

**Resilience and Individualized Community Integration Interventions for Persons with
Traumatic Brain Injuries**

Resilience and Community Integration in Rehabilitation

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This study has received funding from the Fonds de la Recherche en Santé du Québec (FRSQ).

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Why return to a life that no longer makes sense?

Hélène Lefebvre

Abstract

Investigators, caregivers, administrators and service users in the field of rehabilitation are increasingly interested in the concept of resilience, but the literature has very little to offer on interventions aimed at supporting the resilience of persons and their loved ones. This article describes the Personalized Accompagnement Community Integration (ICII), which is intended to support the resilience of persons with moderate to severe traumatic brain injuries (TBIs). An ICII implementation is currently underway and is expected to support social participation and stimulate the resilience of persons with TBIs. It is based on four frames of reference: community integration founded on the person's perception of their community integration, the ecosystemic model, the handicap production process (HPP) model, and the goal-setting process. ICII adopts an intervention perspective centered on the life plan of the person with a TBI.

Keywords: intervention, community participation, resilience, coping skills, rehabilitation, traumatic brain injury (TBI).

Introduction

Why, after having been exposed to a traumatic event such as a traffic accident, can some people return to their lives, yet others collapse? Why do some manage to mourn the loss of what they were before and then rebuild their life plan, while others live in despair? Even though the concept of resilience is not yet well defined, it may provide some answers. Some authors speak of resilience as an outcome, others consider it a collection of personal characteristics, and for still others it is a process. In rehabilitation in Quebec, investigators, caregivers, administrators and service users are increasingly aware of the potential of this concept, even though little has been published on interventions designed to support the resilience of persons who have sustained a traumatic brain injury (TBI) and their loved ones.

This article will describe an individualized community integration intervention (ICII) that encourages maintaining persons with moderate to severe TBIs in their communities as a way of supporting their social participation and fostering greater resilience. An implementation of this intervention is currently underway, and it is being evaluated as part of a research project.

Impacts of traumatic brain injury and rehabilitation

A TBI usually results in severe brain damage that disrupts the psychosocial functioning of the person and their family and friends for a long period of time, if not for the rest of their lives (Gélinas, 1998). The consequences of traumatic brain injuries are generally classified into one of three categories: physical (changes in motor skills, spasticity, chronic pain, fatigue, etc.), cognitive (concentration, language, memory, etc.),

or psychoaffective and behavioural (anxiety, irritability, apathy, impulsiveness, diminished self-esteem, depression, etc.) (Cohadon, Castel, Richer, Mazaux, & Loiseau, 2002).

The treatment and management of persons with TBIs represent a major challenge to the health system. The time required to recover from a TBI may vary, but physical recovery generally takes six months, intellectual recovery takes 12 months, and psychoaffective and behavioural recovery occurs in the two years following the head injury (Cohadon et al., 2002). Rehabilitation professionals report that psychosocial functioning (depression, self esteem, social support, etc.) is one of the most difficult areas to have a positive influence (White, Driver, & Warren, 2008). Currently, the most common psychosocial interventions are individual psychotherapy, crisis management, behavioural or behavioural-cognitive therapy, group interventions, and family therapy. Psychotropic medication is often used to treat symptoms of depression and anxiety (White et al., 2008).

Finally, the social reinsertion stage of persons who have sustained a TBI is a crucial time, both for the person and for their loved ones. The goal is to encourage them in their return to living at home and, as much as possible, foster former life habits, social roles, and productive and leisure activities (Gadoury, 2001; Caisse Régionale d'Assurance Maladie Rhône-Alpes, 2003; Lefebvre, Cloutier and Levert, 2008). Yet despite the considerable contributions being made by care and service organizations in the Quebec network, recent studies have reported considerable gaps in the post-rehabilitation phase (Lefebvre et al., 2008; Ministère de la Santé et des Services sociaux, 1999; Carrière, Reinharz, & Tétréault, 2005; Dumont, Gervais, Fougérollas, & Bertrand, 2004). These

gaps result in significant costs in terms of the social economy: isolation, divorce, depression, suicide, addiction, pathological gambling, and violence (Lefebvre et al., 2008; Lefebvre, Pelchat, Swaine, G elinas, & Levert, 2005; Colantonio et al., 2004; Dell Orto & Power, 2000; Dijkers, 2004; Durgin, 2000; Gosselin, 2003; Minnes et al., 2001; Nochi, 2000; Wagner, Sasser, Hammond, Wiercisiewski, & Alexander, 2000; Webster, Daisley, & King, 1999).

