

## **La nature, les sources et l'impact de l'information sur la capacité d'adaptation des aidants naturels : un projet pilote**

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L'information transmise aux patients et aux familles aux prises avec des troubles de santé comme un traumatisme crânien ou un accident vasculaire cérébral (AVC) s'ajoute à ce que ces personnes savent déjà pour former un corpus de connaissances. Cette étude avait pour objectif d'identifier les besoins des aidants naturels en matière d'information, leurs sources d'information, leurs stratégies de cueillette d'information et l'impact de celle-ci sur leur capacité d'adaptation et leur lien avec les professionnels de la santé. Des groupes de discussions auxquels participaient des proches parents de personnes atteintes de traumatisme crânien ou d'un AVC ainsi que des professionnels de la santé de diverses disciplines travaillant avec cette clientèle ont été menés. Les besoins en information des proches parents portaient sur l'impact du handicap de la personne atteinte sur leur vie quotidienne. Selon le point de vue des professionnels, les besoins des proches portaient sur les incapacités de la personne, leurs stratégies d'adaptation et leurs sources d'information. L'expérience de la vie constituait la principale source de connaissances. Des recommandations en matière d'intervention en soins actifs et de réadaptation ont été émises à partir des résultats de l'étude.

Mots clés : familles, connaissances, santé, professionnels de la santé, traumatisme crânien, AVC

# **Nature, Sources, and Impact of Information on the Adjustment of Family Caregivers: A Pilot Project**

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The information conveyed to patients and families dealing with a health problem such as traumatic brain injury or stroke combines with what they already know to form a new pool of knowledge. The aim of this pilot study was to describe the information needs of family caregivers, their sources of information, their strategies for gathering information, and the impact of the information on their adjustment and their relationship with health professionals. Focus groups were held with close relatives of persons who had sustained a traumatic brain injury or a stroke and with health professionals from various disciplines working with these clientele. The information needs of relatives concerned the impact of the person's disabilities on their everyday lives. From the professionals' point of view, the information needs of close relatives concerned the person's disabilities, their coping strategies, and their information sources. Life experience was the main source of knowledge. The results form a basis for recommendations regarding interventions in acute care and rehabilitation.

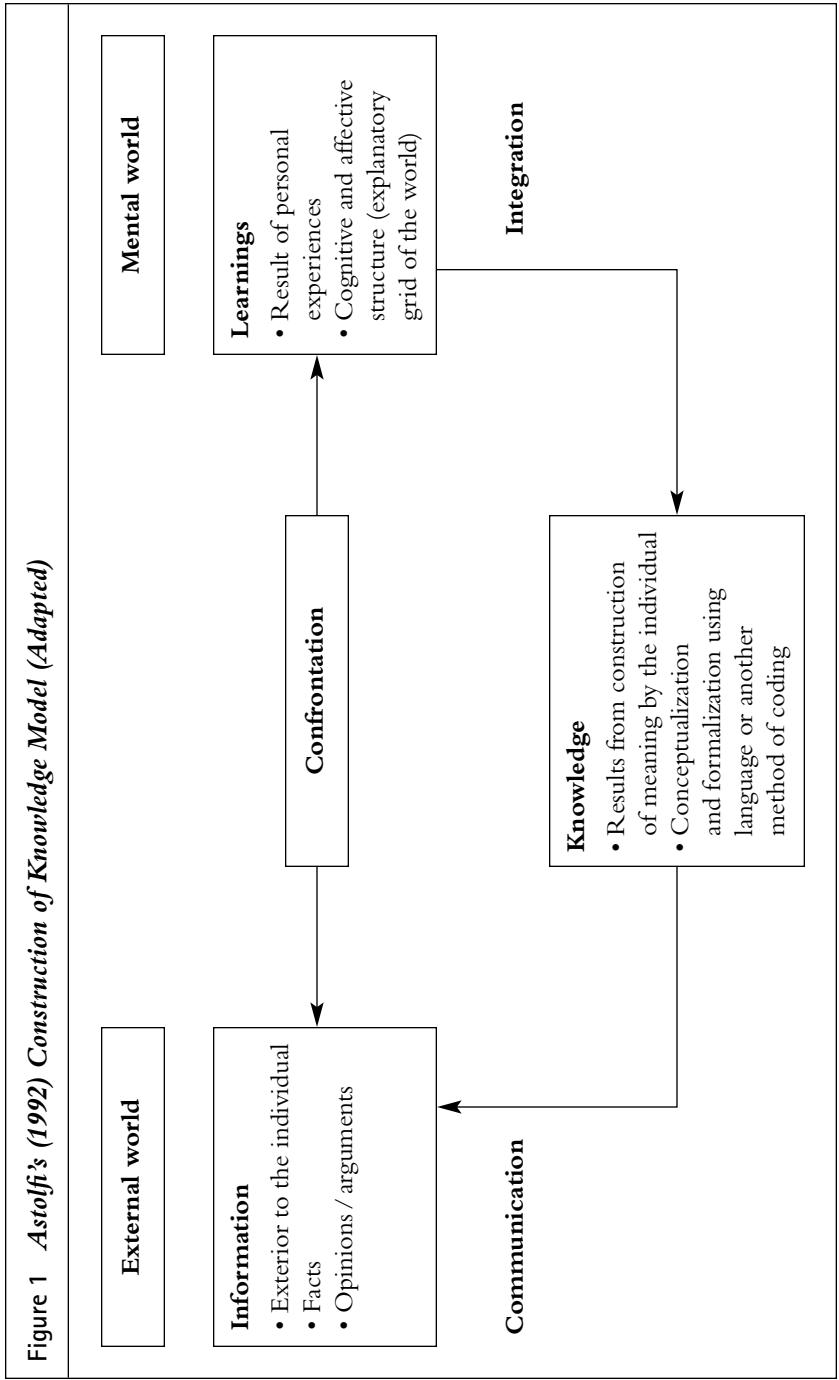
Keywords: Families, knowledge, health, health professionals, head injury, stroke

