# The Promise of a Qualitative Case Study Approach for Research on Caregiver Involvement in Inpatient Traumatic Brain Injury Rehabilitation

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### Résumé:

(traduction)

**Objectif**: Démontrer que, théoriquement, une approche qualitative par étude de cas est fort prometteuse pour la recherche sur l'implication des soignants dans la réadaptation après une lésion cérébrales traumatique (LCT) chez les patients hospitalisés.

**Méthodes**: Une approche narrative sur la réadaptation post-LCT et des études de cas issues de la littérature sont présentées afin d'expliquer notre raisonnement préconisant l'utilisation d'une approche qualitative par étude de cas pour faire de la recherche dans ce domaine.

**Résultats**: Nous avons découvert qu'il existe quatre raisons interconnectées qui expliquent pourquoi cette approche de recherche est bien adaptée pour étudier l'implication des soignants dans la réadaptation post-LCT chez les patients hospitalisés. Plus spécifiquement, une approche qualitative par étude de cas nous permet : (a) de comprendre le contexte de la réadaptation post-LCT; (b) de tenir compte de la complexité de l'implication des soignants; (c) d'adapter la recherche aux besoins pratiques et éthiques des patients avec une LCT et de leurs soignants; et (d) de développer de la recherche congruente à la théorie centrée sur la famille.

Conclusion: Une approche qualitative par étude de cas est capable de tenir compte de la complexité et du contexte qui entourent l'implication des soignants dans la réadaptation post-TBI chez les patients hospitalisés. Une approche par étude de cas est aussi congruente avec les circonstances de la réadaptation en milieu hospitalier et peut prendre en considération la théorie centrée sur la famille, une théorie importante afin de comprendre pleinement l'implication des soignants.

Soignant, étude de cas, qualitative, la réhabilitation, une lésion cérébrale traumatique

### Mots-clés:

# **Abstract:**

**Purpose:** To demonstrate that, theoretically, a qualitative case study approach holds substantial promise for conducting research on caregiver involvement in inpatient traumatic brain injury (TBI) rehabilitation.

**Methods:** Narrative reviews of the TBI rehabilitation and case study literature are presented to explain our rationale for advocating the use of a qualitative case study approach for research in this area.

**Results:** We found that there are four interconnected reasons why this research approach is well suited for investigating caregiver involvement in inpatient TBI rehabilitation. More specifically, a qualitative case study approach allows us to: (a) address the context of inpatient TBI rehabilitation; (b) account for the complexity of caregiver involvement; (c) adapt research to the practical and ethical needs of TBI inpatients and their caregivers; and (d) create research that is congruent with family-centered theory.

**Conclusion:** A qualitative case study approach has the ability to address the complexity and context that surrounds caregiver involvement in inpatient TBI rehabilitation. A case study approach is also congruent with the characteristics of inpatient rehabilitation settings and can take into consideration family-centered theory, which is instrumental to understanding caregiver involvement.

Caregiver, case study, qualitative, rehabilitation, traumatic brain injury

**Keywords:** 

#### Introduction

Caregivers play an important role in the short- and longterm rehabilitation of individuals (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012; Foster et al., 2012). This is especially true of caregivers whose loved ones are recovering from a traumatic brain injury (TBI). During the early phase of recovery, in acute care and inpatient rehabilitation, caregivers can play a valuable role by, for example, acting as a source of information for the healthcare team and assisting in goal setting and care planning (Foster et al., 2012). During later phases of recovery, caregivers support the patient with TBI as he/she attempts to live independently, and reenter school, work, and other community -based activities (Degeneffe, 2001). The literature suggests that caregiver involvement in the patient's rehabilitation for TBI can determine the degree of his/her recovery (Kreutzer et al., 2009). Specifically, studies have shown that patients with TBI have better cognitive and physical functional outcomes when their loved ones are actively involved in their rehabilitation (Braga, Da Paz Junior, & Ylvisaker, 2005; Chua, Ng, Yap, & Bok, 2007; Sherer et al., 2007). This support and care is also viewed as an important predictor of behavior change during the early stages of recovery from brain injury. It is believed that involving caregivers in inpatient rehabilitation may increase patient participation and thus, result in greater potential for outcome improvement (Harris, Eng, Miller, & Dawson, 2010).

