Content Analysis of Qualitative Research on Children and Youth With Autism, 1993–2011: Considerations for Occupational Therapy Services

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OBJECTIVE. Through a content analysis of qualitative research published 1993–2011, we sought to determine how qualitative research can inform clinical reasoning among occupational therapy practitioners to support evidence-based, occupation-focused services for children and youth with autism and their families.

METHOD. A qualitative literature search of journals inside and outside occupational therapy, including international journals, yielded 125 articles. We reviewed 110 articles that met inclusion criteria, 79 of which were coded by four occupational therapists with experience working with families with a child or youth with autism.

RESULTS. Nineteen content codes were initially derived. Three themes were identified: (1) service challenges for the family, (2) day-to-day experience of autism, and (3) reframing family.

CONCLUSION. This content analysis illustrates how qualitative research may help occupational therapy practitioners make comprehensive, occupation-based intervention decisions by considering the lived experience of children and youth with autism and their families.

OBJECTIVE. Children and youth with autism spectrum disorder (ASD) and their families are becoming one of the most commonly served populations by pediatric occupational therapy practitioners. Recent data from the Centers for Disease Control and Prevention (2014) indicate that the prevalence of ASD in children is about 1 in 68. Thus, it is important that practitioners use the most complete evidence to inform their decision making when working with this population.

In 2014, the American Occupational Therapy Association (AOTA) published the third edition of the Occupational Therapy Practice Framework: Domain and Process. This document identifies the domain and process of occupational therapy by summarizing “interrelated constructs” (AOTA, 2014, p. S1). These constructs are “linked inextricably in a transactional relationship” (p. S4) and promote occupation-based practice by stressing the importance of considering all areas of occupation through the occupational therapy process of evaluation, intervention, and outcomes. According to the Framework, the client is not necessarily limited to the person with the disability and may include the family and other stakeholders, organizations, and populations.

Concurrent with the development and implementation of the Framework, evidence-based practice, or use of research to inform practice, has emerged as a critical responsibility of occupational therapy practitioners. Evidence-based practice shapes and informs a practitioner’s clinical reasoning and may influence which services for children and youth with autism are reimbursed. The Centennial
Vision of the occupational therapy profession explicitly states, “We envision that occupational therapy is [an] evidence-based profession with a globally connected and diverse workforce meeting society’s occupational needs” (AOTA, 2007, p. 613). Together, the Framework and the Centennial Vision are being used to shape research priorities and discussions about and implementation of occupational therapy services.

Given these priorities, it is important that practitioners have available to them evidence that supports clinical decision making based on both occupational needs and client factors. This two-pronged approach to decision making has been discussed in the literature as a top-down versus bottom-up approach to services (Coster, 1998; Gutman, Mortera, Hinojosa, & Kramer, 2007). An evidence review by Case-Smith and Arbesman (2008) on occupational therapy services and autism informed the bottom-up, or client factors, approach but did not provide insight into the occupation-based needs of this population. Evidence on an occupation-based, or top-down, approach provided by qualitative studies may be valuable to decision making in occupational therapy practice (Coster, Gillette, Law, Lieberman, & Scheer, 2004), particularly with children and youth with autism because of the importance of participation in context, including physical and social environments, and the intense impact of the diagnosis on the functioning and quality of life of the family. Understanding the child’s and the family’s lived experience of the diagnosis, the intervention, and subsequent outcomes is of critical importance for the success of occupational therapy services.

During the process of providing occupational therapy services, practitioners use many types of clinical reasoning (Schell & Schell, 2008). Among them are procedural reasoning, which addresses the accuracy of evaluation and the effectiveness of intervention procedures; interactive reasoning, which concerns the establishment and maintenance of an effective therapeutic relationship with the client; and conditional reasoning, concerned with identifying feasible outcomes for the client in the client’s life world (Fleming, 1991). Historically, quantitative studies have informed procedural reasoning (Tomlin, 2008), whereas qualitative studies have informed interactive and conditional reasoning by providing knowledge of the insider perspective and valued occupational outcomes to enhance practitioners’ clinical reasoning and empathy.

