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“Tears in My Eyes ’Cause Somebody Finally Understood”: Client Perceptions of Practitioners Following Brain Injury

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Key Words: characteristics (of occupational therapists) • professional–patient relations • role

Objective. The purpose of this study was to identify practitioner qualities and traits that clients with brain injury see as important.

Method. An opportunistic sample of 51 participants with brain injury was interviewed about perceptions of service access and effectiveness. An interview guide was used to gather data for this phenomenological qualitative study. Four interviewers individually conducted audiotaped interviews, which were then transcribed. Coding and theme development were completed using HyperRESEARCH™ software.

Results. Three themes regarding practitioner qualities emerged from the data: (a) roles of the provider, (b) perceived helpfulness of services, and (c) personal characteristics of the providers. Beneficial provider roles included advocate, friend, mentor, and team member. Perceptions of helpfulness of the services included relevance, meaningfulness, practical application, skill development potential, and whether periodic feedback on progress was provided. Personal characteristics of the provider valued by the participants were clear and honest communicator, supportive, respectful, good listener, and understanding.

Conclusions. Practitioners need to pay increased attention to the perceptions of care and services of clients with brain injury. The current study closely supports previous research related to quality of care in the medical and community arenas and offers some additional suggestions to professionals who work with persons with brain injury, including learning how to time giving information to clients and how to understand client concerns without being prescriptive. Future research in this area needs to focus on and describe providers who demonstrate an ability—through their willingness to don a variety of roles, their helpful services, and their personal characteristics—to meet the unique needs of clients with brain injury.

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Consumers of medical and rehabilitative services expect both quality and effective care. The professional and personal characteristics of health care practitioners affect the therapeutic relationship and, ultimately, the success of treatment provided. What qualities in their health care practitioner do clients respond to best? Practitioner traits and styles, as defined by clinicians and educators, are as follows:

- Active listener (Cassell, 1991; Gauthier, 1997; More & Milligan, 1994)
- Understanding and empathic (Coles, 1998;

- Coulon, Mok, Krause, & Anderson, 1996; Gauthier, 1997; Jensen, 1993)
- Competent (Coles, 1998; Coulon et al., 1996; Tanne, 1990; Thompson, 1997)
- Caring (Brody, 1992; Gauthier, 1997; Jensen, 1993; Sourial, 1997; Thompson, 1997)
- Open communicator (Brody, 1992; Tanne, 1990)
- Holistic (Coulon et al., 1996; Glassman, 1991; Jensen, 1993; Sourial, 1997; Thompson, 1997).

When practitioners address these traits or qualities, they increase their chances of providing effective services to the persons who access them.

Recipients of therapeutic care also have an important voice to hear. Though researchers in the health care field are exploring the concepts of morals, virtues, and qualities related to effective practice, few studies exist that describe client perceptions of their providers. Gauthier (1997) advocated strongly for such studies for purposes of education and training. Much work needs to be done in this arena because many professionals in the fields of health care and community services continue to view clients as persons with little to contribute to the conversation about important qualities of good care. One such empirical study from the Netherlands of client perspectives of care concluded that client dissatisfaction is “all ‘between the ears’ of the patients and can only for a very small part be related to practice characteristics or general practitioner characteristics” (Sixma, Spreeuwenberg, & van der Pasch, 1998, p. 222).

Occupational therapists, to their credit, have long been concerned with clients’ perceptions and concerns about the care they provide. In one qualitative study (Gitlin, Luborsky, & Schemm, 1998), older persons who had survived strokes were interviewed about their concerns as occupational therapists introduced assistive technology into their lives. Not only did the study evaluate whether the participants used or liked the devices, but it also probed deeply with the participants into the sociocultural issues behind their acceptance and use of the devices. The investigators found that such issues as potential usefulness of a device were often offset in the minds of the clients by concerns about social acceptability and aesthetics. These findings have important implications in practice for how assistive devices are selected and introduced to clients.

More specifically, in the area of services for persons with brain injury, occupational therapy has sought client perspectives and stories of experiences. Schwartzberg (1994) conducted an ethnographic study examining the experiences of participants in a peer-developed support group for persons with head injury. The results indicated that participants felt “legitimized” as persons who had suffered head injuries that had changed their lives. Through their participation in the group, these persons believed that they belonged and were among others who understood their situations. The conclusions of the study are framed in

the perceptions of the author who, as an occupational therapy researcher, was the cofacilitator of the group and, therefore, in the position of participant-observer.

