COSTS OF CHRONIC DISEASE AND AN ALTERNATIVE TO REDUCE THESE COSTS: CASE STUDY OF END STAGE RENAL DISEASE (ESRD)

A Dissertation

by

WON-IK JANG

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

December 2003

Major Subject: Agricultural Economics

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ABSTRACT

Costs of Chronic Disease and an Alternative to Reduce These Costs:

Case Study of End Stage Renal Disease (ESRD).

(December 2003)

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An improved understanding of the costs of diseases is obtained by conducting a case study of the costs associated with end stage renal disease (ESRD). In estimating the costs of ESRD, the costs incurred by both patients and their primary unpaid caregivers are calculated. Most economic studies of the costs of diseases ignore either the patients' or unpaid caregiver side, focusing on one or the other. From a theoretical standpoint, it is shown unpaid caregiving lowers the costs of diseases to society. Unpaid caregiver lowers the cost, because for unpaid caregiving to occur, the net benefits of unpaid caregiving must be lower than the net benefits of hiring a paid caregiver.

Using patients and their primary caregivers at the Gambro Dialysis Center in College Station, Texas as a case study, estimated total ESRD costs range from $84,000 to $121,000 / year / case. The distribution of these costs is positively skewed. Of the total costs, approximately 2% to 25% can be attributed to unpaid caregiving. Excluding direct medical costs in total ESRD costs, unpaid caregiving is 14% to 65% of total

ESRD costs. Consideration of unpaid caregiving costs is, therefore, an important component of the costs of diseases. These estimates are conservative as the costs associated with lifestyle changes and health effects are noted, but no monetary value is placed on them. Results also indicate the patients' and caregivers' perception of the quantity of caregiving varies.

An alternative water supply system to improve the efficiency of water supply systems taking into account water pricing, marketing, and treatment costs is proposed. This system treats and supplies water differently depending on the source of the water and if the end-use of the water is a potable or non-potable use, then may reduce treatment costs. Decreased treatment costs may make more stringent water standards more affordable. More stringent water standards may cause a decrease in the risk of water-related diseases including ESRD induced by water-borne toxins. Reducing the risk of ESRD will reduce society's costs associated with chronic illnesses. Possible benefits and costs of the proposed system are discussed, but not calculated.

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This dissertation is dedicated to my father and mother. Without their financial support and belief in me, I could not have finished my studies at Texas A&M.

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CHAPTER I

INTRODUCTION

Many people provide care for their family, relatives, and friends without receiving monetary compensation. In fact, "Nearly 25% of all households have at least one adult who has provided care for an elderly person at some point during the past 12 months" (MetLife, p. 2). To provide care, these unpaid caregivers incur time, monetary, and other costs, including income loss, mental stress, and unexpected changes in lifestyle. Such costs should be included in calculating the costs of diseases. Unpaid caregivers may, however, underestimate caring time and impact on their life (MetLife).

One disease that often requires caregiving is end stage renal disease (ESRD). ESRD is a total and permanent loss of kidney function (National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), 2003). When the kidneys fail, the body retains fluid and harmful wastes build up leading to death within 72 hours if not treated. A person with ESRD requires medical treatment to replace the work of the failed kidneys (NIDDK, 2003). In 1999, the prevalence (current total diagnosed cases) of ESRD in the U.S. was 424,179 cases, with an incidence (newly occurring cases) of 89,252 cases in the U.S. (NIDDK, 2002). Manns, Taub, and Donaldson estimate that in 1997, Medicare spent $15.64 billion for patients with ESRD to pay for direct medical costs in the U.S. They further estimate that in developed counties, 1% to 2% of overall

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health budgets are spent on ESRD care, although only 0.08% of the population has ESRD (Manns, Taub, and Donaldson).

In Texas, the prevalence of ESRD was 22,791 cases and the incidence was 5,246 cases in 2002 (Texas Department of Health). For the same year, prevalence of ESRD was 89 cases and the incidence was 23 cases for Brazos County, Texas (Texas Department of Health). The Texas Kidney Health Care Program spent $19.8 million statewide and $51,500 in Brazos County in 2002 (Texas Department of Health). This program provides financial assistance for medical costs such as outpatient drugs, uninsured medical services (inpatient and outpatient dialysis services and access surgery), reimbursement for travel related to accessing services for ESRD, and premium payments for eligible Medicare recipients.

Despite the economic costs of ESRD, ESRD has received less attention in the economic literature relative to other diseases such as cancer, AIDS, and Alzheimer's. Studies that have estimated the cost of ESRD have generally concentrated on direct medical costs. Costs associated with unpaid caregivers are sometimes noted as important, but are usually not estimated.

Study Objectives

The overall objective of this study is to improve our understanding of the costs associated with illnesses by providing a more complete estimate of patients' and caregivers' costs beyond explicit medical expenses. To satisfy this overall objective, the study has two specific sub-objectives. The first sub-objective is to estimate the costs associated with ESRD for both ESRD patients and their unpaid caregivers. The second

sub-objective is to develop a framework for a municipal water supply system that may reduce the costs of treating water to more stringent potable levels and increase the efficiency of the system.

To obtain these objectives, an overview and theoretical background of unpaid caregiving is provided. Next, a case study of the costs of ESRD for patients of the Gambro Dialysis Center, College Station, Texas is provided. Finally, several examples of water systems, which are currently being operated, are illustrated and a conceptual model of a municipality water system is presented that potentially could lower the cost of treating water to safer potable levels, as well as increase economic efficiency. Benefits and costs associated with the proposed conceptual system are discussed.

Study Organization

Chapter II contains a brief literature review of studies addressing costs associated with diseases. A more complete literature review, in terms of the number of studies, is contained in Appendix A. These previous studies provide background on costs that should be considered in estimating the costs of diseases. Further, several studies have provided estimates of the monetary value of various costs for different diseases, including unpaid caregivers' costs.

Also contained in Chapter II is necessary theoretical background illustrating why the unpaid caregivers' cost, including time and income costs, should be considered in the costs of diseases. This theoretical model also shows that unpaid caregiving may reduce the costs associated with diseases when compared to the case of no unpaid

caregiving. This result is based on the assumption a disease is contracted. Obviously, the case of no diseases results in the lowest costs to society.

Data collection methodology for the case study on ESRD patients and their unpaid caregivers is provided in Chapter III. Descriptive statistics of the data for patients and their primary unpaid caregivers are also provided in this chapter. These statistics for most questions are calculated and summarized independent of the other questions.

In Chapter IV, a case study approach is used to calculate the costs of ESRD, which includes unpaid caregivers' cost, as well as patients' medical and non-medical costs. Based on data provided by ESRD patients undergoing dialysis at the Gambro Dialysis Center in College Station, Texas and their primary unpaid caregivers, estimates for various costs categories are obtained. Questionnaires used in this case study are in Appendices B and C. Cost categories obtained from these questionnaires are patients' indirect medical costs (costs for transportation, home care, paid caregiver, and medical equipment), patients' non-medical costs (income loss, expenses for household chores, one-time costs, changes in quality of life, changes in personal lifestyle, and time spent for travel), caregivers' out-of-pocket expenses (costs for extra food, transportation, and miscellaneous items, income loss, expenses for household chores, one-time costs), and caregivers' personal quality costs (health effects, changes in quality of life, changes in personal lifestyle, and time spent for caring).

In contrast to previous studies concerning the cost of ESRD, the objective of the fourth chapter is to provide a calculation of the total costs of ESRD including both

patient and unpaid caregiver costs. Although this value is not the value of avoided ESRD, it provides a lower bound on the benefits associated with avoided kidney diseases. This value is a non-quantifiable benefit discussed in the Federal Register concerning changes in the U.S. standard for arsenic in drinking water (U.S. EPA, 2001a). There appears to be a strong correlation between arsenic and the incidence of kidney disease (Brown and Fan; Guo et al.; Morris; National Institute of Environmental Health Sciences). Less arsenic consumption in drinking water may, therefore, reduce the risks of kidney disease. An efficient water supply system under enhanced drinking water standard lowers the risk of ESRD.

In Chapter V, a "combined dual water supply system" is formalized, which may lower the costs of removing toxins and other contaminants from the potable water supplies and increase the amount of water available to municipalities. This proposed system may, consequently, make more stringent drinking water standards more affordable. Strengthened standards concerning arsenic and other heavy metals may help to reduce the risk of kidney disease. The objective of this chapter is to develop and formalize a municipality water supply system that increases efficiency. However, the chapter does not take the next step of attempting to place costs and benefits on the potentially more efficient system. The main characteristic of the proposed system is to separate water supply into two uses, potable and non-potable. About 50% of total water supplied by public water systems are used for households / domestic uses, and 60% of households / domestic uses are non-potable uses (Leeden, Troise, and Todd; Solley, Pierce, and Perlman, 1993, 1998). At least 30% of the water supplied by public systems

is, therefore, for non-potable uses. Current systems treat, however, all incoming water to the same standards. Thus, 30% of water from public system may be treated to a higher standard than necessary. By reducing the quantity of water treated, the proposed system may reduce total treatment costs. By reducing treatment costs, it may become economically feasible to strengthen drinking water standards. With strengthened drinking water standards, risks of water related diseases, such as kidney disease may decrease. The system also contains provisions for the use of reclaimed water, which effectively increases the quantity of water available to the municipality. The case study presented in Chapters III and IV provides lower bound estimates concerning the health benefits from reduced ESRD from strengthened water standards. Further, delivering water by potable and non-potable use may also provide for a differential pricing structuring. Such a structure has the potential to make water pricing and marketing more efficient.

In the last chapter, a summary of the study is presented, along with limitations of the study and potential research issues for future studies.

CHAPTER II

LITERATURE REVIEW AND THEORETICAL BACKGROUND OF COSTS OF DISEASES

As societies evolve, environmental degradation and increasing concern for human health become critical issues. Economic studies estimating the health care costs for specific diseases are common. Health care costs include direct / indirect medical care costs, non-medical costs, paid caregivers' costs, as well as unpaid caregivers' time, health and financial burden. Historically, most medical economic studies have focused on only the direct / indirect medical care costs and opportunity costs of the patient. Family members, relatives and friends who provide care for patients without monetary payment are known as unpaid caregivers. Until recently, costs incurred by unpaid caregivers have been relatively ignored.

Concern about unpaid or informal caregiver's costs is evident. Covinsky et al. analyze the impact of illnesses (nine diagnoses) on families. Their results suggest 60% of families with patients lose some portion of the family income. Seventeen percent of families change their personal arrangements to care for patients. Arno, Levine, and Memmott estimate the costs associated with all unpaid informal care for ill and disabled adults in 1997 at approximately $196 billion in the U.S. Hayman et al. estimate the yearly cost of informal caregiving for cancer patients at $4,200 / year / patient. Shellenbarger claims that "With a labor shortage in long-term care and the cost of home-health assistance rising, government and private insurers are moving on several fronts to

cover what in the past has been free, family caregiving" (Shellenbarger, p. D1). She states families should regard it as a serious option to explore. In most studies, only one aspect, either the patient's side or the unpaid caregivers' side, is the focus.

Previous Studies

The most common categories of direct medical costs are hospitalization (cost of inpatient), medical professionals (physician, dentist, lab specialist etc.), medication, nursing home care, whereas, common indirect medical costs categories are for home health care and health insurance (Cooper and Rice; Harrow, Tennstedt, and McKinley; Hodgson (1983, 1994); Hodgson and Cai; Hodgson and Cohen (1999a, 1999b); Hoffman, Rice, and Sung; Leigh et al.; Liu and Hay; Mark et al.; Meek, McKeithan, and Schumock; Scitovsky and Rice; Scitovsky, Cline, and Lee; Strassels et al.; Sullivan and Weiss; Thom; Weinberger et al.; Weiss, Gergen, and Hodgson). In Appendix A, results from selected studies are summarized with regards to different cost factors. (Cost factors vary according to the authors' definitions of costs in Appendix A.) A few studies are discussed here.

Hornberger, Garber, and Jeffery compare the direct medical costs of ESRD in Detroit, U.S. to Manitoba, Canada. The costs in Detroit are $503 higher / month / patient than in Manitoba. They claim, "Even though the U.S. ESRD Medicare program has succeeded in assuring access to life-prolonging medical care, adopting universal coverage under a mandatory federal program cannot by itself guarantee that costs of treating Americans ESRD patients will fall to Canadian levels" (Hornberger, Garber, and Jeffery, p. 696). Max, Rice, and MacKenzie estimate the lifetime cost of injuries

(because of motor vehicle accidents, falls, firearms, poisonings, fire / burns, drownings, and other) in the U.S. to be $158 billion in 1985, which includes medical costs and opportunity costs of patient.

Medical costs, however, are not the total value associated with human health to the individual or society. Patients incur direct medical costs, but patients also usually lose some level of productivity and income because of the disease (Hoffman, Rice, and Sung; Houts et al.; Huang, Cartwright, and Hu; Mark et al.; Max, Rice, and MacKenzie; Mullins et al.; Scitovsky and Rice; Sullivan and Weiss; Thom; Ward et al.; Weiss, Gergen, and Hodgson; Whetten-Goldstein et al.). These types of costs are usually expressed and divided into two categories: morbidity costs because of reduced productivity and mortality costs because of premature death (Cooper and Rice; Hodgson (1983, 1994)). Menon and Assiff review studies concerning the burden to employers because of employees' illnesses. In 2000, they found only 35 articles discussing indirect costs of illness. They define indirect costs as absenteeism, productivity loss, short- or long-term disability, and drug costs. Menon and Assiff contend that even though diseases have a significant impact on employers, there is no standardized measure to quantify this impact.

In addition, unpaid caregivers such as primary family, other relatives, and friends have to forgo work / leisure time to care for a patient, as well as incur out-of-pocket financial costs (Houts et al.; Huang, Cartwright, and Hu; Langa et al., 2001, 2002; Liu and Hay; Max, Webber, and Fox; Meek, McKeithan, and Schumock; National Alliance for Caregiving (NAC 2002a); Ostbye and Crosse; Stommel, Given, and Given;

Stommel, Collins, and Given; Weinberger et al.; Whetten-Goldstein et al.). Metropolitan Life Insurance Company estimates employers' cost for working unpaid caregivers in the U.S. are about $11.4 billion / year (NAC 2002b).

Several studies have attempted to place a value on income loss because of caregiving. A recent study estimates the lost time because of elder care. Ettner shows that men who co-reside with a disabled parent work 2.93 hours less per week and women work 2.65 hours less per week by using the data set of 1987 National Survey of Families and Households. Other medical studies estimate the value of informal caregiving with regards to the stroke, dementia, and diabetes. Hickenbottom et al. claim informal caregiving for elderly stroke victims costs $3,700 / year / patient, which is $1,200 higher than caring for elderly who have not experienced a stroke. In the case of a stroke patient who has an additional health problems which are related to the stroke, the cost of informal caregiving rises up to $7,900 / year (Hickenbottom et al.). Moore, Zhu, and Clipp claim that the annual costs of informal care to elderly with dementia are $18,385 / patient, which includes caregiving time ($6,295) and caregiver's lost earnings ($10,709). Langa et al. (2002) estimate the yearly costs of informal caregiving for elderly with diabetes. They conclude the yearly costs are $2,800 / patient in the case of elderly without diabetes and $4,500 in the case of elderly patient who has diabetes and is taking insulin (Langa et al., 2002). These studies imply the informal caregivers' costs incurred with a disease maybe substantial.

Studies have also conducted qualitative analysis about caregivers' burden, without providing specific monetary values. Most of these studies focus on caregivers'

health and well-being such as depression, physical stress, lack of sleep, fatigue, and headaches (Cattanach and Tebes; Emanuel et al.; Haley; Newcomer et al.). Veltman, Cameron, and Stewart show, however, in addition, to the negative effects there are positive effects associated with caregiving, such as feelings of gratification, love, and pride. Neumann et al. compare the health utility between Alzheimer's disease patients and caregivers. They conclude caregivers' health utility may not be changed with the severity of disease, even though the patients' health utility decreases as the disease progresses.

Conceptual Background for Unpaid Caregiving

It is obvious that one person's actions affect other family members' utility. Becker used a theoretical framework to illustrate the effect of altruism among family members. He claims that the altruism is more efficient in increasing the family's well-being, than it is in the market to increase society's well-being. Usually in a household, family member(s) provide some patient care. As noted earlier, this is known as unpaid caregiving. Altruistic behavior, such as caring for a patient, has a cost to the altruistic individual and to the household, but at the same time reduces paid caregiver costs and has other benefits. In this section, it is illustrated how unpaid caregiving affects the household's utility and what factors should be considered in calculating unpaid caregivers' costs.

Household's Utility Function

Consider, a two-person household in which the household's utility function is

(1) $U^F = g(U^H, U^W)$

where U^F is the household's utility function, U^H is person one's utility function (husband), and U^W is person two's utility function (wife). Based on Becker, individual family member's utility functions can be expressed as

(2) $U^H = f(X_{H1}, X_{H2}, X_{W1}, X_{W2})$, and

(3) $U^W = f(X_{W1}, X_{W2}, X_{H1}, X_{H2})$

where X_{H1} is medical care consumed by husband, X_{H2} is a composite good, which includes all other goods consumed by husband including leisure activities, X_{W1} is medical care consumed by wife, and X_{W2} is a composite good, which includes all other goods consumed by wife including leisure activities.

Normal assumptions concerning the individual's utility function are assumed, including 1) goods provide utility, 2) all goods are normal goods, as an individual consume more of a good, his / her utility level increases, and 3) the marginal utility of the good decreases as he / she consumes more. The second assumption ensures the first derivatives of the utility function are positive, which is expressed mathematically as $\frac{\partial U^H}{\partial X_{H1}} > 0$, $\frac{\partial U^H}{\partial X_{H2}} > 0$, $\frac{\partial U^W}{\partial X_{W1}} > 0$, and $\frac{\partial U^W}{\partial X_{W2}} > 0$. Each partial derivative gives the marginal utility of the good. This assumption indicates that as the husband (the wife) consumes more X_{H1} (X_{W1}) and X_{H2} (X_{W2}), his (her) utility increases. The third assumption forces the second derivatives of the utility functions to be negative. Mathematically, this assumption is expressed as $\frac{\partial^2 U^H}{\partial X_{H1}^2} < 0$, $\frac{\partial^2 U^H}{\partial X_{H2}^2} < 0$, $\frac{\partial^2 U^W}{\partial X_{W1}^2} < 0$, and

$\frac{\partial^2 U^W}{\partial X_{W2}^2} < 0$. This assumption indicates that as the husband (wife) consumes more, the amount of his (her) increased utility per consumed good decreases. Their utilities increase at a decreasing rate.

Similar assumptions on the household utility function are imposed as with the individual utility functions. As an individual's utility increases, the household's utility also increases, $\frac{\partial U^F}{\partial U^H} > 0$ and $\frac{\partial U^F}{\partial U^W} > 0$, and the second derivatives of the household's utility function are negative, $\frac{\partial^2 U^F}{\partial U^{H^2}} < 0$ and $\frac{\partial^2 U^F}{\partial U^{W^2}} < 0$. The first assumption implies that as family members' utility increase, the household's utility also increases. In other words, the marginal utilities of the household with respect to the utility of the husband and the utility of the wife are positive. The second assumption implies that the utility of the household increases at a decreasing rate. Further, it is assumed the prices of goods consumed are same for the husband and wife and time spent by a spouse for caring a patient is in part an altruistic behavior. The altruistic nature of unpaid caregiving arises from many diverse sources including marriage vows, religious encouragement, and a general human nature to help those who are suffering.

Graphically, the trade-off between goods in the household is illustrated in figure 1. Figure 1 is a simplified analysis for graphical consideration. Here, $\overline{X}$ indicates a composite good, which is the sum of X_{H2}, X_{W1}, and X_{W2}. Line segment AA' represents

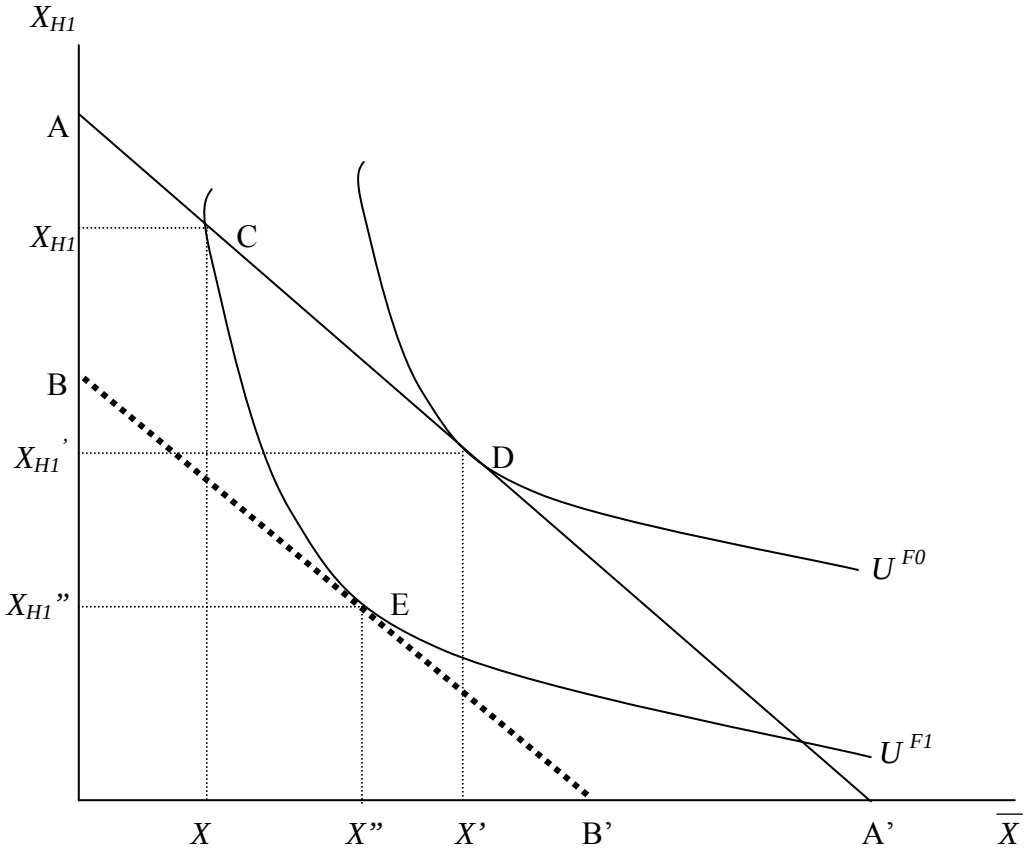


Figure 1. Trade-off between medical care (X_{H1}) for household member, the husband, and all other goods ($\overline{X}$) in the household

the household's initial budget constraint. Any combination of X_{H1} and $\overline{X}$ represented by this line or below could be purchased by the household. The curves represented by *U* are indifference curves. As one moves along any given curve, the utility level of the household remains the constant. Household utility increases as one moves in a northeastern direction, that is, U^{F1} represents the lower utility level than U^{F0}.

Let the point D be the initial point before any illness in the household. There is a level of variable medical care costs being incurred in absence of an illness. These costs

are preventive costs. The tangent point D between the budget constraint and utility function represents the point of maximum household utility. Now, assume the husband is diagnosed with a chronic illness. Medical care consumption (X_{H1}) now increases for the husband. The household may move from point D to the point C in which the minimum amount of medical care necessary to keep the husband alive is paid. As the household moves from D to C, the utility level of the household decreases. Let the distance between X_{H1} and X_{H1}' represents the minimum amount of medical care required to keep the husband alive. Under the assumption, the husband wishes to remain alive, the household must spend on medical care the distance between X_{H1}' and X_{H1} to care for the husband's chronic illness. Because the distance X_{H1}' to X_{H1} equals the distance between A and B, the household's effective budget line becomes BB' (dashed line). The effective budget constraint is defined as the household's budget constraint minus minimum medical care costs necessary to keep the patient alive. Given budget constraint BB', the household's utility is maximized at the point E. As shown in figure 1, the household consumes less of $\overline{X}$ and X_{H1} and experiences a lower utility level. Obviously, the shape of the indifference curves will determine the final consumption combination. Changes in the utility function caused by the chronic illness may cause changes in the shape of the indifference curves, thus determining the final outcome. In general, consumption of $\overline{X}$ will decrease and spending on overall medical care will increase. Overall medical care includes the minimum amount of health care (distance AB) and variable health care given by the good X_{H1}. The distance AB is similar to

compensating variation (CV), which is one of measurement of welfare change. CV is the total amount of money necessary for an individual or a household to return to the previous level of well-being. Because there are many non-monetarized aspects such as mental stress or altruistic nature in health issue, in this theoretical development do not interpret the distance AB as exact CV.

Now, assume the wife, as an unpaid caregiver, replaces some of the paid caregiver costs. In this case, the household's effective budget line increases, because the household saves the money paid to caregivers. The change in the effective budget constraint occurs, because the substitution of unpaid caregiving for paid caregiving. This substitution will only occur when the benefits (altruistic nature) minus the costs (income loss, time, monetary, etc.) are greater than the net benefits associated with hiring a paid caregiver. This is shown in figure 2 as budget constraint GG'. Utility is now maximized at point F. The household's utility, U^{F2}, is larger than the utility, U^{F1}, associated with point E (with no unpaid caregiving). Costs of paid caregiving decrease, therefore, total medical care costs decrease. This decrease allows increasing consumption of other goods (combination of X_{H1}^{*} and X^{*}). An important effect of the existence of unpaid caregiver is, therefore, to alter the consumption bundle of the household and result in higher utility level of the household compared to the case of all paid medical care. Higher utility occurs because of increase consumption of the goods and, as noted earlier, there are benefits associated with altruistic behavior.

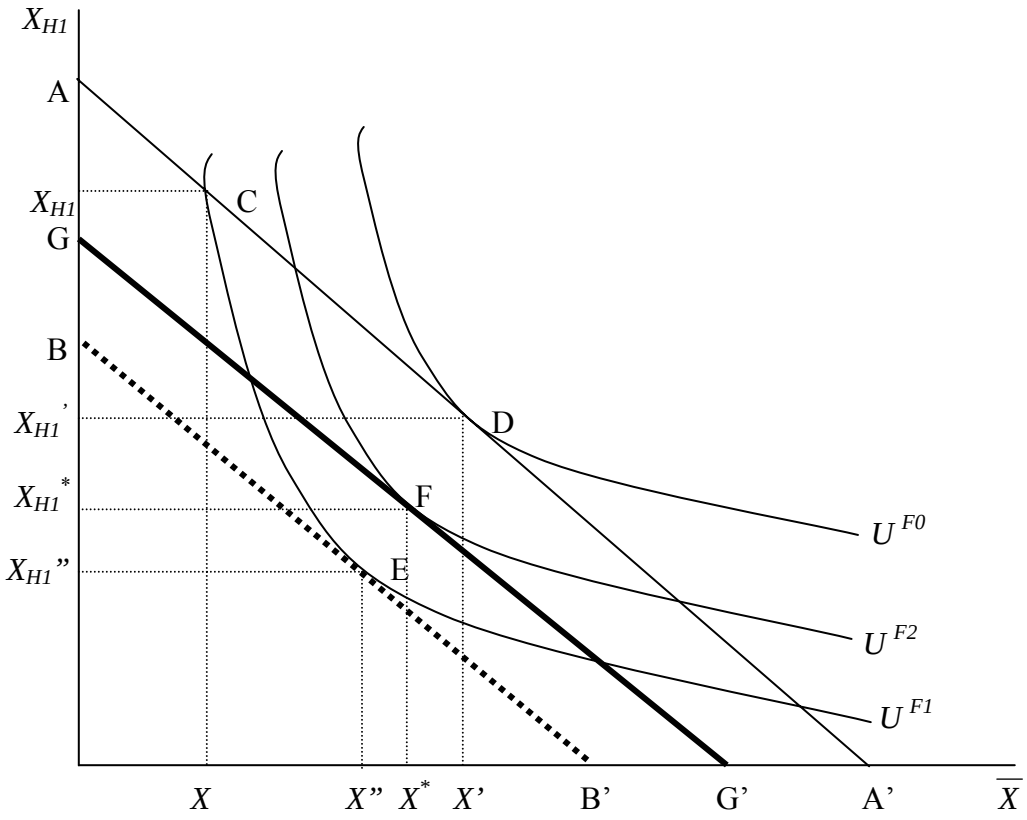


Figure 2. Effect of a unpaid caregiver to the household's utility level

The example shown in figures 1 and 2 and associated discussion illustrate that the value of unpaid caregiver should be considered when estimating the costs of diseases. If a working wife becomes an unpaid caregiver to replace paid caregivers, there may be additional income loss to the household, if her caregiving affects her work. Such an income loss causes an additional decrease in the budget line to somewhere between BB' and GG'. Also, unpaid caregiving changes the consumption of the composite good $\overline{X}$.

The patient may have much higher preference for health than any other goods. In this case, a non-typical shape of indifference curve such as "lexicographic ordering" (Malinvaud) may occur in an individual's preference ordering. The lexicographic ordering occurs when an individual shows very high preference to a good. Here, this preference is akin to the assumption of wanting to stay alive.

Utility Maximization of the Household

Each good, $X_{H1,}$ X_{H2}, $X_{W1,}$ and X_{W2} is a function of time spent on all activities. If the husband spends more time working, he earns more money, allowing the household to consume more goods. Therefore, each good can be expressed as

(4) $X_{Hi} = h(T_{H1}, T_{H2}, T_{H3}, T_{W1}, T_{W2}, T_{W3})$, and

(5) $X_{Wi} = h(T_{W1}, T_{W2}, T_{W3}, T_{H1}, T_{H2}, T_{H3})$

where i = 1, 2, T_{H1} is the husband's time associated with a disease, T_{H2} is the husband's time associated with work, T_{H3} is the husband's time associated with all other activities, T_{W1} is the wife's time associated with a disease, T_{W2} is the wife's time associated with work, and T_{W3} is the wife's time associated with all other activities. Time associated with a disease includes all treatment time if the individual has the disease and unpaid caregiving time for the other member of the household. Each individual's utility function is, therefore, expressed as a function of time by substituting equation (4) into equation (2) and equation (5) into equation (3). Individual's utility functions become

(6) $U^H = f(T_{H1}, T_{H2}, T_{H3}, T_{W1}, T_{W2}, T_{W3})$, and

(7) $U^W = f(T_{W1}, T_{W2}, T_{W3}, T_{H1}, T_{H2}, T_{H3})$

The total time available to each individual is a fixed amount (a constant), such as 24 hours / day or 365 days / year. Mathematically, this can be stated as $T_{H1} + T_{H2} + T_{H3} = T$ and $T_{W1} + T_{W2} + T_{W3} = T$. Because T is constant, once T_{H1} and T_{H2} are determined, T_{H3} is decided. This implies that as the husband (the wife) spends additional time associated with the disease, activities such as working and / or recreation must be reduced. As he (she) reduces his (her) work, the household income decreases. Consequently, the budget line is shifted downward, which decreases the household's utility level. T_{H3} can be expressed as $T_{H3} = T - T_{H1} - T_{H2}$. A similar relationship can be derived for the wife's time. Substituting these time constraints into equations (6) and (7), one obtains

(8) $U^H = f(T_{H1}, T_{H2}, T_{W1}, T_{W2})$, and

(9) $U^W = f(T_{W1}, T_{W2}, T_{H1}, T_{H2})$

Equations (8) and (9) indicate the husband's and the wife's utility functions are function of time spent for activities associated with a disease, work, and implicitly all other activities through the time constraints. Substituting equations (8) and (9) into equation (1), the household's utility function, equation becomes

(10) $U^F = g(U^H(T_{H1}, T_{H2}, T_{W1}, T_{W2}), U^W(T_{W1}, T_{W2}, T_{H1}, T_{H2})) = g(T_{H1}, T_{H2}, T_{W1}, T_{W2})$

Households maximize their utility subject to an income (I) constraint

(11) $I = T_{H2}R + T_{W2}R - CSA(T_{H1}, T_{W1})$

where R is the husband's and the wife's wage rate. It is assumed both husband and wife have a same wage rate. CSA is the patient's costs for staying alive, which is a function of times associated with the disease by both the wife and husband. In the case of no

chronic illness in the household, the *CSA* is equal to zero. The household's maximization problem can be solved using the Lagrange multiplier (λ) technique. The constrained maximization problem is

(12) $$\max L = \max_{T_{H1}T_{H2}T_{w1}T_{w2}} g(T_{H1},T_{H2},T_{W1},T_{W2}) + \lambda (I - T_{H2}R - T_{W2}R + CSA(T_{H1},T_{W1}))$$

where λ is the Lagrange multiplier. Maximization is achieved by satisfying the first-order (F.O.C) and the second-order conditions (S.O.C) (Silberberg). The F.O.C are satisfied by setting the first derivatives of *L* with respect to T_{H1}, T_{H2}, T_{W1}, T_{W2}, and the Lagrange multiplier equal to zero. The F.O.C are,

(13) $$\frac{\partial L}{\partial T_{H1}} = \frac{\partial f}{\partial T_{H1}} + \lambda \frac{\partial CSA}{\partial T_{H1}} = 0 ,$$

(14) $$\frac{\partial L}{\partial T_{H2}} = \frac{\partial f}{\partial T_{H2}} - \lambda R = 0 ,$$

(15) $$\frac{\partial L}{\partial T_{W1}} = \frac{\partial f}{\partial T_{W1}} + \lambda \frac{\partial CSA}{\partial T_{W1}} = 0 , \text{ and}$$

(16) $$\frac{\partial L}{\partial T_{W2}} = \frac{\partial f}{\partial T_{W2}} - \lambda R = 0 .$$

Individually, the equations (13) and (15) indicate the husband's marginal utility (MU), $\frac{\partial f}{\partial T_{H1}}$, and the wife's MU, $\frac{\partial f}{\partial T_{W1}}$, of the time associated with a disease must be equal to $\lambda \frac{\partial CSA}{\partial T_{H1}}$ and $\lambda \frac{\partial CSA}{\partial T_{W1}}$. The Lagrange multiplier, λ, is interpreted as a unit of marginal utility of the time spent for the disease per dollar. Equations (14) and (16) indicate the husband's (the wife's) MU must be equal to λR.