In their review of the quantitative evidence for the effectiveness of intervention for people with autism, Case-Smith and Arbesman (2008) found six approaches worthy of attention. These approaches focused predominantly on changing the person with the diagnosis by addressing client factors (i.e., a bottom-up approach) to affect impairments directly. The six approaches are (1) sensory-based interventions, (2) relationship-based interventions, (3) developmental skill-based programs, (4) social cognitive skill training, (5) parent-directed or -mediated approaches, and (6) intensive behavioral intervention. Interventions that focus on adapting the sensory, physical, or social environment, which are harder to study through randomized controlled trials because of the uniqueness of each family’s situation as well as ethical challenges, did not appear prominently in the review. Nor was evidence apparent addressing the most effective means of establishing and maintaining a therapeutic relationship between the practitioner and the family. Additionally, information regarding direct links to the occupation-based desires of this population (i.e., a top-down approach) was not explicitly addressed.

Although client factors or impairments are certainly relevant to intervention for this population, services may be enhanced and better outcomes achieved if occupational therapy practitioners have clear evidence to help inform a top-down approach to decision making. A practitioner who uses evidence to move fluidly between a bottom-up and top-down perspective may enable better intervention outcomes. Thus, the gaps in the quantitative evidence may be directly addressed through evidence provided by qualitative studies that take into account the lived experience of children and youth with ASD and their families.

The purpose of the current content analysis was to determine how qualitative research published between 1993 and 2011 can inform the clinical reasoning of occupational therapy practitioners to support evidence-based, occupationally focused services for children and youth with ASD and their families. Specifically, we sought to answer the following research question: Given the results of the Case-Smith and Arbesman (2008) meta-analysis, does qualitative research provide additional insights regarding occupational therapy service provision for children and youth with autism and their families?

Method

In two independent searches, 125 qualitative articles published between 1993 and 2011 were identified that may help inform occupational therapy services for children and youth with autism and their families. An occupational therapy postprofessional graduate student completed the first search, and 2 years later, we performed the second search and analyzed the data from both searches.

Databases searched included Medline, CINAHL, ERIC, PsycINFO, Social Sciences Abstracts, Sociological...
Abstracts, Linguistics and Language Behavior Abstracts, RehabData, and EBSCOHost. These databases contain peer-reviewed articles, are commonly used by occupational therapy practitioners, and represent the breadth of professionals working with this population. Consistent search terms, such as autism, autism spectrum disorders, children and youth, qualitative research, parent perspectives, families, coping, and diagnosis, were used for both searches. Journals both inside and outside occupational therapy (e.g., psychology, medicine, education, sociology) were included, as was work across a variety of disciplines published internationally. The process was deliberately broad to ensure that all relevant qualitative research was included. Articles were excluded if they were theoretical in nature, were not peer reviewed, or used only a quantitative methodology. Articles using a mixed method (i.e., qualitative and quantitative) were included. Fifteen articles across the two searches were excluded because they were a duplicate or were an opinion piece rather than a qualitative study.

Coding occurred as the researchers read the articles. In both searches, the articles included in the analysis were read 2 times or more. The coding strategy consisted of assigning a group of symbols to each article. For example, a heart meant “parenting,” and a dash meant “school.” Symbols were also assigned for the voices represented in the article; for example, a filled-in triangle meant “child or adolescent with ASD” and an open triangle meant “parent.” This system of coding made it easy to go back to articles for triangulation and future coding and grouping.

Forty-nine articles from the first search (articles published January 1993 through April 2008) were reviewed by a postprofessional master’s student (a Fulbright scholar) who had extensive expertise in pediatrics. The student initially identified meaning units and then condensed these meaning units, from which 20 codes were developed (Table 1; Cavanagh, 1997; Graneheim & Lundman, 2004).

