

Knowledge Translation of Communication & Cognitive Strategies for Persons with Traumatic Brain Injury

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Abstract

This project focused on knowledge translation of evidence-based communication and cognitive strategies for persons with acquired brain injury (ABI). Research demonstrates effective strategies, but the implementation of recommendations does not necessarily come to fruition in everyday care contexts. Caregivers are often left to deal with the long-term consequences of ABI with limited support or understanding of ABI. This project aimed to develop a resource toolkit for caregivers of people with ABI (family, staff, or health care professionals). Potential users of the toolkit (e.g., caregivers, clinicians) reviewed the toolkit and provided feedback. Results of the feedback and implications are discussed.

Knowledge Translation of Communication & Cognitive Strategies for Persons with Traumatic Brain Injury

The focus of this project was on knowledge translation of research in the area of communication and cognitive strategies for community re-integration for persons with acquired brain injury (ABI) in order to promote evidence-based practice. There is a significant amount of research on the effectiveness of various intervention approaches for persons with ABI; the implementation of recommendations from this research, however, does not necessarily come to fruition in everyday care contexts. Additionally, rehabilitation services for persons with ABI are limited, often leaving caregivers to deal with the long-term consequences of ABI with limited support. The aims of this project were to develop a resource toolkit for caregivers of people with ABI, and to obtain feedback from potential users of the toolkit.

Knowledge Translation

Knowledge translation (KT) aims to apply research findings to relevant real world contexts through a system of interactions between researchers and knowledge users to link evidence and practice (Campbell, Schryer-Roy, Jessani, & Bennett, 2008; Canadian Institute of Health Research [CIHR], 2006; Davis et al., 2003). Synthesis of research findings, exchange of information, and interaction between the research community and research users are necessary for KT to occur (CIHR). Knowledge translation is an integral part of evidence-based practice, and provides validity to research and highlights clinical needs.

Intervention Needs

Unfortunately, service providers and caregivers of persons with ABI report a lack of caregiver services and resources (Caron et al., 2010; BIANs, 2007). Indeed, health care professionals locally have reported that the available services for persons do not meet the needs of persons with ABI. The development of evidence-based caregiver resources through knowledge translation is needed.

Training of a communication partner, such as a caregiver, may produce significant changes to the communicative behaviour of an individual with ABI (Tu, Togher, & Power, 2011; Togher, McDonald, Code, & Grant, 2004). Communication partners can facilitate opportunities for success in communication by providing appropriate supports to the individual (e.g., providing the opportunity to take on an information-giving role); communication partners can also reduce the communication potential of a person with ABI when using unsupportive behaviours (Godfrey & Shum, 2000; Jorgensen & Togher, 2009; Togher, 2000; Togher et al., 2004, 2009, 2010). Studies have also shown that some behaviours of parents may exacerbate problem behaviours and/or executive dysfunction in children with ABI compared to other behaviours (Potter et al., 2011; Woods et al., 2011). Alternatively, therapy designed to create positive interactions between parent and child through parent coaching has been demonstrated to reduce negative behaviours in a child with severe ABI (Cohen et al., 2011).

This project aims to develop an evidence-based resource toolkit for caregivers of persons with ABI. The toolkit followed the intervention approach of positive behavioural supports (PBS), an evidence-based framework for cognitive and psychosocial rehabilitation for persons with ABI, specifically positive everyday routines proposed by Ylvisaker and colleagues (e.g., Ylvisaker & Feeney, 1998; Ylvisaker et al., 2008).

A second major component included in the resource toolkit is Spaced Retrieval Training (SRT). SRT is a shaping procedure used to teach or re-teach facts or skills to individuals with memory loss. SRT is simple and easy to administer and has been successfully used with a number of clinical populations who experience memory loss, including people with ABI (Vance et al., 2010; Campbell et al., 2007; Turkstra & Bourgeois, 2005).

Method

Designing the Toolkit

The following resources were reviewed: parent and teacher resources, caregiver and teacher manuals, and treatment efficacy research on ABI intervention. The content of the resource toolkit was developed by using the collaborative positive behavioural support intervention approach of Positive Everyday Routines proposed by Ylvisaker and Feeney (1998) combined with the errorless learning techniques of Spaced Retrieval Training. To our knowledge, these two approaches, PBS and SRT, have not appeared together in any available resources for caregivers, and both are evidence-supported approaches.

