

Living Environments for People with Moderate to Severe Acquired Brain Injury

Milieux de vie pour les personnes vivant avec une
lésion cérébrale acquise modérée ou sévère



by ANGELA COLANTONIO, PHD

*Saunderson Family Chair in Acquired Brain Injury Research,
Toronto Rehabilitation Institute*

*Professor, Department of Occupational Science and Occupational Therapy
University of Toronto
Toronto, ON*

DANA HOWSE, MASP

*Dalla Lana School of Public Health
University of Toronto
Toronto, ON*

BONNIE KIRSH, PHD

*Graduate Department of Rehabilitation Science
Department of Occupational Science and Occupational Therapy
University of Toronto
Toronto, ON*

TERESA CHIU, PHD

*Department of Occupational Science and Occupational Therapy
University of Toronto
Toronto, ON*

RACHEL ZULLA, BA
Dalla Lana School of Public Health
University of Toronto
Toronto, ON

CHARISSA LEVY, MHSC
Toronto ABI Network
Toronto Rehabilitation Institute
Toronto, ON

Abstract

Objective: This study examines the issue of living environments for persons with acquired brain injury (ABI), with the aim of identifying factors that enable or act as barriers to appropriate living environments.

Method: A qualitative study involving 31 semi-structured interviews conducted with 56 key informants representing various relevant sectors: institutional, community, residential and non-residential, consumer/advocacy and government/policy from six regions in the province of Ontario, Canada.

Results: The study identified such barriers as lack of ABI-specific facilities, beds and trained staff and a poorly coordinated system in many areas, with long wait lists for specialized residential settings. Clients with ABI need individualized treatment, making development of a standardized model of care difficult, particularly for those with co-morbid conditions. Solutions such as more flexible options for clients and better trained staff emerged.

Conclusions: The study presents solutions to challenges and limitations in addressing appropriate living environments for persons with ABI.

Résumé

Objectif : Cette étude examine la question des milieux de vie pour les personnes vivant avec une lésion cérébrale acquise (LCA) dans l'objectif de déterminer les facteurs qui facilitent ou font obstacle à un milieu de vie adéquat.

Méthodologie : Il s'agit d'une étude qualitative comprenant 31 entrevues semi-dirigées auprès de 56 informateurs clés représentant divers secteurs : institutions, communautés, milieu résidentiel et non résidentiel, clientèle/groupes d'intérêts, gouvernement et politiques provenant de six régions de la province de l'Ontario, Canada.

Résultats : L'étude a permis de repérer six obstacles tels que le manque d'installations, de lits et de personnel formé pour les cas de LCA, de même qu'un système peu coordonné dans plusieurs zones et de longues listes d'attentes pour les résidences spécialisées. Les patients vivant avec une LCA ont besoin de traitements individualisés, ce

qui rend plus difficile l'élaboration d'un modèle standard, particulièrement pour ceux qui présentent un état de comorbidité. Parmi les solutions, il pourrait y avoir une plus grande flexibilité de choix pour les clients et une meilleure formation pour le personnel.

Conclusions : L'étude présente des solutions aux défis et aux limites touchant le milieu de vie approprié pour les personnes vivant avec une LCA.

AQUIRED BRAIN INJURY (ABI), WHICH CAN RESULT FROM TRAUMATIC OR non-traumatic events, is a leading cause of death and disability worldwide (O'Reilly and Pryor 2002; Cameron et al. 2001; Thurman et al. 1999). A recent report identified over 30,000 emergency visits and/or hospitalizations for ABI in Ontario in one year alone (Colantonio et al. 2009). Advances in medicine, medical technology and rehabilitation have increased survival rates and life expectancies such that survivors may live for decades with disability. Persons who sustain traumatic injuries are often young, and even mild injuries can lead to long-term disability (Colantonio et al. 1998; O'Connor et al. 2005). The consequences for families and caregivers, in terms of caregiving responsibilities and quality of life, are enormous (Kolakowsky-Hayner et al. 2001; DeMatteo et al. 2008). Families require long-term support, but most professional interventions are provided during the acute period (Lefebvre et al. 2005; Leith et al. 2004). In addition, a large percentage (11%) of all acute care admissions have at least one alternate level of care day, indicating difficulties in care options beyond the acute care setting (Colantonio et al. 2009).

The goal of this study was to gain a better understanding of placement issues related to living environments for adults with moderate to severe ABI in the post-acute phase. Specifically, we explored inappropriate living environments, defined as those that fail to meet all of an individual's ABI-specific housing, support and treatment needs, as well as potential solutions to improve quality of life, by capturing the perspectives of a broad range of providers, consumer advocates and government policy administrators.

