

Families' Needs of Patients With Acquired Brain Injury: Acute Phase and Rehabilitation

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Abstract

Purpose: The aim of this study was to identify and compare the needs of families of patients with acquired brain injury (ABI) in acute care and rehabilitation settings.

Design: A descriptive exploratory study was conducted.

Methods: Data were collected in the acute care setting and in the rehabilitation setting during meetings with families ($n = 54$) of patients with ABI using the Family Needs Questionnaire.

Findings: In both settings, families identified obtaining information about ABI or the patients' health as the most important need, followed by support from health professionals.

Conclusion: For families, accessing information about the disease situation was important regardless of patients being in the acute care or rehabilitation phase. To provide tailored care for these families, it is important to assess information needs systematically already in the acute phase of hospitalization.

Clinical Relevance: A paradigm shift is desirable to include families in care, identify their needs, and support them in a more tailored way.

Keywords: Brain injury; family; hospitalization; neurology; nursing.

Introduction

Acquired brain injuries (ABIs) are the leading cause of disability in adults worldwide (Mar et al., 2011). In 2010, 2.5 million of people in Europe were suffering from a traumatic brain injury (TBI) or a stroke (Gustavsson et al., 2011), which are the two main forms of ABI. Stroke remains the second leading cause of death after cardiovascular diseases (World Health Organization, 2014), and its incidence is still growing (Feigin et al., 2015).

According to the International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001), a health problem can affect three domains:

organ function and anatomical structures, activity, and participation. All these areas can be compromised temporary or permanently in patients with ABI, depending on the severity of the injury and the spread of the lesion. Disabilities in physical health, cognitive functions, behavior, and change in personality could appear. Although cognitive impairments can be more difficult to diagnose, compared to physical injuries, they often have devastating consequences for the patient and its family (Leonhardt, Schmukle, & Exner, 2016).

Thus, having a family member suffering from ABI constitutes a crisis situation for the whole family. They face many challenges, which may affect their dynamics and functioning (Wolters Gregório, Stapert, Brands, & van Heugten, 2011) and impact their quality of life and their emotional and physical health (Murray, Maslany, & Jeffery, 2006). Because of the sudden and unpredictability of the ABI, patients and their families find themselves in situations for which they were unable to prepare (Mores et al., 2013). Knowing the needs of families and of each family member during the acute and postacute phases of patients with ABI is essential to enable coping and prepare for the future (Degeneffe, 2015).

Family is the largest group of survivors and caregivers and provides up to 75% of care required by people with ABI (Shanmugham, Cano, Elliott, & Davis, 2009). The role

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of caregiver often endorsed by the family is difficult: in addition to their own suffering and routine, family caregivers are responsible for the welfare, security, comfort, and coordination of care for their loved one. These responsibilities can represent a significant burden with consequences on their own physical and mental health. Families need to be included in the care planning of their loved one (Creasy, Lutz, Young, & Stacciarini, 2015). The recovery process and the patients' quality of life depend on the families' well-being (Lehan, Arango-Lasprilla, de los Reyes, & Quijano, 2012).

Literature Review

Despite existing research of needs and experiences of persons living with someone suffering from a stroke or a TBI, the focus is predominantly on caregivers specifically. However, the entire family is hardly considered at all, as it does not constitute a part of the unit of care. The needs of the families are, therefore, not identified systematically in clinical settings. Being aware of the families' needs can help nurses and interprofessional team to provide targeted care to these families and to improve quality of care (Lefebvre, Pelchat, & Levert, 2007).

Hospitalizations due to ABI constitute a critical point in time for patients and families. In the acute phase, care provided by the interprofessional teams is mainly targeted to maintaining neurological and homeostatic stability and preserving vital functions. Family members are often in shock and are unable to understand or retain the information given to them. Intense emotions such as anxiety, grief, sadness, and fear are present throughout the care pathway. These areas often remain unaddressed and therefore constitute the most unmet needs among relatives (Norup et al., 2015). Lack of information promotes suffering, and families feel incompetent (Kreutzer, Livingston, et al., 2009). Moreover, the patient's condition can change rapidly, leaving relatives in a state of confusion. In such moments, families are focused on the patients and have little interest in themselves.

