

## Review Article

# The Ambulatory and Home Care Record: A Methodological Framework for Economic Analyses in End-of-Life Care

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Received 1 October 2010; Revised 14 February 2011; Accepted 10 March 2011

Academic Editor: Laraine Winter

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Provision of end-of-life care in North America takes place across a multitude of settings, including hospitals, ambulatory clinics and home settings. As a result, family caregiving is characteristically a major component of care within the home. Accordingly, economic evaluation of the end-of-life care environment must devote equal consideration to resources provided by the public health system as well as privately financed resources, such as time and money provided by family caregivers. This paper addresses the methods used to measure end-of-life care costs. The existing empirical literature will be reviewed in order to assess care costs with areas neglected in this body of literature to be identified. The Ambulatory and Home Care Record, a framework and tool for comprehensively measuring costs related to the provision and receipt of end-of-life care across all health care settings, will be described and proposed. Finally, areas for future work will be identified, along with their potential contribution to this body of knowledge.

## 1. Introduction

Health care restructuring in North America has resulted in an increased emphasis on ambulatory and home-based end-of-life care [1]. Home-based healthcare services are characterized by limited resources and escalating healthcare costs. In some areas, publicly financed home-based end-of-life programs have been established to provide community care and team-based multidisciplinary care to individuals at home. While the home environment is often the first choice for patients and family members, home-based care may place higher demands on family members, particularly when a patient has complex and immediate health care needs and is close to death.

Although a high proportion of home-based end-of-life care is provided by family caregivers, little empirical attention has been devoted to the identification and measurement of the full range of costs incurred by patients and their caregivers. Most economic analyses of home-based care are limited to measurement of publicly financed care. Despite the fact that a high proportion of end-of-life care is provided by family caregivers, particularly in the home setting, time

spent by these caregivers is often perceived as having no or minimal monetary value [2]. Time allocations to care, if not provided by family caregivers, may have necessitated the acquisition of a privately funded caregiver. Measuring only health system costs, whether publicly or privately financed, may therefore lead to an inaccurate estimate of relative resource costs associated with alternative health care settings or interventions, particularly when family costs represent a large portion of overall costs.

In this paper, we discuss the methodological aspects of end-of-life care costs. Methodological elements of the empirical literature will be presented and areas that have been neglected in this body of literature will be identified. We present the Ambulatory and Home Care Record (AHCR), a framework and tool to inform future research that measures end-of-life care costs from a societal perspective [2–4]. Measuring costs from a societal perspective dictates that all resource costs, irrespective of payer, be considered. Finally, research areas that can be addressed using the AHCR methodological framework and tool will be identified and the potential contribution of these suggested topics will be provided.

## 2. Economic Empirical Studies on End-of-Life Care

The economic research literature on end-of-life care has been dominated by studies measuring publicly financed health services; few studies have examined costs incurred by patients and their caregivers. Excluding patient and caregiver resource costs in studies comparing home-based care to in-patient care results in underestimates of the value, types, and sources of resources consumed in various health care settings. The absence of information on the costs of an episode of end-of-life care limits health planning and may unduly restrict access to such services if managers and/or clinicians overestimate these costs or if there is significant uncertainty in such cost estimates.

Measuring privately financed resources and time devoted to caregiving is essential because the work dedicated by family members in the home environment is intense, particularly as the patient nears death [5–10]. Several empirical studies have indicated that families report end-of-life caregiving to be psychosocially demanding [9–24] and financially straining [9, 10, 12, 21, 23, 25–27]. Measurement of family member costs is difficult for a number of reasons. Research in this area is costly as it requires prospective design to accurately assess caregiver time and costs. Furthermore, recruitment of caregiver participants is particularly challenging as many caregivers are already overtaxed caring for their terminally ill family member, thus less likely to agree to participate, and consequently, those that do participate are likely to be ones that experience less intensive caregiving responsibilities. However, excluding patient and caregiver resource costs in such studies underestimates the value and type of resources consumed in various health care settings, thus it is important that studies are designed in such a way to overcome and minimize these barrier and potential biases.