From equations (15) and (16), the relation of $\frac{MU_{T_{W1}}}{MU_{T_{W2}}} = \frac{CSA_{T_{W1}}}{R}$ can be derived.

This condition indicates the marginal rate of substitution (MRS) between T_{W1} and T_{W2} should be equal to the ratio of $\frac{\partial CSA}{\partial T_{W1}}$ and R. $\frac{\partial CSA}{\partial T_{W1}}$ is the wife's marginal cost for caring husband and R is her wage rate. Using the same procedures, the relations of $\frac{MU_{TH1}}{MU_{TH2}} = \frac{\partial CSA/\partial T_{H1}}{R}$, $\frac{MU_{T_{H2}}}{MU_{T_{W1}}} = \frac{R}{\partial CSA/\partial T_{W1}}$, and $\frac{MU_{T_{W2}}}{MU_{T_{H1}}} = \frac{P_1}{P_2}$ can be derived. These relations imply that an individual should equate the MRS of the two times spent to the ratio of the marginal costs of the CSA and wage rate. In addition, λ can be expressed such as $\lambda = \frac{MU_{T_{H1}}}{\partial CSA/\partial T_{H1}} = \frac{MU_{T_{H2}}}{R} = \frac{MU_{T_{W1}}}{\partial CSA/T_{W1}} = \frac{MU_{T_{W2}}}{R}$. This condition implies each time spent should yield the same *MU* per dollar on the time (Nicholson, p.114). Even though the wife's marginal cost of CSA is larger than her wage rate, she may provide caregiving for her husband, because she may have some non-monetarized benefits from providing caregiving. The remaining F.O.C condition is

(17) $$\frac{\partial L}{\partial \lambda} = I - T_{H2}R - T_{W2}R + CSA(T_{H1}, T_{W1})$$

This condition indicates the optimal solution must satisfy the income constraint given in equation (11).

The sufficient S.O.C for this maximization problem are satisfied, if the determinant of the bordered Hessian of the second partials derivatives is positive (Silberberg). In the utility maximization problem, the S.O.C imply that the MRS is

diminishing. MRS is the ratio of the marginal utility of time spent T_{H1} to the marginal utility of time T_{H2} (Nicholson, p. 91). Here, it is assumed the S.O.C are satisfied.

As shown in above, by satisfying the F.O.C and S.O.C, the household achieves a utility maximization subject to budget constraint. If a household member becomes chronically ill, the household's consumption is changed because of additional expenses of medical care including paid caregiving. The budget constraint may also change because of income loss because of the disease. Consequently, the household's utility decreases. Unpaid caregiving, however, can replace some paid caregiving, thereby reducing the medical care expenses of the household, increasing the purchase of other goods, and increasing utility of the household. If a family member devotes his / her time to care for a patient, he / she may experience an income loss, and / or changes in his / her personal life such as less sleep, less recreation, and more mental stresses. These changes have economic costs, even if family care is unpaid (Shellenbarger).

The conceptual framework illustrates the necessity of trade offs in maximizing a household's utility. If unpaid caregiving is to occur, the household will incur either a loss in income or a loss in leisure time. These losses caused by the illness cause a utility loss to the household, thus should be considered as part of the cost of the illness. In the conceptual framework, illness decreases the utility of the individual and household. The costs of the illness contain the foregone income loss and decrease consumption of non-medical goods. The unpaid caregiving can substitute for some paid medical costs, but this substitution in household may incur either a loss in income or in leisure time.

Avoiding double counting of the costs of the illness is important as several utility functions and resource constraints are involved.

CHAPTER III

DATA COLLECTION METHODOLOGY AND DESCRIPTIVE STATISTICS

One objective of this study is to obtain improved estimates of the cost of ESRD, including appropriate values for unpaid caregiver's opportunity costs. To do this, a case study is conducted by using the population of ESRD patients treated at the Gambro Dialysis Center in College Station, Texas and their primary caregivers. Data collection methodology and descriptive statistics of the cost data from the patients and their primary unpaid caregivers' are discussed.

Data Collection

Primary data used in this case study was obtained from ESRD patients and their primary unpaid caregivers. Questionnaires were distributed to all ESRD patients and their primary unpaid caregivers who are undergoing hemodialysis treatments at the Gambro Dialysis Center in College Station, Texas (Tan, 2002). This center serves patients from three counties (Brazos, Grimes, and Robertson) and is the only outpatient dialysis location within a 50-mile radius (Tan, 2003). A total of 115 ESRD patients were identified. Two different questionnaires were given to each patient, one to be completed by the patient and the second to be completed by the patient's primary unpaid caregiver.

Data collection occurred between November 15, 2002 and January 17, 2003. Of the 115 questionnaires distributed, 68 patients (59%) and 39 caregivers (34%) returned their questionnaires. Among the 47 patients who did not return the questionnaire, it is unknown how many have an unpaid caregiver. The questionnaires contain questions

regarding the patients' and the caregivers' additional expenses associated with their ESRD and their caregiving. Expenses associated with items such as home care, paid caregiver, household chores, transportation, medical equipment are assumed to be monthly costs. Other items such as home renovation, changes in automobile, purchasing additional automobile are assumed as a one-time costs.

Because of the methodology used, the data collection procedure is considered as a case study. All patients of a limited population were given the chance to answer the questionnaire. Copies of the questionnaires are in Appendices B and C. In the following sections, responses for most questions are summarized independent of the other questions.

Patients' Descriptive Statistics

Socio-Demographic

Socio-demographic characteristics are summarized in tables 1 and 2. Of the 68 patients who completed the questionnaire, 50% of the patients (34 patients) are male and 50% (34 patients) are female. In Texas, 48% of ESRD patients are male and 52% are female in 2002 (Texas Department of Health). In U.S., 55% of ESRD patients are male and 45% are female in 2001 (U.S. Renal Data System).

Thirty-four percent of the patients (23 patients) are white, 38% (26 patients) are black, and 27% (18 patients) are Hispanic. One patient did not provide his / her race. In Texas, 27% of ESRD patients are white, 29% are black, 42% are Hispanic, and 2% are all other races in 2002 (Texas Department of Health). In U.S., 60% of ESRD patients are white, 32% are black, 2% are Hispanic, and 6% are all other races in 2001 (U.S.

Renal Data System). Twenty-seven percent (18 patients) have an 8th grade or lower education, whereas 41.2% (28 patients) have between an 8th grade and high school education. Thirty-two percent (22 patients) attended college with seven patients obtaining a bachelor degree. Three percent (2 patients) have post-bachelor education. The average age of the responding patients is 59.3 years old, with the youngest being 28 and the oldest being 91 years (table 3).

Table 1. Socio-Demographic Characteristics of the ESRD Patients

	Frequency	Percent
	Sex	
Male	34	50.0
Female	34	50.0
Total	68	100.0
	Race	
White	23	33.8
Black	26	38.2
Hispanic	18	26.5
Missing	1	1.5
Total	68	100.0
	Education	
K-8th Grade	18	26.5
9th Grade-12th Grade	28	41.2
Some College	13	19.1
Bachelor Degree	7	10.3
Post-Bachelor	2	2.9
Total	68	100.0

Table 2. Education of ESRD Patients by Race and Sex

	Education					
	K-8th	9th-12th	Some College	Bachelor Degree	Post Bachelor	Total
Sex			White			
Male	1	6	1	2	2	12
Female		5	5	1		11
Total	1	11	6	3	2	23
			Black			
Male	3	6	2	1		12
Female	1	7	3	3		14
Total	4	13	5	4		26
			Hispanic			
Male	6	1	2			9
Female	6	3				9
Total	12	4	2			18

Seven percent (5 patients) live in College Station, 50% (34 patients) live in Bryan, and 43% (29 patients) live in the other cities such as Caldwell, Calvert, Hearne, and Navasota. The average number of years since the start of treatment is 3.2 years (table 3). The longest time a patient had been on dialysis is 24 years, whereas 22% (15 patients) had just recently began dialysis.

Table 3. Age of ESRD Patient, Years of Treatment, and Distance to Dialysis Center

	Mean	SD	Max	Min
Age	59.3	13.6	91	28
Years of treatment	3.21 years	4.31	24 years	0 year
Distance to the center	18.32 miles	13.82	62 miles	0.5 miles

The average distance the patient lives from the dialysis center is 18.3 miles with range from half a mile to 62 miles (table 3). Nineteen percent (13 patients) reside within less than 5 miles from the Gambro Dialysis Center and 10% (7 patients) reside more than 35 miles away from the center. It is identified 46% of patients (31 patients) travel to the center with their unpaid caregiver, whereas 47% of patients (32 patients) travel to the center alone. The remaining 7% (5 patients) travel with paid caregivers.

The average distance from patients' residences to the dialysis center in College Station is 36.64 miles for round trip. Because patients usually have three treatments per week, this would average about 5,716 miles per year to the center and back for treatment (36.64 miles × 52 weeks × 3 times / week = 5,716 miles / year). Main mode of transportation to the center is by automobiles (69%, 47 patients) and bus (9%, 6 patients) (table 4).

Table 4. Modes of Travel to he Dialysis Center Used by ESRD Patients

Travel Types	Frequency	Percent
Walk	1	1.47
Drive (Self)	16	23.52
Ride w/ Other	31	45.58
Taxi	1	1.47
Bus	6	8.82
Medical Transportation	1	1.47
Walk or Ride w/ Other	1	1.47
Drive (Self) or Ride w/ Other	2	2.94
Drive (Self) or Bus	1	1.47
Ride w/ Other or Taxi	1	1.47
Ride w/ Other or Bus	4	5.88
Ride w/ Other or Medical Transportation	1	1.47
Bus or Medical Transportation	1	1.47
Drive (Self) or Bus or Medical Transportation	1	1.47
Total	68	100.0

In addition, each of the following modes was used by at least one patient, taxi, walking and medical transportation such as ambulance. Eighteen percent (12 patients) use more than one mode of transportation (table 4).

Expenses Associated with ESRD

Patients were asked to provide increases in monthly expenses associated with home care, payment for caregivers, household chores, and medical equipment that can be directly attributed to their ESRD. It is assumed that if a respondent provided a cost to any of above item(s) and not the other item(s), the expenses for item(s) not provided are zero. Average increase in expenses caused by the patients' ESRD are $30.88 / month for home care, $7.56 / month for paid caregiver, $41.69 / month for household chores, and $23.86 / month for medical equipment (table 5). Because people do not renovate a residence or change vehicles on a monthly basis, patients were asked to provide total expenses since the onset of their ESRD for home renovations, changes in their automobile, and purchasing an additional automobile. Home renovation expenses averaged $150.44 / patient. Changes in their current automobile averaged less than one dollar, whereas automobile purchased averaged $1,291.91 (table 5).

Table 5. Patients' Expenses Directly Attributed to ESRD

Expenses	Mean ($)	SD	Min	Max
		Monthly Expenses		
Home Care	30.88	242.66	0.00	2000.00
Paid Caregiver	7.56	62.33	0.00	514.00
Household Chores				
Lawn	12.94	29.42	0.00	150.00
Cleaning	6.18	23.25	0.00	150.00
Grocery	15.90	57.79	0.00	300.00
Errand	1.91	8.33	0.00	.50.00
Other	4.76	20.33	0.00	125.00
Total Household Chores	41.69	79.84	0.00	315.00
Medical Equipment	23.86	108.86	0.00	800.00
		One-time Expenses		
Home Renovation	150.44	512.06	0.00	3000.00
Changes in Car	0.74	6.06	0.00	50.00
Purchasing Additional Car	1,291.91	4692.27	0.00	30000.00

Employment Status

Most of respondents (62 respondents, 91%) are currently not working (three homemakers, 21 unemployed, and 38 retired). Three respondents are working full time, while the remaining three are working part time. All working respondents indicated they had not decreased the hours they worked because of their ESRD, despite the time demands of treatment and the impact of the illness.

Among the 68 patients, 49% (33 patients) indicated they have experienced no change in their employment status. In other words, their ESRD did not affect to their employment status. Four percent (3 patients) did not provide information concerning their previous employment status at the time they were diagnosed with ESRD. In

addition, there were two cases (3%) of "from homemaker to retired" and one case (2%) of "from retired to unemployed."

Among the remaining 43% (29 patients), twenty-eight patients indicated their employment status changed because of their ESRD (table 6), 1) from working full-time to retired (15 cases), 2) from full-time employment to unemployed (9 cases), 3) from part-time employment to retired (2 cases), 4) from part-time employment to unemployed (1 case), and 5) from part-time employment to homemaker (1 case). Another case indicated a change from retired to part-time employment. This patient also retired two years early because of her ESRD. Three patients of these 29 patients did not provide how early they retired because of their ESRD. In addition, six patients of the 29 patients indicated their ESRD did not affect their retirement decision. Therefore, 20 patients (29%) retired early because of their ESRD. These 20 patients are included in the calculations involving early retirement. The average numbers of years of early retirement of these 20 patients are 10.7 years. The minimum number of years early retirement was taken is two years and maximum number of years is twenty-two years. Several unemployed patients (4 patients) are also included in the calculation of early retirement, if their unemployment is because of their ESRD. These four unemployed patients answered they retired early because of their ESRD. These patients are considered as a case of temporal retirement because of the ESRD. Among 27 patients who were full-time worker, 24 patients (89%) are currently unemployed or retired (table 6).

Table 6. Changes in Patients' Employment Status

Previous Employment	Current Employment					Total
	Full-time	Part-time	Homemaker	Unemployed	Retired	
Full-time	3			9	15	27
Part-time		2	1	1	2	6
Homemaker			2		2	4
Unemployed				8		8
Retired		1		1	18	20
Total	3	3	3	19	37	65

Income Distribution

Patients' income distributions by race and education level are given in tables 7, 8, and 9. Forty-seven percent (32 patients) stated their current income was less than $10,000 per year. Twenty percent (14 patients) indicated an income level between $10,000 and $20,000, and only 9% (6 patients) said they have an income of more than $20,000. Twenty-four percent (16 patients) did not provide an answer to the current income question.

Table 7. Current Income Distribution of ESRD Patients

	Frequency	Percent	Cumulative Percent
< $10K	32	61.5	61.5
$10K-$20K	14	26.9	88.5
$20K-$30K	3	5.8	94.2
$30K-$50K	1	1.9	96.2
$50K-$75K	2	3.8	100.0
Total	52	100.0	

Table 8. Current Income Distribution by Race of ESRD Patients

	< 10K	10K-20K	20K-30K	30K-50K	50K-75K	
White	8	9	1	1	2	21
Black	14	3				17
Hispanic	10	2	2			14
Total	32	14	3	1	2	52

Table 9. Current Income Distribution by Education Level of ESRD Patients

	< 10K	10K-20K	20K-30K	30K-50K	50K-75K	
K-8th	10	3	1			14
9th-12th	14	5				19
Some College	4	4	2	1		11
Bachelor Degree	4	2				6
Post-Bachelor					2	2
Total	32	14	3	1	2	52

Table 10. Previous Income Distribution of ESRD Patients

	Frequency	Percent	Valid Percent	Cumulative Percent
< $10K	10	14.7	34.5	34.5
$10K-$20K	12	17.6	41.4	75.9
$20K-$30K	2	2.9	6.9	82.8
$30K-$50K	5	7.4	7.2	100.0
Sub total	29	42.6	100.0	
Missing	39	57.4		
Total	68	100.0		

The patient's previous income was defined as the income level at the time the patient retired, if their retirement was caused by their ESRD. The previous income distribution is shown in table 10. Thirty-two percent (22 patients) said their income level when they retired was less than $20,000. Ten percent (7 patients) indicated a

previous income of more than $20,000. The questionnaire was designed such that only patients who retired early because of their ESRD answered the previous income level. Therefore, 1) if a patient is still working, 2) if a patient retired before he / she diagnosed with ESRD, 3) if a patient retired regardless the ESRD, 4) if a patient has been unemployed, 5) if a patient is currently unemployed, not retired, or 6) if a patient has been a homemaker, the patient should not have answered the question about previous income. For the question about previous income level, among 68 responded patients, 57% (39 patients) did not provide an answer. Of these 39 patients, 1) five patients are still working, 2) sixteen patients retired before they were diagnosed with ESRD, 3) three patients retired regardless their ESRD, 4) seven patients had been unemployed, 5) three patients are currently unemployed, not retired, and 6) two patients have been homemakers. The remaining three patients did not provide an answer, these are the missing values (table 11).

Table 11. Cases of Un-answered Previous Income of ESRD Patients

Reason	Frequency
Still working (full-time)	3
Still working (part-time)	2
Have been retired	16
Retire regardless ESRD	3
Have been unemployed	7
Currently unemployed, but not retired yet	3
Have been a homemaker	2
Missing	3
Total	39

Changes in Personal Life

About 17% of the respondents (12 of 67 patients, 1 missing) indicated they changed their residence because of ESRD. In addition, 40% of respondents (25 of 62 patients, 6 missing) cancelled vacation plans or reduced vacation time because of their ESRD. Job changing because of ESRD is relatively rare (9%, 5 of 54 patients, 14 missing). Such low percentage of job change is partially because many patients were retired, unemployed when diagnosed, or have retired.

Quality of Life

To evaluate the quality of life of patients, the index of well-being (IWB) is used (Deniston et al.). Patients indicated a number between one and seven which relates to their satisfaction level in their life for nine questions (table 12). Steps in calculating the IWB are as follows (Deniston et al.). First, the average of the indicated satisfaction levels for questions one through eight is calculated. Second, the calculated average from the first step is added to the patient's indicated value on question nine multiplied by 1.1. For example, if the average of question one through eight is five and the patient's response on question nine is six, then $5 + (1.1 \times 6) = 11.6$ is the patient's calculated IWB. The potential range of IWB is from 2.1 to 14.7. The number 2.1 indicates an individual has the lowest satisfaction for his / her current life, where as the number 14.7 indicates an individual has the highest satisfaction for his / her current life. The responding patients' average IWB is 10.75. Fifty percent of the patients had a lower index than the average. The range of the calculated IWB for the patients is the same as

Table 12. Index of Well-Being of ESRD Patients

Item (One – Seven)	Mean	Max	Min	SD
Q1. Boring – Interesting	4.66	7.00	1.00	1.95
Q2. Miserable – Enjoyable	5.00	7.00	1.00	1.84
Q3. Useless – Worthwhile	4.98	7.00	1.00	1.94
Q4. Lonely – Many friends	5.31	7.00	1.00	1.88
Q5. Empty – Full	5.14	7.00	1.00	1.76
Q6. Discouraging – Encouraging	4.84	7.00	1.00	1.75
Q7. Disappointing – Rewarding	4.98	7.00	1.00	1.79
Q8. Brings out the worst in me – Brings out the best in me	4.89	7.00	1.00	1.82
Average Q1 - Q8	5.00	7.00	1.00	1.62
Q9. (Overall Satisfaction of your life) Very dissatisfied – Very satisfied	5.23	7.00	1.00	1.70
Index of Well-Being	10.75	14.70	2.10	3.21

the potential range of the index, 2.1 to 14.70. About 83% of the patients' IWB are between 7 and 14.

Types of Caregiver and Caregiving Demand

Respondents were asked about caregiver involvement, 1) no need for caregiver, 2) paid caregiver, 3) in-town unpaid caregiver, 4) out-of-town unpaid caregiver, 5) caregiver is not available, and 6) other. A patient could indicate more than one type of caregiver. Of the 68 patients, twenty-five percent (17 patients) stated they do not need a caregiver. Eleven patients (16%) have paid caregivers. Forty patients (59%) have in-town unpaid caregivers. Seven patients (10%) said they have out-of-town unpaid caregivers. Two patients (3%) said caregivers were not available, and one patient indicated other. Ten patients (15%) indicated they have more than one type of caregiver.

In the questionnaires, an unpaid caregiver was defined as any person who provides patient care without receiving monetary payment. However, it appears in many

cases, patients do not consider family members as caregivers. For example, a patient may have indicated his / her spouse gave the patient a ride to the dialysis center, but the patient also indicated he / she does not have an unpaid caregiver. Such responses imply patients may feel either his / her spouse is not an unpaid caregiver or providing transportation is not caregiving.

Patients were asked what types of caregiving they needed, what types of caregiving the in-town and out-of-town unpaid caregivers provide, and how the caregivers provide care (tables 13, 14, 15 and 16). Patients were asked not to answer these three sets of questions if the patient does not use an unpaid caregiver(s). Caregiving is categorized into 10 items, 1) legal advice and issues, 2) financial management, 3) spiritual / social / community activities, 4) household management and / or modifications, 5) transportation, 6) nutrition, meal preparation, grocery shopping, 7) housekeeping activities, 8) mobility support, equipment, rehabilitation, 9) personal hygiene, and 10) medical and / or nursing treatment(s) and medication(s). For each category, the patient circled a number between one to five, with a one indicating the patient never needs caregiving in that category, a three indicating caregiving is sometimes needed, and a five indicating help is always needed. Regarding how the caregivers provide the care, caregiving methods are categorized into six items, 1) caregiver comes to patient, 2) patient goes to caregiver, 3) phone, 4) regular mail, 5) e-mail, and 6) other. For each category, a one indicates a caregiver never uses the method for caregiving, a three indicates a caregiver sometimes uses the method, and a five indicates a caregiver always uses the method.

Table 13. How Often the ESRD Patients Indicated They Need Help with Various Caregiving Categories

	Valid Obs	Mean	SD	Min	Max
Legal advice and issues	57	2.61	1.35	1.00	5.00
Financial management	55	2.69	1.43	1.00	5.00
Spiritual / social / community activities	56	2.66	1.39	1.00	5.00
Household management and / or modifications	54	2.63	1.51	1.00	5.00
Transportation	59	3.73	1.50	1.00	5.00
Nutrition, meal preparation, grocery shopping	59	3.20	1.54	1.00	5.00
Housekeeping activities	58	3.31	1.51	1.00	5.00
Mobility support, equipment, rehabilitation	57	2.39	1.37	1.00	5.00
Personal hygiene	57	2.25	1.37	1.00	5.00
Medical and / or nursing treatment(s) and medication(s)	56	2.77	1.54	1.00	5.00
Average		2.82	1.08	1.00	5.00

Table 14. How Often the ESRD Patient Indicated In-Town Unpaid Caregivers Help with Various Caregiving Categories

	Valid Obs	Mean	SD	Min	Max
Legal advice and issues	48	2.40	1.35	1.00	5.00
Financial management	49	2.59	1.43	1.00	5.00
Spiritual / social / community activities	49	2.71	1.39	1.00	5.00
Household management and / or modifications	49	2.96	1.51	1.00	5.00
Transportation	50	3.36	1.50	1.00	5.00
Nutrition, meal preparation, grocery shopping	49	3.14	1.54	1.00	5.00
Housekeeping activities	48	3.42	1.51	1.00	5.00
Mobility support, equipment, rehabilitation	49	2.33	1.37	1.00	5.00
Personal hygiene	49	2.41	1.37	1.00	5.00
Medical and / or nursing treatment(s) and medication(s)	48	2.50	1.54	1.00	5.00
Average		2.77	1.08	1.00	5.00

Table 15. How Often the ESRD Patient Indicated Out-of-Town Unpaid Caregivers Help with Various Caregiving Categories

	Valid Obs	Mean	SD	Min	Max
Legal advice and issues	29	1.38	0.78	1.00	4.00
Financial management	29	1.55	0.95	1.00	4.00
Spiritual / social / community activities	27	1.52	0.94	1.00	4.00
Household management and / or modifications	27	1.52	0.94	1.00	4.00
Transportation	27	1.67	1.24	1.00	5.00
Nutrition, meal preparation, grocery shopping	27	1.44	0.89	1.00	4.00
Housekeeping activities	27	1.70	1.07	1.00	4.00
Mobility support, equipment, rehabilitation	27	1.48	0.89	1.00	4.00
Personal hygiene	27	1.37	0.88	1.00	5.00
Medical and / or nursing treatment(s) and medication(s)	27	1.33	0.73	1.00	4.00
Average		1.52	0.80	1.00	3.70

Table 16. How the ESRD Patient Indicated Out-of-Town Unpaid Caregivers Provide Help

	Valid Obs	Mean	SD	Min	Max
Caregiver comes to patient	24	1.83	1.40	1.00	5.00
Patient goes to caregiver	24	1.42	0.93	1.00	5.00
Phone	24	2.17	1.55	1.00	5.00
Regular mail	24	1.58	1.10	1.00	5.00
E-mail	23	1.30	0.93	1.00	5.00
Other	18	1.06	0.24	1.00	2.00
Average		1.22	0.47	1.00	2.33

Several patients completed these questions even though they indicated they have no unpaid caregiver(s). In these cases, the patients' answers may show what type of help the patients need. In the table 13, higher means indicate patients need more help for that

item. Patients indicated they need the most help on transportation (3.73), housekeeping (3.31), and nutrition, grocery shopping (3.20) among the ten types of caregiving. In tables 14 and 15, higher means indicate the patients feel they are provided more help for that item from the in-town caregiver or out-of-town caregivers. The patients responded they receive more help from in-town caregivers and out-of-town caregivers on housekeeping (3.42, 1.70), transportation (3.36, 1.67), and nutrition, grocery shopping (3.14, 1.44) than for the other items. Out-of-town caregivers use the phone (2.17) and come to patient (1.83) as the main methods of providing care (table 16).

Unpaid Caregiver's Descriptive Statistics

Socio-Demographic

Of the 115 distributed unpaid caregiver questionnaires, 39 questionnaires were returned (34%). Twenty-six percent (10 of the 39 caregivers) are male and 74% (29 caregivers) are female. The average age of the caregivers is 54.9 years. Twenty-eight percent (11 caregivers) had an 8th grade or lower education (tables 17 and 18). Forty-one percent (16 caregivers) had an education level between 9th and 12th grade. Eight percent (3 caregivers) attended college, with 10% (4 caregivers) earning Bachelor degrees and another 8% (3 caregivers) completing work beyond the Bachelor degree. Five percent (2 caregivers) did not provide their education level. More than half (20 caregivers) of the caregivers are spouses of the patients (table 19). Twenty-one percent (8 caregivers) are children of the patient. Thirteen percent (5 caregivers) are parents of the patient, and one caregiver is a friend of the patient. The remaining one caregiver did not answer the question.

Table 17. Socio-Demographic Characteristics of the Caregivers

	Frequency	Percent
	Sex	
Male	10	25.6
Female	29	74.4
Total	39	100.0
	Race	
White	16	41.0
Black	11	28.2
Hispanic	12	30.8
Total	39	100.0
	Education	
K-8th	11	28.2
9th-12th	16	41.0
Some College	3	7.7
Bachelor Dgree	4	10.3
Post-Bachelor	3	7.7
Missing	2	5.1
Total	39	100.0

Table 18. Education of Caregivers by Race and Sex

	Education					
Sex	K-8th	9th-12th	Some College	Bachelor Degree	Post Bachelor	Total
			White			
Male	1	2	1		2	6
Female	1	5		2	1	9
Total	2	7	1	2	3	15
			Black			
Male		2				2
Female	1	4	1	2		8
Total	1	6	1	2		10
			Hispanic			
Male	2					2
Female	6	3	1			10
Total	8	3	1			12

Table 19. Relationship Between Caregivers and ESRD Patients

	Frequency	Percent
Parents	5	12.8
Spouse	20	51.3
Sister / Brother	4	10.3
Daughter / Son	8	20.5
Friend	1	2.6
Missing	1	2.6
Total	39	100.0

Caregiving Supply

Caregivers were asked what types of caregiving they provide. Caregiving was categorized into the same 10 categories as on the patients' questionnaire. As with the patient questionnaire, caregivers selected a level of caregiving based on a one to five scale for each category. A one indicates they never provide caregiving in that category, a three indicates caregiving is sometimes provided, and a five indicates help is always provided for that category. Caregivers' responses to the types of caregiving provided are summarized in table 20. A higher mean indicates the caregivers feel they provide a higher level of care for the category. The caregivers provide the most care for housekeeping (4.24) and nutrition, grocery shopping (4.32) (table 20). Personal hygiene caregiving had the lowest average (2.76) among the 10 categories.

Comparing caregivers' responses to patients' response on the 10 categories provides an indication of how patients feel about the amount of caregiving needed relative to caregivers' perceptions concerning the level of caregiving provided. In table 21, the average of each category for the different caregiving question are given.

Table 20. Types of Caregiving Provided by Caregiver as Indicated by the Unpaid Caregiver

	Valid Obs	Mean	SD	Min	Max
Legal advice and issues	37	3.46	1.73	1.00	5.00
Financial management	38	3.61	1.53	1.00	5.00
Spiritual / social / community activities	38	3.95	1.35	1.00	5.00
Household management and / or modifications	37	3.95	1.45	1.00	5.00
Transportation	38	3.79	1.58	1.00	5.00
Nutrition, meal preparation, grocery shopping	38	4.32	0.93	1.00	5.00
Housekeeping activities	38	4.24	1.17	1.00	5.00
Mobility support, equipment, rehabilitation	38	2.95	1.66	1.00	5.00
Personal hygiene	38	2.76	1.57	1.00	5.00
Medical and / or nursing treatment(s) and medication(s)	37	3.24	1.66	1.00	5.00
Average		3.56	1.20	1.00	5.00

Although the averages are not 100% comparable, patients indicated less caregiving was needed than caregivers indicated they are provided. This result may imply that a specific caregiving (or behavior) is not a considered caregiving by the patient, but the caregiver feels it is caregiving. For example, patients may feel a meal preparation is not caregiving, however, his / her spouse may feel a meal preparation is a caregiving. Further, the differences may indicate the need for patients to feel independent. Finally, the differences may also indicate caregivers may overstate their role when compared to the patient's perspective.

Caregiving Time

Caregivers, on average, devote about 14.4 hours per week during the weekday (Monday through Friday, 8 a.m. to 5 p.m.) and about 20.9 hours during the weekday nights (5 p.m. to 8 a.m.) for caregiving (table 22). On weekends, they devote about 14 hours to caregiving. On average, a caregiver spends about 49 hours / week for patient caring (7 hours / weekday (14.4 / 5 + 20.9 / 5 = 7.06) and 7 hours / weekend day (14.3 / 2 = 7.15)). Some caregivers believed staying with the patient is itself caregiving. In these cases, the caregiver stated they provide care 24 hours a day, 7 days a week.

Table 21. Comparison Between Patients and Caregivers Responses Concerning about Caregiving

	Perspective			
	A	B	C	D
Legal advice and issues	2.61	2.40	1.38	3.46
Financial management	2.69	2.59	1.55	3.61
Spiritual/social/community	2.66	2.71	1.52	3.95
Household management	2.63	2.96	1.52	3.95
Transportation	3.73	3.36	1.67	3.79
Nutrition, grocery shopping	3.20	3.14	1.44	4.32
Housekeeping activities	3.31	3.42	1.70	4.27
Mobility, rehabilitation	2.39	2.33	1.48	2.95
Personal hygiene	2.25	2.41	1.37	2.76
Medical and nursing treatment	2.77	2.50	1.33	3.24

Perspective A: what patients feel about how much caregiving they need.
Perspective B: what patients feel about how much caregiving is provided by in-town unpaid caregiver.
Perspective C: what patients feel about how much caregiving is provided by out-of-town unpaid caregiver.
Perspective D: what caregivers feel about how much caregiving they provide.

Table 22. Unpaid Caregiver' Caring Time for ESRD Patient

	Valid Obs	Mean	SD	Min	Max
Daytime Care	26	14.38	14.64	0.00	45.00
Nighttime Care	26	20.90	25.63	0.00	75.00
Weekend Care	24	14.25	17.08	0.00	48.00
Average (1 day)	28	7.08	7.43	0.00	24.00

Daytime (8 a.m. – 5 p.m., Mon – Fri) / week
Nighttime (5 p.m. – 8 a.m., Mon – Fri) / week
Weekend: Saturday and Sunday

Employment Status

Forty-six percent (18 caregivers) are currently working either full-time (36%, 14 caregivers) or part-time (10%, 4 caregivers). The other twenty caregivers are retired (31%, 12 caregivers), unemployed (13%, 5 caregivers), or homemakers (8%, 3 caregivers). One caregiver did not complete the question regarding employment status. Only two caregivers stated they reduced their work hours because of their caregiving. One caregiver reduced his workload by 12 hours per month, whereas the other caregiver indicated she reduced her working by 120 hours per month.

