A major challenge facing individuals with brain injury and the rehabilitation professionals who assist them is the acquisition of current, understandable information. Health professionals in hospitals usually provide initial information, which patients with brain injury and their families often find inadequate. They then find it necessary to seek information from independent sources. One such source, TBI-INFO, an information dissemination service, conducted a survey to determine how effectively it was satisfying consumer and professional demands. Responses generally indicated that the acquisition of information improved patients’ integration into the community and enhanced their understanding of brain injury and its effects. Most of the information respondents received was new to them, most shared the information with others, and many requested information more than once. Half of the respondents changed their approach to a specific situation as a result of information they received. These results show that independent sources are capable of providing information that improves the perceived quality of life for individuals with traumatic brain injury.

Health information for patients has been shown to enhance rehabilitation outcomes, increase compliance with management techniques for chronic illness, and improve outcomes after medical procedures [1–4]. Information is also an important component of the medical decision-making process [5]. Health professionals, patients, and family members all need to make “informed” decisions. Individuals dealing with the effects of traumatic brain injury have special information needs.

Each year, approximately 380,000 U.S. residents seek medical care for head injury. Of these, between 40,000 and 65,000 will experience long-term disabilities from the injury [6]. Traumatic brain injury (TBI) is defined by the Traumatic Brain Injury Model System Data Management Steering Group as “external mechanical force causing damage to brain tissue as evidenced by loss of consciousness, or post-traumatic amnesia or objective neurologic findings that can be reasonably attributed to traumatic brain injury on physical or mental status examination, with or without skull fracture” [7].

Information about medical treatment of brain injury in the acute care and rehabilitation stages can be found in the medical literature. But information about the various aspects of community integration for persons with brain injury is scattered across many disciplines, so it is not easily accessed through traditional reference methods. The Rehabilitation Research and Training Center on Community Integration of Persons With Traumatic Brain Injury (RRTC) has developed a computerized information retrieval system, TBI-INFO, which brings together information about community integration from a wide variety of publications and media. This information service, located at the State University of New York at Buffalo, is international in scope and accessible to anyone who calls or writes. A nominal fee sometimes is charged to cover printing and mailing of bibliographies. This paper describes a survey that explored TBI-INFO client satisfaction and use patterns.

BACKGROUND

The RRTC is funded by the National Institute of Disability Rehabilitation Research (NIDRR), a division of the U.S. Department of Education. The objective of the RRTC information dissemination project is “to develop a system for gathering, storing, and disseminating the current research findings, legislation and case law and demonstration projects that relate to persons with traumatic brain injury and to serve as a national resource and information center on all as-

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pects of psychological, social, community and family oriented research and service delivery issues.”

Since 1988, a comprehensive database of information has been developed on community integration for individuals with traumatic brain injury. The database has grown from 1,600 citations and abstracts to more than 5,000 publications and documents spanning the years 1970 to the present. Meanwhile, the TBI-INFO information service has had a steady increase in requests over the years. From fifty-two requests for information in all of 1990, the service has expanded to accommodate approximately fifty requests each month.

Because the literature in the database is drawn from many disciplines and is accessed by both professionals and nonprofessionals, abstracts have been written without jargon so that they may be understood easily by most readers. The rewriting of abstracts also permits the use of “people first” language, which emphasizes abilities rather than disabilities. The Medical Subject Headings (MeSH) of the National Library of Medicine have been adopted as the controlled vocabulary for indexing TBI-INFO entries.

Pro-Cite bibliographic software is used to manage the database. The software permits searching on any word or phrase in any field, provides a variety of forms for the entering of data, and can print bibliographies in a variety of formats. Everyone at RTC who has used the TBI-INFO database has found Pro-Cite to be easy to use and flexible.

In addition to its large collection of journal articles, the specialized library has grown to include 450 books, videos, and government reports. This collection of resources is the most comprehensive available on the topic of living with the consequences of brain injury. The service is unique in that it provides specialized information at levels appropriate for persons who have experienced brain injuries, for their families, and for health professionals.