Participants in the same support group for persons of head injury (Schwartzberg, 1994), were questioned about their own perceptions of the helpfulness of the group (Schulz, 1994). Their answers—in their own voices—were gathered using a semistructured interview, a structured interview, and a ranking activity. The participants’ responses showed that having the opportunity to share their feelings was the most important facet of the group, whereas hearing others’ opinions was the least helpful. The outcomes of this study also suggested that the participants felt less troubled by their injury and were more desirous of having control of the support group process than was originally believed by the researchers.

In an informational article, Jackson (1994) noted that occupational therapists, along with other rehabilitation professionals, need to take the long view of needs of persons with traumatic brain injury as well as take on the role of advocate. She proposed that persons with traumatic brain injury actually need increased assistance with supported living and housing and vocational pursuits. Even though funding for such services is difficult to obtain, Jackson concluded that occupational therapists need to step in and advocate for these client needs.

When occupational therapists begin their work with clients with brain injury, they must be cognizant of the many realities they will encounter. In an early ethnographic study, Krefting (1989) described the feelings of loss of self experienced by persons with brain injury as they seek to reenter the community. She found that these persons used several conscious and subconscious coping mechanisms to cover their changed selves, including “concealment, blind spots, and redefinition” (p. 71). Some persons with brain injury, through speaking either excessively or very little, often seek to disguise their thinking and communication problems (concealment). Others appear completely unaware of their problems and the impact their new challenges bring to themselves and to those who live and work with them (blind spots). Some persons with brain injury and their family members are able to minimize the life changes that have occurred and to reframe current situations (redefinition); for example, a son is still considered a worker after injury by his family even though he now works in a closely supervised, sheltered employment setting. Krefting’s study clarifies that service providers, including occupational therapists, need to be aware of the significant amount of coping persons with brain injury and their families are doing as they seek to come to grips with the life changes they face.

Persons with brain injury, their families and friends, and service providers all experience the needs, services, and outcomes of the rehabilitation experience differently. Issues

such as “depression, impaired self awareness, lay versus professional terminology, values, observational opportunities, and impact/burden” (Malec, Machulda, & Moessner, 1997, p. 1) lead to differing perceptions of all parties involved. An appropriate starting point for comprehensive research on services to persons with brain injury and their effectiveness, however, remains in the expressed experiences of the client. The purpose of the present study was to describe and seek to understand through the clients’ own words what qualities of medical and rehabilitation providers are perceived to either help or hinder the healing and rehabilitation process for persons with brain injury.

Method

This article represents a portion of a larger grant-funded research project conducted between 1995 and 1998 (Sample & Darragh, 1998). For the present article, issues related to the qualities of professional service providers were noted and analyzed. This topic of service provider qualities was not targeted originally by the investigators, but as is often the case in qualitative inquiry, it emerged from the stories of the study participants. Because the participants time and again mentioned the qualities, traits, skills, and attitudes of their service providers and the perceived impact these qualities had on their recovery from injury, we believed that a thorough analysis and reporting of the findings were in order.

Participants

The sampling method used for the study was primarily opportunistic (Patton, 1990), involving structured recruitment activities at various local Brain Injury Association support group meetings. Thirteen support groups are located throughout the state of Colorado, including both rural and urban regions. The majority of the participants for this study were recruited from four of these groups. Within the support groups, word-of-mouth recruitment occurred via a snowball sampling technique, as participants referred the investigators to other potential candidates for the study (Bogden & Biklen, 1992; Patton, 1990). To be included in the study, volunteer participants had to have sustained a brain injury more than 1 year before their interview.

For the purposes of this study, acquired brain injury was defined as an injury to the brain as a result of external force, such as a fall, auto accident, gunshot wound, or assault; a situation that caused lack of oxygen to the brain, such as a drug overdose or near-drowning, resulting in anoxia; or an internal injury, such as a brain tumor or poisoning. Fifty-one persons with an acquired brain injury were interviewed for this study. The participants varied widely in their ages (from those still in high school at the time of injury to those married with careers and grown children), geographic location (rural, urban), and years after injury (see Table 1). The participants lived in supported living, with their families, or independently.

