



ORIGINAL ARTICLE / ORIGINAL / ORIGINALE

Needs Experienced and services received according to mild brain injury patients and families

Necessidades experientes e serviços recebidos de acordo com pacientes cerebrais leves ferimentos e familias
Necesidades experiencia y servicios recibidos de acuerdo con leves pacientes de lesión cerebral y sus familias

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ABSTRACT

Objective: the project sought to document the perceptions and points of view of the MTBI patient, their family and the professionals about their experience. **Methodology:** This qualitative pilot project was realized with focus groups with MTBI persons, family members and professionals. **Results:** The results show the needs of MTBI patients and their families with regards to their difficulties in obtaining appropriate information, family support, services to answer their needs and ease social integration. **Conclusion:** This pilot study enabled us to compile a profile of the subjective perception of the actors involved with respect to the needs of the MTBI clientele, the care and services received and their efficacy as viewed subjectively. **Keywords:** mild traumatic brain injury (MTBI), needs, services

RESUMO

Objetivo: O projeto buscou documentar as percepções e pontos de vista do paciente MTBI, sua família e os profissionais sobre a sua experiência. **Metodologia:** Este projecto-piloto qualitativa foi realizada com grupos focais com pessoas MTBI, familiares e profissionais. **Resultados:** Os resultados mostram as necessidades dos pacientes MTBI e suas famílias com relação às suas dificuldades na obtenção de informações adequadas, o apoio da família, serviços para responder às suas necessidades e facilitar a integração social. **Conclusão:** Este estudo piloto nos permitiu elaborar um perfil da percepção subjetiva dos atores envolvidos em relação às necessidades da clientela MTBI, os cuidados e serviços recebidos e sua eficácia como visto subjetivamente. **Palavras-chave:** lesão cerebral traumática leve (MTBI), as necessidades, os serviços

RESUMEN

Objetivo: El proyecto busca documentar las percepciones y opiniones de los pacientes MTBI, sus familias y los profesionales acerca de su experiencia. **Metodos:** Este proyecto piloto se llevó a cabo grupos de enfoque cualitativo con personas con MTBI, familias y profesionales. **Resultados:** Los resultados muestran las necesidades de los pacientes MTBI y sus familias con respecto a sus dificultades para obtener la información adecuada, servicios de apoyo familiar para satisfacer sus necesidades y facilitar la integración social. **Conclusión:** Este estudio piloto nos ha permitido elaborar un perfil de la percepción subjetiva de los actores involucrados con respecto a las necesidades de la clientela MTBI, la atención y los servicios recibidos y de su eficacia la vista subjetiva. **Palabras clave:** lesión cerebral traumática leve (MTBI), las necesidades, los servicios.

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INTRODUCTION

Treatment and follow-up of individuals with MTBI are a major challenge for the health system and compensation organizations in Quebec. In Canada, 85% of traumatic brain injury are mild and 15% are severe. Approximately 600/100,000 people are admitted to hospital every year for a mild traumatic brain injury (TBI) and 11/100,000 for a severe TBI⁽¹⁾.

In Quebec, at least 5,000 people are estimated to suffer a TBI each year, 40% of them as the result of a motor vehicle accident. MTBI cases account for 75 to 88% of all TBIs⁽²⁻⁴⁾.

Unfortunately, the lack of standardized procedures for assessment and follow-up restricts the possibility of documenting what happens to this clientele⁽⁵⁾. Similarly, there is little documentation on how well the services currently offered by the health system fit the needs of persons with MTBI and their families.

This article presents the results of a qualitative pilot study aimed at compiling a profile of the needs met or not met by trauma services following a MTBI, with respect to both the client and their family.