Methods

An "inappropriate living environment" was defined a priori by the study researchers as one that fails to meet all of an individual's ABI-specific housing, support and treatment needs. A qualitative approach generated the perspectives of ABI service providers, consumer advocates and government representatives, using data obtained from semi-structured interviews (Miles and Huberman 1994).

Participants

Purposeful sampling was used to recruit information-rich participants (Patton 2002).

Potential participants were identified from the investigators' resources, the Toronto ABI Network, provincial ABI service providers and related agencies (i.e., rehabilitation facilities, advocacy groups, community care access centres [CCACs], residential care providers, acute care facilities) and the provincial Ministry of Health and Long-Term Care (MOHLTC). Key staff members known to have extensive experience with the ABI population were selected from each organization and invited to participate in semi-structured interviews. Invitation letters were mailed to all potential key informants. Additional letters were later mailed to people who were suggested by recruited participants or by people on the original mailing list who declined the invitation to participate. Interviews were scheduled with willing participants during follow-up phone calls within one to two weeks after the mailing. In some cases, several telephone exchanges were required before interview dates could be scheduled. The interviewer would attempt to contact the informant up to three times before conceding loss-to-follow-up. Representation was obtained from each type of service provider and organization (Table 1) across MOHLTC-defined geographical regions.

TABLE 1. Number of interviews, by stakeholder category

Provider category	Number of interviews (%) n=31
Residential	9 (29)
Non-residential	6 (19)
Institutional	7 (23)
Government/CCAC	6 (19)
Advocacy/Consumer groups	3 (10)

Fifty-six respondents participated in 31 interviews. Sixteen interviews involved one participant; the remainder involved two to five participants. Respondents represented several different ABI-related job positions (Table 2) and had worked with the ABI population for a mean of 12.4 years, with 60% for 10 or more years. Twenty-nine per cent of respondents reported that their experience with the ABI population was in the public sector, and 8% had experience working with privately funded clients. Of the 63% who reported experience in both public and private sectors, more than half (59%) reported that "about 90% of their experience was with the public sector."

Respondents were asked to read and sign a consent form at the beginning of each interview. They were informed of the study's purpose, the interview's content and the confidential and voluntary nature of their participation.

TABLE 2. Number of respondents in job position

Current position	Number of respondents (%) n = 56
Director/Executive Director	17 (30)
Program Manager (oversees programs but has little direct contact with client)	13 (23)
Caregiver/Practitioner	13 (23)
Care Coordinator (ensures program of care is appropriate to client needs)	6 (11)
Program Consultant	3 (5)
Intake Facilitator (manages referrals and intake of clients)	2 (4)
Case Manager/Community Liaison (assists client with referrals, accessing services in community)	2 (4)

Data collection

The interview consisted of preliminary closed-style screening questions for demographic purposes, and open-ended questions about resources available, protocols followed and challenges faced by both service providers and clients in trying to find appropriate living environments for people with ABI. The interview format was pilot-tested with a service provider and adjusted accordingly. See the Appendix for the open-ended interview questions.

Thirty interviews were conducted face-to-face; one was conducted over the phone. Interviews lasted 45–90 minutes and were audiotaped and later transcribed.

Data analysis

Interview transcripts were imported into a qualitative software program, N6 (purchased online from QSR International – 2007 Cambridge, MA), for analysis.

A process of inductive analysis was employed. One researcher (DH) carefully reviewed the transcripts, coded the data line by line (open coding) and grouped them into categories and themes. The “lack of resources” theme, for example, emerged from several sub-themes (lack of appropriate structural facilities; lack of ABI-trained staff; accessibility), which were created as a result of collapsing several codes: space/resource issues, lack of properly trained staff, lack of awareness among doctors, no resources for young people, distance between clients and service, and several codes related to suggested changes/solutions to the existing ABI system. Initial codes were created from the interview schedule, and more codes were added after the researcher reviewed the

transcripts and identified common ideas/responses. Then, interview data (participant responses) pertaining to the codes were organized accordingly. Consistent with a “triangulation of researchers” method, whereby researchers work in partnerships or teams to bring different perspectives to the research to explore themes and interpretations across those perspectives (Denzin 1970; Brannen 1992), a second researcher (RZ) examined the transcripts to become familiar with the data. Together, the researchers refined the coding scheme and re-coded the data using an axial coding process (Lincoln and Guba 1985) to bring previously coded data together under broader categories (Creswell 1998; Glaser and Strauss 1967). Selective coding involved developing theoretical propositions (Creswell 1998; Glaser and Strauss 1967).