Table 1
Participant Demographics

Characteristic	<i>n</i>
Gender	
Female	27
Male	24
Living situation	
Alone	38
With family	5
Supported living	8
Years postinjury	
Range	1–32
Mean	8
Type of injury	
Traumatic brain injury	46
Brain tumor	2
Toxicity	1
Neurological	2

Study Approach

A phenomenological approach was used for this qualitative study. Patton (1990) described phenomenological inquiry as a focus on “what people experience and how they interpret the world” (p. 69). Patton also noted that persons experiencing a similar phenomenon share an “essence” (p. 70). In this study, phenomenological inquiry enabled us to examine the shared experiences of persons with brain injury as they sought medical and rehabilitative supports and services and attempted to reenter their lives and communities. Using this qualitative approach, we conducted open-ended, in-depth interviews to identify emerging themes common to the study participants.

Each participant was interviewed once. The investigators used an interview guide (Patton, 1990) that contained four broad questions, with accompanying probes added as needed to aid the inquiry process:

1. How has your (social, vocational, recreational, home) life changed since your injury?
2. What services or supports did you use after your injury?
3. Did you have any difficulty accessing any of the services or supports you needed?
4. Were there any services or supports you believed you needed but did not get? (For those who did not understand this question, the following question was asked: If you could invent a service that could have helped in your recovery, what would it be?)

To enhance the reliability and trustworthiness of the data collection process, a form of triangulation was used. Triangulation of data collected by multiple interviewers (Patton, 1990) increased the potential richness of the data. Two of the investigators and two additional interviewers conducted interviews over a 3-year period. All interviewers asked the same questions and in the same order. The interviewers trained together on appropriate probes and methods of verbal intervention in case the participants wandered off track during the interviews.

Data Collection

The investigators used two steps in data collection. The first step involved a basic information data sheet to obtain demographic information and a description of the brain injury. The information was written down with each participant before the audiotaped interview session. These demographic data were then used for purposes of describing the participants as a group (e.g., by living situation).

The second step was the interview itself, which was audiotaped. The interview guide was used to ensure that (a) certain topic areas would be covered during the interview while preserving the flexibility and informality of a conversation and (b) the conversational style of the approach helped put the participants at ease with the interviewer. The subject matter often proved to be very personal and emotional for participants; therefore, the interviewers' aim was to promote trust and empathy with the participants so that they might freely discuss the topics of interest. The interview questions were designed to elicit information regarding services and supports accessed along with perceptions about the services without imposing the interviewer's opinions or perspective. Using a transcription machine, the investigators transcribed the tapes directly into a word processor. They then transferred the saved text files from word processing programs into HyperRESEARCH™ software (Hesse-Biber, 1991–1994) for sorting and analysis.

Investigators' Perspectives

Some background information relating to the three investigators is included here to provide the reader with a greater understanding of their motivation and reasoning processes. Two investigators have an extensive background in designing and delivering employment-related services to persons with brain injury. The third investigator, who was a graduate-level occupational therapy student during the research process, has a background in clinical service with persons with brain injury. The investigators possess a strong philosophical approach to their work, which is best articulated as a consumer-driven, choice-focused, non-medical model of service delivery. In the course of their work, the investigators have seen the life devastation experienced by many persons with brain injury due to lack of access to appropriate services and lack of information and resources given to them after their injury. Over the years, the investigators have sought methods to increase community readjustment of persons with brain injury as well as to coordinate service delivery at the local level so that these persons might access care in a more timely and cost-efficient manner. The investigators have believed for several years that lack of access to timely, affordable, and effective services by persons with brain injury is a very real problem and one that needs to be explored in-depth. Hence, the investigators pursued grant funding and embarked on the larger study of which some of the results are presented here.

Data Analysis

Because of the vast amount of material generated by the participants, we used the qualitative data analysis software HyperRESEARCH (Windows version) to organize and sort the data. With a strategy known as triangulating analysts (Patton, 1990), the data were analyzed by two investigators who independently coded each interview and subsequently generated a combined code list to ensure consistency between investigators and a thorough analysis. The investigators then analyzed the coded interviews for emergent themes reflecting the qualities and perceived helpfulness of practitioners who had worked with the study participants. This thematic analysis led to the revision and collapsing of certain code words that depicted similar content (e.g., *screamed at client* and *belittling* were combined into the code *disrespectful treatment*). Next, specific words and phrases were examined more closely so that they could be combined into more global or conceptual themes related to the topic of interest. For example, the code words that described the ways providers behaved toward the participants, such as *friend*, *mentor*, *advocate*, and *team member*, were subsequently grouped together under the theme of "roles of the provider." As is true in qualitative research, the investigators were the primary instrument of analysis (Patton, 1990), using HyperRESEARCH primarily to assist in sorting and organizing the findings.

