Content Analysis of Qualitative Research 2011-2014 on Clients Affected by Autism Spectrum Disorder:

Implications for Occupational Therapy Practice

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Abstract

Objectives Using a content analysis, this study explored relevant qualitative research conducted on individuals with autism and their families and determined its contribution to occupational therapy intervention and evidence based practice. In addition, this study will seek to update and enrich data collected by Tomlin, Swinth, and Luthman (2011).

Method Sixty-two articles, of 70 gathered, published between 2011 and 2014 in a variety of scientific disciplines were collected and reviewed using a content analysis methodology to extract and summarize themes relevant to occupational therapy practice. Articles included either the perspective of the individual with autism or of their family members. Demographic data, trustworthiness, and theme prevalence were documented.

Results Both deductive and inductive processes (Elo & Kyngas, 2007; Kondracki, Wellman, & Amundson, 2002) were used to extract and organize themes. Three themes (*service challenges*, the *lived experience* of autism, and *reframing family*) were derived from Tomlin et al. (2011) and were used in an *a priori* method to fit themes from more recent articles. During the review process, new themes emerged and existing themes were reorganized according to prevalence in and relevance to each article. The *lived experience* became an overarching theme. *Services challenges* were split into *societal stigma* and *service provider* categories. *Adaptation* emerged as a new theme, split into the categories of *resilience* and *reframing family*.

Conclusion The themes in this body of research were explored via the experiences of the informants (from their point of view) and enhanced current AOTA literature. Most importantly, this study found that the use of qualitative data in tandem with quantitative data to inform evidence based practice may be beneficial for occupational therapists in the treatment of autism spectrum disorder for individual clients with autism and their families.

Occupational therapy is an evolving evidence-based science-driven field that seeks to validate its client-centered care through rigorous research and is founded on the belief that the client's perspective on their treatment is a critical part of prognosis and recovery. Therefore, there is a need to make research as client-centered as possible to remain ethically consistent with the field's founding philosophies (Hammell, 2001). In 2014, the American Occupational Therapy Association (AOTA) published the 3rd edition of the Occupational Therapy Practice Framework (OTPF-3). A major revision from the previous OTPF-2 is the addition of therapeutic use of self to the process of therapy (AOTA, 2014). "Occupational therapy practitioners develop a collaborative relationship with the clients to understand their experiences and desires for intervention" (OTPF-3, 2014, p. S12). The new edition stresses the responsibility of practitioners to use their own clinical reasoning, experiences, and self-understanding in their practice. Occupational therapists use the practice scope of the OTPF-3, their own professional skills, and evidence-based practice (EBP) within their specific domain of practice with the clients they serve. In this process, outside evidence is used by occupational therapy practitioners to better inform services provided to, among others, individuals with autism and their families (Tomlin, Swinth, & Luthman, 2011).

The OTPF-3 defines the process of occupational therapy as "the client-centered delivery of occupational therapy services" (AOTA, 2014, p. S10). In conjunction with this philosophy, the therapist must understand the complex nature of client factors, performance skills, performance patterns, context and environment, and activity demands as they relate to occupation. Practitioners must also use research relevant to their practice setting as evidence to inform their decision-making process. Traditionally, quantitative research has dominated the medical and rehabilitation fields as the strongest provider of valid, external evidence collected

under rigorous conditions. Hamell (2001) explained that recipients of health care services have criticized this type of research methodology because they feel it fails to account for all factors that may be affecting an individual's occupational performance. Tomlin and Borgetto (2011) created an alternative research evidence model suggesting occupational therapists may gain valuable insight to inform practice through qualitative as well as quantitative research. Using qualitative studies for evidence based practice (EBP) may be especially helpful to practitioners (Coster, Gilette, Law, Lieberman, & Shiller, 2004), specifically when serving individuals with autism and their families, due to the importance of considering environmental and contextual factors with this population (Tomlin et al., 2011).

The full potential of qualitative research to inform practice is currently unknown; however, evidence from qualitative studies may provide valuable insight to occupational therapy practitioners. Qualitative research has a strong link to client-centered practice and, when analyzed rigorously, can provide an enriching perspective to use in evidence-based practice true to the founding philosophies of the field. Using both qualitative and quantitative research to develop and test theories may harmonize occupational therapy's client-centered focus and its scientific purpose.

Background

Due to its rapidly increased prevalence over the past 15 years, autism spectrum disorder (ASD) is receiving increased attention from health professionals, researchers, and the general public. In 2007, about 1 in 150 children were diagnosed with the disorder; by 2010, it was estimated that 1 in 68 were diagnosed (Centers for Disease Control and Prevention [CDC], 2014). The American Occupational Therapy Association (AOTA, 2010) provided a list of challenges individuals with autism experience in various

occupations that should be attended to by occupational therapists. These challenges can include, but are not limited to, the following: activities of daily living and instrumental activities of daily living (e.g., personal hygiene and grooming, communication, shopping, and cooking), rest and sleep, education (e.g., written language skills and transitions in the school environment), work (e.g., job seeking and job performance), play and leisure, and social participation.

Occupational therapy services and ASD. According to the OTPF-3, "clients are now defined as persons, groups, and populations" (AOTA, 2014, p. S2). Just as ASD affects individuals with the disorder differently, the impact of the diagnosis on social and familial systems should also be considered in a case-by-case basis (Phelps, Hodgson, McCammon, & Lamson, 2009). Phelps et al. (2009) used qualitative methods to research the challenges faced by caregivers of children with autism. In their study, caregivers reported feelings of exhaustion, stress, sadness, hopelessness, and depression due to the temporal demands of caring for a child with autism. Furthermore, research also has shown a lack of opportunities for parents to even express their response to these experiences (Case-Smith & Arbesman, 2008; Phelps et al., 2007, Schall, 2000; Stoner, Angell, House, & Bock, 2007).

Traditionally, occupational therapists have focused intervention on sensory challenges, self-care, and social participation goals for younger children with ASD and transition-related goals for older children (Case-Smith & Arbesman, 2008). Occupational therapy's potential scope of practice for this population is much broader and includes supporting the child's engagement in all aspects of occupation.

