

**ORIGINAL RESEARCH**

# Being a Woman With Acquired Brain Injury: Challenges and Implications for Practice



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**Abstract**

**Objectives:** To explore the experiences of women with acquired brain injury (ABI) to gain greater insight into their general and sex- and gender-specific health and well-being concerns, and to identify areas for future research.

**Design:** A qualitative pilot study using interpretive description methodology and a sex-and gender-based analysis of data collected through focus groups.

**Setting:** Community.

**Participants:** A sample of survivors, and formal and informal caregivers of women with ABI (N=16).

**Interventions:** Not applicable.

**Main Outcome Measures:** Not applicable.

**Results:** Participants identified significant barriers to achieving optimal health and well-being for women survivors of ABI, including a lack of knowledgeable professionals. We identify 3 interrelated themes: (1) experiences shaped by gender norms and roles; (2) experiences influenced by physiological phenomena, including perceived hormone imbalances; and (3) experiences surrounding interpersonal relationships and sexuality.

**Conclusions:** Post-ABI care should include education about the influences of sex and gender on health and well-being. Acknowledging the impact of gendered roles, and the broader sociopolitical context of gender and disability, is important to develop appropriate services and supports after ABI. Incorporating effective communication strategies between patient and health care professional can also be a potent rehabilitation strategy.

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Brain injury is a leading cause of death and disability globally.<sup>1</sup> Historically, research on brain injury has been based primarily on male samples, reflecting higher male incidence rates.<sup>2,3</sup> Researchers increasingly acknowledge that both sex (biological

construct) and gender (social construct) have a significant effect on health experiences<sup>4</sup> and are calling for sex- and gender-based analyses to be a priority in research.<sup>5</sup> Yet, despite awareness that biological variances between males and females<sup>3,6,7</sup> and gendered social norms<sup>8-10</sup> result in distinct experiences of brain injury for men and women, there is still limited empirical research considering the implications of those differences for women. The need for an approach to study design and analysis that takes these differences into account has been identified among stakeholders.<sup>3,8,10-14</sup>

Acquired brain injury (ABI) is an “umbrella term” that encompasses a range of brain injuries from both traumatic and nontraumatic causes, and can vary in severity from mild to severe; the consequences of sustaining an ABI include physical,

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neurocognitive, and/or psychological impairments.<sup>15</sup> Limited research has explored the long-term lived experiences of women with ABI from both survivor and caregiver perspectives, and research focusing specifically on women is scarce in the literature on ABI. This research is necessary to identify disparities in health care policy and service provision, and to develop solutions resulting in better outcomes for women with ABI.<sup>3,10,16</sup>

The objectives of this pilot study were to gain greater insight into the experiences of seeking and maintaining health and well-being among women with ABI through a sample of women survivors, caregivers, and health care professionals, and to identify areas for future research.

## Methods

### Participants

A convenience sample was recruited through the Brain Injury Association of Canada's website and through word-of-mouth communication. Women were eligible to participate if they were Canadian residents,  $\geq 18$  years of age, had sustained an ABI at any age, and were able to communicate in English. Eleven women were recruited, all with non-stroke-related ABI. The average age of these participants was 49 years (range, 20–65y), with an average of 14.9 years' experience living with ABI (range, 5–30y). At the time of the study, 5 women were engaged in volunteer activities, 3 were primarily homemakers, and 1 woman was self-employed (table 1).

Eligible caregivers were  $\geq 18$  years of age, were able to communicate in English, and provided personal care or health care services for girls or women with ABI who live in Canada. The second stakeholder group consisted of 3 formal and 2 informal caregivers. The formal caregivers were female health care professionals (age range, 20–65y) with a diverse range of years of experience (5–40y). The 2 informal caregivers were a parent and a spouse.

### Data collection

This qualitative study used focus groups to explore the experiences of women living with ABI. Two focus group sessions were held with the women, composed of 6 participants in the first session and 5 in the second. The group compositions were based on participants' preference and availability as indicated during the recruitment stage, and in consideration of the distance traveled to allow time for the women to rest before the session. The location was fully accessible. Discussions were conducted by an experienced female moderator. Survivor group discussions lasted 1 1/2 hours, and caregiver sessions were 1 1/4 hours in length. All sessions were audio recorded and transcribed verbatim. See table 2 for the focus group questions.

### Data analysis

The analysis was conducted in keeping with the principles and techniques of interpretive description methodology, a qualitative research approach aligned with a constructivist and naturalistic orientation to inquiry, to construct knowledge useful in clinical health care settings.<sup>17</sup> Transcripts were analyzed by members of the research team. The analysis consisted of a qualitative process

**Table 1** Demographic characteristics of women with lived experience of ABI

Characteristic	Women With Lived Experience (N = 11)
Age group (y)	
18–45	2
46–55	6
56–65	3
Type of brain injury	
Traumatic	10
Nontraumatic*	1
Years since injury	
<5	1
5–10	3
11–20	4
21–30	3
Main daily activity(ies) <sup>†</sup>	
Paid employment outside the home	0
Self-employed	1
Volunteer	5
Homemaker	3
Other	4

\* One participant had a non-stroke-related anoxic brain injury.

† Some participants listed >1 activity.

of attaching descriptive codes to segments of text within and across the focus groups. These codes were reviewed, and relationships and patterns within the codes allowed us to group them into categories based on commonalities. Topic-oriented categories were further refined and formulated into fewer analytical categories related to health and well-being and clinical implications through an inductive, iterative process.<sup>17,18</sup>

Triangulation of data was used to enhance trustworthiness of the findings: information was sought from participants across different stakeholder groups to identify and verify patterns of convergence. Triangulation has been identified as a particularly effective means of gaining an inclusive and comprehensive understanding of a topic,<sup>19</sup> and is considered an integral component of interpretive descriptive methodology.<sup>17</sup>

Ethics approval was provided by the Toronto Rehabilitation Institute-UHN.

## Results

Three key themes emerged from the analysis: (1) an ideal woman—experiences shaped by gender norms and roles; (2) a body unfamiliar—experiences influenced by physiological phenomena; and (3) a new sexuality—experiences regarding interpersonal and sexual relationships. These themes are discussed below; participant quotes are from a caregiver (C) or a woman with lived experience (WLE).

### An ideal woman

The first theme highlights the intersection of disability and gender and its impact on social interactions, family relations, gender identity, and gendered role expectations. Participants agreed that being a woman with ABI affects not only the way others perceive them, but also how social interactions are performed. Interpersonal interactions are shaped by culturally defined and entrenched

#### List of abbreviations:

ABI acquired brain injury

WLE woman with lived experience

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