BACKGROUND

Mild traumatic brain injury

TBI is a physiological perturbation of cerebral function triggered by impact and associated with a reduction or change in the level of consciousness⁽⁶⁾. It has four main degrees of severity: severe, moderate, mild and minor. The criteria associated with a medical diagnosis of MTBI are very precise and comprise a set of conclusive signs including a Glasgow Coma Scale score⁽⁷⁾ of between 13 and 15, thirty minutes after the accident, loss of consciousness lasting 0 to 30 minutes, and post-injury amnesia lasting 0 to 24 hours. Computerized axial tomography of the brain or magnetic resonance imaging may be positive⁽⁸⁾.

In the hours and days following MTBI, post-concussion symptoms of a physical, psychological and cognitive nature are generally present⁽⁹⁾. Balance difficulties, memory problems or a slowing in the processing of information, and headaches may appear. These sequelae usually dissipate with time. Most people who suffer a MTBI recover within 3 to 6 months of the injury, without complications or functional difficulties⁽¹⁰⁾. However, 5 to 15% of them develop problems evolving into a chronic condition that may persist for years after the accident^(5,10-11). These symptomatic manifestations tend to be disconcerting for clinicians, not only because of their persistence, but also their intensity, which often exceeds their objective neurological or neuropsychological findings⁽¹²⁾.

The etiology and intensity of these persistent sequelae are also at the centre of a major debate in the scientific community. Some authors attribute them to psychosocial factors such as the patient's pre-injury personality and psychosocial functioning⁽¹³⁻¹⁴⁾. Other authors interpret them as an emotional reaction to the event^(12,15), while others still offer a purely organic explanation⁽¹⁶⁾ or a combination of

both⁽¹⁷⁾. Nevertheless, they all realize that the person is likely to endure psychological distress that may worsen and become chronic over time, and that an adjustment disorder may appear⁽¹⁴⁾. Adjustment disorder implies that the person experiences marked suffering and significant difficulty functioning in their educational, professional and social setting. In some cases, this psychological distress may also affect family members, who feel powerless in the face of the injured person's suffering⁽¹⁸⁻¹⁹⁾.

Services offered

A number of North American programs have been developed to offer coherent, standardized follow-up in response to the specific needs of MTBI victims⁽²⁾. However, there is currently a certain heterogeneity in the services offered for MTBI victims in the early phase, i.e. the first three months post injury. There are regional differences with respect to partnership between hospitals and physical rehabilitation centres. And the rehabilitation intervention for persons presenting an adjustment disorder more than 3 months after a MTBI continues to be debated⁽²⁰⁾.

A national survey of 68 Level 1 trauma centres in the United States has revealed a lack of consensus and consistency in identifying and treating patients following a MTBI⁽²⁰⁾. These authors attribute this heterogeneity to the fact that the treatment guides are incomplete in terms of intervention and treatment. This finding on the lack of consensus has led a few authors to develop guidelines based on the scientific literature and the recommendations of experts⁽²¹⁾. The recommendations stemming from these writings stress the importance of a clear, standard definition of MTBI and a standardized protocol for assessing the clientele. In terms of early intervention, the current guidelines recommend the transmission of information explaining that the symptoms may be normal, following up by telephone, offering psychological support and rehabilitation services, and promoting the rapid resumption of professional, educational and social activities.

Underlying these guidelines is the finding that most MTBI-related problems resolve spontaneously after three months. Similarly, the scientific literature has major shortcomings as regards the impacts of the follow-up provided for the MTBI clientele in the early or late phase. Furthermore, little is known about the experience and perception of families with respect to the victim's post-injury reactions. Yet the development of chronic problems in the individual may have long-term repercussions on their own and their family's social participation.

METODOLOGY

Objectives

This pilot study essentially aimed to compile a profile of the needs, met or unmet by trauma departments, of both the MTBI patient and their family. More specifically, the project sought to document the perceptions and points of view of the MTBI patient, their family and the professionals involved with this clientele with respect to needs in the areas of information, support, screening services,

early intervention and social integration of the individuals and their families.