## **Introduction**

In a health situation, the information conveyed to the patient and family helps to ensure the transfer of new knowledge and skills to daily life. This information is integrated with existing knowledge to form a new body of knowledge that gives people a degree of control. Knowledge acquired in a contextualized setting leads individuals to integrate new skills that make them more autonomous in their choices with respect to the situation (Bouchard, 1999; Vygotsky, 1985).

Family caregivers glean their information from various sources — for example, from health professionals, discussions with relatives or friends, and print or electronic media (Tooth & Hoffmann, 2004). The Internet is a major new source of informal knowledge that can enrich daily life and serve to empower (Fostier, 2005; Journal du Net, 2002).

Accordingly, it is essential to ensure that patients and family caregivers are properly informed, and above all that the information they receive matches their needs and concerns and is easily transferable to their daily



lives (Rodgers, Bond, & Curless, 2001). Health professionals have to recognize people's knowledge, be receptive to their reality, and make sure they are satisfied with the information they receive (Tooth & Hoffmann, 2004). The increasingly structured involvement of family members in the management of the rehabilitation process is redefining the dynamic of discussions with professionals, who are now coming to view the knowledge of family caregivers as credible (Bouchard, 1999).

Yet, surprisingly, in contrast to the situation in oncology, psychiatry, and cardiology, there is hardly any literature on the information needs of individuals who have suffered a traumatic brain injury (TBI) or stroke (cardiovascular accident, or CVA) and their families. Research findings show that even though these two clienteles are very different and experience distinct repercussions, they have similar information needs. Family caregivers require information on prevention; TBI or CVA; medical and rehabilitation interventions; short, medium, and long-term prognoses; strategies for coping with stress; social support; experiences of family members of other TBI or CVA patients; how to reintegrate daily living; and long-term services for TBI patients (Lefebvre, Pelchat, G elinas, Michallet, & Levert, 2005; Lefebvre, Pelchat, Swaine, G elinas, & Levert, 2005; Paterson, Kieloch, & Gmiterek, 2001) and CVA patients (Garrett, & Cowdell, 2005; O'Connell, Baker, Prosser, 2003; Pierce, Finn, & Steiner, 2004; Van Veenendaal, Grinspun, & Adriaanse, 1996). Research findings show that many of these needs are not being met (Garrett & Cowdell, 2005; Lefebvre, Pelchat, G elinas, et al., 2005; Lefebvre, Pelchat, Swaine, et al., 2005; O'Connell et al., 2003; Paterson et al., 2001; Pierce et al., 2004; Van Veenendaal et al., 1996). Moreover, studies comparing the perceptions of family caregivers with those of health professionals have revealed several differences (Lefebvre, Pelchat, Swaine, et al., 2005; Van Veenendaal et al., 1996).