Results

Thematic analysis revealed three major themes related to the perceived qualities and practices of service providers that participants reported as affecting the practitioner-client relationship in a helpful-unhelpful or valuable-not valuable way. Participants' experiences with providers reflected their perceptions of the roles of the provider, the helpfulness of the services provided, and the personal characteristics of the provider.

Roles of the Provider

[I] kept all my emotions and such in check for so [long], all the way from boarding school. That they [providers] kind of brought out, opened the Pandora's box of feelings and thoughts that I never, either never knew I had or had suppressed or hidden for so long. And they brought them out gently. And I was able to, they were able to connect with me. They really were. I'll never forget it.

Very seldom did the study participants speak about the technical expertise of the service providers who had worked with them after their brain injury. The interpersonal relationship between the service provider and the individual participant, however, seemed to have affected the participant's perception of the treatment received and its efficacy. In some cases, the stories the participants told revealed that their feelings of "relationship" with the providers were the most important part of the therapy. These relationships were played out in the roles the providers took on during the participant's recovery process. For example, one young

man described his physical therapist as a *friend*:

Then when I went to the physical therapist, I really enjoyed it. She was, she was more than a physical therapist; she was like a friend. I could talk to her and stuff like that. About my life and my mom and my friends, and how things are going.

Another participant described her massage therapist as a mentor:

I massage with [massage therapist]. That probably, right now...is what's holding me together. She's not always a massage person, she's, gosh, what would you call her? She's our mentor, she's just, she's been there too. You know, been there, done that...knows all the ins and outs, and she keeps us on our feet and keeps us going.

Participants emphasized that being included as a part of the team and in the treatment planning process helped them to feel in control of their treatment. In some cases, the participant needed active assistance with taking charge: "I was referred to an occupational therapist. And he was the one that really helped me. And also broke the logjam and finally got me a little more in charge of my recovery." Good service providers were also advocates for the needs of their clients, according to the study participants. They provided information, case management, and assistance with referrals:

I think for me, by having a case manager...I think she was beneficial for me because she turned me on to things I didn't know, that I was eligible for, or that I could look into....So, like, she set us up with a program with a speech therapy and a cognitive and even my vision therapy where people come to the house and work with me.

In contrast, the participants reported that when their providers did not play these roles, their services became frustrating. In some cases, participants interpreted their lack of inclusion as a team member as a power struggle: "Whatever I suggested was not done. What she [the physician] suggested, was. Those kinds of power struggles are unnecessary, especially when you don't have the ammunition you need to hold your own."

Helpfulness of the Services Provided

The second thematic category involved the participants' descriptions of services and providers that were helpful. Occupational therapists frequently were the subjects of the participants' stories.

It was important to many of the participants that their providers offered services that were relevant. One woman described how occupational therapy services delivered in the home were *relevant* and *meaningful* to her after her loss of activities of daily living abilities:

She did little things like helping me learn how to—we learned how to make the bed, pick things up, run the vacuum, do things like that. And then she was also, you know, she would take me shopping. And then, after my husband left and I needed to find someplace else to live, she was the one who took me around, and we looked at different apartments and townhouses and picked out the townhouse that I moved into. So she was very helpful.

The participants also often described the *use of practical suggestions or strategies* in treatment. Some practitioners

assisted their clients with the development and use of tools or adaptive equipment to compensate for functional losses:

It takes a lot just to do one small thing anymore. She [occupational therapist] taught me—realized what was going on and gave me strategies to help me compensate, and she got me a day timer and taught me how to do that. So she helped me a lot. I was really out of the automatic pilot. Every single thing took so much for me to do.

One participant described the practical suggestions offered by an occupational therapist:

Interviewer: So what kind of things did they help you with at home?

Participant: At home, it was like mainly how to take care of myself. Hygiene and stuff. How to brush my teeth, 'cause I, it's really weird, how to dress myself, 'cause it's really weird when you, when, it sounds simple to brush your teeth, dress, dressin' yourself, it sounds pretty simple, but you do it so often. In the morning, do you pay attention to how you put your shirt on?

Interviewer: Uhn-uhn.

Participant: See, neither did I. So they said, "Here, put this on," and I, I had no clue how to put it on.

