

Family Caregiver Support After ABI – Perspectives of Families and Service Providers

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Funded by:



Project Research Team

Kathryn Boschen, Ph.D., Toronto Rehabilitation Institute,
(Principal Investigator)

Gary Gerber, Ph.D., West Park Healthcare Centre

Caron Gan, RN, MScN, RMFT, Bloorview Kids Rehab

Clare Brandys, Ph.D., Private Practice, Neuropsychology

Judy Gargaro, M.Ed., Toronto Rehabilitation Institute,
(Project Coordinator)

Advisory Committee of professionals and family members
of persons with an acquired brain injury (n=9)

Objectives

- Present qualitative findings from ONF funded study on family caregiver support after ABI
- Highlight lived experience of family members
- Present findings from key informant interviews with ABI providers in Ontario
- Discuss implications for practice and service delivery

Experience of Families After ABI

“Rarely, the consequences are positive in that a family is brought together, finding a new meaning in life. More commonly, the consequences are highly negative, as wives take on roles for which they never bargained, mothers begin again roles they had long ago relinquished, and families become isolated....Head injury hurts families emotionally, socially, and financially.”



Brooks, D.N. (1991). The Head-Injured Family. *Journal of Clinical and Experimental Neuropsychology*, 13(1):155-188

Best Practices Initiative

- Three decades of research on disruptive effects of ABI on families
- ONF initiative
 - Move beyond discussing or describing caregiver stress and burden
 - Identify “effective” ways to reduce it
 - Promising Practices
 - Evidence-based Practices

Caregiver Focus Groups

- 6 Focus Groups
 - 3 groups in the Greater Toronto Area
 - 3 in other Ontario locations
- At least 1 year post injury (mean = 5 years)
- Living with a person with ABI
- Self identified as a caregiver

Focus Group Participants (n = 39)

- Female (72%), Male (28%)
 - Parents (56%)
 - Spouses (36%)
 - Sisters (5%)
 - Daughter (3%)
- Age range:
 - Caregivers: 18 – 79 years
 - Person with ABI: 12 – 60 years

Semi-structured Interviews

- Caregiver issues and needs
- Challenges in getting services and supports
- Helpful services and supports
- Ideal world scenario

Qualitative Analysis

- Content analysis of verbatim transcripts conducted by 3 team members
- Key themes identified:
 - Coping
 - Supports that worked
 - Supports needed
 - Barriers
 - “Ideal world” recommendations

Coping

- Overwhelmed and pulled in different directions
- Isolation
- Frustration with emotional and behavioural sequelae of ABI
- Stress related to profound life changes and future planning



“I got to the point in my life that I said that I was going to take X’s life and my life.... Because I couldn’t go on anymore.”

Supports that Worked = Supports That Are Needed

- Supports that worked are the same as the list of needed services
 - **BUT** not all participants had access to the same supportive services
- Often supportive services ended prematurely, if available at all

Supports that Worked/Are Needed


- Supports for client with ABI (e.g., day programs, therapy, personal care)
- Respite
- Formal and informal counselling
- Caregiver support groups
- Education about brain injury

"I can get some counselling on how to deal with him. That will be really valuable. Because that's what I need. I need how to deal with situations and just to understand the anger and where it comes from and how you can respond to it – Because I have been trying to deal with that myself....You can't do it yourself."

Supports that Worked/Are Needed

- Internet resources
- Tangible support (e.g., housekeeping, paperwork, errands, shopping, wills)
- Supports for siblings and children
- Case management/advocacy
- Financial/Future planning

Systemic Barriers


- Quantity and age-appropriateness of services
 - Professionals' lack of understanding and knowledge of ABI
 - Lack of continuity
 - Reactive services, not proactive
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Societal & Personal Barriers

Societal:

- Lack of understanding & awareness of ABI
- Stigma

Personal:

- Lack of time
 - Fatigue
 - Childcare issues
 - Culture and/or language
- 

"it's hard like as you said people don't understand [...] when you say brain injury, that the picture that people get in their head is a lot different than [...], memory problems and cognitive problems and why specifically you cannot leave this person by themselves."

What Would Help.....