Overall, there is little evidence about the information needs of family caregivers of TBI or CVA survivors, their sources of information, and the impact of the information they do receive. Moreover, almost no studies have investigated the comparative perceptions of family members and health professionals. Therefore, a pilot project on this subject was conducted in summer 2005.

### **Conceptual Framework**

The conceptual framework for the study was Astolfi's (1992) Construction of Knowledge Model (Figure 1), which provides guidelines for understanding and analyzing the role of information in the acquisition of the knowledge necessary to care for a person with TBI or stroke. For Astolfi, knowledge is an articulated and organized group of learnings

and information. The learnings are connected to an individual's unique history (personal experiences, cognitive and affective structure) and the information is external to the individual (facts, opinions, and arguments). Therefore, the purpose of information is to increase learnings and then knowledge. Communication is the instrument of this process.

### **Purpose and Objectives**

The purpose of the study was to document, from their own perspective and that of the health professionals working with them, the information needs of families grappling with a medical situation (TBI, CVA). More specifically, the project sought to identify, from the points of view of families and health professionals: (1) the information sources and strategies used by family caregivers for obtaining information, (2) the nature of the information sought and obtained, and (3) the impact of this information on the adjustment of family caregivers and on their relationship with health professionals.

### **Methods**

This qualitative pilot project followed the tradition of exploratory empirical research and used co-construction of reality in an interdisciplinary approach (Van der Maren, 1995). The research results stemmed from (i.e., were co-constructed from) the interaction between the participants during focus groups. This method provided an opportunity to ascertain, reflect on, and examine the points of view of different people in order to understand the experience of each participant. The study fell within the constructivist paradigm, with the co-construction of comments stemming from the interaction between the researchers and the participants (Guba & Lincoln, 1989).

### **Sample**

The convenience sample consisted of six family caregivers of individuals who had suffered a TBI or CVA and eight health professionals working with these clientele. Although they are very different and have distinct repercussions, these two clientele (TBI and CVA) were selected because the health situations are sudden and unexpected. Furthermore, no studies have investigated the information needs of TBI populations. Participation was purely voluntary. Sample size was determined by institutional constraints with respect to recruitment (feasibility) and data saturation in the context of a pilot project (Pirès, 1997). Participants were recruited by internal collaborators based on precise criteria, at a functional rehabilitation centre (i.e., aimed at recovery of physical, cognitive, and sensorial abilities) and a rehabilitation centre specializing in social reintegration

(i.e., focused on the resumption of social roles and daily living activities), both in the Greater Montreal area.

For family caregivers, inclusion criteria were: be living with or responsible for an adult who had suffered a TBI or CVA; be aware of the person's diagnosis; be fluent in French; reside in Greater Montreal; and be over 18 years of age. The individuals for whom they were caring had to have completed the functional rehabilitation phase and experienced social reintegration; this criterion was used because the type of information needed in order to adapt to a health situation varies with each phase of care (Lefebvre, Pelchat, Swaine, et al., 2005). Inclusion criteria for health professionals were: be employed at a rehabilitation centre for TBI or CVA patients and their families; and have worked with one of these clientele for more than 2 years.

All the family caregivers taking part in the study were women ( $N = 6$ ). Most were the spouse of a person who had suffered a TBI or CVA an average of 3 years earlier (range = 1–5 years). The family caregivers were aged 27 to 66 (mean age = 49.7). Most were university graduates. Their employment status varied: employed full time, retired, unemployed.

