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Cost of informal care for patients with cardiovascular disease or diabetes: current evidence and research challenges

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Abstract

Purpose—Patients with cardiovascular disease (CVD) or diabetes often require informal care. The burden of informal care, however, was not fully integrated into economic evaluation. We conducted a literature review to summarize the current evidence on economic burden associated with informal care imposed by CVD or diabetes.

Methods—We searched EconLit, EMBASE, and PubMed for publications in English during the period of 1995 to 2015. Keywords for the search were *informal care cost*, *costs of informal care*, *informal care*, and *economic burden*. We excluded studies that (1) did not estimate monetary values, (2) examined methods or factors affecting informal care, or (3) did not address CVD or diabetes.

Results—Our search identified 141 potential abstracts and, 10 of the articles met our criteria. Although little research has been conducted, studies used different methods without much consensus, estimates suffered from recall bias, and study samples were small, the costs of informal care have been found high. In 2014 US dollars, estimated additional annual costs of informal care per patient ranged from \$1,563 to \$7,532 for stroke, \$860 for heart failure, and \$1,162 to \$5,082 for diabetes. The total cost of informal care were ranged from \$5,560 to \$143,033 for stroke, \$12,270 to \$20,319 for heart failure, and \$1,192 to \$1,321 for diabetes.

Conclusions—The costs of informal care are substantial, and excluding them from economic evaluation would underestimate economic benefits of interventions for the prevention of CVD and diabetes.

Keywords

Informal caregiving; Economics; Diabetes; Heart disease; Stroke; Chronic illness

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1. Introduction

Informal care—unpaid care provided by families or non-family volunteers to fulfill patients' need to accomplish activities of daily living (ADLs), such as bathing, dressing, and eating, or instrumental ADLs (IADLs), such as shopping, cooking, and managing money—is often necessary for patients with cardiovascular disease (CVD) or diabetes, especially for those who are elderly. Informal care improves the health and well-being of patients with CVD and diabetes.[1–3] Patients who received informal care were less likely to need physician visits and overnight hospital stays, compared with those who did not receive informal care.[4] Also, informal care reduces the high economic burden from utilization of formal care, such as nursing home care and home health services.[5, 6]

Patients' quality of life could be improved by caregivers. However, the informal caregivers' quality of life may deteriorate because of caregiving. The burden of informal care can be substantial among the elderly population with CVD or diabetes. Informal caregivers of CVD and diabetes patients frequently report various types of strains.[7, 8] Mental health burdens, such as distress, depression, and anxiety, are commonly reported by informal caregivers of CVD and diabetes patients.[9–11] Informal caregivers are also more likely to report poor physical health than non-caregivers.[12]

In addition, the economic burden of informal care for the elderly is substantial, estimated as \$522 billion in the US in 2012.[13] While chronic diseases are the global leading causes of disability, CVD and diabetes are two of the most prominent chronic diseases closely linked together because of sharing common behavioral risk factors.[14] As global incidence and prevalence of CVD and diabetes are growing steadily, informal caregiving costs for CVD or diabetes patients become an important public health issue.[15] For instance, the prevalence of diabetes among adults were 4.7% in 1980 and became 8.5% in 2014 globally.[16] Diabetes is also known as a primary cause of blindness, kidney failure, and limb amputations, which require a significant amount of informal caregiving.[16] CVD, the number one cause of death, caused 31% of total global deaths.[17] Stroke caused 11.8% of all deaths in 2013 and the sixth leading cause of disability worldwide.[17, 18] Furthermore, the future economic burden of informal care is expected to increase rapidly because of the aging of the population, which results in a high prevalence of CVD or diabetes. In spite of its public health importance, the economic burden associated with informal care for patients with CVD or diabetes is often overlooked and has not been sufficiently addressed in economic literature, such as cost-of-illness studies and economic evaluation literature. No reviews exist that summarize current knowledge on this topic.

