Nothing About Us Without Us: Searching for the Narrative of Disability

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“Nothing about us without us” is a mantra likely originating in South Africa’s disability rights movement. It has since been adopted by many disability rights advocacy groups to communicate that individuals with disabilities should be at the forefront of any decision or policy-making that affects their lives. Historically, individuals with disabilities have been disenfranchised by societal systems including the systems of medicine and rehabilitation (Kielhofner, 2005). Professionals whose clients are individuals with disabilities too often have been the decision makers about issues that affect their clients without involving the clients themselves.

Persons without disability are automatically outsiders to the disability experience and therefore cannot have the same level of insight about issues that impact individuals with disability (Smart, 2001). Consequently, disability studies values documented experience of individuals with disabilities above all other sources of information about disability and promotes the idea that individuals with disabilities should be included in decisions related to services, accessibility, and rights (Kielhofner, 2004).

Narrative

How then, can occupational therapists without disabilities, who are outsiders by definition, better understand the disability experience? A good place to start is by searching to grasp our clients’ experiences and by listening to what they present as the narrative of their disability and their lives. The story of an individual’s experience with disability can reveal how occupation has worked in the individual’s life and what his or her expectations are for the future (Vrkljan & Miller-Polgar, 2001). Listening for the narrative enables occupational therapists to get a more complete understanding of the direction in which the client is headed and why. Further, it keeps our focus on the individual instead of a diagnosis or disability. Finally, client narratives may challenge our assumptions and thus provide avenues to deepen our overall understanding of disability experience.

Important work related to narrative has been done in occupational therapy. The Model of Human Occupation describes narrative as the vehicle through which persons organize their occupational lives (Kielhofner, 2002). Other work underscores the importance of narrative reasoning (Mattingly, 1991, 1998), using narrative during assessment and intervention (Braveman, Helfrich, Kielhofner, & Albrecht, 2003; Jonsson, Josephsson, & Kielhofner, 2000; Lyons, Phipps, & Berro, 2004; Simmons, Crepeau, & White, 2000), and the “legitimacy” of using narrative to understand occupation (Clark, Carlson, & Polkinghorne, 1997).

Narrative is much more than the subjective portion of an assessment. Occupational therapists should have a good grounding in how to elicit a narrative from a client. Therapists need to listen to the full story an individual builds, including what may not seem salient to preconceived ideas about what is important or relevant. The perspective that the person with a disability has on his or her disability and life experience should direct what we learn.
Evidence-Based Practice/Client-Centered Practice

As occupational therapy embraces the tenets of evidence-based practice, our publications and educational experiences have focused on how to be knowledgeable consumers of and participants in empirical research. The point has been made, and rightly so, that occupational therapists have an ethical obligation to know what the current research says about the effectiveness of our therapeutic interventions (Law, 2002). What can get lost, however, is the importance of the client’s perspective as evidence about what will likely be beneficial. In true client-centered services, the client, or individual with disability, has the power to be the decision maker; and his or her story should be in the foreground of the therapeutic relationship.

Barriers To Hearing the Narrative

Unfortunately, there are many barriers to hearing the client’s narrative and those barriers are often unknowingly reinforced by our workplaces, communities, and our own practices. To begin with, by virtue of our position as “therapist” we have more power than our clients. We are usually considered to be an expert by the client, his or her family, our employers, and the system within which we work. The client may not feel that his or her story is worthy of telling to an expert, or may not include important details when describing his or her experience.

In so many settings where a traditional medical model prevails, professional service focuses on “fixing the problem” in a timely fashion. Faced with a choice between administering a checklist and eliciting a narrative, therapists may feel compelled to use the former, more quantifiable tool. The demands of reimbursement may also dissuade a therapist from using time to engage a client in sharing his or her narrative.

There is growing research in occupational therapy that focuses on narratives of persons with disability. However, such qualitative research (e.g., qualitative case studies and ethnographic inquiry) are sometimes perceived to be at lower levels of the research hierarchy (Law, 2002). Thus, within occupational therapy, it will be important to recognize the value of qualitative inquiry based on client narratives as evidence for individualized practice. For example, a recent study found that the type of narrative generated through the Occupational History Interview II (Kielhofner et al., 1998) predicts client outcomes (Kielhofner et al., 2004).