Study Design

This pilot project is a qualitative descriptive study. It used co-construction of reality in an interdisciplinary approach⁽²²⁾. This method provided an opportunity to learn about, reflect on and examine the point of view of the different parties in order to understand the experience of individuals and families with respect to the response to their needs for health services as provided by the healthcare system⁽²³⁾. The data collection method was focus groups with MTBI individuals, their families and health professional working with this clientele. The advantage of this method is that it brings to light a wide range of information from many people at once, encourages the spontaneous expression of ideas⁽²⁴⁾ and compares different points of view.

Data collection

The data was collected by means of focus groups. Each group (persons-relatives, acute care health professionals, rehabilitation professionals) was met with separately, so as to obtain the point of view of each concerning: 1) the changes observed in the person who had suffered MTBI, 2) the perceived needs of these individuals and 3) the quality of care and services received and the follow-up. The discussion was led by a researcher from the team, assisted by an observer.

Sample

The participants were recruited by a resource person at a dedicated trauma hospital and a rehabilitation centre. The sample comprised 9 acute care professionals, 11 rehabilitation professionals, 7 persons with MTBI and 5 family members. Tables I, II and III present the sociodemographic characteristics of participants.

Table I- Sociodemographic characteristics of professionals.

Characteristics	Proportion of sample	
Discipline	<ul style="list-style-type: none"> • Clinical coord.: 5.0% • Occupational therapist: 10.0% • Nurse: 15.0% • Neurosurgeon: 5.0% • Neuropsychologist: 30.0% 	<ul style="list-style-type: none"> • Physiotherapist: 15.0% • Psychologist: 5.0% • Social worker: 10.0% • Emergency physician: 5.0%
Care phase	<ul style="list-style-type: none"> • Acute care: 45.0% 	<ul style="list-style-type: none"> • Rehabilitation: 55.0%
No. of years' clinical experience*	2.5 to 32 years (mean: 11.75; standard deviation: 9.55)	
No. of years' experience with TBI clientele	2 to 18 years (mean: 6.95; standard deviation: 4.98)	

*two data items missing

Table II - Sociodemographic characteristics of persons with MTBI.

Characteristics	Proportion of sample	
Age	19 to 60 (mean: 36.63; standard deviation: 14.10)	
Sex	<ul style="list-style-type: none"> • Women: 62.5% 	<ul style="list-style-type: none"> • Men: 37.5%
Length of time since accident	3 to 69 months (mean: 24.5 months; standard deviation: 21.8)	
Compensation	<ul style="list-style-type: none"> • SAAQ: 62.5% 	<ul style="list-style-type: none"> • CSST: 37.5%
Civil status	<ul style="list-style-type: none"> • Single: 37.5% 	<ul style="list-style-type: none"> • Common law spouse: 62.5%
Dependent children	<ul style="list-style-type: none"> • Yes: 37.5% 	<ul style="list-style-type: none"> • No: 62.5%
Education	<ul style="list-style-type: none"> • Primary: 12.5% • Secondary: 50.0% 	<ul style="list-style-type: none"> • College: 37.5%
Occupation	<ul style="list-style-type: none"> • Full-time work: 37.5% • Part-time work: 12.5% 	<ul style="list-style-type: none"> • Student: 25.0% • On sick leave: 25.0%

Table III - Sociodemographic characteristics of families.

Characteristics	Proportion of sample	
Age	20 to 65 (mean 46.83; standard deviation: 14.64)	
Sex	<ul style="list-style-type: none"> • Women: 66.7% 	<ul style="list-style-type: none"> • Men: 33.3%
Relationship with person with MTBI	<ul style="list-style-type: none"> • Spouse: 33.3% • Parent: 33.3% 	<ul style="list-style-type: none"> • Sibling: 16.7% • Friend: 16.7%
Residing with the person	<ul style="list-style-type: none"> • Yes: 50.0% 	<ul style="list-style-type: none"> • No: 50.0%
Civil status	<ul style="list-style-type: none"> • Married: 33.3% • Common law spouse: 50.0% 	<ul style="list-style-type: none"> • Single: 16.7%
Education	<ul style="list-style-type: none"> • Primary: 20.0% • High school: 40.0% 	<ul style="list-style-type: none"> • College: 40.0%
Occupation	<ul style="list-style-type: none"> • Full time work: 66.7% • Head of household: 16.7% 	<ul style="list-style-type: none"> • Student: 16.7%