In this study we conducted a narrative literature review of studies about informal care costs for patients with CVD or diabetes to document the magnitude of economic burden and the methods used to derive estimates for informal care costs. We also determined and discussed factors which may explain the heterogeneity of the economic burden of informal care. Such information will be useful for improving estimates of economic burden associated with each disease and shaping future research in the field of economic costs of informal care. Although informal caregivers' health issues and burden of those health problems could be substantial,

costs of informal caregiving associated with health deterioration of caregivers were not examined in the current study because of limited existing research.

2. Literature selection

The review included English language peer-reviewed journal articles published between January 1995 and May 2015. We used PubMed, MEDLINE, and EconLit, and extended the search by checking the references of the relevant articles. Keywords for the search were *informal care cost*, *costs of informal care*, *informal care*, and *economic burden*. Among 141 potential abstracts from our search, we excluded review articles, editorials, and commentaries (Figure 1). We further excluded studies that (1) did not provide informal care time cost in monetary terms, (2) addressed measurement methods only, (3) examined factors that affect informal care only, and (4) did not investigate CVD or diabetes. Articles on neurological conditions were included if stroke was included as a part of the condition.

Ten articles met our selection criteria and were included for the review. Of the selected articles, six were for stroke [19–24], two were for heart failure [25, 26], and two were for diabetes [27, 28].

3. Results

Data description of the literature

As shown in Table 1, the four US studies used national surveys for the elderly population, which included both patient and non-patient groups as well as both recipients of informal care and those who did not receive any informal care services. Data sources for the six non-US studies were surveys of patients with specific diseases and their caregivers, who were recruited from hospitals or registries. All non-US studies had fewer than 500 subjects. Respondents who reported burden of informal care were care recipients or caregivers. Data for seven studies gathered informal care information from care recipients supplemented by a proxy or a caregiver when information from the care recipient was not sufficient. Data for the remaining three studies were based on caregivers' reporting.

ADLs and IADLs were included as activities requiring assistance from informal caregivers in six studies (Table 1). In addition to ADLs and IADLs, two studies included household activities of daily living (HDL), such as housecleaning, washing, ironing, chores, and gardening [24, 27]. Another study examined community, domestic, and personal activities of daily living as care areas [19], while another examined personal care, communication, administration, therapy/leisure, psychosocial, transport, and supervision [21]. The remaining two studies did not mention care areas [23, 25].

Methods for deriving the cost estimates

Two cost estimation methods were employed in the literature: replacement approach (RA) and opportunity cost approach (OCA). RA, also known as proxy good method (PGM), assumes that the value of informal care is the same as the value of paid care, while OCA measures the value of informal care as the value of informal caregivers' foregone time [19,

24]. Three studies used both RA and OCA [19, 24, 27]. Six studies used RA only [20–22, 25, 26, 28], and one study used OCA only [23].

Various types of regression analyses were applied to estimate informal care burden (Table 2). Three studies used two-part models [20, 26, 28], comparing someone with and without a disease. This model is appropriate for analyzing data with significant numbers of zero observations, as was the case for many respondents who did not use informal care.

Cost estimates

We categorized the studies into disease-attributable informal care cost and total informal care cost. For instance, if a stroke patient reported 20 hours of informal care per week, the hours attributable to stroke could be far fewer than 20 hours if the patient has other chronic conditions or long-term disabilities that also may require informal care.

Five studies estimated total informal care burden for CVD and diabetes caregivers or patients (Tables 3). Total average weekly informal care hours ranged from 12.4 to 22 hours for stroke patients [23, 24]. Total informal care hours of heart failure patients were 44.9 hours per caregiver in Spain [25]. In Thailand, average weekly informal care hours among diabetes patients were 14.9 hours per caregiver [27]. Total average annual costs of informal care per person using 2014 US dollar value and average local wages were \$5,560–\$143,033 for stroke patients [21, 23, 24], \$12,270–\$20,319 for heart failure patients [25], and \$1,192–\$1,321 for diabetes patients [27].

All four US studies estimated informal care burden attributable to CVD and diabetes (Table 4). Weekly informal care hours attributable to stroke in the US ranged from 2.5 to 12.5 hours per patient, varying by whether a patient had stroke-related health problems or not [20, 22]. Hours of informal care attributable to heart failure and diabetes were 1.6 hours per patient per week [26] and 1.9 to 8.3 hours per patient per week [28], respectively. Annual costs of informal care attributable to each disease based on 2014 US dollar values were \$1,563–\$7,532 per stroke patient [20, 22], \$862 per heart failure patient [26], and \$1,162–\$5,082 per diabetes patient [28].