It is, therefore, imperative to carefully explain the situation to the families so that they can grasp the meaning, understand their role in the care of the patient, and potentially undertake first steps in adjusting to the changed situation (Khabarov, Dimitropoulos, & McGillicuddy, 2015). Families need honest information specific to their situation and tailored to their needs in order to manage the uncertainty and the changing situation (Degeneffe, 2015). In the acute phase, family members need information about the diagnosis, prognosis, and treatment as well as about the factors influencing the evolution of the injury, such as the quality of care and the type of rehabilitation

provided (Kreutzer, Marwitz, Sima, & Godwin, 2015; Norup et al., 2015). Information must be relevant and specific to the situation, but also complete and provided continuously, be it orally or in writing. For families, it is important that health professionals are honest, understandable, accurate, and consistent (Coco, Tossavainen, Jääskeläinen, & Turunen, 2011). Families want to create a true partnership with healthcare professionals from the beginning of the acute phase. Because of the uncertainty of the prognosis and the effect of treatments, families experience much frustration and fear (Degeneffe, 2015). Families want to be considered as active partners in decision-making about the patient situation and not as mere visitors (MacIsaac, Harrison, Buchanan, & Hopman, 2011).

In the Western world, institutions offer opportunities for patients with ABI to receive intensive inpatient rehabilitation—the goal being to maintain or improve function for activities of daily life and achieve social and working reinsertion and a quality of life as good as possible (Mühl & Vuadens, 2011). In postacute phases, information continues to be an important issue. Families need to understand the impact of the ABI on the patients' daily life and their own life. It is essential that families comprehend the extent of the patients' deficits. Subsequently, families can develop coping strategies to manage the changes in daily life (Lefebvre, Levert, Pelchat, & Lepage, 2008) and to deal with the emotions and behaviors of their loved one (Bakas et al., 2016). Relatives also report the need for more practical support, including how to adapt to the requirements of the patients' new routine (MacIsaac et al., 2011). As soon as patients transition to the long-term, chronic phase of the ABI, families require information on health system resources, on social services, on their rights, and on their personal needs (Bakas et al., 2016; Lefebvre & Levert, 2012; Tverdov, McClure, Brownsberger, & Armstrong, 2016) and support to maintain social life (Perry & Middleton, 2011). Many patients present difficulties as a result from ABI, regarding access to work due to communication impairments and inabilities in using everyday life technology and activities of daily life (Fallahpour, Kottorp, Nygård, & Lund, 2015). Sequelae of ABI can negatively impact on the patients' role within the family as they may no longer be able to work or have to change their workplace. Therefore, the economic situation of the family may suffer, as well as their social standing.

Differences exist regarding needs of families of patients with TBI among countries such as Mexico, Spain, Denmark, and Norway. These differences are due to local conditions. Emotional and instrumental support needs were less important for Mexican families in comparison to families from Spain or Denmark, for instance (Norup et al., 2015).

Switzerland is a strongly federalist country, and a total of four different languages are spoken and considered main languages, namely German, French, Italian, and Rumantsch. In addition, the Swiss healthcare system differs considerably from other healthcare systems in relation to financial and organizational structure, political environment, and educational background of health professionals. Hence, understanding the families' needs within the context of the French part of Switzerland during the acute and post-acute phases of the disease trajectory of ABI is essential to contribute in continuous improvement in quality of care for patients with ABI and their families.

Theoretical Framework

For this study, the Calgary Family Assessment Model (CFAM; Wright & Leahey, 2013) was chosen as a theoretical framework, as it considers the family as a unit of care. Family is defined as *a group of people linked by deep emotional attachment and a sense of belonging to groups where everyone identifies as family members*. This definition is coherent with the actual structure of families. Systems theory, cybernetics, communication, and change theory constitute the conceptual basis of this model. The CFAM considers the family as partners in care. This model offers a structured approach to a comprehensive assessment of the family, the associated relationships, and the interactions. Thus, the influence of health-related problems on the whole family can be identified. As the focus of this study was on family needs, a systemic perspective was essential. This framework helps to *think family* and thus constitutes a paradigm shift. Employing a systemic view of the patient with ABI and the family is innovative in the Swiss context.

Aim

The purpose of this study was to describe and compare the needs of families of patients with ABI in acute care and rehabilitation settings, in order to improve the quality of support offered to them.

Methods

Research Design and Setting

A cross-sectional, exploratory descriptive study was conducted with approval of the local ethics committee at department of clinical neurosciences of a university medical center in acute hospitalization unit (AHU; service of neurosurgery and acute neurological rehabilitation unit) and in postacute neurorehabilitation centers (PARC; one PARC in university medical center and one local PARC) in the French part of Switzerland between fall 2013 and winter 2014.