Data analysis

A thematic content analysis model based on the procedure of Paterson, Thorne, Canam and Jillings⁽²⁵⁾ was applied to the data obtained. First, an exhaustive summary was compiled from the audio tape by the researcher and moderator for each discussion group. The summaries were then compared and, where necessary, completed. An initial analysis enabled the themes that emerged

from the remarks to be identified and their meaning extracted. This method was completed with a second level of analysis to identify areas of convergence and divergence in the comments, and pinpoint common threads. This analysis was approved by the study's co-researchers to ensure internal validity.

Criteria of scientificness

The methodological rigour of the qualitative aspect of the study was based on the following quality criteria⁽²⁶⁻²⁷⁾: 1) credibility (similar to internal validity), which was assured by comparing the summaries for each discussion group, by triangulation of the data obtained during regular validation of the reports of the work group meetings, with summaries of the highlights of an interview, and with a synthesis of handwritten notes and the keeping of a log; 2) transferability (similar to external validity), which was assured by the detailed description of the study's context, to allow the reader to understand and predict a similar situation in a similar context; 3) consistency (comparable to fidelity), which was achieved by noting any change to the research process in the log.

RESULTS

The results of this pilot study enabled the identification of the fundamental needs of persons with MTBI and their families, with respect to follow-up, information and psychological support. They clarified to what extent these needs are responded to or not with the current service offering.

Need for expert, early follow-up

The results demonstrate that the majority of acute care professionals found that in 47% of cases, the diagnosis turned out to be wrong; the individuals had not suffered a MTBI. At the same time, the diagnosis also seems difficult to establish when the person has suffered multiple injuries. Under these circumstances, the MTBI nearly always seems to be regarded as of secondary importance.

The work of the acute care team does not end when the person is discharged. Post-hospitalization follow-up is based on a *"patient self-care model"*. While they are in hospital, MTBI patients are given a pamphlet explaining the problems or discomfort likely to occur during the three months following the accident, and giving the name of a person to contact if necessary. Telephone follow-up is done two to three weeks after the person is discharged. This procedure identifies residual difficulties when there are any, and allows patients to be referred to the appropriate resources. It has the additional advantage of reaching individuals whose needs may not have been properly assessed. Based on the clinical experience of the acute care professionals, the success rate of this follow-up is acceptable.

The experience of rehabilitation professionals, persons with MTBI and their families was slightly different. The professionals felt that the diagnosis and treatment protocols vary according to the hospital and the geographic location, in an urban or rural environment. As well, most of the people met with were from rural communities and reported having to wait 1 to 24 months for the services of a rehabilitation centre. These findings concurred with the comments of rehabilitation professionals working in centres in outlying regions. They found that the MTBI clientele arrived late in this phase of care, on average 6 to 8 months after the injury.

This waiting period is very difficult for both the individuals and their families, who feel they are

being left to cope alone. Adding to the seriousness of the situation is the fact that some of them have no family physician. The findings showed that in most cases where the current follow-up was insufficient, the individuals were developing chronic problems. The information pamphlet was often lost or discarded after being read. Most people said they remembered receiving a telephone call, *"from someone who called and asked questions to see how I was"*. However, people did not remember who called or why. In their opinion, this was not an effective follow-up method. The person only became aware of their difficulties and their need for assistance gradually. Only after several months did most of them begin the formalities for receiving rehabilitation services: psychologist, physiotherapist, neuropsychologist, etc. In most cases, this took place in private clinics. Most rehabilitation professionals criticized the limited expertise of these resources and their functional orientation, which lacks a global, holistic view of the person with MTBI. When the person was referred to a healthcare network rehabilitation centre, communication with clinicians working in the private sector was often difficult and also with the public resources. Most rehabilitation professionals reported that accessing information was often a laborious process and made it difficult to assure continuity in the rehabilitation process; this in turn leads to a less favourable prognosis of recovery.

