ORIGINAL ARTICLE

Exploring Postinjury Living Environments for Children and Youth With Acquired Brain Injury

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ABSTRACT. DeMatteo CA, Cousins MA, Lin C-YA, Law MC, Colantonio A, Macarthur C. Exploring postinjury living environments for children and youth with acquired brain injury. Arch Phys Med Rehabil 2008;89:1803-10.

Objectives: To explore and describe the extent to which children and youth (10−18y) with acquired brain injury in Ontario are living in environments considered inappropriate, to describe the nature of services and supports in those environments, and to determine appropriate living environments for children and youth with acquired brain injury.

Design: A mixed-methods approach with a case-study design was used in which the living environment represented the case. This article reports on the qualitative component.

Setting: Community agencies and service providers.

Participants: Forty-four service providers across a wide range of profit and nonprofit services for children and youth with acquired brain injury throughout the province of Ontario.

Interventions: Not applicable.

Main Outcome Measure: Semistructured in-depth interviews with participants.

Results: Seven major themes emerged from the data: *kids go home*, *a continuum of appropriateness*, *show me the way home*, *same chapter different story*, *cracking the acquired brain injury code*, *who said care was fair*, *and coping*, *and managing and advocating*: *new dimensions for families*. Important service recommendations were also reported.

Conclusions: Most children and youth with acquired brain injury are living at home. The level of appropriateness of the environment for children and youth after acquired brain injury can depend on multiple interrelated factors including type and severity of acquired brain injury, existing services and service delivery, acquired brain injury knowledge, and family's ability to cope and manage.

Key Words: Adolescent; Brain injuries; Child; Environment; Family; Rehabilitation.

EACH YEAR IN THE United States, more than 1 million children and youth sustain brain injuries with 30,000 permanently disabled because of their injuries.[1,2] For the year 2003 to 2004, 5000 children and youth were admitted to hospital for head injury in Canada.[3] However, the prevalence of TBI may be greater than reported because the Canadian Institute for Health Information reports only documented major trauma cases.[3,4]

Models of disability support the importance of supportive environments for children and youth with acquired brain injury and disability. The person-process-context-time conceptual model by Bronfenbrenner[5] provides a framework for conceptualizing the influence of the environmental factors on children and youth with acquired brain injury, including changes within the person, social environment, and institutional environments that may have a detrimental impact on quality of life and participation in everyday activities. According to this model, health and developmental outcomes are the result of complex interactions among the active biopsychologic aspects of the person and the persons, objects, and symbols in the environment over time.[5] The World Health Organization's *International Classification of Functioning, Disability and Health* model also emphasizes environmental factors and their interaction with body function and structures, activities, and participation in relation to disability.[6]

However, the extent and nature of living environments for people with acquired brain injury are unknown because there has been little study of the environments to which children and youth return to after brain injury. Researchers in the United Kingdom report that obtaining an accurate picture of the living environments and outcomes of children with disabilities has been difficult to determine, given the limited availability of quality data and the absence of children's experiences in the literature who have been separated from their families.[7]

The 3 main objectives of the study were (1) to explore the extent to which children and youth age 10 to 18 with acquired brain injury are living in environments that would be considered inappropriate, (2) to describe the nature and extent of services and supports in relation to their living environments, and (3) to determine what constitutes an appropriate environment for children and youth with acquired brain injury from the perspective of service providers knowledgeable in the field of brain injury.

METHODS

For the purpose of this study, *acquired brain injury* was defined as damage to the brain that occurs after birth and is not related to a congenital disorder or a degenerative disease. Damage may be caused by a traumatic injury to the head or by

List of Abbreviations

TBI	traumatic brain injury

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a nontraumatic cause such as a tumor, aneurysm, anoxia, or infection.[8]

A mixed-methods approach with a case-study design was used in which living environments of children and youth with acquired brain injury in the province of Ontario, Canada (population, 12.6 million) represented the case. A case study is a methodology that allows an in-depth exploration of a phenomenon, which may be a group of people, a program, a situation, or an event.[9] In this study, the case was the living environment of children and youth with brain injury in Ontario. This study examined living environments at 1 point in time, thereby making the study cross-sectional in nature.