Results

Analyses revealed five challenges associated with finding appropriate living environments for individuals living with the effects of ABI: (1) lack of resources, (2) minimal coordination of services, (3) inappropriate waiting environments, (4) a two-tiered ABI system and (5) the need for individualized treatment.

1. Lack of resources

The greatest challenge in providing appropriate services and living arrangements for people with ABI that was reported by all types of providers was the lack of resources and infrastructure, specifically the lack of structural facilities, ABI-trained staff and accessibility.

LACK OF APPROPRIATE STRUCTURAL FACILITIES

One of the main barriers to finding appropriate living environments for the growing number of clients with ABI is a lack of ABI-specific community placements. Many patients, once ready to be released from acute care and rehabilitation facilities, have nowhere to go.

... the single [biggest] impediment in finding a placement is that there's no space. So even if we do assist them in finding a pathway ... the end goal is probably not going to be realized because it's just a lack of resources. (Non-residential provider)

Keeping patients with ABI in hospital beds longer than necessary reduces the number of beds available for new patients who require acute care (associated with high healthcare costs), a situation that unnecessarily inflates system costs and is an

inefficient allocation of resources. A common solution is to discharge patients with ABI to long-term care homes that often have beds available to accommodate non-geriatric patients but which often do not offer ABI-specific or age-appropriate services to address the unique cognitive and behavioural needs of these patients. Many providers noted the lack of spaces in residential facilities designed for individuals at an advanced stage of recovery who are ready to integrate back into society. This type of facility is usually the final destination for clients and has little turnover. Clients at this stage of recovery may be ready to live in income-based housing. However, these spaces are also limited owing to rising rental costs and injury-related symptoms and disability, factors that prevent most clients with ABI from finding employment with sufficient income to afford this type of living arrangement.

Respondents noted that residential providers and CCACs offer support to clients with ABI living at home or in long-term care facilities through day programs, which provide special rehabilitative care and offer family members a break from full-time caregiving responsibilities. Limited resources and funding, however, make offering this type of programming difficult, and availability varies across regions, residential providers and CCACs. Only some residential providers and CCACs have the staff or space to run such programs in-house, and the selection of off-site locations is limited by small budgets. Day programs are commonly offered in older buildings that lack elevators and wheelchair ramps, making attendance difficult for those with physical limitations.

Providers also indicated that few living environments are structurally equipped to deal with clients with ABI who exhibit behavioural problems or aggression. Many lack a secured unit where individuals exhibiting dangerous behaviours can be contained, a measure that is necessary to ensure the safety of clients with ABI, staff and other patients. The alternative – treating behavioural clients in psychiatric wards – is often inappropriate, as many clients with ABI exhibit violent behaviour in episodes (Eames and Wood 2003) and may not require full-time psychiatric care.

LACK OF ABI-TRAINED STAFF

Over the course of their recovery, individuals with ABI require the services of various healthcare professionals and providers, but respondents reported that the availability of these services does not meet the need. In many environments (i.e., nursing homes, residential facilities) the ratio of patients to caregivers is high, making provision of adequate care difficult. Many living environments, such as supported living apartments and residential facilities, have no on-site healthcare professionals to deal with medical emergencies.

Providers also reported a shortage of healthcare professionals with formal training specific to ABI.

They are not comfortable with and don't have the training for the behavioural and the cognitive ... coming out of university they have ... great backgrounds, they don't have the practical training so ... in terms of challenges, it's finding enough staff who have the qualifications to work with ABI.
(Residential provider)

Finally, many providers perceived that misdiagnosis or delayed diagnosis of ABI is common. They noted that medical professionals may not be trained or experienced in differentiating between symptoms of mental illness and symptoms of brain injury. Diagnosis is further complicated by an overlap of symptoms across conditions and the latent manifestation of symptoms months or even years after the injury (Karon et al. 2007; Brenner et al. 2009). Providers reported that patients who are misdiagnosed or diagnosed late are deprived of rehabilitation, regular monitoring and long-term follow-up critical for them to reach their full rehabilitation potential.

ACCESSIBILITY

Providers said that geographic distance and boundaries often pose challenges in providing ABI services. Rural regions of the province, in particular, have fewer ABI facilities and programs. Clients must often travel long distances to access needed services and must choose between obtaining less appropriate care in or near their home community and moving away from their family and community to receive the best care available.