- “Telebrain”: 24-hour telephone information line
- Access to peer support: telephone and computer, not necessarily face-to-face
- Continuity and reliability of service providers



“To me an ideal world would be Telecare. You have someone assigned to phoning these people occasionally about every six months and saying, “How are things going, how can we help you?” And they’re aware of what’s going on. And then they can tell them at that time.... “Have you tried this? Have you tried that?” ..It’s caring for the ones that are hurting at the time.”

Other Suggestions....

- Advocacy and help to navigate the system
- ABI-knowledgeable service providers
- Financial “break” on mortgages and ABI costs
- In-home respite: emergency and planned

Key Informant Interviews (n=16)

- 9 Ontario programs/agencies (Thunder Bay, London, St. Catharines, Richmond Hill, Toronto, Oshawa)
- 2 Ontario networks
 - Ontario Brain Injury Association,
 - Toronto ABI Network
- 1 Ministry of Health representative
- 4 researchers in US

Ontario Findings

- Most services focus on client with ABI
 - Services for family members are incidental
- Only one identified program offered formalized support to families
- If available, services for family members include:
 - Education about ABI and Resources
 - Support Groups
 - Individual Counselling

Challenges

- Funding, lack of services, and waitlists
- Ethnically diverse populations
- Front end loaded
- Private services more available to families
- Large catchments outside GTA

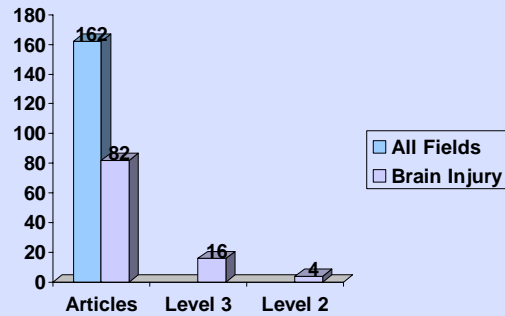
Interview Findings

CONVERGENCE of findings from family members and service providers/researchers indicate need for more:

- Services for spouses, parents, siblings, & children and family system
- Community based services – access as needed, long term
- One stop shopping – menu of services
- Proactive approach
- Networking and collaboration



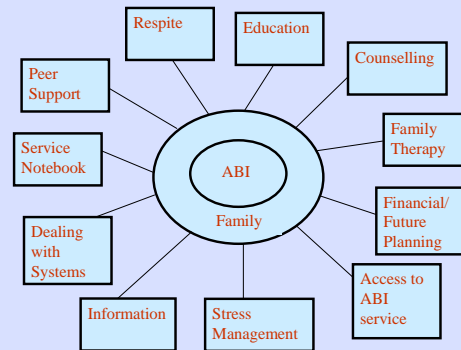
The Research Evidence



Research Shortcomings

- Lack of rigour
- Poor description of intervention
- Lack of standardization of intervention
- Inconsistent use of validated measures of program effectiveness
- Issues of parent and spouse addressed, **NOT** the family system

Menu of ABI Caregiver Services



Services for Families Looking Back - 1990's in Toronto

- Family Support Group (parents, adult siblings, spouses - up to 60 years)
- Groups for siblings and children of survivors
- HIAT/BIAT Spousal Support Group
- Spousal Educational Support Series
- BIAT Family Support Group
- Family Support Service (counselling for families of survivors 16 – 60 years)

And Now...

- Out of **40** publicly funded groups listed on ABI Network website, only 4 just for families in the community:
 - Parent Support Group (kids/younger teens)
 - Family Support Group (family members of survivors 16 – 25 years)
 - Sibling Support Group (6 – 13 years)
 - Parents of Young Adults & Teens with Epilepsy

Evidence-Based Projects

- Peer Mentoring
 - OBIA Project
 - Rehabilitation Institute of Michigan (Hanks)
- Brain Injury Family Intervention
 - Medical College of Virginia (Kreutzer)
 - Toronto – adolescent version
- Problem-Solving Training
 - Spain Rehabilitation Centre, Alabama (Elliott)
- Cognitive-Behavioural Family Treatment
 - Institute for Rehabilitation and Research, Texas (Sander)

Thinking Forward

- Build in more direct services for family members
- Pick from the menu of services
- Extend mandate beyond walls of institution
- Develop partnerships

Thinking Forward

- Ensure consistent use of outcome measures across settings
- Include research & evaluation components
- Develop partnerships



Contact Information

Dr. Kathryn Boschen, Study Director
(416) 597-3422, ext. 6205
boschen.kathy@torontorehab.on.ca