The health professionals taking part in the study ( $N = 8$ ) were mostly women and their mean age was 39.4 (range = 29–55). Their professional disciplines were physiotherapy ( $n = 2$ ), psychology ( $n = 3$ ), and social work ( $n = 3$ ). Most worked in a rehabilitation centre specializing in social reintegration. They had 2 to 24 years' clinical experience (mean = 13.8) and 2 to 22 years' experience with the TBI or CVA clientele (overall mean = 9.2).

### ***Data Collection***

Focus groups were used to collect the data because of their potential for eliciting an abundance of diverse information from many people at once and encouraging the spontaneous expression of ideas (Krueger, 1994; Merton, Fiske, & Kendall, 1990). Participation in a focus group made family caregivers and professionals more aware of the problem; this in turn stimulated their desire to structure their actions with a view to self-managed development. The researchers met with the family caregiver and health professional groups separately, to ensure that no bias was introduced through interaction between the two categories.

A semi-structured interview guide was developed. It was divided into three themes, corresponding to the study objectives and emerging from the literature review: nature of information sought and obtained, sources of and strategies for finding information, and effects of information on the adjustment of family caregivers and on their relationship with the health professionals.

The groups were led by a researcher assisted by a research professional, who played an observer role and made notes on both verbal and non-verbal data (Dilorio, Hockenberry-Eaton, Maibach, & Rivero, 1994). Moderation of the group adhered to the principles of group dynamics described by Mucchielli (1983). The focus groups, which lasted 2 hours on average, were audiotaped and transcribed verbatim.

Participants were asked to fill out forms specifying their sociodemographic characteristics. Analytical notes (questions, ideas, wonderings, curiosities, examples, categories, codes, etc.) were made for each focus group. A research log was also kept on the evolution of the project: the researcher's thoughts and feelings and concerns about bias; the research situation (what was done, by whom and when); articles read.

### ***Ethical Considerations***

Ethics approval was obtained from the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, with which the participating rehabilitation organizations were affiliated. Before commencement of data collection, the participants were asked to complete a research consent form. They were informed that if they found it upsetting to recall the events associated with the themes discussed, they could be put in touch with a health professional for assistance. In addition, it was explained that the results would be confidential and that they were free to withdraw from the study with no consequences for themselves or their relative with the medical condition. Confidentiality was ensured by assigning each participant a numeric code. The researchers alone have access to identifying information and will not release it to a third party unless required to do so by law. Videotapes were kept under lock and key in the researcher's office at the research centre and were destroyed upon completion of the project.

### ***Data Coding and Analysis***

Focus group proceedings were transcribed *in extenso*. A content analysis approach was used (Mayer & Deslauriers, 2000). The data were then vertically analyzed for thematic content (i.e., specific to each focus group). Each statement was coded by unit of meaning and grouped by theme, in order to reduce the amount of data and to extract the meaning of the statement. The researcher read and approved the transcriptions and data coding. Inter-group triangulation of the results (family caregiver results, health professional results) enabled the researchers to synthesize the information needs of families in the context of the health situation. The process was iterative — that is, analysis was built upon and fine tuned as it proceeded, supported by consulting the log and the analytical, methodological, and theoretical notes.

Four basic analytical categories were established beforehand. *Nature of the information* covered statements relating to all information sought. *Sources of information* comprised statements concerning sources other than the health professionals. *Search strategies* were the means by which people obtained information, such as the media or relatives. *Impact of the information* covered how the information affected people's adaptation and their relationship with the professionals, as well as what they found satisfactory or unsatisfactory.

### ***Scientific Criteria***

Methodological rigour was based on the following criteria (Guba & Lincoln, 1989; Laperrière, 1997): (1) credibility (similar to internal validity), which was ensured by triangulation of data sources, obtaining of consensus on data analysis (interrater reliability of transcript coding), and validation of meeting reports by the head researcher at regular intervals; and accuracy of data, which was verified by the audio- and videotapes; (2) transferability (similar to external validity), which was ensured by describing the study's context in detail so that the reader could identify and predict a similar situation in a similar context; and (3) consistency (similar to reliability), which was ensured by entering in the log any changes in the research process.