Research findings

Our research of the last ten years has found that satisfactory social participation is linked to the TBI person's ability to integrate into the community (Lefebvre, Vanier, et al., 2004; Lefebvre et al., 2007; Lefebvre et al., 2008). Today, with ten years of post-rehabilitative care, these persons are isolated and often idle, since most of them cannot return to the workplace and rehabilitation departments pay little attention to leisure activities (Dutil, Bier, & Gaudreault, 2007; Lefebvre et al., 2008; Lefebvre, Pelchat, Swaine, G elinas, & Levert, 2004). Furthermore, a large percentage of these persons experience poor community integration and require long-term assistance before they can take up activities of daily living (ADL) (Gordon et al., 2006). Generally speaking, the return to the community is difficult for many TBI persons if they do not benefit from medium and long-term psychosocial support that takes into account their needs and potential (Lefebvre et al., 2008; Dutil et al., 2007; Lefebvre, Vanier, et al., 2004; Gordon et al., 2006; Lefebvre et al., 2007). In addition, Cullen, Chundamala, Bayley and Jutai (2007) demonstrated that recovery from a TBI may continue for many years after the rehabilitation period, yet rehabilitation services are mainly limited to the first two years

following the trauma. The lack of resources in the community effectively limits the accessibility and availability of care and services that could support the person through their adaptation to life at home, and it causes a breakdown in service continuity. Many persons have managed to overcome this lack of resources through their adaptation strategies and the support from their loved ones who, with time, become exhausted from the burden of everyday life with a TBI person (Lefebvre et al., 2008; Frosch et al., 1997). These compensatory mechanisms are not enough to support satisfactory social participation in the person's community integration. Despite the strategies proposed by caregivers and those developed by the persons themselves, the gains begin to erode due to lack of support and stimulation in the medium and long term. This is particularly true of life habits, which can only be stimulated in the context of the person's day-to-day life. In addition, in the post-rehabilitation phase TBI persons would like to have medium to long-term support from someone who would get to know them and play a stimulating role in their lives, but not be a health professional (to avoid what they have called the "white coat syndrome") (Lefebvre et al., 2008). This is why there is an urgent need for interventions that support the resilience of these persons.

Notions of resilience

Given the research findings and the problems left by a TBI, an intervention designed to support resilience appears to hold promise. Before we describe the intervention, we should take a closer look at the concept of resilience and briefly describe the qualities that are considered resilient and the associated protection factors.

There is no consensus at this time on how to define resilience; the definitions vary according to the author's goal. For Tisseron (2007), resilience is both the capacity to withstand a trauma and the capacity to rebuild following the trauma. Cyrulnik (2008) describes resilience as being able to return to a certain type of development after a crash, a traumatic psychic agony, and in adverse conditions while retaining in one's memory a representation of the injury as a new way of organizing the ego.

For Richardson, resilience is the « process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protection factors » (2002, p. 308), whether personal or environmental. Richardson, Neiger, Jensen and Kumpfer (1990) propose a highly convincing theoretical model of resilience that we use in the ICII framework. Their model can be summarized as follows: the stressor, filtered by individual and environmental protection factors, disturbs the individual's biopsychospiritual state of homeostasis. Following the disturbance and by implementing an adaptive learning process, the individual reintegrates a state that may consist of a dysfunctional reintegration, a reintegration with losses, a return to a state of homeostasis that existed before the disturbance, or a resilient reintegration in which the protection factors are re-enforced, renewed or developed.

