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Quantifying Disease-Specific Indirect Economic Burden Using Survey Research Methods as a Component of Estimating the Total Economic Burden of a Disease

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Introduction

- The total economic burden of disease includes direct medical and indirect costs. Direct medical costs are frequently measured and relevant to payers and health systems.
- However, indirect costs are rarely included in economic burden estimates despite their relevance. Furthermore, caregiver burden is often not incorporated in estimates.
- Disease-specific burden results can be leveraged by health technology assessment (HTA) processes to then measure the value of treatments at alleviating that burden.

Objectives

- A methodological framework for estimating the annual, disease-specific, indirect economic burden of disease on patients and caregivers was developed.
- This research methodology framework aims to measure the indirect burden of disease in a manner that enables integration into total disease burden estimates that can then be incorporated into value assessment methodologies.

Methods

- Published research for measuring the indirect burden of disease and its components were reviewed. Indirect cost domains were identified in the literature.
- A past study to understand the indirect burden of all rare diseases was utilized as a seed article. Further literature on other cost domains was incorporated.
- Measurement and monetization (as available) methodology were identified and abstracted.
- Following the data abstraction, appropriate calculations to “monetize” and “annualize” impacts in each domain/component were synthesized and/or determined based on the available literature and additional publicly available estimates (e.g., value of a volunteer hour, value of a caregiving hour, average hourly earnings, etc.). This included:
  - Identifying necessary variables for each calculation to be captured through the patient survey or other sources
  - Identifying available data sources needed to populate or parameterize each variable
- Methodologies were aggregated and adapted to develop a conceptual framework and survey instruments – for patients and caregivers – for estimation of the annual indirect burden of a disease through measurement of healthcare costs not covered by insurance, non-medical costs, formal/informal caregiving, reduced work productivity, absenteeism, lost social productivity, loss of earnings due to forced early retirement, and loss of earnings due to other forced occupational changes.
- To assign an economic value to each domain, we reviewed whether cost data could be established by a patient or caregiver, and if not determined which representative, publicly available cost data could be best leveraged for use in the costing. For example, we utilized publicly available costing information to determine the average value of a volunteer hour, caregiving hour, etc.
- Ultimately, two survey instruments – one for caregivers and one for patients - were designed to reflect and capture the necessary patient and caregiver inputs as outlined in the conceptual framework based. These instruments reflected findings of the literature review and the monetization/annualization methodology development.
- These surveys can be deployed and paired with a direct cost analysis (e.g., a retrospective cohort claims-based study assessing costs) to estimate the total burden of a specific disease.

Figure 1: Elements of the Total Economic Burden of a Disease Inclusive of Impacts to Patients and Caregivers