So I think sometimes, there has ... [to be some] sort of a compromise – like do you want services close to home or do you want the absolute right services which are eight hours away. (Institutional provider)

Respondents reported that in large urban centres, clients without transportation may be unable to access valuable ABI care-related programs or services. The use of public transit requires certain cognitive and motor-related abilities that may have been compromised since the injury, and yet many survivors of ABI do not have the required visible physical disability to access special transportation services.

2. Lack of coordination of services

Another commonly reported challenge to finding appropriate living environments for people with ABI is the minimal coordination of services. Many respondents reported that the delivery of healthcare for survivors of ABI is a “patchwork of services” in which “pockets of services are available and usually with wait lists.”

Provincially, there is no formal systematic approach to link clients to services. Many respondents who serve clients outside the GTA reported a lack of organization in the current system and indicated that the absence of a central process has led to gaps, primarily at the rehabilitation and community re-integration stages.

... there's confusion of roles – no one knows how does the CCAC handle it, compared to how does the acute care system handle it, compared to how do other services handle it ... [things] occur by happenstance, ... it's kind of good fortune when placement happens, as opposed to logical result of.
(Residential provider)

Providers noted that because there is no coordination of services, individuals in similar situations and exhibiting the same symptoms might take different pathways for the same type of care.

Many providers reported that the absence of a provincial registry to catalogue all facilities in the province that offer services to the ABI population impedes communication among service providers and with ABI clients. Many respondents indicated that they did not know the full range of services available within their community and region and found it difficult to connect clients with appropriate care facilities, forcing patients to wait in their current living arrangement. Communication is especially limited between acute care centres and residential or community support providers.

Many clients are lost in the system because their movements between different stages of care are not monitored. The current system lacks a clear protocol on patient follow-up and on transference of patient information during transition periods. All providers felt strongly that individuals with ABI need to be tracked to ensure that they receive the best care as soon as possible and in the most appropriate living environment available.

LACK OF A POLICY FRAMEWORK

Respondents suggested that the MOHLTC lacks an ABI policy and uses a haphazard approach to ABI service provision.

... with the MOH there's really no policy framework for acquired brain injury. There are services that are funded, but there is nothing in mind ... [unlike] mental health, which sort of lays it out and says that ... for people with this type of problem, these are the kinds of services that you ... would want to see We have the definition of services, but how people get to them ... it often seems ad hoc. (Residential provider)

3. Inappropriate waiting environments

The mandate at every stage of care is to rehabilitate the patient to a point where he or she can progress to the next stage of care. However, discharge from the current living environment is often not possible because appropriate facilities for survivors of ABI are often full and have long wait lists. Residential facilities have the longest waiting periods, where waits of two to five years or more were reported. Furthermore, the available facilities may be inappropriate for the client's gender, age or both.

... putting a 22-year-old woman who has a brain injury that requires lifelong support and 24-hour supervision ... into an Alzheimer's ward ... it's an inappropriate placement. (Consumer advocate)

Clients with ABI who cannot access the next stage of care are forced to wait or settle for alternative living arrangements. Remaining in an environment that no longer addresses the patient's needs may delay further rehabilitation, and while alternative environments (e.g., nursing homes, long-term care homes) provide the basic required care, they are inappropriate because they are primarily devoted to geriatric care and do not offer ABI-specific services such as rehabilitative care and vocational opportunities.

... and what that means, of course, is you've just spent a whopping big whack of my taxpayer's money to put people through a program ... approaching their maximum potential for independence, and then you're going to discharge them ... you will see those gains disappear very quickly and you've wasted my taxpayer's money. (Consumer advocate)

As with children and youth with ABI (DeMatteo et al. 2008), the most commonly reported default placement for adults with ABI is at home with family. The family home is often an inappropriate living environment for survivors of ABI because the family may have difficulty coping with the demands placed on them. Alternatively, family members capable of providing care in the short term are subject to caregiver burnout over the long term, particularly if the caregiver is aging and is eventually unable to provide care.

... oftentimes the families just reach a point where their own mental health is beginning to suffer because of it ... and maybe there are a host of services coming in ... but it's not a full quality of life ... and ... the family just gets to the point where they're burnt out and so they're looking for permanent placement. (Government provider)

4. Two-tiered system: Private versus public funding

Interviews suggested that the ABI system is two-tiered, having a private and public sector. The nature and cause of a client's brain injury seem to determine whether he or she will access private or public care. Individuals who suffer a traumatic brain injury (TBI) in a motor vehicle or workplace accident generally receive compensation from an insurance settlement. Some respondents reported that clients with ABI in the private sector typically have quicker access to services and receive more appropriate care than those in the public sector.