Almost ninety percent of the caregivers (35 caregivers) stated their caregiving did not affect their retirement decision. Less than 3% (1 caregiver) stated he retired two years early because of his caregiving. Eight percent (3 caregivers) did not answer the question. Among these 35 caregivers who stated caregiving had no affect on their retirement, eighteen caregivers (21%) are currently working.

Income Distribution

Caregivers were asked the same questions as the patients concerning income. Fifty-four percent (21 caregivers) have income less than $20,000, whereas 26% (10 caregivers) have income greater than $30,000 (table 23). Eight caregivers (21%) did not provide their income (table 23). The relationship between current income level and education level is shown in table 24. Higher income levels are generally associated with more education.

Table 23. Income Distribution of Caregivers

	Frequency	Percent
< $10K	10	25.6
$10K-$20K	11	28.2
$20K-$30K	4	10.3
$30K-$50K	3	7.7
$50K-$75K	2	5.1
> $75K	1	2.6
Missing	8	20.5
Total	39	100.0

Table 24. Relationship Between Income and Education of Caregiver

	Current Income						
Education	< 10K	10K-20K	20K-30K	30K-50K	50K-75K	>75K	Total
K-8th	4	3		1			8
9th-12th	6	6		1			13
Some College			3				3
Bachelor Degree		2	1	1			4
Post-Bachelor					2	1	3
Total	10	11	4	3	2	1	31

Changes in Personal Life

More than half (51.3%, 20 of 38) of caregivers have changed their vacation plans because of patient caring (table 25). Only 7.7% of caregivers (3 of 39) changed their job because of their caregiving (table 25). Three caregivers (7.7%) reported they changed their residence because of caring the ESRD patient (table 25). No caregiver hired another person to take care of his / her other family members so the caregiver could provide care to the ESRD patient.

Table 25. Changes in Caregivers' Life Caused by Their Caregiving

	Frequency	Percent
	Changed vacation plans	
Yes	20	51.3
No	16	41.0
Missing	3	7.7
	Changed job	
Yes	3	7.7
No	32	82.1
Missing	4	10.2
	Changed residence	
Yes	3	7.7
No	35	89.7
Missing	1	2.6

Additional Expenses

Respondents were asked to provide additional expenses associated with their caregiving for food, transportation, medical equipment, household chores, and other miscellaneous items (table 26). Average monthly additional expenses are $72.11 month for food,

$37.97 / month for transportation, $4.61 / month for medical equipment, $6.85 / month for household chores, and $17.50 / month for other miscellaneous items.

Table 26. Caregivers' Expenses Directly Attributed to Caring for ESRD Patients

Expenses	Mean	SD	Min	Max
		Monthly Expenses		
Food	72.11	144.73	0.00	700.00
Transportation	45.17	59.95	0.00	200.00
Medical Equipment	4.61	18.02	0.00	100.00
Household Chores				
Lawn	1.58	9.73	0.00	60.00
Cleaning	0.00	0.00	0.00	0.00
Grocery	4.61	28.39	0.00	175.00
Errand	0.66	4.06	0.00	25.00
Other	0.00	0.00	0.00	0.00
Total Household Chores	6.85	29.90	0.00	175.00
Other Miscellaneous	17.50	44.84	0.00	185.00
		One-time Expenses		
Home Renovation	2.42	11.81	0.00	70.00
Changes in Car	0.00	0.00	0.00	0.00
Purchasing Additional Car	657.89	3,322.94	0.00	20,000.00

Food, Transportation, Household chores, and Other miscellaneous: $ / month
One-time expenses; expenses incurred since the onset of caregiving.

In addition to monthly expenses, caregivers were asked to provide total costs for home renovation, modification to their car, and car purchasing caused by their caregiving. Average total costs for home renovations were $2.42 and $657.89 for car purchases. No caregiver indicated modifications were necessary to their car. In calculation of expenses for household chores, home renovation, and car purchasing, the double counted data with patients' expenses are replaced with zero. To avoid double counting, when calculating these costs, some reported costs were replaced with zero if

the patient and the caregiver lived together and stated the same costs. Because it is was not asked whether the patient and the caregiver live together, living arrangements are deduced by comparing number of family members, their relationship, and their answers concerning the amount of household expenses.

Quality of Life

To evaluate the quality of life of caregivers, the index of well-being (IWB) used in the patient questionnaire was also asked of the caregivers (see discussion associated with table 12). The average caregivers' IWB is 11.77 (table 27). The caregivers' average IWB is higher than the patients' average IWB (10.75). Forty-one percent (16 caregivers) had a lower index than the average IWB. Eight caregivers (21%) did not answer the quality of life questions.

Existence of Secondary Caregiver

Fourteen primary caregivers (36%) indicated there is another caregiver(s) (secondary) who also provides care for the ESRD patient (table 28). A summary of the primary and secondary caregivers' relationship to the ESRD patient is given in table 28. Spouses are the largest percentage of primary caregiver. Children are the largest percentage of secondary caregivers.

Table 27. Index of Well-Being of Caregivers

Item (Scale: One – Seven)	Mean	SD	Min	Max
Q1. Boring – Interesting	5.03	1.53	1.00	7.00
Q2. Miserable – Enjoyable	5.48	1.33	2.00	7.00
Q3. Useless – Worthwhile	5.82	1.51	1.00	7.00
Q4. Lonely – Many friends	5.25	1.59	2.00	7.00
Q5. Empty – Full	5.66	1.43	2.00	7.00
Q6. Discouraging – Encouraging	5.27	1.88	1.00	7.00
Q7. Disappointing – Rewarding	5.56	1.72	1.00	7.00
Q8. Brings out the worst in me – Brings out the best in me	5.69	1.53	1.00	7.00
Average Q1 - Q8	5.46	1.27	2.75	7.00
Q9. (Overall Satisfaction of your life) Very dissatisfied – Very satisfied	5.74	1.21	4.00	7.00
Index of Well-Being	11.77	2.41	7.15	14.70

Table 28. Distribution of the Primary and Secondary Caregivers

	Primary	Percent	Secondary	Percent
None			22	56.4
Parents	5	12.8	0	0.0
Spouse	20	51.3	1	2.6
Sister/Brother	4	10.3	2	5.1
Daughter/Son	8	20.5	7	17.9
Friends	1	2.6	1	2.6
Volunteer	0	0.0	1	2.6
Daughter/Son & Friend	0	0.0	1	2.6
Sister/Bro & Relative	0	0.0	1	2.6
Missing	1	2.6	3	7.7
Total	39	100.0	39	100.0

Caregivers indicated the amount of caregiving provided by the secondary caregiver(s) (table 29). Responses show how the primary caregiver feels about the level of caregiving secondary caregivers provide. Fourteen caregivers indicated secondary caregiver(s) provide help to the ESRD patient. Only these fourteen caregivers should

have answered the question about secondary caregiver. However, approximately 27 caregivers completed the questions concerning types of caregiving by secondary caregiver. Because the questions are summarized independent of the other questions, the summary of the secondary caregiveing includes all 27 responses. Primary caregivers, on average, feel secondary caregivers provide more transportation care (2.78) than any other category. The next highest type of care was household management. All other types of caregiving had means less than 2.

Table 29. Types of Caregiving Provided by Secondary Caregivers

	Valid Obs	Mean	SD	Min	Max
Legal advice and issues	27	1.67	1.14	1.00	5.00
Financial management	27	1.78	1.12	1.00	5.00
Spiritual / social / community activities	27	1.85	1.20	1.00	5.00
Household management and / or modifications	28	2.04	1.20	1.00	5.00
Transportation	27	2.78	1.45	1.00	5.00
Nutrition, meal preparation, grocery shopping	27	1.89	1.19	1.00	5.00
Housekeeping activities	27	1.63	0.88	1.00	4.00
Mobility support, equipment, rehabilitation	27	1.52	0.89	1.00	4.00
Personal hygiene	27	1.26	0.53	1.00	3.00
Medical and / or nursing treatment(s) and medication(s)	27	1.56	0.85	1.00	3.00
Average		1.80	0.77	1.00	3.30

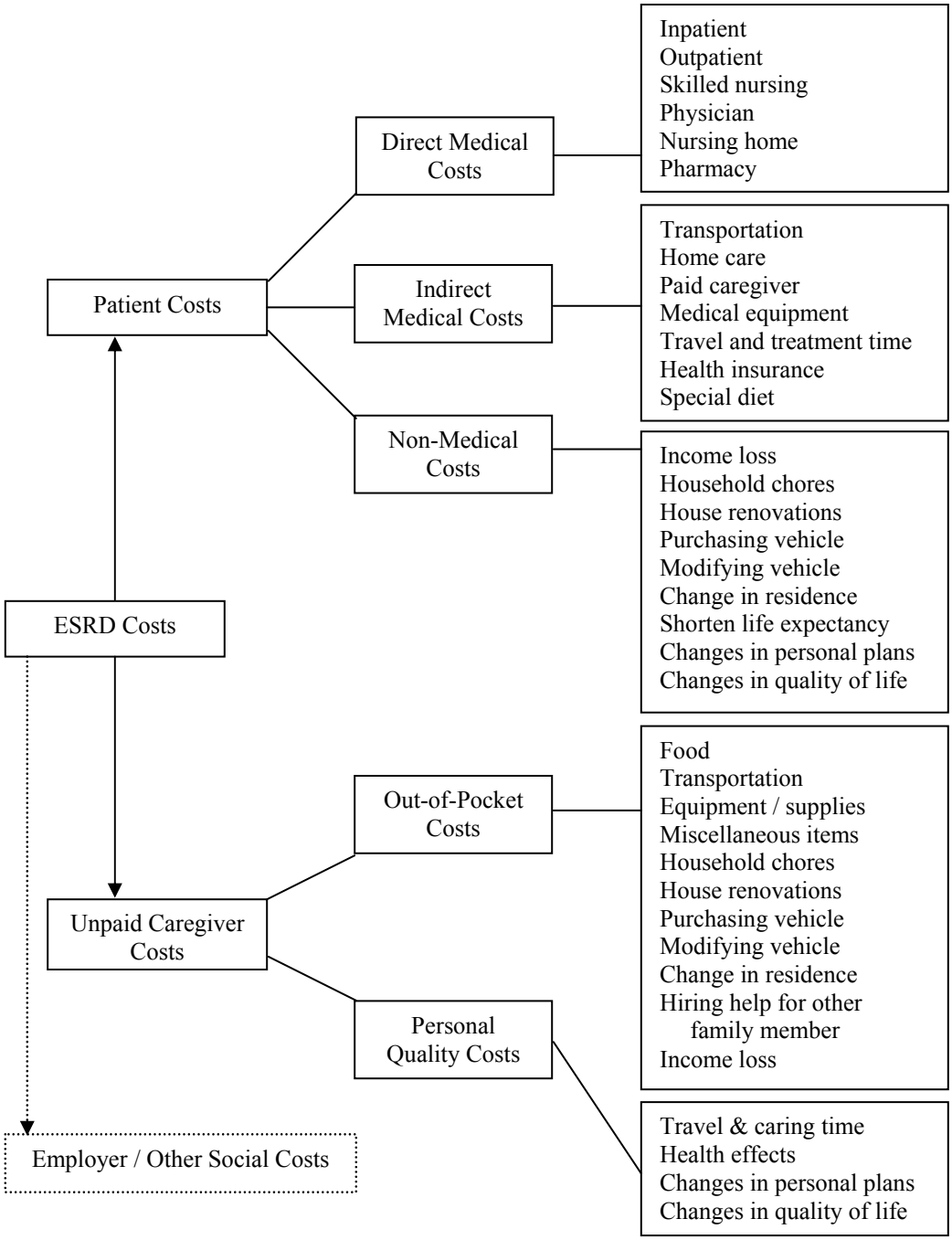
CHAPTER IV

COSTS OF ESRD: CASE STUDY

The objective of this chapter is to calculate the costs to patients and unpaid caregivers of End Stage Renal Disease (ESRD). This chapter provides a more complete calculation of the costs associated with ESRD and, thus, savings from reduced risk of ESRD. For estimation of the costs of ESRD, the following variables are considered (figure 3):

- *direct medical costs* - inpatient, outpatient, skilled nursing, physician, nursing home, and pharmacy;
- *indirect medical costs* - transportation, home care, paid caregiver, medical equipment, time spent for treatment and travel, health insurance, and special diet;
- *patients' non-medical costs* - income loss, additional expenses for household chores, home renovation, purchasing additional vehicle, modifying vehicle, and changing residence, shorten life expectancy, changes in personal plans, and changes in quality of life;
- *unpaid caregivers' out-of-pocket costs* - additional expenses for food, transportation, any equipment for caring, and other miscellaneous items, additional expenses for household chores, home renovation, purchasing additional vehicle, modifying vehicle, changing residence, hiring help for other family member, and income loss; and
- *unpaid caregivers' personal quality costs* - time spent for patient caring and travel, health effects, changes in personal plans, and changes in quality of life.

Data for direct medical costs are available from U.S. Renal Data System (U.S. RDS). Indirect medical costs such as expenses for transportation, home care, paid caregiver, and medical equipment are ascertained from the patients' questionnaire. Costs for health insurance and special diet are not asked in the questionnaire.



- Employer / other social costs are not included in calculation of ESRD costs in this study.

Figure 3. Categorized costs of end stage renal disease

Questions regarding patients' non-medical costs such as patients' income loss, additional expenses for household chores, home renovation, purchasing additional vehicle, residence changes are included in the questionnaire. No monetary values are calculated for changes in personal plans, shorten life expectancy, and changes in quality of life, but effects are asked of the patients. It is nearly impossible to estimate the true economic cost of these categories.

Unpaid caregivers' out-of-pocket costs are ascertained from the caregivers' questionnaire. Unpaid caregivers' personal quality costs are asked, but monetary values are not estimated. As with similar patients' cost categories, these costs are nearly impossible to quantify in monetary values. These categories have been referred to in several studies (Covinsky et al.; National Alliance for Caregiving (2002a)), but no study was found that estimated an appropriate monetary value (or developed a methodology to estimate a cost) for these categories.

In this chapter, patients' and caregivers' time to travel to the dialysis center, patients' time spent for treatment, and caregivers' caring time are converted to monetary values. Patients' and caregivers' time are valued using three wage rates. Because most ESRD patients are retired, it is difficult to value their opportunity costs. In addition, patients' and caregivers' income losses are calculated. These income losses potentially include the values of patients' and caregivers' time. The secondary impacts from unpaid caregiving such as negative impact to caregivers' employers and children are not considered in the costs calculation. The costs are calculated on per patient basis applicable to patients at the Gambro Dialysis Center and their primary unpaid caregivers

in the study population. Other costs such as costs to employers and society (figure 3) are not considered here. Double counting is a potential problem when including these costs. Further, data are not available to calculate these costs.

For the most part, only average costs for the above cost categories are presented in the text. Histograms and cumulative density function for the different cost categories are presented in Appendix D. Similar methodologies are used to calculate unpaid caregivers' and patients' costs.

Direct Medical Costs

Medicare covers 80% of direct medical costs for ESRD treatment. The remaining 20% is paid by personal insurance or Medicaid, directly by the patient, or the medical agency foregoes the fee as bad debt. These percentages are almost identical nationwide (Tan, 2002). Although patients may not incur these costs directly, society experiences these costs, as such they are applicable in estimating the true costs ESRD.

The most recent data from the U.S. Renal Data System (U.S. RDS) are used to calculate the direct medical treatment cost of ESRD. According to the 2002 annual report from U.S. RDS (the most recent available information), Medicare paid $56,158 / ESRD patient / year in 2000 (U.S. RDS). As previously noted, Medicare covers only 80% of the direct medical cost of an ESRD patient. The remaining 20% of the direct medical cost amounts to $14,039. Direct medical cost of an ESRD patient is, therefore, approximately $70,197 / year in 2000. The consumer price index (CPI) is used to convert the 2000 costs into 2002 values. The converted direct medical cost of an ESRD patient at the Gambro Dialysis Center is approximately $73,336 / year. Because the CPI

is most likely lower than medical cost inflation rate, this cost can be considered a conservative estimate.

Indirect Medical Costs

Patients' Transportation Costs

In calculating transportation costs, each patient's type of transportation and miles they travel to the dialysis center are used. Transportation costs are calculated individually for each of the 68 patients in the case study. Among the patients, 47 travel to the dialysis center by automobile only, nine patients use some other type of transportation such as bus (6 patients), taxi (1 patient), walk (1 patient) and special medical transportation (1 patient). As shown earlier in table 4 (Chapter III), twelve patients answered they use more than one type of transportation to travel to the dialysis center.

Travel costs for each transportation type are calculated (table 30). For the patient who walks, travel cost is assumed to be zero. For the 16 patients who drive themselves to the center, each patient's number of one-way miles to the dialysis center is multiplied by 109.2 to calculate their annual travel cost ($0.35 / mile × 2 for round trip × 3 trips / week × 52 weeks / year = 109.2). In calculating the cost of driving an automobile, a rate of 35 cents / mile is used. This rate is used as a guide for state employees to use when traveling by automobile in Texas (Strayhorn). The average travel cost of the 16 ESRD patients who use their automobile and travel to the center by themselves is approximately $1,720 / year / patient (table 30).

Table 30. Travel Cost by Modes of Travel to the Dialysis Center (Unit: $ /Year)

Travel Types	Frequency	Mean	SD	Min	Max
Walk	1	0.00	-	-	-
Drive (Self)	16	1,719.90	1266.28	546.00	3,931.20
Ride w/ Other	31	1,127.75	1398.37	0	4,368.00
Taxi	1	14,142.96	-	-	-
Bus	6	78.00	0.00	78.00	78.00
Medical Transportation	1	46,800.00	-	-	-
Walk or Ride w/ Other	1	0.00	-	-	-
Drive (Self) or Ride w/ Other	2	1,201.20	154.43	1,092.00	1,310.40
Drive (Self) or Bus	1	1,240.20	-	-	-
Ride w/ Other or Taxi	1	3,276.00	-	-	-
Ride w/ Other or Bus	4	1,368.00	1374.86	78.00	3,315.00
Ride w/ Other or Medical Transportation	1	23,836.80	-	-	-
Bus or Medical Transportation	1	23,439.00	-	-	-
Drive (Self) or Bus or Medical Transportation	1	16,754.40	-	-	-
Total	68	2,945.72	7119.76	0.00	46,800.00

Source: calculated from patient and caregiver questionnaires.

The thirty-one patients who travel with a caregiver are divided into three cases, 1) their caregivers provided additional transportation costs (10 cases), 2) their caregivers stated they incur no additional travel costs (11 cases), and 3) their caregivers did not provide an answer to the question concerning additional transportation cost (10 cases). The transportation costs paid by the patients who are in the first case are assumed to be zero. Their caregivers provided the additional transportation expenses; these costs are included in the caregivers' expenses. Assuming a zero cost for these 10 patients avoids double counting transportation costs. For the second case, travel costs are calculated in the same manner (actual miles × 109.2) as for the costs of those patients who drive themselves. For the third case, it is hard to identify who pays for the travel between the

patient and the caregiver. It is more reasonable to assume the caregiver drives and pays, that is, the travel costs in these cases should be included in the caregivers' transportation costs. Among the 10 caregivers in the third case, eight caregivers did not turn in the questionnaire. The transportation costs for these eight caregivers are counted, therefore, in the patients' costs. For the other two caregivers, who turned in the questionnaire, their costs are counted in caregivers' transportation costs. The two patients' transportation costs are assumed to be zero. These 31 patients who accompany a caregiver spend about $1,128 / year / patient for transportation (table 30).

An average rate of two taxi companies in Bryan/College Station area is used in calculating the cost of using a taxi (AAA University Taxi and Advantage Taxi). One company charges $4 basic fare plus $1.65 / mile, whereas the other company charges $4.50 basic fare plus $1 / mile. There is one patient who only uses a taxi to travel to the dialysis center. This patient lives approximately 31 miles way from the dialysis center and spends about $45 on average for one-way trip ($35.5 + $55.15 = $90.65 / 2 = $45.33). The patient's annual spending for taxi is about $14,143 ($45.33 × 2 for round trip × 3 trips / week × 52 weeks / year). Six patients use the bus to travel to the center. The bus fare in Bryan / College Station is $0.25 (for elderly, children, and disabled patrons) per ride (City of Bryan Planning Department). If a patient uses the bus only, he/she spends $78 per year ($0.25 / trip × 3 trips / week × 52 weeks / year × 2 for round trip) for bus transportation. To use special medical transportation (e.g. ambulance), a patient has to qualify for disability status and financial need (Tan, 2003). The cost of

using medical transportation is $300 / trip (Tan, 2003). The patient does not pay for this medical transportation, but rather, it is supported by government funds (Tan, 2003). For the patient who uses only special medical transportation, a cost of $46,800 / year is incurred.

In the cases of patients using multiple transportation types, it is assumed that the patient uses each mode of transportation in the same proportion. Unfortunately, the questionnaire did not ascertain the number of times each type of transportation is used. This assumption is, therefore, made for simplicity. Transportation costs for patients using different types of transportation becomes the simple average of the annual costs for each transportation type. One patient walks or rides with a caregiver. Travel costs for this patient are zero, because the costs associated with walking are zero and the caregiver of the patient provided additional travel costs. The transportation cost is included in the caregivers' expenses. Two patients either drive by themselves or ride with a caregiver. For these two patients, transportation costs are calculated using "actual miles × 109.2," because these two patients use automobiles and their caregivers did not provide additional transportation costs. One patient either drives or uses the bus. For this patient, the average of "actual miles × 109.2" and bus fare is used to calculate transportation costs. One patient who lives about 10 miles away from the center uses a taxi or rides with a caregiver. This patient spends about $17.50 for a round trip, when a taxi is used. Transportation costs are the average of expenses for taxi and "actual miles × 109.2". The costs of the four remaining combinations of multiple transportation, 1)

ride with other or bus (4 patients), 2) ride with other or medical transportation (1 patient), 3) bus or medical transportation (1 patient), and 4) self-driving or bus or medical transportation (1 patient) are calculated in a similar fashion.

On average, an ESRD patient at the Gambro Dialysis Center spends $2,946 / year on transportation to and from the dialysis center (table 30). However, the patients incur a wide range of costs. One patient lived close enough to walk to the center, thus incurring no transportation costs. On the other hand, one patient uses medical transportation exclusively at a cost of $46,800 per year. As expected, transportation costs are a function of the distance the patient lives from the dialysis center and the overall health of the patient. Two caveats are necessary in interpreting transportation costs. First, because of the nature of the calculations, society will incur these costs, but the patients may not necessarily pay these amounts. Two reasons for this are 1) the government subsidizes some of the transportation costs and 2) caregivers' cost for transportation is included for some of the patients. Caregivers' cost being including in the patients' cost is because some caregivers did not provide transportation cost data. Second, actual total transportation costs are higher than the average presented in table 30, because of the inclusion of some transportation costs in the caregivers' section to avoid double counting. Examining both patients' and caregivers' (see "Unpaid Caregivers' Out-of-Pocket Costs" section) transportation costs provides a better estimate of total transportation costs.

Patients' Costs for Home Care, Paid Caregiver, and Medical Equipment

As shown in table 5 in Chapter III, patients spend on average $30.88 / month for home care and $7.56 / month for paid caregivers. Annual expenses for these two items are, therefore, $370.56, and $90.72. An average of $23.86 / month is spent on medical equipment, giving a yearly total of $286.32 / patient. An annual total of $747.60 is spent for these three items (home care, caregiver, and medical equipment) per ESRD patient at the Gambro Dialysis Center.

Patients' Time Costs

Time spent for traveling to the dialysis center and time for dialysis treatment are important indirect medical costs incurred by ESRD patients. Sixty-three patients are divided into two groups 1) residents of the Bryan / College Station (BCS) (35 patients), and 2) patients residing outside of BCS, living in town such as Hearne, Navasota, Caldwell, and Calvert (28 patients). Five patients did not provide information concerning their residences. The average distance to the dialysis center is 8.23 miles for residents of Bryan / College Station and 30.93 miles for residences outside BCS. It is difficult to obtain appropriate data about average running speed in towns and on highways, because many factors must be considered, such as number of traffic signals, number of intersections, number of vehicles, etc. (Kim).

To calculate time spent on traveling to the dialysis center, the following assumptions are made. Patients travel at the posted speed limit assumed to be 35 miles / hour in town and 65 miles on highway. Patients residing in the BCS area use local streets. Patients residing outside of BCS area pass through their hometowns by using

local streets, then use a highway to travel to BCS, and finally travel through College Station to reach to the dialysis center. To pass through each town, it takes 10 minutes. Travel time associated with all transportation modes (auto, taxi, bus, and medical transportation) is same. These assumptions provide a lower bound on travel time; for example, the actual running speed is usually lower than the speed limit, because of traffic. With these assumptions, it is expected that it take about 15 minutes for one-way trip to the center for patients living in BCS (8.23 miles × 60 minutes / hour ÷ 35 miles / hour = 14.11 minutes ≈ 15 minutes). This travel time translates into approximately 30 minutes / round trip. Over the course of the year, a BCS patient spends 78 hours per year traveling to and from the center (30 minutes / round trip × 3 round trips / week × 52 weeks / year ÷ 60 minutes / hour = 78 hours / year). For patients residing outside BCS, the expected travel time is 50 minutes for one-way trip (30.93 miles × 60 minutes / hour ÷ 65 miles / hour ≈ 28.5 minutes plus additional 20 minutes to pass through the two towns). Patients outside BCS spend approximately 260 hours / year to travel to the center (100 minutes / round trip × 3 round trips / week × 52 weeks / year ÷ 60 minutes / hour = 260 hours / year). Weighting by the percentage of BCS and outside BCS area residents, the average travel time is 159 hours / year / patient ($35/63 \times 78 + 28/63 \times 260$). Dialysis treatment lasts approximately 4 hours. ESRD patients, therefore, spend approximately 624 hours per year (4 hour treatment × 3 treatments / week × 52 weeks) undergoing dialysis treatment. The weighted average number of hours spent traveling to the center and for treatment is approximately 783 (159 + 624) hours per year.

It is difficult to evaluate an appropriate value of time in monetary terms. In this case study, most of patients are retired or unemployed. In addition, calculated income loss may cause potential double counting in valuing of time. Finally, dialysis time may become social time for some patients, complicating estimation of monetary cost on the time spent in treatment. A considerable number of hours are devoted, however, to treating ESRD. To put the number of hours in perspective, 783 hours translates into approximately 98 eight-hour workdays or 19.5 workweeks. Time is obviously a large cost associated with ESRD. Of the total number of hours in a year, approximately nine percent are spent for traveling to the treatment center or for treatment.

Hodgson (1983, 1994) argues correctly, the time spent by patients for treatment should be included in the costs of the illness. For at least the last four decades, attempts have been made to value time (Feather and Shaw). Resources including time should be valued at their opportunity cost (Griffin). In cost benefit analysis, most unemployed market resources should be valued at a zero cost. This is because their opportunity cost is zero, that is, the resources are not being used in the market place (Griffin). This may not be the case, however, with unemployed people. Shaw suggests individuals who are retired, between jobs, or have a low wage, do not necessarily have a low opportunity cost of time (Shaw). Patient's time is divided between time spent for medical treatment, work, and leisure (including all other activities). Increasing medical treatment time forces work and / or leisure time to decrease. Therefore, the opportunity cost of work and / or leisure should be used to value time spent for treatment. Given the difficulties with valuing a catchall time category, leisure (which includes everything from sleeping

and eating to vacation time), the most typical methodology to value time is to use a wage rate. In many cases, sensitivity analysis on the wage rate is conducted. This procedure is followed here.

Three wage rates are considered. The same rates are used for placing a cost on both patients' and caregivers' time. The first is a zero wage rate. This rate obviously assumes no opportunity costs for time. Next, the minimum wage rate of $5.15 / hour is used. This rate is the minimum the person would receive in the market. Finally, the nation average wage rate from health aides of $11.20 / hour is used (Arno, Levine, and Memmott). This last wage rate is based on the argument put forth by Arno, Levine, and Memmott that if unpaid caregivers were not proving the care, this care would have to be replaced by paid caregivers. Further, ignoring altruistic aspects, the argument could made that if the unpaid caregiver valued their time at more than this rate, they would purchase paid caregiving and not provide the level of unpaid caregiving being provided. These last two arguments apply to valuing unpaid caregivers. However, the higher rate for patients may also be relevant, because the majority of the patients are not in the job market. Provided they could work, an argument for a higher wage rate is by not being in the workplace, they value their time more than the wage rate they would receive.

On average, an ESRD patient at the Gambro Dialysis Center incurs costs associated with time that range from $0 / year (zero wage rate, lower bound) to $4,032.45 / year ($5.15 × 783 hours, middle bound) to $8,769.6 / year ($11.2 × 783 hours, upper bound). These estimates are from all of 63 patients who provided an answer about their residence. Of these 63 patients, 11 patients indicated income losses.

Their income losses may already include their time costs as such the above time costs may include double counting. For conservative estimates, these 11 patients' time costs are assumed to be zero (nine patients are in BCS area and two patients are in out of BCS area). Under this assumption, an ESRD patient has time costs of $0 / year (lower bound), $3,370.68 / year (middle), and $7,330.4 / year (upper bound) (table 31).

Table 31. Time Costs of Patients and Unpaid Caregivers

	$0.00 / hour	$5.15 / hour	$11.20 / hour
Patient	$0.00	$3,370.68	$7,330.40
Unpaid Caregiver with 24 / 7	$0.00	$13,122.20	$28,537.60
Unpaid Caregiver without 24 / 7	$0.00	$2,250.55	$4,894.40

Expenses for Health Insurance and Special Diets

Additional Expenses for health insurance and special diet were not asked in the patient and caregiver questionnaires, because it is hard to distinguish whether the expenses for these two categories are caused strictly by ESRD or co-morbidities. In addition, eating a special diet may improve the overall health of the patient, therefore, potentially giving an overall net benefit to this category. The incremental expenses for these two categories are not calculated, but are noted. The average total calculated indirect medical cost of ESRD patients at the Gambro Dialysis Center is $ 7,064 / patient / year ($2,945.72 for transportation + $747.60 for home care, caregiver, and medical equipment + $3,370.68 for travel and treatment time with using a rate of $5.15 / hour).

Patients' Non-Medical Costs

Annual Costs for Household Chores

For household chores such as lawn mowing, house cleaning, grocery shopping, errands, and other miscellaneous chores, an ESRD patient at the Gambro Dialysis Center spends on average of $12.94, $6.18, $15.90, $1.91, and $4.76 / month (table 5 in Chapter III). The average total amount for household chores is, $500.28 / year / patient. Again, a wide range of costs is seen, ranging from $0.00 to almost $4,000 / year.

Income Loss

Data concerning income level at time of retirement and current income level are used to calculate the patients' income loss because of their ESRD. Patients' income losses are calculated in 2002 terms. Regarding employment status, five patients did not provide information concerning their employment status and income level. Further, it could not be identified how ESRD impacted employment for three patients. These eight cases are excluded in the calculations.

Forty-one percent (28 patients) stated their ESRD did not affect their employment status. These 28 patients comprise the following cases, 1) the patient was retired when he/she was diagnosed with ESRD (18 patients), and 2) the patient was not employed or a homemaker when diagnosed with ESRD (ten patients). The questionnaire is designed such that patients did not provide information on previous income levels, if their ESRD did not affect their retirement. Because these 28 patients did not provide their previous income level, it is assumed that there is no change in their income level caused by their ESRD. Income losses associated with ESRD for these 28 patients are

assumed to be zero. Eight other patients answered their ESRD did not affect their retirement. The income losses associated with ESRD of these eight patients are also assumed to be zero. Five patients answered they are still working. Income changes of these five patients are assumed to be zero. In addition, one patient indicated an increase in her income. The patient was not employed and had a previous income of less than $10,000. Currently, the patient is retired, and has an income between $10,000 and $20,000. This increase in income may be caused by the government disability benefits, which would be a cost to society. However, it is not clear what caused the increase in income. Because it could not be determined if this patient's income change was not caused by ESRD, this patient's income loss is assumed to be zero. Income losses associated with ESRD for 42 patients' are, therefore, assumed to be zero. The questionnaire also included questions asking if the patients' ESRD affected the patients' working hours. No patients, including the five working patients, indicated they changed their working hours because of their ESRD.

The remaining 18 patients answered that their ESRD affected their retirement. Average number of years the patient retired early for these 18 patients is 11 years. Among these 18 patients, seven patients stated there was no change in their income level. The income losses of other patients (11 patients) are calculated individually using the following methodology.

First, each patient's income at time of retirement is converted into 2002 dollars using the consumer price index (CPI) as the inflation rate. This step is necessary, because patients were asked to provide their current income, which would be in 2002

dollars and income at the time of retirement. Second, the difference between the patient's current income and income at time of retirement in 2002 dollars is calculated. Third, based on the number of years the patient retired early and assuming an average age of 62 for retirement (Gendell), the present value (PV) of the patient's lost income is calculated. Results using two discount rates (3% as a lower bound and 7% as an upper bound) are presented. A seven percent discount rate is the mandated rate from 1992 in all benefit / costs analysis by all U.S. government agencies (Tietenberg) and 3% is used to represent a social discount rate. In a report from U.S. EPA, these two rates are used to conduct a sensitivity analysis on benefits and costs estimation (U.S. EPA, 1999). Unfortunately, in the questionnaire, it was not asked when the patient retired. Instead, it was asked how many years early the patient retired because of ESRD. The assumption of retirement at 62 years, therefore, is necessary to approximate when the patient retired.