Despite the key role that caregivers play, we know relatively little about caregiver involvement in adult inpatient TBI rehabilitation. There is minimal research on how the role of caregivers unfolds and how it is best facilitated by healthcare providers (Foster et al., 2012). To elucidate their complex roles in the rehabilitation of adults with TBI and to determine how healthcare providers can facilitate (or hinder) caregiver involvement during inpatient care, researchers need to explore the use of different research approaches for investigating this topic, including the use of approaches situated in qualitative paradigms. In this paper, we demonstrate that, theoretically, a qualitative case study approach holds substantial promise for conducting research on caregiver involvement in inpatient TBI rehabilitation. We explore the key features of case study research and delineate four interconnected reasons why this research approach is well suited for investigating this topic area.

# What is a Qualitative Case Study Approach?

Qualitative research has been surrounded by debate, and case study research is no exception. Case study research is one of multiple approaches to qualitative inquiry; however, the prominent theorists in qualitative research continue to debate what exactly it is and therefore, it may be somewhat difficult for those conducting research in TBI rehabilitation to clearly understand this approach. Stake (2005) proposes that case study research is not a methodology but a purposeful choice of what is to be studied, such as a person or event, bounded by time and place. Yin (2009) and Creswell (2013) instead argue that case study research is in fact a methodology, consisting of its own theory and analysis of how inquiry should proceed. In line with Yin and Creswell's views (Creswell, 2013; Yin, 2009) and to ensure rigor and quality in qualitative TBI rehabilitation research, we also consider case study research a methodology. The case study approach has a long history across many disciplines, including anthropology, law, political science, psychology, and medicine, and this is due in part to the case being the unit of analysis. Within the diversity of disciplines using case study research, it has been reported as valuable to evaluation and practice research for patient assessment, and documenting and analyzing care implementation processes and health outcomes (Gilgun, 1994; Yin, 2003).

# **Key Features of a Qualitative Case Study Approach**

It is important to understand the defining features of a case study approach before utilizing this approach in TBI research. Yin (2009) defines case study as "an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" (p. 18). The primary feature of case study research is the case as the unit of analysis and thus begins with the identification of one or more cases, such as a person, a group, an organization, or an event (Creswell, 2013). After identifying the case(s) of interest, a researcher must understand and decide his/her intent for conducting the case study. The intent may be to illustrate a unique case or to understand a problem, such as the lack of understanding regarding caregiver involvement in adult inpatient TBI rehabilitation (Creswell, 2013). Case studies are appropriate for exploring complex situations and allow for an in-depth

understanding of the case(s) (Yin, 2003). To obtain this level of understanding, a researcher must collect various forms of data, such as interviews, observations, documents, artifacts, or audiovisual materials (Creswell, 2013).

Whether a single case or multiple cases are chosen for a study, data analysis may consist of analyzing the case as a whole or as individual components within the case, or across cases to provide a comparison. During analysis, the researcher can identify themes and create a thorough description of the case(s). In order to effectively present the findings for the knowledge user, the researcher can then organize the themes chronologically, across cases for comparison, or present them as a theoretical model. Lastly, the researcher should offer the knowledge user concluding statements on his/her lessons learned from studying the case(s) (Creswell, 2013).

# **Types of Case Studies**

Yin (2003) outlines six different types of case studies: exploratory, descriptive and explanatory, each in either a single or multiple case study format. Simply put, a single case study is when a researcher chooses to study one case, whereas a multiple case study is when a researcher studies two or more cases. An exploratory case study is typically used when little is known about a phenomenon and it aims to identify potential questions and hypotheses for subsequent studies. A descriptive case study aims to thoroughly describe the case(s) within their context. Finally, an explanatory case study explains how something happened, implying a cause and effect relationship.

