Contribution of Qualitative Research to Evidence in Practice for People With Autism Spectrum Disorder

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Appraising the best available evidence substantiating and informing occupational therapy practice is a commonly expressed obligation for the profession (American Occupational Therapy Association [AOTA], 2007). In this article we argue for the full inclusion of qualitative research, on parity with quantitative research, as a source for evidence of relevant and effective occupational therapy practice, review the limitations of quantitative research, and outline the distinctive contributions of qualitative studies to the practice of occupational therapy for people with autism spectrum disorder (ASD). In addition, we describe the role of qualitative studies in the fulfillment of the Centennial Vision (AOTA, 2007) and recommend three action steps for the profession.


For autism spectrum disorder (ASD) interventions, one of the earliest occupational therapy literature evidence reviews was by Case-Smith and Arbesman (2008), later updated by Case-Smith (2010). Both studies relied exclusively on quantitative research. Valuing research evidence by its internal validity makes an important contribution toward justifying practice, but it has distinct limitations (Hammel, 2004; Tomlin & Borgetto, 2011), both theoretical and practical. First, this type of intervention effectiveness research quantifies the effects of intervention on the average client (Tomita, 2006, pp. 248–262). Although such research is not necessarily bound by this limitation, it investigates less often the different effects for subgroups of clients (Case-Smith & Arbesman, 2008) and, even less often, the effects on individual clients. Practitioners seeking to use the best available evidence in their client-centered practices must make a careful inference as to whether “group effect” evidence actually applies to the current client (Thomas & McCluskey, 2014, p. 41).

Second, quantitative experimental research is often conducted under optimal, controlled conditions, so the results may not be readily generalizable to the natural environments that are the client’s context (Tomlin & Borgetto, 2011); a well-known exception is Clark et al. (1997). Third, experiments tend to lack statistical power when comparing heterogeneous groups of modest size, frequently the case in occupational therapy–relevant studies (Johnston & Dijkers, 2012). Fourth, quantitative designs present an intrinsic difficulty when investigating more than a few variables at a time (because of too few participants) and raise the challenge of statistically establishing interaction effects among variables, for which power requirements are even more stringent than for main effects (Cohen, 1988, pp. 369–402).

Finally, the variables of interest may originally have come from the conceptualizations of researchers, not of clients and families, with the exception of studies designed as participatory research (Taylor, Suarez-Balcazar, Forsyth, & Kielhofner, 2006). Quantitatively measuring skills without accurately assessing occupation and participation as experienced by clients would be insufficient to achieve the end goal of occupational therapy interventions as defined by the

Contributions of Qualitative Research

Qualitative research promises to make contributions of distinctive value in a full, comprehensive appraisal of evidence to support occupational therapy practice (Scheer, Arbesman, & Lieberman, 2008). First, qualitative research helps identify the variables of most concern to clients and families by including their perspective on, and values and opinions about, their experience of having ASD or parenting a child with ASD, navigating the health care and education systems, fighting stigma, redefining family identity, and restoring family occupational roles (Swinth, Tomlin, & Luthman, 2015). The best available quantitative evidence, if that evidence has omitted the issues crucial to clients and their families, has missed the mark of supporting client-centered, occupation-based occupational therapy practice.

Second, in general, by definition qualitative research is client centered. It can illuminate the full complexity of family challenges and adaptations in the face of a diagnosis of autism. It can describe interactions among multiple variables in detail with one or a few participants, providing possible insight into how many relevant factors can interrelate. Third, qualitative research supports occupational therapy practitioners’ conditional and interactive reasoning by revealing the phenomenal world of client families and the challenges they face in today’s society, by deepening practitioners’ understanding, and by enhancing their capacity for empathy and therapeutic use of self. It can also inform the scope and focus of procedural reasoning by identifying the most meaningful outcome variables to establish as goals and to monitor.