Extrapolating these results on the basis of disease prevalence and disease-attributable costs, the total annual estimates of informal care costs in the US were \$8.7–\$15.6 billion for stroke, \$3.1 billion for heart failure, and \$4.4–\$8.7 billion for diabetes [20, 22, 26, 28]. Annual estimates of stroke-associated informal caregiving costs in Australia were \$23–\$45 million in 2014 US dollars [21]. Details about adjusting weekly informal care hours and 2014 US dollar values are shown in Appendix 1.

4. Discussion of the estimation methods

Results from this review show that burden of informal care is significant for stroke, heart failure, and diabetes patients. In addition, sizable heterogeneity was observed in estimated informal care burden for each of these conditions among reviewed studies. This variability was caused by several factors, which made it difficult to directly compare study results. First, choice of cost estimation method (OCA vs. RA) affects estimated costs of informal

care because of different unit monetary values; this was often considered as a part of sensitivity analyses [19, 24, 27]. Additionally, the choice in using OCA or RA depends on survey questions about hours of informal care and availabilities of unit monetary values. OCA could be adapted when informal care hours were derived from foregone hours of doing other activities due to informal care, and values of foregone hours were known. In contrast, RA could be chosen when informal care hours were estimated from hours used to provide informal care activities, such as supporting ADLs and IADLs, and a market value of providing each informal care activity was available.

Some studies reported informal care burden attributable to a disease while others reported total informal care burden of patients with a disease or caregivers of those patients. Those two estimates were significantly different, and the purpose of those estimates were different as well. Estimation of total informal care burden is mainly used to understand the total burden for informal caregivers.[23] It can be helpful for developing policies supporting informal caregivers and for evaluating impacts of those policies. We found that all non-US studies, except one study from Australia,[19] reported total informal care burden in this review. On the other hand, cost of informal care attributable to a disease is a key component of cost-of-illness analyses and is helpful for understanding diminishable informal care burden when the disease is prevented.[28] All US studies in the current review reported informal care costs associated with a disease.

Another factor affecting estimated burden was whether the respondents were the caregivers or care recipients. It is known that there could be a reporting discrepancy between a caregiver and a care recipient.[29] Among the elderly population who have memory problems or cognitive disabilities, data from caregivers may be more reliable than the data from care recipients.[29] When a patient has multiple caregivers, however, interview all caregivers is difficult, and one caregiver may not know about another's informal care burden. In that case, data from care recipients may be more complete. Thus, reports from both sides are required to reduce reporting biases and could provide a range of informal care burden estimates. In connection with respondents, some studies reported burden of informal care per caregiver and others reported the burden per patient. Per-patient estimates are best used for cost-of-illness analyses while per-caregiver estimates are useful for understanding the burden of caregivers.

Whereas most survey questionnaires asked about hours used to provide each informal care activity or overall hours to provide informal care activities, the selection of informal care activities included could affect estimated informal care burden. For instance, studies with ADLs and IADLs as informal care assisted areas may show fewer informal care hours than studies considering ADLs, IADLs, and HDLs. van den Berg and his colleagues showed that each activity area required a significant amount of informal care for stroke patients, while Chatterjee et al. supported that finding with diabetes patients.[24, 27] Developing a comprehensive standard set of informal care activities would help to avoid underestimation of informal care burden. Similarly, when the estimates are applied to cost-of-illness analysis, double counting issues must be considered. For instance, when assistance in household activities, such as housecleaning, washing, and cooking, is counted as burden of informal

care, productivity losses in household activities among care recipients should not be included in cost-of-illness to avoid double counting.

