

ORIGINAL RESEARCH

Gender and Transition From Pediatric to Adult Health Care Among Youth With Acquired Brain Injury: Experiences in a Transition Model



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Abstract

Objective: To explore gender and sex differences in experiences of transitioning to adult health care among young adults with acquired brain injury (ABI) who take part in a coordinated model of transitional care.

Design: Descriptive design using in-depth semistructured qualitative interviews.

Setting: Interviews over the phone and in person.

Participants: Participants (N=18) included 10 young adults with a diagnosis of ABI (4 women, 6 men; age range, 19–21y) and 9 parents (8 women, 1 man) from the Greater Toronto Area, Ontario, Canada.

Interventions: Not applicable.

Main Outcome Measure: Semistructured interviews with participants.

Results: Our findings highlight several commonalities and differences relative to sex and gender among young adults with ABI who are transitioning from pediatric to adult care. Both young adult men and women experienced a similar transition process and similar organization, continuity, and availability of care. Sex differences were found in relational factors (eg, communication, family involvement, social support). Young adult men, and parents of the men, differed in their transition regarding relational factors (eg, communication, family involvement).

Conclusions: Our findings show that young adult men and women with ABI who have taken part in a transition preparation program experience similarities in organization, continuity, and availability of care, but they experience differences in relational factors (eg, communication, family involvement).

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Transition to adulthood is an area of concern for young adults with acquired brain injury (ABI). As young adults reach adulthood, their readiness for transition varies.¹⁻³ Health services are often lacking; there are poor links between pediatric and adult rehabilitation services,³⁻⁶ and the limited availability of appropriate

and comprehensive care can pose challenges.^{4,7,8} Common barriers to a successful transition include the following: lack of coordinated care, lack of health professionals' knowledge, and lack of preparation for young adults.^{3,6,9,10} Poor transitions, including gaps in continuity of care, can negatively influence health outcomes and meaningful participation in life.¹¹⁻¹⁴ Therefore, understanding the transition experiences of young adults with ABI is critical.

Unfortunately, few transition models are available to maintain continuity of care for young adults with ABI.¹⁵ To address this gap, 1 pediatric and 1 adult rehabilitation center in Ontario,

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Canada, partnered to facilitate successful transitions to adult health care.² They developed a transition model to maintain continuity of coordinated care for young adults with cerebral palsy and ABI.^{2,8} Multiprofessional clinical teams at each facility provide transitional rehabilitative care coordination to young adults and their families, based on the following 4 best-practice principles of health care transition: (1) transition should be gradual and timed; (2) care should be interdisciplinary, comprehensive, and coordinated; (3) young adults and families should be taught skills in disability management and transition readiness; and (4) transition preparation should be person centered, using a holistic approach.²

In evaluating young adults' experiences of this transition model, our study addresses several gaps in the literature. We explore the experiences of young adults who have taken part in a longitudinal (1y) transition program. Among the few studies evaluating transition programs, most have focused on diabetes⁹ and have not included a qualitative component. Previous qualitative studies on transition to adult care have often had problems with recall bias.^{3,10,16} Our study has captured the transition process, a noted gap in the literature.¹⁰ There is also a lack of research on sex and gender differences in transition experiences.

Exploring sex and gender differences among young adults with ABI as they transition to adult health care is important because sex and gender influences many ABI outcomes,^{17,18} reflecting differences in biochemical and brain functioning and socioemotional responses to coping with injury.¹⁹⁻²⁴ Although research on sex/gender and ABI is growing, most studies have focused on adults. Among the few studies on ABI involving young adults, findings suggest girls have a more emotional style of coping, whereas boys tend to demonstrate anxiety or aggression.²⁵

Methods

Design

This article draws on a larger, mixed-method, longitudinal study exploring continuity of care among young adults with cerebral palsy and ABI (see Tsybina et al⁸). As part of the study's outcome evaluation, young adults and parents consented to participate in a qualitative interview exploring changes in health and social services and transition experiences. In this article we draw on those interview findings to explore sex and gender differences in experiences of transitioning to adult health care among young adults with ABI participating in a linked model of transitional care.

Sample and recruitment

The Research Ethics Boards at Holland Bloorview Kids Rehabilitation Hospital, Toronto Rehabilitation Institute, and Sunnybrook Health Sciences Centre approved this study. Clients of Holland Bloorview who turned 16 years of age between September 2008 and August 2010, who had a primary diagnosis of ABI, and who received transition services were eligible to participate.⁸ The research team sent an information letter to all eligible clients (n=88), and they contacted consenting young adults and parents after the client's eighteenth birthday to arrange an interview.⁸

List of abbreviations:

ABI acquired brain injury

Participants

The research team interviewed 10 young adults (6 men, 4 women) diagnosed with ABI (age range, 19–21y) and 9 of their parents (8 women, 1 man) from Ontario, Canada (table 1). One young adult in the parent–young adult dyads could not be interviewed because of their cognitive level of functioning. The cause of ABI varied among participants. Of the young adults, all 4 women and 5 of the 6 men lived at home. Five of the young adults (3 of the 4 women, 2 of the 6 men) were attending college, 2 men were attending high school, and the remainder were not attending school.

Data collection

We conducted interviews with parents and young adults, lasting an average of 29 minutes each, between June and September 2013. We used a semistructured interview guide, with questions influenced by transition principles.² We used probes to draw out experiences of transition readiness and sex/gender (appendix 1).

Data analysis

Interviews were audio recorded and transcribed verbatim. The 4 authors trained in qualitative research independently read all transcripts and noted key themes. Using our research question as a guide, we used a constant comparative, open-coding approach.²⁶ We took measures to ensure the rigor and trustworthiness of our findings.²⁷ First, 4 of the authors were involved in coding data and verifying themes. Second, we engaged in reflexive team discussions to consider how our experiences may have influenced our interpretation of findings.^{26,28} Third, we kept an audit trail of decisions regarding theme development.²⁶ Finally, we used representative quotes to reflect participants' experiences.²⁸

Results

Our findings highlight the structural, relational, and personal barriers and facilitators that young adults experienced during their transition to adult health care (table 2).

Structural factors

Organization and continuity of care

At the time of our interviews, 7 young adults (3 women, 4 men) had transitioned to adult care; 1 woman was on a waitlist; and 2 men had not yet transitioned. Transitioned young adults said they were connected with the appropriate providers in the adult system, and all the transitioned participants reported experiencing continuity of care. For example, 1 parent (participant 3b) reported, "I thought the information followed her...I didn't feel like we were starting from her first concussion." In the young adult group, 3 out of 4 women and 5 out of 6 men described the transition as well organized. Young adults who reported a negative transition experience (1 woman, 1 man) wanted information to be more understandable, and they wanted more follow-up from pediatric providers.

Availability of care

In the young adult group, all but 2 men said that transition support and access to adult services were available. One man (participant 8a) felt the transition program was not helpful or needed, whereas the other man (participant 9a) lived much further away and found the program difficult to access.

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