A quantitative systematic review by Case-Smith and Abresman (2008) revealed the following six treatment categories where evidence of intervention effectiveness exists for individuals with ASD: sensory-based, relationship-based, developmental skill-based, cognitive skill training, parent directed or mediated approaches, and intensive behavioral intervention; the first three are most closely related to the goals of occupational therapy intervention. Case-Smith and Arbesman (2008) confirmed what most parents of children with ASD know: some of these strategies may help some individuals and not others. Thus, professionals must take into account the individual differences of the child and their family. Tomlin et al. (2011) noted a gap in the evidence provided by Case-Smith and Arbesman's (2008). The gap is evident in the following inconsistencies with the philosophy of occupational therapy: the studies focused on "changing the individual," there was a lack of recognition of "the uniqueness of each family's situation," and the review did not address the importance of a "therapeutic relationship between the therapist and the family" (Tomlin et al., 2011, p. 5). These limitations may be due to the inclusion of only traditional Level I through Level III studies and the exclusion of qualitative research studies in their review.

Qualitative and quantitative research methodology. Traditionally, quantitative research methods are more accepted by the medical field, leading to criticism of the inclusion of studies with qualitative methods in reviews (Custard, 1997). Many qualitative studies have been conducted but, because the "higher" levels of evidence do not include qualitative methodology, there is a lack of initiative to recognize qualitative research as EBP. "Qualitative research can be defined as the study of people and events in their natural setting" (Stein, Rice, & Cutler, 2013, p. 146). Using this methodology,

the researcher examines all environmental and social influences on the informants' experience to develop themes. When used correctly or in conjunction with quantitative research, qualitative studies can identify and account for factors that quantitative methods alone usually cannot. Quantitative research seeks to manipulate and control extraneous variables, such as the environment, to focus specifically on the effect of the independent variable on the dependent. Occupational therapy professionals use a holistic approach to intervention, including considerations of how the environment affects the individual and vice versa (Custard, 1997). Furthermore, Yerxa (1991) explained that the reduction and isolation of these variables might "produce distorted or irrelevant data" (p. 201) and instill a false sense of confidence from the evidence gained in experiments. By including qualitative data, researchers can study the impact of confounding variables, such as environment and social impact, in relation to occupational tasks. Confounding "extraneous" variables can provide critical information about a client's unique needs to occupational therapy practitioners. "Ethically, it is essential to understand the patient's goals and how he or she experiences daily occupations" (Yerxa, 1991, p. 202). Occupational therapists who focus first on the client's occupational performance demonstrate a top-down approach to treatment. There is great clinical value in a topdown approach, which can be informed by qualitative data collection. Quantitative research in health care has often promoted a bottom-up approach, focusing on the changing of the individual by assessing relative effectiveness of treatment methods on body structures and functions, and behavioral skills and patterns, sometimes excluding the complexity of engagement in occupation.

Stoner et al. (2007) is one example of how qualitative evidence may help therapists gain valuable information relevant to the client's unique values and experience. A collective case study of qualitative data from 8 participants was used. Stoner et al. (2007) examined the challenges for children with ASD of transitioning during the school day and transitioning out of school on the following two planes: horizontal (transitions within a daily routine) and vertical (larger life transitions that happen in the development and aging process of every human). Caregivers expressed a need to be involved in the planning of all types of transitions (Stoner et al., 2007). Researchers and practitioners alike should recognize the importance of including the family's perspective when developing transition plans, both short term and long term (Stoner et al., 2007). Practitioners can validate their client's concerns, such as transition challenges, through the inclusion of qualitative research evidence.

Including qualitative research to understand caregivers' perspectives. There is a lack of qualitative research focusing on the caregivers of individuals with ASD (Phelps et al., 2009) and the published research that is available may not be widely read or accepted because it does not consist of experimental studies. There is a gap between professional awareness and the lived experience of families, which can cause parents and caregivers to seek out information without professional guidance (Schall, 2000). Schall (2000) conducted a qualitative study using three families as informants. This study uncovered the feelings of fear parents experience when thinking about their child with ASD transitioning into adult life (Schall, 2000). The federal Individuals with Disabilities Education Improvement Act ensures education through graduation age; however, after the child graduates from school, parents find little available support. The

only help available is through the mental health system (Schall, 2000). Parents of children with ASD often face discrimination due to the lack of public and professional knowledge about their child's complex disorder. Another qualitative study by Phelps et al. (2009) unveiled similar challenges, this time with 80 informants. "The overwhelming conclusion from caregivers was the need for more education for some providers in the medical, judicial, and educational systems" (Phelps et al., 2009, p. 31). It is one responsibility of occupational therapists to educate caregivers on how to best help their child. There should be an efficient way for therapists to gain insight from current literature on the lived experience of families affected by ASD that would promote good communication between the therapist and client. Interventions are more successful when there is good collaboration among professionals as well as between professionals and families (Stoner et al., 2007) and may result in better outcomes (Tomlin et al., 2011).

The benefit of content analyses. Tomlin et al. (2011) conducted a content analysis of 59 articles addressing various factors faced by individuals or families living with autism from a variety of disciplines that included qualitative methodology or mixed methodology. They identified three key themes relevant to clients affected by autism: service challenges, the lived experience of autism, and reframing family. In relation to service challenges, caregivers expressed confusion in choosing what services were best for their child. Caregivers also reported increased levels of stress from poor relationships with professionals. The lived experience of autism is a "prevalent theme across many of the articles" (Tomlin et al., 2001, p. 9). Families experience a variety of challenges on a day-to-day basis and fear for what will happen in the future. However, they also discovered that some families improved in their ability to cope with stress and were

proud of the strength they gained by having a child with autism. *Reframing family* was examined in two ways. First, families reported the need to restructure their routines, family identity, and family dynamic. Second, there was a need for support from professionals to aid in the reframing of the family's routines. These preliminary findings can help provide professionals with a broader base of evidence on which to support their clinical reasoning. Although these themes were constructed from 59 articles, Tomlin et al. (2011) cautioned readers not to overgeneralize the findings because there are at least 60 additional articles yet to be reviewed. It is one of the goals of the current study to expand upon these preliminary findings by updating the review of relevant literature.

The current study will seek to validate the use of qualitative studies in combination with quantitative experimental research in order to enrich the evidence for practice. A mixed-methods approach to informing practice may help occupational therapists provide evidence-based treatment as well as client-centered care. Therefore, the purpose of this study was to explore the contribution of qualitative research on individuals with autism and their families for informing practitioners, in order to promote the most effective interventions for these families.