Finally, qualitative research can complement the establishment of causality in experimental studies: Through thick description of the phenomenon under study, it can expose “causal streams” of events from intervention to outcome, intensively documented from the testimony of a few individuals. Prolonged engagement by the qualitative researcher allows for extended data collection and performing the comparisons and contrasts necessary to infer relationships of causality (Borgetto, Tomlin, Trickes, Max, & Pfingsten, 2015; Hansen, 2014).

U.S. Contributions to Qualitative Research on Children With Autism

Spitzer (2003) advocated for a qualitative approach, participant observation, to unfold the occupational being of young children with autism, concluding that to understand the subjective meaning of occupation is a complex and challenging endeavor, especially when developmental, linguistic, and perceptual differences exist between researchers and participants. . . . Through active participation of the researcher, power differences can be minimized; the child’s “voice” can be heard in a dialogue of action with the researcher; and the child may acquire his or her own felt sense of the research process. (p. 74)

Despite Spitzer’s eloquent rationale more than a decade ago for a qualitative approach to understanding the life of a child with ASD that could inform occupational therapy practice, relatively few qualitative studies on autism have been published in the occupational therapy literature.

We located six qualitative studies on families with a child with autism in the U.S. literature published between 2004 and 2014 (DeGrace, 2004; Dickie, Baranek, Schultz, Watson, & McComish, 2009; Foster, Dunn, & Lawson, 2013; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Suarez, Atchison, & Lagerwey, 2014). (Findings from our international colleagues and from other disciplines are considered in Swithn et al., 2015.) The U.S. results can be summarized as follows: From the accounts of five families, DeGrace (2004) found that the diagnosis of autism was associated with massive effects on family life—in short, lost occupations. By implication, the role of occupational therapy consists of helping restore family occupations. Dickie et al. (2009) documented from the reports of 66 parents (37 of a child with autism and 29 with a typically developing child) the extreme sensory experiences of children with autism, with sounds and food usually causing negative experiences and touch and movement bringing pleasant ones. They concluded that a requirement for occupational therapy with such families is for the therapist to comprehend the child in context, fostering better rapport between the therapist and the family and increasing the relevance and therefore the effectiveness of therapy. Such therapy would consist of enhancing families’ adaptive experiences (Dickie et al., 2009).

Kuhaneck et al. (2010) drew testimony from 11 mothers of children with autism. The mothers described an enduring burden of the diagnosis on family activities of daily living and occupations, with a strong need to obtain relief and occasional family joy and to fight social stigma. By implication, the role for occupational therapy with such families is to educate parents on techniques for daily scheduling and sharing of the caregiving burden; to provide parents with knowledge of the diagnosis, of the health and educational systems, and of the laws and policies that govern them; to support parents in being proactive against stigma; and to encourage them to see the positive aspects of their circumstances.

Schaaf et al. (2011) interviewed four families with a child with autism. They identified six themes in the families’ lives, four of which described the enduring challenges of the diagnosis for family life and two of which concerned strategies used to overcome the challenges. They concluded that the appropriate role for occupational therapy is to help families adapt activities, routines, and environments to increase the participation of the child in family life and to educate parents about the relationship between sensory processing and environments (Schaaf et al., 2011).

Suarez et al. (2014) also interviewed four mothers of a child with autism...
concerning their mealtime experiences. These mothers described unfulfilled hopes for family quality time and identified the causes of the difficulties as trouble keeping the child seated at the dining table, the limited variety of foods the child would eat, and the child’s sensitivity to the temperature and texture of foods. The mothers recounted their strategies to overcome these challenges, most of which were ineffective. Suarez et al. further documented the mothers’ confusion, frustration, and striving for answers. The researchers concluded that occupational therapy practitioners working with families of a child with autism should be prepared to include increasing mealtime participation in the scope of their intervention.

Finally, Foster et al. (2013) used qualitative interviewing to establish outcome evidence for occupational therapy coaching of 10 mothers of a child with autism. They revealed that from the perspective of the mothers, the coaching necessitated building a relationship of mutual trust, and it instilled skills and habits of analysis and reflection into the interplay of the child, occupations, and the environment. These building blocks led participants to increased mindfulness and self-efficacy as a parent of a child with special needs (Foster et al., 2013).