Some practitioners had helped their clients to learn *new skills to substitute for functional losses associated with the injury*. For example, one participant learned to use her left arm because her right arm was so painful that she was unable to use it:

So, she [occupational therapist] came to my office and watched me work. And, she said, [that] I'm right-handed. She said, "You need to do everything you can with your left hand." And throughout all of this, I had been telling all of the doctors how much my right hand and arm hurt and that it didn't feel right. And they kept saying, "Oh, well," you know, "that will go away." And, you know, finally somebody [occupational therapist] said, well, "So quit using it." So, now you notice I write left-handed. And I do everything I can left-handed....So, that was nice to finally hear a real concrete suggestion on something. And I was injured in July '94, and that was in July '95 that somebody told me that. So, it took a year and all these doctors and all these therapists for somebody to finally tell me something concrete.

Participants also described practitioners who *gave periodic feedback about progress* as helpful. They valued the concrete information the practitioners provided:

I had some biofeedback with Dr. B....and they intermittently did testing just to see how I was progressing, so it was kind of encouraging to see what, you know, "Hey, last time we tested you, you couldn't do this. Well, now you were able to accomplish this and that type of thing."

Participants were quick to point out providers and services that they perceived as not helpful. For example, the following participant described occupational therapy services as irrelevant: "Oh, the OTs, they just...stick a needle up and down your arm to see if you can feel it. That was with sharp, dull, sharp, dull...and that's what they still do." Additionally, the participants had trouble with services that *did not feel individualized*. Vocational rehabilitation services came under criticism:

They really didn't understand me at [vocational rehabilitation]. They said I had to do things the way they had things worked out. I must obey them, you know. They didn't do individualized things for me. Actually, they were kind of cruel to me....But like, they stuck me with doing menial tasks while working with retarded [sic] people is what happened. Which I really don't remember too well, but my mom does, and it sure wasn't very...working with retarded people. I may have

seemed kind of that way, I guess, to put me in there, but I wasn't retarded...putting boxes together with retarded people. So they didn't help me a lot I don't think.

One participant actually believed that her occupational therapist encouraged her to be a "cripple":

I was talking about the OT, and the fact that that seemed sort of superfluous, you know, it didn't seem...really seem important. She was teaching me how to live a crippled life...and I wasn't about to live as a cripple, you know...I wasn't about to live...with...you know, with...attendant care, and...you know...in an adapted house, and...an adapted kitchen. I mean, I could not see myself doing that, I just couldn't, and so that's what...made me think that there was...silly, stupid...what the...activities, you know, crocheting...what'd she have me do?

Occasionally, participants would remember services and providers that had done *more to frustrate them than to help*:

Participant: Then I had a guy that was supposed to be doing occupational therapy...stuff, that drove me nuts.

Interviewer: How come?

Participant: Because he wanted me to do things that...I couldn't do, and the trying of it was so frustrating that most of the time I wanted to murder him.

Interviewer: Like what kinds of things?

Participant: [A]dd columns on an adding machine, stuff like that.

Personal Characteristics of the Provider

The personal characteristics of the providers often increased the participants' perceptions that they had received helpful, effective care. As would be expected, clear and honest communication between the providers and the participants was a critical element and a perceived necessary practitioner skill:

I went to see Dr. D., and she really has been helpful in terms of this...."You are a head-injured person." And one, she just acknowledged that, which is nice. And two, "Head-injured people seem to have these sorts of problems. So let me tell you about them, and let me see if you're experiencing them. If you've got these problems, then let's deal with them." So, that was nice. But I do feel there's something else I need, and [the occupational therapist] provides me with a lot of that. Like whenever I go see her, I always leave feeling better, and she's totally in tune to me. And, you know, we get along great and stuff.

Participants appreciated professionals who were *straightforward* about their prognosis and admitted that they did not know whether the participants were going to get better. Even though this was frustrating to hear, the participants preferred it over "false hope." Several participants appreciated the honesty of the occupational therapists who worked with them: "Yeah, he does not lie to me about anything that concerns me. He doesn't misrepresent himself to try to make me feel good."

Participants valued professionals who would discuss treatment options and solicit the participant's opinions about those options. One participant described his interaction with his physician as *supportive and respectful* and as being listened to:

He listens to my perception about all of it; he supports me. If I have a summary or an evaluation or a sense of direction that I think is appropriate for me at this time, I'll tell him why I think it's appropriate, where I want to go, and then ask for his feedback. And he supports me verbally and psychologically [sic]. I can sense that he is not, what do you call it? Not looking down on me.