Method

Research Design

A literature review of articles using qualitative methodology pertaining to ASD published between 2011 and 2014 was conducted with the goal of updating the literature review of Tomlin et al. (2011). The process included analyzing the content to extract similar themes across articles and constructing a content analysis from that data. The studies were critically evaluated and the content was extracted and organized in a

systematic fashion to ensure credibility. The current study used an *a priori* data analysis approach, guided by the three main themes already extracted by Tomlin et al. (2011). By this design, a deductive approach was used by coding data into preexisting categories (Elo & Kyngas, 2007; Kondracki, Wellman, & Amundson, 2002). An inductive approach was also used to uncover evidence of any additional fitting themes found during the data collection process. The research committee and chair reviewed and approved new themes in order to strengthen replicability. Since the aim of this study involved communicating concise evidence from a broad range of research, the content analysis method helped to categorize information potentially helpful to occupational therapy practitioners.

Inclusion Criteria

Key search terms included the following: *autism, autism spectrum disorder, children and youth, qualitative research, parent perspectives, families, coping,* and *diagnosis.* These are the same key terms used by Tomlin et al. (2011) and are consistent with the key terms used by Case-Smith and Arbesman (2008). In addition to content relevance, articles had to have used a qualitative or mixed methodology (a combination of qualitative and quantitative data). Literature was excluded if it was strictly quantitative or theoretical in nature. Articles including comorbidities were included. Selecting articles based on these criteria ensured that the analysis includes all qualitative data relevant to autism and the aim of this study. In total, 70 articles were found and 62 articles meet this inclusion criterion.

Articles from a variety of disciplines were included but had to be applicable to occupational therapy services and relevant to the purpose of this study. Since the goal

was to find contextual similarities across a broad scope of research, articles were included by way of relevance sampling, also known as purposive sampling, to obtain all relevant text that met inclusion criteria (Krippendorff, 2004). An extensive search through online databases PubMed, CINAHL, PsychInfo and ERIC was conducted. Journals from the following disciplines were included in the search: occupational therapy, education, medicine, psychology, psychiatry, qualitative science, neuroscience, mental health, behavior, early intervention, nursing, physical therapy, social work, development, and sociology. In addition, there were a number of articles that were not specific to any discipline. Tomlin et al. (2011) included articles from 1993-2011; therefore, this study's research focused on articles from later 2011-2014 to extend the work of the earlier review.

The articles reviewed were related to services provided for individuals affected by autism and their families. Informants in these studies must have experienced the diagnosis of autism first hand by either self or an immediate family member. Studies were excluded if the informants were exclusively health care or service providers. If a study included the perspectives of both individuals/families and a service provider, data were only collected from parts of the study that focused on the individuals and/or families. This strategy ensured the themes collected for the present study represented the emic experience and all studies with valuable information were included.

Trustworthiness of Qualitative Studies

The author was mindful of the rigor used in each article by recording data related to the article's use of trustworthiness (through processes such as triangulation, peer checking, and member checking). Guba (1981) outlines the following four dimensions of

trustworthiness: 1) credibility (consistent with internal validity); 2) transferability (consistent with external validity); 3) dependability (consistent with reliability); 4) confirmability (consistent with objectivity). Guba's (1981) model specified how rigor was to be obtained in each of these categories. Credibility was analyzed by the following ways: prolonged engagement at a site, persistent observation, peer debriefing, triangulation, collection of referential adequacy materials, member checks, the establishment of structural corroboration, and the establishment of referential adequacy. Transferability criteria included the following: purposive sampling, the use of thick descriptive data, and the use of a thick description of contextual factors. Dependability was documented by the use of the following: overlap methods/triangulation, stepwise replication/ "split-half' reliability, the establishment of an audit trail, and the use of a dependability audit. Confirmability was explored through the use of the following: triangulation, the practice of reflexivity, and the arrangement of a confirmability audit (see Appendix).

Instrumentation

According to Krippendorff (2004), reliability in a content analysis is insured by the stability (a non-changing test-retest), reproducibility (ensuring the process can be replicated), and accuracy (standardization of the method). To account for stability and accuracy, a chart format was used as a case survey for each of the articles (see Appendix). A format used by Ryan (2013) inspired the original layout of the table to strengthen the replicability of the present research; the table was adjusted to reflect the aim of this study. Ryan (2013) conducted a systematic review of qualitative research to synthesize evidence pertaining to the experiences of those recovering from stroke and

their families. Similar to Ryan (2013), the current survey will include the demographics and internal characteristics of each of the articles. Additions included methodology, a separate table for trustworthiness, and a separate table for themes. Themes from Tomlin et al. (2011) were included in the instrument and helped the author investigate if thematic links existed with the previous research.

Procedures, Theme Extraction, and Data Analysis

Each article was reviewed in a systematic fashion and read at least three times. In the initial pass, the researcher identified and recorded the characteristics in the survey table (see Appendix). These characteristics include title, author, year, journal, country of data collection, the number and perspective of the informants, the methodology used, and types of steps used to enhance trustworthiness. The first pass also served to give the researcher an overview of the themes presented by the authors of each study and understand the research as objectively as possible.

The second pass was used to deductively fit ideas from the studies into the preexisting themes of *service challenges*, *the live experience*, and *reframing family*. These
themes have been extracted from Tomlin et al. (2011), accounting for 18 years of
literature. Thus, it was unlikely that an entire new set of themes would emerge. In
addition, any emerging data relevant to a new theme was noted through a process of
recording of subthemes that were unrelated to the pre-existing themes. A color-coding
system was used to ensure organization and served as a baseline for intracoder reliability.

The third pass helped to review highlighted/color-coded portions for any errors.

The highlighted passages were then quantified into their respective thematic category. In

order to be considered a theme, the idea had to appear at least four times within the article. Articles were numbered for quick reference.

The researcher randomly selected three articles that were reviewed by the research committee, coded by each committee member, and compared to strengthen the trustworthiness and replicability in coding themes. In attempt to systematically extract themes, a replicable process was documented. The researcher looked for keywords or phrases that matched with a subtheme or theme. For example, if the informants' words included an emotion word such as *like*, *dislike*, *guilt*, or *fear*, the concept was likely to be recorded in the *lived experience* category. In the Appendix, each chart has a key statement under each thematic concept demonstrating that theme's presence in the study. Emic phrases are italicized. If the author felt that no emic statement could concisely summarize the presence of a theme, an etic statement from the author's interpretation was recorded. There is no one-size-fits-all approach to content analysis methodology; however, the researcher attempted to uphold a consistent process of thematic extraction.