Available information from the review described above was modified so that it was appropriate for caregiver use. Types of information included in the caregiver resource are: (1) ABI education, (2) an introduction to themes in brain injury research, (3) key resources for caregivers, and (4) chapters including descriptions of and strategies for dealing with identity issues, challenging behaviours, memory deficits, and executive dysfunction following ABI.

Obtaining Feedback on the Toolkit

Following completion, the toolkit was distributed to caregivers and individuals with ABI (who were identified by caregivers) for review. Caregivers and brain injury survivors were recruited from a local group home and a brain injury association. Speech-language pathologists and other healthcare professionals (e.g., occupational therapists) were also invited to review the toolkit. Healthcare professionals were recruited through a brain injury association, government providers of ABI services, and other ABI experts known to the researchers.

A Caregiver Feedback Form was used to gather feedback from caregivers, ABI survivors, and professionals regarding the value and appropriateness of the resource for use in daily living. The questionnaire included five visual analogue scales on aspects of the toolkit, and six open-ended questions. The results of the questionnaire were summarized for the mean ratings and common qualitative comments.

Results

Ten of the 17 people who were invited to provide feedback on the toolkit responded: three caregivers, one ABI survivor, and six professionals (four SLPs). Average ratings for each item are summarized in Table 1. On the 10-point scale, the overall scores revealed favourable views of the resource toolkit.

Respondents were also asked to answer open-ended questions by providing qualitative comments (see Table 2). Seven common themes emerged from the qualitative comments. Four reflected positive perspectives on the resource toolkit. Half of the professionals felt that the toolkit contained good content. As well, the majority of caregivers and half of the professionals felt that the examples were helpful. In particular, caregivers felt that the sections that explained the reasons for the behavioural sequelae were the strengths of the resource.

Discussion

The emphasis on everyday functioning and the integration of an antecedent-focused approach with suggestions for contextualized practice are important features of the toolkit, as these themes have been well-established in the existing research and clinical recommendations for community reintegration (Arco & Bishop, 2009; Ylvisaker, Turkstra, & Coelho, 2005). The toolkit also confronts the well-documented need for individualized intervention (e.g. Douglas, 2010; Ylvisaker & Feeney, 2000) through providing a variety of strategies and encouraging caregivers to try a number of approaches to see what works best for the individual. The application of research findings within the toolkit is considered to be one of the major strengths of the resource. The development of caregiver resources is of great value and in high demand. More research is required to understand how best to serve individuals and their caregivers. With further modifications and evaluation, this resource toolkit holds the potential to be a valuable resource for caregivers of persons with ABI. Further details on the feedback and revisions made will be discussed.

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Table 1

Means of the Ratings on the 10-Point Scale by Type of Respondent

Items	Caregivers (n =2) M	ABI Survivors (n=1) M	Professionals (n =6) M	All (n =9) M
Enough Information	0.5	3.5	2.1	2.1
Clear Strategies	5.8	3.0	3.6	4.0
Valuable Content	1.3	3.5	2.6	2.4
Helpful Toolkit	5.8	3.3	2.8	3.5
Will Use the Toolkit in the Future	5.8	n/a	2.6	3.7

Table 2

Most Frequent Comments and the Number and Percentage of Respondents Endorsing Each

Comments	Caregivers (n = 2) n	ABI Survivors (n = 1) n	Professionals (n = 6) n	All (n =10) n (%)
Examples were helpful	3	0	3	6 (60%)
Good work/much effort involved in the development of the toolkit	2	0	3	5 (50%)
Language level is too high/too much jargon for average person	1	1	3	5 (50%)
Should include information on coping with psycho-emotional needs	2	0	1	3 (30%)
Explanations of the reasons for behaviours/how brain injury affects behaviour were strengths	2	0	1	3 (30%)
Good content	0	0	3	3 (30%)
Should be separated into multiple documents	1	0	1	2 (20%)