A resilient person has certain personal qualities that may help them confront adversity. This adversity may also be a positive force, to the extent that it helps them develop and it re-enforces these qualities, which will prove useful in the future. They are called resilience qualities or characteristics (Richardson, 2002). The qualities that influence an individual's resilience are their psychosocial attributes (personal, social and

organizational competencies), family support and cohesion (problem solving, stability, and mutual support), and external support (ability to develop close relationships with family members and friends) (White et al., 2008). Resilience is not a personality trait that someone does or does not possess; it is the product of ordinary or adjustable competencies that can be learned, developed or lost, depending on one's life experiences (White et al., 2008). A short list of such competencies includes self esteem, problem-solving skills, critical judgment, humour, self-discipline, optimism, creativity, humility (Richardson, 2002), and the meaning that one gives to events (Frankl, 2005), to name a just a few. These competencies may be acquired through disturbance and re-integration, i.e., by being confronted with situations of adversity. They may also be developed or improved by interventions focused on the person's strengths, by education, or by the person learning key competencies valued in their environment (White et al., 2008).

A person's resilience may also be influenced by protection factors. These factors are the person's attributes, environments, or situations that appear to moderate the risks and adversity. These individual, family, or environmental characteristics may also be either protection factors or risk factors, depending on their intensity and their nature and according to their context (Jourdan-Ionescu, 2001).

Individualized community integration intervention

In a systematic review of the literature (1980-2006), McCabe et al. (2007) demonstrated that the intervention programs provided in outpatient clinics or in the community support efforts to return persons with a TBI to a state of functional autonomy. In addition, it would appear that persons who have participated in cognitive rehabilitation

programs report more satisfaction with their quality of life and their integration in the community, and that interventions that promote cognitive strategies allow more individuals to return to full-time productive activities. Finally, social support helps persons gain more control over their lives (Noreau & Tettamanti-Taiana, 2005). Few authors have specifically addressed individualized community integration interventions for TBI persons that feature collaboration with community organizations and the public health care and services network.

Frame of reference

ICII is based on four relevant frames of reference: (1) a conceptualization of community integration founded on the person's perception of their community integration (McColl et al., 1998; McColl, Davies, Carlson, Johnston, & Minnes, 2001); (2) the eco-systemic model (Bronfenbrenner, 1986), which links individual characteristics, the person's immediate and distant environments, values, attitudes and social policies; (3) the handicap production process (HPP) model, which links personal characteristics with the person's ability to act on their environment (Fougeyrollas, Bergeron, Cloutier, Côté, & St. Michel, 1998; Fougeyrollas & Noreau, 1997); and (4) the goal-setting process (Lefebvre, 2009; 2008), a divergent and convergent communication approach that allows the person to reflect on both their integration in the community and the process by which the intervention is developed in partnership, in order to choose for themselves a prospective project that will be as realistic as possible.

The view adopted in ICII has the intervention centered on the person's life plan – whatever that plan may be – to help them maintain their ability to exercise life habits and

attain a level of social participation that they find satisfying. ICII therefore aims to activate the person's strengths through their personal characteristics and their relationships with their environment.

ICII consists of supporting TBI persons in their activities of daily living (ADL). The attendant's role is to encourage the TBI person to carry out the ADL that they feel are important and that they find problematic or want to maintain. This approach seeks to complement other interventions – mainly therapeutic and provided by professionals – that provide only a partial response to the TBI person's need for community integration. ICII provides stimulation – in 2 two-hour sessions per week over a period of 12 months – that targets the person's abilities to exercise their life habits and fulfill the social component of their lives. According to the literature (Bourque, 2005; McCabe, et al., 2007), this approach appears to more successfully support community integration and improve social participation. It involves trained and paid attendants who are not health professionals but who have an interest in working with TBI persons, and this leads to improved management by community resources. The attendants are trained in the TBI's impacts on the person and their family, in communication approaches that foster exchanges with TBI persons, and in the therapeutic relationship. A five-day training session has been developed with caregivers specialized in traumatic brain injuries. The training comprises a theoretical component on the traumatic brain injury and its physical, psychological, communication, and social impacts. It also includes participation with a caregiver in an activity at the rehabilitation centre, participation with a caregiver in interventions in the home or in the community, and participation in two social activities provided by a Quebec association of people with TBIs (the Association Québécoise des Traumatisés

Crâniens, AQTC). During the intervention, the attendants prepare an intervention report that describes actions taken by the TBI person and the attendant to attain the objectives, as well as unforeseen events that could affect the person's ability to execute their ADL.