A systematic literature review was conducted to identify original studies that have assessed economic outcomes in end-of-life care. PubMed and MEDLINE were searched (period = 1998–2009). The key word terms used were “Palliative care” AND “costs” AND [“terminal care” OR “utilization” OR “financial outcomes” OR “hospice” OR “home care”]. In addition, several journals that were directly relevant to the topic were also examined. Finally, a snowballing technique was implemented whereby references cited in the relevant articles were examined and included if they proved relevant to the research topic. Articles were excluded from search results if not specific to end-of-life care, if cost measurement was not the primary focus, or if cost analysis was limited to a particular component of palliative care (e.g., specific treatment, specific service use). This search strategy resulted in the identification of 18 studies investigating economic outcomes of end-of-life care. We approach our discussion of these studies herein by identifying which cost categories have been considered; these studies are represented in Table 1.

Most studies that measured in-patient costs attributable to end-of-life care have been designed to assess cost savings associated with the implementation of new in-patient end-of-life care programs [31, 32, 37, 39] or interventions

[28, 30, 33, 36]. These studies captured only public costs from a health system perspective and over a relatively short period from hospital admission until death. In contrast, Oliver and colleagues [35] conducted a more complete assessment of the in-patient costs of all hospitalizations from the time of initial cancer diagnosis until death. Although this study provided insight into hospital costs at various points over the illness trajectory, it did not capture home and ambulatory costs between hospitalizations and it did not address out-of-pocket or time costs borne by patients and their families/friends.

Studies which have assessed the cost of home-based end-of-life care have either compared home-based programs to institutionally based end-of-life care or to regular home-based care [3, 4, 29, 38], looked at changes in costs after the introduction of home-based end-of-life care programs [40], or measured costs of a home-based palliative care program [34]. Only one of these six studies that exclusively measured home-based health system costs included all aspects of public system expenditures [4]; however, an important component of overall costs (i.e., private costs) was excluded. In three studies, only staff time dedicated to end-of-life care was included and other health system costs, such as laboratory/diagnostic tests [3, 29, 40] and medications [3, 29] were excluded. One pilot study measured all public expenditures of ambulatory health system costs associated with a home-based palliative program, but did not include private expenditures [34]. In addition, in one study, health system costs were measured by assessing budgeted resource use prior to the implementation of a home-based program [40]. As these six studies only emphasize public health system costs, they underestimate the full range of economic costs incurred. Out-of-pocket expenditures for medications, care providers, and travel expenses, as well as time costs associated with the receipt and provision of formal and informal health care services may be substantial contributors to overall costs.

In two other studies, both public and private costs associated with home-based end-of-life care were measured [5, 6]; however, not all relevant components were captured. In both of these studies, system costs were comprehensively measured along with families’ out-of-pocket health care expenses. One assessed only privately financed appointments and out-of-pocket costs [5], while the other measured only out-of-pocket costs and labor market time losses [6]. Since time lost from household work or leisure was not assessed, the full economic contribution of caregivers to home-based end-of-life care was not captured.

One recently published study assessed both hospital and home-based end-of-life care costs from a societal perspective in five different regions across Canada [7]. Although this study provides insight into end-of-life care costs, there were two categories that were not captured. Time missed from the labour market was not captured, leaving lost income for caregivers as well as costs incurred by employers missing. Furthermore, this study did not assess resource costs covered by third party insurance. In addition, caregivers’ time devoted to caregiving was measured by asking respondents to report an estimate of a typical day over the past 2 weeks, not allowing for variation in caregivers’ during the two-week period.

TABLE 1: Cost categories captured in the end-of-life empirical literature, by study.