Results

Article Search

Seventy articles emerged in the initial search through databases PubMed, CINAHL, PsychInfo and ERIC. Of these, 62 met the inclusion criteria to be analyzed and coded. Three articles (Hoogsteen, & Woolgate, 2013a, Hoogsteen, & Woolgate, 2013b, & Hoogsteen, & Woolgate, 2013c) used the same informants but were coded differently in each publication. These articles were analyzed separately in this study.

Article descriptions. The 62 reviewed articles were derived from 15 areas of science. Ten were not specified (see Table 1). The most common was autism-specific

research, appearing in journals such as *Autism*, and accounting for 29% of the articles collected. Eight were from nursing literature and 6 from occupational therapy literature. Studies conducted within the U.S. accounted for 32% of the articles making it the most represented country in the search. A majority of the studies were done outside the U.S. with Canada, Australia, and the United Kingdom as the most common. The articles that had mixed informants (e.g. parents and the individual with autism) were divided and counted in their respected category. The 62 articles yielded a total of 1,852 informants, a majority of articles collected data from the parents of children with autism (n = 1,604) (see Table 1). In terms of methodology used, 65% of the articles reported conducting semi-structured interviews with their informants. Almost every study specified the method in which they gathered and analyzed their data. The most common types of approaches include grounded theory, phenomenological approach, mixed methods (qualitative and quantitative), and thematic analysis (see Table 2). In total, 10 articles used some kind of qualitative analysis program such as NVivo or ATLAS-ti.

The use of rigor in these articles is of particular importance to the aim of the present study. Guba's (1981) model identifies four domains to evaluate naturalistic inquiry: credibility, transferability, dependability, and confirmability. Fifty-seven (92%) articles used at least one aspect of credibility, the most common type being peer debriefing (Guba's term for peer checking); 56 (90%) accounted for transferability, most commonly via collecting thick descriptive data; 47 (76%) displayed dependability, the most common type was establishing an audit trail; and 43 (69%) used methods to ensure confirmability, most commonly using reflexivity.

Theme Reorganization

Upon completing the coding process, the author realized there were some themes that appeared more than others. With the goal of a thematic organization that was true to the voices of informants, the themes were reorganized according to their prevalence. The research committee was consulted and the new organization was agreed upon. The use of a deductive process to examine the prevalence of the three existing themes (*lived experience, service challenges*, and *reframing family*) was successful and did yield results that fit into these three themes. However, an additional theme emerged (*adaptation*) and the presence of each theme varied in prevalence, inspiring the reorganization (see Figure 1).

The Lived Experience and its Impact on Occupational Performance

The *lived experience* was an over arching category which concerned the perspective from which the article was written as well as feelings and emotions of those affected by ASD. Fifty-four articles included themes related to the *lived experience*. Sixteen of these articles included the perspective of the individual with autism.

Informants with ASD expressed dealing with feelings of anxiety (Ahlstrom & Wentz, 2014; Brown & Carey, 2012), fear (Brown & Carey, 2012), and over-stimulation (Ashburner, Bennett, Rodger, & Ziviani, 2013). Fifty-one articles addressed the *lived experience* of the family (parents, siblings, and extended). Despite the trials of raising a child with autism, many parents had positive things to say about the experience such as having admiration for their child (Brookman-Fraze, Baker-Ericzen, Stadnik, & Taylor, 2012) or gaining valuable life experiences (Markoulakis, Fletcher, & Bryden, 2012). Due

to stigma and other challenges of raising a child with autism, some parents expressed guilt (Chamak & Bonniau, 2013) or feelings of being overwhelmed, isolated, and struggling with time management (Safe, Joosten, & Molineux, 2012).

Activities of Daily Living/Instrumental Activities of Daily Living

(ADL/IADL). Autism can negatively impact an individual's ability to perform ADL and IADL. Kirby, Dickie, and Baranek (2014) explained, "for these children, fear or anxiety related to sensory experiences seems to be playing a role in limiting their participation in daily activities." (p. 8). In addition to the child with autism, the ADL/IADL of family members and the family unit can be disrupted. Parents report feelings of exhaustion and stress affecting the ability to care for oneself and maintain their typical role in the family (Ahlstrom & Wentz, 2014; Aylaz, Yilmaz, & Polat, 2012; Ludlow, Skelly, & Rohleder, 2012). One mother demonstrates how her own health is affected by having a child with autism: "You've got so many things over you that I have to really convince myself to get into the shower. It's just one more thing I've got to do." (Hodgetts, Nicholas, Nicholas, Zwaignenbaum, & McConnell, 2013, p. 143). Shopping and being out in a public place were difficult tasks for some parents due to their child's disruptive behaviors (Coogle, Guerette, & Hanline, 2013; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). Families especially experience stress during dinnertime and bedtime (Marquenie, Roger, Mangohig, & Cronin, 2011). Sometimes multiple meals have to be cooked to accommodate the child with autism's food desires. One study noted: "None of the mothers said they found success at being able to sit down as a family for a meal consistently" (Suarez, Atchison, & Langerwey, 2014, p. 105).

Rest and Sleep. For individuals with autism, sleep preparation, participation, and routines can be negatively affected (AOTA, 2010). Marquenie et al. (2011) explained that bedtime usually involved routines and idiosyncrasies controlled by the child with autism, causing the parent to feel "trapped" and disengaged from other occupations at that time (p. 152). Many parents expressed feelings of exhaustion due to putting their child's needs before their own. "Parents expressed that the majority of their energy was spent on their child with autism which often led to fatigue, exhaustion, and burning out." (Hoogsteen, & Woodgate, 2013a, p. 137).

Education. In many of the studies, parents voiced concerns about the services they were receiving from their child's school. Some felt that the teacher was not qualified to handle their child's behavior (Aylaz et al., 2012; Dillon & Underwood, 2012; Hurlbutt, 2011). Others felt the problem was at an administrative level (Huws & Jones, 2013; Safe et al., 2012; Haertl, Callahan, Markovics, & Sheppard, 2014; Weiss, Wingsiong, & Lunksy, 2014). Because of struggles with the education system, parents may turn to homeschooling their child (Huws & Jones, 2013). Additionally, education went beyond making sure their child had appropriate access to education, many parents reported educating themselves about autism and how to best help their child.