In addition to serving the public, TBI-INFO has provided information to state and federal legislators, insurance companies, and state departments of health. Many of the problems faced by families coping with brain injury could be diminished by changes in government policies concerning disability. For example, Medicaid waivers could be provided for treatment at home rather than treatment in institutions. To ensure that laws and regulations serve the best interests of persons with brain injury and the community at large, policy makers and others in government need reliable, accurate information about brain injury.

Federal priorities

Providing disability information has been identified as a priority by several federal agencies. For example, the Department of Health and Human Services’ Healthy People 2000 lists this goal: “Increase to at least 40 percent the proportion of people with chronic and disabling conditions who receive formal patient education including information about community and self-help resources as an integral part of the management of their condition” [8].

In position papers from the Third National Injury Control Conference, “Setting the National Agenda for Injury Control in the 1990s,” the following goal was recognized: “A high priority should be given to funding proposals for information dissemination and technology transfer among researchers, clinicians, all health-care providers, injured persons and their families, and community members” [9].

The Knowledge Utilization Program funded by the NIDRR has published the report Using Knowledge and Technology to Improve the Quality of Life of People Who Have Disabilities. The report emphasizes the importance of access to information and knowledge in the successful community integration of persons with disabilities. The report suggests that NIDRR “assess the use of information systems by applicants for funds” and promote equal access to information by people who are geographically dispersed. Equal access is defined to include access by telephone and mail at a nominal cost, with TDDs available to people who are deaf [10].

Because of the importance placed on information for individuals with disabilities, RTC officials decided to evaluate TBI-INFO in the context of these federal priorities.

The importance of information seeking

Persons with chronic diseases and disabilities. In the literature of both information science and medicine, there are many examples of stressful circumstances in which a person seeks out information. Information seeking can be identified as a coping mechanism, and people who are successful in their information seeking may have better medical outcomes than those who are not [11-12].

The most obvious sources of information about medical problems are health professionals. However, research has demonstrated that individuals in medical situations often go beyond health professionals in seeking information. For example, in a study of information-seeking behaviors of pregnant women, the most frequently cited major sources of information were health providers and books. The same study found that patients frequently want more information than they receive from their physicians and that most people use multiple sources for information about health care [13]. Beisecker found, for example, that most patients desired a wide range of information about their medical condition, even though this need often was not obvious in their interaction with physicians [14].
Information seeking is a process that takes place over time. Wiggins, who studied information gathering among cardiac patients, found that patients and family members could not absorb an unlimited amount of information at a stressful time, such as when a patient is in a critical care unit of a hospital. Individuals in Wiggins' study reported that, following discharge, they often became depressed at home and that questions arose that spouses could not answer. This situation contributed to conflict within the family [15]. Research with families coping with the effects of traumatic brain injury suggests that securing answers to these questions from another source—once the physician is no longer involved with the patient—may relieve fears and conflict among family members [16].

Barsevick found that patients facing a stressful medical procedure were more confident about their ability to deal with health problems if they received information about the procedure [17]. In addition, patients who are well informed about their medical condition worry less and can manage their health care better than other patients [18].

**Persons with traumatic brain injury.** To make important decisions about their medical care, persons who experience brain injury and their families need information about how the injury is likely to affect their lives. Health professionals who assist these individuals also need up-to-date information about treatment.

Information seeking is critically important for individuals and families facing the results of brain injury [19]. Beukelman identifies acquiring information, including self-instruction and information gathering, as one of the three fundamental challenges to families when a family member experiences a brain injury and outlines several pitfalls for families and professionals when they exchange information about the effects of brain injury. For example, family members appear to prefer written materials in simple language, but physicians often speak in medical jargon that the family members may not be able to understand. In time, family members may learn the jargon, but, initially, they need information in lay language [20].