Study (Authors' Names)	Economic study objectives and design <i>Health service utilization/measured costs</i>	Public			Private	
		In-patient	Home and ambulatory	Out-of-pocket (labour market)	Time losses (Household work/leisure)	Third party insurance
Axelsson and Christensen [28]	Hospitalization costs of patients enrolled in a home-based palliative care service were compared with a matched historical cohort receiving institutionally based care and a cohort of patients eligible for but not receiving the palliative service (Sweden). <i>Measured costs: in-patient days from diagnosis to death, number of admissions, duration terminal hospitalization.</i>	×				
Bruera et al. [4]	A retrospective study comparing acute-care costs in terminally ill patients during their last hospital admission prior to and after implementation of a regional palliative care program. <i>Measured costs: number of cancer deaths, mean LOS, total number of in-patient days, palliative hospice care and consult teams, physician and specialist billings (Canada).</i>	×	×			
Brumley et al. [3]	A prospective study comparing service utilization of a palliative care program with regular home health care (California). <i>Measured costs: ED visits, physician office visits, hospital days, skilled nursing facility days, home health and palliative visits days on hospice.</i>	×	×			
Brumley et al. [29]	A randomized controlled trial to evaluate the ability of an in-home palliative care program to reduce medical costs in comparison to standard care. <i>Measured costs: emergency visits, physician office visits, hospital days, skilled nursing facility days, home health and palliative care visits, palliative physician home visits, days on hospice.</i>	×	×			
Chan et al. [6]	A prospective study to determine the societal cost a palliative care program from first admission until death (Hong Kong). <i>Measured costs: in-patient care (hospital and hospice), outpatient services, Chinese and herbal medicines, supplies privately obtained, income lost by patients/caregivers.</i>	×	×	×	×	
Cowan [30]	Review of administrative data to evaluate costs of an in-patient palliative care consultation service compared with inpatients receiving usual care (USA). <i>Measured costs: Hospital length of stay and hospital charges.</i>	×				

TABLE 1: Continued.

Study (Authors' Names)	Economic study objectives and design Health service utilization/measured costs	Public			Private	
		In-patient	Home and ambulatory	Out-of-pocket (labour market)	Time losses (Household work/leisure)	Third party insurance
Dumont et al. [7]	A prospective study of palliative care to compare resource utilization, service use, and associated costs in five regions across Canada. <i>Measured costs: in-patient days, out-patient visits, home care visits, phone calls, medical equipment use, transportation costs, caregiver time spent on household chores, errands, and personal care for the patient.</i>	×	×	×	×	
Elsayem et al. [31]	Retrospective review of in-patient costs associated with patients enrolled in a Palliative Care In-patient Service (USA). <i>Measured costs: number of inpatient days and hospital billing.</i>	×				
Fassbender et al. [2]	Retrospective review (administrative databases) to evaluate health system costs of palliative care before and after implementation of a community-based palliative care service (Canada). <i>Measured costs: community care, in-patient, physician, and medications.</i>	×	×			
Gómez-Batiste et al. [32]	Prospective multicentre study to compare in-patient costs and resource utilization of a palliative care service compared with historical data prior to implementation of the service (Spain). <i>Measured costs: in-patient acute care, in-patient palliative care, ED visits, palliative care outpatient clinic, physician visits.</i>	×	×			
Hanson et al. [33]	Prospective case-control study to determine the impact of palliative care consultations on hospital costs of terminally ill hospitalized patients (USA). <i>Total hospital costs, length of stay, average daily costs.</i>	×				
Johnson et al. [34]	Pilot study to evaluate service use and costs of a home-based palliative care program (Canada). <i>Measured costs: personnel support, laboratory tests, nursing visits, nutritional counseling, occupational therapy, medical supplies and equipment, medications.</i>		×			
Oliver et al. [35]	A retrospect chart analysis to determine resource use and costs of patients diagnosed with small lung cell carcinoma from diagnosis until death (United Kingdom). <i>Measured costs: in-patient days, outpatient visits, investigations, laboratory tests, medications, radiotherapy fractions, hospice in-patient days and outpatient visits, community nursing visits, social service support consultations.</i>	×	×			

TABLE 1: Continued.