Participants emphasized the importance of providers *understanding* the specific needs of persons with brain injury. Service providers who had experience in working with persons with brain injury were perceived to have knowledge about appropriate evaluation, treatment, and outcome expectations, a quality participants described as important and comforting. To assist one participant with her return to work in dentistry, the occupational therapist went to her office and watched her treat patients to increase his understanding of her return-to-work problems. She described the situation as follows:

And he said, "I'd like to come to your office and watch you work," he said, you know. So, at the end of the session, after I'd tried to drill on some teeth, and, and he [the occupational therapist] watched me treat a patient...he said, "I've obviously been to the dentist," and he said, "I didn't have a clue." And he said, "Now I know what you've been trying to do. I don't think," he said, "I don't see how you're going to continue." And he was really the first one that said, "I don't think you're going to make it." And that was real hard to hear. But, it was nice that somebody was finally honest with me too. I mean, I had tears in my eyes, and I do again....'Cause somebody finally understood.

The investigators also received a great deal of information about *unhelpful personal characteristics* of providers. As would be expected, these characteristics and behaviors were antithetical to the helpful ones discussed previously. Some participants believed that providers were *unwilling to listen* to them and, in some cases, believed that their opinions and ideas had been dismissed as "absurd." At times, participants believed that providers were *disregarding* them: "I don't dislike her. I feel there was an unprofessional decision made, and I feel like she didn't listen to me [before she made it]."

Vocational rehabilitation counselors often came under sharp criticism from participants who believed that the counselors had been disrespectful and adversarial with them:

[The counselor] told me, "You'll never amount to anything. You'll only be able to get a minimum wage job. Wanting to go to school is like someone with an IQ of 65 wanting to be a CEO of a company; it's just not going to happen."...And I was still in the midst of going, "Is it really true? Am I not going to be able to?" So that is just one little thing I've had to overcome.

Poor communication, even between staff members, was a source of participant dissatisfaction with a provider or service agency:

So, that's something that kind of irritates me. It's like how, how in the heck are we supposed to know what we're supposed to do with our life, when the staff, the people that work with us daily, don't know what the heck we're supposed to be doing? We, we've, you know, we've got reason to be forgetful what, what not to do. But they, they got to open up their communication lines between the, within the, so that they know what's going on, so that we know what's going on. You see what I'm saying?

Service providers who provided information in *absolute* terms were perceived as inexperienced or not knowledgeable. This was sometimes true for providers who seemed pessimistic:

The only neurologist I've ever seen....told my family that if I ever get out of my coma, that I'd be a vegetable. Well, apparently that's, obviously that's not true because now I hold down a job, I can walk, I do my exercises, I live on my own, I take care of myself, I don't depend on anyone for anything, I have my own car I drive. So for her to say that, it was just, it was just wrong.

[I have had] three occupational therapists, who say because I have limited memory abilities, I am unemployable. I think they're wrong.

This was also sometimes true for providers who seemed optimistic:

My neurosurgeon was like, you know, you'll get better, you'll get better. It'll be all right. And that's all she kept saying. And I was like, she had no explanation for what was going on. And I understand why now looking back on it. She doesn't deal with that [brain injury]. She didn't know.

The participants often were concerned about service providers who seemed to lack an understanding of the implications of brain injury in their lives. One participant believed that her psychologist minimized her symptoms:

I mean, I thought the world of this guy [the psychologist]. I thought, you know, he has really gone on, and he knows this and he knows that. And he said something about, "Yeah, but you guys aren't having to deal with that much at all, you should see some of the other clients I've worked with." And so I had to tell him. I said, "You know, but we're not dealing with the same things, and we're not them. We have our own agenda going on here."...But I'm thinking, "I've got to educate this PhD guy here who is working with head injury?" You know, what is going on with that? It really pisses me off. It's like, get a clue people.

Another participant grieved that many professionals and the community in general often do not understand the devastating implications of an often physically "invisible" brain injury:

And so there needs to be a lot more knowledge in the field, and it's really sad that so many people are going untreated, which they are. And there needs to be a lot more help because people like myself, I know there's a hell of a lot more wrong with me than appears for somebody just to talk to me on the street.

Discussion

Perceptions of provider roles, helpfulness of services and providers, and personal characteristics of providers were all topics represented in the participants' experiences of care after their brain injuries. The findings suggest that helpful providers do not simply dispense services, but deliver services in a manner that reflects a certain treatment philosophy, addresses the self-identified needs of persons with brain injury, demonstrates the providers' professional knowledge and skills, and displays the providers' distinctly positive personality traits and characteristics.