Seventy-six additional articles were identified during the second search (published May 2008 through December 2011). Before analysis of these articles, 15 of the articles from the first search were randomly selected, and the coding was peer reviewed by the researchers, who are three occupational therapists with advanced degrees and expertise in pediatrics and research to ensure consistency (the graduate student who conducted the first review was not involved in the second review). These researchers completed an initial review of the 76 articles; articles that did not meet the inclusion criteria were excluded. Because the researchers found a high level of consistency in content with the first review, they randomly selected 30 of the 76 articles and did in-depth coding using the procedure from the first review.

To increase credibility and trustworthiness, the researchers met regularly to share coding strategies; identify themes; and discuss consistencies, inconsistencies, and unique findings across articles. After several in-depth discussions, the researchers reread and coded the articles a second time. Four additional codes (identity/cultural identity, play/leisure, advocating, and support) were added to the content analysis. As the researchers completed this further content analysis, they grouped content and codes to develop initial themes (Graneheim & Lundman, 2004) on the basis of the participants’ words, commonalities among codes, and the researchers’ experiences working with children and youth with ASD and their families. Two or more researchers read each article to control for bias, and this ongoing peer review resulted in the synthesis of initial themes and codes into three key conceptual themes. At this point, the researchers determined that saturation of the content and themes had occurred, and the additional 46 articles were not reviewed beyond the initial read.

Individual bias within each article was considered, but given that the articles were qualitative and represented the voices of the participants, we did not explicitly address internal bias. However, consistent with qualitative research, we did consider the trustworthiness of the study design (e.g., triangulation, clear method of analysis, member checking) for each article reviewed.

<table>
<thead>
<tr>
<th>Code</th>
<th>Mentions in Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perspectives/experiences/insights of</td>
<td></td>
</tr>
<tr>
<td>Child/adolescent with autism</td>
<td>16 20.3</td>
</tr>
<tr>
<td>Parents</td>
<td>54 68.4</td>
</tr>
<tr>
<td>Professionals (e.g., therapists, teachers)</td>
<td>10 12.7</td>
</tr>
<tr>
<td>Sibling</td>
<td>2 2.5</td>
</tr>
<tr>
<td>Perspectives addressing</td>
<td></td>
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<tr>
<td>Activities of daily living/work</td>
<td>8 10.1</td>
</tr>
<tr>
<td>Advocatinga</td>
<td>6 7.6</td>
</tr>
<tr>
<td>Coping strategies</td>
<td></td>
</tr>
<tr>
<td>Individuals with autism</td>
<td>6 7.6</td>
</tr>
<tr>
<td>Grandparents/siblings</td>
<td>2 2.5</td>
</tr>
<tr>
<td>Single family member</td>
<td>27 34.2</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>22 27.8</td>
</tr>
<tr>
<td>Friendship</td>
<td>2 2.5</td>
</tr>
<tr>
<td>Identity/cultural identitya</td>
<td>12 15.2</td>
</tr>
<tr>
<td>Intervention/interaction with professionals</td>
<td>28 35.4</td>
</tr>
<tr>
<td>Parenting</td>
<td>15 19.0</td>
</tr>
<tr>
<td>Play/leisurea</td>
<td>4 5.1</td>
</tr>
<tr>
<td>School</td>
<td>12 15.2</td>
</tr>
<tr>
<td>Sensory processing</td>
<td>6 7.6</td>
</tr>
<tr>
<td>Supporta</td>
<td>11 13.9</td>
</tr>
<tr>
<td>Social interaction/competence/skills</td>
<td>15 19.0</td>
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*aThese codes were added after the initial 49 articles were read and coded.*
Results

The 79 articles reviewed for this study were found in journals of occupational therapy, special education, child development, family studies, sociology, and psychology. The studies were conducted in the United States \((n = 37, 46.8\%)\), the United Kingdom \((n = 19, 24.1\%)\), Australia \((n = 14, 17.7\%)\), Israel \((n = 3, 3.8\%)\), Canada \((n = 2, 2.5\%)\), Taiwan \((n = 2, 2.5\%)\), China \((n = 1, 1.3\%)\), and France \((n = 1, 1.3\%)\). Three studies \((3.8\%)\) used mixed methodology, and 8 \((10.1\%)\) used the Internet as their source of data.