# Reasons for Using a Case Study Approach to Explore Caregiver Involvement in Inpatient Traumatic Brain Injury Rehabilitation

A Case Study Approach Addresses the Context of Inpatient TBI Rehabilitation

Context is the site, location, environment, or milieu that surrounds an area of investigation (Mathison, 2005). It is often multi-layered and made up of organizational, social, and political dimensions, which can facilitate or hinder research efforts. Since the context of TBI rehabilitation settings can impact patients and staff members as well as influence the level of involvement of caregivers in rehabili-

tation processes, it is an important variable to consider when conducting research. A case study approach allows researchers to study a phenomenon that is not readily distinguishable from its context (Yin, 2003) and thus, it represents a promising research approach for investigating caregiver involvement in TBI rehabilitation. Within this specific rehabilitation setting, caregivers often play a unique and especially active role in the care and services provided to patients (Degeneffe, 2001; Rosenbaum, King, Law, King, & Evans, 1998). The inpatient rehabilitation setting in itself is equally distinct, interconnecting many disciplines and service providers who work with patients and their caregivers. Thus, the inclusion of context is very important when conducting research in this area. Through the use of a case study approach one may be able to answer the following research questions while at the same time recognizing the distinguishing traits of this setting: How are caregivers involved in adult inpatient TBI rehabilitation? How do rehabilitation professionals facilitate (or hinder) caregiver involvement in adult inpatient TBI rehabilitation?

A Case Study Approach Accounts for the Complexity of Caregiver Involvement in Inpatient TBI Rehabilitation

One of the main benefits of using a qualitative case study approach is that it allows a researcher to examine complex situations (Yin, 2009). This is especially appropriate for both caregiver involvement and inpatient TBI rehabilitation. Caregiver involvement is a complex phenomenon and might be considered more so with adult patients. While caregiver involvement might be more readily viewed as inherent in pediatric rehabilitation, the interactions between an adult patient and their caregiver(s) can become complex when the patient is able and willing to participate in their own rehabilitation. In decision making and other care processes, the patient's perspectives and needs may vary from those of their caregiver(s), creating a complex dynamic. The perspectives of the caregivers may also differ from those of the healthcare providers caring for and providing services to the patients. It is important to recognize that caregiver involvement is not meant to remove control or responsibility from patients who are capable of making decisions and participating in their own care. Healthcare providers are therefore responsible for balancing the best interests of the patient with the recognition of caregivers' perspectives and needs, and professional expertise (Allen & Petr, 1998).

This complexity also extends to the rehabilitation setting itself. A rehabilitation setting encompasses professionals from a multitude of disciplines and various other important stakeholders. Rehabilitation for patients with TBI involves a collaborative team approach including medicine, nursing, rehabilitation therapy, psychology, social work, as well as the caregivers and patients themselves. Depending on individual needs, rehabilitation services may include occupational therapy, physiotherapy, therapeutic recreation, speech-language therapy, and cognitive rehabilitation, among others. These stakeholders interact on a day-to -day basis in decision making with a common goal of successful outcomes for both patients and caregivers. While each team member brings a unique perspective and expertise to a patient's care, outcomes are dependent on the successful integration of team members and productive interactions (Behm & Gray, 2012). Therefore, the interdisciplinary makeup of rehabilitation units/centers and their programs not only make these settings unique, but also lead to their dynamic and complex nature, which can be challenging to study.

A qualitative case study approach allows researchers to capture and explore this complexity through the inclusion of multiple perspectives (Yin, 2009). Given all those involved in inpatient TBI rehabilitation, there are certainly many perspectives to consider. Patients, caregivers, and the healthcare providers caring for and providing services to patients with TBI are important sources of information to acknowledge when researching caregiver involvement in TBI rehabilitation. Complexity can also be captured by relying on multiple forms of data (Yin, 2003). For example, using a case study approach, researchers can conduct qualitative interviews with patients, caregivers, and healthcare providers. They can observe conversations and interactions between patients, caregivers, and healthcare providers, as well as events such as team rounds and case conferences. They can collect and analyze documents relevant to patient care such as chart notes, policy and procedure documents, and any materials given to caregivers. Finally, they can collect relevant demographic information to develop a complete picture of caregiver involvement in inpatient TBI rehabilitation.

# A Case Study Approach Adapts to the Practical and Ethical Needs of Inpatient TBI Rehabilitation

As mentioned above, in rehabilitation, each patient and caregiver is considered unique (Rosenbaum et al., 1998) and as such, each patient's case is unique. In inpatient TBI

rehabilitation, healthcare providers will develop, with the patient and their caregiver(s), an intervention plan that is tailored to the patient's and caregiver's needs (Tsaousides & Gordon, 2009; Ylvisaker et al., 2007). For this reason, it is appropriate to view the patient, his/her caregiver(s), and associated healthcare providers as participants within a distinct and individual case. This demonstrates that case study research is well suited to inpatient TBI rehabilitation. Furthering this argument, case study research is respectful of the importance of viewing individuals as unique but also as embedded within a system. While each patient is viewed as having his/her own set of impairments and needs, he/she is also viewed within the context of his/her support system and environment. Nutt (2012) argues that this perspective is important in practice for the sake of respecting multiculturalism and remaining culturally competent and ethically sound in both care and research activi-