Work. Griffith, Totsika, Nash, and Hastings (2012) found that individuals with autism feel their diagnosis has had a negative impact on their ability to find meaningful and successful employment. Informants also expressed that increasing awareness about ASD for the public, professionals, and employers would be beneficial in reducing stigma and mitigating some of their employment challenges.

Raising a child with autism can be a time-consuming task. Some parents reported having to leave their jobs or change to occupations with flexible hours to be able to care for their child (Fletcher, Markoulakis, & Bryden, 2011; Hoogsteen & Woodgate, 2013a).

Play. Some children with autism struggle with forming and retaining friendships or even playing with others. An informant from Calder, Hill, and Pellicano (2012) explained this challenge by saying, "Sometimes I want to play by myself" (p. 306). Other studies reported that play was inhibited by social stigma and bullying in both primary and secondary school (Dillon & Underwood, 2012; Divan et al., 2012). One child reported, "Students act differently because they know I'm autistic, they're like 'he's the weird kid'" (Calzada, Pistrang, & Mandy, 2011, p. 237). Older individuals with ASD may cope with their social ailments by playing on team sports (Haertl et al., 2014).

Leisure. Individuals with autism may seek leisure activities that may or may not be considered a "typical" leisure activity. For example, listening to computer game sounds or movie sounds can be just as enjoyable as listening to music (Ashburner et al, 2013). For the parents of a child with autism, challenging behaviors can be a barricade for going out into the community and spending leisure time with friends (Aylaz et al., 2012). Managing the household while caring for a child with ASD could also inhibit leisure time inside the home for all family members. Safe et al. (2012) noted that mothers of children with autism expressed that leisure can be a positive coping strategy.

Social Participation. Social participation is a challenge for most individuals with ASD of all ages. Younger children may prefer to be alone instead of playing with friends. This can be due to lack of internal motivation to engage or stem from a child's difficulty in picking up on social cues. The level of a child's motivation to make and

keep friends seemed to be a determining factor in the number of friends they report having (Calder et al., 2012). Young adults and adults reported having trouble with socializing, leading to feelings of isolation, leading to anxiety and depression (Griffith et al., 2012; Haertl et al., 2014). The tendency to remain isolated does not imply that all people with autism desire to be alone. Some wish to have relationships with others, but feel they are lacking the necessary skills to do so (Haertl et al., 2014).

Autism can also negatively affect the family's ability to participate in social occupations. Parents report struggles in making and maintaining friends leading to feelings of isolation from their communities (Hock, Timm, & Ramish, 2012; Joosten & Safe, 2014; Ludlow et al., 2012; Lutz, Patterson, & Klein, 2012). One informant said, "unless they are living it, they don't understand" (Joosteen & Safe, 2014, p. 254). Support groups or knowing other parents with a child on the spectrum can be a helpful coping tool for parents (Ludlow et al., 2012; Lutz et al., 2012; Minne & Semrud-Clikenman, 2012).

Service Challenges

Half of the reviewed articles (n = 31) included the theme *service challenges*. Service challenges emerged on both an individual level (specific concerns related to service providers) and societal level (such as stigma). In some cases, as illustrated in the following quote, both levels can impact a family's access to services.

Parents expressed dissatisfaction with having to wait to receive services, not obtaining information and/or services desired, and not receiving services delivered in a manner convenient to families or tailored to their child's and family's need (Coogle et al., 2013, para. 40).

Service Providers. Fourteen articles indicated struggles with individual service providers including therapists, doctors, social workers, and teachers. One of the most

common concerns was with the skill levels of teachers and educators (Aylaz et al., 2012; Dillon & Underwood, 2012; Haertl et al., 2014). According to some parents, teachers did not know enough about ASD and the school itself did not provide enough support for their child, especially in secondary school (Dillon & Underwood, 2012). This lack of support drove some parents to homeschool their children (Hurlbutt, 2011). Haertl et al. (2014) found that most parents believed this dilemma exists due to a lack of training, education, and access to accommodations to support children with ASD, rather than the complexities associated with the disorder.

Parents reported that service providers and therapists do not take the time to understand the family's life as a whole and the difficulties these mothers experienced (Joosteen & Safe, 2014). Parents also expressed concern about their health care providers' level of education about ASD and qualifications to serve their children (Brookman-Frazee et al., 2012; Foster, Dunn, & Lawson, 2013; Ryan & Salisbury, 2012; Strunk, Pickler, McCain, Ameringer, & Meyers, 2014). In Strunk et al. (2013), one informant explained, "I felt like I had to educate the doctors regarding my son's autism" (p. 332). Informants also indicated a lack of positive communication with service providers. Therefore, some doctors were unconcerned and reluctant to diagnose (Ryan & Salisbury, 2012) while others were insensitive to family needs (Desai et al., 2012; Joosten & Safe, 2014).

Societal Stigma. Nineteen articles indicated informant struggles receiving proper services on a systemic level. A number of these articles indicated a need for more education and training specific to ASD for professionals and service providers (Algahtani, 2012; Calzada et al., 2011; Hoogsteen & Woodgate, 2013a; Mackintosh,

Goin-Kochel, & Myers, 2012; Muskat, Riosa, Nicholas, Roberts, Stoddart, & Zwaigenbaum, 2014). Calzada et al. (2011) explained, "... it seemed that local services did not understand their child's needs or did not know how to meet those needs" (p. 236). Informants from rural communities believed physicians and nurses lack experience necessary to provide good information for parents (Hoogsteen & Woodgate, 2013a).

Another service challenge was finding and accessing services specific to autism and the needs of the family (Brookman-Frazee et al., 2012; Divan et al., 2012; Griffith et al., 2012; Hodgetts et al., 2013; Hodgetts, Zwaigenbaum, & Nicholas, 2014; Hoogsteen & Woodgate, 2013b; Hoogsteen & Woodgate, 2013c; Strunk et al., 2014; Weiss et al., 2014). Finding proper services can be especially challenging for those living in rural communities (Hoogsteen & Woodgate, 2013c). To meet the unique needs of individual families, interventionists must be aware of the cultural norms of their client and build a collaborative relationship before intervening (Cheremshynski, Lucyshyn, & Olson, 2013).