... Is there types of insurance? ... so they're going to pick up some of the cost. Because then those people can tap into attendant care services, like a level of service that might not be available through [publicly funded services]. So for the person who has that extra insurance or maybe they had some kind of a lawsuit and there was a settlement ... there's monies available to pay for those extra kind of things. (Government representative)

Conversely, some providers indicated that private services are not automatically provided to clients using private funds. Private funding sources first assess the individual to ensure that he or she meets eligibility criteria for compensation and healthcare. For this reason, access to care may be delayed or denied, and the patient's health outcome may be compromised. In addition, many clients with ABI require lifelong support, and private funding, which lasts for a finite period of time, is often insufficient.

5. Need for individual treatment

Inappropriate placements were defined by the majority of providers as placements that do not meet or adapt to an individual client's ABI-specific needs. People with ABI differ with respect to their behaviours, mental health, physical health, co-morbid conditions and substance abuse problems, yet the current system's generic, one-size-fits-all program of care does not reflect these differences and is challenged in finding appropriate placements for individuals at each stage of care. Respondents suggested that the need for treatment on an individual basis makes developing a standard approach to placing and treating clients with ABI difficult.

... they're different from each other ... so it's very hard to get a common set of cognitive disabilities, and psycho-social [problems] ... they're like snowflakes ... it's very difficult to ... develop the right basket of services (Residential provider)

The presence and complexity/stability of co-morbid conditions makes placing clients with ABI more difficult. Many facilities, for instance, are not equipped to monitor and treat patients with tracheotomies or schizophrenia, conditions that require high levels of medical care in addition to the care required for the ABI.

Clients also have varying cognitive, behavioural and psychiatric needs that may present significant barriers to receiving appropriate care. Aggressive behaviours – specifically, violent outbursts often associated with brain injury – are especially problematic.

... clients who present with forensic and mental health dual-diagnosis issues are often not accepted into placement facilities because their staff cannot cope with the behaviours Aggressive behaviour seems to be a very common barrier for placement. (CCAC provider)

Residential facilities do not have medical personnel on staff available 24 hours a day, and clients may not be able to access acute care centres should immediate psychiatric care be required. Finally, ABI has been linked with increased substance abuse (Graham and Cardon 2008), a problem that many facilities are not equipped to handle.

Providing support to clients with ABI who have cognitive deficits, especially short-term memory loss, can be challenging. The level of consistent supervision and time commitment required for this type of care is often difficult for caregivers to provide. As a result, such clients are inappropriately placed in highly supervised environments (e.g., long-term care homes) that provide personal care (e.g., assistance with showering, medication), but rarely offer rehabilitative care or opportunities for clients to complete tasks independently.

Solutions

It is evident from the results above that much modification to the current system is needed. Solutions include additional resources, coordination of services, and respite and individualized care (Table 3).

Some respondents suggested that the MOHLTC should mandate ABI care providers to join the Toronto ABI Network, an association of 20 publicly funded ABI service agencies and organizations that offers information for providers about available resources and wait-listed services, as well as educational materials (Toronto ABI Network 2009). It was cited as invaluable in linking patients and case workers with resources. Other regions are attempting to create similar networks.

A variety of services are required to meet the needs of all clients in the ABI system and allow patients and their families to customize their program of care.

TABLE 3. Proposed solutions

Recommendation	Potential goals and benefits
Additional investments	
Living environments and discharge locations including apartments serviced by other agencies, outpatient programs and conversion of space in long-term care settings into specialized units and/or for short-stay housing	Provision of long-term appropriate living environments
More secured units incorporated into facilities	Meet demands of clients with aggressive and other challenging behaviours
Programs to enhance the knowledge and skills of ABI healthcare professionals and support workers across the province	Address the need for more ABI trained staff and professionals
Funding of accessible transportation that is available to all consumers, including those without physical disability	Reduce transportation barriers
Community partnerships and networks to promote greater exchange of information and reduce delays in service provision	Enhanced coordination across services
A province-wide tracking system of patients	Identify resource needs and system weaknesses and promote consistent case coordination
Intra-governmental coordination and collaboration	Address range of health/social/environmental needs of ABI patients
More respite care, home visits, counselling, etc. for families as well as financial and/or technical assistance to physically modify homes	Reduce the rate of caregiver burnout and address resultant placement challenges
Individualized care via continuous coordination from the beginning of care	Allow for better decision-making regarding care and greater flexibility to address client/family needs within the community in order to keep people out of more costly institutionally based services for a longer period.

