Original Article

Methodological challenges collecting parent phone-call healthcare utilization data

Paula Moreau, RN, MSN [a,*], Sybil Crawford, PhD [a], Susan Sullivan-Bolyai, DNSc, CNS, RN, FAAN [b]

[a] University of Massachusetts, Worcester, MA, USA
[b] NYU College of Nursing, New York, NY, USA

ARTICLE INFO

ABSTRACT

Recommendations by the National Institute of Nursing Research and other groups have strongly encouraged nurses to pay greater attention to cost-effectiveness analysis when conducting research. Given the increasing prominence of translational science and comparative effective research, cost-effective analysis has become a basic tool in determining intervention value in research. Tracking phone-call communication (number of calls and context) with cross-checks between parents and healthcare providers is an example of this type of healthcare utilization data collection. This article identifies some methodological challenges that have emerged in the process of collecting this type of data in a randomized controlled trial: Parent education Through Simulation-Diabetes (PETS-D). We also describe ways in which those challenges have been addressed with comparison data results, and make recommendations for future research.

© 2015 Elsevier Inc. All rights reserved.

Given the need for greater cost containment throughout all areas of the healthcare environment, translational science and comparative effectiveness research are gaining greater prominence as a critical approach to determining intervention value (Sullivan & Goldman, 2011). Accordingly, a growing number of clinical trials include economic endpoints to demonstrate an intervention's potential for cost effectiveness along with its clinical effectiveness (Bingham, 2009; Frick & Stone, 2009; Owens, Qaseem, Chou, & Shekelle, 2011; Stone, Lee, Giannini, & Bakken, 2005). In response to the recommendations by the National Institute of Nursing Research and other groups encouraging researchers to pay greater attention to cost-effectiveness analysis (Frick & Stone, 2009; Stone et al., 2005), nursing researchers are increasingly addressing the significance of costs and cost consequences of interventional research designed to improve care (Bensink et al., 2013)

Healthcare utilization data (HCUD) are an important component of cost-effective analysis. HCUD expressed as outcome measures of patient resources consumed, can be used to determine whether a treatment or intervention is cost effective as well as clinically effective (Owens et al., 2011). The measurement of healthcare utilization variables can present a number of methodological challenges. Numerous factors can influence utilization, and many unanticipated issues can arise in the process of identifying and collecting pertinent data (Anderson & Newman, 2005; Bhandari & Wagner, 2006).

This article identifies some methodological challenges that emerged in collecting HCUD in one randomized controlled trial (RCT): Parent

Education Through Simulation–Diabetes (PETS-D), and discusses ways in which those challenges have been addressed and measured. We begin with a brief review of the literature to help explicate the importance of using HCUD in research, and to identify associated considerations when collecting this type of data.

1. Healthcare utilization and its contribution to clinical outcomes

Healthcare utilization can refer to a range of healthcare uses and expenditures, but it frequently refers to patient utilization of the following four categories of services: (a) ambulatory care, including visits and telephone calls to a healthcare provider (HCP) in an office or outpatient setting; (b) inpatient care (number of hospital admissions and length of hospital stay); (c) emergency department visits; and (d) adherence to prescription medications received (Davis, 2011). The extent to which a particular group utilizes such services can provide important indicators about the appropriateness of resources accessed and whether they are being underutilized or overutilized (Anderson & Newman, 2005). Such data are critical in performing a cost analysis of current technologies and treatments and may provide important indications for policy and future research (Davis, 2011; Janicke & Finney, 2003; Newacheck & Kim, 2005).

1.1. Implications for research

HCUD can be used in research studies as an important variable to determine efficacy and comparative cost effectiveness or cost consequences of an intervention. For example, Wagner et al. (2001), in a retrospective

cohort study that examined HCUD adjusted for demographic and healthcare characteristics, demonstrated that a sustained reduction in HbA$_{1c}$ levels of adults with diabetes represented a significant cost savings for health maintenance. In some studies, healthcare utilization can be the primary variable of interest in determining whether an intervention is effective at reducing unnecessary healthcare expenditures.

White-Traute (2013) was able to demonstrate in a prospective randomized controlled study that certain developmental interventions for mothers and their premature infants (the H-HOPE intervention) resulted in decreased levels of healthcare utilization. Infants receiving the H-HOPE intervention had significantly fewer acute care visits for illness and slightly less overall healthcare utilization, resulting in reduced cost of preterm infant care. Although the data were limited by the fact that only maternal self-report of infant HCUD were collected, there was also evidence to suggest that the intervention may have resulted in (a) enhanced infant growth and development leading to decreased illness and (b) increased mothers' confidence and understanding of preterm infant behaviors, in effect reducing "anxiety related" visits.

Although institutional cost savings such as those presented in the studies above are an important variable of interest, an accounting of other costs or cost consequences could be equally valuable to assess (Stone et al., 2005). For example, a comparison of economic consequences of one intervention over another that incorporates variables such as the extent of lost earnings of patients or parents who are unable to work as a result of healthcare activity could yield important information. Similarly, a comparison of direct and indirect costs of other important correlatives such as depression, patient or parental anxiety, and psychosocial adjustment would be beneficial in order to evaluate more rigorously the comparative economic benefits of an intervention that extend beyond immediate healthcare costs (Stone et al., 2005).

