

ORIGINAL RESEARCH

Long-Term Health Service Outcomes Among Women With Traumatic Brain Injury



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Abstract

Objectives: To (1) assess long-term health care service utilization and satisfaction with health care services among women with traumatic brain injury (W-TBI); (2) examine barriers that prevent W-TBI from receiving care when needed; and (3) understand the perceived supports available for W-TBI.

Design: Retrospective cohort study.

Setting: Community.

Participants: W-TBI (n = 105) 5 to 12 years postinjury and women without TBI (n = 105) matched on age, education, and geographic location.

Interventions: Not applicable.

Main Outcome Measures: Pre- and postinjury data were collected using a questionnaire administered via a semistructured interview. Questions on health services utilization, satisfaction with and quality of services, barriers to receiving care, and perceived social support were from the Canadian Community Health Survey; additional questions on perceived social support were from another large-scale study of people with moderate to severe brain injury.

Results: Compared with women without TBI, W-TBI reported using more family physician and community health services. W-TBI reported that they did not receive care when needed (40%), particularly for emotional/mental health problems. Significantly more W-TBI reported financial and structural barriers. There were no significant differences in reported satisfaction with services between women with and without TBI.

Conclusions: Health service providers and policymakers should recognize the long-term health and social needs of W-TBI and address societal factors that result in financial and structural barriers, to ensure access to needed services.

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Globally, traumatic brain injury (TBI) is a leading cause of disability for those younger than 45 years,^{1,2} and approximately one third of TBIs are sustained by girls and women.^{3,4} Researchers have reported that women with TBI (W-TBI) are more likely to have fewer children, and experience more amenorrhea and postpartum difficulties compared with age-matched women without TBI⁴⁻⁶; W-TBI also report more emotional, cognitive, and somatic difficulties than men with TBI.⁶⁻¹¹ Furthermore, W-TBI experience considerable risk of abuse, and loss of emotional and financial support.¹² Despite these findings, women's health

outcomes remain understudied.^{13,14} Therefore, research on women's lived experiences of TBI needs to be performed, not only to address this knowledge gap but also to explore how and why women living with TBI experience health and health care services differently than men living with TBI, or differently than women with no health conditions and with non-TBI-related impairments or disabilities. As researchers point out, even if health concerns are similar, biological processes (eg, reproductive system, life expectancy) and social contexts (eg, socioeconomic inequality, vulnerability to violence, culture) can lead to dramatically different outcomes.¹⁵⁻¹⁷

Advances in medical technology and care have improved the survival rate after TBI, thus increasing the demand for and use of community-based medical services.¹⁸⁻²⁰ In Canada, hospital and physician services are publicly insured, which theoretically allows for accessible and ongoing care; however, long-term community care and rehabilitation services are offered on an inconsistent basis and are largely dependent on an individual's insurance or other personal resources to pay privately for services.^{21,22} The presence of multiple barriers to accessing health services for people with chronic disability or illness has long been recognized,^{23,24} particularly for women.²⁵⁻²⁷ Although several barriers to accessing care have also been identified by patients with TBI, their families, and health care providers,^{21,28-33} little is known about the utilization of and access to health services specifically by W-TBI over the long-term.³⁴ Moreover, satisfaction with access to health services is consistently reported as problematic by patients with chronic illness.^{22,35,36} The acknowledgment that TBI should be considered a chronic illness requiring long-term attention^{37,38} places TBI within this broader health services context and provides an opening for extending this query to women living with TBI.

The objectives of this study were to (1) assess health care service utilization, perceived quality of care, and perceived satisfaction of care among W-TBI compared with women without TBI; (2) understand the health care access barriers that prevent W-TBI from receiving care when needed; and (3) examine the perceived social supports available for W-TBI.

Methods

This is a retrospective cohort study involving 8 acute care and rehabilitation facilities across Ontario. A major focus of this study was to compare the reproductive health of W-TBI with that of women without TBI, and results have been reported elsewhere.⁴ The current article focuses on additional data gathered during the original study about (1) health care service utilization, (2) perceived quality of and satisfaction with care, (3) barriers to accessing care, and (4) social support availability.

Study population

Health records of female patients admitted to participating facilities from January 1996 through December 2002 were reviewed by authorized medical records staff for eligibility, and letters were

sent by the medical records staff to these potential participants with study information, consent forms, and information regarding participation. Cases were defined as records indicating a diagnosis of moderate to severe TBI, classified using a Glasgow Coma Scale (GCS) score of <13; if GCS scores were unavailable, loss of consciousness for >30 minutes, abnormal findings on computed tomography scans, or posttraumatic amnesia of >1 day was used to indicate moderate to severe TBI at the scene of injury or at the hospital.^{4,39,40} Study participants were 18 to 40 years of age at the time of injury, currently living in the community, and able to communicate in English and provide signed consent. Of 367 women who were potentially eligible, 238 (64.9%) could be contacted, and of those, 105 (44.1%) consented to take part in the study. The study's authors were unable to determine how non-participants differed demographically from those who participated because ethics guidelines limited the review of medical records by the study team without the participants' consent.⁴¹ Control participants were recruited by a third party through random digit dialing and were matched with cases by age (± 5 y), geographic location (using first 2 digits of postal code), and education (± 1 level). Research ethics boards of all participating centers approved this study.

Data collection

We used measures from a larger questionnaire that was developed to explore the impact of TBI on women's health.⁴ Overall, the questionnaire collected demographic and pre- and postinjury personal information (eg, age, education, marital status, employment status), injury-related details, information on women's general and reproductive health, and satisfaction with and use of services. The measures used for the current study on utilization of and satisfaction with health care services were largely adapted from the Canadian Community Health Survey (CCHS).⁴² The CCHS is a cross-sectional national survey that collects data on health status and health care utilization and is used for surveillance purposes. The CCHS is regularly reviewed by expert health authorities for quality and relevance and is rigorously tested for validation. It is comparable to the National Health Interview Survey in the United States.⁴³ Additional measures of social support were drawn from large studies of people with moderate to severe brain injury.⁴⁴ In the present study, we focused on responses related to health services: utilization, barriers, and satisfaction. We questioned the availability of social and emotional support and support with daily living activities (eg, can you count on anyone to give you emotional support/extra help with daily tasks?) and asked about sources of support (professional, family/friends) and frequency of use before and after brain injury (very frequently, frequently, or infrequently). Perceived satisfaction with interaction with a family doctor was rated on a 5-point scale of satisfaction from very satisfied to very dissatisfied. The ratings available for perceived quality of care were excellent, good, fair, or poor. For women who had experienced a pregnancy, we asked about the quality of and satisfaction with care by the physician providing obstetric/gynecologic care. Respondents were also asked about utilization of other community-based health care received outside a hospital or doctor's office, such as home nursing care, home-based counseling or therapy, personal care, or community walk-in clinics. Respondents were asked to rate their satisfaction with the interactions with community-based health care providers and the perceived quality of care. Details of respondents'

List of abbreviations:

CCHS	Canadian Community Health Survey
GCS	Glasgow Coma Scale
OR	odds ratio
TBI	traumatic brain injury
W-TBI	women with traumatic brain injury

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