As an example of the methodology, assume a patient is 50 years old in 2002. This patient stated he / she retired 15 years early because of his / her ESRD. With the assumption of 62 as the retirement age, he / she would have been expected to retire in 2014. It is assumed that the patient retired in 1999 (2014 – 15 = 1999). The patients' income level at time of retirement was $15,000 and his / her current income level is $5,000. To obtain the real income loss and its present value, first, the previous income level ($15,000 in 1999) is converted to 2002 values using the appropriate annual consumer price indices. For sake of simplicity, assume the value of $15,000 in 1999 is $17,000 in 2002. The patient's yearly income loss in 2002 dollars is $12,000 ($17,000-

$5,000). It is assumed this loss in real dollars is constant from 2002 to 2014. Present value of the patient's income loss is then calculated as

$$(18) \quad \text{PV of Income Loss} = \sum_{i=0}^{n} \frac{Loss}{(1+r)^i} + \sum_{t=1}^{m} PLoss_{2002-t}(1+r)^t$$

where n is number of years from 2002 to projected year of retirement without ESRD, r is discount rate, Loss is income loss in 2002 dollars, $PLoss_{2002\text{-}t}$ is an income loss in year 2002-t, and m is the number of years the patient retired before 2002. In this example, n is 12 (2014-2002), r is 3% or 7%, Loss is $12,000, and m is 3. For calculation of previous income losses (Ploss), previous income level (1999 dollars) and current income level (2002 dollars) are converted to 2001, 2000, and 1999 dollars using the appropriate CPI. Then, the income loss of each year is inflated to 2002 dollars using the discount rate.

In table 32, it is shown when the patient retired, how early retired, income loss in 2002, and present values of income losses for each of 11 patients who indicated a positive income loss. The average income loss of 60 patients (49 patients with no income loss and 11 patients with a positive income loss) in 2002 is $4,147.53. The present value of average income loss is $52,523.94 using a 3% discount rate and $54,655.07 using a 7% discount rate (table 33). The range of the net present value of the income loss with 3% discount is $0 - $546,231.48, and $0 - $571,101.66 for the 7% discount (table 33).

Table 32. Observations of Patients' Income Losses and Present Value (PV) of the Income Loss

	C-I	P-I	I-L in 2002	PV of I-L (3%)	Annual I-L (3%)	PV of I-L (7%)	Annual I-L (7%)
Patient 1 (1996, n=15)	1	2	12,199	172,694.57	14,466.08	170,819.65	18,755.11
Patient 2 (1998, n=16)	2	4	29,147	417,205.41	33,214.08	378,039.15	40,018.54
Patient 3 (1989, n=8)	1	2	16,762	120,285.18	17,135.37	143,249.81	23,989.72
Patient 4 (1996, n=21)	1	2	12,199	224,862.14	14,609.03	204,661.74	18,927.73
Patient 5 (1991, n=21)	1	2	14,813	298,515.99	19,394.23	324,800.07	30,038.48
Patient 6 (2002, n=23)	1	2	10,000	169,369.17	10,314.18	120,612.40	10,319.25
Patient 7 (1996, n=14)	1	4	40,864	546,231.48	48,355.76	548,426.19	62,709.53
Patient 8 (1996, n=11)	1	4	40,864	443,532.71	47,936.01	466,613.27	62,225.89
Patient 9 (2002, n=3)	1	2	10,000	29,134.70	10,300.04	28,080.18	10,700.07
Patient 10 (1979, n=16)	1	2	32,169	411,112.52	32,729.02	571,101.66	60,455.79
Patient 11 (1997, n=11)	2	4	29,835	318,492.47	34,421.94	322,899.94	43,060.79

C-I, P-I, I-L indicates Current Income Level, Previous Income Level, and Income Loss respectively.
Three and seven percent are two assumed discount rates.
Forty-nine patients indicated zero income loss because of their ESRD.
Eight patients were excluded in calculation because of missing values.
Previous income means the income level at time of retirement.
Income levels: 1=less than $10K, 2=$10K-$20K, 3=$20K-$30K, 4=$30K-$50K
Median of each level = $5000, $15000, $ 25000, $40000
Individual's income loss is a difference between two medians of previous income and current income.
The first number in parenthesis indicates the patient's retired year and the second number indicates how many years early the patient retired.

$$\text{PV of Income Loss} = \sum_{i=0}^{n} \frac{Loss}{(1+r)^i} + \sum_{t=1}^{m} PLoss_{2002-t}(1+r)^t$$

where n is number of years from 2002 to projected year of retirement without ESRD, r is discount rate, Loss is income loss in 2002 dollars, Ploss2002-t is real income loss in 2002 dollars for years before 2002, and m is the number of years the patient retire before 2002.
Projected retirement years of patients 3 and 10 are 1996 and 1994. It is assumed they have no income loss after projected retirement age (Patient 3: No income loss after 1996 and Patient 10: No income loss after 1994).

Annualized income losses are $4,714.59 (using a 3% discount rate) and $6,353.35 (using a 7% discount rate). Annualized values indicate ESRD patients at the Gambro Dialysis Center have average yearly income loss of $4,714.59 or $6,353.35. For annualizing the income loss, the annuity equivalent methodology is used (Barry et al.). The annualized income loss using this methodology accounts for the time value of money for the income losses in previous years.

Table 33. Descriptive Statistic of Patients' Income Losses and Its Present Value

	Mean ($)	SD	Min	Max
Income Loss in 2002	4,147.53	10151.52	0.00	40,864.00
PV of Income Loss (3%)	52,523.94	129377.72	0.00	546,231.48
Annualized Income Loss (3%)	4,714.59	11620.15	0.00	48,355.76
PV of Income Loss (7%)	54,655.07	138087.48	0.00	571,101.66
Annualized Income Loss (7%)	6,353.35	15892.69	0.00	62,709.53

Sixty patients are included in this calculation.

One-Time Costs

Patients on average reported costs of $150.44 for home renovations. Two vehicle costs that patients experienced are an average of $1,291.91 / patient for purchasing vehicles and $0.74 / patient to modify currently owned vehicle(s) (table 5 in Chapter III).

As a part of patients' non-medical costs, the one-time costs for home renovation, additional vehicle, and changing residence are annualized. Because it was not asked when the patient renovated their home, purchased or modified their vehicle(s), and changed residence, it is not possible to identify the year of when the one-time costs were incurred. It is assumed, therefore, total one-time costs are distributed evenly over the 25

years of the data set (between 1978 and 2002). The year 1978 is the earliest year that a patient started dialysis treatment, and the year 2002 is the latest year a patient started the treatment. Time value of the 25 years is not considered. With these assumptions, an ESRD patient at the Gambro Dialysis Center spends $6.02 for home renovation, $51.71 / year for purchasing additional vehicle(s), and $0.03 / year for car modification.

As noted earlier, about 17% of patients changed their residence because of ESRD. Moving costs are approximately $70 / hour for three men (Agg's Moving Service, 2003a; ABC Moving & Storage). Although it depends on the house size and other factors, an average of four hours is estimated for a private home move (Agg's Moving Service, 2003b). Using these assumptions, moving expenses are calculated. The average expense for moving in this case study is approximately $47.60 / patient (68 patients × 17% × $70 / hour × 4 hours for moving = $3,236.80, $3,236.80 ÷ 68 patients = $47.60 / patient). It is assumed all patients' moving costs are same and each patient moves only once because of their ESRD during the 25 years. For changing residence, a patient spends $1.95 / year. This cost value does not include a "hassle" and time costs associated with changing residences.

The total costs ($59.71 / year / patient) for these four categories (home renovation, purchasing vehicle, modifying vehicle, and changing residence) are annualized one-time costs of ESRD patients at the Gambro Dialysis Center.

Non-Monetarized Costs

Costs for shorten life expectancy, changes in personal plans, and changes in quality of life are included in this category. Letourneau et al. found that one and three years

survival rates after beginning dialysis are 93% and 74% for patients between 50-60 years and 80% and 45% for patients over 75 years. They concluded life expectancy of patients who began dialysis above 75 years is significantly shorter than for patients who began dialysis between 50-60 years (Letourneau et al.). On average, one-year mortality rate of ESRD patients is 10% after beginning dialysis, i.e. 10% of ESRD patients die within one year after beginning dialysis (Tan, 2003). It is reasonable to assume that a healthy individual has a longer life expectancy than ESRD patients. One can, therefore, conclude positive costs for shorten life expectancy. One methodology often used to calculate the monetary value of life is the value of statistical life (VSL). The VSL can be defined as follows. If each member of the population of 100,000, who experience a reduction of 1/100,000 in their risk of premature death as the result of a regulation, were willing to pay $20 for this reduction, the VSL is $2 million (U.S. EPA, 1999). This amount indicates, however, the value of reduced risks, not the value of a saved life. The VSL does not value a shorten life expectancy.

Monetary costs associated with changes in life such as changes in vacation plans and job changes are usually not included as the cost of illness. These changes, however, represent costs, which may be incurred because of the disease (Hay and Ernst). For this reason, this cost is included in the cost category. Hodgson (1983) mentioned unwanted job changes should be included in the costs of illness as a part of non-medical costs. No study was found that evaluated monetary costs of changes in lifestyle because of a specific disease. The questionnaire did not ask specific costs of lifestyle changes, but did ask if changes had been made. Patients indicated ESRD caused such changes

(vacation plan changes 40%, and job changes 9%, in addition, to early retirement). Although not monetarized, lifestyle changes are positive costs to ESRD patients.

Concern about the quality of patients' lives is increasing (Deniston et al.). Even though, there is no consensus about what constitutes quality of life (QOL), its definition usually includes items such as health status and satisfaction (Neto et al.). Many studies use different indices to evaluate the QOL such like Index of Well-being (IWB), Activities of Daily Living Index (ADL), and Sickness Impact Profile (SIP) (Deniston et al.). Unfortunately, no study has developed a methodology to convert the quality of life indices into monetary values. "Quality of life (QOL) has been receiving attention in the last decades as an outcome measure and it has been enthusiastically adopted by physicians, politicians, economists, and health administrators" (Neto et al., p. 101). As discussed earlier, the patients' IWB in this case study is 10.75 with a perfect quality of life score being 14.7. Deniston et al. calculated several indexes including the IWB to evaluate the quality of life of ESRD patients in Michigan. They interviewed 742 ESRD patients during 1984 through 1986. Deniston et al.'s average IWB score was 10.55, which is similar to the average index here.

The ESRD patient's caregivers' IWB averaged 11.77, about 9.5% higher than the ESRD patients. Although not completely comparable, these values indicate the caregivers' satisfaction level of their life is higher than the patients' satisfaction level. Merkus et al. found that the QOL of dialysis patients in Netherlands was lower than the general population sample (Merkus et al.). Unfortunately, cost constraints do not allow for obtaining an IWB for the general healthy population of Brazos County. Using the

above two comparisons between patients and other groups of people, it can be inferred that ESRD causes a positive cost to the patients in terms of QOL.

Unpaid Caregivers' Out-of-Pocket Costs

Annual Costs for Food, Transportation, Equipment / Supplies, and Miscellaneous Items

Caregivers' additional expenses for food, transportation, equipment / supplies, and miscellaneous items are $72.11, $45.17, $4.61, and $17.50 / month (table 26 in Chapter III). Annual costs for these items are, therefore, $865.32, $542.04, $55.32, and $210.00. As noted in Chapter III, to avoid double counting, when calculating these costs, some reported costs were replaced with zero if the patient and the caregiver lived together and stated the same costs.

Annual Costs for Households Chores

For household chores, lawn mowing, grocery shopping, and errands, unpaid caregivers spend an average of $1.58, $4.61, and $0.66 / month / caregiver (table 26 in Chapter III). The average total amount for household chores, therefore, is $82.20 / year / caregiver. Because many caregivers live together with the ESRD patient, double counting for household chores is an issue. Double counted observations are avoided by using the same methodology as the case of out-of-pocket costs. For the double counted observations, it is assumed the caregivers' additional costs for household chores are zero. No caregiver indicated they incur additional expenses for house cleaning and other household chores (table 26 in Chapter III). In addition, no caregiver hired help to care for his / her other family members so the caregiver could provide care to the ESRD patient.

Income Loss

To calculate caregivers' lost income, the methodology used to calculate patients' income loss is applied to the data provided by the caregivers. Of the 39 caregivers who responded, 31 stated their caring did not affect their employment status. Six caregivers stated their employment status changed because of caring for the patients. Two caregivers did not provide information about their employment status. These two caregivers are treated as missing values.

Of the 31 caregivers who indicated no change in their employment status, eleven caregivers indicated no change in their income levels. The questionnaire was designed to provide data on previous income level, if the caregiver is currently retired. Therefore, if a caregiver answers his / her current income, but does not answer his / her previous income level, it is assumed the caregiver is currently working and experiences no change in his / her income level because of the caregiving. Under these assumptions, of the 31 caregivers, ten caregivers are included in this case. These ten cases are assumed to have zero income loss because of the caregiving. Of the 31 caregivers, five caregivers (four retired, and one homemaker) answered their income had decreased. However, these five caregivers answered that their patient caring did not affect their retirement. Because their retirements were not related to their caregiving, the income loss because of caregiving is zero in these five cases. Remaining five caregivers did not provide information about both current and previous income. These are treated as missing values. Consequently, of the 31 caregivers who indicated no change in their

employment status, twenty-six cases indicated zero income loss, and five cases are missing values.

Among the six caregivers who indicated a change in their employment status, three caregivers showed no change in income level. Two caregivers did not provide their income level. The first three cases are, therefore, assumed to have a zero income loss caused by caregiving. The other two cases are treated as missing values. The remaining caregiver showed an increase in income level. Similar to the patients' case, it is not clear what caused the increase in income. This caregiver's income loss because of the caregiving is assumed to be zero.

With the above assumptions, 30 caregivers (26 of 31 and 4 of 6) indicated zero income loss because of the caregiving. Nine caregivers are treated as missing values. It may be, therefore, extrapolated that most caregivers who take care of the ESRD patient have little income loss because of patient caring in this case study. However, one caregiver answered he retired two years early to provide patient caring, and two caregivers indicated a decrease in their working hours (one by 120 hours / month and the other by 12 hours / month). The caregiver who indicated a decrease of 120 hours / month in work hours may have a large decrease in her income. These respondents indicate patient caring has some affects on the caregivers' income in this case study. Because we did not ask caregivers when they retired or when they began caregiving, it is, unfortunately, not possible to approximate the caregivers' retirement time and to calculate their losses with the data obtained from the caregivers. Income losses are,

therefore, noted as a positive cost, but no monetary value can be estimated from the available data.

One-Time Costs

Caregivers reported incurring costs on house renovations and purchasing additional vehicles (table 26 in Chapter III). Average home renovations costs is $2.42 / caregiver. Caregivers spent an average of $657.89 / caregiver for purchasing vehicles. No caregiver incurred expenses for modifications to their vehicle. Similar to expenses for household chores, overlapped observations with patients' responses are replaced with zero to avoid double counting.

With regards to the cost of residence change because of caregiving, the same rate used in calculating the patients' moving costs is used to determine caregiver costs. Approximately eight percent (7.7%) changed their residence because of their caregiving. As in the case of other costs, an attempt is made to avoid double counitng. The average moving cost is approximately $21.56 / caregiver (39 caregivers × 7.7% × $70 / hour × 4 hours for moving = $840.84. $840.84 ÷ 39 caregivers = $21.56 / caregiver). Using the same assumptions used in calculating patients' costs (total one-time costs distributed evenly over 25 years), annualized total average of caregivers' one-time costs are $26.32 for purchasing vehicle, $0.86 for changing residence, and $0.10 for house renovation.

Unpaid Caregivers' Personal Quality Costs

Time Costs

As described earlier (see "caregiving time" section and table 22 in Chapter III), a caregiver, on average, spends 49 hours / week (7 hours / weekday and 7 hours / weekend day) or 2,548 hours / year. To put the number of hours in perspective, 2,548 hours translates into approximately 318.5 eight-hour workdays or 63.7 workweeks / year. Time is a large cost associated with patient caring in caregivers' case. Of the total number of hours in a year, approximately 29% are spent for patient caring. Care must be taken, however, in interpreting the number of hours spent on caregiving. Many caregivers indicated 24 / 7 as the number of hours of caregiving. Obviously, a caregiver is not providing specific care 24 hours a day seven days a week. The caregiver is, however, available to help the patient most of the day. In calculating these hours of caregiving, the number of hours stated by the caregiver is used. These hours should be considered as the caregivers' perception of the number of hours of caregiving. As noted earlier, some caregivers travel to the dialysis center with the patient. The caregivers' travel time to the center is a cost.

It is difficult to distinguish from the caregivers' answer whether caregivers counted their travel time as a part of caring time. Further, simply adding the amount of patients' travel time to the caregivers' case may cause double counting problems, because some caregivers answered they care their patient for 24 hours / day. Therefore, it is assumed travel time is included in the number of hours of caregiving.

For a lower bound number of caregiving time, the average number of hours of caregiving is calculated leaving 24 / 7 responses out. Under this assumption, caregivers spend an average of 8.4 hours / week (4.4 hours / weekday and 4 hours / weekend) for patient caring or 437 hours / year. To put this number of hours in perspective, 437 hours translates into approximately 54.6 eight-hour workdays or 10.9 workweeks / year.

The same methodology used in calculating patients' time costs is used to place a monetary value on caregivers' time. Six costs are presented. Using the three wage rates, time costs are calculated using the 24 / 7 responses and then leaving out the 24 / 7 responses. Double counting with income losses is not an issue, because income losses are assumed to equal zero for caregivers. Unpaid caregivers time costs range from $0 / year (zero wage rate, lower bound) to $13,122.2 / year ($5.15 × 2,548 hours, middle) to $28,537.6 / year ($11.2 × 2,548 hours, upper bound when using the 24 / 7 responses) in this case study. Time costs are lowered to range from $0 / year (zero wage rate, lower bound) to $2,250.55 / year ($5.15 × 437 hours, middle) to $4,894.4 / year ($11.2 × 437 hours, upper bound when the 24 / 7 responses are excluded) (table 31).

Non-Monetarized Costs

Most categories in this cost are same as the patients' case. One difference is caregivers' health effects are considered instead shorten life expectancy as considered for patients. Twelve caregivers (31%) experienced mental stress because of caregiving and ten caregivers (26%) experienced financial hardships because of caregiving. Even though no monetary value is imposed, mental stress is an important cost in many studies

(Cattanach and Tebes; NAC 2002b). In addition, caregivers experienced changes in vacation plan (51%) and employment (8%). Theses costs are noted as positive costs associated with ESRD.

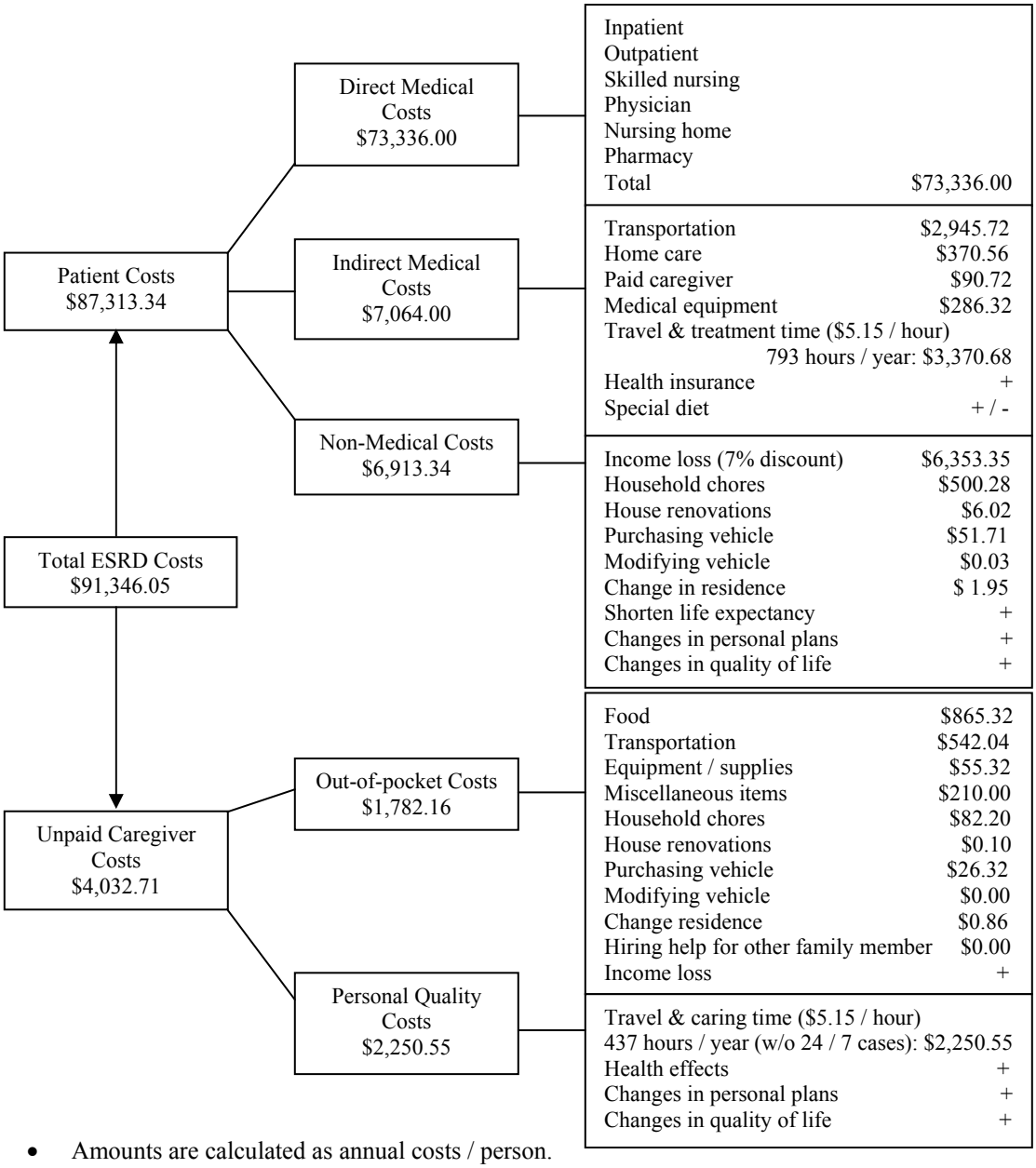
Total Costs of ESRD

Total annual costs of ESRD in this case study are calculated approximating 2002 dollars. The most important component of this case study is to calculate the cost of ESRD including both patients' and unpaid caregivers' costs. The total annual costs of ESRD for patients and caregivers are summarized in table 34 and figure 4.

In table 34, sensitivity analysis on the discount rate, wage rate, and caregiving time is presented. The range of total ESRD costs is from $84,086.06 / year / case (3% discount rate and no time opportunity costs) to $121,592.82 / year / case (7% discount rate, wage rate of $11.2 / hour, and including 24 / 7 cases). Estimates in figure 4, break the "best guess" costs (7% discount rate, wage rate of $5.15 / hour, and excluding 24 / 7 time amounts by caregivers) into various components. This scenario is chosen as the 'best guess" because the 7% discount is comparable to discount rates used in federal government benefit costs analysis, thus, aiding comparisons. The minimum wage places a conservative, but positive cost on time. Eliminating the 24 / 7 caregiving time responses provides a more realistic view of actual caregiving time. With the "best guess" scenario, the total ESRD costs are $91,346.05 / year / case. Histograms and cumulative density functions show that each individual cost components, as well as total patients' and caregivers' costs are positively skewed (figures 5 and 6 and Appendix D).

Table 34. Annual ESRD Costs with Three Wage Rates and Two Discount Rates

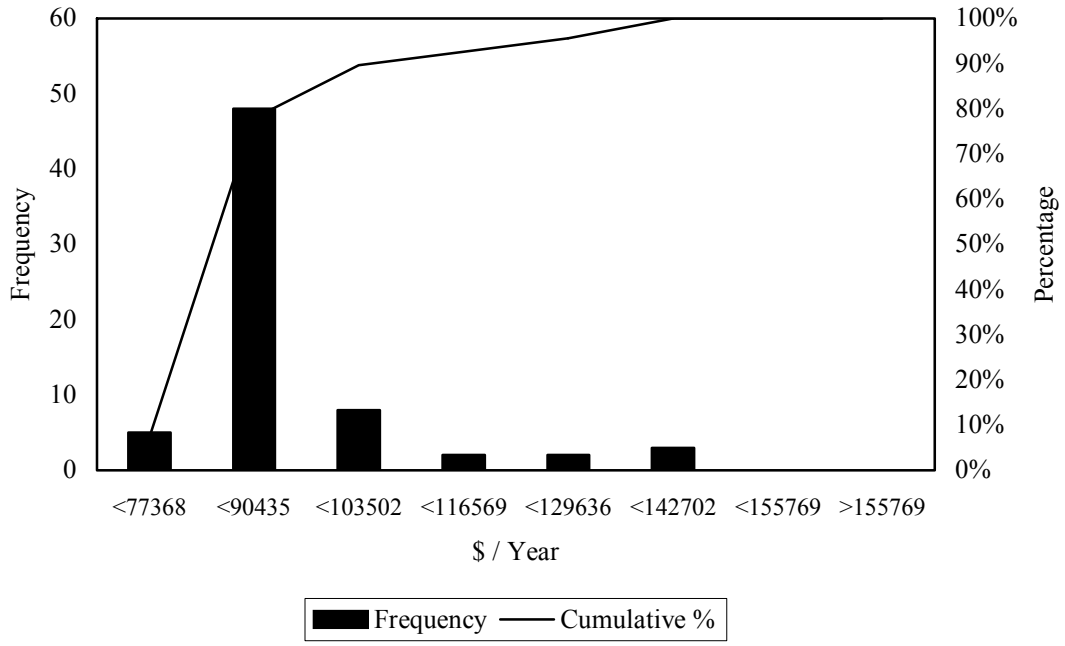
Individual	Cost Categories	Wage Rate $0.00 / hr	$5.15 / hr	$11.20 / hr
	3% Discount Rate, without 24 / 7 Cases			
Patients	Direct Medical	73,336.00	73,336.00	73,336.00
	Indirect Medical	3,693.32	7,064.00	11,023.72
	Non-Medical	5,274.58	5,274.58	5,274.58
Total Patients		82,303.90	85,674.58	89,634.30
Unpaid Caregivers	Out-of-Pocket	1,782.16	1,782.16	1,782.16
	Personal Quality	0	2,250.55	4,894.40
Total Unpaid Caregivers		1,782.16	4,032.71	6,676.56
Total Costs		**84,086.06**	**89,707.29**	**96,310.86**
	3% Discount Rate, with 24 / 7 Cases			
Patients	Direct Medical	73,336.00	73,336.00	73,336.00
	Indirect Medical	3,693.32	7,064.00	11,023.72
	Non-Medical	5,274.58	5,274.58	5,274.58
Total Patients		82,303.90	85,674.58	89,634.30
Unpaid Caregivers	Out-of-Pocket	1,782.16	1,782.16	1,782.16
	Personal Quality	0	13,122.20	28,537.60
Total Unpaid Caregivers		1,782.16	14,904.36	30,319.76
Total Costs		**84,086.06**	**100,578.94**	**119,954.06**
	7% Discount Rate, without 24 / 7 Cases			
Patients	Direct Medical	73,336.00	73,336.00	73,336.00
	Indirect Medical	3,693.32	7,064.00	11,023.72
	Non-Medical	6,913.34	6,913.34	6,913.34
Total Patients		83,942.66	87,313.34	91,273.06
Unpaid Caregivers	Out-of-Pocket	1,782.16	1,782.16	1,782.16
	Personal Quality	0	2,250.55	4,894.40
Total Unpaid Caregivers		1,782.16	4,032.71	6,676.56
Total Costs		**85,724.82**	**91,346.06**	**97,949.62**
	7% Discount rate, with 24 / 7 Cases			
Patients	Direct Medical	73,336.00	73,336.00	73,336.00
	Indirect Medical	3,693.32	7,064.00	11,023.72
	Non-Medical	6,913.34	6,913.34	6,913.34
Total Patients		83,942.66	87,313.34	91,273.06
Unpaid Caregivers	Out-of-Pocket	1,782.16	1,782.16	1,782.16
	Personal Quality	0	13,122.20	28,537.60
Total Unpaid Caregivers		1,782.16	14,904.36	30,319.76
Total Costs		**85,724.82**	**102,217.70**	**121,592.82**



- Amounts are calculated as annual costs / person.
- Amount of income loss, house renovations, Appropriate vehicle, and Changes in residence are annualized.
- + indicates a positive cost associated with ESRD, - indicates a negative cost (net benefit) associated with ESRD, and + / - indicates the net cost or benefit is undetermined. In all three cases, the costs are not estimated.
- Employer / other social costs are not considered in this calculation.
- The best guess: combination of 7% discount rate, rate of $5.15 / hour, and without 24 / 7 cases

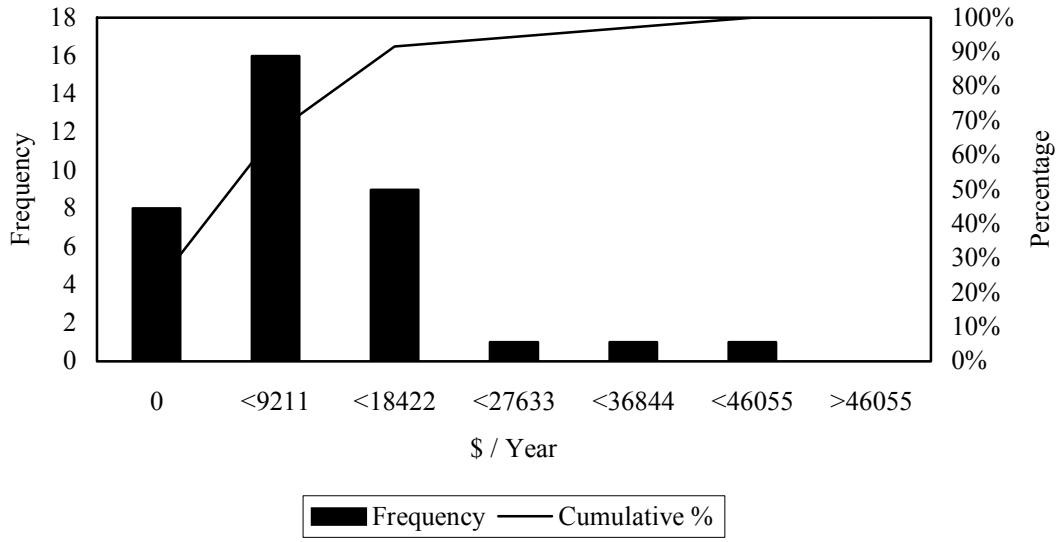
Figure 4. Total best guess annual costs of end stage renal disease

Within the different scenarios presented in table 34, several cost components, by design, do not change: patients' direct medical costs of $73,336 and the caregivers' out-of-pocket expenses of $1,782.16. The discount rate and wage rate affects the indirect medical costs (time costs) and the non-medical costs (income loss), whereas the wage rate and caregiving time assumptions affect the caregivers' personal quality costs (time costs).



The case of 7% discount rate and wage rate of $5.15 / hour

Figure 5. Histogram of total patients costs



The case of wage rate of $5.15 / hour and without 24 / 7 cases

Figure 6. Histogram of total caregivers costs

Patients' non-medical costs range from $5,274.58 to $6,913.34 (table 34). One cause of this range is the different assumptions made in calculating annualized income losses / patient. Based on the discount rate assumed, annualized income losses range between $4,714.59 (3% discount rate) and $6,353.35 (7% discount rate). Patients' non-medical costs of time are $0 (wage rate of $0.00 / hour), $3,370.68 (wage rate of $5.15 / hour), or $7,330.40 (wage rate of $11.2 / hour). Non-monetarized patients' non-medical costs of shorten life expectancy, changes in personal plans, and changes in quality of life are not valued. These cost categories are, however, will be positive costs to ESRD patients. The monetarized total patients cost in this study ranges from $82,303.90 to $91,273.06 / year / patient (table 34). The skewed nature of patients' total costs are illustrated in the histogram of total patients' costs presented in figure 5. Using the best

guess estimates of the total costs of ESRD disease, direct and indirect medical costs ($73,336 + $7,064) represent 88% of the total ESRD costs ($91,346.05), by far the largest cost component. Patients' non-medical costs represent 8% of the total ESRD costs. Because direct medical costs dominate total costs and are usually paid by insurance and government programs, the percentage of patients' non-medical costs to total costs not including direct medical costs is found. In this case (direct medical costs are excluded in total costs), the patients' non-medical costs are 38% of the total costs of ESRD. Overall all scenarios, patients' non-medical costs range from 4% (11%) to 8% (56%) of total costs including (excluding) direct medical costs. Indirect medical costs range from 4% (23%) to 11.5% (48%) of total costs including (excluding) direct medical costs.

Annual average unpaid caregivers personal quality costs range from $0 to $28,537.6. Two reasons for the range are the wage rate used to value time and assumptions on the amount of caregiving time. Responses of 24 hours seven days a week are use in one scenario in calculating caregiving time and are treated as missing values in the second scenario. It is not unexpected that time would dominate unpaid caregiving costs, as this is the resource caregivers have to provide to patients. Using the best guess scenario the total annual unpaid caregivers' costs are $4,032.71 / caregiver (out-of-pocket costs of $1,782.16 and personal quality costs of $2,250.55). Unpaid caregivers' percentage of total ESRD costs using the best guess scenario is 4.4% including direct medical costs and 22% excluding direct medical costs. For the various

scenarios presented in table 34, the unpaid caregivers' percentage of costs range from 2% (14%) to 25% (65%) including (excluding) direct medical costs in the total costs.