The content analysis revealed 19 codes (see Table 1) representing the breadth and depth of topics addressed. Articles reviewed contained at least three and as many as five of these codes. Through reading and rereading the articles and conducting peer review meetings, the researchers synthesized the codes into conceptual themes. The conceptual themes identified in the 49 articles of the first review and 30 articles of the second were (1) service challenges for the family, (2) day-to-day experience of autism, and (3) reframing family.

Service Challenges for the Family

Service challenges were a major source of stress for many families, who found gaining access to services to be daunting, disruptive, and financially straining (Brookman-Frazee, Baker-Ericzén, Stadnik, & Taylor, 2012; Kuhaneck, Burroughs, Wright, Lem enczyk, & Darragh, 2010; Osborne & Reed, 2008): “Overall, parents consistently indicated that the diagnostic process was confusing and highly stressful, although many also indicated that they were relieved once their children were diagnosed with an ASD” (Brookman-Frazee et al., 2012, pp. 365–366). Although many participants described early concerns about the child’s or youth’s development or about changes in the child’s or youth’s status (e.g., mental health needs related to behavioral challenges in school), specific diagnosis took time, and access to critical services thus was often delayed.

For many families, where to go and how to determine which services were most appropriate were not clear. The confusion was even more pronounced when multiple professionals were involved (Brookman-Frazee et al., 2012; Osborne & Reed, 2008), and some participants found the “interpersonal skills of some professionals” to be poor (Osborne & Reed, 2008, p. 309). Some informants reflected on the challenges that arose when families and service providers disagreed about intervention (Gray, 1993). Thus, accessing and negotiating services and establishing relationships with professionals were a source of overwhelming stress for many families and people with autism. As Phelps, Hodgson, McCarmon, and Lamson (2009) noted,

Caregivers often first come into contact with service providers when seeking a diagnosis for their child. . . . This journey to diagnosis is often followed by entrance into the special education system. Once the child transitioned into the special education system, caregivers’ frustrations were unmistakable. Many caregivers did not feel heard or acknowledged. . . . One of the most significant findings of this study, seeing as communication and trust of professionals is a gauge of parental satisfaction, . . . [is that] “professionals in the medical field lack the patience and understanding of dealing with persons with autism.” The overwhelming conclusion from caregivers was the need for more education for some providers in the medical, judicial, and educational systems. (p. 31).

Times of transition may be an additional aspect of negotiating the services within a system that may be especially difficult for people with autism and their families (Stoner, Angell, House, & Bock, 2007). Although researchers identified factors that can support successful transitions (e.g., child-centered services, adequate communication and preparation), many families experienced frustration when working with professionals to prepare for and implement transitions across settings. Often this frustration resulted in increased stress during an already stressful time.

Day-to-Day Experience of Autism

The day-to-day experience of autism from the perspective of family members (DeGrace, 2004; Gray, 2006; Kuhaneck et al., 2010; Mascha & Boucher, 2006; Phelps et al., 2009; Schall, 2000; Stoner et al., 2007) or children or youth with autism (Browning, Osborne, & Reed, 2009; Carrington & Graham, 2001; Carrington, Templeton, & Papinczak, 2003; Huws & Jones, 2008; Jones, Quigney, & Huws, 2003) was a prevalent theme in many of the articles. Family members reflected on the challenges and rewards of having a child diagnosed with autism (Farrugia, 2009; Kuhaneck et al., 2010). Some were surprised at their strength amid the challenges, and others expressed frustration with gaining access to the system and obtaining appropriate supports.