A team working as an interprofessional partnership (a project management committee, or PMC) was formed of caregivers from the public and community network, a representative from a health and social services centre (a Centre de Santé et de Services Sociaux, or CSSS), administrators, TBI persons, their loved ones, and researchers. The PMC's mandate is to partner with all stakeholders and help identify ADL that the person can work on in their natural environment with an attendant, implement the ICII, and train and support the attendants. In addition, the committee helps match attendants to TBI persons. It oversees the effective implementation of the ICII and serves as another participant in the coaching of attendants. Each month, an individual designated by the PMC follows up with attendants at a formal meeting, and other meetings are held as required by the needs of each attendant. The PMC meets approximately once each month, and an audio recording serves as minutes of the proceedings.

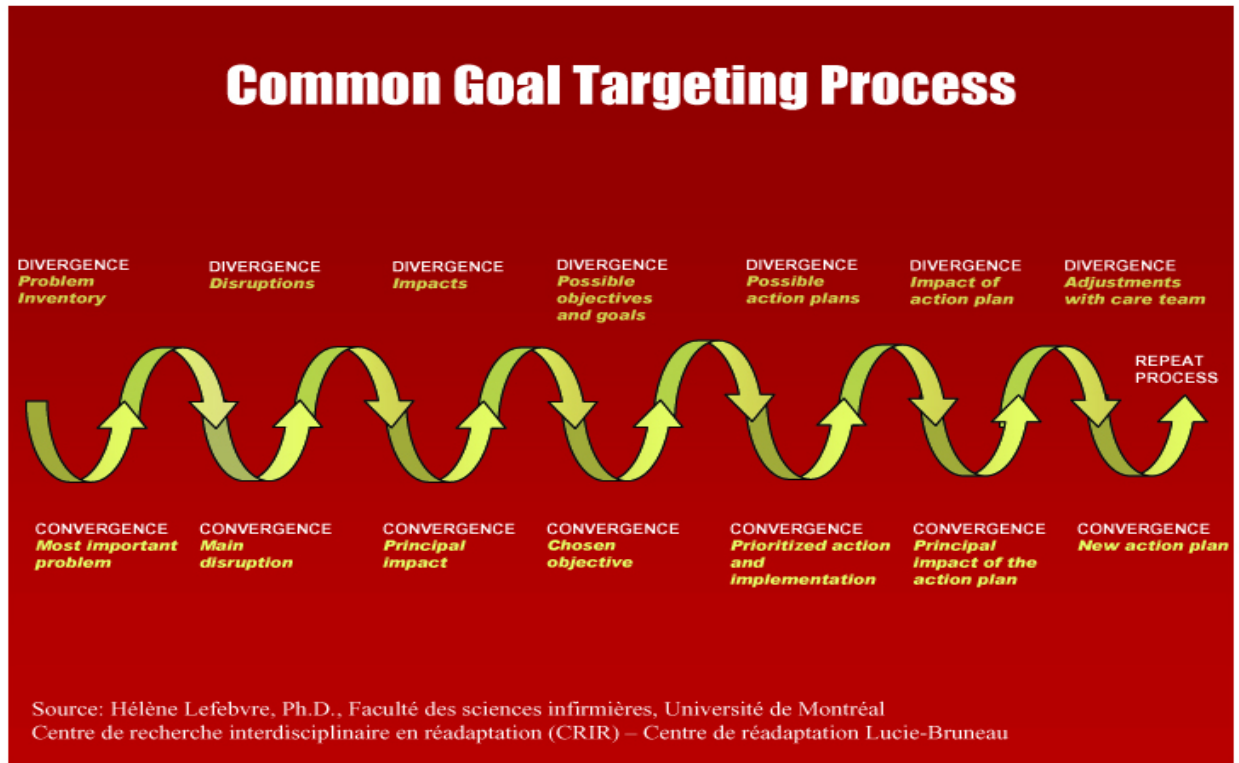
For each participant, a sub-committee is formed of a caregiver, a researcher and a project collaborator who is responsible for preparing a summary of the ADL that need to be worked on and for reporting progress to the PMC. A member of this sub-committee also meets with the participant, and together they determine an area of work of interest to the participant. However, the person's objective remains the priority.