An in-depth exploration of living environments was accomplished through the integration of both qualitative and quantitative methods. Interviews were conducted with key informants, and data on children and youth with acquired brain injury were also collected from various organizations providing services to children and families. Quantitative methods used a cross-sectional design to collect both retrospective and prospective longitudinal data. This article focuses on the qualitative aspect of this mixed methodology. All procedures involving key informants followed protocol and were in accordance with the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board, who approved this study.

Purposeful sampling, which involves selecting participants because of their characteristics,[10] was used. Key informants were identified through recommendations from the research team, study participants, service providers, research reports, government ministries, and the World Wide Web. Inclusion criteria for key informants were people with knowledge and experience in the field of acquired brain injury and children's services, including acquired brain injury service providers, government ministries, and advocates across Ontario. Potential participants were contacted by telephone, email, and mail to participate in a 1-time qualitative interview. Interviews were conducted face-to-face in the community and over the telephone, varying in length from 30 minutes to 2 hours.

Using a semistructured interview guide, the interview focused on questions about children and youth between the ages of 10 to 18 with acquired brain injury and their environments (appendix 1). Data collection was terminated when saturation was achieved. All interviews were taped and transcribed. Content was coded and categorized using content analysis. Consensus of the research team determined main themes. Content analysis was chosen to be the best method of analysis because of the large volume of interviews conducted and the exploratory nature of study objectives. Multiple methods ensuring rigor and trustworthiness of data were used, such as analyst triangulation,[11] which was achieved when multiple members of the research team participated in coding of individual text and main themes. Both prolonged engagement and persistent observation[12] methods were used by interviewing participants over a significant amount of time in the field (6mo) and conducting in-depth interviews. Member checking[12] was conducted by distributing a brief newsletter highlighting results to key informants that asked for their feedback to ensure validity and credibility of results.

RESULTS

Forty-four people were interviewed across 26 different public and private organizations between December 2005 and May 2006. Geographically, key informants represented all 5 regions of Ontario. Most key informants worked for organizations based in cities such as Hamilton or Toronto in the Golden Horseshoe (55%), while 10 were from Southern and Western Ontario, 7 from Northern Ontario (including Thunder Bay), and 3 from Eastern and Central Ontario. Twenty-five key informants were interviewed over the telephone, and 19 were interviewed in the field, typically at their place of employment. Table 1 is a detailed frequency table about key informants.

Table 1: Characteristics of Key Informants (N=44)

Characteristic	n	%
Interview type		
Face-to-face	25	57
Telephone	19	43
Sex		
Male	12	27
Female	32	73
Geographical region		
Eastern and Central	3	7
Golden Horseshoe	24	55
Northern	7	16
Southern and Western	10	23
Perspective		
Advocacy	3	7
Government	11	25
Direct service provider	30	68
Organization's/program's focus		
Acquired brain injury or brain injury	16	36
General (included acquired brain injury)	28	64
Years of experience (acquired brain injury and/or pediatric)		
5−9	6	14
10−19	16	36
20+	9	20
Other	13	30
Target service population		
Children, youth, and families	19	43
Children, youth, and adults	16	36
Youth and adults	7	16
Other	2	4
Funding source		
Private (for profit)	10	23
Public (ie, government ministries)	31	70
Mixed	1	2
Unknown	2	5

Content analysis was performed using the qualitative software program N7.[13,a] Approximately 50 hours of interviews were transcribed and coded into 7 categories, containing over 180 codes resulting in the 7 main themes, summarized here.

Kids Go Home

Consensus from key informants confirmed that most children go home eventually if not immediately postinjury and are living at home now. Key informants also listed living environments external to the family home, such as rehabilitation centers, nursing homes, private and publicly funded residential facilities, group homes, foster homes, and associate care homes, as well as jail, on the street, and out of the country.

> Most of them are at home. If you look at the discharges from all the various hospitals or hospital-based programs, you will find that about 80% or more are sent home. Why are they sent home? Because there is nothing to provide services for them. There are not enough places for them to go, and so they go home and the families do the best they can. (participant 37)