Thus, broadening the economic analysis of healthcare research to involve complex appraisals of factors beyond simple cost-savings is critically important. The appropriateness of outcomes and resources to evaluate will vary depending on the questions being asked and the perspective of the analysis (Frick & Stone, 2009; Stone et al., 2005). A hospital administrator, for example, may be interested in direct medical costs and resources consumed as a result of an intervention, whereas patient care providers might also be interested in a comparison of direct nonmedical costs, such as a reduction in transportation costs or childcare costs to patients and families (Stone et al., 2005). Others might be more concerned with the complexity of metrics that incorporate prolonged years of life or adjustments for improved quality of life when evaluating or comparing different interventions (Frick & Stone, 2009; Stone et al., 2005).

An increasing number of nationwide databases have become available, which enable secondary analyses of a wide range of health issues including cost, health provider practice patterns, and access to healthcare programs (Bernstein et al., 2003). In addition, secondary data analysis of HCUD can yield significant findings that can positively or negatively affect the direction of future studies. For instance, a utilization study by Raphael, Zang, Liu, and Giardino (2010) used national children's health data to investigate the relationship between high parenting stress and healthcare utilization, finding a significant correlation between increases in parenting stress and the frequency of emergency care visits. Even controlling for psychosocial and sociodemographic variables, they determined that parents with high parenting stress were more likely (adjusted odds ratio, 1.24; 95% confidence interval 1.10–1.41) to seek emergency care for their children compared to parents with low parenting stress. These findings led the authors to consider whether interventions aimed specifically at reducing parental stress might help to decrease the frequency of unnecessary emergency care visits.

1.2. General consideration about HCUD collection

Collection of accurate HCUD is a complex process that involves consideration of a range of methodological challenges (Anderson & Newman, 2005; Bhandari & Wagner, 2006). Although chart audits are considered the "gold standard" for retrieval of HCUD (Killeen, Brady, Gold, Tyson, & Simpson, 2004; Ritter et al., 2001), they can be time-consuming and costly, and may not always provide the most accurate information (Bhandari & Wagner, 2006; Killeen et al., 2004; Ritter et al., 2001). In a comparison study of patient self-report with medical utilization frequency, Ritter et al. described a tendency for provider records to contain missing data in some cases and speculated that this was likely related to the fact that there may have been unrecorded visits—especially visits outside of the health maintenance organization.

In an attempt to capture HCUD that may not be recorded in the medical records, researchers have increasingly employed patient or family self-report methods of data collection to cross-check services utilized. However, there are reliability and validity challenges with this type of data collection as well. Several authors have discovered tendencies for patients to either underreport or overreport utilization of healthcare services (Bhandari & Wagner, 2006; Killeen et al., 2004; Ritter et al., 2001). Bhandari and Wagner conducted a comprehensive review of articles on the accuracy of self-report data. The review reveals that patient self-reports can be influenced by a number of variables including (a) the patient's cognitive ability, (b) the recall time frame (underreporting increases the longer the time between visit and reporting), and/or (c) frequency of visits (participants tend to forget visits as the number of visits increases).

Bhandari and Wagner (2006) also found that the type of visit could influence either overreporting or underreporting, observing that participants tended to underreport visits that were perceived to be embarrassing or stigmatizing. For example, they found a tendency to underreport visits related to issues of mental health or alcoholism. However, the authors recognized that some studies have also shown overreporting of such visits, and speculated that some visits may be perceived by patients to be more significant and thus more likely to stand out in their memory, even to the point of affecting the accuracy of reporting.

Questionnaire design has been found to be instrumental in determining the accuracy of patient self-reporting, affecting comprehension, the motivation to answer, and even the timing of the report. Use of reminders, or "ticklers," also has been found to be helpful in self-reporting healthcare utilization (Bhandari & Wagner, 2006). The Internet is increasingly being used as a means of patient self-report, with good effect (Bhandari & Wagner, 2006). Because systematic errors can occur in both self-report data and provider documentation, a dual source of data collection is likely to yield more robust and accurate data than a single source (Jordan, Jinks, & Croft, 2006; Killeen et al., 2004).

2. Specific methodological challenges with analysis of parent call data

Analysis of parent call data to pediatric providers has been shown to be an important indicator of healthcare utilization, as it can identify potential cost savings not otherwise considered in healthcare utilization studies (Jordan et al., 2006; Leibowitz, Day, & Dunt, 2003). In one prospective survey (Bunik et al., 2007), for instance, parent calls to a pediatric after-hours call center in Denver, CO ($N = 8980$), 46% ($n = 4130$) of the total number of parents responding reported that they considered their calls to be urgent and would have sought emergency care had they not reached a HCP by phone. However, only 13.5% ($n = 558$) of those calls were deemed to be urgent by the HCP who received the call. Conversely, among the number of parents who reported they intended to keep their children at home ($n = 1886$), 15% ($n = 283$) of those cases were deemed by the HCP to be urgent and referred to the emergency department (ED). Thus, the authors were able to identify a significant net cost savings to the healthcare institution based on the utilization analysis of these calls. The calls also provided a significant measure of how families were managing children's conditions, what further