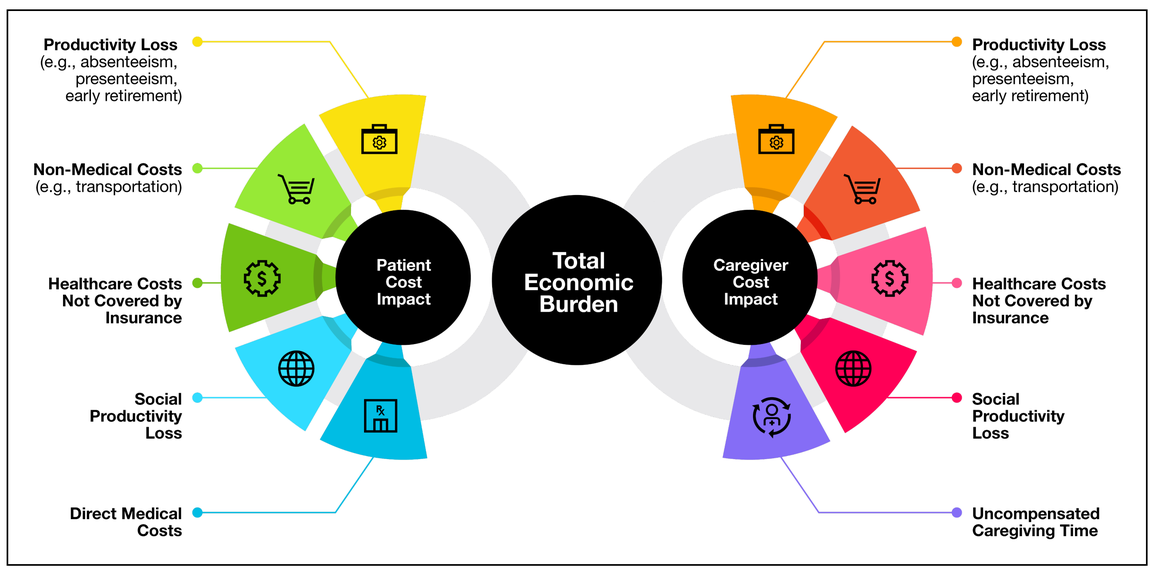
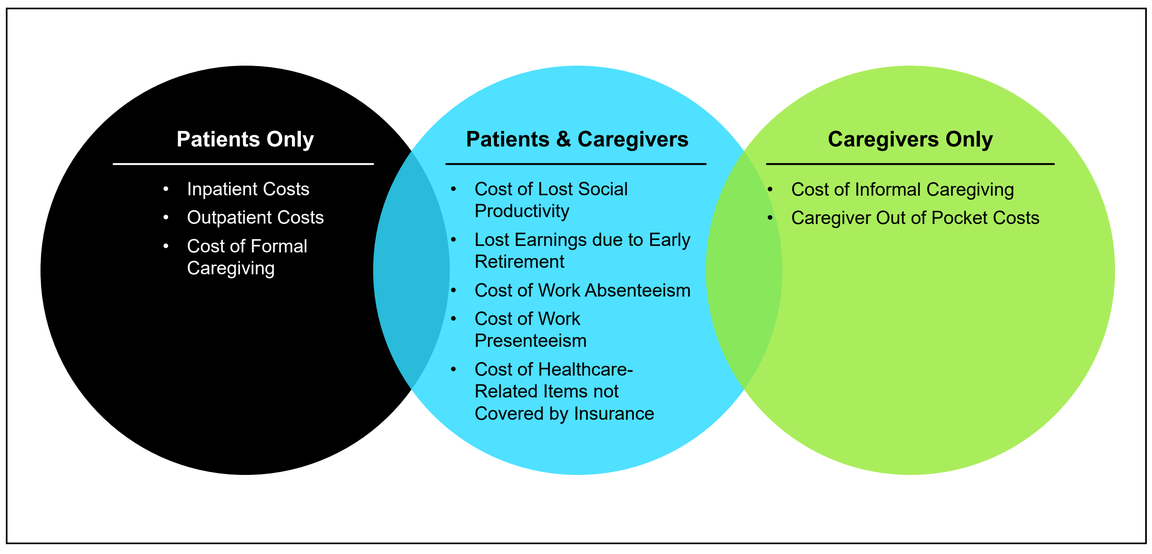


Figure 2: Financial Impact Analysis Elements for Patients and Caregivers



Results

- The indirect cost approach was ultimately synthesized into five key domains: productivity loss, non-medical costs, healthcare costs not covered by insurance, social productivity loss, and uncompensated caregiving time.
- For productivity loss, the human capital approach, rather than the friction cost approach, was found to more easily enable the calculation of productivity loss through survey research.
- This framework provides a method for estimating the indirect burden of disease, incorporating these costs into the overall economic burden of disease estimates. It is intended to be implemented through survey instruments targeted at both patients with the specific disease of interest and their informal caregivers, ensuring relevance to each group.
- By applying this framework across multiple diseases, it becomes possible to compare the main drivers of disease burden across various conditions.
- To ensure that the framework remains specific to each disease, it is recommended to conduct interviews or literature reviews to identify significant impacts, particularly occupational and financial, like major out-of-pocket costs associated with a given disease.
- Additionally, it is crucial to ensure that the survey questions and tools are carefully formatted for accessibility and relevance to the disease of interest, with input from patients, caregivers, and providers in an advisory capacity during development.

Conclusions

- Building upon existing methodologies, this study developed a comprehensive framework to measure the economic indirect burden of disease through survey research.
- This framework organizes indirect costs into five domains—productivity loss, non-medical costs, healthcare costs not covered by insurance, social productivity loss, and uncompensated caregiving time—allowing for a nuanced understanding of the factors that contribute to the total economic impact of diseases.
- By pairing this framework with direct medical cost estimates, it becomes possible to capture the full scope of disease burden, providing crucial insights for healthcare decision-making.
- This holistic approach enables stakeholders to make more informed resource allocation decisions, helping to identify areas where interventions may have the greatest impact.
- Furthermore, measuring the total disease burden can support global health technology assessments (HTA) and value assessments by providing a basis for estimating the social value of medical innovations. Such assessments are essential for evaluating the benefits of new treatments and ensuring equitable access to healthcare improvements.
- This framework can also be adapted across multiple disease areas, facilitating cross-condition comparisons and advancing our understanding of disease impacts on society.

References

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