The conclusions from all six studies (total of 71 families of a child with autism) can be summarized as follows: The occupational therapy practitioner’s role is to investigate and comprehend the child and family context, to educate parents about aspects of the diagnosis in today’s society, and to enhance family adaptations to restore and support family occupations. Complementing this support for the “expert” role of the practitioner were the findings of Foster et al. (2013), which demonstrated evidence of the effectiveness of coaching rather than telling parents what to try.

Without the documented insights provided by these qualitative studies, quantitative investigations of intervention effectiveness might result in an accumulation of evidence about achieving goals that are less relevant to the daily challenges families face. The next logical step for researchers and practitioners alike is to uncover evidence for better outcomes resulting from these insights and the corresponding intervention approaches, following the lead of Foster et al. (2013), and through mixed-methods studies.

Possible Future Contributions of Qualitative Research to Practice

In partnership with quantitative research methodologies, future qualitative studies on autism could provide evidence of the outcomes of occupational therapy on the basis of the above formulation of the outlines of practice with families of a child with autism. By what means should occupational therapy practitioners turn family stressors, challenges, and problems into adaptations for preserving or restoring family occupations and optimizing client participation in meaningful activities? How much effect can an intervention be expected to have, and over what period of time? How would families of a child with autism describe the benefits derived from the intervention of occupational therapy practitioners? These questions may constitute an outline for future research on ASD of direct relevance to occupational therapy practitioners.

Fulfillment of the Centennial Vision

AOTA’s Centennial Vision is as follows: “We envision that occupational therapy is a powerful, widely recognized, science-driven, and evidence-based profession with a globally connected and diverse workforce meeting society’s occupational needs” (AOTA, 2007, p. 614). A report on the development process noted that one reason for the Centennial Vision was the “misalignment between the current occupational therapy priorities and the external environment” (AOTA, 2006). Qualitative research is one road to the realization of this vision.

Qualitative research can inform occupational therapy practitioners, researchers, and educators about the lived needs of people with ASD and their families in their natural environments. If applied in practice, such knowledge translation may result in a better alignment of occupational therapy services with the needs of these individuals. Scientific inquiry, both in the United States and worldwide, into the needs of and services for people with ASD and their families increasingly includes qualitative research (see Swinth et al., 2015). This global resource is providing key information for practitioners, researchers, and educators, particularly in revealing the occupation-based needs of this population.

Finally, the results of available qualitative studies on people with ASD and their families offer a unique insight that should influence service delivery decisions and may enable occupational therapy practitioners to advocate for the needs of this population in powerful and meaningful ways. The use of qualitative inquiry by practitioners, researchers, and educators to inform professional decision making could not only result in better services for people with ASD and their families but also help fulfill the Centennial Vision.

Action Steps for the Profession

We propose three action steps for occupational therapy practitioners, educators, and researchers:

1. By virtue of its distinct effectiveness in enhancing the professional reasoning of occupational therapy practitioners, explicitly incorporate qualitative research into the evidence enterprise by adopting the Research Pyramid (Tomlin & Borgetto, 2011) or another suitable model for the systematic, logical portrayal of research findings. Recognize qualitative research not as a tangential methodology but as one of value at parity with quantitative research for its potential contribution to improving occupational therapy decision-making.

2. Conduct evidence reviews that are comprehensive, including experimental, quasi-experimental, single-subject, descriptive, and qualitative research methodologies (i.e., a “pyramid” review; Tomlin & Borgetto, 2011).

3. As practitioners, avail ourselves of the growing body of knowledge created through qualitative research to enhance practice and more effectively meet the occupational needs of society.
Conclusion

Occupational therapists can use both quantitative and qualitative studies to inform their decision making concerning services for children with ASD and their families. Through the use of multiple methodologies, the critical reasoning of the occupational therapy practitioner may better address the broad and multifaceted needs of this population. ▲

References