Non-monetarized personal quality costs of caregivers do not include health effects, changes in personal plans, and changes in quality of life. Because of excluding the non-monetarized costs, the presented costs are conservative estimates. As with the patients' total costs, the histogram of total caregivers' costs shows a skewed distribution of costs (figure 6). Similar to patients, some caregivers experience a cost much higher than the average, but most are near the costs presented in this discussion. As noted, the best guess total annual costs of ESRD in this study are $91,346.05. Monetarized patients' non-medical costs are $6,913.34 / year, whereas, monetarized unpaid caregivers' personal quality costs are $2,250.55 / year. These cost amounts are maybe lower than one might expect. Lower costs are a function of many patients being either retired or unemployed at the time of diagnosis of ESRD. Because costs for changes in patients' / caregivers' quality of life and personal plans, patient' shorten life expectancy, and caregivers' health effects are not included in this calculation, the costs presented are conservative estimates.

Finally, differing perceptions of caregiving by patients and caregivers may affect the final cost calculations. Although, specific definitions of caregiving and caregiver were provided on the questionnaire, responses were not always consistent. As noted earlier, a specific behavior such as giving rides or meal preparation is caregiving in some caregivers' perspective, but is not caregiving in some patients' perspective. It seems that they think these behaviors are just a part of being family members or friends. On the

other extreme, a few caregivers' perception was "staying with patient" itself comprises caregiving 24 hours a day seven days a week.

CHAPTER V

RESTRUCTURING WATER SUPPLY SYSTEMS: ALTERNATIVE TO REDUCE COSTS OF ESRD

In Chapter IV, it is shown the costs of ESRD are at least $84,000 / year / case for the Gambro Dialysis case study. These costs may range as high as $121,000 / year / case. ESRD is a burden on our society. In this chapter, a potential restructured water supply system, which may reduce the risk of ESRD, is developed. As noted earlier, consumption of arsenic in drinking water has a strong correlation with kidney disease. A more efficient water supply system, which makes strengthened drinking water standard more affordable, may reduce the risk of ESRD onset and, in turn, reduce society's costs for life-long treatment of this disease. In addition to the reduced ESRD costs, a more efficient water system may reduce risks of all other water related (acute and chronic) diseases. There will be unpaid caregivers' costs for caring for the patients with these diseases. These benefits also should be considered as a part of benefits from a more efficient water system.

Historically, municipal water delivery systems have been designed and managed to create a sufficiently large supply such that the probability of any tangible shortfall is very small (Griffin and Mjelde; Howe and Smith). Within these large systems, all water is treated to meet U.S. Environmental Protection Agency's (EPA), state and local standards, regardless of the end use of the water. Such traditional approaches to managing municipal water supplies are changing. Griffin and Mjelde (p. 414) state, "In

light of the high and growing costs of water development, it may be sensible to revise the water planning paradigm, so that periodic shortfalls are regarded as acceptable, even planned events." Since 1982, rapid development of drought plans has been adopted by state and local governments in the U.S. By 2000, 29 states in the U.S. have drought plans (Wilhite et al.). Many cities currently have, for example, complementary plans for dealing with water shortfalls and conservation (Chesnut, Buckwalter, and Parsons; Reed and Johnson; Lemberg; Renwick and Green). Also, since 1983, many communities have adopted dual water distribution systems and various states have promulgated guidelines and regulations for purveyors and users of reclaimed wastewater (American Water Work Association, p. 1).

Development and size of municipal systems are not the only changes taking place in the water sector. Water scarcity issues, in a large part, can be traced to the institutional structure and arrangements associated with water systems. Municipal water is usually supplied by a regulated utility that faces no competition and has the ability to pass reasonable costs through the system. Traditionally, such utilities recovered the cost of treating and distributing the water, but considered the water a free good (Tietenberg). For economic efficiency, water must be marginal-cost priced, including a scarcity value for the water (Tietenberg; Hall). However, traditionally, water price has been set equal to average cost and does not include scarcity value (Tietenberg).

Related to reforms in water pricing is water marketing. Restrictions on water transfers have kept treated water from moving to its highest valued users. Gaffney argues existing water markets do not work because sellers are under-motivated, obsolete

subsidies abound, and rent seeking distorts allocation. He contends that the total social wealth from using our limited natural water supplies can be increased by allocating the water to higher valued uses. He promotes water marketing as a remedy to achieve greater economic efficiency. The driving force behind all of the above changes is the rising financial and environmental costs of delivering water. Murphy et al. (p. 375) note, "One of the problems with proposals for substantial institutional change in water systems is that modifications and irreversibility make the process slow, cautious and costly to society."

Restructuring the municipal water delivery / treatment system paradigm may be a fruitful area for increasing efficiency. In the current system, most water entering municipal systems is handled the same regardless of its ultimate use. It may be useful to rethink this paradigm and handle water differently based on end-use, source, and quality of supply. As discussed below, changes in this area are starting to appear at the municipal level. The primary objective of this chapter is to propose an alternative to current municipal water systems in hopes of stimulating innovations for improving efficiency and sustainability of water systems.

Typical Municipal Water Supply Systems

A schematic of an typical municipal water supply system in the U.S. is shown in figure 7. Harremoës notes that the concepts and materials for many urban water systems (and possibly parts of the system itself) have been around for some 150 years, and that these systems have performed well for over a century. Water from various sources enters the water treatment and distribution system. Within this current water system, all

water is treated to same standard regardless of its ultimate use. Treatment includes coagulation, sedimentation, filtration, and disinfection (U.S. EPA, 2001b). Treated water is used for both potable (e.g., drinking and bathing) and non-potable (e.g., lawn watering and toilet flushing) uses. After use, wastewater is treated in large facilities and then returned to the environment, typically as surface water.

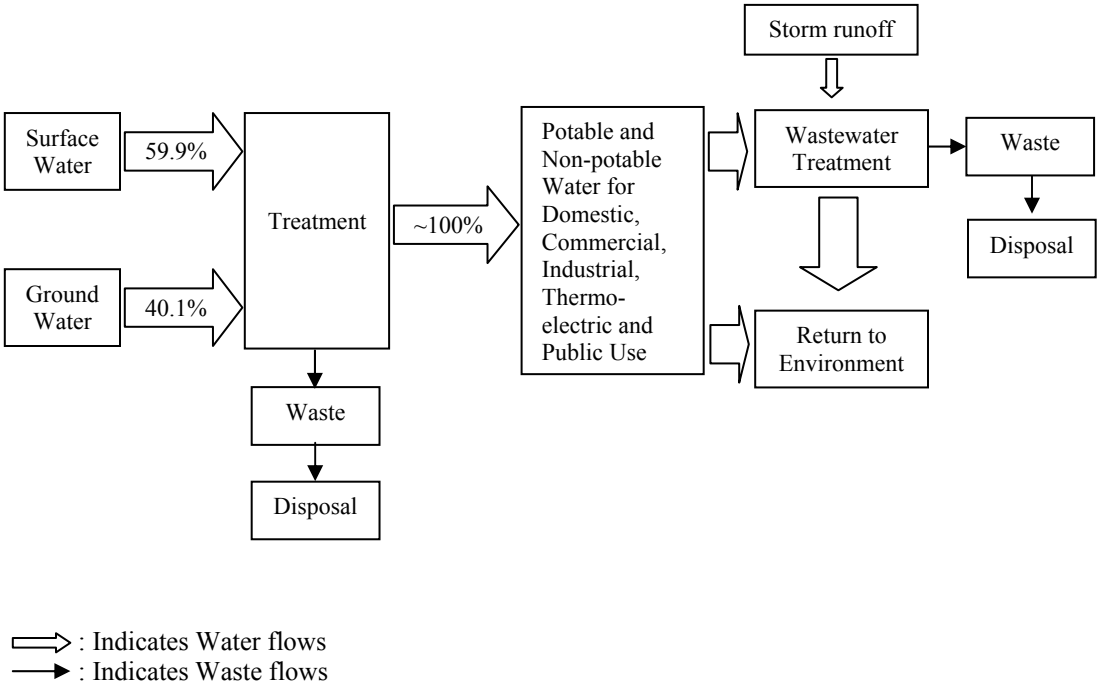


Figure 7. Schematic of a typical U.S. municipal water supply system
(Groundwater and surface water percentages from Leeden, Troise, and Todd: figure 5-5)

As shown in figure 8, treated water is distributed for domestic, commercial, industrial, thermoelectric power, and public uses. In 1995, the amount of water use from public water systems in U.S. was approximately 40.2 billion gallons per day (Solley,

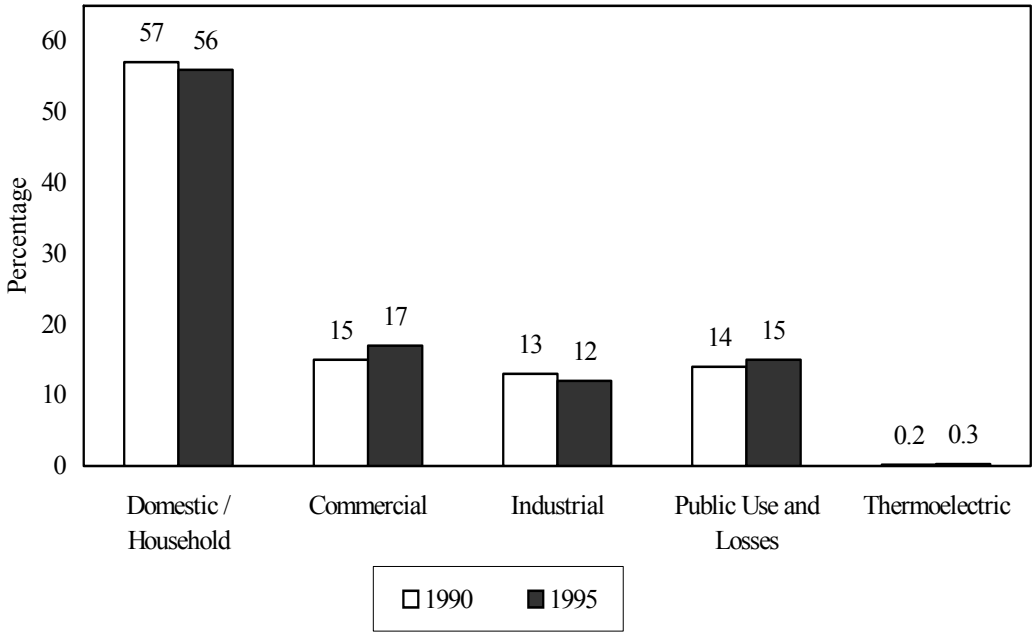


Figure 8. Percentage of water use from public water supply systems in the U.S. (Source: Solley, Pierce, and Perlman, 1993, 1998)

Pierce and Perlman, 1998). Of this amount, approximately 56% was for domestic use, with the remaining 44% for non-domestic uses (commercial (17%), industrial (12%), thermoelectric (0.3%), and public use and losses (15%)) (Solley, Pierce, and Perlman, 1998). During the nineties, these percentages have remained constant.

On average, a person in the U.S. uses 31,573 gallons of water each year or an average of 86.5 gallons of water per day (Leeden, Troise, and Todd, table 5-25). Among the various household water uses (figure 9), outdoor activities such as lawn watering, gardening, and car washing account for 32% of the water used (Leeden, Troise, and Todd, table 5-25). The remaining 68% of water is used for indoor uses 28% for flushing toilets (24 gallons), 23% for bathing (20 gallons), 10% for washing clothes (8.5 gallons),

4% for dishwashing (3.75 gallons), 2% for drinking and in kitchen (2 gallons), and 1% for garbage disposal (0.75 gallon) (Leeden, Troise, and Todd, table 5-25). Using these percentages, 60% (toilet flushing, car washing, and lawn watering) of the treated water used is treated to a standard beyond what may be necessary. Unfortunately, similar percentages for industrial water use are not available for water supplied by public water systems.

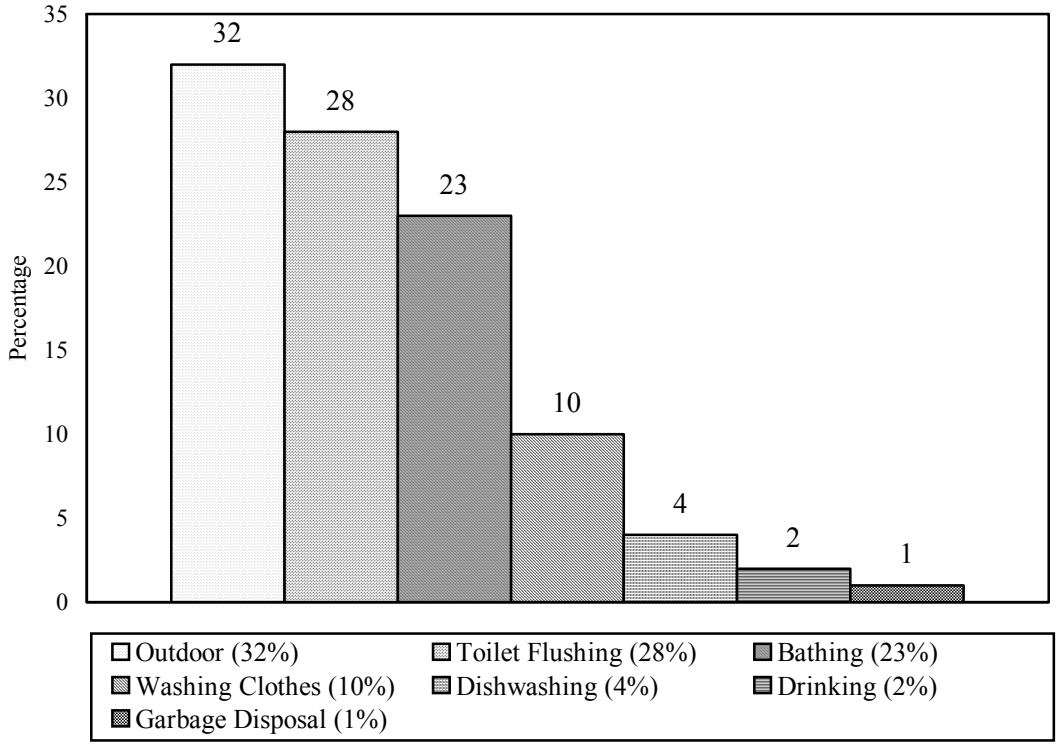


Figure 9. Water use from public supply in a household in the United States in 1990 (Source: Leeden, Troise, and Todd, table 5-25)

In 1999, the U.S. EPA conducted the Second Drinking Water Infrastructure Needs Survey (U.S. EPA, 2001d). This survey documents capital investment needs of public water systems eligible to receive Drinking Water State Revolving Fund (DWSRF) monies over the next 20 years. According to this survey, the total infrastructure needs nationwide are projected to be approximately $150 billion for the 20-year period from January 1999 through December 2018. Thirty-eight billion dollars are for treatment, $83.2 billion for transmission and distribution, $18.4 billion for storage, and $9.6 billion for source (U.S. EPA, 2001d). The need to replace, upgrade, and install infrastructure will increase as the nation's water systems continue to age and population increases.

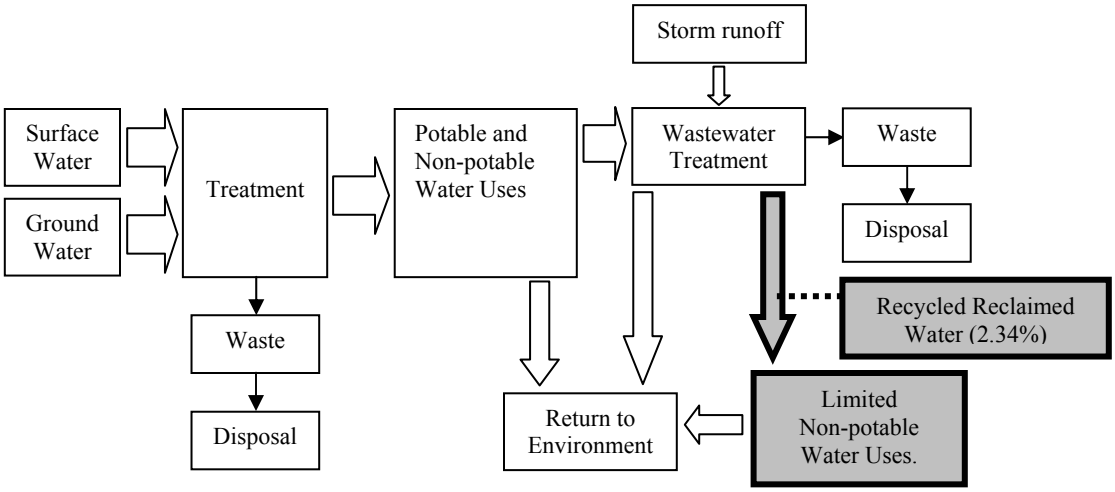
Examples of Dual Distribution Systems

As noted earlier, changes in water delivery systems' infrastructure and management are already occurring. The driving forces behind such changes are the increasing scarcity of high quality water, increasing costs associated with developing new water sources, increasing environmental concerns, and sustainability issues. In this section, two examples of dual systems, which are currently being operated are described. One is a system, which re-uses reclaimed wastewater, whereas the other system uses separate water sources for irrigation uses.

Reclaimed / Reused / Recycled Water

The use of reclaimed municipal wastewater (figure 10) is an example of changes in the infrastructure used to deliver water. This system represents a change toward dual distribution water systems. Water from all water sources is initially treated to the same standard regardless of its ultimate use. The distinguishing characteristic of the system in

comparison to the typical system (figure 7) is the use of reclaimed wastewater for non-potable uses such as outdoor watering, rather than returned directly to the environment. In 1995, 2.34% of wastewater in the U.S is reused (Solley, Pierce, and Perlman, 1998, table 29). This percentage has remain fairly consistent since 1990 (2.56%) (Solley, Pierce and Perlman, 1993, table 30).



⇨ : Indicates Water flows
→ : Indicates Waste flows
Shaded parts indicate the differences with figure 5.

Figure 10. Schematic of a municipal water distribution system with reuse
(Percentage of total water reused in the U.S. in 1995 is from Solley, Pierce, and Perlman, 1998, table 29)

The reuse of municipal wastewater is not a new idea. American Water Works Association discusses, for example, non-potable water reuse legislation in states such as California, Florida, and Arizona. Mantovani et al. reviewed sixty-five water reuse

systems in the U.S. and other countries. Water reuse has been, for example, a part of water management plans for more than 25 years in the greater Los Angeles area (Selby and Helm). They argue that by using reclaimed water, electric utility generating stations and other industrial facilities can reduce their need for water from higher quality water sources, thus conserving these sources for potable use. Such dual systems require two distribution systems, one for potable water and another for reuse water (Okun, 1997). Most reuse systems provide non-potable water for agriculture irrigation, industry use, ground water recharge, or municipal landscape watering.

Water reuse is becoming an increasingly important option in many parts of the world. Water reuse is being explored or used in water scarce parts of the U.S., for example, California (Selby and Helm; Rosenblum; Sheikh, Jaques, and Cort), Florida (Allhands et al.; Johnson), Hawaii (Durham, Bourbigot, and Pankratz), and Arizona (Durham, Bourbigot, and Pankratz). Worldwide, plants for recycled water use are being operated or planned in the Middle East, including Saudi Arabia (Al-A'ama), Israel (Brenner et al.; Lazarova et al.), and Kuwait (Hamoda). In Europe, for example, reuse is occurring in Greece (Tsagarakis et al.) and Italy (Barbagallo, Cirelli, and Indelicato; Bonomo, Nurizzo, and Rolle). Lazarova et al. overviewed the role of wastewater reuse in Spain, United Kingdom, Italy, and France. He et al. contend China is also an area with the potential for water reuse. Various types of water reuse in 17 diverse countries such as Japan, Singapore, Peru and the U.S. are illustrated in the manual from U.S. EPA (U.S. EPA, 1992).

Many studies of water reuse have been conducted with most of the studies being technical in nature (e.g. Jolis et al.; Krofta et al.: U.S. EPA,1992) or concerned with the use of non-potable water for agriculture crops or landscape irrigation (e.g. Sheikh, Jaques, and Cort; Krofta et al.; Okun, 2000). Jolis et al. identified 27 million gallons / day of potential demand for reclaimed water in the City and County of San Francisco for industrial use, toilet flushing, decorative fountains, irrigation and landscaping and examined several wastewater treatment technologies. Krofta et al. examined alternative treatment methods for wastewater and recommend higher treatment levels. Shelef and Azov argue the use of reclaimed water should occur first in agricultural irrigation, watering public parks, sport fields, and golf courses, but reclaimed water use in toilet flushing in high-rise hotels and office buildings should be considered in the future. Behind the increasing attention to using reclaimed water is the recognition that many different non-potable activities can reduce demands for water from higher quality water sources. (Higher quality water implies less treatment required to become potable.) Thus, higher quality water sources would be used in activities that require potable water such as drinking or bathing (Selby and Helm). Filteau, Whitley, and Watson note that in successful reuse projects, the most common motivating factor is the creation of an alternative or a supplemental water source. Another factor is the absence of appropriate means to dispose of wastewater. They further note, "A reuse project will not go far without demand for the reclaimed water, a cost-effective means to deliver the product, public acceptance, funding and perhaps most importantly, strong leadership" (Filteau, Whitley, and Watson p. 31).

Benefits of reused water include benefits such as limiting effluent discharges to environment (Durham, Bourbigot, and Pankratz; Hamoda; Rosenblum; Barbagallo, Cirelli and Indelicato), conservation of higher quality water sources (Durham, Bourbigot, and Pankratz), and reuse systems maybe cheaper to develop than new water sources (Filteau, Whitley, and Watson). Feinerman, Plessner, and DiSegni Eshel conclude that wastewater is a useful input to other processes, if the water is reclaimed and recycled. Filteau, Whitley, and Watson suggest reuse water systems can provide economic growth. They argue "Reuse project can create over 3000 jobs in the City of Harlingen, Texas" (Filteau, Whitley, and Watson, p. 32).

However, besides the obvious financial costs associated with building reuse systems for additional treatments, potential environmental costs exist, including the risk of exposure to contaminants (Ganoulis and Papalopoulou). Durham, Bourbigot, and Pankratz (p. 83) note communities considering any non-potable dual distribution system are ". . . still faced with institutional, legal, and liability issues inherent . . ." in the services.

Ellis notes in 1978 that the quantity of reclaimed water is less than one-tenth of one percent of municipal and industrial water demand. He argues that fresh water saved through greater utilization of reclaimed water would be substantial. Durham, Bourbigot, and Pankratz (p. 90) conclude, "The future will be dominated by unrelenting demands for increasing quantity and quality of reuse water produced at decreasing costs." In China, 55% of industrial water consumption and 14% of urban water consumption can be supplied by reclaimed water (He et al.)

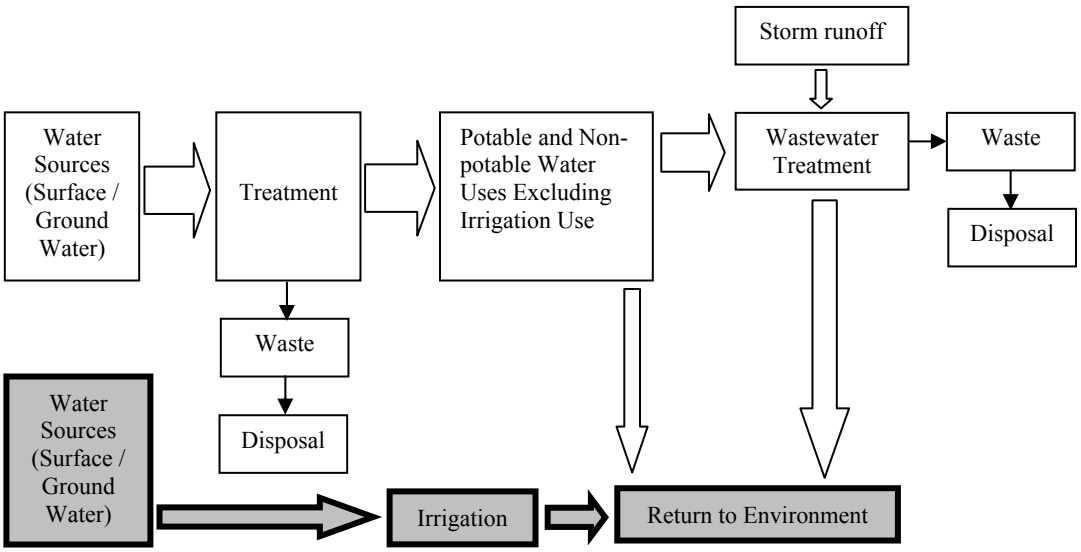
Separate Irrigation Dual Distribution Systems

The second type of dual system is to separately supply potable and irrigation water (not reclamation water) to residences. A simplified schematic of this system is given in figure 11. The most distinct features of this system are that separate water sources are used and water is delivered directly to customers for irrigation uses without treatment. This system has received little attention in the literature relative to the typical system and reuse systems. This system is similar to the reuse water systems previously discussed in that potable and non-potable water are supplied separately. Many of the benefits such as conserving water sources for potable use and costs such as constructing separate systems for deliveries, which are associated with reuse systems, also apply to separately supplied irrigation systems.

An example of such a dual water system is the Salt River Project (SRP) in Arizona (Salt River Project, 2001a). This system supplies irrigation water from separate water sources through canals. Customers order water for irrigation during designated periods. If a customer does not order, no water is delivered. Also, there is a planned "dry-up" season during which no water is delivered (Salt River Project, 2001b).

Proposed Combined System

In this section, a model of a combined dual distribution system is proposed. This system combines the current typical municipal system with both types of dual systems presented above. A schematic of the proposed combined system is shown in figure 12. In this system, wastewater is recycled for non-potable uses (as in the reuse dual system).



⇨ : Indicates Water flows
→ : Indicates Waste flows
Shaded parts indicate the differences with figure 5.

Figure 11. Schematic of a dual municipal and irrigation water system

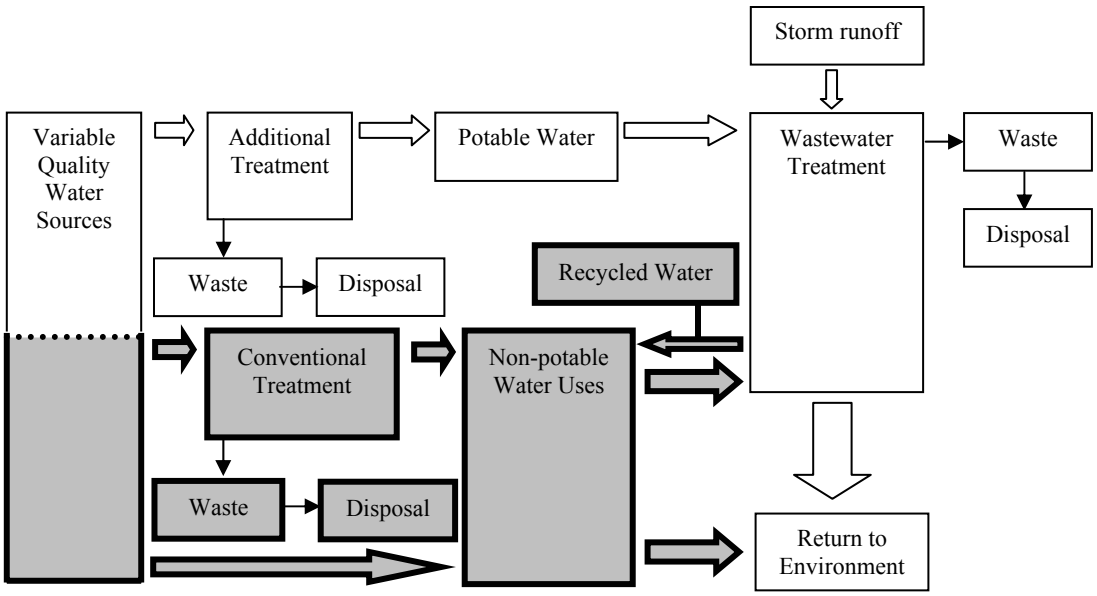
In addition, water can enter the system with limited or no treatment for non-potable uses (as in the irrigation system). A distinct difference to the typical system is that water is handled and treated differently based on its ultimate use and quality. In the case of high quality of water sources, water can delivered without treatment for non-potable uses. Water for potable uses is treated to meet higher standards than water for non-potable uses. Thus, a considerably lower proportion of water is treated to meet potable water standards.

Potential benefits and costs associated with the implementation of a combined dual water supply system are summarized in table 35. These benefits and costs will vary between municipalities for several reasons. First, it is difficult to quantify some benefits, such as flexibility in using / managing different water source or costs, and customer's perception concerning the use of non-potable water. Second, each municipality's specific conditions, such as the characteristics of the regional watershed, weather, and seasonal characteristics, will affect the benefits and costs. Third, the benefits and costs will depend on implementation of the combined system. Finally, not every benefit will be realized or cost incurred by each municipal system implementing the combined dual systems. Benefits and costs associated with the proposed combined system fall into three interrelated, general categories financial and economic, system management, and health and environmental. Like most environmental projects, high investment costs occur immediately and maintenance costs occur continuously, whereas benefits will most likely be long term in nature, even occurring after several decades. Therefore, the timing of the projected costs and benefits is an important issue.

Potential Benefits

Financial and Economic Benefits

A major financial benefit is that total treatment cost should decrease because less water needs to be treated to potable water standards. An example of minor decreases in treatment cost is the decrease amount of fluoride and chlorine added only to water for potable uses versus treating all water. Also, the amount of waste created from treating the initial water to potable standards will also be reduced, again, because of the



⇨ : Indicates Water flows
→ : Indicates Waste flows
Shaded parts indicate the differences with figure 5.

Figure 12. Schematic of proposed dual water supply system with reuse

decreased volume of water treated. Besides lower waste disposal costs, less waste implies potential environmental benefits.

It was noted above that an important change taking place in U.S. water supply systems is the move toward marginal cost pricing. With the proposed combined system, differential pricing could be used. Different prices can be charged for potable and non-potable water, based on the amount of treatment necessary, cost of the water source, and the quality of the water. At the consumer level, one meter could be installed for potable water and another for non-potable water. Differential pricing, based on total costs of the

Table 35. Summary of Potential Benefits and Costs Associated with a Combined Dual Distribution System

Potential Benefits	Potential Costs
Financial and Economic	
Lower Total Treatment Costs	Upgrading and Retrofitting Infrastructure
Lower Disposal Costs	Increased per Gallon Treatment Costs
Differential Water Pricing	Education for Customers' Perception
Water Marketing	
Stimulate Economic Growth	
Cheaper Water Sources	
System Management	
Increased Flexibility in Use of Different Water Quality Sources	Abuse in System Control
Increased Flexibility in System Management Including Seasonal and Drought Management	Institutional Barriers
Reduced Consumer's Inconvenience	Increased in Waste Management – Decentralized in Management
Environmental and Health	
Stricter Standards for Potable Water	Increased Risk of Consumption of Contaminants
Increased Conservation and Sustainability of Water Sources	Consumer Perception Concerning Use of Non-Potable Water
In-Stream Flows ?	In-Stream Flows ?

water, would help achieve economic efficiency. Differential pricing and differential uses of water based on quality and costs may also help promote water marketing. This combined system may help stimulate economic growth through increase availability of water. Implementing the combined system may be less costly than mining of old or

development of new water sources. Development of a reuse system may, for example, be cheaper than building a new dam.

System Management Benefits

The proposed combined system may increase flexibility in managing water supply systems. One source of increased flexibility would be in the use of the different water sources. If a water source is, for example, high enough quality for irrigation, but not for drinking, water from this source could be delivered directly to customers for irrigation without treatment. In turn, economic efficiency would increase because various water sources could be used according to their quality and cost of production and delivery. Further, municipalities may be able to purchase rights to water designated for agriculture use. Such water may be able to be used for lawn watering without changes in water rights.

Increased flexibility in the control over the water supply may occur in times of seasonal water shortages. Currently, drought management plans are concerned with decreasing outdoor use. With the combined system, fewer restrictions may be needed for the use of non-potable water because of the reuse component. Reuse water is derived from potable uses, which are not usually restricted during seasonal shortfalls.

The combined dual distribution systems may give managers increased flexibility in how systems are managed and reduce consumers' inconveniences. With this system, even if there are problems in one system, the other system can still be operated. Currently, such problems shut down the entire water supply. Computer technology has

advanced such that the proposed system, which has a more complex infrastructure in treatment, delivery, and maintenance than current systems, can be managed.

Environmental and Health Benefits

With this combined system, it may become economically feasible to implement stricter drinking water standards. For example, U.S. EPA's 01/22/01 rule mandates a change in arsenic standard in drinking water from the current 50 μg / liter to 10 μg / liter (U.S. EPA, 2001e). This mandate will require compliance by 54,000 community water systems by 2006 (U.S. EPA, 2001e). U.S. EPA estimates the total compliance costs for the January 22, 2001 rule are about $195M / year nationwide (U.S. EPA, 2001c). The proposed water system may reduce compliance costs by treating only the water for potable uses. In addition, stringent standards will allow health benefits, such as reduced risk of chronic illness from long-term consumption of toxins in water.