Sample

Convenience sampling was used (Fortin & Gagnon, 2010). A total of 38 patients with moderate to severe ABI with cognitive impairments were identified when they were admitted to the AHU or to the PARC. The respective family members, that is, the patients' legal representatives designated under the Swiss Civil Code (Art. 378b: "CC 210 Swiss Civil Code of 10 December 1907", n.d), were identified and recruited for the study with another family member if possible ($n = 54$).

Inclusion criteria for patients were as follows: >18 years, hospitalized for >7 days, and have ABI with cognitive impairments.

Inclusion criteria for family members were as follows: >18 years, speak and write French fluently, and associated with the patient as decreed by law. Swiss law is very strict for people unable to give their consent to participate in a study. Therefore, the list drawn from the law (Art. 378b: "CC 210 Swiss Civil Code of 10 December 1907," n.d.) was used to identify the legal representatives.

Inclusion criteria for other family members were as follows: >18 years, speak and write French fluently, and considered as a family member by the patients or the legal representatives.

Data Collection

Sociodemographic data, family functioning characteristics, and importance of needs were collected from the participating family members.

Family Assessment

The genogram as described in the CFAM (Wright & Leahey, 2013) provides an overview of the whole family. It was used to identify all relevant members of a family and to obtain sociodemographic data from the participating family members (i.e., age, gender, education, profession) and family-relevant data such as internal and external structure characteristics (i.e., family composition, extended family, or social class) and functional characteristics (i.e., role, relationship, home structure).

Functional Capacities of the Patient

Based on the ICF (World Health Organization, 2001), data on the patients' learning capacities, knowledge application, communication skills, self-management skills, autonomy in everyday activities, relationships with others, social life implication capacities, and ABI were collected. The evolution of the prognosis was assessed 2 days and 2 weeks after admission to the AHU.

Family Needs Questionnaire

The Family Needs Questionnaire (FNQ; Kreutzer & Marwitz, 1989), which was specifically developed and validated for

families of patients with ABI, was used to assess needs. A Cronbach's alpha ranging from .79 to .89 has been reported (Kreutzer, Stejskal, et al., 2009). For this study, the FNQ was translated into French using backward-forward translation procedures (Le May et al., 2008). This version was subjected to a thorough scrutiny by the researchers involved in this study. The French version of this questionnaire presented good internal consistency with a .95 Cronbach's alpha for this population.

The FNQ consists of 42 items, is self-administered, and takes about 20 minutes to complete. There are six subscales: (1) Information need concerning health (i.e., patient status, treatment, diagnosis, prognosis, etc.), (2) Need for emotional support (i.e., friends network, discuss feelings), (3) Need for instrumental support (i.e., help for keeping house clean), (4) Need for professional support (i.e., to have support for managing patient's conditions and behaviors changes), (5) Need for community support network (i.e., to discuss with other family members or friends about patient conditions), and (6) Need for involvement in care (i.e., to be included in patient care pathway). Each item assesses the perceived importance of needs. Responses are on a 4-point Likert scale (1 = *not important*, 2 = *slightly important*, 3 = *important*, 4 = *very important*). A score for each subscale is calculated. An open space is offered for comments.

Procedure

Families meeting all inclusion criteria were identified by the nurse manager of the participating hospital departments and were informed of the study. Families who had indicated their interest in the study were subsequently contacted by the researcher. At that moment, the study protocol was presented. A 24-hour reflection period was granted. Families who still agreed on participation then were asked to sign the consent form. An interview appointment was planned. After the consent form was signed, the patients' sociodemographic and functional data were collected. At the interview appointment with one or two family members, the genogram was completed first, followed by the administration of the FNQ. The researcher remained with the participants to answer questions and to provide support if necessary.

Data Analysis

For the analysis of patients' sociodemographic and functional capacities, descriptive statistics were applied. Family genogram data (i.e., sociodemographic characteristic data of family members, internal and external structure, family functioning) were also analyzed by using descriptive statistics to determine frequencies and such. The FNQ

was analyzed according to the developers' specification manual (Kreutzer & Marwitz, 1989). Normality test were conducted. Differences in continuous variables were assessed using one-way ANOVA for normally distributed data and the Kruskal-Wallis rank test for nonnormally distributed data. Differences were considered statistically significant at $p < .05$ (two-tailed). Analyses were performed using Stata Release 13 (StataCorporation, 2013).

