The Experience of Being an Occupational Therapist With a Disability

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Objective. This study addressed what it is like to practice as an occupational therapist with a disability.

Method. Open-ended interviews using a phenomenological approach were conducted with 10 participants until data saturation was achieved. Each transcripted interview was coded for categories, and the common themes across transcripts were identified.

Results. These major themes were identified: “I am sensitive to their needs”; “The issue is how to cope with life”; and “Recognize your own strengths and limits.” Each theme had several subcategories.

Conclusions. Occupational therapists with disabilities approach their practice from a unique perspective and may be able to motivate and challenge clients in a different manner than therapists without disabilities. Therapists with disabilities perceive themselves as uniquely skilled persons who have developed successful strategies to cope with the experience of disability.


Persons with disabilities are becoming increasingly visible in North American society. Further, 7.5% of the professionals working in the health assessment and treating occupations (e.g., physicians, dentists) have a disability, and 16.6% of those in health services occupations (e.g., occupational therapists, physical therapists) have a disability (International Center for Disability Information, 1997). According to the most recent American Occupational Therapy Association (1990) member survey, which identified data about therapists with disabilities, 4.2% of responding occupational therapists and 6.3% of occupational therapy assistants who responded had some type of disability. Because of the potential effect of the Americans With Disabilities Act of 1990 (ADA; Public Law 101–336) on employment, the number of occupational therapists with a disability can be expected to increase.

To date, there has been little written about the experience of the occupational therapist with a disability. Three articles (Hanebrink, 1997; Joe, 1997a, 1997b) provided anecdotal information relating personal life, practice, and fieldwork stories.

Two research-based articles were pertinent. Elliott, Hanzlik, and Gliner (1992) examined the attitudes of 105 registered occupational therapists and 98 certified occupational therapy assistants toward occupational therapists with a disability and found that the attitudes varied depending on the type of disability. When the disability was related to a mental illness or to AIDS, attitudes were less favorable than when the disability was physically relat-
ed, such as a spinal cord injury.

Mutchnick and Blount (1996) conducted a pilot study regarding knowledge of the ADA and the attitudes of occupational therapist supervisors toward occupational therapist employees with a disability. Six of the 10 respondents indicated that they made reasonable accommodations for employees with disabilities.

In the related field of nursing, Pohl and Winland-Brown’s (1992) phenomenological study on the meaning of disability and its influence on the perception of self-worth among nurses with disabilities yielded two themes: self-image and support. Within self-image, three categories were elaborated on: powerlessness, hope, and anger. Support was further represented as psychosocial and financial.

What appear to be lacking are studies that describe the experience of practicing occupational therapy as a therapist with a disability from an insider’s perspective. In this approach, “The primary emphasis is on the phenomenon itself exactly as it reveals itself to the experiencing subject in all its concreteness and particularity” (Giorgi, 1971, p. 9). The current study used the phenomenological approach described by van Manen (1990) to elaborate on the experience of practicing occupational therapy as a therapist with a self-proclaimed disability.

Method

Participants

Purposive sampling (Morse, 1989) and snowball sampling (Patton, 1990) were used to secure participants. Advertisements were also posted on the Internet, on sites that occupational therapists frequent and in OT Week (“At Large,” 1997). When potential informants contacted the researcher, she explained the study and selected participants who (a) were registered occupational therapists, (b) were accessible for interviews, and (c) had a self-proclaimed disability.

Ten participants were interviewed regarding the nature of their experience as occupational therapists with a disability. All participants were women and had worked in both physical disabilities and psychiatry settings. Their work histories ranged from 8 months to 27 years. Seven of the 10 participants had disabilities when they attended occupational therapy school. Self-reported disabilities included hearing impairment (2), postpolio syndrome with scoliosis (3), below-the-knee amputation (1), systemic lupus erythematosus (1), legal blindness (2), and cubital tunnel syndrome with thoracic outlet syndrome (1).