## **Results**

### ***Opinions of Family Caregivers***

The results show that the families needed mostly information about the impact of the deficits on daily life and ways of dealing with this as well as the long-term consequences of the health condition. To acquire this knowledge, family caregivers consulted health professionals, written information, the media, and the Internet. The information they obtained helped them to understand the deficits, develop coping strategies, and collaborate with the professionals. The fact remains, however, that people were still not entirely satisfied. Their main complaint was lack of information and the way in which information was conveyed.

***Nature of the information.*** The results show that the information needs of family caregivers had to do with how the person's deficits would affect day-to-day life. Family caregivers needed information about strategies for dealing with the deficits (difficulty organizing one's personal life, scheduling various appointments, planning social activities, etc). Most family caregivers also said they were anxious about the person's future and the long-term consequences of the health condition.

Family caregivers reported that information obtained from health professionals concerned the diagnosis, the prognosis, and rehabilitation



but that what had the most impact was the professionals' advice about issues arising in day-to-day life.

**Information search strategies.** In their quest for information, many family caregivers surfed the Internet, watched television programs about the medical condition, and read books on the subject. Some said they had to press hospital staff to give them the information they wanted, especially in acute care.

They reported that they consulted the Internet when the health problem first arose but gradually abandoned this strategy or used it only occasionally. Information found on the Internet mainly concerned progress and medical innovations.

Consulting with health professionals enabled family caregivers to bridge the information gap and find out about care and services. Some people got their information from talking to the professionals because they were unaware of other sources.

**Impact of the information.** The information obtained by family caregivers gave them a fuller understanding of the health condition and enabled them to mitigate the person's deficits; sometimes it helped them to collaborate more closely with the health professionals. For example, reading books, articles, and brochures helped them to learn more about the health condition. The knowledge they acquired made them aware of the most recent advancements that might improve their life situation and the patient's condition.

Advice, tools, and methods provided by professionals played a prominent role in the family caregivers' adjustment to the new life situation. People said they had modified their daily activities and lifestyle based on the person's capacities and incapacities.

Finally, the knowledge of family caregivers sometimes contrasted with that of the professionals from whom they sought solutions. When people brought their own information to an appointment, it sometimes helped to forge collaboration between the family caregivers and the professionals.

The results show that some family caregivers were unhappy about the way in which information was conveyed to them, especially in acute care, and felt they had been left all alone with their uncertainties. Regarding services offered after rehabilitation, some family caregivers reported that they did not get all the information they needed about financial aspects or resources available. Also, many people said they were unaware of a brochure issued by the Quebec automobile insurance board about traumatic brain injury and how it affects day-to-day living. Others had never heard of the Association québécoise pour les traumatisés crâniens (Quebec's brain injury association) or had only vaguely heard about it, had never consulted it, and could not recall receiving information about

it. The lack of information was sometimes due to the emotional shock of being told of the diagnosis and the subsequent refusal to accept the situation. One person deplored the fact that the professionals hardly asked what the family caregivers were experiencing in caring for the affected person.

Lastly, family caregivers said they would have liked to see more videos about the condition of their loved one and to talk things over with peers; they also felt that the public should be better informed about what life is like for people in disability situations.

### ***Opinions of Health Professionals***

From the point of view of health professionals, the information needs of the family caregivers were associated mainly with the deficits resulting from the medical condition, strategies for dealing with the condition, and the long-term consequences of the condition. The health professionals identified various strategies used by families, such as consulting the Internet, the media, and written materials and talking with health professionals and peers. Life experience seemed to be the main source of knowledge. Participation in therapies was a useful means of transferring knowledge, but the professionals who were interviewed reported that family caregivers played little part in this process. The results also show that information obtained by the family caregivers had an impact on their adjustment to the health situation and on their relationship with the health-care team. The professionals acknowledged that lack of information was a source of frustration for family caregivers.

***Nature of the information.*** The results show that the information needs mentioned by family caregivers to the professionals during appointments concerned mainly the functional aspects of the health condition (walking, talking, working, etc.) and the long-term prognosis. Relatives were also concerned about possible interventions (medical innovations, alternative medicine, etc.) and treatment methods.