Study (Authors' Names)	Economic study objectives and design <i>Health service utilization/measured costs</i>	Public			Private		
		In-patient	Home and ambulatory	Out-of-pocket (labour market)	Time losses (labour market)	Time losses (Household work/leisure)	Third party insurance
Penrod et al. [36]	Retrospective analysis of administrative data to examine hospital utilization and direct costs of a palliative care consultation program in comparison to usual care in two centers (USA). <i>Measured costs: LOS, ICU LOS, medical supplies, laboratory and radiology services, physician, nursing, contract, and all other labour.</i>	×					
Shnoor et al. [5]	Retrospective case-control cost analysis of patients receiving home hospice services in comparison to conventional health services in the two months prior to death (Israel). <i>Measured costs: medications, laboratory tests, radiographs, imaging, home and hospital procedures, medical equipment, in-patient days, ED visits, surgical procedures, any other treatment for which the service providers were paid.</i>	×	×	×			×
Smith et al. [37]	Case-control study to measure the cost of care in a dedicated in-patient palliative care unit. Daily costs of the palliative care unit were compared to in-patient costs prior to transfer to unit, as well as to patients who died using conventional medical services. <i>Measured costs: daily charges in-patient and costs of days prior to transfer to palliative care unit.</i>	×					
Tamir et al. [38]	Retrospective review of administrative databases to compare health service utilization during the last year of life in patients receiving home-specialized palliative care with nonspecialized care (Israel). <i>Measured costs: ambulatory procedures, laboratory, imaging, consultations, in-patient costs and LOS, ED visits, physician visits, oncology treatments.</i>	×	×				
White et al. [39]	Longitudinal case study to measure costs of a hospital-based palliative care unit in the 20 days prior to death. Costs of care were compared between the palliative care unit, the ICU, and other units. <i>Measured costs: average cost per day of patients who died in the hospital.</i>	×					

None of the aforementioned studies utilized an instrument that had been standardized and evaluated. As in all aspects of methodology, the use of a standardized and evaluated questionnaire supports the validity and reliability of the study results.

### 3. Framework for Measuring Home-Based End-of-Life Costs

We propose the use of the Ambulatory and Home Care Record (AHCR), a standardized and comprehensive framework and tool, to measure costs within the end-of-life context from a societal perspective [2–4] (see Appendix). This approach gives equal consideration to costs borne by the health system as well as those costs borne by care recipients and informal caregivers, such as family members and friends. This perspective values out-of-pocket expenses as well as time devoted to caregiving [36, 41]. The importance given to such caregiving time is based on the premise that such time may have been used in other activities such as market labour, leisure, or household work, and hence represent foregone opportunities [3]. This is considered a major advantage given that time costs can represent a significant proportion of total healthcare costs [42].

The AHCR was developed in 1997 by the authors in response to the gaps and inconsistency of systematic economic evaluations in assessing health system costs associated with ambulatory and home-based health services. Items for the questionnaire were determined through research with economics literature and focus groups with health economists, health care professionals, and patients within both pediatric and adult settings. Its content validity was further evaluated with a panel of experts and revisions were made accordingly.

The AHCR is designed as a prospective tool which can be self-administered or completed in a face-to-face or telephone interview. An electronic version of the AHCR has been developed to facilitate real-time data entry and to expedite the valuation process. The psychometric properties of the AHCR in collecting publicly financed health services was evaluated with a cohort of cystic fibrosis patients where prospective self-administered AHCR reports were compared with administrative data; agreement ranged from moderate to perfect ( $\kappa = 0.41-1.0$ ) [43]. Since inception, the AHCR has been used for a range of clients by age, care setting, and clinical condition, and in several countries [42, 44–58]. Items in the AHCR are categorized as publicly financed expenditures or privately financed expenditures (Table 2). Publicly financed expenditures include all costs incurred by the public sector in the organization and delivery of health care services. Public expenditures comprise those costs associated with the use of ambulatory services, in-patient services, and home-based health services. Privately financed care includes *all* health care costs not publicly insured and/or financed. This includes third party insurance payments, out-of-pocket payments by patients and their families/friends, time costs incurred by family caregivers, and costs to employers when caregivers are absent from the workplace. Third party insurance refers to the amount of money

TABLE 2: Framework for the assessment of end-of-life costs.