The proposed combined system will help meet the increasing demand for water by recycling, differential water pricing, and water marketing, thereby creating environmental benefits. By using recycled water, the amount of water drawn from water sources may be reduced. Reuse can delay development of new water sources; thus, the sustainability of water sources may increase. In the case of northern California, for example, the reclamation of wastewater will delay by 10 years a $150 million investment in a new ocean outfall (Durham, Bourbigot, and Pankratz). However, because the combined system will affect water drawn from and returned to the environment, the system will have an unpredictable impact on instream flows and downstream users.

Potential Costs

Financial and Economic Costs

Although many benefits are associated with the proposed combined system, these benefits come at a cost. One of the largest costs will be the cost to upgrade or retrofit the infrastructure of the current system. This cost includes the public supply system, transmission, treatment, distribution, and storage, but also costs to retrofit commercial establishments, residential homes, industrial plants, and municipal users. System level examples of such costs are the additional distribution pipes and parallel storage that would have to be installed. Consumers will also experience additional costs. Existing residential homes, for example, would have to be retrofitted with outdoor (and possibly indoor) piping for non-potable uses. New homes will have to install different piping for potable and non-potable uses. If stricter potable water standards are implemented, treatment cost per gallon treated will increase.

System Management Costs

Benefits in system management do not come without potential management and bureaucratic costs. Increased flexibility in managing the combined system carries the potential for abuse of control over the more complex system. Legal and institutional barriers may increase with implementing such combined systems in response to new issues concerning water rights, liability, and human health. Increased number of facilities translates into extra bureaucracy and employment. Increased employment is a cost to the system, but may be a benefit to society if the workers are drawn from the unemployed ranks.

Environmental and Health Costs

Potential health benefits, which are because of increased quality standards of potable water in the combined system, may be offset by the costs of greater risk of potential consumption of contaminants in non-potable water. Outdoor water use implies a higher probability of consumption of contaminants in the non-potable water. Currently, consumers perceive little harm from public water, whether from fountains, tap, or toilet. Will the customer enjoy outdoor yard activities with their children without hesitation? Increasing non-potable uses may require a shift in responsibility from the municipal water authority to the consumer for exposure risk. With this shift, new liability issues will arise, however small the actual risk. Acceptance by consumers of the differences in water quality will be critical for successful and efficient implementation of this proposed combined system. Education and public awareness campaigns will be necessary for the customer's acceptance.

Lastly, consequences of implementing the combined system may affect environmental and economic costs to downstream users because of changes in water withdrawals and return flows. The affect on costs is unpredictable depending on the specific municipality and watershed. These may have long term effects on municipal and watershed management practices.

Concluding Remarks

As shown in figures 8 and 9, over 50% of treated water from public supply system is being used in household and domestic purposes, and about 60% of water usage in households is non-potable. These figures imply at least 30% of water from public

supply systems does not have to be treated to potable water standards. This water can be supplied by other water sources that have lower water quality or by reclaimed wastewater. The "30%" is a minimum level of water amount, because no data or information is available about commercial, industrial, public, and thermoelectric uses. It is argued there are many potential benefits, as well as costs in implementing the combined water supply system. As previously mentioned, the magnitude of the benefits and costs varies depending on how the system is implemented. In no way are we proposing municipalities go out and upgrade immediately to the combined system. If such a system were implemented, a piecewise approach is the most likely efficient solution. New buildings and developments are prime candidates for implementing this combined system. The costs of installing distribution pipes, for example, are already incurred in new developments. The combined system could piggyback on the traditional system, thus lowering installation costs. The need to upgrade municipalities' water system infrastructure is an ongoing project. Another candidate for implementing the combined system is installing the necessary dual distribution system in conjunction with system upgrades. Again, this would make the costs of installing the proposed combined system more affordable.

Efficient implementation of the combined system must account for economic incentives. Proper pricing of the different water resources is necessary for economic efficiency. This includes water marketing. But the importance of consumers' perceptions cannot be overstated. Economic incentives will not succeed if customers will not accept reuse and non-potable differences in quality. In turn, liability issues will

need to be addressed regarding the perceived risk of toxin consumption in non-potable water. The benefits and costs of the proposed system are municipality specific. Further studies are necessary concerning the benefits and costs of altering traditional water systems. Specific case studies of implementing the combined system are necessary. In addition, the legal and environmental effects of changes in water withdrawals and return to the environment need careful investigation. Regardless, increasing demand along with increasing costs of potable water supply will inevitably stimulate changes to current water systems. The proposed combined water system may, therefore, be a model for improved quality of drinking water while conserving our fresh water supply.

CHAPTER VI

CONCLUSIONS

In this study, comprehensive annual costs of ESRD are calculated using a case study approach. ESRD, a chronic disease, requires expensive dialysis treatment for the remainder of the patients' life. The most distinguishing feature of this study is the incorporation of both unpaid caregivers' costs and patients' costs in determining the costs of ESRD. Most previous studies consider only patients' or unpaid caregivers' costs, but not both. Further, these studies do not explicitly address unpaid caregiving for ESRD patients. One study suggests that in the developed world, approximately one percent of total medical expenses are related to ESRD, but less than 0.08% of the population have ESRD. Studies on ESRD costs are, however, rare. Using the structure of most current municipal water supply system as a base, a modified water supply system, which may reduce societal costs associated with toxins known to induce ESRD, is proposed.

A simple theoretical framework shows unpaid caregiving is important because such caregiving substitutes for the more expensive paid caregiving. This substitution increases the household's consumption over the case of all paid caregiving. If the net benefits (including the altruistic benefits and costs associated with caregiving) from the unpaid caregiver are greater than the net benefits from paid caregiver(s), this substitution will occur. Unpaid caregiver, when it occurs, decreases society's costs associated with diseases, including ESRD.

Depending on assumptions made concerning the opportunity costs of time, discount rate, and amount of caregiving time, estimated annual total ESRD costs range from $84,086.06 to $121,592.82 / year / case. Of the various sensitivity analysis on these parameters, the "best guess" scenario is a 7% discount rate, a wage rate of $5.15 / hour, and excluding responses from caregivers stating they provide care 24 hours a day seven days a week. Under this scenario, the annual total ESRD costs are $91,346.05 / year / case. Of this amount, 88% ($80,400) are direct and indirect medical costs and 7.6% are non-medical costs. Patients' costs are 96% of the total ESRD costs, whereas costs associated with caregiving are 4%. However, the caregivers' percentage increases up to 25%, depending the assumed discount rate, wage rate, and caregiving time. The relatively small portion of total costs attributable to caregivers may reflect why studies concerning comprehensive costs of diseases are rare. In addition, there are many non-monetarized cost components such as changes in personal plans, shorten life expectancy, and health affects not included in the above cost estimates. Estimating the monetary values of these items will obviously increase total costs and change the portion of non-medical costs and / or unpaid caregivers' costs. Further, costs associated with caregivers who are not the primary unpaid caregiver are not included. The magnitude of these costs is unknown. Finally, secondary effects of caregiving, such as effects on caregivers' employers, are not considered.

The distributions of patients' and caregivers' costs are positively skewed. For most individual cost items, there are many values of zero and a few of high values. The main reason for these skewed distributions is for many patients, the individual cost item

was not incurred. For example, only a few patients had to renovate their homes to accommodate their disease. These patients incurred the costs of renovations, whereas most patients had a zero cost here. Another example is transportation. Several patients were ill enough that specialized medical transportation had to be used to transport the patient to the dialysis center. Most patients traveled by automobile at a much lower cost. Skewed costs are important in policy design and analysis. Overall, the average costs of ESRD maybe around $100,000, but any individual may experience much higher costs.

Differing perceptions among patients and caregivers as to what constitutes caregiving also play an important role. The altruistic nature of caregiving may arise because caregiving is “what family members do for other members and what friends do for friends." As such, it appears some people did not consider all acts of care as caregiving. Another additional interesting point is patients’ perception of caregiving appears to be different from the caregivers’ perception of caregiving. Overall, it appears caregivers’ felt they provided more help than the patients’ felt they received. These differing perceptions cause some minor inconsistencies, as illustrated in the following example. Providing transportation is caregiving from caregiver A’s perspective, but not from caregiver B’s perspective. Caregiver A may answer his / her transportation costs increased because of caregiving, whereas caregiver B answered no increase in his / her transportation cost because of caregiving. Such differences in perceptions are another potential cause of skewed costs’ distributions.

It is informative to compare results of the present study to previous studies on unpaid caregiving. This study shows more than 50% of caregivers experienced a change

in their personal plans including vacation plans, whereas Covinsky et al. show only 17% of families with patients (for nine diagnoses) experienced a change in their personal plans. Previous studies have shown unpaid caregivers have income losses (MetLife, and Whetten-Goldstein et al.). In the caregivers' questionnaire, only two of the 31 caregivers indicated a reduction in working hours in the case study here. No income loss could be calculated here because of the responses given by the caregivers. The "best guess" unpaid caregivers' costs in this case study are approximately $4,000 / year / caregiver. The unpaid caregivers' costs associated with ESRD are potentially higher than for elderly patients with strokes or diabetes. Hickenbottom et al. claim the informal caregiving for the elderly who have had a stroke is $1,200 / year / patient higher than for the elderly who have not experienced a stroke. Langa et al (2002) conclude the informal caregiving for the elderly with diabetes is $1,700 / year / patient higher than for the elderly who do not have diabetes. These results are reasonable, because stroke and diabetes patients do not require regular expensive treatments such as dialysis. The best guess cost ESRD is, however, a little lower than some other studies, such as Hayman et al. ($4,200 / year / patient in the case of elderly with cancer) or Whetten-Goldstein et al. ($5,386 / year / patient in the case of Parkinson's disease). The estimated costs in this case study are less than half of the costs reported in Hay and Ernst ($8,648 / year / patient in the case of Alzheimer's disease). Other studies of the costs of Alzheimer's disease show a much higher informal caregiving costs (Leon and Moyer $33,204 / year / unpaid caregiver and Max, Webber, and Fox $34,272 / year / unpaid caregiver). Differences in unpaid caregiving costs arise partly because each study included different

cost categories and used different methodologies to calculate unpaid caregiving costs. More important, the nature of ESRD may increase the cost of unpaid caregiving relative to some conditions such as stroke or diabetes, but lower the costs of unpaid caregiving relative to other diseases, such as cancer, Alzheimer's, Parkinson's, dementia, and AIDS. ESRD tends to inflict older people, however, most patients with ESRD can perform every day tasks. Much of their lifestyle changes occur because of the need for dialysis three days a week. As patients live with ESRD, co-morbidities become, however, increasingly important.

As an alternative to reduce society's costs associated with ESRD, a conceptual municipal water supply system is proposed. The most distinguishing feature of this water system is that the water is treated differently according to its end-use and source. This system may increase water efficiency through differential pricing, enhanced water marketing, and reduction in total treatment costs. Reduced total treatment costs occur because of a decrease in the amount of water treated. The proposed system may make more stringent water standards for potable use and lower standards for non-potable use possible. More stringent potable water standards may decrease the risk of ESRD by reducing consumption of water-borne toxins such as arsenic and lead. Consequently, societies' total costs of ESRD may decrease. The proposed system is not, however, a free good. Implementing the proposed system will require substantial infrastructure and management changes.

Study Limitations and Future Research

The main limitation and opportunity for future research in the calculation of the costs of ESRD is in the procedure used for data collection. The questionnaires were distributed to patients and caregivers when they came to the dialysis center for treatment. Questionnaires were returned at a later date. Face-to-face interviews may have been a better procedure to obtain the case study data. Such a procedure may have eliminated some of the missing observations and trained interviewers could have explained any ambiguities in the questionnaire. In addition, in face-to-face interviews perceptions on definitions for cost categories and caregiving behaviors may be more standardized. Estimation of the potential benefits and costs associated with the proposed water supply system is not conducted because of resource limitations. As such, it is not clear if the proposed system will decrease the risk of ESRD, reduce societies' overall costs associated with water-borne illnesses, and increase water use efficiency. Estimation of these benefits and costs is an attractive avenue for further multidisciplinary research.

There are other important issues not considered in this study, such as ethical consideration, externalities, and inferences that can be made. These issues are not only limitations, but provide opportunities for future research. As an example of ethical considerations, consider the estimation of opportunity costs of an individual's time. Time costs for all patients and all unpaid caregivers time are calculated using the same rate. However, the opportunity costs of time between patients and caregivers, between working individuals and retired individuals, and between rich persons and poor persons may be different. Such ethical issues are beyond the scope of this study. ESRD may

create externalities, given the institutional arrangements, which pay the majority of the costs associated with the disease. For example, increases in the incidence of ESRD will increase society's economic burden, which may increase of taxpayers' financial burden for the disease. Further, insurance rates may increase if the incidence of the disease increases. Examining the costs of diseases in an externality framework, maybe a fruitful approach. Concerning inferences, the calculated ESRD costs in this study may not be applicable to the other regions. Socio-demographic characteristics in this case study such as portions of races are different than those of the U.S. ESRD population. Age of patients, however, is similar to the U.S. ESRD population. ESRD patients' age and race that are included in the study are, however, similar to the ESRD population of Texas. Expanding the study to patients beyond those at a single dialysis unit would make the results more applicable to a wider-based ESRD population. Using a statistical approach to sample a larger patient population is desirable. Unfortunately, cost constraints did not allow for such an approach in this case study.

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APPENDIX A

LIST OF PREVIOUS STUDIES ASSOCIATED WITH COSTS OF DISEASES

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Bennett, Cvitanic, and Pascal. (AIDS)	Inpatient services (hospital stay), Outpatient services such as physician visits, laboratory tests.	Home care, other non-medical professionals, household assistance, Insurance/legal assistance.	N/A	Financial assistance from family, friends, and volunteers.	N/A
Cattanach and Tebes. (Elder Impairment)	N/A	N/A	N/A	Negative effects on health, psychosocial functioning (stress, coping behaviors) – No monetary value is evaluated.	N/A
Cooper and Rice. (Assorted 16 Diseases)	Hospital care, Physicians' services, Other professionals' services, Dentists' services, Drug and drug sundries, Eyeglasses and appliances, Nursing home care	Expenses for prepayment and administration, Government public health activities, Other health services, Research, Construction	Morbidity, Mortality	N/A	N/A
Decock, Depoorter, De Graeve, and Colebunders. (HIV & AIDS)	Hospitalization, Consultation, Investigation, Medication, Psychological care, Diet product	Transport	N/A	Informal care by volunteers, relatives, friends.	N/A
Emanuel, Fairclough, Slutsman, and Emanuel. (Any Disease w/o HIV & AIDS)	N/A	N/A	Sell assets, take out a loan or mortgage, get additional job to pay for health care costs.	Depressive symptoms. Interfering personal life. Psychological distress.	10% of household income was spent on health care costs.

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Ernst, Hay, Fenn, Tinklenberg, and Yesavage. (Alzheimer)	Hospital days, Physician visits, Nursing home, Ambulance, Medication.	Residential care, Adult day care, Paid in-home care, Purchased meals	N/A	Unpaid In-home care	N/A
Harrow, Tennstedt, and McKinlay. (Disabled Elders)	N/A	Nursing home care in Massachusetts: $93.39 / day ($35,533 / yr)	N/A	Informal care: Personal care: $9.08/h, Housekeeping $6.58/h, Meals: $6.58/h, Managing finances: $12.66 /h, Arranging services: $17.39/h, Transportation: $9.08/h	N/A
Hay and Ernst. (Alzheimer)	Diagnosis ($874), Nursing home ($5326), Long-term mental hospital ($322), Short-term acute hospital ($434), Physicians ($418), Drug and medical supply ($244)	Home care ($1774), Travel ($167)	N/A	Family-provided home care ($8684), Family members' time ($256)	N/A
Hellinger. (1990) (AIDS)	Hospital, Nursing home, Drug and alternative therapies.	Home health, Counseling.	N/A	N/A	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Hellinger. (1993) (HIV)	Inpatient, Outpatient visits, Drug costs	Home health, Long-term care	N/A	N/A	N/A
Hellinger, Fleishman, and Hsia. (AIDS)	Ambulatory medical visits, Emergency room visits, Hospital days, and Drugs.	Home health visits	N/A	N/A	N/A
Hodgson. (1983) (Comprehen-sive Costs of Illnesses)	Hospitalization, Outpatient clinical care, Nursing home care, services of primary physicians and specialist, Drugs and drug sundries, Rehabilitation counseling and other rehabilitation costs, Speech devices related to overcoming impairment	Home health care, Transportation, Certain household expenditures, Certain property losses	Morbidity, Mortality, Patient time to visit physician, other professionals, Psychosocial costs	Family members' time to care patient, Unwanted job changes, lost opportunity for promotion and education	N/A
Hodgson. (1994) (Comprehen-sive Costs of Illnesses)	Medical care expenditures (Hospitalizations, Outpatient clinic care, Nursing home care, Services of primary physicians, specialists, dentists, and other health care professionals, Drug and drug sundries, Rehabilitation)	Home health care	Output lost because of cessation or reduction in productive activity caused by morbidity, mortality or disability.	Output lost because of cessation or reduction in productive activity caused by caring patient.	N/A
Hodgson and Cai. (Hypertension)	Hospital care, Physician service, Prescription drug, Nursing home care	Home health care	N/A	N/A	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Hodgson and Cohen. (1999a) (Diabetes)	Hospital care, Physician and other professional services, Prescription drugs and medical durables, and Nursing home care	Home health care	N/A	N/A	N/A
Hodgson and Cohen. (1999b) (Circulatory Diseases)	Hospital care, Physician and other professional services, Prescription drugs and medical durables, and Nursing home care	Home health care	N/A	N/A	N/A
Hoffman, Rice and, Sung. (General Chronic Conditions)	Hospital stays, Physician and other professional visits, Emergency Dept. visits, Dental visits, Prescribed medicines, and Medical equipment and supplies.	Home health care visits	Morbidity costs, and Mortality costs	Caregiving costs (includes both the costs of providing the services and the costs to employers when employee needs leave time for caregiving	N/A
Hornberger, Garber, and Jeffery. (ESRD)	Medical costs were divided only to three categories:1) Physician, 2) Outpatient, and 3) Inpatient.	N/A	N/A	N/A	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Houts, Lipton, Harvey, Martin, Simmonds, Dixon, Longo, Andrews, Gordon, Meloy, and Hoffman. (Outpatient Chemo-therapy)	N/A	N/A	N/A	Wages lost ($35.82 / week)	Food, Transport, Lodging, Family care, Clothing, Telephone, Non-medical healing, Other miscellaneous.
Huang, Cartwright, and Hu. (Dementia)	Hospital care, Physician services, Drug, Other medical equipment, Nursing home services, Social agency services	Community home care	Loss of the lifetime productive value of human capital (lost productivity), The subjective value of the loss of life (Morbidity, Mortality)	Time spent for caring patient.	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Langa, Chernew, Kabeto, Herzog, Ofstedal, Willis, Wallace, Mucha, Straus and, Fendrick. (Elderly w/ Dementia)	N/A	N/A	N/A	Receiving care: Mild Dementia: 8.5 h/w, Moderate Dementia: 17.4 h/w, Severe Dementia: 41.5 h/w. Cost of care: Low-range: $5.9/h, Mid-range: $8.2/h, High-range: $10.8/h	Yearly cost = 8.5 × 5.9 × 52 weeks = $2,607.8 (Mild and Low-range case)
Leigh, Bowlus, Leistikow, and Schenker. (Hepatitis C)	Hospitalization, Physician visits, Nursing home care, Drugs, Medical supplies, Dental services	Public health care expenditures such as construction of hospitals, and government public health activities	N/A	N/A	N/A
Leon, Cheng and, Neumann. (Alzheimer)	Number of hospital days from overnight hospital stays, Number of emergency room visits, Number of doctor visits, Number of prescribed medication, Number of skilled nursing facility days	Number of days in an adult day care program, Monthly use of a homemaker, Monthly use of personal care services.	N/A	Time spent on activities of daily living (ADL), Time spent on household chores.	N/A
Leon and Moyer. (Alzheimer)	Annual costs for nursing home: $42,336 / patient.	N/A	NA	Assisted living: $33,204 / patient. --- $ 9,132 (per patient) cheaper than nursing home care.	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Leon and Neumann. (Alzheimer)	Inpatient hospital stays, Emergency room visits, Doctor visits, Prescriptions, Skilled nursing home care	Adult day care, Homemaker services, Personal care services	N/A	N/A	N/A
Liu and Hay (Cytomegalo-virus: CMV)	Outpatient care, Hospital care, and Medications.	Paid caregiver costs	N/A	Unpaid caregiver costs	N/A
Mark, Woody, Juday, and Kleber. (Heroin Addiction)	Medical care costs (such as inpatient, outpatient, physician, emergency)	Medical complications, Health insurance administration, Crime costs	Productivity costs (such as mortality, unemployment, incarceration, lower earnings)	N/A	N/A
Max, Webber And, Fox. (Alzheimer)	N/A	Nursing home care cost: $ 4,272 / yr	N/A	Changed jobs, Reduced work hours, and Early retirement: $ 34,272 / yr	N/A
McDonnell, Redekop, Van der roer, Goes, Ruitenberg, Busschbach, Breteler, and Rutten (Alzheimer)	Hospitalization prior to admission to a nursing home, Hospitalization for any other reason, General practitioner visits, Psychiatric care, Home for the elderly, Nursing home.	N/A/	N/A	N/A	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Meek, McKeithan, and Schumock. (Alzheimer)	Nursing home care, Hospitalization, Physician visits, Drug	Social services including adult day care	Lost productivity, Premature death	Lost productivity	N/A
Menon and Assiff. (Literature Review)	N/A	N/A	N/A	Burden of employers: Absenteeism, Less productivity, Short- or Long term disability, Drug costs	N/A
Mullins, Whitelaw, Cooke, and Beck. (HIV)	N/A	Disability-related unemployment benefits, Loss of economic productivity, Community and informal services	N/A	N/A	N/A
Murman. (Alzheimer)	Physician visits, hospitalization, Nursing home care	N/A	Time costs, Lost productivity costs	Time costs, and Lost productivity costs of caregivers	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
National Alliance for Caregiving. (April 8, 2002b) (No Specific Disease)	N/A	N/A	N/A	Replacing employees: $4,933M / yr, Absenteeism: $397M / yr, Partial Absenteeism: $488M / yr, Workday interruptions: $3,765M / yr, Eldercare crises: $1,084M / yr, Supervisor's time: $805M / yr	The aggregate cots of caregiving in lost productivity to U.S. business is $11.4 billion / year.
National Alliance for Caregiving. (April 8, 2002c) (No Specific Disease)	N/A	N/A	N/A	Hours of caregiving: Average 17.6 h / w. Physical and Emotional strain: 1) less time for their family, 2) given up vacations, hobbies, or other activities, 3) physical and mental health problem.	Spend their own money: $152 /month. Non-spouse caregiver who are living with and providing financial support for the person with AD is spending average $261 /month.

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Newcomer, Yordi, DuNah, Fox, and Wilkinson. (Alzheimer)	N/A	N/A	N/A	Tested whether improved access to community-based care reduces perceived burden and depression among primary caregivers of people with dementia	→ No significant changes in caregiver's burden and depression. (No monetary values regard to caregiver's burden and depression are evaluated.)
Ostbye and Crosse. (Dementia)	Long-term care institution, Drugs, Hospital, Diagnosis	Paid care in community (Homemaker, Home-delivery meal, In-home personal care, In-home nursing care, Respite care etc.)	N/A	Caring activities of daily living (ADLs)	N/A
Rice, Fillit, Max, Knopman, Lloyd, and Duttagupta. (Alzheimer)	Physician visits, Prescription medication, Emergency department visits, Acute hospitalization, Long-term care (such as nursing home care)	N/A	Loss of wages and productivity	Loss of wages and productivity, Early retire, Increased physical and psychiatric morbidity.	N/A
Rice, Fox, Max, Webber, Lindeman, Hauck, and Segura. (Alzheimer)	Hospital, Nursing home, Physician visits, Medications, Medical items, Social services: Value of $12,572 for community-base and $42,049 for institutional care.	Activities of Daily Living (ADL) and Instrumental ADL: $ 34,517 for community-based and $5,542 for institutional care.	N/A	N/A	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Scitovsky, Cline, and Lee. (AIDS)	Hospital stays (Inpatient services) : $27,571 (lifetime charge)	N/A	N/A	N/A	N/A
Scitovsky and Rice. (AIDS)	Hospital services, Physician services, Nursing home, Hospice services, Lab tests.	Home care	Morbidity cost (lost productivity), and Mortality cost (lost earnings)	N/A	N/A
Stommel, Collins, and Given. (Dementia)	N/A	N/A	N/A	Labor costs of caregiver, labor costs of other family members, and labor costs of other formal care providers and all other non-family members	Total cost to family: $4,979 (Total cash expenditure, $1,680 + Total unpaid costs including labor costs, $3,299)
Stommel, C. Given, and B. Given. (Cancer)	N/A	N/A	Loss of earnings	Labor costs of caregiver, and labor costs of other family members	Expenditures for hospital and physician services, nursing home, medication, visiting nurses, home health aides, purchases of special equipment, supplies, and food and supplements.

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Strassels, Smith, Sullivan, and Mahajan. (Lung Disease)	Inpatient admissions, Prescribed drugs, Outpatient clinic visits, Office visits, Emergency department	Bed days, Restricted activity days, Lost work days	N/A	N/A	N/A
Sullivan and Weiss. (Asthma)	Hospital use & Emergency Dept. use (50% of total direct medical care costs)	N/A	Value of disease-related morbidity, Premature mortality, Productivity loss, and the value of the psycho-social afflictions of the disease.	N/A	N/A
Thom. (Neoplasms, Arteriosclerosis, and Diabetes)	Hospital care, Professional care, Drug, Nursing home care	Home care	Indirect morbidity, Indirect mortality.	N/A	N/A
Ward, Javitz, Smith, and Whan. (Chronic Respiratory Disorders)	N/A	N/A	Lost income (Average $3,143 / yr)	N/A	N/A

APPENDIX A (Continued)

Author(s), (Disease)	Patient Direct Medical Costs	Patient Indirect Medical Costs	Patient Non-Medical Costs	Caregiver Personal Quality Costs	Caregiver Out-of Pocket Expense
Weinberger, Gold, Divine, Cowper, Hodgson, Schreiner, and George. (Dementia)	Hospital visit, Visiting nurse, Physician visit, Nursing home, and Emergency room visit. = Total $544.8	In-home companion, Adult day care, Respite care, Household help, Financial/Legal services, Other health services, Mental health counseling, Meal preparation, and Chores. = Total $619.5	Used charges as an estimate of expenditures for care, whether paid out-of-pocket or by a third party.	Caregivers' time was excluded.	N/A
Weiss, Gergen and, Hodgson. (Asthma)	Inpatient hospitalization, Hospital outpatient services, emergency room services, Physicians' services, and Medication	N/A	Loss of school days, Loss of work, and Mortality loss	N/A	N/A
Welch, Walsh and, Larson. (Alzheimer)	Nursing home expenditure: $ 4.3 M – 6.4 M (2.5 yrs / resident) Hospital utilization (Part A Medicare expenditure): $ 1,180 / yr	N/A	N/A	N/A	N/A
Whetten-Goldstein, Sloan, Kulas, Cutson, and chenkman. (Parkinson's Disease)	Burden to Society ($ 6,115 / patient): Hospital expenses, Doctor visits, Visits other professionals, Drugs, Formal care, Equipment, Compensated earning loss	N/A	413 hrs less housework / person, 187 hrs less yard work / person.	Informal care ($5,386 / person), Earning loss ($12,082 / person)	Burden to family ($ 1,148 / patient): Hospital expenses, Doctor visits, Visits other professionals, Drugs, Formal care, Equipment, Compensated earning loss

APPENDIX B

PATIENT QUESTIONNAIRE

Estimating ESRD Costs: Non-Medical and Caregiving

Patient Questionnaire

Bryan Nephrology Center

Bryan, Texas

Patient Name:_____
(For Dr. Tan's use only. Name will be deleted after returning this back to the Bryan Nephrology Center.)

If you have any question regarding this questionnaire, please contact Dr. Frederick Tan at 979-775-9384 or 979-226-9998. Thank you for your cooperation.

The first section is important background information.

1.1. Your gender: ____Male ____Female

1.2. Your age: ____Years

1.3. Your racial or ethnic background: [Check any that apply.]
____White ____Black ____Hispanic ____Asian
____Other [Please specify.]_____

1.4. Your highest level of education completed is: [Please check one.]
____Grade school (K-8)
____High school or equivalent (Grade 9-12)
____Some college
____Bachelor / Associate degree
____Post undergraduate

1.5. Including yourself, how many members of your household belong to each age group? [Please provide a number for each category.]
____Under 18 ____19-24 ____25-44 ____45-64 ____65 or older

1.6. What year did you start dialysis? _____Year

1.7. What city do you live in? _____ City

1.8. Your current residence is:
____Own home / apartment
____Rental home / apartment
____Retirement home
____Caregiver's home
____Nursing home
____Other [Please specify.]_____

The second set of questions will be used to estimate the cost of traveling from your residence to the dialysis treatment center.

2.1. How many miles do you travel to get to the dialysis center?
Approximately _____miles

2.2. How do you usually travel to the dialysis center?
____Walk
____Drive yourself
____Ride with other(s)
(Relationship with the patient:_____)
____Taxi
____Bus
____Medical transportation including ambulance
____Other [Please explain.]_____

2.3. When you go to the dialysis center for treatment, are you usually accompanied by a caregiver? [Check all that apply.]
____No
____Yes, with a paid caregiver
____Yes, with an unpaid caregiver

The third set of questions is to identify the cost of ESRD care that you have to pay.

"Home Care" is defined as skilled professional care by a nurse or aide who comes to your residence and provides medical treatment and tests.

3.1. How much do you spend for "Home Care" before reimbursement?
Approximately _____dollars per month

A "paid caregiver" is a person who provides care as part of his / her job.

3.2. How much do you spend for a "paid caregiver" before reimbursement?
Approximately _____dollars per month

"Household Chores" costs are costs associated with hiring someone for the following household chores because of your ESRD. Please do not provide a cost if you would have hired someone regardless of your ESRD.

3.3. How much do you pay for someone else to do the following "household chores" since ESRD onset?
Lawn mowing / gardening: Approximately _____dollars per month
House cleaning: Approximately _____dollars per month
Grocery shopping: Approximately _____dollars per month
Running errands: Approximately _____dollars per month
Other: Approximately _____dollars per month
[Please specify.]_____
Other: Approximately _____dollars per month
[Please specify.]_____

Costs for equipment and renovations needed since ESRD onset.

3.4. Since the onset of your ESRD, have you purchased any special medical equipment or supplies (such as an oxygen, wheelchair), because of your ESRD?
____No
____Yes, my total costs are approximately _____dollars.
Purchased item(s): _____
_____
_____
(If there are more, please use the back of this page.)

3.5. Since the onset of your ESRD, have you renovated your residence because of your ESRD (for example: bathroom, grab bars, special furniture, etc.)?
____No
____Yes, my total costs are approximately _____dollars.
Renovation or changes made:
_____
_____
_____
_____

3.6. Have you changed your car because of your ESRD (for example: adding hand break, accelerator control, etc.)?
____No
____Yes, my total costs are approximately _____dollars
Change(s) made :
_____
_____
_____
Purchased additional or different car ____Yes ____No
If yes, Approximate purchase price _____
Trade-in value of old vehicle _____
(Please provide best estimates, if unknown.)

The fourth set of questions is used to identify costs of ESRD that may change your income.

4.1. Your current employment status is:
____Employed full time
____Employed part-time
____Full-time homemaker
____Unemployed
____Retired

4.2. If you are employed, have you changed the number of hours you work because of your ESRD?
____No change
____Yes, approximately _____more hours per month
_____less hours per month

4.3. Approximately, what was your before tax annual income last year?
____Under $10,000
____$10,001 to less than $20,000 ____$20,001 to less than $30,000
____$30,001 to less than $50,000 ____$50,001 to less than $75,000
____More than $75,000

4.4. Your employment status when you were diagnosed with ESRD was:
____Employed full time
____Employed part-time
____Full-time homemaker
____Unemployed
____Retired

4.5. Did your ESRD force you to retire early?
____No
____Yes, approximately ____year(s) early.
Year of retirement _____

4.6. If you answered yes to question 4.5, approximately, what was your before tax annual income at retirement?
____Under $10,000
____$10,001 to less than $20,000 ____$20,001 to less than $30,000
____$30,001 to less than $50,000 ____$50,001 to less than $75,000
____More than $75,000

The fifth set of questions asks about possible changes in your lifestyle because of your ESRD.