Findings

Sample Characteristics

For this study, a total of 38 families were included. Sixteen families comprised one patient and two members of the family; 22 families comprised one patient and only one family member. Tables 1 and 2 show sociodemographic characteristics of patients and family members. For patients ($n = 38$), the median age was 62 years old, and most of them are men suffering from moderate to severe ABI. Patients were equally distributed between AHU and PARC. Most of the patients were suffering from stroke and demonstrated partial capacities as evaluated by the ICF. The median age of the subsample of family members ($n = 54$) is 51.5 years. In this study, family members were predominantly women and Swiss. The majority of the participating family members

Table 1 Patients' characteristics

Patients' Sociodemographic Characteristics	<i>n</i> (%)
Gender	
Women	13 (34.2)
Men	25 (65.8)
Hospitalization unit	
Postacute neurorehabilitation center	20 (52.6)
Acute hospitalization unit	18 (47.4)
Lesion	
Illness	28 (73.7)
Oncology	6 (15.8)
Traumatic	4 (10.5)
Prognostic (2 days after occurrence) ^a	
Improving	22 (57.9)
Stagnant	8 (21.0)
Aggravating	8 (21.1)
Length of stay	
>1 month	16 (42.1)
<10 days	11 (28.9)
10 days to 1 month	11 (29.0)
Origin	
Swiss	21 (55.3)
French	6 (15.8)
Italian	6 (15.8)
Education	
College	16 (42.1)
Graduate	16 (42.1)
Postgraduate	6 (15.8)

^aPrognostic was based on medical opinion.

Table 2 Family member's characteristics

Family Member's Characteristics	M (SD)	n (%)
Age	51.2 (15.8)	
Men		20 (37.0)
Relationship		
Conjoint		24 (44.5)
Children		18 (33.3)
Parents		10 (18.5)
Others		2 (03.7)
Education		
Graduate		19 (35.2)
Postgraduate		18 (33.3)
College		17 (31.5)
Origin		
Swiss		27 (51.9)
French		12 (23.1)
Italian		9 (17.3)

were spouses and children. About family characteristics, half of the patients were considered to be the head of the family, and only one third of the patients' family homes were considered only partially suitable for the patients after ABI (Table 3).

Importance of Needs as Ranked by the Family Members

The perceived importance of needs for family caregivers was examined by using the FNQ with its six subscales (Graph 1). The most important perceived needs are information ($M = 3.7, SD = 0.3$) and professional support ($M = 3.4, SD = 0.6$) for both samples, followed by community support ($M = 3.3, SD = 0.7$), involvement with care ($M = 3.2, SD = 0.6$), emotional support ($M = 3.0, SD = 0.8$), and instrumental support ($M = 2.9, SD = 0.7$).

The FNQ offers a free-text option for comments by the participants. Overall, the family members most often mentioned that they wished for more time to talk to health professionals. It was also important for them to address questions to health professionals, to feel supported by the health professional, and to feel confident in confronting the situation as a result.

Table 4 shows the difference between the perceived importance of needs by family members of AHU patients and PARC patients: Engagement in care ($p = .05$) was found to be the only one statistically significant difference between the perceived importance of needs by the family members regarding engagement in care in AHU versus PARC. Other differences between AHU and PARC for other dimensions of FNQ are not statistically significant.

Discussion

Sample Characteristics

Throughout the world, more men than women suffer from ABI (mainly from stroke), and the medium age is

around 50 years (Feigin, Barker-Collo, Krishnamurthi, Theadom, & Starkey, 2010). The characteristics of this patient population correspond to similar populations in other countries. In this study, a majority of younger women were identified as family members, which is similar to other studies.

Participants in this study were hospitalized for less than 1 month. The participating patients were all either in AHU or PARC. In contrast, the majority of studies on needs of families of patients with ABI do not focus on specific periods during the disease trajectory. The long-term care setting has been studied predominantly. This is surprising given that much happens during the short period of acute and postacute care. The developments in AHU and PARC can have important consequences on long-term care.

