year). The median for child care expenses was $4,000 per year (n=5).

Twenty-three percent of these families reported some or all of their OTC medication and supply costs were tax deductible or met criteria for reimbursement from their Flexible Spending or Health Saving Accounts. Only 17 of these families had Flexible Spending Accounts, and 11% had Health Saving Accounts. The remainder of the families either did not know or were not eligible for such tax savings plans that could cover some of their out-of-pocket health care expenses.

Summary of all out-of-pocket expenses. These families reported a variety of insurance types and premium costs and a wide range of out-of-pocket amounts paid for HPN-related care. The median in these out-of-pocket expenditure categories was used to estimate the average spent per year. Overall, the out-of-pocket expenses for health insurance premiums could be as high as $4,752 if the family required a supplemental prescription plan. Based on data from this sample, HPN patients pay an average of $3,627 per year out-of-pocket for co-payments and deductibles and up to $10,096 per year for expenses such as long distance phone calls, home care assistance, child care, housekeeping services, and travel costs for medical services or for attending a medical education conference. Co-payments for emergency room visits and other out-of-pocket costs were estimated on an annual basis. Premiums, deductibles, and co-payments for physician's visits and prescriptions were reported on a monthly basis (see Table 2).

Discussion

Data from this study suggest costs to families for annual health insurance premiums and other HPN-related out-of-pocket expenses are substantial and widely variable. All totaled, the HPN families pay an average of $17,923 per year out-of-pocket for HPN. In addition, as found in Part I (Piamjariyakul et al., 2010), these families average non-reimbursed billing costs (typically 20% of charges) for health service use and one yearly hospitalization was $12,943. Thus, HPN families total annual average out-of-pocket plus non-reimbursed costs of $30,866 is startling when compared to the average annual U.S. household income in 2007 of $50,233 (U.S. Census Bureau, 2008). Potentially half of the annual family income may be required for out-of-pocket costs related to HPN.

Further, a German study of costs related to inflammatory bowel disease (the most common reason for HPN) found over half of the non-reimbursed health care costs were attributed by families to loss of work time and necessary

early retirement (Stark et al., 2006). A study limitation is that it did not address work time loss or career delays because of HPN. For HPN patients and caregivers who are in the prime of their working careers, with children and mortgages, the financial impact of missing work or opportunities for promotion could be dramatic with a lifelong effect.

In the United States, out-of-pocket costs for OTC supplies, travel for health services, and long distance phone calls to professionals are not typically included in third-party payers cost of care. In France, where specialty centers manage HPN, these out-of-pocket costs to families are reimbursed for travel expenses and home care services (Tu Duy Khiem-El Aatmani et al., 2006).

As in other chronic home care studies, annual out-of-pocket expenditures of families in this sample varied from none to thousands of dollars per year (Bernard, 2007). Deductibles and co-payment amounts varied even within the same insurance company depending on the type of plan the patient qualified for and costs were reported to continue to increase annually. In 2008, the average employee paid $3,394 to cover their family's medical insurance premium while our data revealed HPN families pay $4,200 out-of-pocket (AHRQ 2009b). In some instances, HPN patients who met criteria for publicly funded state high-risk insurance pools reported paying little or no out-of-pocket costs, but worried coverage was being depleted statewide (Zerzan, Edlund, Krois, & Smith, 2007). The National Coalition on Health Care (2008) reported workers paid 12% more for employer-sponsored health insurance premiums in 2008 than they did in 2007. It is notable 77.9% of those filing for medically related bankruptcy already had health insurance (Himmelstein, Thorne, Warren, & Woolhander, 2009). This high rate of medically related bankruptcies aligns with our data revealing each family has large annual out-of-pocket expenses, costly health insurance premiums, deductibles, co-payments, and supply or equipment bills to pay (Zerzan et al., 2007).

The costs of managing complex chronic care at home cannot be completely understood until all out-of-pocket costs have been defined, described, and tabulated.

Compared to data from a previous national HPN population, the proportion of patients in this current sample who qualified for medical disability benefits increased from 40% to 55%. Comparisons in Table 1 between this sample and another HPN population collected in 2002 (Smith, 2002) revealed 5% to 7% more patients in the current sample rated their family income as "can't make ends meet" and reported they "have just enough but no more" after paying bills. Also, these income adequacy ratings found a significant 21% decrease in families having only "a little extra money left over" after paying their monthly bills. In contrast, in this current study there was an increase of almost 10% of families reporting "always have money left over" compared to the 2002 HPN sample. The increased percentages of those reporting always having money left over and those having less than enough money in this sample is not explained by the known association between higher incomes and increasing age (Swartz, 2006). However, these data may align with the past decade in the U.S. economy where "the poor become poorer" and those at higher income levels gained more disposable income (Organisation for Economic Co-operation and Development [OECD], 2008). Yet the unreimbursed and out-of-pocket expenses families paid for HPN care were reported to rapidly deplete family savings.

Implications and Conclusions

At the time of this study, families in the United States with chronic illnesses were reported to pay more than 10% of their income for out-of-pocket expenses for their health services (Bernard, 2007). Yet, our interview data confirmed that even with insurance coverage (often with multiple plans and/or disability coverage) HPN families report expensive insurance premiums, co-payments, deductibles, and numerous other out-of-pocket costs which can easily exceed 10% of their income. While these families were thankful for having insurance, several also noted the financial burden that results from increasing premiums and deductibles and the co-payments for health care professional services.

The costs of managing complex chronic care at home cannot be completely understood until all out-of-pocket costs have been defined, described, and tabulated. Non-reimbursed and out-of-pocket costs paid by families over years for complex chronic care negatively impact the financial stability of families. A flexible health care spending account could help patients and families with these costs (Vaughan, 2009). We strongly recommend all future economic impact studies include data collection on out-of-pocket costs.

These data indicated national health care reform must take into account the long-term financial burdens of families caring for those with complex home care. Any changes that may increase the out-of-pocket costs or health insurance costs to these families can also have a negative long-term impact on society when greater numbers of patients declare bankruptcy or qualify for medical disability. Advocacy for these families by the Oley Foundation, health professional groups, and third-party payers include design-

ing approaches that help reduce non-reimbursed expenses. **$**

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