The professionals said they gave patients and their families various kinds of information: general information (medical facts about the health condition, written material), personalized information (“because the whole book does not apply to the injured person”), information about the impact of the deficits (“what the relative is going to go through in this process”), and information concerning the future (“for later, what will become of them”). A lot of the knowledge conveyed to the family concerned ways of making things easier for caregivers — for example, making them aware of the risk of exhaustion — repeated as often as necessary to ensure that it was applied in practice, fostering better integration.

**Information search strategies.** The health professionals identified various strategies used by the family caregivers to meet their information needs. People consulted the Internet, the media (newspapers, television), and articles, books, and brochures, talked with their peers, and interacted with the health professionals. According to the professionals, however, the most effective way people acquired knowledge was through their own life experience; this was more effective than searching for information.

The health professionals regarded the Internet as a major source of information: A family caregiver can go on the Internet and contact specialists all around the world; they can obtain exhaustive information on a topic and discuss it with health experts. Yet the professionals said their clientele did not often use the Internet, for a number of reasons: lack of access, lack of skills in information and communication technology, stability of the condition such that further search was not deemed necessary, and the nature of the information found.

The professionals reported that, with regard to knowledge acquisition by family caregivers, their approach was to suggest strategies and guide them in the direction of appropriate resources. They also pointed patients and their families to the most relevant sources of information for their particular needs.

The professionals tended to view family caregivers' participation in workshops and therapies as a positive strategy, promoting the flow of information between health professionals and family caregivers. However, they deplored the fact that relatives hardly ever took part in information activities or intervention planning meetings; they noticed increased involvement by the relatives when the patient's file was about to be closed. In general, the family caregivers did not proactively seek out information, even when the information would have been very helpful.

**Impact of the information.** The comments of the professionals reveal that information can have an impact on family caregivers' adjustment to the health situation and on their relationship with the health-care team.

With regard to the possible repercussions of information, the professionals identified a number of barriers to adaptation. Some pointed out that inaccurate or contradictory information can undermine adjustment and rehabilitation. One professional cited problems caused by misconceptions: When information is incorrect, professionals have to set the record straight; this entails qualifying and supplementing information found in the media, such as the accessibility and high cost of equipment featured on Web sites.

Information also affected the relationship with the professionals. When family caregivers brought information to an appointment, it provided a starting point for discussion and debate. As the family caregivers became more knowledgeable about the health condition, they

tended to become more demanding in terms of professional expertise. A number of health professionals believed that the family caregivers' trust in and respect for their professional competence materialized in a relational framework. They indicated that this trust in the other's expertise was reciprocal. They valued the family caregivers' knowledge in that hands-on expertise is key to the adjustment and rehabilitation process. This attitude seemed to be appreciated by family caregivers.

The results show that for communication to be effective one must first ascertain what information the family caregivers have and whether they have absorbed it. All the professionals agreed that a key factor is how and when information is conveyed. They stressed the importance of sounding upbeat and focusing on positive aspects, successes, and abilities. Normalization and the questioning of restrictive beliefs were part of the positive approach adopted by these professionals.

Finally, the results show that the lack of information referred to by the families was also acknowledged by the professionals. The fact that a definitive long-term prognosis was not possible created a sense of uncertainty among family caregivers. The professionals also reported that talking to specialists during the acute-care phase is often no simple matter; the specialists tend to be short of time and uncomfortable breaking the news of a poor diagnosis or disclosing information involving bad news.

However, the professionals tended to qualify these explanatory factors. The family caregivers' sense that they lacked information was also caused by their difficulty remembering or understanding the information because of their sketchy medical knowledge (vocabulary, roles of the various professionals, how the system works) and their emotional state.

## **Discussion**

The goal of this pilot project was to document the information needs of family caregivers in the context of a health situation (TBI or CVA), from their own point of view and that of the relevant health professionals. The results show that the points of view of the families converged with those of the health professionals. They enable us to draw an integrated analytic profile of the information needs of family caregivers and how these mesh with the interventions used. These findings have major clinical implications that translate into communication and collaboration, to provide family caregivers with information that meets their needs and fosters their adjustment to the situation.

### ***Profile of Information Search by Family Caregivers***

The results of the study highlight the consistent nature of family caregivers' information needs, regardless of the health problem (TBI or

CVA). The concerns of these people — the health condition, its long-term consequences (anticipation of behaviours, capacities and deficits, coping strategies, etc.), and what will happen to the patient day to day — have been pinpointed as key elements in the process of adjusting to a health situation (Hummelinck & Pollock, 2006).