According to the professionals, communication between most hospitals and rehabilitation centres is difficult. In some instances, collaboration is better established, but the information transmitted from acute care is often incomplete (differential diagnosis, assessment results, etc.). This shortcoming is a serious hindrance to a rapid rehabilitation intervention catering to the specific needs of each client. This delayed their rehabilitation treatment, and was detrimental to their recovery.

Need for clear, accurate information

All the professionals taking part in the study agreed that the absence of a standardized protocol means that the quality and quantity of information given to people with MTBI and their families varies from one hospital to the next. And surprising as it may be, the clinical experience of rehabilitation professionals showed that most clients do not retain information conveyed to them during the acute care phase. All the MTBI subjects and their families said they could not recall receiving information about the diagnosis or prognosis at that phase of care. A number of them said they had received information to the effect that *"their problems would resolve with time"*.

Lack of information has disastrous consequences for the individuals who develop chronic difficulties in the medium and long term, and for those around them. They agreed that their problems did not necessarily disappear with time. The findings showed that all their difficulties were magnified by poor knowledge of the various symptoms and their origin: physical pains and headaches, attention and

concentration problems, fatigue, aggressiveness. Faced with impairments that they did not understand, and unable to resume their pre-injury functional level, these individuals saw their self-esteem diminish. Some deficits, such as irritability, concentration and attention problems, fatigue and headaches, constituted major barriers to their social integration: conversations became demanding, noise bothered them. People had more and more trouble maintaining satisfactory relations with their entourage. And the sense of powerlessness and social isolation stemming from lack of information was certainly related to the depression experienced by most participants.

This situation also had a negative impact on family members. They had little understanding of the person's experience. Their life as it was before the MTBI was disrupted. Most family members spoke emotionally of their desire to support the person, and their sense of powerlessness because they did not have information about the difficulties involved or strategies for coping. They felt they had been left to their own devices, not knowing where to turn in the healthcare system. Sometimes there were conflicts within the couple and the family, which increased the social isolation and sense of powerlessness experienced by everyone involved. They reported that lack of information leads to delays in requests for rehabilitation services. These delays help to crystallize, even aggravate, deficits, and the prognosis for recovery becomes less hopeful.

Most professionals agreed that the patient's state of shock at the time of the initial care prevents them from retaining information. The information conveyed during rehabilitation is designed to adjust the information retained during the acute care phase and explore how the person has built up a psychological representation linked to the difficulties experienced. For individuals with chronic difficulties, lack of information led to delays before the formalities were begun to obtain rehabilitation services. This delay contributed to making all deficits more resistant to treatment.

DISCUSSION

The findings of this study demonstrate interdependency between emotional distress and the physical and cognitive manifestations. The fatigue and stress involved when people attempt to deal with the demands of the environment and adapt to it may exacerbate certain symptoms such as headaches and dizziness^(10,15). The results showed that both these components in the experience of these patients were part of a vicious circle in which deficits increase stress and psychological suffering, which in turn trigger a recrudescence of symptomatic manifestations. This dynamic seems to contribute to undermining the social participation of the person and their family: daily tasks become difficult, social contact is awkward, and feelings of incompetence and powerlessness are heightened as a result.

Promoting expert, early, proactive, long-term follow-up

The MTBI situation is a substantial adjustment challenge⁽¹⁴⁾. The results of this study show that the

task was made even more complex because a number of the individuals and their families were left to their own devices for a long period, with no support from the environment and no information. The resources in the environment should be able to rectify this problem, among others with *expert, early, proactive and long-term* medical and paramedical follow-up for people with persistent difficulties. Studies show that telephone follow-up is an effective tool. With various clienteles, it enhances continuity of care and lowers costs for the healthcare system⁽²⁸⁻²⁹⁾. Telephone follow-up also seems to be of benefit for families, who felt supported⁽³⁰⁾. Given various guidelines for telephone follow-up that imply the expertise of the person in charge of this follow-up. In other words, there is reason to suggest that care teams should be trained in remote follow-up⁽³¹⁾.