I'd like to see a larger range of options available to us for placement. Right now ... if folks cannot go to long-term care, and their families cannot care for them, there are few other viable options. (Residential provider)

Two providers noted the economic benefit of offering more flexible services. Because many families require services for only part of the day, many functional patients with ABI could live at home instead of at an expensive long-term care facility. To provide ABI care on an individual basis, services should be coordinated from the beginning of care. However, within the public sector, this intensive case management would require more case managers, discharge planners, social workers and, ultimately, more funding.

Discussion

This study explored the perspectives and experiences of ABI service providers, consumer advocates and government representatives regarding the availability and accessibility of appropriate living environments for persons with ABI in a Canadian setting. Interviews revealed that challenges associated with finding appropriate living environments result from structural and systemic weaknesses, including insufficient resources and coordination of services, inappropriate waiting environments, a two-tiered funding system and an absence of services that meet the individualized needs of the ABI population. Solutions to these issues were also proposed.

The challenges reported by the ABI service providers are similar to those reported by survivors of ABI and their families. In a US study (Leith et al. 2004), persons with traumatic brain injury and their families reported a need for an early, continuous and comprehensive service delivery system. They felt that a state-wide agency devoted to the coordination and execution of a comprehensive service delivery system would address the challenges in accessing appropriate ABI care. They identified a need for survivors of ABI to connect with the system early, to enable families to make informed decisions, to encourage survivors of ABI to live as independently as possible, to assist family caregivers by offering more respite and in-home health services, and to maintain follow-up contacts. They also reported a need for information and education for service providers, clients and their families, including more specialized training for ABI support staff and health professionals.

Providers in this study indicated that survivors of ABI generally have quicker access to more appropriate services if the cause of their injury makes them eligible for private funding such as insurance payments or legal settlements. However, they also noted that private funding can create other barriers to appropriate care. Previous research found that Canadian and US survivors of ABI and their families experience frustration in trying to access private funding, reporting that compensation and services were often difficult to obtain and that they had to justify their needs repeatedly to the compensation agent (Lefebvre et al. 2005; Leith et al. 2004).

Providers offered a number of solutions that may begin to address problems within the existing ABI system. They felt that a wider range of options would provide more choice and availability, allowing service providers to develop programs of care to meet the individual needs of ABI survivors.

Many of the reported challenges result from a lack of sufficient funding allocated for the ABI population. Providers in this study stated that government funding is allocated on the assumption that patients with ABI get better, move through the system and recover; however, this is not the reality for all ABI survivors. US survivors of ABI felt that law- and policy makers do not know enough about their short- and long-term needs (Leith et al. 2004). Policy makers must be better informed about the needs of survivors of ABI so that more funding, and more long-term funding, can be devoted

to this population, and ABI-specific living environments and services can be made available. Increased funding could also help provide more professional services and specialized settings with trained staff. In the long run, this approach may be less costly to society, because a stable living environment with early interventions may reduce hospitalization or the use of health services.

Despite the weaknesses in the ABI system, some progress has been made in the last few years. Some publicly funded ABI-specific housing already exists. The MOHLTC recently provided \$5.6 million to provide better care for patients with severe behavioural problems and has expressed interest in building more specialized ABI units. The presence of the Toronto ABI Network has enabled providers to offer more adequate and efficient services, and many providers felt the Toronto ABI Network should be a model for developing a province-wide network to improve ABI service provision in Ontario. A centralized system, whereby information about all ABI service providers in Ontario (e.g., services offered, availability and information about ABI clients) is updated and shared, would address the problems associated with the current lack of coordination within the ABI system.

A potential limitation of this study is that interview participants were not specifically asked who should be responsible for implementing the recommendations that they were proposing. It is evident, however, that most of these solutions, particularly the provision of post-acute care, fall within the mandate of the MOHLTC both centrally and more locally, as more funding is being transferred to local health integration networks (LHINs). While efforts to improve the system should start with the MOHLTC, many of the solutions listed in Table 3 require collaboration between the MOHLTC and a wide range of ministries, agencies, associations and brain injury networks at the municipal, provincial and federal levels.