Additionally, burden of informal care depends on disease severity. For instance, patients who had stroke-related health problems used more informal care than those who had stroke but without stroke-related health problems [20]. Also, diabetes patients using insulin treatment had higher needs of informal care than the diabetes patients without any medication for diabetes treatment.[28] Age, which increases limitations in ADLs and IADLs, could be another potential factor to affect the burden of informal care, especially total informal care costs.[30] Estimates of informal care hours and costs could also vary by study country. Patients in developing countries may use more informal care hours than patients in developed countries. The monetary value of informal care in developing countries, however, could be lower than the value in developed countries because of lower hourly wages in developing countries. For instance, Riewpaiboon et al. indirectly supported this point by showing that costs of informal care in urban area (developed area) was higher than that in rural area (developing area) in Thailand. [23]

5. Closing remarks

Results of this review indicate that informal care costs for stroke, heart failure, and diabetes patients are substantial and should be included in cost-of-illness literature. Several factors, including cost estimation methods, data sources, study location, and severity of disease, may affect estimates of informal care burden. Although various methods are already developed to estimate informal care burden, no consensus exists about analytic methods. It is important to conduct sensitivity analyses using various methods. However, it is also important to gain consensus on estimation methods, especially for a comparison of estimates from different diseases, which is important for decision makers.

To better integrate the cost of informal care into cost-of-illness literature, we believe standardizing methods for estimating informal care costs is critical. Based on our review, we suggest the following standards: (1) conduct proper analysis for estimating disease-attributable informal care cost to avoid overestimation resulting from multiple diseases per patient, (2) collect patient-level data that include all informal caregivers' burden, (3) use a comprehensive set of help areas and less memory-dependent collection methods, and (4) conduct sensitivity analysis using various cost estimation methods and data assumptions.

Improving the quality of research to collect accurate hours of informal care and investigation of proper ways to estimate costs could improve the cost estimates. For instance, all the reviewed studies used informal care hours from a retrospective time diary. The quality of data depended entirely on the interviewee's recall ability. Monitoring respondents or gathering survey data using a leave-behind time diary, which leaves a time diary form with a respondent and asks him or her to complete the form on appointed days, could avoid possible biases and improve data quality. Sample size and representativeness of samples also could be an issue. Because many studies used samples with fewer than 500 subjects, it is important to develop a sufficient data set for estimation.

Increasing data quality is an important step for producing robust study results and expediting the integration of these costs into economic evaluations as well as cost-of-illness analyses. Since informal care costs associated with CVD or diabetes are substantial, including accurate cost estimates prevents underinvesting on prevention or intervention strategies for these diseases.

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References

1. Clark AM, et al. The complex nature of informal care in home-based heart failure management. *J Adv Nurs*. 2008; 61(4):373–83. [PubMed: 18234035]
2. Evans RL, et al. The family's role in stroke rehabilitation. A review of the literature. *Am J Phys Med Rehabil*. 1992; 71(3):135–9. [PubMed: 1627278]
3. Greenwood N, Mackenzie A. Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas*. 2010; 66(3):268–76. [PubMed: 20430542]
4. Van Houtven CH, Norton EC. Informal care and health care use of older adults. *J Health Econ*. 2004; 23(6):1159–80. [PubMed: 15556241]
5. Bonsang E. Does informal care from children to their elderly parents substitute for formal care in Europe? *J Health Econ*. 2009; 28(1):143–54. [PubMed: 18950879]
6. Charles KK, Sevak P. Can family caregiving substitute for nursing home care? *J Health Econ*. 2005; 24(6):1174–90. [PubMed: 15979742]
7. Bugge C, H Alexander, Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke*. 1999; 30(8):1517–23. [PubMed: 10436093]
8. Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health*. 2008; 20(5):483–503. [PubMed: 18420838]
9. Blake H, Lincoln NB, Clarke DD. Caregiver strain in spouses of stroke patients. *Clin Rehabil*. 2003; 17(3):312–7. [PubMed: 12735539]
10. Li TC, et al. Quality of life of primary caregivers of elderly with cerebrovascular disease or diabetes hospitalized for acute care: assessment of well-being and functioning using the SF-36 health questionnaire. *Qual Life Res*. 2004; 13(6):1081–8. [PubMed: 15287274]
11. Low JT, S Payne, Roderick P. The impact of stroke on informal carers: a literature review. *Soc Sci Med*. 1999; 49(6):711–25. [PubMed: 10459884]
12. Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci*. 2007; 62(2):P126–37. [PubMed: 17379673]
13. Chari AV, et al. The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey. *Health Services Research*. 2014
14. World Health Organization. [cited 2016 October 31] Integrated chronic disease prevention and control. Available from: http://www.who.int/chp/about/integrated_cd/en/
15. GBD 2015 Disease and Injury Incidence and Prevalence Collaborators, Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet*. 2016; 388(10053):1545–1602. [PubMed: 27733282]
16. World Health Organization. *Global report on diabetes*. WHO Press; Geneva, Switzerland: 2016.
17. Writing Group M, et al. Heart Disease and Stroke Statistics-2016 Update: A Report From the American Heart Association. *Circulation*. 2016; 133(4):e38–360. [PubMed: 26673558]
18. World Health Organization. [cited 2016 October 31] Priority medicines for Europe and the world update report, 2013: Chapter 6 Priority diseases and reasons for inclusion (Background paper 6). 2013. Available from: http://www.who.int/medicines/areas/priority_medicines/en/