Data Collection

Data were collected using open-ended interviews (Morse & Field, 1995) conducted either by telephone (n = 3) or e-mail (n = 7). The first interview began with the broad question, “Describe the experience of practicing occupational therapy as a therapist with a disability.” The number and length of interviews varied, depending on the information volunteered by the participant. Interviews were continued until data saturation (Morse & Field, 1995) was achieved. The telephone interviews were tape recorded and transcribed verbatim.

For the e-mail interviews, the researcher maintained contact with the participants for whatever time was necessary to fully address the phenomenon. This decision was determined by consensus between the researcher and the participant and ranged from 3 to 5 weeks. Complete text printouts were obtained for e-mail interviews and treated as a transcript.

Procedural and reflective observations were recorded to aid in the interpretation of the data (Patton, 1990). These observations included pauses in the dialogue, changes in tone, changes in voice (e.g., use of a personal or impersonal pronoun), delayed responses, or a request to rephrase. These observations were consistent regardless of interviewing method; respondents using e-mail used punctuation such as “…” to indicate pauses and phrases within parentheses to describe tone [e.g., (Ha! Ha!)].

Data Analysis

All 10 transcripts were reviewed while data were being collected and after data collection was complete. Data were reduced during the data collection process in order to further investigate unexpected or emergent data with participants (Howe, 1991). A transcript was shared with each participant, who was asked to verify whether it represented her own meaning of the experience.

Data were organized into categories using a multistage process. First, the preliminary categories were taken together as a whole. Second, they were modified according to provisional codes and grouped into themes. Some data fit more than one category. Third, a statement that could be supported by appropriate quotations from the interviewees was written to explain the theme. This multistage analysis for categories and themes led to identification of the “structures of experience” (van Manen, 1990, p. 79) involved in practicing occupational therapy as a therapist with a disability. All themes and categories were named using the participants’ own words.

Trustworthiness

Lincoln and Guba (1985) suggested four criteria for rigor in research: truth value, applicability, consistency, and neutrality. Truth value in the current study was addressed through participant review of both transcripts and the description of themes. Applicability, which relates to the richness of description, was addressed through a detailed characterization of the participants. This characterization aids the reader in deciding how to use the information. Consistency refers to stability over time and equivalence (Brink, 1989). Stability and equivalence were addressed by member checks in which participants reviewed both trans-
scripts and interpretations for accuracy. No participant’s data required changes, indicating some stability in their reporting of the information.

The researcher’s interpretations of the participant’s descriptions were reviewed for the viability of the interpretations by an expert in phenomenological research. After agreement regarding the interpretations and verification of the analysis by the participants, the researcher had the additional responsibility of clearly indicating in text what was an actual quote and what was the interpretation agreed on by the participants involved in the study.

Findings

Three themes were identified from the data: “I’m sensitive to their needs”; “The issue is how to cope with life” and “Recognize your own strengths and limits.” Quotations from all 10 participants expressed a connection with one of the categories included within the theme. The theme “I’m sensitive to their needs” included the categories of “Increased empathy” and “I have a repertoire to draw on.” The second theme, “The issue is how to cope with life,” included the categories of “You’ve just gotta realize it’s not a limitation”; “My disability was questioned”; “Pain and fatigue”; “Overcompensation”; and “Time control.” Finally, “Recognize your own strengths and limits” included the categories of “You need to speak up” and “I’m not the only person out there.” In the following quotations, participants are represented by pseudonyms.

I’m Sensitive to Their Needs

This theme describes how a personal disability can increase sensitivity to the needs of clients. This sensitivity began with the initial meeting between therapist and client because “it can be a point of contact” (Sara). It continued through treatment, where being “sensitive to their overall experience of disability and interactions with the world” (Terri) was increased because the therapists shared this disability experience. Informants further believed that their disability decreased the client’s attempts at manipulation “because I have a disability. So that puts us on an even keel, an even table” (Lynn). Two categories further elucidated the meaning of this theme to the participants.

Increased empathy. One outcome of being sensitive to the needs of clients is increased empathy. As Nancy explained, “At times, it is easier to empathize with others who also struggle with gadget intolerance.” This empathy may come about through sharing the experience and culture of disability. As a result of this shared experience, “I increase my own awareness to the way others need to cope with a disability, disease, or injury” (Penni). These therapists found that by not hiding their disability, they could “use it as a point of empathy and motivation for [their] clients” (Candy). According to these participants, empathy is a unique strength that is not shared by therapists who do not have disabilities.