Access to services is not a problem unique to the United States, but is also an issue on an international level. In China, parents reported "battling" the service system; frustrations were because of poor communication, a lack of positive outcomes, and a disorganized public health system. (Ho, Yi, Griffiths, Chan, & Murray, 2014; Sun et al., 2013). Finding proper interventions was also a problem for parents in India (Divan et al., 2012). In Canada, one mother explained, "It's not that the service providers have been horrible, but to actually get the services has been horrible" (Hodgetts et al., 2013, p. 142). In France there has been an improvement in services over time, although many parents are still dissatisfied with the services available to their children (Chamak & Bonniau,

2013). Informants in Saudi Arabia reported that doctors did not provide treatment options, so families turned to cultural/religious-based treatment (Alqahtani, 2012).

Adaptation

The informants of 47 studies identified how change, learning experiences, and growth can help those with autism and their families to adapt and improve their quality of life. In this study, adaptation represents both positive and negative change as well as linear and non-linear progress. The adaptations made by an individual with autism or their families include critical changes in the family dynamic and resilience to the challenges faced subsequent to the autism diagnosis. In the literature reviewed for this study, adaptation appears to be a necessary skill for these individuals and families. One mother explained, "First we constantly blamed each other, but later being educated people we realized that we can go nowhere by blaming and set off to find out what we should do for our child (Aylaz et al., 2012, p. 398). The ability to problem solve and move forward past the diagnosis is beneficial and can lead to advantages such finding services and resources (Calzada et al., 2011).

Reframing Family. Lutz et al. (2012) found most of their informants agreed that "the whole family had autism, not just the child" (p. 210). Siblings assumed a supportive role in their relationships with their siblings with ASD and sometimes were even responsible for some of the duties of a caregiver, (Angell, Meadan, & Stoner, 2012; Divan et al., 2012; Tozer, Atkin, & Wenham, 2013). Older siblings expressed feelings of "their own sense of responsibility regarding safety and care" of their sibling (Angell et al., 2012, p. 8). Extended family members were used for financial and respite support (Divan et al., 2012).

Parents were often caught in struggles with maintaining relationships with extended family, other children, and their spouses due to the amount of time and attention dedicated to their child with autism (Aylaz et al., 2012; Divan et al., 2012). In order to attend social events, one family describes attending parties in shifts. "We just don't go both together because we've gotta look after [our son]" (Hines, Balandin, & Togher, 2014, p. 167). Many parents described having to adapt their roles and routines in order to provide the care necessary for their child with ASD. Parents have had to leave or switch their jobs, sacrifice lifestyle, advocate for their child's services, and organize their days around the child with autism (Fletcher et al., 2011; Joosten & Safe, 2014). Others have taken on the role of the caregiver, teacher, or therapist (Freuler, Baranek, Tashjian, Watson, Crais, & Turner-Brown, 2014; Joosten & Safe, 2014; Lutz et al., 2012; Safe et al., 2012). "Mothers could not simply focus on being a mother." (Safe et al., 2012, p. 298). Relationships between partners also have to be reframed. One informant described, "... and then your relationship switches from being lovers and partners to being the leaders in the family, the facilitators, the executive committee" (Hock et al., p. 411).

Resilience. Thirty-five articles discussed ways in which the informants were showing resilience. Resilience can be defined as finding support, increasing education, and learning through experiences how to cope with autism or autism in the family. Many individuals with autism reported coming up with their own coping methods (Ahlstrom & Wentz, 2014; Griffith et al., 2012; Haertl et al., 2014; Smith & Sharp, 2013). Informants discussed various strategies to help them cope with their unusual sensory experiences. Methods included avoidance, escape, planning ahead, self-stimulatory behavior, music, carrying a heavy bag while walking, deep pressure, ignoring it, or increasing self-

awareness (Smith & Sharp, 2013). Other individuals reported learning a variety of ways to cope with their social ailments such as finding one good friend, finding a support group, playing on team sports, or observing others (Haertl et al., 2014).

Siblings of those with ASD also described ways of making progress in their own lives. In Angell et al. (2012), informants would use a variety of coping strategies to help them deal with their siblings' adverse behaviors. Some learned to find people they could talk to about the situation, while one child used an online support group. Many explained ASD to others outside the family. Some even taught their siblings with ASD about appropriate behaviors, especially socially.

Many parents of children with ASD showed resilience by learning more about autism (Abbott, Bernard, & Forge, 2012; Desai et al., 2012; Hoogsteen & Woodgate, 2013a; Hoogsteen & Woodgate, 2013c), problem-solving while dealing with their child's behavior, treatments, and symptoms (Dillon & Underwood, 2012; Divan et al., 2012; Mackintosh et al., 2012), and finding support for themselves through support groups (Desai et al., 2012; Ludlow et al., 2012; Lutz et al., 2012). Demonstrating resilience, one parent describes her decision to learn more about autism, "And then within two days, I was at the library looking for information...I was like, okay now, I have to figure this out, I have to find out where we're going and where we're at." (Hoogsteen, & Woodgate, 2013c, p. 3). There was no treatment that was universally beneficial for all families. Some families were able to report that they found something that worked. "I really like ABA and the improvement he has made with it." "We love the OT – that seems to make the greatest difference in his life..." (Mackintosh et al., 2012, p. 54). The ability for these families to seek information and useful services exemplifies strength needed to

adapt to the demands of a lifestyle changed by an autism diagnosis.

Discussion

Previous Qualitative and Quantitative Outcomes

Case-Smith and Arbesman (2008) conducted a methasynthesi of Level I, II, and III studies using quantitative or mixed methodology. Similar to the aim of the current study, Case-Smith and Arbesman (2008) sought to succinctly summarize studies of autism spectrum disorder from a variety of disciplines to be applicable to occupational therapy practice and enhance clinical reasoning. In contrast to the current study, Case-Smith and Arbesman's (2008) research focused on interventions and their effectiveness rather than understanding the lived experiences of autism from an emic perspective. Although they succeeded in supplying a list of intervention categories commonly researched, there are gaps between their findings and the actual practice of clientcentered occupational therapy. Tomlin et al. (2011) noted the following shortcomings: (1) interventions focused on "changing the individual" (p. 5); (2) studies including the environmental and contextual factors contributing to the intervention were not accounted for due to the nature of Level I, II, and III studies; and (3) the absence of therapeutic use of self in treatment. Case-Smith and Arbesman (2008) however, accounted for some of these shortcomings, explaining the importance of individualized and personalized occupational therapy intervention:

The practitioner's selection of intervention methods not only is based on the evidence but also is determined by factors such as the client's preferences, the setting where services are provided (e.g., home-based, center-based, school), the resources available, the family's preference and stage of life, and the occupational therapy practitioner's experience and expertise. All of these variables need to be considered when applying the results of an evidence-based review of the literature. (Case-Smith & Arbesman, 2008, p. 425).