19. Dewey HM, et al. Informal care for stroke survivors: results from the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*. 2002; 33(4):1028–33. [PubMed: 11935056]
20. Hickenbottom SL, et al. A national study of the quantity and cost of informal caregiving for the elderly with stroke. *Neurology*. 2002; 58(12):1754–1759. [PubMed: 12084872]
21. Jackson D, McCrone P, Turner-Stokes L. Costs of caring for adults with long-term neurological conditions. *J Rehabil Med*. 2013; 45(7):653–61. [PubMed: 23811791]
22. Joo H, et al. Cost of informal caregiving associated with stroke among the elderly in the United States. *Neurology*. 2014; 83(20):1831–7. [PubMed: 25305152]
23. Riewpaiboon A, et al. Economic valuation of informal care in Asia: a case study of care for disabled stroke survivors in Thailand. *Soc Sci Med*. 2009; 69(4):648–53. [PubMed: 19573969]
24. van den Berg B, et al. Economic valuation of informal care: lessons from the application of the opportunity costs and proxy good methods. *Soc Sci Med*. 2006; 62(4):835–45. [PubMed: 16137814]
25. Delgado JF, et al. Health care and nonhealth care costs in the treatment of patients with symptomatic chronic heart failure in Spain. *Rev Esp Cardiol (Engl Ed)*. 2014; 67(8):643–50. [PubMed: 25037543]
26. Joo H, et al. Cost of informal caregiving for patients with heart failure. *Am Heart J*. 2015; 169(1):142–48. e2. [PubMed: 25497259]
27. Chatterjee S, et al. Cost of informal care for diabetic patients in Thailand. *Prim Care Diabetes*. 2011; 5(2):109–15. [PubMed: 21334276]
28. Langa KM, et al. Informal caregiving for diabetes and diabetic complications among elderly Americans. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*. 2002; 57(3):S177–S186.
29. Allen RS, et al. Pain reports by older hospice cancer patients and family caregivers: the role of cognitive functioning. *Gerontologist*. 2002; 42(4):507–14. [PubMed: 12145378]
30. Moudouni DKM, et al. The relationship between formal and informal care among adult Medicaid personal care services recipients. *Health Services Research*. 2012; 47(4):1642–1659. [PubMed: 22352871]

Appendix 1: Adjustment of informal care hours and costs

We examined weekly informal care hours and annual informal care costs. When a study provided only monthly or annual informal care hours, we derived weekly informal care hours by dividing monthly informal care hours by 4.3 weeks per month or dividing annual informal care hours by 52 weeks per year. In the same way, when a study provided only weekly or monthly costs of informal care, we derived annual costs of informal care by multiplying weekly costs of informal care by 52 weeks per year or multiplying monthly costs of informal care by 12 months per year.