I have a repertoire to draw on. Having a personal disability also allowed the participants to develop a repertoire of ideas for accommodations. Penni described the process of acquiring this repertoire as “not an easy lesson to learn and [one that] can require years to acknowledge.” Participants shared this knowledge with their clients through stories and through role modeling.

Types of accommodations described included the use of physical aids (e.g., computers, spy glasses, talking books); the use of alternative communication methods (e.g., a computer for documentation); development of a problem-solving process for physical access problems, and the use of energy conservation techniques. In addition, participants described bartering with other therapists to trade practice responsibilities that were difficult for the participant for tasks within her capabilities. Bartering was not always easy. “At the same time, it seemed harder to get help because it would take extra time in planning and coordinating with other people’s schedules” (Ethel). Both accommodations and the bartering process were used to keep the total job expectations evenly distributed.

Participants believed that the accommodations that they shared were perceived as effective by their clients because “patients have commented optimistically with the general attitude ‘I figured if you could do it, I could do it, too’” (Sara). Therapists without disabilities cannot vouch for the efficacy of these accommodations with the same veracity.

The Issue Is How To Cope With Life

Participants did not perceive their disability as a barrier to practice. Rather, they viewed themselves as competent, skilled therapists. They all shared the perspective expressed by Lynn: “The disability is not the issue; the issue is how well do they [the clients] cope with life?” Participants described five concepts that they believed contributed to this theme:

1. “You’ve just gotta realize it’s not a limitation”
2. “My disability was questioned”
3. “Pain and fatigue”
4. “Overcompensation”
5. “Time control”

You’ve just gotta realize it’s not a limitation. All participants described a process of personal growth regarding their disability. The process began with the acknowledgment of personal strengths and limitations. Terri summarized the experiences of the other therapists: “I found that those who were successful were able to recognize their own limitations and adapt effectively, [and] those who failed…would not recognize limitations, or could not adapt, and were defensive about it.” Next, the participants recounted how living with a disability fostered the development of coping strategies that resulted in their accep-
tance of themselves as persons with disabilities. Penni indicated that "having to live with a disability daily has shaped me into the person I am today and continues to influence how I interact with my clients.” Finally, they believed that, through accepting themselves, others would view them as able persons who happened to have a disability.

My disability was questioned. Eight of the 10 participants described incidents in which stereotypes and assumptions affected their professional practice. These assumptions were perceived as both positive and negative. For example, Nancy explained, “They challenged me not to let my disability stand in the way,” and she was encouraged to not use her disability as “an excuse” (Candy). Sometimes, the beliefs of others created unrealistic expectations regarding practice. Nancy articulated her frustration, “I found myself pushed to my limits, and found it difficult to be heard that I was maxing out on what I could do.” When the disability was a hidden one, “people were less likely to help. Yet, when I wore my splint, they were less reticent about helping, versus when I didn’t have it, when I had this hidden disability” (Evel).

Candy described how stereotypes limited her professional practice:

See, she [the supervisor] had already said in her mind, ‘Well, this girl can’t see, so therefore she can’t do this, and this, and this, so therefore I’m going to put her in this area.’ Before she even met me, before she even knew what I was capable of.

Although most participants described difficulty in getting into occupational therapy school, barriers during fieldwork, and some difficulty in securing entry-level positions all articulated that as their résumés grew, employers and peers began to see them as able therapists, not persons with disabilities. These therapists collectively have held extensive management and supervisory positions. They indicated that once they established their skills in the eyes of others, they were able to practice and advance professionally, and their competence was no longer questioned.

Pain and fatigue. All participants noted that they lived with daily pain and fatigue. Donna acknowledged the need to mediate her workday against her pain levels: “I realized I could not continue to push my body into doing what was painful or I would not be able to work at all.” Because pain and fatigue were variable, there was uncertainty regarding their capacity on any given day. To handle these factors, these participants developed some of the coping strategies discussed under “I have a repertoire to draw on,” which they believed enhanced their ability to function as a successful therapist.