Expenditure category	Resource
<i>PUBLIC</i>	
(i) Ambulatory	Health care professional appointments Clinic visits Laboratory and diagnostic tests Treatment (chemotherapy and radiation) Medications Supplies and equipment Emergency room visits
(ii) In-patient	Hospitalizations Nursing home Hospice care
(iii) Home	Home Care: nursing, personal support/ homemaking, occupational therapy, physiotherapy, oxygen therapy, diagnostic tests
<i>PRIVATE</i>	
(i) 3rd Party insurance	Health care appointments Medications Hospitalizations Supplies and equipment
(ii) Out-Of-Pocket	Health care professional appointments Home caregivers Travel expenses Medications Supplies and equipment Insurance payments
(iii) Caregiver Time Losses	Time devoted by family/friends to caregiving v(i) Time lost from paid market labour (ii) Time lost from leisure/house hold work time
(iv) Employer	Time missed by employees who are family caregivers

paid by insurance companies to cover healthcare services. Private health insurance can be paid for by employers or paid for by patients/families if they purchase it themselves. Out-of-pocket costs include the amount of money paid by families for consultations with healthcare professionals (not covered by public funding), household help, medications, supplies, travel expenses, and private insurance expenditures. Caregiver time costs refer to the monetary value assigned to time losses incurred by unpaid caregivers in relation to the patient’s care (e.g., time spent caring for the patient, time spent traveling to and from consultations). This lost time is quantified in economic terms by assigning a monetary value to lost time.

To value end-of-life resources, we access various sources. Fee-for-service rate schedules are used to determine physician and laboratory service unit costs. Rates used for resource expenditures by the relevant home care agencies are employed to determine the cost of publicly financed home-based provider services. Medication costs paid for by the government are derived using the public drug

insurance formulary rate. Out-of-pocket costs incurred by families are self-reported and any reimbursements received from drug plans or medical insurance are subtracted from these expenses. Hospitalizations are assigned to designated case mix groups [59, 60], and valued in accordance with associated resource intensity weights [61–63]. Finally, time costs are assigned a monetary value using the human capital approach [64]. This approach applies current average earnings by age and gender to lost market time and imputes the market value of time withdrawn from leisure and household work. To value time lost from *market labor*, age-/sex- based earnings estimates from the National Census are used and adjusted for employer paid benefits and vacation days and holidays. Time lost from *household work/leisure* is valued using the estimated earnings of a homemaker from the National Census and adjusted for fringe benefits, and vacation days and holidays. Consequently, the valuation of time lost is dependent on the sources of such caregiving time, that is, whether time is diverted from the labour market, household work or leisure.

The AHCR has been used to evaluate two aspects of end-of-life care and published in the literature [8]. First, costs associated with a home-based end-of-life program in two provinces in Canada [8] were assessed over the end-of-life care trajectory, from time of admission into the program until death. Second, data from the AHCR was used to assess the predictors of place of death (home versus institution) within a sample of patients enrolled in a home-based program in Toronto [57]. Based on this data and consideration of the extensive needs of the end-of-life care discipline [21, 65–68], below we recommend a multitude of economic research topics that require further study and their importance.

It should be noted that other standardized costing tools for use in medical patients are available. However, these tools have not been developed in the context of end-of-life care, thus pose several limitations for economic studies of terminally ill palliative care patients.

#### **4. Uses of Economic Outcome Data Generated by the AHCR Framework**

There are five main ways in which the AHCR methodological framework can be utilized to assess the end-of-life care environment. These approaches are discussed in the five sections below. The ACHR can be partnered with other data collection instruments to ascertain a comprehensive assessment of the overall home-based end-of-life environment, and such data may be analyzed in a multitude of ways to describe the economic context within which care is provided. We provide suggestions as to what types of questions can be answered using this framework, while providing some examples of our previous work, and how the information may be used to inform practice.

*4.1. Cost Category Comparisons.* The data generated by the AHCR can allow for a patient-level analysis. Each participant's responses to the AHCR yield four subsets of resource

costs: (1) publicly financed health system costs, (2) private third party insurance expenditures, (3) privately financed out-of-pocket costs, and (4) private time costs. The four cost categories can also be aggregated to yield total societal costs. Assessments of and comparisons with other end-of-life interventions and programs is feasible; comparisons can be made between total societal cost and between subsets of resource costs. Previous applications of the AHCR have revealed that patient and family costs comprised a large portion (from 65% to 72%) of the total costs associated with ambulatory and home-based care [42, 47–56]. Although these previous studies were conducted with patients/families with a variety of chronic and acute conditions, these findings highlight the important contribution of time costs to overall costs in caregiving environments.