The Ministry of Training, Colleges and Universities, for example, could have an additional role to play in addressing the lack of interest in or sufficient availability of health-related training programs that have a focus on brain injury. Specialized community agencies and advocacy groups also have a role in promoting and providing ABI-related training to those already working with ABI survivors. The Ministry of Transportation and relevant municipal governments are key players in addressing the lack of appropriate transportation (both within and between urban centres/regions) for clients to access care and support. The Ministry of Municipal Affairs and Housing, as well as other arms of government that offer financial assistance to people renovating their homes to accommodate disability (i.e., Canadian Mortgage and Housing), should be involved to address the need for affordable supportive housing. Should there be an increase in lockdown/secure units, the Ministry of Community Safety and Correctional Services would have a role in promoting awareness/training for staff regarding clients who may benefit from referral to such resources. Finally, efforts to monitor, track and document patient needs and care programs, as well as initiatives to exchange informa-

tion, would require the participation of provincial ministries as well as established brain injury networks. Overall, it is evident that intra-governmental coordination and collaboration are necessary to address post-acute care needs of ABI consumers.

Because respondents represented existing organizations and institutions, many of the solutions offered were within the range of existing options. Innovative approaches – such as the use of technology for individual support (especially in more underserved areas), home modifications to complement or reduce staffing requirements, and more accessible education programs for staff in residential or institutionalized settings – did not emerge. Consideration should be given to innovative technology and its ability to enhance the quality of life of long-term consumers.

The results of this qualitative study represent the perspectives of stakeholders from different parts of Ontario who deal directly with ABI survivors daily and are intimately aware of the challenges faced by people who are seeking ABI-appropriate living environments. Because the participants represented a wide variety of organizations, job positions and provincial regions, we believe that the results offer a fairly accurate and broad portrayal of what is happening in the existing ABI system province-wide. The study's findings should, however, not be generalized or assumed to be representative of the perspectives and experiences of all ABI service providers in Ontario. This study provides an overview of challenges to appropriate living environments for persons with ABI as well as a range of possible solutions, and we hope it will form the basis for improving post-acute care after acquired brain injury.

Acknowledgements

The authors wish to thank all research participants and staff who made this report possible. In addition, we gratefully recognize support from the Ontario Neurotrauma Foundation, the Ontario Ministry of Health and Long-Term Care grant to the Toronto Rehabilitation Institute and the Toronto Rehabilitation Institute Foundation. The authors thank Dagmar Gross for assistance with the preparation of this manuscript.

Correspondence may be directed to: Angela Colantonio, PhD, Professor, Department of Occupational Science and Occupational Therapy, University of Toronto, 160 – 500 University Ave, Room 950, Toronto ON M5G 1V7; tel.: 416-978-1098; fax: 416-946-8570; e-mail: Angela.colantonio@utoronto.ca.

REFERENCES

- Brannen, J. 1992. "Combining Qualitative and Quantitative Approaches: An Overview." In J. Brannen, ed., *Mixing Methods: Qualitative and Quantitative Research*. Aldershot, Hants: Avebury.
- Brenner, L., R. Vanderploeg and H. Terrio. 2009. "Assessment and Diagnosis of Mild Traumatic Brain Injury, Posttraumatic Stress Disorder, and Other Polytrauma Conditions: Burden of