When families are ready to seek information, they frequently do not know where to find it [21]. Damrosch, who surveyed nurses and physicians in hospitals, concluded that patient education programs are often a low priority in hospitals and, therefore, are not well developed [22]. Because the family's information gathering continues beyond the hospital phase of treatment, health professionals should alert families to sources of information that will be available after the patient is discharged [23].

Family members coping with brain injury consistently rated satisfaction with information from hospitals as "low" in a survey conducted by McMordie et al. [24]. Specifically, families reported that little or no information was provided on long-term effects of head injury such as cognitive and personality changes. A need for planned patient information in medical settings has been documented by Sweetland, who found that giving patients written materials in addition to personally explaining medical information increased their understanding and recall [25]. McMordie has documented a specific need for multifaceted patient and family education programs concerning head injury. McMordie found that education and information needs change but remain important through hospitalization, rehabilitation, discharge, homecoming, and community integration phases. Just as cardiac patients needed follow-up information after they had dealt with the initial crisis, families coping with brain injury also have ongoing information needs [26].

In medical settings, the staff often perceives anger and denial on the part of patients with brain injury and families. Families often perceive pessimism and insensitivity on the part of staff [27]. Information from a neutral source may help calm emotions that cause conflict in the rehabilitation setting. For example, knowledge about ongoing research in rehabilitation after brain injury can help families become aware of their options and ensure that they make educated, informed choices about the type, cost, and duration of rehabilitation programs. However, according to a study by the NIDRR, "Little attention has been paid to getting scientific knowledge directly to the ultimate consumers" [28].

**THE SURVEY**

The main purpose of the survey described here was to explore the degree to which TBI-INFO meets the needs of individuals who request information and to learn how the information provided is used. The following questions were of particular interest:

- Who is contacting TBI-INFO, and are they satisfied with the information they receive?
- Do people with brain injury, their families, and professional service providers share the information they receive?
- Do people with brain injury, their families, and health professionals use information from TBI-INFO to respond to specific situations, solve problems, and improve community integration?

**Method**

Survey questionnaires were sent to 297 people who had received information from TBI-INFO from January 1991 through March 1992. There were 112 re-
sponses, for a response rate of 38%. The largest group of respondents was health professionals (41%), followed by persons with brain injury (19%), family members (15%), researchers (11.6%), and educators (7.1%). Individuals with brain injury and their family members had a higher rate of response to the survey than did professionals. Nearly 57% of information seekers were professionals, but they made up only 41% of respondents. Persons with brain injury and their family members constituted 27% of information seekers and 34% of respondents.

A two-page questionnaire was developed, based on a survey by the Rochester Regional Library Council, Rochester, New York. The council surveyed physicians to define the usefulness of information from hospital-based medical libraries [29].

The first question in the TBI-INFO survey asked respondents to identify themselves (e.g., as individuals with brain injury, family members, educators, researchers, advocates). Other questions asked about the number of times information was requested, how many people the information was shared with, and if the information changed a response to a situation. To answer the last question, respondents could choose from eleven statements that characterized and rated the information received.

A statement at the end of the questionnaire invited comments about the information service and the information received. A copy of the survey is provided as an appendix.

Results

Data analysis initially was directed toward determining the usefulness of searches by TBI-INFO. More than half of the respondents (55.4%) said the information they received had changed the way they responded to a specific situation, and 39.3% said the information had solved a specific problem. Even though most of the people who telephone TBI-INFO already are informed about brain injury, nearly half (47.3%) said the information they received was new to them.

More than 90% of the responses were positive. Only eleven people (9.8% of the sample) reported they were "dissatisfied" with the searches. Review of written comments from those respondents indicated that several of their requests involved topics that were too general (e.g., community integration) or too specific (e.g., pre-injury incest) to be useful in searches. In addition, several of those respondents were family members who were dissatisfied because the injured relative still had the problem about which they had requested information.

Persons with brain injury were more likely to have made repeated requests than were family members or professionals. More than a third (42.9%) of persons with brain injury reported requesting information three or more times, while only 17.6% of family members and 10.9% of professionals did so (Figure 1).