*4.2. Private/Public Relationship.* Measuring all relevant cost categories in the end-of-life care context allows for the examination of the relationship between private and public expenditure and the determination of whether they substitute or complement each other. In addition, it is possible to examine the proportion of total costs associated with the key end-of-life care components such as physician visits, nurse visits, personal support worker visits, ambulatory physician appointments, and other home-based and ambulatory appointments. This type of analysis would permit health service planning and resource allocation within programs and across sites of care.

*4.3. Temporal Cost Assessment.* A prospective approach to measuring costs allows for a longitudinal assessment over the care trajectory. A comprehensive assessment of private and public costs of both home and institutional costs over the entire end-of-life care trajectory allows for an understanding of how costs change over time, how they behave as patients near death, and how possible changes in the intensity of care provision might modify outcomes, such as place of death, quality of life for patients and caregivers, and overall costs of the episode of care. In our previous work, we found that costs increased exponentially as the care recipient approached death [8]. Because caregivers provide a significant amount of care and are responsible for coordinating home-based care, it is essential to obtain an understanding of the care environment in order to ensure that they are being supported in their efforts. By characterizing the distribution of societal costs, insight into the financial burden experienced by families throughout the end-of-life care trajectory can be obtained. Such information offers the potential to gauge the relationship between family caregiving activities and various other cost components. Findings from this may be used to identify a role for caregiving allowances and other forms of caregiver support. This temporal assessment of costs has the potential to inform policy as aspects of care may be appropriately modified at each time point in the end-of-life care trajectory.

*4.4. Cost Predictors.* The AHCR methodological framework also permits the examination of factors that predict public

and private resource utilization. Specifically, the sociodemographic and clinical factors that predict the propensity and intensity of end-of-life service use and what predictors are important at different times in the trajectory can be examined. For example, in our previous work, we found that age, gender, living arrangement, activities of daily living (ADL), number of chronic conditions, and the interaction between both public expenditure and ADL level were shown to increase private expenditures [42]. Furthermore, in another study, we assessed predictors of end-of-life costs [8]. Three variables were found to be significant predictors of total costs: time to death, functional status, and living arrangement. Total societal costs increased as time to death decreased. This observation was expected because as patients near death, their care needs increase, and consequently their use of resources increases. Patients who had poorer functional status incurred greater total costs compared with those with better functional status. This was expected because as a patient's level of functioning falls, he/she requires more care, thereby increasing resource costs. Patients who lived alone had lower total costs than those who lived with others. It is postulated that these higher costs are attributable to having a caregiver who is more accessible to provide care, relative to those not living with their caregiver.

**4.5. Standardized Method for Economic Evaluation.** Systematic evaluation of the costs associated with the provision and receipt of ambulatory and home-based health services is an essential component of research aimed at determining which interventions and sites of care are most cost-effective. The AHCR is a standardized resource and costing tool that enables accurate comparisons of the resource implications for different services and for diverse patients. Application of AHCR methods would enhance the efficiency with which scarce resources in the area of end-of-life care are allocated.

## 5. Conclusions

The AHCR was developed in response to the need for a standardized, comprehensive instrument to obtain and value resources associated with ambulatory and home-based health programs. The AHCR allows for a greater appreciation of the differences in end-of-life care costs between home and hospital based services, and the relationship between public and private expenditures. Application of the AHCR, when used in conjunction with quality of life, caregiver burden, and performance scales, can provide information that will gauge the relationship between family caregiving activities and other cost components within the home setting. Issues concerning access to services, as well as their quantity and quality can be highlighted. Understanding cost implications may inform the targeting of services to those patients and their families. By measuring costs longitudinally we can observe changes over end-of-life care trajectory. This knowledge will indicate areas for resource shifting and potential cost savings.