For comparison, we adjusted informal care cost into 2014 US dollars with the following equation:

$$\frac{\text{CPI in } 2014 \text{ at a study country}}{\text{CPI in a study year at a study country}} \times \frac{\text{Informal caregiving costs from a study}}{\text{PPP exchange rate in } 2014 \text{ (local currency per US dollar)}}$$

Consumer price indices (CPI) of each study country were from the World Bank, and purchasing power parity (PPP) exchange rates were from the Organisation for Economic Co-operation and Development (OECD). For Thailand, which is not a member of OECD, we used the PPP conversion factor from the World Bank.

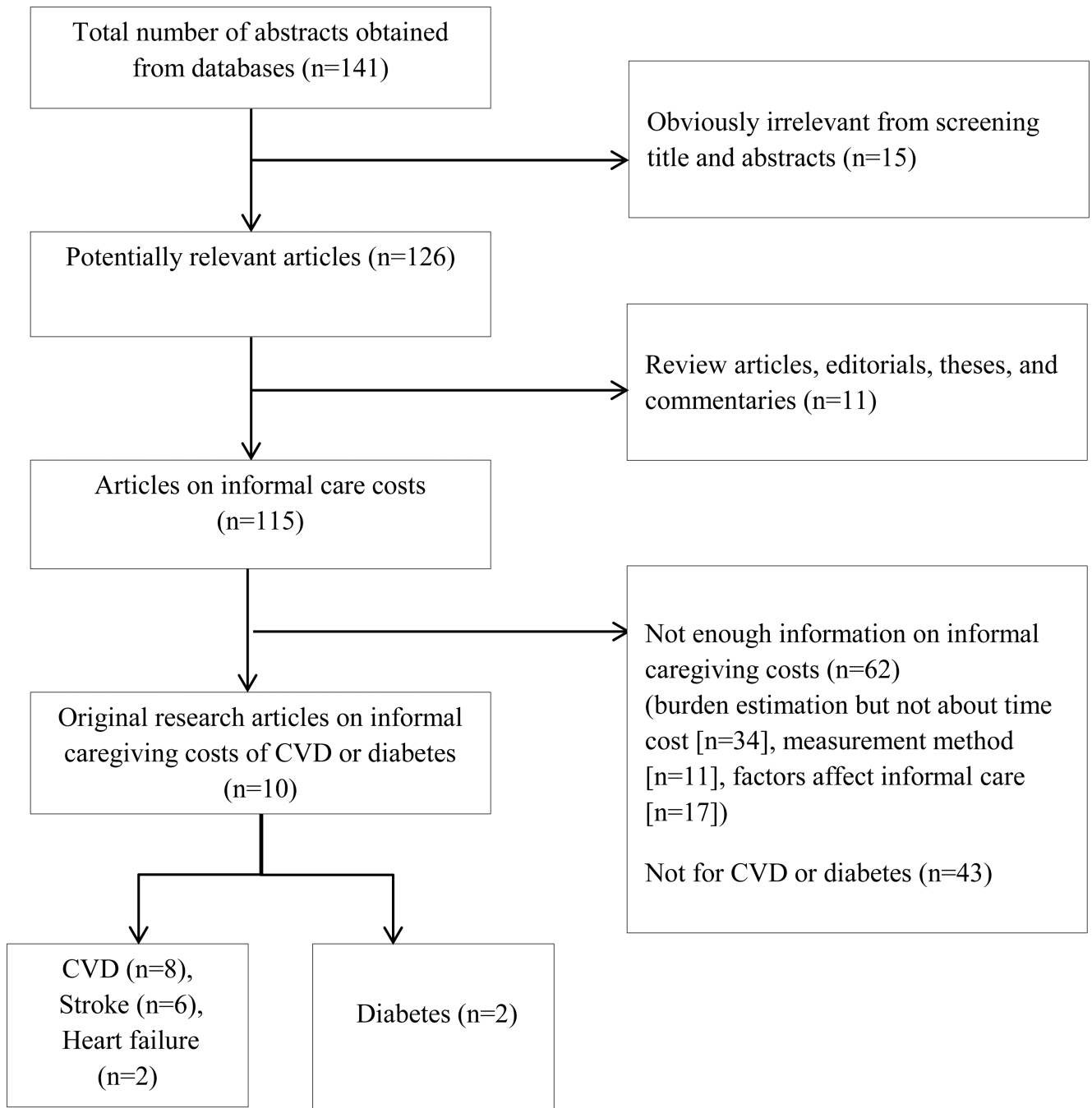


Figure 1. Literature selection of informal care costs for people with cardiovascular disease (CVD) or diabetes, 1995–2015