Overcompensation. Participants indicated that in their attempt to be viewed as successful therapists and team players, they sometimes overcompensated. Nancy explained, “In general, I...need to be more careful of how I perceive the support and caring attitudes of others, as well as how I am perceived by others.” When support and the attitudes of other patients were not reflected on, participants indicated that they could misinterpret this support as pity or a belief that the therapist with a disability was not “up to the job” (Penni). This often drove these participants to overcompensate, “but you are driven to be the best because you are ‘not quite all there.’ You have to overcompensate, and you may even become a little obnoxious for want of acceptance” (Laura). Participants did not view this overcompensation as negative or positive but acknowledged its existence in their struggle for advancement as professionals.

Time control. The therapists suggested that time had an influence on their practice. Control over the daily schedule made it easier to handle their practice and helped to compensate for the pain and fatigue factors mentioned previously. Candy suggested that

a lot of it is time management. I still have an hour of treatment to go. I just know I can’t go and do charts...so I try and structure my days so that documentation and treatment plans and referrals are done in the morning, when my eyes are the best.

The disability itself may have increased the time needed to perform job functions, such as the “time (needed) to be mobile in the community” (Penni). Linda acknowledged that this need for control of time affected others, and “it would take extra time in planning and coordinating with other people’s schedules.” Many of the therapists achieved control over time through advance planning, careful selection of areas of practice or site of employment, and personal time management techniques.

Recognize Your Own Strengths and Limits

All participants revealed the value of learning their own strengths and limitations. The process often elicited strong emotions:

This limit testing, although something I wanted to do, also was very frustrating at times, I found myself fighting pain on a more regular basis. Then I would alternate between feeling angry or being pragmatic, matter-of-fact about it, trust in God’s help and let go, or both. (Nancy)

Having a disability was seen as contributing to their personal success. Penni stated, “I believe that having to personally adjust, cope, and grow as an individual requires an open mind to trying other approaches, new ideas, and the willingness to fail but still consider myself successful.” In many ways, the disability was not viewed as a medical problem but as a part of the participant’s personal culture.

You need to speak up. As part of recognition of strengths and weakness, participants had become self-advocates.

If I have trouble with something I’ll ask and say “Look, I can’t read this.”...You need to be, and this is hard, you need to speak up. When something’s not right, when someone’s giving you a hard time because they think you can’t do something, you’ve got to become your own self-advocate. You can’t just take their crap, just because you have a disability. (Candy)

Assertiveness, however, required the right approach. As Penni suggested, “I try to ask for help when I need it and, in return, help other staff members. I ask for help, not demand...
Participants also discussed the social supports that assisted them in living within their strengths and limits. Candy acknowledged the value of networking with other therapists with disabilities: "They want to know they're not the only person out there who has to deal with this." When this network is not established, feelings of isolation may occur. Linda depicted this by stating, "I felt even more removed from the staff so I had a hard time asking for help 'cause that means tracking someone down. Everyone always seemed busy." In addition to the support of coworkers, these participants described a rich social support system consisting of family and friends. Candy summarized the general feeling of the participants, stating, "They're always there when I need them. I don't think a lot of them understand...but everybody tries." These participants indicated that their success and their perception of the nature of occupational therapy might be attributed to their belief in the importance of interdependence.

Discussion

The purpose of this study was to describe the experience of practicing occupational therapy as a therapist with a disability. Using a phenomenological approach, three themes were identified that appear to be interrelated and not hierarchical in nature. On the basis of the data, an occupational therapist with a disability approaches practice from a unique perspective and may be able to motivate and challenge a client in a different manner than other therapists. This perspective occurs because of the direct and personal experience of the therapist with a disability and was reflected by statements in the categories of "Increased empathy"; "I have a repertoire to draw on"; and "You've just gotta realize it's not a limitation."

Therapists with disabilities perceive themselves as uniquely skilled persons who are able to offer the field of occupational therapy insight into the experience of work as an employee with a disability. This was reflected in the categories of "Overcompensation" "Need to speak up"; and "Time control."