As a result of having a child or youth with ASD in the home, these families experienced unique challenges and changes in their daily occupations. Many activities, routines, and rituals were changed to revolve around the needs of the child or youth with ASD (Gray, 2001). Some mentioned fear of the unknown as a constant in their lived experience: “Parents also spoke of their concern about the unknown. They did not know how much their child would progress,
they sought out other parents . . . to listen to their stories, and hoped for as much progress as possible” (Stoner et al., 2007, p. 35).

The day-to-day experience of having a child with autism resulted in changes to the social lives of many parents and the construction of a new family identity (Farrugia, 2009). In more recent publications, parents increasingly reflected on the positives and strengths that were part of this lived experience: “Although overwhelming stress might result from raising a child with autism, 17 families reported that their coping mechanisms improved because of this experience” (Altiere & Von Kluge, 2009, p. 146); distinct coping strategies assisted in developing a positive attitude (Kuhaneck et al., 2010). The challenges and changes were dynamic, calling for ongoing growth and adaptations in families’ lives, both individually and as a family, and the availability of service providers for support, information, and strategies (Gray, 1993; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

Reframing Family

The reframing family theme had two dimensions: family and provider. For families of children with autism, reframing family involved restructuring their expectations for parent–child interactions, family routines, and even the structure of their home (Altiere & Von Kluge, 2009; DeGrace, 2004; Schaaf et al., 2011). A participant in Gray’s (2001) study reported,

You don’t have a normal family life. Our whole family has to cater to Jane’s needs. You can’t go out very often as a family. You’ve got to watch her a lot more closely, a lot more closely than normal for someone her age. I think the whole family has more or less had to shoulder the burden and that includes [my sons]. (p. 1252)

Many families and older youth exerted considerable energy to resist the stigma of the diagnosis and thus reframe family and self by constructing a changed identity (Farrugia, 2009). This reframing was not always negative; one informant reflected, “We are better, more patient, and understanding towards life in general. It has changed the big picture and put life into perspective” (Phelps et al., 2009, p. 29).

The studies also highlighted the dimension of service providers, who help reframe family by providing services and support in partnership with families, caregivers, and children and youth with autism. Strategies identified included working with families to modify routines or lifestyles, find stress relief, implement appropriate accommodations across environments and contexts both inside and outside the home (Larson, 2006), and increase families’ knowledge of the diagnosis and laws to facilitate their child’s participation in occupation in the community.

Discussion

Although the six approaches identified by Case-Smith and Arbesman (2008) provided some initial evidence of intervention effectiveness relevant to occupational therapy services for children and youth with autism, the emerging conceptual themes from the current content analysis of published qualitative research contribute to a deeper understanding of their families and the ways their occupations are enhanced or inhibited by this diagnosis. This understanding in turn may enhance occupational therapy practitioners’ clinical reasoning when working with this population.

Many of the studies in the Case-Smith and Arbesman (2008) review used a bottom-up approach to services, meaning that they addressed the disability or client factors specific to the diagnosis of autism and the evidence for re-mediating these deficits. Left unaddressed, however, were large realms of the Framework (e.g., habits, routines, family and community participation), the child’s or youth’s life context (which includes parents, siblings, and classmates), and the clinical reasoning processes crucial to the practice of occupational therapy (e.g., interactive reasoning, conditional reasoning). The findings of the current study are consistent with the emerging shift in disability research from a disablement framework to a framework with a greater emphasis on health and well-being (Larson, 2006) and participation in life roles and expectations.

Occupational therapy practitioners can benefit from using both quantitative and qualitative research to inform practice when working with children and youth with ASD and their families. The qualitative research and the disablement literature support emphasizing and building on the strengths of people with autism and their families (Larson, 2006). The use of a top-down approach to intervention is consistent with current trends in occupational therapy as well (AOTA, 2014). Additionally, the qualitative evidence helps support services not only for children and youth with ASD but also for other clients such as family members and the systems these families must navigate.