When the participants reflected on the practitioners who had worked with them, they consistently referred to the many roles the providers played in their lives: a friend, a mentor, a team member, an advocate. These roles depict

a relationship that puts the client at the center and as the focus. The findings of this study suggest that without additional attention paid to the interpersonal professional-client relationship, the resulting services may seem incomplete, ineffective, and perhaps detrimental.

It should come as no surprise to occupational therapists that the services labeled as helpful by the participants were those that were perceived as relevant, meaningful, practical, innovative in replacing lost skills, and framed with periodic feedback on progress. Judging from the results of this study, the field of occupational therapy continues to be unique in its ability to help persons with brain injury feel that they are improving in their recovery and in the process of returning to their lives. More than any other findings in this study, the content embedded in this theme of service helpfulness is an affirmation that the philosophical approach of occupational therapy would serve well for other disciplines that seek to work with persons with brain injury.

The personal characteristics of service providers that were seen positively by the participants, repeats, nearly verbatim, the findings of the many studies cited in the introduction to this article. Professionals working with persons with brain injury need to be clear, honest, respectful, not overly optimistic or pessimistic, supportive, listening, and understanding. These preferred provider characteristics coincide with Schwartzberg's (1994) findings that brain injury support group members felt that being listened to, believed, and legitimized in their feelings about their injuries were important components of their support groups. Whether it be from family members, peers, or professionals, persons with brain injury continue to seek understanding and active listening from others. If indeed the goal of practitioners working with persons with brain injury is to promote the best possible outcomes of the service process, then practitioners must reflect on their personal approach to the delivery of those services.

The findings of this study highlight several important skills and approaches to service that professionals need to develop. As Krefting (1989) noted, persons with brain injury and their families are coping with many life-changing problems and challenges. Experience and time spent (either professionally or personally) with persons with brain injury and their families can increase the abilities of service providers to work positively with them. As the participants stated, they do not appreciate being compared with people with other types of illness or injury, and they resent having practitioners refuse to flex their typical procedures to work with a client as an individual. Persons with brain injury often have extremely complex cognitive, emotional, and physical issues. Sensitivity to the complexity of the new lives these persons are living is a necessary skill for the practitioner.

Timing also is a critical skill for working and communicating with persons with brain injury. Heifetz (1994) dis-

cussed the dilemma medical professionals and others have when they need to break difficult news to people. A caring professional will try to reveal information only as a client is prepared to hear it. Heifetz noted that the keepers of the information must establish trust with the client and watch for signs of readiness for more realistic news. In many of the participants' stories repeated here, the professionals either went overboard in pessimism or minimized real problems the clients already knew they had. Either way, the trust was broken following the miscommunications, which undoubtedly had an impact on the client's relationship with the practitioner. According to Heifetz, there are signs and signals that people give to the keepers of information. For example, one of the participants in this study was coming to the realization that she was not going to be able to continue as a dentist, but was unwilling to say it out loud. The occupational therapist could sense that the participant was ready to deal with this difficult news and accompanied her to work where the situation could finally be realistically confronted. The timing was essential, and the therapist was in tune enough with the client to know that she was ready to hear the difficult news.

Another skill that may influence the ability of the practitioner to work positively with persons with brain injury is empathy. Over and over, the participants reported how important it was that the professionals understand them and their issues. By empathy, we do not mean that practitioners decide what they themselves would want if they had the injury. We mean that practitioners need to understand how the client feels and what the client wants. These feelings and wants can change from day to day as a result of the cognitive and emotional deficits resulting from the injury. Additionally, the practitioner may need to probe deeply with the client because, as Krefling (1989) suggested, the client may be covering up some of his or her problems. Active, intentional, and caring listening is required by the service provider to develop client-specific empathy. From the findings of this study, it appears that practitioners must avoid making such statements as, "If I were you, I would..." Such a statement demonstrates a lack of client-specific empathy and shows the client that he or she as an individual is not being heard. As Schulz (1994) found, persons with brain injury dislike opinions offered by others about their situation. Whether it comes from family members, support group members, or service providers, persons with brain injury consistently complain about others' opinions being thrust upon them. Practitioners need to resist the temptation to voice their own opinions about what the client "should" do. Instead, they need to try to determine clearly the client's own opinion. Once the client believes that the professional is concerned only with the client and with addressing the client's self-identified needs may the client be more willing to hear the professional's informed opinions about courses of action to take in rehabilitation

and community reintegration.