Table 1

Data description of studies of informal care costs for cardiovascular disease or diabetes patients, 1995–2015

| Study/Year/Country | Data Sources | Respondents | Study subjects | Care Areas |
|--------------------------------------------|----------------------------------------------------------------------------------------------------------|---------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| Stroke | | | | |
| Hickenbottom et al. 2002, US [20] | Asset and Health Dynamics (AHEAD) Study 1993 | Care recipients (Proxy) | Nationally representative aged 70 years or older (n=7,443; stroke 656) | ADL/IADL |
| Dewey et al. 2002, Australia [19] | North East Melbourne Stroke Incidence Study (May 1996 to April 1997) | Care recipients | Stroke patients (n=340, mean age=74 years old) | Other * |
| van den Berg et al. 2006, Netherlands [24] | EDISSE study | Primary caregivers | Stroke patients (n=218, mean age=72 years old) | ADL/IADL/HDL |
| Riewpaiboon et al. 2009, Thailand [23] | Survey at the Sirindhorn National Medical Rehabilitation Center and Buriram Hospital (Aug. to Oct. 2006) | Caregivers (Primary caregivers) | Stroke patients registered at hospital during Jan.2001 to Dec. 2005 (n=149, mean age=66 years old) | N/A |
| Jackson et al. 2013, UK [21] | Caregiver Activity Survey (Nov. 2007 to June 2009) | Family caregivers | Adults with neurological conditions (n=282, mean age= 51 years old;stroke: n=18) | Other ** |
| Joo et al. 2014, US [22] | Health and Retirement Study (HRS) 2006 and 2008 | Care recipients (Proxy) | Aged 65 and older with stroke and matched non-stroke (n=449; stroke 230) | ADL/IADL |
| Heart failure (HF) | | | | |
| Delgado et al. 2014, Spain [25] | Interview for HF patients recruited in the specialized cardiology clinics of 7 Spanish hospitals | Patients (Caregivers) | Older than 18 years old symptomatic HF patients (n=374, mean age=62 years old; 137 caregivers) | N/A |
| Joo et al. 2015, US [26] | HRS 2010 | Care recipients (Proxy) | Nationally representative aged 50 or older (n=19,762; HF 943) | ADL/IADL |
| Diabetes mellitus (DM) | | | | |
| Langa et al. 2002, US [28] | AHEAD Study 1993 | Care recipients (Proxy) | Nationally representative aged 70 years or older (n=7,443; DM 993) | ADL/IADL |
| Chatterjee et al. 2011, Thailand [27] | Survey for DM patients at Waritchaphum hospital (Jan. –Mar. 2009) | DM patients (Caregivers) | Randomly selected DM patients at Waritchaphum hospital in 2008 (n=475, mean age=62 years old with caregiver, 58 years old without caregiver; 190 caregivers) | ADL/IADL/HDL/HAC |

Notes: ADL (Activities of Daily Living), IADL (Instrumental ADL), HDL (Household ADL), HAC (Health Care Activities)

* Community, domestic, and personal ADL

** Personal care, communication, administration, therapy/leisure, psychosocial, transport, supervision

Table 2

Methods applied for estimating the economic burden of informal care

| Study/Year/Country | Analytic method | Cost estimation method |
|--------------------------------------------|---------------------------------|-------------------------------|
| Stroke | | |
| Hickenbottom et al. 2002, US [20] | Two-part model | RA |
| Dewey et al. 2002, Australia [19] | Pre- and post-stroke comparison | RA/OCA |
| Van den Berg et al. 2006, Netherlands [24] | Tobit regression | PGM/OCA |
| Riewpaiboon et al. 2009, Thailand [23] | N/A | OCA |
| Jackson et al. 2013, UK [21] | Regression analysis | RA |
| Joo et al. 2014, US [22] | Difference-in-difference | RA |
| Heart failure | | |
| Delgado et al. 2014, Spain [25] | Ordered probit model | PGM |
| Joo et al. 2015, US [26] | Two-part model | RA |
| Diabetes mellitus | | |
| Langa et al. 2002, US [28] | Two-part model | RA |
| Chatterjee et al. 2011, Thailand [27] | N/A | PGM/OCA |

Notes: RA=replacement approach, OCA=opportunity cost approach, PGM=proxy good method.