These variables align with the themes developed in the current study. The setting, resources available, and the practitioner's expertise can account for *service challenges* to guide intervention approaches. The family and client's values and preferences relate to the *lived experience* and the choice of intervention methods must be carefully considered to facilitate the most effective means of promoting *adaptation*.

Many similarities also exist between the current study and a thematic synthesis conduced by DePape and Lindsay (2014). DePape and Lindsay (2014) synthesized qualitative literature whose informants were parents of children with autism. The current study is slightly more comprehensive as it also includes data from the point of view of individuals with autism. In addition, DePape and Lindsay (2014) was not tailored to a specific field of science, such as occupational therapy. DePape and Lindsay (2014) identified the following six themes: (1) prediagnosis, (2) diagnosis, (3) family life adjustment, (4) navigating the system, (5) parental empowerment, and (6) moving forward. All of these themes were explored as the "parent's experience with ASD" organized in a chronological order (p. 4). Although the current study assumes a different organization style, the parent experience is comparable to the *lived experience*. Family life adjustment parallels *reframing family*, navigating the system is similar to *service challenges*, parental empowerment assumes *adaptation*, and moving forward is comparable to *resilience*.

Integrating Themes into Occupational Therapy Practice

Although data for this study were collected from a variety of disciplines and areas of science, the author sought to succinctly summarize this body of research to be applicable to the practice of occupational therapy. Occupational therapy is a

rehabilitation field that is unique in its approach to treatment. Practitioners use their own individual clinical reasoning through therapeutic use of self and decisions based on evidence, using occupation to promote participation in meaningful activities. By combining clinical reasoning and critical inquiry, occupational therapy is an art and a science. The results of this study can further strengthen the core literature that occupational therapists use to guide their clinical reasoning and interventions. Thereby, each of the themes will be examined through an occupational therapy intervention lens by comparing them to the Occupational Therapy Practice Framework, 3rd edition (AOTA, 2014), *The Scope of Occupational Therapy Services for Individuals With Autism Spectrum Disorder Across the Life Course* (AOTA, 2010), intervention approaches, and guides for facilitating positive change in the lives of individuals with autism and their families.

The Lived Experience and the Occupational Therapy Practice Framework and Statement for ASD. The information about the *lived experience* gathered in this study can be used to guide clinicians to make their approach to treatment as client-centered as possible.

Statement. The theme lived experience supports the areas of occupation identified as challenges in the official statement *The Scope of Occupational Therapy Services for Individuals With Autism Spectrum Disorder Across the Life Course* (AOTA, 2010). Each area of occupation (ADL, IADL, rest and sleep, education, work, play, leisure, and social participation) can potentially be a challenge for individuals with ASD (AOTA, 2010). The qualitative literature used in this study can enhance the practitioner's understanding of the occupational struggles outlined in these areas of occupation and provide

information about these struggles from the viewpoint of the client who lives them.

OTPF-3 Domain. The Occupational Therapy Practice Framework 3rd edition (OTPF-3) recognized the "importance and impact of the mind-body-spirit connection as the client participates in daily life." (p. S4). This mind-body-spirit connection can be better understood by examining the life experiences of individuals with ASD and their families. The data from this study enhances the OTPF-3 domain by examining the lived experience of ASD and relating it to the areas of occupation. "Occupational therapists are skilled in evaluating all aspects of the domain, their interrelationships, and the client within his or her contexts and environments" (OTPF-3, 2014, S4). Understanding the lived experience of one's client by learning their unique values and beliefs can enhance the therapeutic relationship between the therapist and individual with ASD and their family. Furthermore, examining the *lived experience* can give insight into how the diagnosis of ASD can alter one's participation in meaningful occupations. The OTPF-3 states, "Occupations can contribute to a well-balanced and fully functional lifestyle or to a lifestyle that is out of balance and characterized by occupational dysfunction." (2014, p. S6). For example, results showed increased levels of stress for parents with children with ASD negatively affecting their ability to participate in occupations such as social participation, leading to feelings of isolation (Hock et al., 2012; Joosten & Safe, 2014; Ludlow et al., 2012; Lutz et al., 2012). However, participating in support groups can lead to a more positive engagement in social participation (Ludlow et al., 2012; Lutz et al., 2012; Minne & Semrud-Clikenman, 2012).

OTPF-3 Process. The occupational therapy process includes evaluation, intervention, and outcomes (OTPF-3, 2014). An emphasis on client-centeredness is

present in all three areas of the process. Of particular importance is the collection of the occupational profile during evaluation as the therapist seeks to understand the *lived* experience of their client by understanding their occupational history and experiences (OTPF-3, 2014). Results from this study can enrich a therapist's knowledge of possible areas of occupational dysfunction and use this information to guide the gathering of data to create an occupational profile. Occupational therapy intervention may result in better outcomes if the therapist uses this information about the *lived experience* to guide their clinical reasoning process to provide services that are client centered (Tomlin et al., 2011).

Service Challenges and Intervention Approaches. This theme supports *The Scope of Occupational Therapy Services for Individuals With Autism Spectrum Disorder Across the Life Course*. This official statement explains:

At the individual level, collaboration with family, caregivers, educators, and other team members is essential for understanding the daily life experiences of individuals with an ASD and those with whom they interact. At the organizational level, services may focus on educating staff and designing programs and environments that are more socially inclusive for persons on the autism spectrum. At the population level, occupational therapy practitioners may engage in education, consultation, and advocacy initiatives with ASD consumer groups (AOTA, 2010, p. S217).

In line with this statement, the current study found that *service challenges* exist on an individual and societal level. Many informants reported a need for increased education at all levels of service provision. Occupational therapists can intervene at each level to improve services provided to those with ASD and their families. These results are consistent with findings from Tomlin et al. (2011), which determined that client's needs can be best addressed by occupational therapy practitioners who are educated in navigating the system.