At the same time, the results of this study show that the current post-hospital follow-up is characterized by its short duration. Unfortunately, it is more in the long-term that people become aware that their deficits are persistent. And some studies show that the individuals who experience symptoms three months after the injury are the ones at risk for persistent problems in the long term⁽³²⁾. Telephone follow-up should therefore go on for longer in order to fill the current gaps that leave people without resources until they begin the formalities for obtaining rehabilitation services.

Continuity of follow-up also requires better liaison between the various resources (hospitals, private clinics, rehabilitation centres, compensation organizations). The results of this study demonstrate that while collaboration between certain healthcare system institutions is sometimes well established, this is not always so. Forming a partnership between establishments would improve continuity of services and simplify the introduction of a screening protocol for MTBI and systematic intervention with this clientele.

Transmitting clear, accurate information

At present, the lack of resources for long-term follow-up is all the more serious in that individuals and their families receive little or no information enabling them to identify and understand their difficulties. Although providing written information during the acute care phase is recognized as a useful intervention. The results of this study show that the emergency care context is recognized as not conducive to retention of information by the patient, particularly in the context of MTBI and the associated confused state, and clinicians often appear to underestimate the importance of information as part of the rehabilitation process for these individuals⁽²⁹⁾.

This lack of information generates uncertainty, which may be detrimental to the prognosis in the medium and long term. This uncertainty is extremely trying for the person and their family. Uncertainty is one of the factors likely to amplify the intensity of symptoms following a MTBI, especially when it is associated with other factors such as pain, anxiety, loss of control over a situation, and inability to be in contact with the environment.

Information gives a person a sense of control over the situation and their environment and promotes

their adjustment to a health problem. When patients and their families are informed, they have more confidence in their own resources, and can play an active part in the whole care process⁽³³⁻³⁴⁾. Approaches that foster a partnership between patient and care team acknowledge the person's strengths and skills and are effective in the rehabilitation of MTBI⁽³⁵⁾.

Include family dimension in service offer

The findings of this study, together with the scientific literature, show that the situation of the person with MTBI is also hard on the family⁽¹⁸⁻¹⁹⁾. The accident and acute care cause a lot of anxiety. Persisting deficits may subsequently require the whole family dynamic to be reorganized, with family members taking on more responsibilities than before. During this study, relatives talked of feelings of powerlessness, physical and emotional exhaustion and the financial decline of the family. Most of them said there was a lack of information about the medium and long term consequences and the resources available. The results of this study show that the existing service offer fails to respond to the need of the families, which is basically a matter of support as they go through this experience. Judging by the experience of participants, support for the family is a major problem at the acute care stage, because most of the efforts are focused on the person with MTBI. Subsequently, the assistance plan of compensation organizations means that relatives do not benefit from services. Yet it is generally acknowledged that TBI is a difficult situation for the family and that they would benefit from support services⁽³⁶⁻³⁷⁾. These findings clearly demonstrate the importance of including the family dimension in the current service offering, and in particular by providing support for family members.

CONCLUSION

This pilot study enabled us to compile a profile of the subjective perception of the actors involved with respect to the needs of the MTBI clientele, the care and services received and their efficacy as viewed subjectively. While medical expertise responds to the needs of most MTBI victims, the fact remains that current services fall short when dealing with clients who develop persistent deficits. The absence of information and continuity of care makes the recovery of these individuals and the adjustment of their families a difficult process. The findings of this study point to the urgent need to develop longitudinal studies of the efficacy of services offered to this clientele, in terms of the resumption of social roles and the evolution of symptoms, so as to improve the care and services offered and provide more effective support for their rehabilitation.

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