Obtaining Medical Records for Women With Intellectual Disabilities in a Community-Based Health Promotion Intervention

Swaine, J. G., Parish, S. L., Ghosh, S., Luken, K., & Wright, G. A.  

Abstract: There is a critical need for objective data about receipt of preventive healthcare screenings that are not subject to self-response bias. However, no available evidence indicates which methods are effective for obtaining retrospective medical record data for women with intellectual disabilities (ID) receiving care in the community. This article describes a procedure for obtaining retrospective medical record data for 199 women with ID who took part in a community-based, multisite, randomized controlled trial of a health education intervention. Data were analyzed to determine rates of correct physician identification and physician response rates during the 2006–2009 study periods. To assess accuracy in identifying physicians and response rates over time, McNemar's test of paired proportions for dependent samples was used. Physician identification varied over time with correct identification being highest in more recent years. The majority of practices responded to our requests for medical record data; however, response rates and item completion rates were highest for the most recent data, with rates declining significantly for data from earlier years. Obtaining retrospective medical record data from community-based medical practices is possible, but difficult. Therefore, researchers should budget resources to accommodate a lengthy process with extensive follow-up. Researchers interested in older medical data face additional challenges in obtaining complete records.