A lack of research in economic outcomes in end-of-life care impedes informed decision-making by practitioners,

TABLE 3

Type of health care professional (see list below)	Number of hours health care professional visited
Nurse	2 hrs (6 visits)
Personal support worker	22 hrs (12 visits)

Examples of health care professional: nurse, palliative physician, personal support worker, occupational therapist, physiotherapist, physician.

health managers, and policy decisions makers; it may give rise to insufficient levels of financial support for patients and caregivers when programs are unable to be transparent and accountable for resources expended. AHCR findings will help senior administrators and managers in monitoring resource costs and the quality of home-based end-of-life care. This framework can greatly benefit: practitioners and health managers of community-based end-of-life care teams who aim to meet health and social care needs of patients; managers at regional and local level who are responsible for resource allocation, program design, and quality improvement; or policy decision makers engaged in program evaluation, funding decisions, and who are responding to the need for accountability.

## Appendix

### Ambulatory and Home Care Record Coyte and Guerriere 1998

(1) *Health Care Appointments at Home [Does not Include Any Health Care Professionals You Paid]*. Which health care professionals visited *the patient* at home in the past two weeks, from [Start of interview period] to [End of interview period]? (see Table 3).

(2) *Health Care Appointments Outside the Home*. Did *the patient* see a health care professional outside of the home, from [Start of interview period] to [End of interview period]? (see Table 4).

(3) *Care to the Patient by Paid Care Providers*. Did you (or another family member) pay money to anyone to care for *the patient* at home, from [Start of interview period] to [End of interview period]? (see Table 5).

(4) *Medications/Supplies/Equipment*. Did you (or another family member) buy or receive supplies/equipment or buy medicine (prescription or over-the-counter) for *the patient*, from [Start of interview period] to [End of interview period]? (see Table 6).

(5) *Care to the Patient [Provided by You, Another Family Member, Friend, Neighbour [Does not Include Anyone You Paid]*. What is the total number of hours you and your family and other caregivers spent caring for the patient, from [Start of interview period] to [End of interview period]? (see Table 7).



TABLE 4

Type(s) of visit (see examples below)	Method of travel	If by car		Other travel costs, for example, taxi		Other costs, for example, food	
		Total distance (Km)	Parking costs	Type	Amount	Type	Amount
Oncologist	Car	8	\$23	—	\$	Food	\$5
Personal support worker—	—	—	\$	Taxi	\$40	—	\$
	—	—	\$	—	—	—	\$

Examples of visits: medical oncologist, radiation oncologist, family doctor, nurse, emergency room, physiotherapist, medical/lab test (please specify)

Examples of tests: blood test, X-rays, ultrasound, CT, MRI

Examples of methods of travel: car, public transit, taxi.

TABLE 5

Type of care provider (see examples below)	Total paid to care provider	Will you be reimbursed for this money? (yes or no) If yes, indicate % or amount reimbursed
Physiotherapist	\$75	80%
Personal support worker	\$200/8 hrs	No

Examples of Care provider: nurse, personal support worker, occupational therapist, physiotherapist.

TABLE 6

Name of medicine or description of equipment/supplies (e.g., syringes, thermometer)	Amount paid by you		Provided by home care agency. If equipment, borrowed or given to you to keep?
	Total cost of medicine (including dispensing fee) or supplies/equipment (rented/purchased)	Will you be reimbursed for this money? (yes or no) If yes, indicate % or amount reimbursed	
Acetaminophen	\$10	No	No
Nutritional Drinks	\$13	Yes (90%)	No

TABLE 7

Care provider age/male (M) or female (F)	Total number of hours you/care provider spent providing care over the past 2 weeks	Number of hours you/care provider took away from employment over the past 2 weeks		
		Unpaid leave	Sick leave	Vacation time
Female/50 yrs old	42	—	—	7.5 hrs
Male/70 yrs old	70	N/A	N/A	N/A

\* NA: Not applicable because care provider is not employed outside the home.

Examples of care: traveling to and attending health care appointments, suctioning, resting, changing a dressing, feeding.

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