- Adversity Hypothesis." *Rehabilitation Psychology* 54(3): 239–46.
- Cameron, C., S. Pirozzo and L. Tooth. 2001. "Long-Term Care of People Below Age 65 with Severe Acquired Brain Injury: Appropriateness of Aged Care Facilities." *Australian and New Zealand Journal of Public Health* 25(3): 261–64.
- Colantonio, A., D.R. Dawson and B.A. McLellan. 1998. "Head Injury in Young Adults: Long-Term Outcome." *Archives of Physical Medicine and Rehabilitation* 79(5): 550–58.
- Colantonio, A., D. Parsons, R. Vander Laan and B. Zagorski. 2009. *ABI Dataset Pilot Project Phase 1 Report*. Retrieved April 7, 2010. <http://www.onf.org/documents/ABI_Dataset_Phase_1_Final_Scientific_ReportJune13.pdf>.
- Creswell, J. 1998. *Qualitative Inquiry and Research Design: Choosing among Five Traditions*. Thousand Oaks, CA: Sage Publications.
- DeMatteo, C., M. Cousins, C.-Y. Lin, M. Law, A. Colantonio and C. Macarthur. 2008. "Exploring Postinjury Living Environments for Children and Youth with Acquired Brain Injury." *Archives of Physical Medicine and Rehabilitation* 89(9): 1803–10.
- Denzin, N. 1970. *The Research Act in Sociology*. London, UK: Butterworth.
- Eames, P. and R. Wood. 2003. "Episodic Disorders of Behavior and Affect After Acquired Brain Injury." *Neuropsychological Rehabilitation* 13(1&2): 241–58.
- Glaser, B.G. and A.L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Graham, D.P. and A.L. Cardon. 2008. "An Update on Substance Use and Treatment Following Traumatic Brain Injury." *Annals of the New York Academy of Sciences* 1141: 148–62.
- Karon, S., J. Lazarus and L. Holman. 2007. "Challenges and Approaches to the Identification of Traumatic Brain Injury among Nursing Home Residents." *Journal of Head Trauma Rehabilitation* 22(6): 350–59.
- Kolakowsky-Hayner, S.A., K.D. Miner and J.S. Kreutzer. 2001. "Long-Term Life Quality and Family Needs After Traumatic Brain Injury." *Journal of Head Trauma Rehabilitation* 16(4): 374–85.
- Lefebvre, H., D. Pelchat, B. Swaine, I. Gélinas and M.J. Levert. 2005. "The Experiences of Individuals with a Traumatic Brain Injury, Families, Physicians and Health Professionals Regarding Care Provided throughout the Continuum." *Brain Injury* 19(8): 585–97.
- Leith, K.H., L. Phillips and P.L. Sample. 2004. "Exploring the Service Needs and Experiences of Persons with TBI and Their Families: The South Carolina Experience." *Brain Injury* 18(12): 1191–208.
- Lincoln, Y.S. and E.G. Guba. 1985. *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications.
- Miles, M.B. and A.M. Huberman. 1994. *Qualitative Data Analysis: An Expanded Sourcebook* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- O'Connor, C., A. Colantonio and H. Polatajko. 2005. "Long-Term Symptoms and Activity Limitations After Traumatic Brain Injury: A Ten-Year Follow-up." *Psychological Reports* 97(1): 169–79.
- O'Reilly, K. and J. Pryor. 2002. "Young People with Brain Injury in Nursing Homes: Not the Best Option!" *Australian Health Review* 25(3): 46–51.
- Patton, M. 2002. *Qualitative Research and Evaluation Methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Thurman, D.J., C. Alverson, K.A. Dunn, J. Guerrero and J.E. Snizek. 1999. "Traumatic Brain Injury in the United States: A Public Health Perspective." *Journal of Head Trauma Rehabilitation* 14(6): 602–15.

Toronto Acquired Brain Injury (ABI) Network. 2009. Retrieved April 7, 2010. <<http://www.abinetwork.ca>>.

Appendix: Open-Ended Interview Questions

Overview questions

1. How does the health/rehabilitation system enable placement of persons with TBI/ABI?
2. What are some of the challenges within the system in placing people with TBI/ABI?
3. Are there typical "pathways" followed by people seeking placement? If so, what are they?
4. What are your organization's *admission* criteria? What are your *exclusion* criteria?
5. What catchment area do you serve?
6. How large is your staff?
7. What programs/services are provided by your organization?
8. (For residential programs) What is the average length of stay? How many clients does your organization serve per year?
9. Can you estimate how many clients have been referred to your organization but are still waiting for services? How long have the clients at the head of your wait lists been waiting?
10. How many clients have been referred to your organization but were denied service? What reasons were given for denying service?
11. (For residential programs) Where are clients with TBI/ABI living while they wait? Do you consider it to be appropriate or inappropriate for them and why?
12. What changes would you like to see in the system that would enable more effective and efficient placement?

Specific questions

1. Is there a difference between ABI and TBI in how it affects placement (what is considered appropriate/inappropriate)? If yes, how so?
2. What are some of the needs of persons with TBI/ABI that are important to consider in placement?
3. How are these needs being addressed?
4. How are they *not* addressed?
5. How would you define/describe an *appropriate* placement for persons with TBI/ABI?

6. How would you define/describe an *inappropriate* placement for persons with TBI/ABI?
7. Are there any specific characteristics of TBI/ABI patients that put them at greater risk for needing placement and for being more likely not to get it?
8. What are some additional factors affecting placement (e.g., co-morbid conditions, age, etc.)?
9. What changes would you like to see that would enable more effective and efficient placement?
10. What are the characteristics of individuals who were denied access? Why were they denied access?