Patterns of sharing information were similar for all respondent groups, with a majority of each group sharing information with three to fifty people. Less than 20% of each group shared information with more than fifty people. All respondents with brain injury shared information with more than three people, as did most professionals and family members (Figure 2). The average number of people with whom information was shared was slightly more than three. Based on median estimates from the 112 respondents, information from their TBI-INFO searches reached 388
people. If the ratio of people reached per search were applied to the total number of searches from TBI-INFO, the number of people reached would be nearly 4,000.

Although individuals with brain injury and professionals offered similar characterizations of the impact of information they received regarding solving specific problems, family members had different reactions. When asked if information received from TBI-INFO solved a problem, almost half of the injured persons and the professionals said yes, while less than 20% of family members answered yes (Figure 3).

One third of individuals with brain injury and nearly 20% of professionals said the information they received from TBI-INFO improved community integration, while less than 12% of family members said so. Approximately half of each group said the information they received changed the way they responded to a specific situation.

Nearly identical percentages of professionals and family members said some of the information was new to them, while a higher percentage of injured individuals said so. This is noteworthy, considering that all respondents had been dealing with brain injury long enough to have engaged in information-seeking successfully enough to find out about TBI-INFO.

Survey comments

Survey comments suggested that persons with brain injury, their family members, advocacy groups, and professional service providers all seek information about brain injury, and that TBI-INFO meets a variety of their needs. With information from TBI-INFO, family members are able to gain an understanding of the consequences of their loved one’s injury. Understanding can become the first step toward accepting the changes caused by the injury. Comments from two parents illustrate this phenomenon. For example, one mother said,

Before receiving your information, I was unaware of the relationship between mild head injury and math learning ability. My hope is that this will not be a permanent impairment, but, if so, it is easier to deal with now that we are aware of it. At the time of [my son's] concussion the doctors said he could experience some learning disabilities but they gave us no idea what to look for. Nothing obvious was apparent until his failures in math.

The father of a thirty-three-year-old woman who was involved in a motorcycle accident offered the following:

My daughter recovered 90% from her injury. Downward vision, balance, gait, depression, mood swings, lack of self esteem, and motivation still impact on her and our lives.

Your information has helped me clarify or learn to accept and understand the effects of TBI that we have to adjust to and live with.

Besides informing themselves about the impact of an injury, families coping with brain injury must find a way to educate their extended family, friends, neighbors, and others in their support network. Simple written materials that can be shared facilitate this networking [30]. One person responding to the survey wrote, “The information I obtained has helped me in orienting others such as my son’s teachers, his friends, and their parents, to my son’s disability.”

Families also network, as illustrated in the following comment: “I shared your information with the school nurse who would not accept the fact that her own daughter had received a closed head injury in an automobile/truck accident!! She is now convinced and her family is moving on.”

TBI-INFO can be a resource for local advocacy groups when information is needed that exceeds the group’s means. One person from a local support group said, “When families, students doing term papers on head injury, or professionals call requesting information, and our resources are limited or lacking in the material they are looking for, I encourage them to call TBI-INFO and give them your number, if they visit the office I’ll share your recent publication.”

TBI-INFO information also is used by advocacy organizations for persons with other disabilities. A respondent from an epilepsy support group explained how information from TBI-INFO supports activities within that group. Another respondent explained how she uses information from TBI-INFO to reach a variety of support groups.

![Figure 3](image-url) Impact of information

- % of Group
- Improved G
- Solved Prob.
- Changed Response
- New

Requests

- Brain Injured
- Professional
- Family
- All Respondents

Cl x Community Integration
TBI-INFO also can be a valuable source of information to serve providers and health professionals planning educational programs for consumers, as illustrated by a response from a rehabilitation professional: 'I had to prepare a presentation on employing people with head injuries. The material I received provided me with the facts and statistics I needed."