A central finding of the study is the homogeneity of strategies used by family caregivers in different health situations. According to the literature, increasingly family members wish to be informed and to receive justification for and explanation of any intervention that is proposed. The media, the Internet, and scientific articles offer an array of information on a wide range of health situations (Ensemble parlons autrement des cancers, 2001). Age, socio-economic status, and educational level all appear to influence the search strategy (Doumont & Sandrin-Brethon, 2001). The present results suggest that the amount of time elapsed since the onset of the health condition is also a factor.

Although dissatisfaction with information was sometimes glaring, the professionals believed that some families tended to be passive in their quest for knowledge. Research and clinical experience show that knowledge usually stems from experience (Lacroix & Assal, 2003). Such experience-based knowledge (Jarvis, 1992) is rooted in the day-to-day lives of family caregivers as they cope with the limitations and abilities of the affected person. When people face a problem in their daily lives, they wonder about possible solutions, seek useful information, and try things out to see if they work. The resulting knowledge is then incorporated into their existing knowledge in the context of the present experience. This finding could explain why family caregivers' concrete, objective strategies seemed (to the professionals) to be somewhat limited and passive, when in fact the knowledge-acquisition process takes place first and foremost in a subjective register.

Another explanatory factor for this seemingly passive approach is the family's state of shock or even psychological trauma at the time of acute care. Families and professionals alike realize that the sense of having insufficient information is intimately linked to diminished receptiveness, which hinders retention of information (Davis, Kristjanson, & Blight, 2003).

The information needs of family caregivers may be difficult to determine because they can vary from one individual to another and are often identified in retrospect and therefore cannot be met at the time of consultation. Also, the information has to be relevant for the recipients at the time it is conveyed, in order for them to absorb and integrate it (Hummelinck & Pollock, 2006).

In addition to the above reasons why the families felt they lacked information, we should bear in mind a reality intertwined with the

adjustment process: Lack of information breeds uncertainty and insecurity for the relatives and the disabled person alike (Lefebvre, Levert, David, & Pelchat, 2007). Information is seen as having a positive impact on adaptation by giving the family a sense of being in control of the situation and of their environment. This is fundamental to the process whereby people learn and transform themselves positively as they work through the ordeal. Being informed gives patients and their relatives the confidence they need to participate in the care process (Bouchard, 1999; Pelchat & Lefebvre, 2005).

***Profile of Communication in a Context of Collaboration:  
Information to Meet the Needs of Family Caregivers***

The health professionals and family caregivers stressed that the communication of information was affected by both the manner in which it was conveyed and the point at which it was conveyed (Deccache & Meremans, 2000; Paterson et al., 2001). The effects will be beneficial or detrimental, depending on whether the professionals' approach is characterized by openness, circularity, and reciprocity or simply involves a one-way transmission of information (Ramritu & Croft, 1999). The role of professionals is therefore paramount. The contribution of professionals was part of the experience-based learning process identified by family caregivers as both the most common and the most effective strategy for knowledge acquisition. A relationship of trust founded on discussion, collaboration, and valuing of people's knowledge was key to getting them involved and maximizing their adjustment.

The health-care team should use its expert knowledge as a guide in helping patients and their relatives to address a difficult situation, while at the same time acknowledging their expertise and competence in finding, implementing, and evaluating solutions. The patient and relatives should be the focal point of interventions and be regarded as partners whose knowledge is crucial to improving their quality of life (Buttet, 2002; Camden, Baril, & Tétreault, 2005). This process involves first *identifying the knowledge* of family caregivers. By being open to subjective experience, the professional can probe their knowledge and beliefs. This knowledge has to be *recognized as valid* or at least *qualified*. While the print and electronic media are major sources of information, they are secondary and should be used discerningly, because information that is rapidly obtained, plentiful, and readily accessible is not necessarily reliable and accurate (Fostier, 2005). Once the relatives' knowledge is confirmed as valid, the professionals *value it as supporting expertise* (Bouchard, 1999). Communication then becomes circular and reciprocal, with each person's expertise being pooled to form a common body of knowledge that is highly instructive for all. This type of communication promotes absorp-