Another parallel in findings between the present study and Tomlin et al. (2011) is the need for the therapist to approach the individual and family holistically and tailor therapy specific to the needs of the client (Coogle et al., 2013, para. 40; Desai et al., 2012; Joosten & Safe, 2014) implying the use of a top-down approach to therapy. The therapist should approach the process of intervention with the intention of adapting the environment and treating the client, not the autism. This may help provide more comprehensive treatment (Tomlin et al., 2011).

In terms of education, the results of this study imply a lack of understanding and education about ASD for service providers in the schools, leading to conflicts between the school and the child's family. The scope of occupational therapy practice in the schools may be limited by lack of administrator knowledge, or the belief that occupational therapists only address motor and sensory needs (Painter & Handley-More, 2014). If the scope of practice for occupational therapists were more comprehensive in the school setting, some of the unmet needs may be able to be addressed. An example would be other challenged areas of occupation that may be negatively impacting the child's performance in school such as self-care or social participation.

Adaptation and Facilitating Positive Change. As a client-centered approach to treatment, "occupational therapy practitioners develop a collaborative relationship with clients to understand their experiences and desires for intervention." (OTPF-3, p. S12). The client (either the individual with autism or their family members) and their values, beliefs, and goals should inform the therapist's approach to clinical reasoning, especially when the therapist sees a need for *adaptation* within the family or individual.

Inspiring change is not easy, especially when clients cannot focus on the positive

outcomes that occupational therapy intervention may provide. If the treatment plan is as client-centered as possible, clients may even naturally implement change if the topic is facilitated in a way that clients can identify their own solutions. One approach to implementing this kind of change is through solutions-focused therapy. Solutionsfocused therapy works by envisioning life without the problem at hand. Then the "ideal" life would be broken down into small parts, opening the gate for small resolutions (Heath & Heath, 2010). Occupational therapists may be able to best support individuals with ASD and their families by identifying the areas of their lives where positive change can happen by using the client's own goals as motivation to obtain progress and resilience. Heath and Heath (2010) explained, "if you want people to change, you can provide a clear direction or boost their motivation and determination" (p. 181). A strength-based approach can also facilitate positive change in the way therapists frame their treatment. "Occupational therapy practitioners can develop interventions that begin with individual children's strengths and use those to craft carefully selected occupation-based activities, thus creating opportunities to practice increased adaptive behaviors in the context of strengths" (AOTA, 2012, para. 6).

Qualitative Research in Evidence Based Practice of Occupational Therapy

Little research has been done to validate the contribution that qualitative evidence may have on therapeutic impact when used in tandem with quantitative evidence. Tomlin and Borgetto (2011) suggested a more comprehensive approach to evidence based occupational therapy practice explaining that quantitative research (specifically Level I studies like randomized control trials) may limit the practitioner's perspective to a "cause-and-effect conclusion... but would be of uncertain transferability to the real

world" (p. 190). The OTPF-3 (2014) stresses the importance of environmental and contextual factors, which provide insight to the therapist in understanding the complexity of occupational engagement. These are the factors that may be controlled and omitted by quantitative data due to the procedural rigor of higher-level studies. Rigor is important when determining the effectiveness of intervention approaches to be used as evidence based practice. This study examined the trustworthiness (rigor) of the included qualitative studies. A majority (69%) of the studies collected in this content analysis accounted for credibility, transferability, dependability, and confirmability (see Table 3). The study of an informant in their natural environment cannot only be trustworthy, but also specifically applicable to occupational therapy practice. Hammel (2001) explained:

Qualitative approaches to research—like client-centered occupational therapy—seek to study phenomena from the perspectives of the participants. Like occupational therapy, qualitative research views individuals as inseparable from their social, cultural, physical, economic, political, historical, and legal environments, and thus seeks to study people in their natural environments rather than in laboratories or clinics (p. 231).

The use of different types of research in tandem to inform practice may help the therapist account for all areas of occupational dysfunction and intervention planning. Specifically, the use of metasyntheses of qualitative research (such as DePape & Lindsay, 2014) and meta-analyses of quantitative research (such as Case-Smith & Arbesman, 2008) to guide clinical reasoning may provide the most comprehensive approach to evidence based practice (Tomlin et al., 2011).

Limitations

The author attempted to examine data through the lens of occupational therapy.

However, only a few studies were done within the field of occupational therapy;

therefore, the reader should exercise caution when interpreting these findings. The transferability of this study is also a limitation. Theme prevalence and its correlation to demographic characteristics in the study was not examined thoroughly. It is possible that certain themes may be more likely to emerge with a specific demographic of individuals and families. Time was also a limitation to this study. With more time, the author may have been able to include more contextual information such as participant socioeconomic status, gender, and age to increase the transferability of the study. It would have been beneficial to re-read all of the articles one more time to include quotations and data for themes *individual service challenges*, *societal service challenges*, and *resilience*. Only one researcher collected and interpreted data besides a code-recode of three articles by the research supervisor.

Further Directions for Research

This content analysis contributes to an ongoing research project by Tomlin et al. (2011) and is one part of a future metasynthesis to summarize thematic prevalence relevant to occupational therapy and the treatment of clients affected by autism. Preliminary findings combined with the present study and future studies will provide occupational therapy practitioners with more comprehensive evidence on which to base their provision of services. Research pertaining to the effectiveness of programs that include the perspective of the family in the treatment process could also enhance the findings of this study. Also, information from occupational therapists who work with this population could enrich the expansion of these findings. Practitioners could give feedback about using qualitative research in tandem with quantitative research as evidence-based practice during the clinical reasoning process of autism intervention. It

would also be interesting to explore further explore the theme of *adaptation* or change.

Research could answer questions about effective ways to facilitate client change as well as change in occupational therapy evidence based practice.

Conclusion

This content analysis attempted to summarize relevant recent literature from qualitative studies about individuals with autism and their families to be applicable to occupational therapy intervention with this population. The value and trustworthiness of qualitative research was explored. Qualitative research can make important contributions to informing clinical reasoning, therapeutic-use-of-self, and intervention approaches for clients. The findings were compared to Tomlin et al. (2011), quantitative research by Case-Smith and Arbesman (2008), and a qualitative synthesis by DePape and Lindsay (2014).