



Assessing the Burden of Care from the Perspective of Healthcare Professionals

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The burden of care for a disease includes many different cost elements, some of which are easier to measure than others. For example, the costs incurred by a healthcare provider for an episode of care include not only staff wages and supply costs, but also opportunity costs of capital, training, and liability that are more difficult to attribute. Furthermore, many cost elements are not typically recorded in an existing data source, and researchers may need to turn to a primary data collection methodology. One approach is to query healthcare professionals (HCPs) who are responsible for delivery and management of care to the patient. This can yield rich data that is tailored and streamlined to answer the specific research questions of interest.

We are currently conducting a study that assesses the burden of care for patients with schizophrenia and bipolar I disorder who present at emergency departments or psychiatric emergency service units in an agitated state. Many of these patients can be quite agitated and treatment can have diverse and costly effects, such as delays in caring for other patients, loss of revenue due to occupied beds and ambulance diversion, staff injuries and frustration, patient complications due to needle injuries, and property damage.

We elected to assess this burden by interviewing and surveying HCPs who were experienced in caring for agitated patients with schizophrenia and bipolar I disorder. We first conducted qualitative interviews to learn more about the issues and inform the development of a quantitative provider survey. We are now in the process of surveying via the Web 200 HCPs experienced in caring for the target patient population. At present the fieldwork is ongoing for this study.

Qualitative interviews

One-on-one telephone interviews were conducted with 10 HCPs (two emergency medicine physicians, two registered nurses (RN), two hospital administrators and one each of the following: psychiatrist, licensed practical nurse (LPN), hospital aide, and social worker) in the United States. The interviews contained open-ended questions to understand the HCPs' experiences caring for patients with agitation and schizophrenia or bipolar I disorder. The results from the qualitative interviews informed the development of the Web survey.

Web survey

A cross-sectional Web survey of 200 HCPs, including emergency medicine physicians, psychiatrists, RNs, LPNs, hospital aides, social workers, and hospital administrators is being conducted. The survey includes multiple choice questions, rating questions, ranking exercises, and open-ended questions to assess the burden of treating patients, including use of restraints, isolation, boarding, length of stay, staff abuse and injury, and direct costs. For most questions, participants are asked to think about their "most recent patient with agitation and schizophrenia or bipolar I disorder."

HCPs are recruited through an external partner that specializes in clinician recruitment via its proprietary database. Potential participants who meet the screening criteria are emailed an invitation to participate in the study. The email contains information about the survey purpose and a unique link to the survey website. Interested participants click on the unique link and enter the survey website. Recruitment is conducted to ensure geographic diversity.



The Web survey consists of sections on patient management, boarding and length of stay, staff abuse and injury, emotional impact, and demographics. The administrators completed additional items on staff training.

As mentioned above, the purpose of the survey is to obtain information on the real-world burden of treating patients with schizophrenia and bipolar I disorder who are agitated. As such, the survey includes items to address the full burden of care. For example, in the patient management section, items ask about the methods used to decrease the patient's agitation and the sequelae of such methods, such as needle injuries, bruising, and over-sedation. Data on the length of time and number and type of staff required to manage the patients are also collected. In addition, there are several items with visual analogue scales for respondents to rate the emotional impact of caring for patients with schizophrenia and bipolar I disorder who are agitated. For example, during the qualitative interviews, a common sentiment among the HCPs was a high level of frustration when caring for these patients, so the following item is included in the survey:

Please rate your **level of frustration** while caring for your most recent agitated patient with schizophrenia or bipolar I disorder.



Staff taking care of these agitated patients can experience abuse and injury requiring medical attention, including pharmacological treatment and psychological counseling, and resulting in productivity loss in the form of days absent from work. This important information is also collected in the HCP survey.

This study aims to bridge the wide data gap in understanding the comprehensive cost of caring for agitated patients with schizophrenia or bipolar I disorder in the emergency department. The Web survey collects information on many aspects of a healthcare provider's burden that are not contained in existing data sources such as claims data and medical chart data. When assessing the burden of care, researchers should consider utilizing the methodology outlined here to assess the "ghost" costs that are often forgotten and are difficult to assess, leading to underestimation of the real burden of care.

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