Families' Perceived Importance of Needs

The most important need of relatives of patients with ABI, be it in AHU or in PARC, is information from the health-care professional about the patients' health. Although the Swiss healthcare context differs considerably from other countries in relation to structure, financing, and access to

Table 3 Patients' capacities according to the ICF

Patients' Capacities According to the ICF	n (%)
Learning and applying knowledge	
Complete	2 (5.3)
Partial	30 (78.9)
Any	6 (15.8)
Communication	
Complete	2 (5.3)
Partial	21 (55.3)
Any	15 (39.4)
Mobility	
Complete	5 (13.2)
Partial	22 (57.9)
Any	11 (28.9)
Self-care	
Complete	7 (18.4)
Partial	13 (34.2)
Any	18 (47.4)
Everyday activities	
Complete	5 (13.2)
Partial	13 (34.2)
Any	20 (52.6)
Interpersonal interactions and relationships	
Complete	3 (7.9)
Partial	20 (52.6)
Any	15 (39.5)
Community, social, and civil life	
Complete	2 (5.3)
Partial	22 (57.9)
Any	14 (36.8)

Note. ICF = International Classification of Functioning, Disability and Health.

Table 4 Comparison of mean ratings for perceived importance of needs, mean (*SD*), for family members

Subscales of FNQ	AHU <i>n</i> = 28	PARC <i>n</i> = 26	Difference between AHU and PARC <i>p</i> value
Health information	3.68 (0.37)	3.72 (0.30)	.66 ^a
Emotional support	3.22 (0.72)	2.80 (0.90)	.28 ^b
Instrumental support	2.94 (0.64)	2.92 (0.74)	.44 ^b
Professional support	3.55 (0.44)	3.33 (0.69)	.36 ^a
Community support network	3.36 (0.63)	3.33 (0.69)	.94 ^a
Involvement with care	3.35 (0.59)	3.08 (0.61)	.05 ^a

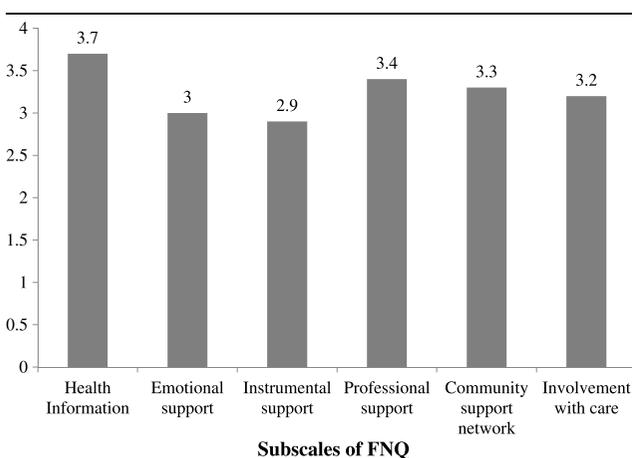
Notes. FNQ = Family Needs Questionnaire; AHU = acute hospitalization unit; PARC = postacute rehabilitation center.

^aWilcoxon rank-sum test.

^bOne-way ANOVA.

care, these findings are similar to previous studies. Relatives of patients with ABI need comprehensive explanations with details and specific information on the patients' health (Degeneffe, 2015; Kreutzer et al., 2015).

The family members have emphasized this need by also using the free-text option provided by the FNQ. The importance of professional support may be related to the severe consequences of ABI on families. The members of a family experience uncertainty related to the patients' prognosis, its slow evolution, and uncertainty about the future. Information given by all healthcare professionals needs to be coherent and specific to their own situation. Also, families need to be treated as such and not as mere visitors (Arango-Lasprilla et al., 2010). Conversely, families in AHU manifested less need for instrumental support (e.g., help with the organization of routine care according to the patient's impairment). It is already known that, in the acute phase, families focus on the actual situation including the patients' prognosis, treatment, and evolution (Lefebvre & Levert, 2012). Hence, the difference in this study concerning the need for involvement in care between families of patients in AHU and PARC demands further exploration.



Graph 1. Global score for perceived importance of needs for family members by subscales of the Family Needs Questionnaire.

Implications for Care

The nurses' role in the care of patients with ABI remains understudied (Portillo & Cowley, 2011). However, nurses constitute a key element of the healthcare system, particularly in departments of care of patients with ABI (Camak, 2015). The nurses' presence 24/7 supports the establishment of a therapeutic relationship. Also, the nurses' presence promotes a good understanding of the families' needs and of the patients' history, which promote patient well-being and families' daily adjustment to the situation (Portillo & Cowley, 2011). Integrating the family as early as possible in the care of the patients with ABI as well as planning care with the families throughout the acute and rehabilitation phase with a vision for life afterwards constitute main recommendations of this study. Understanding needs, considering these, and working with the families are an important starting point to decrease potentially negative consequences for the whole family. For instance, Karahan et al. (2014) found that active rehabilitation could decrease depression and anxiety in stroke caregivers.