Table 3

Total informal care burden for patients with cardiovascular disease or diabetes

| Study/Year/Country | Weekly hours of informal care per person | Year of costs | Annual costs of informal care per person | |
|----------------------------------------------------------|------------------------------------------|---------------|------------------------------------------|----------------------------------|
| | | | Local currency in year of costs | 2014 US \$ |
| Stroke | | | | |
| Van den Berg et al. 2006, Netherlands ^{**} [24] | 12.4 (OCA) 20.2 (PGM) | 2001 € | €0,641.3 (OCA) €1,252–€7,482.4 (PGM) | 16,404 (OCA) 17,345–26,950 (PGM) |
| Riewpaiboon et al. 2009, Thailand [23] | 22 | 2006 baht | 55,711.2 baht | 5,560 |
| Jackson et al. 2013, UK [*] [21] | N/A | 2008 £ | £84,944 | 143,033 |
| Heart failure | | | | |
| Delgado et al. 2014, Spain ^{**} [25] | 44.9 | 2010 € | €7,683–€12,723 (1 year follow-up) | 12,270–20,319 |
| Diabetes mellitus | | | | |
| Chatterjee et al. 2011, Thailand ^{**} [27] | 14.9 | 2008 US \$ | US \$446.04 (OCA) US \$402.48 (PGM) | 1,321 (OCA) 1,192 (PGM) |

Notes:

* denotes per primary caregiver costs.

^{**} denotes per caregiver costs. Otherwise, it is per patient costs.

OCA=opportunity cost approach, PGM=proxy good methods.

Table 4

Informal care burden attributable to cardiovascular disease or diabetes

| Study/Year/Country | Weekly hours of informal care attributable to disease per person | Year of costs | Annual costs of informal care attributable to disease | | | |
|-----------------------------------|-----------------------------------------------------------------------------------------------|---------------|---------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|-------------------------------------------------|-----------------------------------------|
| | | | Per-person estimates | | National estimates | |
| | | | Local currency | 2014 US \$ | Local currency | 2014 US \$ |
| Stroke | | | | | | |
| Hickenbottom et al. 2002, US [20] | Without SRHP: 2.5, With SRHP: 12.5 | 1999 US \$ | Without SRHP: US \$1,100 With SRHP: US \$5,300 | Without SRHP: 1,563 With SRHP: 7,532 | \$6.1 billion | 8.7 billion |
| Dewey et al. 2002, Australia [19] | N/A | 1997 A \$ | N/A | N/A | A \$21.7 million (OCA) A \$42.5 million (RA) | 23.0 million (OCA) 45.0 million (RA) |
| Joo et al. 2014, US [22] | 8.5 | 2008 US \$ | US \$4,356 | 4,790 | \$14.2 billion | 15.6 billion |
| Heart failure | | | | | | |
| Joo et al. 2015, US [26] | 1.6 | 2012 US \$ | US \$836 | 862 | \$3 billion | 3.1 billion |
| Diabetes mellitus | | | | | | |
| Langa et al. 2002, US [28] | DM without medication: 2.4-4.4, DM with oral medication: 1.9-4.0, DM with insulin: 4.0-8.3 | 1998 US \$ | DM without medication: US \$1,000-1,900, DM with oral medication: US \$800-1,700, DM with insulin: US \$1,700-3,500 | DM without medication: 1,452-2,759, DM with oral medication: 1,162-2,468, DM with insulin: 2,469-5,082 | \$3 to \$6 billion | 4.4 to 8.7 billion |

Notes: SRHP=stroke related health problems, OCA=opportunity cost approach, RA=replacement approach, DM=diabetes mellitus.