The ICII is not a rehabilitation intervention. Rather, it is intended to be more like the Big Brother and Big Sister programs, helping TBI persons maintain social participation and resilience.

The philosophy of ICII is to take as its point of departure the person's desire to work on other components that are worth maintaining or improving. The intervention is structured as follows: the participant formulates an objective; plans, with the assistance of the attendant, the stages required to reach their objective; and evaluates what has been accomplished. With this structure, the person can be guided through a constructive and useful process in all their activities.

The goal-setting process (Lefebvre, 2009; 2008) is used to help the person select their plan. The process consists of questions in divergence, meaning that they open onto a group of elements that constitute the situation that leads to convergence or a closing in on the priority item that the person has selected and, ultimately, the item toward which they could make a commitment. The process comprises 14 successive and systematic stages (see Diagram 1).

Diagram 1



ICII: An intervention model centered on resilience

In addition to leading to a more satisfying social participation, the ICII intervention should support the resilience of the TBI person. The approach is an attempt to encourage the use of personal, family and community protection factors; foster the appropriation of knowledge and skills to achieve better autonomy; and support the development of competencies in relationships and within the family.

In addition, the presence of attendants twice each week should help expand the social support available to the family and, in the process, reduce the perception that the TBI is a burden on family members. Finally, the link with community organizations should foster more occasions for social and community participation (Jourdan-Ionescu,

Julien-Gauthier, Chagnon, & Huard, 2005). However, according to Jourdan-Ionescu (2001, 2005), it should be a long-term intervention.

The approach taken in ICII stands in contrast to the expert intervention, which is oriented toward the person's disabilities. Instead, ICII provides a partnership approach centered on the person's strengths and their chosen project. The intervention is built as a collaborative effort of the team, the attendant, the family, and the TBI person. It takes place in the person's natural life environment and offers them several alternatives (Jourdan-Ionescu, 2001). In contrast to the expert approach, the objectives of the intervention are identified from the point of view of the TBI person, and the activities are explored and implemented by the TBI person working together with the attendant. It is a collaborative effort based on partnership and shared responsibility.

Moreover, this partnership approach should lead to a co-development of skills through shared knowledge, shared know-how and self-knowledge in a spirit of reciprocity. This educational intervention should make it possible to co-develop skills, both inside the team of caregivers and researchers and with the attendant, the TBI person, and their loved ones. It allows the person and their loved ones to feel a greater sense of self determination and an expanded capacity to make decisions. The person will feel more in control of their life and more effective in how they manage their health condition.

This partnership approach could also help develop or enhance the TBI person's sense of personal effectiveness by recognizing their skills and the personal resources that they bring to bear (Bandura & Lecomte, 2002; Benight & Bandura, 2004). The very fact that the TBI person participates in the selection of objectives and project planning and

evaluation reinforces their confidence in their abilities. In addition, this approach helps develop their competencies by providing them with a structured process. It should also help them develop useful problem-solving skills, thereby fostering positive adaptations to their situation and allowing them to develop their life plan. The development of new skills and a feeling of personal effectiveness should facilitate their adaptation-transformation.

Conclusion

Implementation of the ICII project is currently underway. Through its supportive approach, it should help TBI persons pursue their development and take greater satisfaction from their social participation. It should help them make greater use of their personal resources and the resources in their environment in order to continue developing their current life plan or develop new life plans that are within their reach and that match their desires. Through its philosophy and approach, ICII should help stimulate or reinforce the resilient qualities of persons with TBIs, and perhaps even counter their loved ones' impression that their condition is a burden. This project should make it possible to develop greater sensitivity among rehabilitation caregivers and in the community concerning what TBI persons are experiencing. Ultimately, the partnership of all the stakeholders involved in this project should foster better knowledge of the problems faced by TBI persons among the caregivers working in primary care, and perhaps even result in them paying more attention to this client group. It is hoped that this intervention will lead to greater social participation by TBI persons.

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