A comprehensive assessment of family functioning, resources, strengths, and needs is necessary to determine risk factors. In particular, the genogram, as proposed by the CFAM, can be helpful in obtaining relevant information. It supports *think family*. In the present study, the CFAM promoted the inclusion of family members, which in turn facilitated access to patients who were limited in their communicative skills. Without the families' contribution, the patients' lives could not have been explored in detail. Involving family members may improve outcomes for themselves, but also for patients (Bakas et al., 2014; Creasy et al., 2015).

Furthermore, nurses do never work alone: The whole interprofessional team should be implicated in care for patient and families with ABI. The *Prifam* program, which is an interprofessional educational program for people with TBI, including healthcare professionals, patients, and families, constitutes one way for students to learn about

communication between health professionals and families in order to develop shared goals for rehabilitation (Lefebvre et al., 2007). Thus, care coordination can be improved, and patients and their families can be accompanied in a more meaningful way. Such interventions contribute to patients and families feeling acknowledged and supported.

Limitations of the Study

In the current context, collecting data on families of patients limited in their communicative skills or incapable of discernment is complex from the perspectives of law, ethics, administration, and organization. Indeed, relatives are solicited from everywhere, on top of their activities of daily life and their work. Organizing appointments has not been easy. However, families often visit their family member on evenings or on weekends, which does not necessarily coincide with regular work schedules. Thus, only a small sample size was obtained for this study and represents the main limitation of this study and reduces the possibility of generalization of the results. This study has employed a descriptive exploratory design, and therefore, the results need to be considered with precaution.

Patients recruited for this study experienced brain injuries associated with cerebrovascular diseases, traumatic injuries, or oncological diseases. Therefore, this sample is heterogeneous, which may have influenced the study results. Hence, heterogeneity should be considered as a limitation.

The instrument used for collecting patient data in correspondence with the ICF did not have any psychometric properties. Nevertheless, interesting data were obtained, which may need to be included in subsequent studies. Although the FNQ had been specifically developed for this population, the completion was considered too long to complete.

Conclusion

This study identified the needs of family members living with a person with ABI in AHU and PARC. As opposed to existing research, our study did include more than one family member and the patient in the acute and postacute phases of treatment. The families' needs in AHU are quite similar to their needs in PARC. This study highlighted that the needs of the families in both settings should be identified and considered in the care of patients with ABI as early as possible. Since the 1970s, a major progress has been made, thanks to the recognition of the key role played by families in such situations. Although this awareness is important as it reduces the impact on physical and mental health of family members of patients with ABI, the results of this study highlight that communication with healthcare providers is essential for families.

Key Practice Points

- In acute and postacute settings, families of patients with ABI needs information and support.
- Family needs for patients with ABI are similar in the Swiss context than around the world despite the originality of the Swiss healthcare system.
- Family members are often involved in care of patients with ABI, and they are not considered as part in the care process.
- A paradigm shift is desirable to think family: consider family members, include them in care, assess their needs, and support them better.

The interprofessional healthcare team is necessary for the comprehensive care of patients with ABI and their families. Further exploration is needed to improve interprofessional communication across the care continuum in order to improve long-term outcomes. Finally, integrated care pathways including advanced nursing practice roles to better coordinate and guide patients and families across the healthcare system are needed. Lack or limited communication between families of patients with ABI and health professionals occur regularly and constitute a key problem. In order to improve patient care, communication between these families and the health professionals needs to be strengthened. Therefore, interventions addressing communication problems are needed in order to improve the families' needs. Family experience, including resources and hopes, needs to be identified in order to provide adequate and tailored support. Interventions recognizing the family as a partner, including mutual exchanges and equal communication, can require significant changes, as a new system of care delivery needs to be implemented. Further studies are needed to develop and test early interventions to support families of patients with ABI. As a result, healthcare professionals need to be prepared. The challenges in today's healthcare system demand new visions in order to improve quality of care for patients and their families.

The authors declare no conflict of interest.

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