5.1. Have you changed your place of residence because of your ESRD (For example: moved closer to medical treatment, moved in with family of friend for caregiving help.)?
____No
____Yes, reason for change is_____

5.2. Have you ever cancelled or reduced your vacation time because of your ESRD?
____No
____Yes

5.3. Have you ever changed your job because of your ESRD?
____No
____Yes

5.4. Please circle the level that you feel about your life for the following items:

a) Boring	1	2	3	4	5	6	7	Interesting
b) Miserable	1	2	3	4	5	6	7	Enjoyable
c) Useless	1	2	3	4	5	6	7	Worthwhile
d) Lonely	1	2	3	4	5	6	7	Many friends
e) Empty	1	2	3	4	5	6	7	Full
f) Discouraging	1	2	3	4	5	6	7	Encouraging
g) Disappointing	1	2	3	4	5	6	7	Rewarding
h) Brings out the worst in me	1	2	3	4	5	6	7	Brings out the best in me

5.5 Please circle the level that you feel about overall satisfaction of your life.

Very Dissatisfied	1	2	3	4	5	6	7 Very satisfied

The sixth and last set of questions asks about the types of caregivers you use and the kinds of care you need because of your ESRD.

Out-of-town unpaid caregiver(s) are the caregiver(s) who live more than 50 miles away from the Bryan / College Station area.

6.1. How many different caregiver(s) do you have?
[Please provide a number for each category.]
____No need for caregiver
____Paid caregiver(s)
____In-town unpaid caregiver(s)
____Out-of-town unpaid caregiver(s)
____Need caregiver(s), but none are available
____Other [Please explain.]_____

If you have no unpaid caregiver(s), please skip to last page.

6.2. For each unpaid caregiver, please provide the following.

What is their relationship to you?	What city & state do they live in?
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

6.3. Circle how often you need help with:
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a)	1	2	3	4	5	Legal advice and issues.
b)	1	2	3	4	5	Financial management.
c)	1	2	3	4	5	Spiritual/social/community activities.
d)	1	2	3	4	5	Household management and/or modifications.
e)	1	2	3	4	5	Transportation.
f)	1	2	3	4	5	Nutrition, meal preparation, grocery shopping.
g)	1	2	3	4	5	Housekeeping activities.
h)	1	2	3	4	5	Mobility support, equipment, rehabilitation.
i)	1	2	3	4	5	Personal hygiene.
j)	1	2	3	4	5	Medical and/or nursing treatment(s) and medication(s)

The next questions will identify what kinds of care the unpaid caregiver(s) provide.

6.4. Circle how often the in-town unpaid caregiver(s) help with:
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a)	1	2	3	4	5	Legal advice and issues.
b)	1	2	3	4	5	Financial management.
c)	1	2	3	4	5	Spiritual/social/community activities.
d)	1	2	3	4	5	Household management and/or modifications.
e)	1	2	3	4	5	Transportation.
f)	1	2	3	4	5	Nutrition, meal preparation, grocery shopping.
g)	1	2	3	4	5	Housekeeping activities.
h)	1	2	3	4	5	Mobility support, equipment, rehabilitation.
i)	1	2	3	4	5	Personal hygiene.
j)	1	2	3	4	5	Medical and/or nursing treatment(s) and medication(s)

6.5. Circle how often the out-of-town unpaid caregiver(s) help with:
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a)	1	2	3	4	5	Legal advice and issues.
b)	1	2	3	4	5	Financial management.
c)	1	2	3	4	5	Spiritual/social/community activities.
d)	1	2	3	4	5	Household management and/or modifications.
e)	1	2	3	4	5	Transportation.
f)	1	2	3	4	5	Nutrition, meal preparation, grocery shopping.
g)	1	2	3	4	5	Housekeeping activities.
h)	1	2	3	4	5	Mobility support, equipment, rehabilitation.
i)	1	2	3	4	5	Personal hygiene.
j)	1	2	3	4	5	Medical and/or nursing treatment(s) and medication(s)

The next question will identify how the out-of-town unpaid caregiver(s) provide care.

6.6. Circle how does (do) the out-of-town unpaid caregiver(s) provide help?
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a)	1	2	3	4	5	They come here (Bryan / College Station Area)
b)	1	2	3	4	5	I go to where he/she/they live(s).
c)	1	2	3	4	5	Phone
d)	1	2	3	4	5	Regular mail
e)	1	2	3	4	5	E-mail
f)	1	2	3	4	5	Other [Please specify.]_____

Please feel free to provide any additional comments in the space below. We welcome your comments.

APPENDIX C

UNPAID CAREGIVER QUESTIONNAIRE

Estimating ESRD Costs: Non-Medical and Caregiving

Unpaid Caregiver Questionnaire

Bryan Nephrology Center

Bryan, Texas

Patient Name:_____
(For Dr. Tan's use only. Name will be deleted after returning this to the Bryan Nephrology Center.)

If you have any question regarding this questionnaire, please contact Dr. Frederick Tan at 979-775-9384 or 979-226-9998. Thank you for your cooperation.

The first section is important background information.

1.1. Your gender: ____Male ____Female

1.2. Your age: ____Years

1.3. Your racial or ethnic background: [Check any that apply.]
____White ____Black ____Hispanic ____Asian
____Other [Please specify.]_____

1.4. Your highest level of education completed is: [Please check one.]
____Grade school (K-8)
____High school or equivalent (Grade 9-12)
____Some college
____Bachelor / Associate degree
____Post undergraduate

1.5. Including yourself, how many members of your household belong to each age group? [Please provide a number for each category.]
____Under 18 ____19-24 ____25-44 ____45-64 ____65 or older

1.6. Your current residence is:
____Own home / apartment
____Rental home / apartment
____Other family member's home
____Retirement home
____Nursing home
____Other [Please specify.]_____

1.7. Your relationship with the ESRD patient:_____

The next question will identify what types of care you provide.

1.8. Circle how often you provide the following care for the ESRD patient:
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a) 1 2 3 4 5 Legal advice and issues.
b) 1 2 3 4 5 Financial management.
c) 1 2 3 4 5 Spiritual/social activities and/or support.
d) 1 2 3 4 5 Household (or apartment) management and/or modifications.
e) 1 2 3 4 5 Transportation.
f) 1 2 3 4 5 Nutrition, meal preparation, grocery shopping.
g) 1 2 3 4 5 Housekeeping activities.
h) 1 2 3 4 5 Mobility support, equipment, and rehabilitation.
i) 1 2 3 4 5 Personal hygiene.
j) 1 2 3 4 5 Medical and/or nursing treatment(s) and medication(s).

The second set of questions asks about your costs of caring for the ESRD patient. Please keep in mind whether the costs are because of caregiving. Normal expenses should be excluded. For example, all households buy food. However, if you have to spend extra money for food because of caregiving, the amount of extra money is your increase in food costs associated with ESRD caregiving.

2.1. How much has your spending on food changed because of your caregiving?
[Compare to your normal food consumption expenses.]
____No difference
____Spend less: Approximately_____dollars per month
____Spend more: Approximately _____dollars per month

2.2. How much has your spending on transportation changed because of your caregiving? [Compare to your normal transportation expenses.]
____No difference
____Spend less: Approximately_____dollars per month
____Spend more: Approximately _____dollars per month
or _____more miles driven

2.3. Do you buy medical or non-medical equipment for the patient with ESRD, when reimbursement is not available for this equipment?
____No
____Yes, approximately _____dollars per month

2.4. Do you purchase other items for caregiving?
____No
____Yes
Item purchased_____ Approximately _____dollars per month
Item purchased_____ Approximately _____dollars per month
Item purchased_____ Approximately _____dollars per month
Item purchased_____ Approximately _____dollars per month
(If there are more items, please use the back of this page.)

The third set of questions is used to identify costs of caregiving that may change your income.

3.1. How many hours do you spend for caregiving in a week? [Please provide an answer for each category.]
Approximately _____hours per weekday between 8 a.m. to 5 p.m.
Approximately _____hours per weekday between 5 p.m. to 8 a.m.
Approximately _____hours per week on weekends

3.2. Your current employment status is:
____Employed full time
____Employed part-time
____Full-time homemaker
____Unemployed
____Retired

3.3. If you are employed, have you changed the number of hours you work since you begin caregiving for the ESRD patient?
____No change
Increased _____ work hours per month
Decreased _____ work hours per month

3.4. Approximately, what was your <u>before tax</u> annual income last year?
____Under $10,000
____$10,001 to less than $20,000 ____$20,001 to less than $30,000
____$30,001 to less than $50,000 ____$50,001 to less than $75,000
____More than $75,000

3.5. Your employment status when you began caregiving for the ESRD patient:
____Employed full time
____Employed part-time
____Full-time homemaker
____Unemployed
____Retired

3.6. Did you retire early due to caregiving for the ESRD patient?
____No
____Yes, Approximately ____year(s) early.
Year of retirement _____

3.7. Approximately, what was your before tax annual income at retirement?
____Under $10,000
____$10,001 to less than $20,000 ____$20,001 to less than $30,000
____$30,001 to less than $50,000 ____$50,001 to less than $75,000
____More than $75,000

The fourth set of questions asks about possible changes in your lifestyle due to caring for the ESRD patient.

4.1. Do you have enough time to care for your family members since you began caregiving?
____No
____Yes

Do you hire a person to take care of your family member(s)?
____No
____Yes, I spend approximately _____dollars per month

4.2. Have you changed your place of residence because of your caregiving?
____No
____Yes, Reason for change _____
(For example: moved closer to ESRD patient, moved closer to medical services.)

4.3. Have you cancelled or reduced your vacation time because of your caregiving?
____No
____Yes

4.4. Have you changed jobs because of your caregiving?
____No
____Yes

4.5. Since beginning caregiving, have you renovated your residence to provide care (include items such as ramps, grab bars, furniture, etc.)?
____No
____Yes, my total costs are approximately _____dollars.
Renovated item(s)
_____
_____

4.6. Have you changed your transportation because of your caregiving?
____No
____Yes, my total costs are approximately _____dollars.
Change(s) made
_____
_____
_____
_____

Purchased additional or different car ____Yes ____No
If yes, Approximate purchase price _____
Trade-in value of old vehicle _____
(Please provide best estimates, if unknown.)

"Household Chores" costs are costs associated with hiring someone for the following household chores because of your caregiving. Please do not provide a cost if you would have hired someone regardless of your caregiving.

4.7. How much do you pay for the following "household chores"?
Lawn mowinge / gardening: Approximately _____dollars per month
House keeping: Approximately _____dollars per month
Grocery shopping: Approximately _____dollars per month
Errands: Approximately _____dollars per month
Other: Approximately _____dollars per month
[Please specify.] _____
Other: Approximately _____dollars per month
[Please specify.] _____

4.8. Please circle the level about your present life for the following items.

a) Boring	1	2	3	4	5	6	7	Interesting
b) Miserable	1	2	3	4	5	6	7	Enjoyable
c) Useless	1	2	3	4	5	6	7	Worthwhile
d) Lonely	1	2	3	4	5	6	7	Many friends
e) Empty	1	2	3	4	5	6	7	Full
f) Discouraging	1	2	3	4	5	6	7	Encouraging
g) Disappointing	1	2	3	4	5	6	7	Rewarding
h) Brings out the worst in me	1	2	3	4	5	6	7	Brings out the best in me

4.9. Please circle the level that you feel about overall satisfaction of your life.

Very Dissatisfied 1 2 3 4 5 6 7 Very satisfied

4.10. Have you suffered mental stress or physical pain because of your caregiving?

____No
____Yes

4.11. Have you suffered financially because of extra expenses for your caregiving?

____No
____Yes

The fifth and last set of questions asks about the kinds of your caregiving for the ESRD patient.

5.1. How often do <u>you</u> help the ESRD patient with:

1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a)	1	2	3	4	5	Legal advice and issues.
b)	1	2	3	4	5	Financial management.
c)	1	2	3	4	5	Spiritual/social/community activities.
d)	1	2	3	4	5	Household management and/or modifications.
e)	1	2	3	4	5	Transportation.
f)	1	2	3	4	5	Nutrition, meal preparation, grocery shopping.
g)	1	2	3	4	5	Housekeeping activities.
h)	1	2	3	4	5	Mobility support, equipment, rehabilitation.
i)	1	2	3	4	5	Personal hygiene.
j)	1	2	3	4	5	Medical and/or nursing treatment(s) and medication(s)

5.2. Are there other family / friend(s) to help you with caregiving for the ESRD patient?
____No
____Yes

What is their relationship to the patient?	What city & state do they live in?
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

5.3. If others help with caregiving: Approximately how often do <u>they</u> help with:
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

a)	1	2	3	4	5	Legal advice and issues.
b)	1	2	3	4	5	Financial management.
c)	1	2	3	4	5	Spiritual/social/community activities.
d)	1	2	3	4	5	Household management and/or modifications.
e)	1	2	3	4	5	Transportation.
f)	1	2	3	4	5	Nutrition, meal preparation, grocery shopping.
g)	1	2	3	4	5	Housekeeping activities.
h)	1	2	3	4	5	Mobility support, equipment, rehabilitation.
i)	1	2	3	4	5	Personal hygiene.
j)	1	2	3	4	5	Medical and/or nursing treatment(s) and medication(s)

5.4. If others help, how do they work with the patient?
1=Never, 2=Rarely, 3=Sometimes, 4=Usually, 5=Always

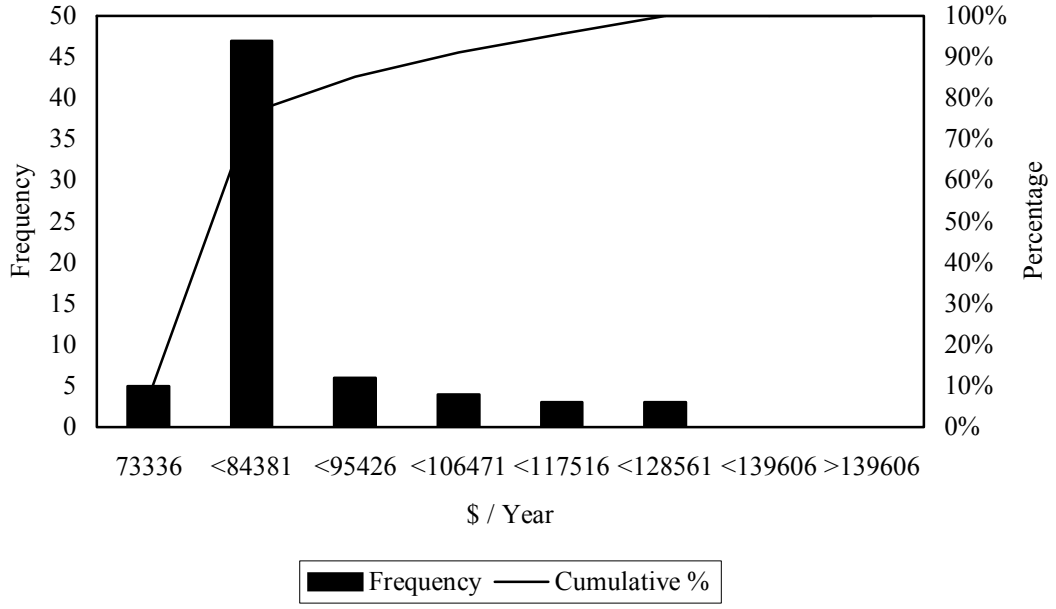
a)	1	2	3	4	5	They come to the patient
b)	1	2	3	4	5	The patient goes to them.
c)	1	2	3	4	5	Phone
d)	1	2	3	4	5	Regular mail
e)	1	2	3	4	5	E-mail
f)	1	2	3	4	5	Other [Please explain.]_____

Please feel free to provide any additional comments in the space below. We welcome your comments.

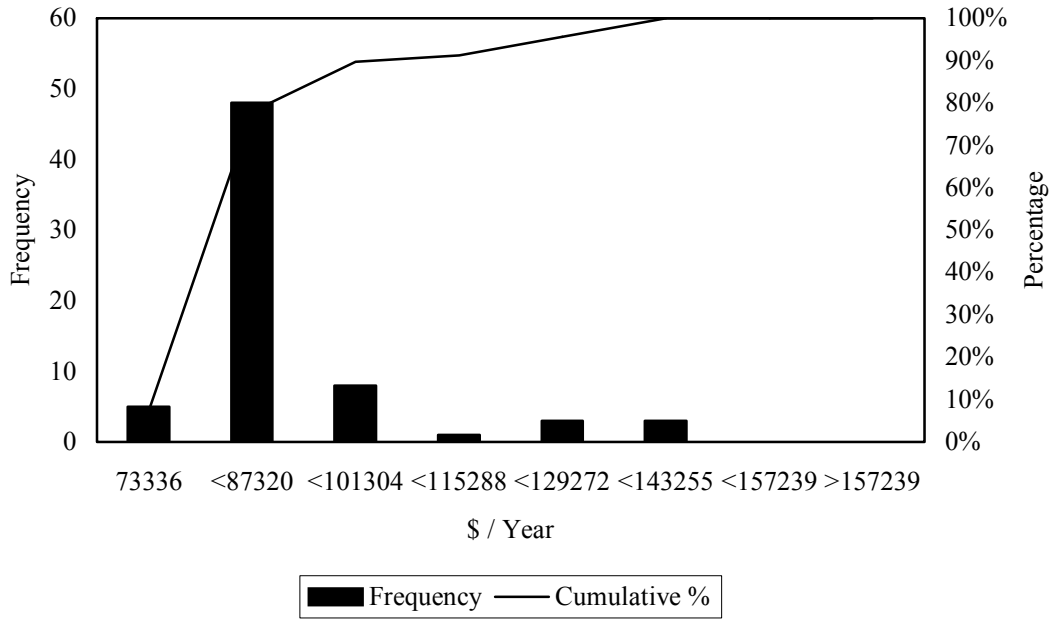
Thank you, we appreciate your patience and cooperation.

APPENDIX D

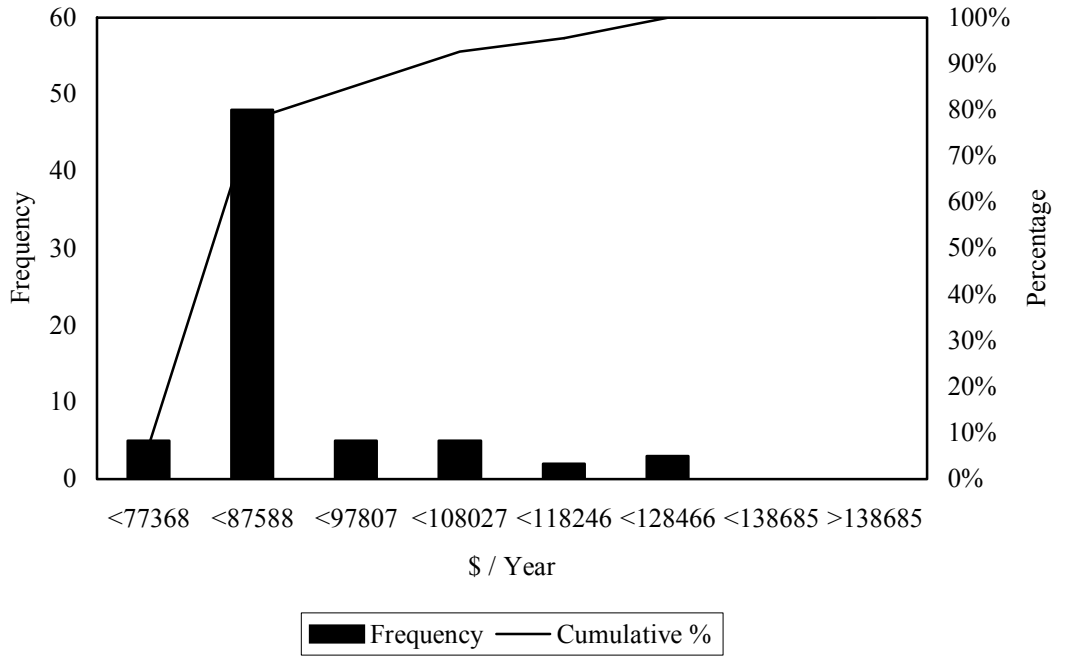
HISTOGRAMS OF COSTS ITEMS



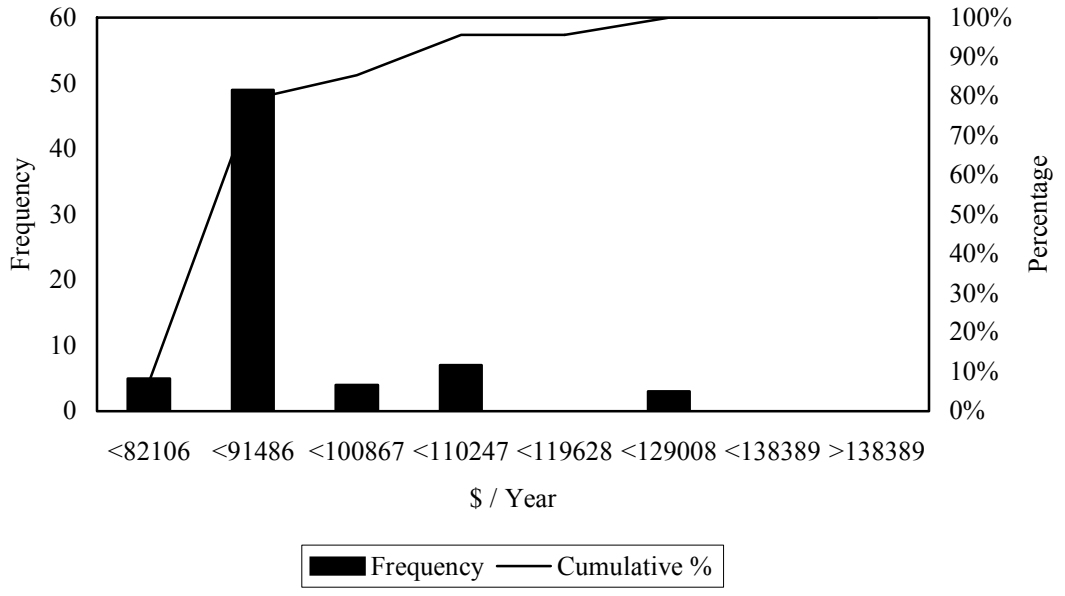
Total Patients Costs (without time costs, 3% discount rate)



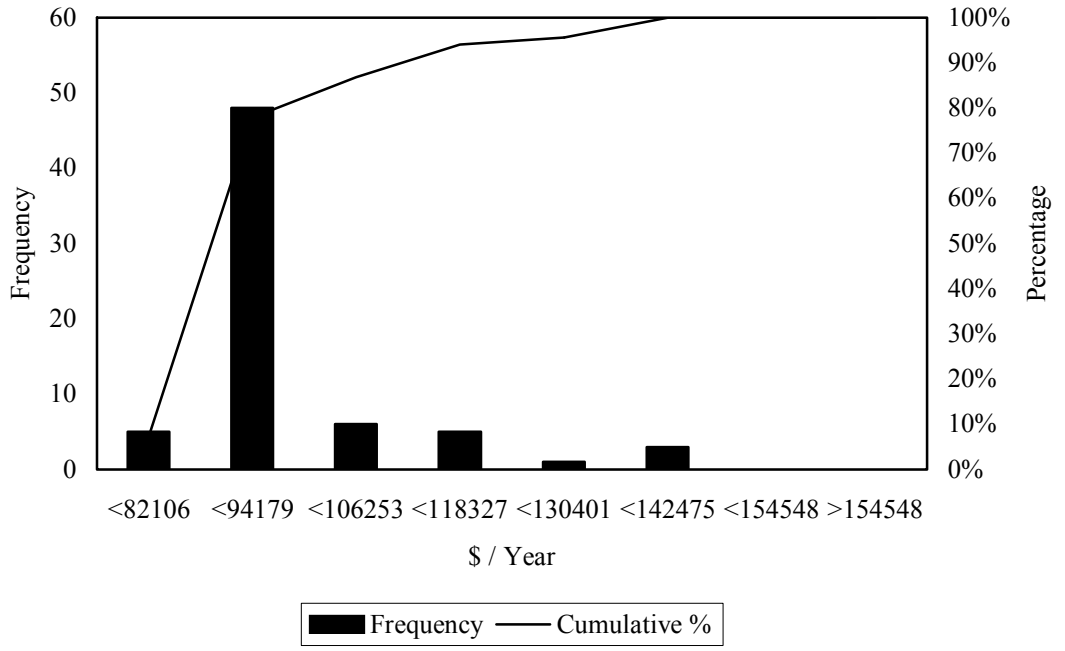
Total Patients Costs (without time costs, 7% discount rate)



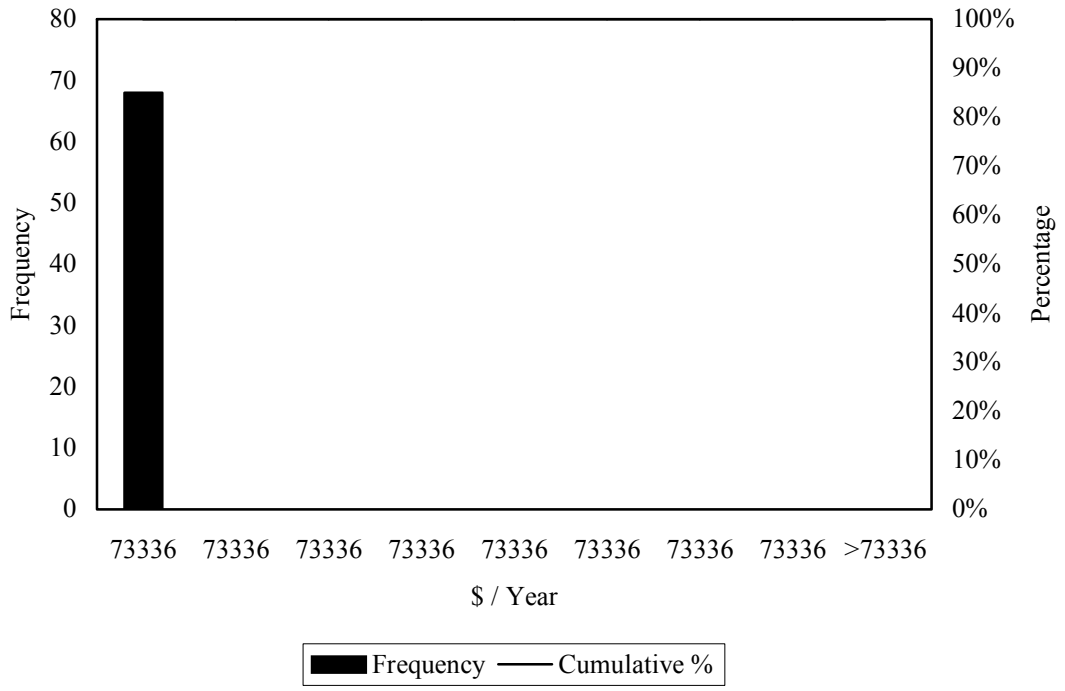
Total Patients Costs (wage rate of $5.15 / hour, 3% discount rate)



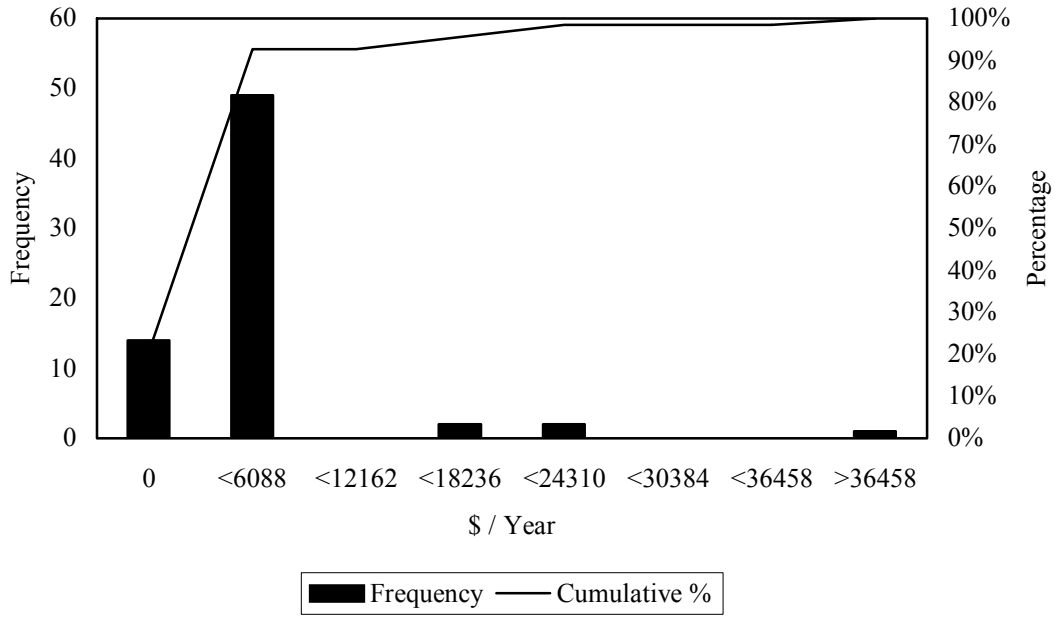
Total Patients Costs (wage rate of $11.2 / hour, 3% discount rate)



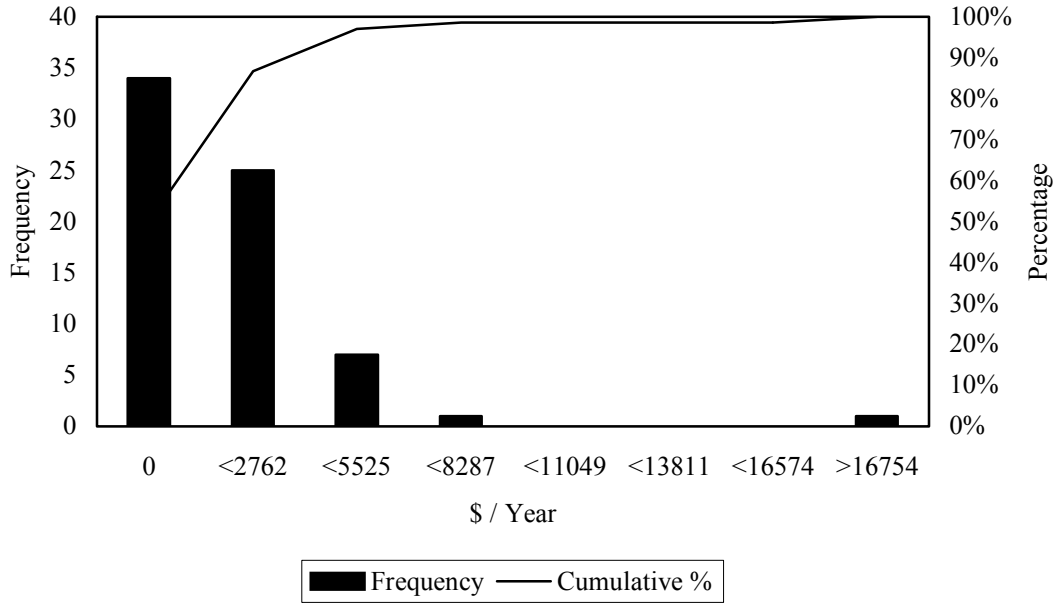
Total Patients Costs (wage rate of $11.2 / hour, 7% discount rate)