For families coping with brain injury, TBI-INFO is one way to learn about the latest research findings. Also, family members sometimes deal with professionals who know very little about brain injury; the sharing of information can help these professionals become better informed. This sharing helps the next person with brain injury treated by that professional. One parent's comments illustrate: "I'm using some of the materials received to educate the key counseling/clinical personnel at the treatment facility where my son is now in residence. The facility does not specialize in brain injury, and the information is very much needed."

Rehabilitation professionals need specific information about how the effects of brain injury differ from those of other neurological problems. Also, when a new rehabilitation facility is being established, new staff members who are licensed in their professional field (e.g., physical therapy, speech therapy) often have little knowledge of brain injury. To be effective, they need to be informed about specific deficits caused by brain injury. A program director wrote, "I run a community integrated employment program and with the budget as tight as it is, your newsletter and information are very helpful. It's nice to be able to pass along relevant information to the job coaches since we are not able to send them to conferences."

DISCUSSION AND CONCLUSION

Results of the survey indicate that a wide variety of individuals need information about brain injury, especially concerning community integration. Persons with brain injury, their family members, and professional service providers who responded to the survey seemed to have the common goal of improving their knowledge of brain injury.

Most people who received information shared it in some way, either through formal events, such as conferences, presentations, papers, or training sessions, or through informal networking. Perhaps the most interesting result of the survey was the fact that individuals with brain injury and their families reported sharing information with health professionals. Because most educational programs in health-related professions devote little time to the possible consequences of brain injury [31–32], consumers and providers of health care have to learn about them together.

Respondents reported that they changed the way they responded to specific situations based on the information they received from TBI-INFO and that they were using the information to solve problems and improve community integration. Survey results demonstrate that information services such as TBI-INFO can address federal priorities calling for information dissemination to persons with disabilities and confirm that these individuals can use information to solve problems and improve community integration.

REFERENCES

APPENDIX

Value of Information about Brain Injury Questionnaire

After you have answered the following questions, please return this completed questionnaire to RRTC at SUNY, 194 Farber Hall; 3435 Main Street; Buffalo, NY 14214.

Your help in completing this questionnaire is appreciated.

1. Please check all categories that apply to you.
   - Person who has experienced a brain injury
   - Family member of a person with brain injury
   - Advocate or member of a nonprofit advocacy group
   - Rehabilitation/health professional
   - Educator
   - Researcher
   - Student
   - Other
   - Please explain

2. Approximately how many times have you requested information from TBI-INFO?

3. Approximately how long ago did you last get information from TBI-INFO? (Circle the answer you believe to be most accurate.)
   - One to six months
   - Seven months to one year
   - More than one year
   - Not sure

4. With approximately how many people did you share the information you received from TBI-INFO? (Circle the answer you believe to be most accurate.)
   - None
   - Fewer than three
   - More than three, but fewer than ten
   - More than ten, but fewer than fifty
   - More than fifty
   - Not sure

5. As a result of the information you received from TBI-INFO, did you change the way you responded to a situation? (Circle the answer you believe to be most accurate.)
   - Definitely yes
   - Probably yes
   - Probably not
   - Definitely not
   - Not sure

   If you answered “Definitely yes” or “Probably yes,” please indicate the importance of the change.

   Unimportant 1...2...3...4...5...6...7 Important

6. How would you characterize the value of the information you received from TBI-INFO? (Check all that apply.)
   - It helped solve a specific problem.
   - It improved community integration.
   - It refreshed my memory of details or facts.
   - On the whole, it was inaccurate or out-of-date.
   - Some of it was new to me.
   - It substantiated what I already knew or suspected.
   - I found most of it irrelevant.
   - I found most of it relevant.
   - It helped me find more information.
   - I found little or nothing of value.
   - It saved me time.

Your comments about the contribution information from TBI-INFO made in your life or practice would be appreciated. Please use the back of this page. If you said information from TBI-INFO helped you solve a specific problem in question 5, please describe the problem and the solution.

Thank you for contributing to the success of this study.

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