Occupational therapy practitioners who are attentive to the challenges of navigating the system may be able to include strategies and support as part of their evaluation and intervention. For instance, once a diagnosis is given, practitioners can listen to the family and ask about their understanding of the diagnosis, ask how to help, refer them to appropriate professionals along the way, and connect them with other families who can relate to their experiences.
Critical also is ensuring that the child or youth with ASD has the necessary communication skills, as appropriate.

Taking into account the day-to-day experience of autism during evaluation and intervention is one way for practitioners to be better informed regarding the needs of children or youth with ASD and their families. Services throughout the occupational therapy process may result in better outcomes if they are family centered and attend to family occupations, daily activities, routines, rituals, and client factors of the child or youth with autism and the family. Practitioners need to understand the unique experiences, perspectives, and feelings of these families.

Family-centered care has been discussed in the literature for many years. In a majority of the articles we reviewed, analyzed, and coded, the importance of communication between the parent and practitioner was directly or indirectly stated. Establishing a therapeutic relationship is critical in helping families make effective accommodations that meet the needs of children and youth with autism. Occupational therapy practitioners can partner with families to scaffold intervention strategies so as to best meet developmental and health needs. Specifically, accommodations can be implemented that address routines, rituals, transitions, and social skills and that accept the unique qualities of the child or youth with autism: “Once in place, routines aided mothers in providing predictable expectations for the child that smoothed the way for participation. . . . Routines helped children feel content” (Larson, 2006, p. 72). Routines also allow families to function better (DeGrace, 2004; Kuhaneck et al., 2010).

Occupational therapy practitioners can support families in their need to reframe family by helping them participate in life roles, make choices and create strategies that work for them, and establish and reestablish routines and accommodations that enable the family to participate in chosen occupations. Attention to social participation and sense of identity as part of evaluation and intervention also helps families address this identified need. Additionally, occupational therapy practitioners should remember that re framing family is not always a negative experience (Kuhaneck et al., 2010) but often is viewed as positive:

If parents dwell on negative attributions of this event [having a child with autism], they are likely to cope poorly with the situation. In the present study, nearly every parent was able to describe a positive learning experience gained from raising his or her child. . . . They noticed that they became more patient, compassionate, humble, and accepting. . . . Parents did not resent their child and viewed him/her as an integral member of their family. Instead of struggling to find a way to cope with the situation, many parents stated that their coping mechanisms had improved, and they had developed more meaningful relationships with friends and family members. (Altieri & Von Kluge, 2009, p. 150)

Implications for Occupational Therapy Practice

The findings of this content analysis, combined with those of Case-Smith and Arbesman (2008), provide occupational therapy practitioners not only with key information for clinical reasoning related to client factors, performance skills, and performance patterns but also key evidence supporting the account of the child’s or youth’s and family’s lived experience. These findings can deepen practitioners’ understanding and thus their judgment in complex situations. In addition, the findings have the following implications for occupational therapy practice:

- Occupational therapy services with this population should consider not only the person with autism but also the impact on family routines, including access to services.
- Optimal practice includes working directly with the child or youth with ASD while attending to the needs of family members and other stakeholders, providing effective coping strategies (Kuhaneck et al., 2010), addressing needs within organizations (e.g., helping organizations or systems understand the unique characteristics and mental health needs of this population; Brookman-Frazee et al., 2012), and addressing the needs of populations (e.g., helping parents of preschoolers contextualize the sensory experiences of their children; Dickie, Baranek, Schultz, Watson, & McComish, 2009).
- Occupational therapy practitioners working with this population should consider the findings of both studies when completing the initial evaluation and throughout the provision of services. They should include questions regarding access to services, day-to-day routines, and family functioning as part of the occupational profile.