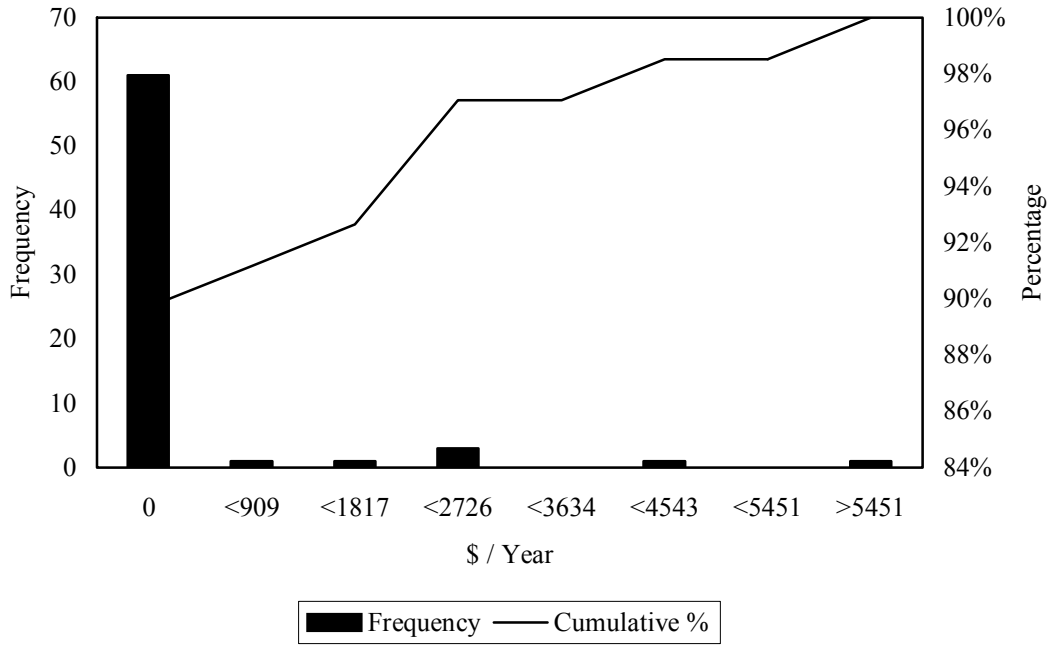
Patients' Direct Medical Costs



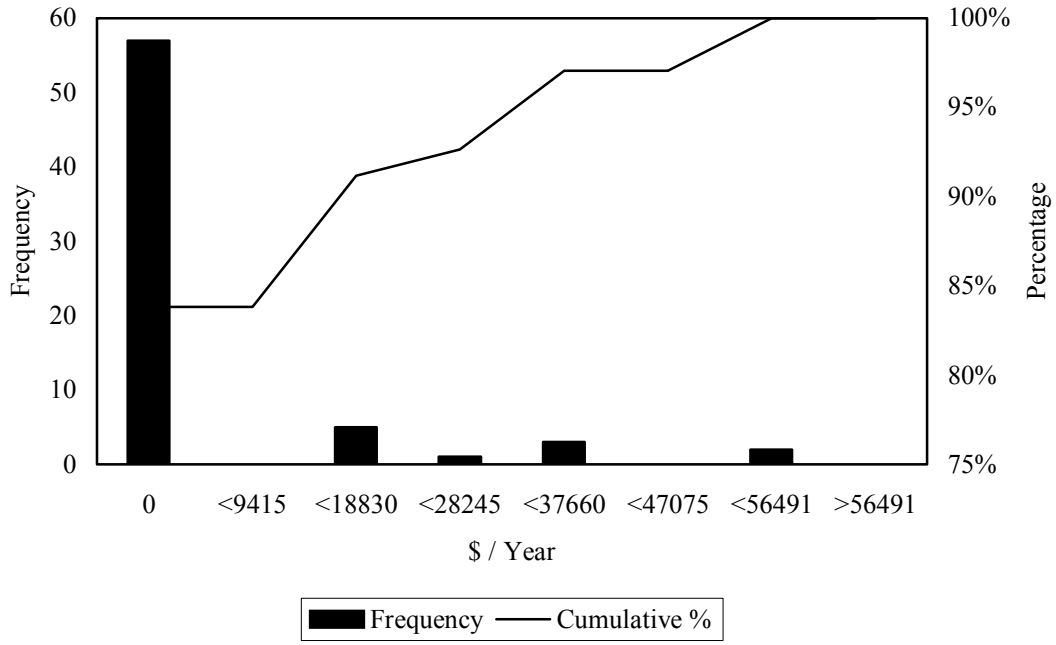
Patients' Travel Costs



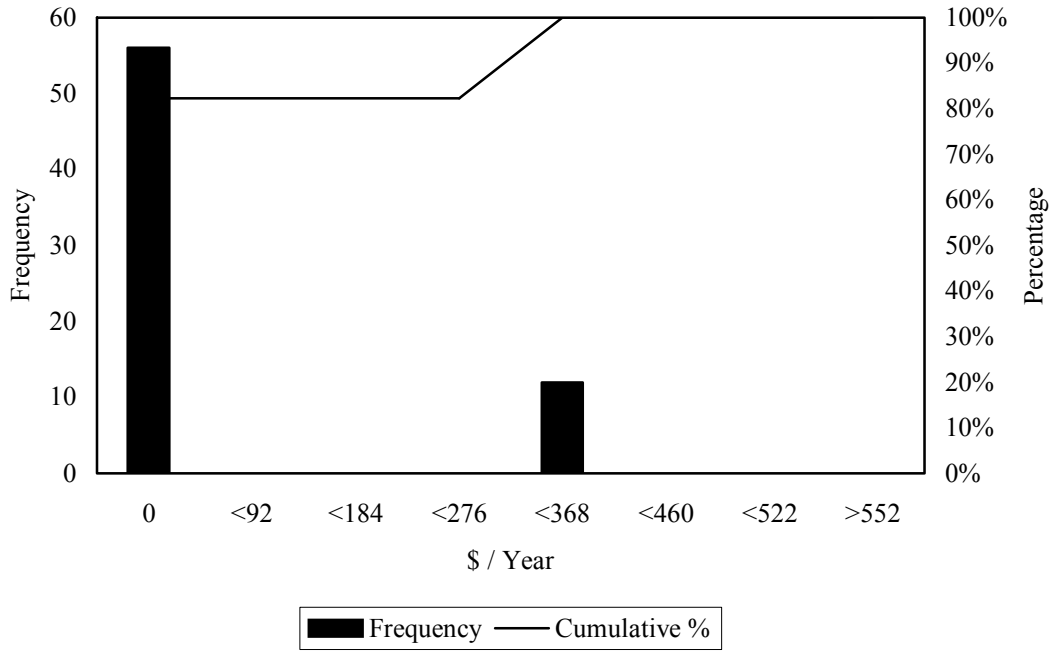
Patients' Costs for Household Chores, Medical Equipment, Home Care, Paid Caregiver, and Home Renovation



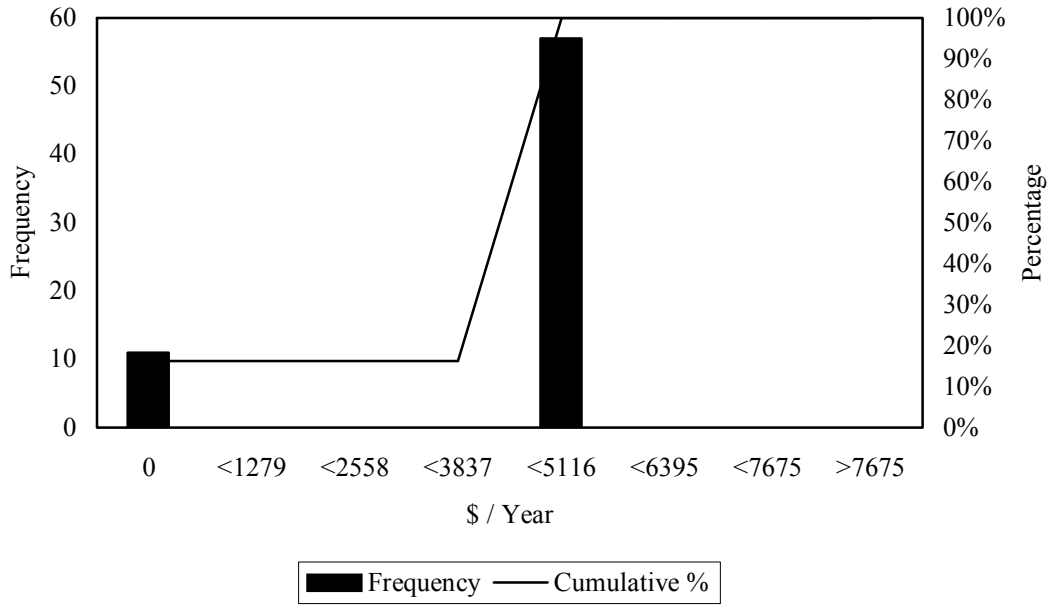
Patients' Car Purchasing



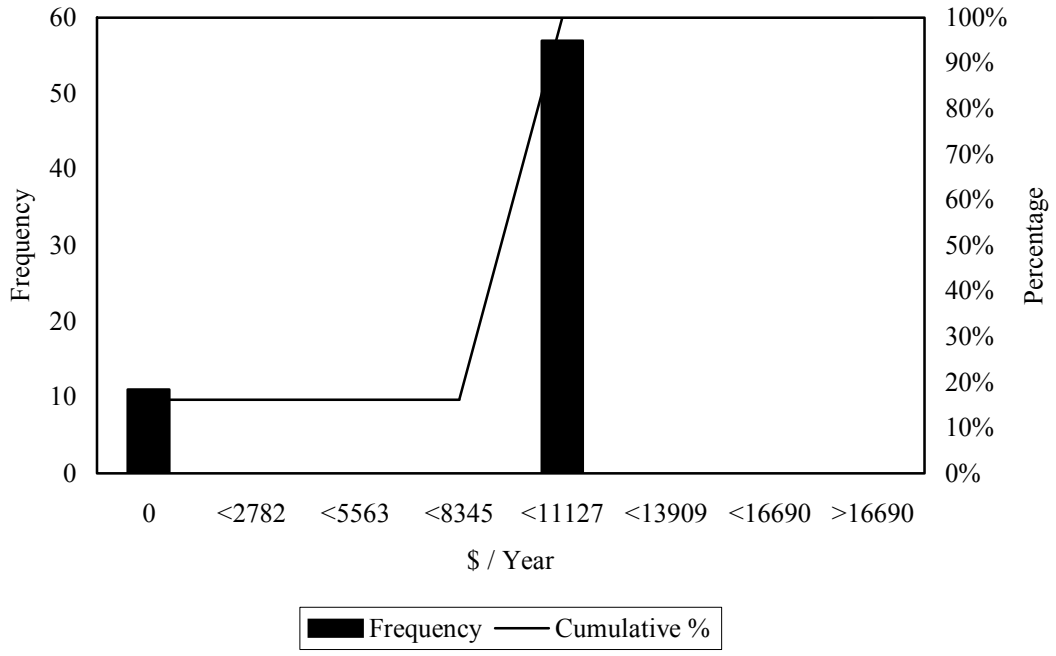
Patients' Income Loss (3% discount rate)



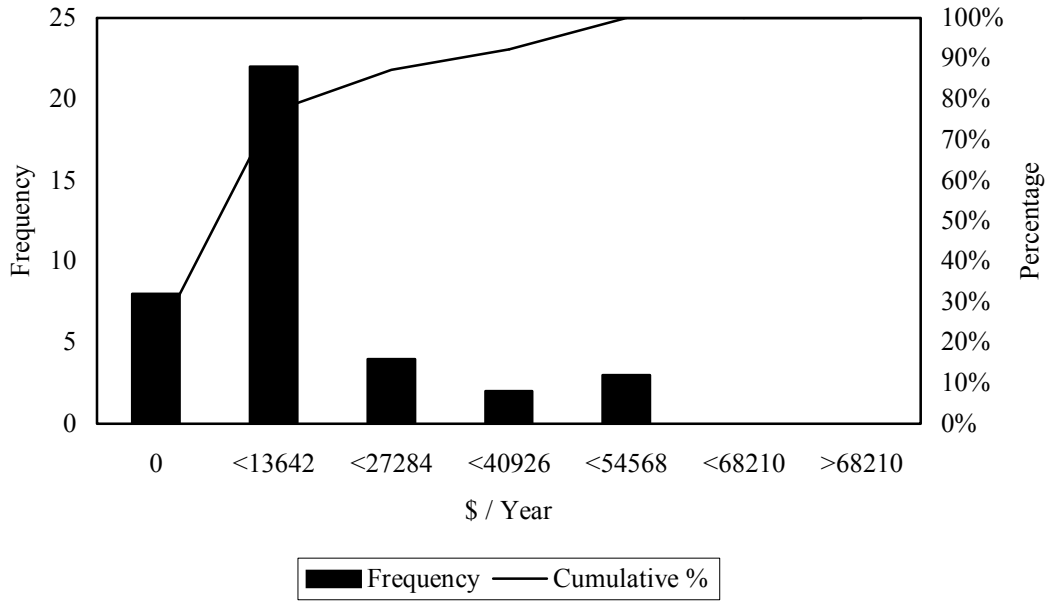
Patients' Moving Costs



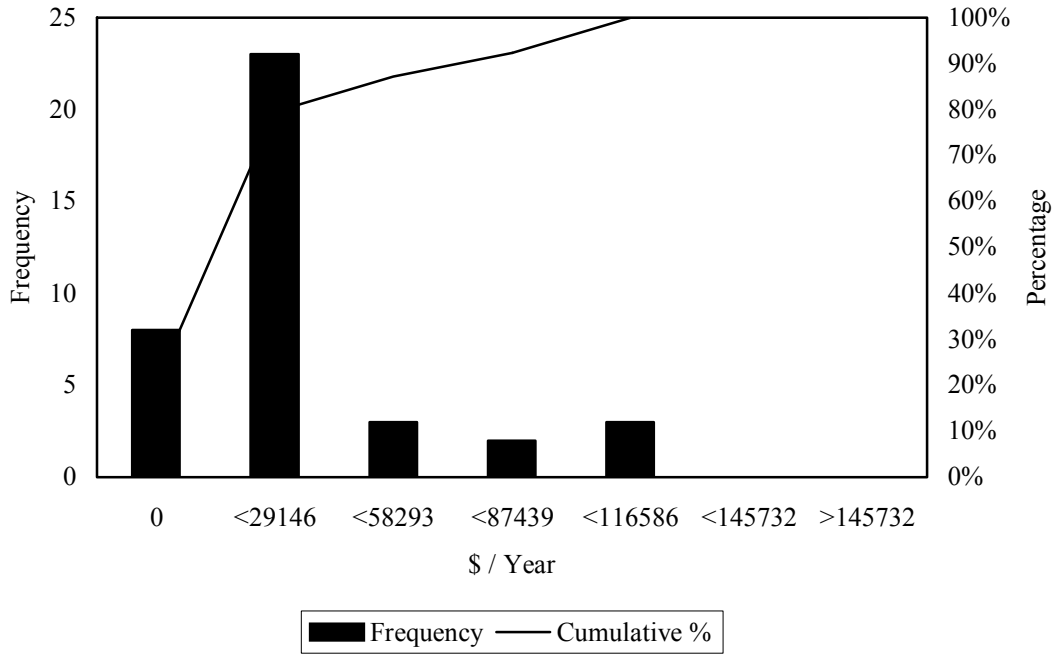
Patients' Time Costs (wage rate of $5.15 / hour)



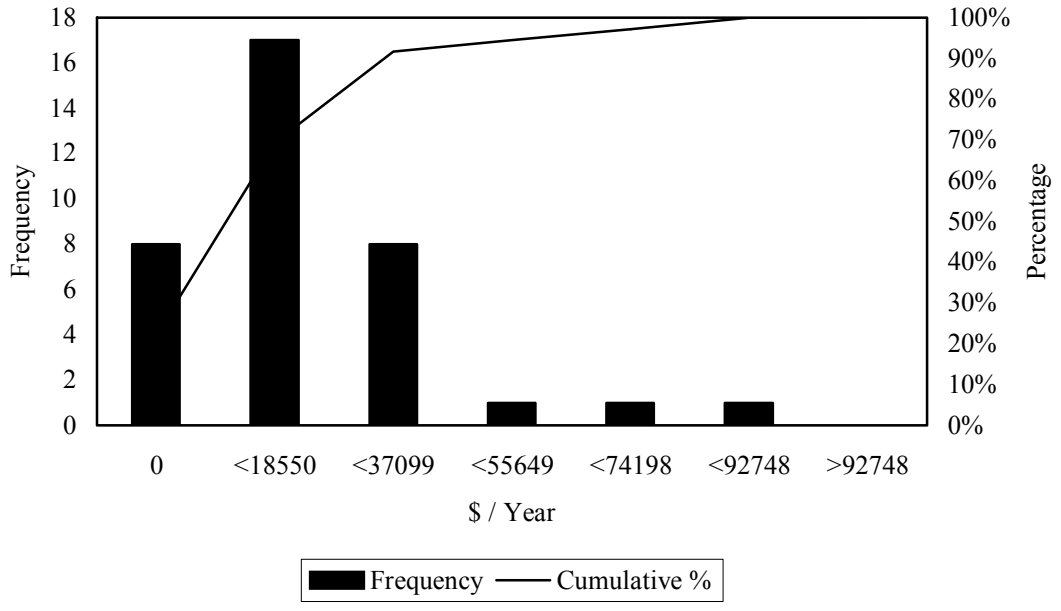
Patients' Time Costs (wage rate of $11.2 / hour)



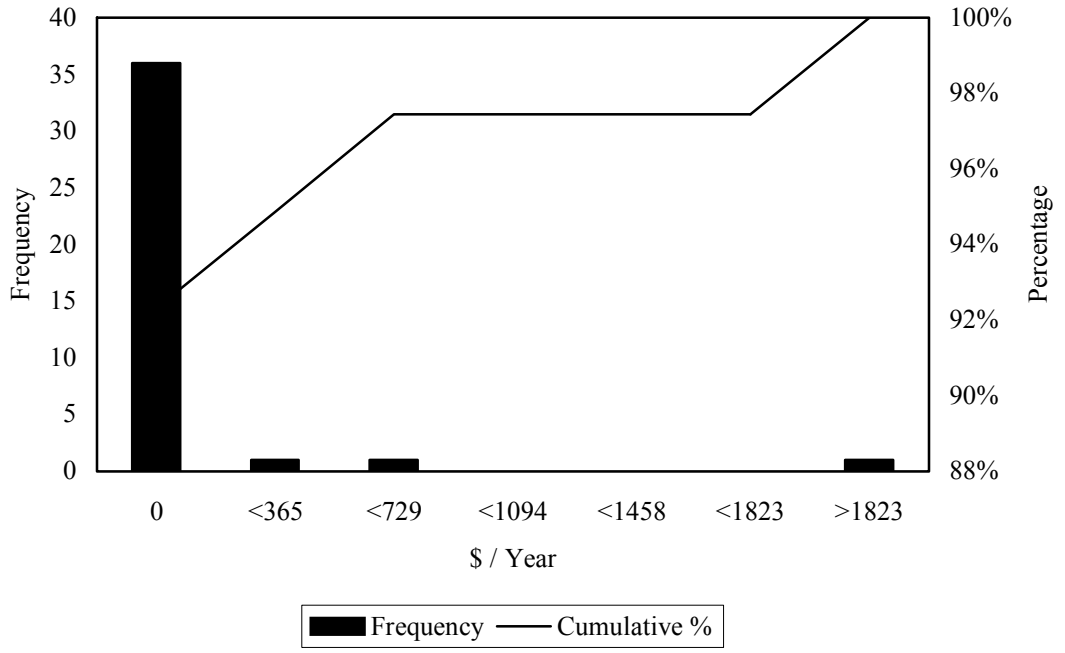
Total Caregivers Costs (wage rate of $5.15 / hour, with 24 / 7 Cases)



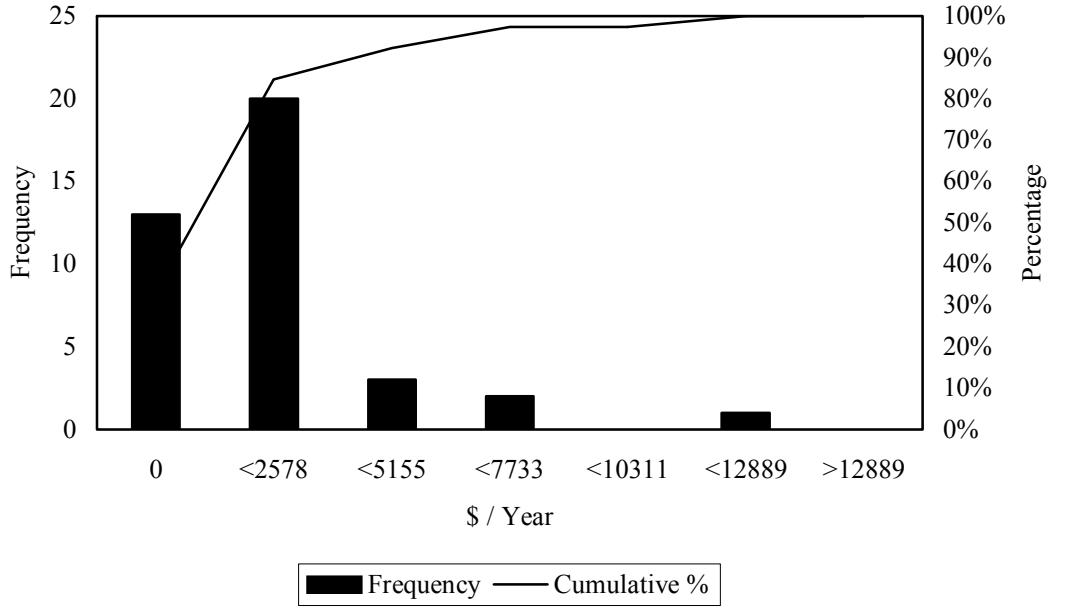
Total Caregivers Costs (wage rate of $11.2 / hour, with 24 / 7 Cases)



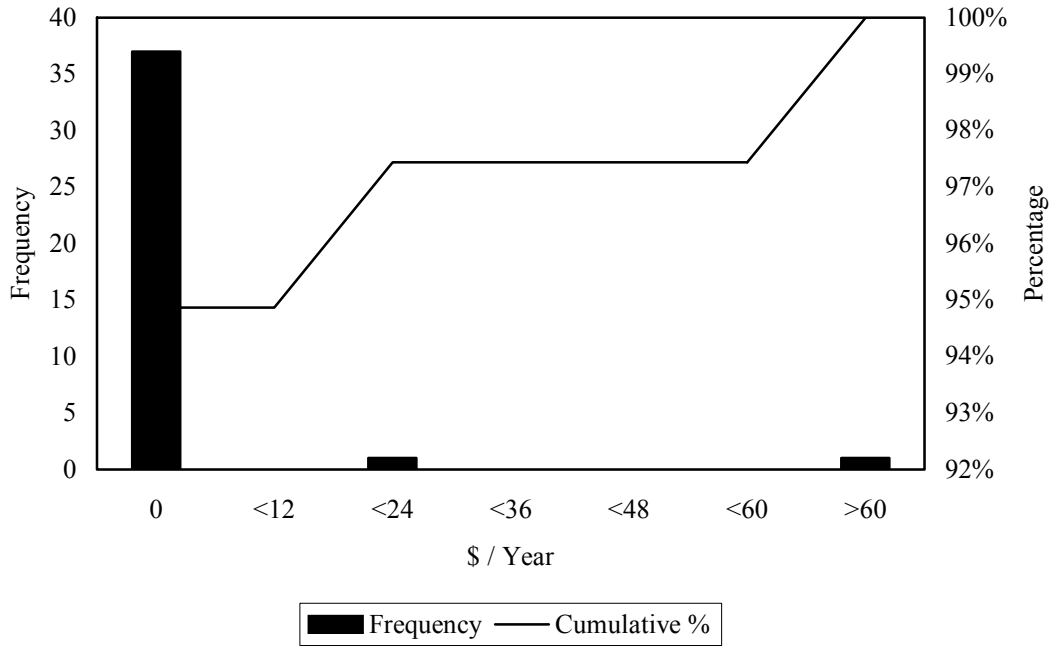
Total Caregivers Costs (wage rate of $11.2 / hour, without 24 / 7 Cases)



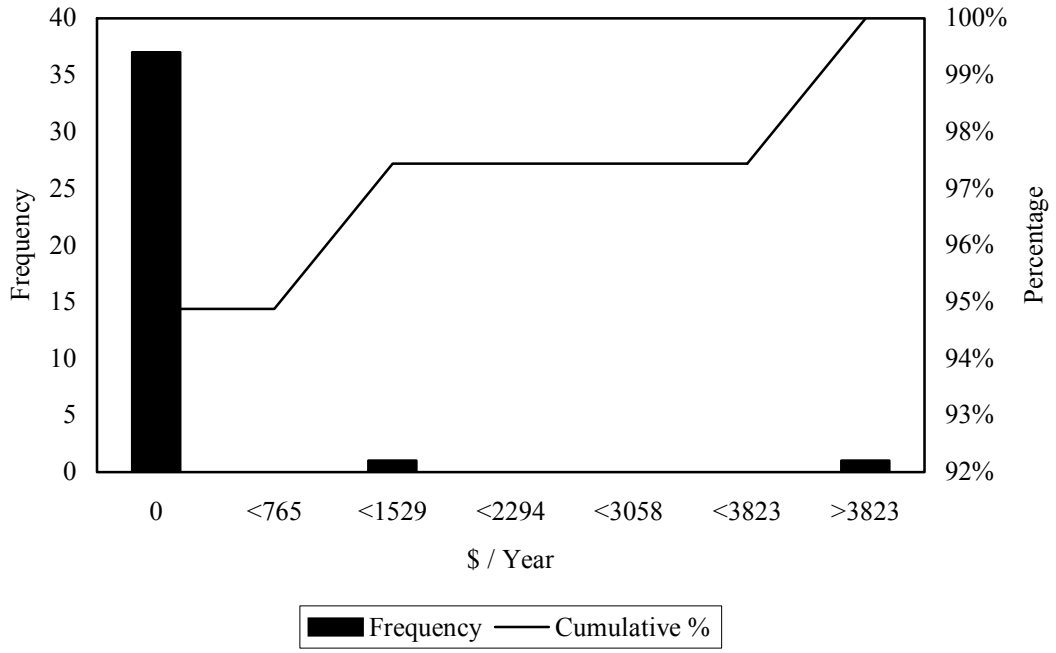
Caregivers' Costs for Household Chores



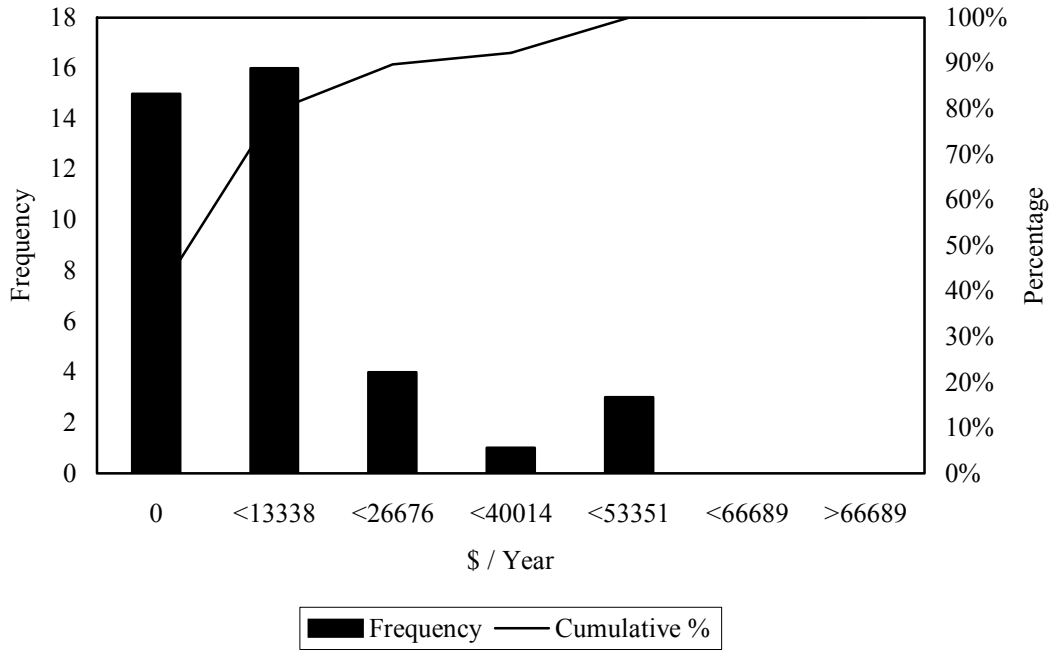
Caregivers' Costs for Food, Transportation, Medical Equipment, and Other Miscellaneous Items



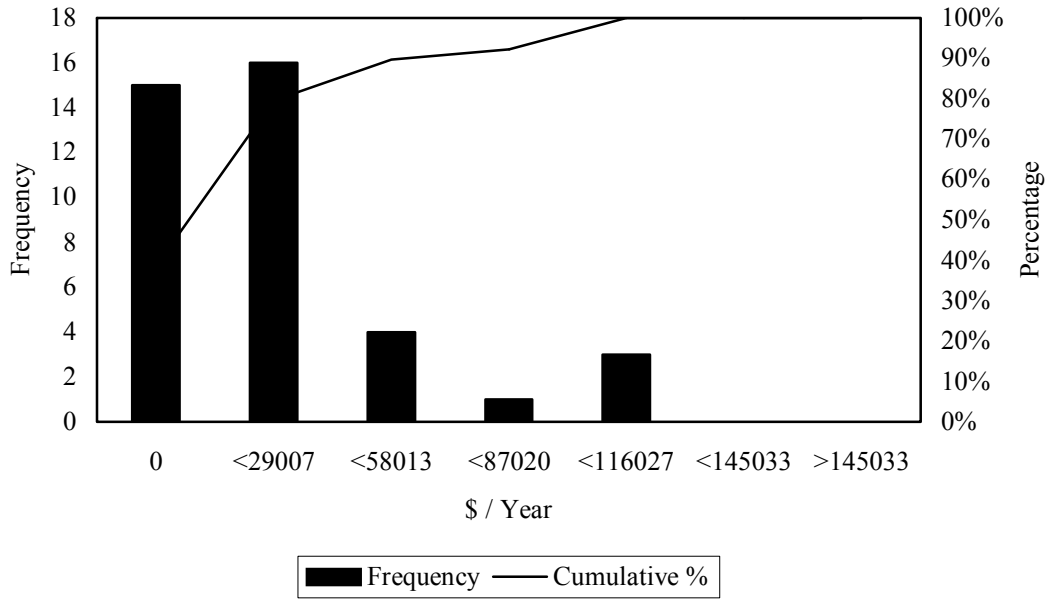
Caregivers' Home Renovation Costs



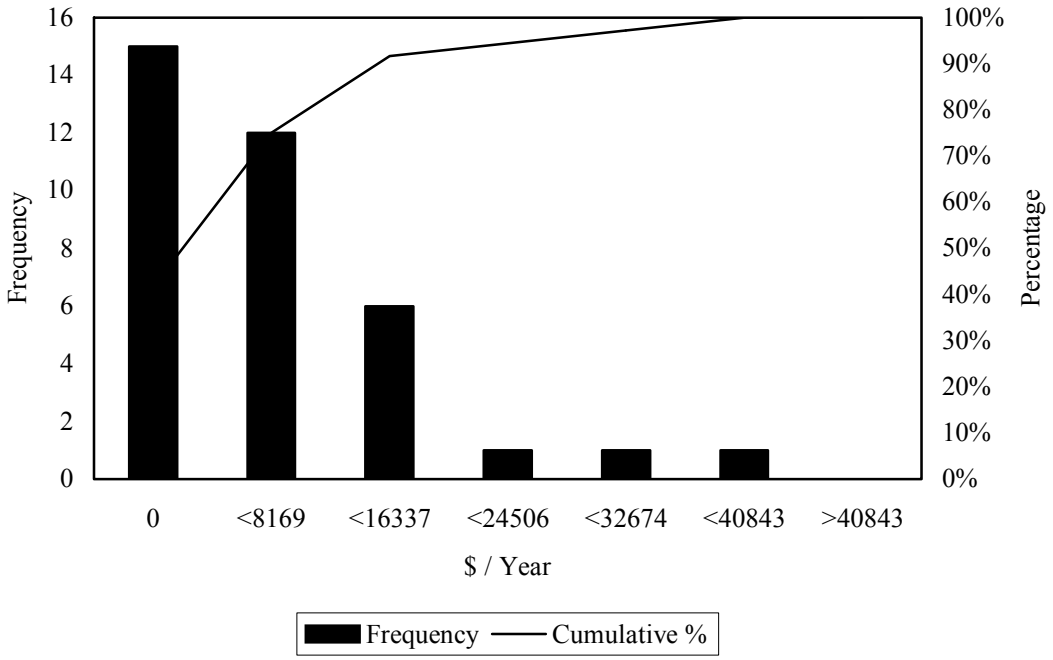
Caregivers' Car Purchasing Costs



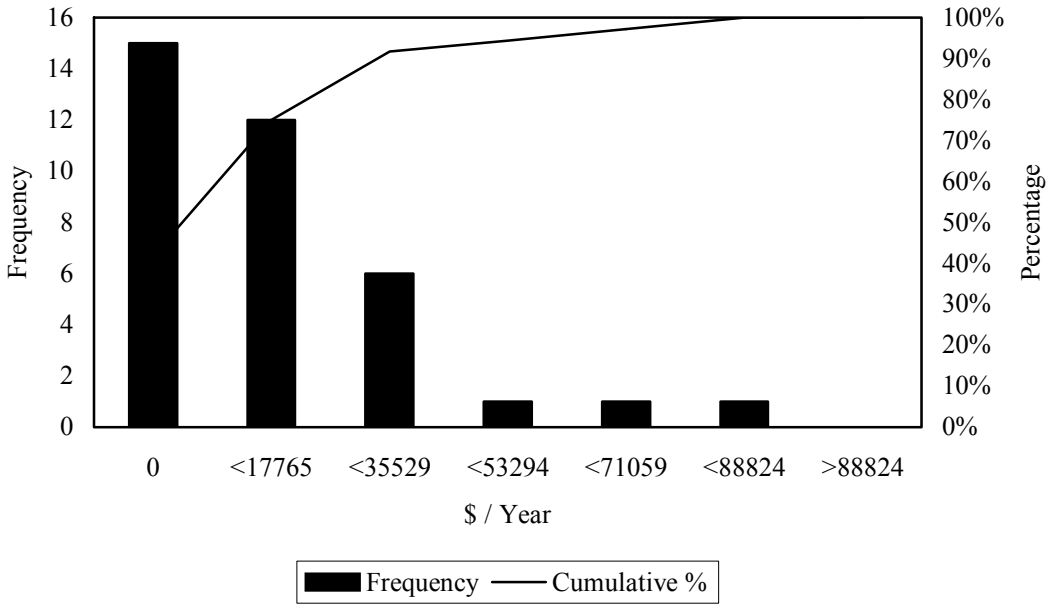
Caregivers' Time Costs (wage rate of $5.15 / hour, with 24 / 7 cases)



Caregivers' Time Costs (wage rate of $11.2 / hour, with 24 / 7 cases)



Caregivers' Time Costs (wage rate of $5.15 / hour, without 24 / 7 cases)



Caregivers' Time Costs (wage rate of $11.2 / hour, without 24 / 7 cases)

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