An old adage says that every story has at least three sides: your side, my side, and what really happened. Often, professionals are tempted to disclaim the stories of persons with brain injury as being exaggerated, untrue, or distorted by impairment caused by the injury. We did not question the veracity of the participants' stories. Instead, we sought to identify and present their personal stories of the care process they experienced after their injuries. The feelings and perceptions that they shared are what they carry out of the service setting and into their lives in the community. We unquestionably can learn a great deal from this information.

As is the nature of qualitative research, further topics for investigation have emerged from the present study. Future research into the nature of service delivery should focus now on creating a more elaborate and detailed profile of what makes a good practitioner for working with persons with brain injury. Researchers need to identify and learn from those practitioners who possess a strong grasp of their many client-centered roles in service delivery, who provide services in such a way that clients with brain injury believe that they are being heard and helped, and who exhibit personal characteristics that promote feelings of trust and success in clients. Further research will increase understanding about how these persons are able to maintain positive practitioner-client relationships in this challenging area of practice. ▲

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References

- Bogden, R. C., & Biklen, S. K. (1992). *Qualitative research for education: An introduction to theory and methods*. Boston: Allyn & Bacon.
- Brody, H. (1992). *The healer's power*. New Haven, CT: Yale University Press.
- Cassell, E. J. (1991). *The nature of suffering and the goals of medicine*. New York: Oxford University Press.
- Coles, R. (1998). The moral education of medical students. *Academic Medicine*, 14, 345-354.
- Coulon, L., Mok, M., Krause, K. L., & Anderson, M. (1996). The pursuit of excellence in nursing care: What does it mean? *Journal of Advanced Nursing*, 24, 817-826.
- Gauthier, C. C. (1997). Teaching the virtues: Justification and recommendations. *Cambridge Quarterly of Healthcare Ethics*, 6, 339-346.
- Gitlin, L. N., Luborsky, M. R., & Schemm, R. L. (1998). Emerging concerns of older stroke patients about assistive device use. *Gerontologist*, 38, 169-180.
- Glassman, U. (1991). The social work group and its distinct healing qualities in the health care system. *Health and Social Work*, 16, 203-212.
- Heifetz, R. A. (1994). *Leadership without easy answers*. Cambridge, MA: Belknap.
- Hesse-Biber, S. (1991-1994). *HyperRESEARCH* [Computer software]. Randolph, MN: Research Ware.
- Jackson, J. D. (1994). After rehabilitation: Meeting the long-term

needs of persons with traumatic brain injury. *American Journal of Occupational Therapy*, 48, 251–255.

Jensen, K. (1993). Care—Beyond virtue and command. *Health Care Women International*, 14, 345–354.

Krefting, L. (1989). Reintegration into the community after head injury: The results of an ethnographic study. *Occupational Therapy Journal of Research*, 9, 67–83.

Malec, J. F., Machulda, M. M., & Moessner, A. M. (1997). Differing problem perceptions of staff, survivors, and significant others after brain injury. *Journal of Head Trauma Rehabilitation*, 12(3), 1–13.

More, E. S., & Milligan, M. A. (Eds.). (1994). *The empathic practitioner: Empathy, gender, and medicine*. New Brunswick, NJ: Rutgers University Press.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Sample, P. L., & Darragh, A. R. (1998). Perceptions of care access:

The experience of rural and urban women following brain injury. *Brain Injury*, 12, 855–874.

Schulz, C. H. (1994). Helping factors in a peer-developed support group for persons with head injury, part 2: Survivor interview perspective. *American Journal of Occupational Therapy*, 48, 305–309.

Schwartzberg, S. L. (1994). Helping factors in a peer-developed support group for persons with head injury, part 1: Participant observer perspective. *American Journal of Occupational Therapy*, 48, 297–304.

Sixma, H. J., Spreeuwenberg, P. M. M., & van der Pasch, M. A. A. (1998). Patient satisfaction with the general practitioner: A two-level analysis. *Medical Care*, 36, 212–229.

Sourial, S. (1997). An analysis of caring. *Journal of Advanced Nursing*, 26, 1189–1192.

Tanne, J. H. (1990). Making doctor right. *Health*, 22, 52–53.

Thompson, J. N. (1997). Moral imperatives for academic medicine. *Academic Medicine*, 72, 1037–1042.