<b>Table 1 Recommendations</b>	
<b>Experience of Family Caregivers</b>	<b>Recommendations</b>
<b>Information search strategies</b>	
<ul style="list-style-type: none"> <li>• Experience-based learning is the main source of knowledge.</li> <li>• Consultation with professionals is a major source of information.</li> </ul>	<ul style="list-style-type: none"> <li>• Be aware that you are the family caregiver's preferred source of information.</li> <li>• Provide information anchored in the family caregiver's subjective experience.</li> </ul>
<b>Communication of information</b>	
<ul style="list-style-type: none"> <li>• Information is often believed to be insufficient, unclear, contradictory, and overloaded.</li> <li>• The terminology is unfamiliar.</li> <li>• Information does not always correspond with what one is concerned about here and now.</li> </ul>	<ul style="list-style-type: none"> <li>• Communicate the information at the right time.</li> <li>• Communicate information addressing issues the family caregiver is concerned about here and now.</li> <li>• Use clear, simple language.</li> <li>• Provide written information as a backup to verbal information.</li> <li>• Repeat and explain information as often as needed.</li> </ul>
<b>Collaboration</b>	
<ul style="list-style-type: none"> <li>• One has a sense of assurance and control when one's opinion is taken into account.</li> <li>• The attitude of professionals has an impact on the quality of interactions and adjustment.</li> </ul>	<ul style="list-style-type: none"> <li>• Forge a relationship of trust based on exchange, listening, and empathy.</li> <li>• Be open to the family caregiver's knowledge (identify, recognize/qualify, value).</li> <li>• Engage in reciprocity of knowledge.</li> </ul>

tion of information and facilitates adaptation (Driscoll, 2000; O'Mahoney, Rodgers, Thomson, Dobson, & James, 1997).

Information addressed to individuals coping with a health situation and their families must be adapted to their needs. For information to be retained and seen as relevant by family caregivers, it has to be *proffered at the right time* (Paterson et al., 2001). Too often, professionals communicate information systematically, regardless of the immediate needs of family caregivers. For information to be conveyed effectively, it has to *correspond with their immediate concerns*. The only way for the professional to ensure this is to co-construct the intervention with the family, exploring their knowledge and concerns as well as their objective and subjective expe-

rience in the particular situation — in other words, their otherness. The information must be *repeated or explained at the right moment* — that is, when the family caregivers so request, or when they reach a particular stage in their journey (Lefebvre, Pelchat, Swaine, et al., 2005; Paterson et al., 2001). All of these considerations have to be supported by the care and service structures.

The results of this study lead to a number of recommendations to support the experience of family caregivers (see Table 1).

### **Limitations**

The fact that this was a pilot project with a small sample limits the generalizability of the results, which reflect the specific experiences of family caregivers and health professionals. Generalizability is also limited by the characteristics of the sample (homogeneous, predominately female university graduates). Therefore, the findings may not be useful in situations where the caregiver is male or is less educated. Although all participants related their stories willingly, some people found certain events difficult to discuss and their perception of these events, when they did discuss them, may have been altered by the passage of time. It is also possible that, for all sorts of contextual reasons, participants censored their comments about their present or past experiences. Moreover, it is often difficult to remember exactly what happened in a specific situation because, as time passes and other events occur, one's original perception may be altered (Baribeau, 1996; Van der Maren, 1995). However, the inter-group triangulation of the results validating the interpretation of the data helped to reduce these biases and promoted scientific rigour.

### **Conclusion**

The above findings point to the importance of developing and implementing a communication approach that fosters adjustment through a learning process based on collaboration and focusing on the patient-professional relationship (Deccache & Meremans, 2000). This depends on all the actors being actively involved in the quest for information. Individuals have to be proactive in their search for information and in their interactions with health professionals, who in turn should encourage and elicit such behaviour and give people the opportunity to discuss their own experience and knowledge in order to pinpoint the family's needs and tailor their responses accordingly. In addition, verbal communication backed up by written information appears to be an effective means of communication; health professionals should move in this direction.



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