Finally, the participants indicated that their disability affected their coworkers, which in turn created personal reactions, the development of compensatory strategies, and the need for support. The categories of "Pain and fatigue"; "My disability was questioned"; and "Not the only person out there" contained statements that related with this association.

There appears to be some relationship between these findings and the themes and categories uncovered by Pohl and Winland-Brown (1992). Their study of the experience of nurses with disabilities uncovered the themes of self-image and support. Self-image was further described as knowing oneself—similar to some of the concepts in the category of "You've just gotta realize it's not a limitation."

Pohl and Winland-Brown described support as involving the person's interpretation of interpersonal interaction and the perceived attitudes of others. In some ways, this may be comparable to the categories "Not the only person out there"; "My disability was questioned" and "Overcompensation."

Limitations

The quality of the data collected was partially determined by the skills of the researcher and the comfort level of the participants regarding disclosure of information. Because the researcher did not know the participants and does not share the experience of disability with them, the participants may have been reluctant to provide richer descriptions of the phenomenon being investigated. The researcher was careful to articulate assumptions and biases and attempted to hold them in abeyance when collecting and analyzing the data. As a further control, an external auditor was used to offset this limitation. The participants were chosen on the basis of the researcher's access to them, which may have eliminated some who wished to participate.

The participants were all women. Although one man responded to the call for participants, he was unable to schedule an interview within the time frame of the study. Most of the participants had been practicing for more than 20 years. It is possible that the experience of a new therapist may be different in many ways than that of these therapists. It is also possible that participants who began occupational therapy school and practice after the implementation of the ADA may have a different perspective on their right to practice.

All participants volunteered, and they may have been more inclined to participate because they believed that they were successful in their practice. Therapists with disabilities who were not as secure may have been reluctant to participate. Finally, the fact that data were collected using telephone interviews and e-mail interview may have influenced degree of disclosure and, ultimately, the richness of the data.

Implications for Practice, Research, and Education

Little has been written about the practice experience of the occupational therapist with a disability. The description of this experience may contribute to the practice of occupational therapy by informing both employers and other therapists about the elements in daily practice that enhance the functioning of the occupational therapist with a disability. This includes the impression that "my disability was questioned," "overcompensation" was necessary, and "pain and fatigue" are part of the daily life-world of these therapists.
The findings also have implications for the education of occupational therapists. Informing occupational therapy schools regarding the repertoire of skills that assist therapists with disabilities both in coping with their practice and in informing their clients about useful accommodations may provide important guidelines for intervention courses. In addition, these therapists provide a rich and insightful group of potential educators, fieldwork educators, and professional role models for students with and without disabilities. Terri, one of the study participants, reported the following conversation that indicated that there are occupational therapy professionals who would limit the ability of persons with disabilities to gain entrance to practice:

There was a great deal of argument about how the ADA would affect OT's [occupational therapists'] education...whose disabilities might be so impairing that they simply shouldn't be allowed to enter OT programs. One clinical education supervisor...stated her unequivocal opinion that students with orthopedic handicaps shouldn't be allowed in OT programs because they couldn't possibly ever complete a fieldwork experience or be effective practitioners. Another stated that people with dyslexia should be rejected because they couldn't read the physicians' orders and would inevitably make mistakes that would lead to patient injuries. I finally pointed out that it seemed to me if we really believed that people with disabilities have the right to be or do anything they want to in life except be an occupational therapist, we'd better stop being mealymouthed and say so up front.

Further investigation of this topic using different participants would provide an interesting comparison of experiences. For example, would male therapists, new therapists, therapists with psychiatric disabilities, or therapists with congenital disabilities describe a different experience? Further, investigation of the experience of occupational therapy assistants, because of their unique position in the health care system, may yield a different understanding of the interrelationship of disability and job status on the described experience. Finally, an exploration of the experience of occupational therapy students with disabilities may enhance the understanding of this developmental experience on future practitioners.

Conclusion
The occupational therapists in this study provided a valuable description of their experiences in practicing occupational therapy. The information is not meant to be generalized but used to create an in-depth understanding of the collective experience of 10 therapists with self-proclaimed disabilities.

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