An example from one of the authors’ caseload illustrates the implications of our findings. A child had recently received a diagnosis of autism, and frustration emerged quickly not only in the family but also in the occupational therapist. The therapist was not present when the family was told about the child’s diagnosis yet had been one of the key professionals to help the family navigate the system thus far. The family wanted to know what the diagnosis meant for their child, how to tell his siblings, and what their family’s future would hold. The mother reported to the therapist that during the meeting in which they learned about the diagnosis, the health care professional had asked whether she or her husband had any questions. The mother
stated that they had remained quiet; they were shocked but felt expected to function well enough to ask questions.

The therapist worked with the family, helping them interpret the recommendations and gain access to resources. The therapist also connected the family with others who could guide them through the world of insurance, other services, and school system rights. Through working with this family to address not only the impairments of the child but also the needs of the family as a whole, the therapist confirmed that actively listening and allowing families to ask questions at their own pace were key to building a therapeutic relationship.

Initially, these parents tried everything to “fix” their child, but the time came when they reframed their family’s occupations by accepting their child for who he was and ceasing to worry about what he was supposed to be or how they should act. The family came to enjoy the child’s “quirks”; at one point, the mother stated, “He has been the best gift to our family. He teaches us that there are a variety of ways to think and act, which does not harm anyone. It is just different.” Through this journey with the family, the therapist also learned to appreciate the child for who he was and to appreciate the child’s and family’s lived experience as they negotiated this new experience.

Study Limitations

Although the results of this content analysis are promising as a resource to help inform the clinical reasoning of occupational therapy practitioners working with children and youth with ASD and other stakeholders, the findings should be interpreted with caution. This content analysis addresses qualitative research published through 2011. Since 2011, qualitative research on children and youth with ASD has increased. Additionally, more occupational therapy–specific articles have been published, both in the United States (Foster, Dunn, & Lawson, 2013; Haertl, Callahan, Markovics, & Sheppard, 2014; Suarez, Atchison, & Lagerwey, 2014) and internationally (Ashburner, Bennett, Rodger, & Ziviani, 2013; Joosten & Safe, 2014; Marquenie, Rodger, Mangohig, & Cronin, 2011). It may be that additional themes will arise from these more recent articles.

A second limitation is that 30 articles from the second review were randomly selected out of 76 for in-depth review. Saturation of the data appears to have occurred, but a new code might have arisen if additional articles had received the same in-depth review.

Directions for Future Research

It may be beneficial for the additional 46 articles to be read and coded. Additionally, a content analysis of articles published after 2011 should be completed. A metasynthesis of the two content analyses would add rigor to the peer review process (Patterson, Thorne, Canam, & Jillings, 2001) and may result in a further refinement of the findings.

After completion of a metasynthesis, additional research will be needed to inform occupational therapy practitioners how to effectively apply these findings to practice. Specific studies could address how practitioners’ understanding of the family’s perspective influences the occupational therapy process, service provision, the family’s health and well-being, and long-term outcomes relevant for the family. Ultimately, a rigorous combination of quantitative (Case-Smith & Arbesman, 2008) and qualitative evidence in a grand metasynthesis (Tomlin & Borgetto, 2011) could provide practitioners with the most comprehensive guidance for making practice decisions for children and youth with autism and their families and for providing families with the assistance they desire in navigating their world.

Conclusion

Through the use of evidence from both qualitative and quantitative studies, practitioners who work with children and youth with autism and their families may be better able to meet the unique needs of each child or youth and family. Occupational therapy practitioners should attend to the qualitative research evidence to

• Inform clinical reasoning,
• Understand the complexities families may face when negotiating systems,
• Have a better understanding of the lived experience of autism,
• Assist families in their reframing of what family occupations mean to them, and
• Best apply the Framework when working with children and youth with ASD and their families by knowing how to move fluidly between top-down and bottom-up approaches during evaluation and intervention.

References