# A Case Study Approach Creates Research that is Congruent with Family-Centered Theory

Family-centered theory has been widely implemented in pediatric rehabilitation practice and many are calling for the universal adoption of this approach in all health services (Bamm & Rosenbaum, 2008), including those that care for adult patients with TBI. Family-centered theory posits that caregivers are central in the lives of individual patients, that health services should be guided by fully informed choices made by patients/caregivers, and that patients'/caregivers' strengths and capabilities should be recognized (Allen & Petr, 1998). Despite the fact that familycentered conceptual frameworks have been developed for the adult population in health care and that caregiver involvement in adult rehabilitation is recognized (Degeneffe, 2001); there remains much to understand about caregiver involvement in adult inpatient TBI rehabilitation (Foster et al., 2012) and how approaches to research can become more family-centered.

Not only does a case study approach provide an opportunity to better understand caregiver involvement in TBI rehabilitation, but it is also a research approach that is congruent with family-centered theory, potentially allowing us to enhance the level of family-centeredness within given research settings. By using a case study approach, researchers can ensure that a variety of caregivers' perspectives are included across cases as well as within cases (Creswell, 2013). They are able to include multiple individuals who influence patients' recovery, including family members,

friends, and significant others and value them as important the TBI rehabilitation context and in understanding caresources of information. A case study approach also enables the use of a variety of data collection methods (e.g., indepth interviews, review of diary entries) that provide caregivers with a medium through which to openly voice their views and concerns about TBI rehabilitation processes and their involvement in them. The use of such methods may provide caregivers with a sense that their voice is being heard and that they have much to offer in terms of advancing the understanding of caregiver involvement in TBI rehabilitation. Finally, a case study approach can exemplify the unique perspectives and situations of each patient and their caregiver(s) and potentially illuminate the reality that patients' and caregivers' priorities can often vary according to their age, the nature of their injuries, and the families' demographic characteristics. Not only is this uniqueness an important component of family-centered theory, but it can also illustrate similar or varying perspectives on caregiver involvement in inpatient TBI rehabilitation.

#### Conclusion

In this paper, we demonstrate how a qualitative case study approach is well suited for exploring caregiver involvement in inpatient TBI rehabilitation. We explain how it can allow us to address the unique context of inpatient TBI rehabilitation, account for the complexity of caregiver involvement, adapt research to the practical and ethical needs of TBI inpatients and their caregivers, and create research that is congruent with family-centered theory. Health care is recognized as a complex organization that is continuously evolving (Walshe, Caress, Chew-Graham, & Todd, 2004) and as such, case study research has the ability to address these complex changes by acknowledging the importance of context in research. It also encourages the inclusion of many data sources and the use of various data collection methods. For research on caregiver involvement in inpatient TBI rehabilitation, a case study approach can consider the complexity of interactions and the interdisciplinary makeup of rehabilitation settings and their programs. Moreover, it is congruent with the characteristics of inpatient rehabilitation settings and practices where a patient and his/her caregiver(s) each play a unique role and together, are viewed as a unique case.

Researchers have developed many approaches to investigation over the years, but none have considered their congruence with family-centered theory, which is instrumental to

giver involvement. Case study research provides an opportunity to better understand caregiver involvement in such a way that is congruent with family-centered theory. Familycentered theoretical concepts can help guide the design of the study as well as the data collection and analyses. By reflecting on a qualitative case study approach, this paper contributes to research methodology and begins to build on the very limited body of literature on how best to investigate caregiver involvement in adult inpatient TBI rehabilitation. To fully recognize both the strengths and limitations of using a qualitative case study approach to investigate caregiver involvement in adult inpatient TBI rehabilitation, we need researchers who are willing to use it in their studies and then reflect on and publish their experiences. As such, the lead author of this paper is currently using a qualitative case study approach to better understand caregiver involvement in adult TBI rehabilitation and will reflect on her use of this unique approach.

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#### **Declaration of Interest**

The authors report no declarations of interest.

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