Eliciting Narratives

Assessments are sometimes mistakenly thought to generate narrative data because they include a client interview. But, the format and task-oriented nature of some interview-based assessments can negate the client’s narrative (Kielhofner & Mallinson, 1995). Occupational therapists are not always equipped to discerning listeners to a client's story in order to pick out the important threads and steer the client to share more information about them. It takes a skilled communicator to guide a client toward the more thematic reflection required for telling a narrative. The active listening and interviewing techniques that occupational therapists are trained in are useful but still may not allow for the full story building we need to do when a client is sharing his or her narrative (Mattingly & Lawlor, 2000). Finally, our own narratives can blind us to another’s story (Kielhofner & Barrett, 1998). Even the context of the practice setting can yield a narrative from a client that is very different from what would be elicited in a more natural environment.

Rather than interviewing a client about his or her diagnosis and reiterating information easily obtained in a chart, narrative interviewing involves questions that facilitate reflection about illness or disability experience. Using more open-ended questions can reveal themes or critical issues for the client as well as obtaining the details about his or her circumstances. For example, a question such as, “Tell me about your home” will facilitate more reflection than, “What kind of a house do you live in?”

Active listening is another technique that lets clients know that the therapist values narrative information enough to remember what they previously stated. It can help the therapist make connections between different statements and possibly identify a theme (Kielhofner, & Mallinson, 1995). The use of familiar physical, social, and emotional environments can trigger a wealth of reflections that would never come up within the stultifying atmosphere of a hospital or clinic.

Increasing One’s Ability To Hear the Story

Using narrative in practice also requires that a therapist can fully appreciate the nature and importance of narratives. The following are some practices therapists can use to improve their ability to appreciate the narrative of any client, and thus better understand the experience of disability.

Reflect on One’s Own Narrative and How It Influences Hearing Other Narratives

Occupational therapists can become sensitized to their own narratives and how they have biased or filtered others' narratives previously heard. Therapists can recognize the stories that they are more likely interested in and those that require more effort in order to listen.

Read or Watch Others’ Narratives

Therapists can immerse themselves in narratives that others have written or documented on film and recognize how they respond to them. Memoirs, autobiographies, and autoethnographies are valuable sources for getting accustomed to hearing other people’s stories, particularly those of persons with disabilities. Without the trappings of a clinical setting and the role of “expert” one can more honestly assess preconceived ideas and biases. Reading narratives or watching depictions of individuals’ experiences with disability can be enlightening, particularly if we have the ability to discuss our responses with other reflective individuals.

Learn More About Narratives in Relation to Disability

Therapists should first become thoroughly familiar with the field’s own literature on narrative and disability. Beyond this, some excellent resources are journals such as Literature and Medicine published by Johns Hopkins University and the online Literature, Arts and Medicine database moderated
by New York University that provide subscribers with continuing scholarly discussion related to the narrative experience of illness and disability.

Disability Studies and Narrative

Finally, it behooves us to broaden our knowledge of the stories of individuals with disabilities. Consider the following brief story of Irving Zola that he, as a participant observer with a physical disability, relates about using a wheelchair:

Subtly, but all too quickly, I was being transformed. As soon as I sat in the wheelchair I was no longer seen as a person who could fend for himself. Although Metz had known me well for nine months, and had never before done anything physical for me without asking, now he took over without permission. Suddenly in his eyes I was no longer able to carry things, reach for objects, or even push myself around. Though I was perfectly capable of doing all of these things, I was being wheeled around, and things were being brought to me—all without my asking. Most frightening was my own compliance, my alienation from myself and from the process. (Zola, 1982, p. 52)

Disability studies literature is replete with stories that range from the brief one above by the founder of disability studies to entire books that tell a disability narrative.

Conclusion

Listening to the narrative of individuals with disability is critical for occupational therapists who wish to better understand disability from an insider’s position. Such listening can make us more effective therapists, better advocates for individuals with disabilities, and more empathic human beings.

References


