The Open Journal of Occupational Therapy

Volume 10
Issue 3 *Summer 2022*

Article 4

July 2022

Addressing Occupational Performance Deficits in a Religious Setting: A Pediatric Case Report

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Recommended Citation

Gee, B. M., & Leatham, D. (2022). Addressing Occupational Performance Deficits in a Religious Setting: A Pediatric Case Report. *The Open Journal of Occupational Therapy, 10*(3), 1-8. https://doi.org/10.15453/2168-6408.1866

Addressing Occupational Performance Deficits in a Religious Setting: A Pediatric Case Report

Abstract

Background: The purpose of this pediatric case report is to document how occupational therapy assisted a family with a child who has a diagnosis of ASD and the religious clergy increase the child's participation in activities in the religious context.

Method: The pediatric case report uses an exploratory approach to explore the process of evaluating challenging psychosocial behaviors and implementing contextual and personal strategies to increase participation in meaningful occupations.

Results: As a result of the occupational therapy recommendations and follow-up consultations, the client demonstrated a reduction in behaviors that were a barrier to her participation in meaningful activities in a religious context. Most notably observed were reductions with verbalizations, excessive movement, verbal outbursts (high volume), wandering, and fighting.

Conclusions: Occupational therapists have a role in addressing the behavioral and emotional challenges that may prevent children with ASD from participating in meaningful religious activities valued by families and their communities. The strategies recommended as a part of this case report represent strategies commonly used in the home, community, and school-based settings. However, this case pediatric report highlights the application of psychosocial/behavioral and contextual recommendations in religious contexts.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

autism spectrum disorder, religious participation, occupational performance, pediatrics

Credentials Display

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DOI: 10.15453/2168-6408.1866

Religious and spiritual beliefs influence a person's health and quality of life. According to the *2014 U.S. Religious Landscape Study*, conducted by Pew Research Center, 55% of the survey respondents indicated they pray daily. Approximately 36% of the adults surveyed indicated they attend a religious service at least once a week. Clinical studies have found that religious people are healthier and require less access to health services (Koenig, 2000; Koenig et al., 2001). It has been reported that religious people have better mental health and a better ability to adapt to stress (Koenig, 2000). Various studies have noted that religious people have lower levels of depressive symptoms (Baker & Cruickshank, 2009; Moreira-Almeida & Koenig, 2006).

The fourth edition of the *Occupational Therapy Practice Framework: Domain and Process* (OTPF-4) introduced religious observance as an instrumental activity of daily living (IADL) (American Occupational Therapy Association [AOTA], 2020). A religious and spiritual expression is defined as:

> Engaging in religious or spiritual activities, organizations, and practices for self-fulfillment; finding meaning or religious or spiritual value; establishing connection with a divine power, such as is involved in attending a church, temple, mosque, or synagogue; praying or chanting for a religious purpose; engaging in spiritual contemplation. (AOTA, 2020, p. 31)

The occupational therapy literature uses religious participation and spiritual participation synonymously, or the use of spirituality as a definition and construct overtakes religious participation (Eyres et al., 2019; Eyres et al., 2018).

In contrast, the OTPF-4 categorizes spiritual participation in religious observance as an IADL and as a meaningful occupation that occurs in a specific context(s) that may be bound by its own set of cultural norms and rules (AOTA, 2020). The inclusion of this occupation in the framework suggests that addressing a client's religious and spiritual needs falls within the scope of occupational therapy practice. For this case report, we only explored religious participation. This determination was made because of the concerns of the caregivers (behavioral management) and the developmental level of the pediatric client highlighted in this report. In this case, supporting the client's participation in the structured child-specific religious educational classes was the primary purpose.

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition with hallmark features that include atypical language and communication skills; poor social interaction; and impaired executive functioning, sensory processing, and motor skill coordination (American Psychological Association, 2013). The condition presents with comorbid psychiatric and medical conditions that may include anxiety disorder, oppositional defiant disorder, attention-deficit/hyperactivity disorder, intellectual disability, immune system irregularities, gastrointestinal disorder, sleep disturbances, and epilepsy and seizure disorder (Masi et al., 2017).

In a cross-sectional national survey in the United States by Lee et al. (2008), caregivers reported their child's quality of life with ASD. The authors reported that in a sample of 173 respondents, 41% stated that their child with ASD was able to attend religious services once per week, with the remaining 59% stating that their child is able to attend services between once per month or not attend at all because of the burden of separating a child with ASD from the home environment (Lee et al., 2008).

Little et al. (2014) reported that in the faith-based activities section from the Home and Community Activities Scale the autism severity of a child impacts the frequency of that child's participation in specific faith-based activities. Using a sample of 713 school-aged children with autism, Little et al. found that

participation was significantly lower in the areas attending church, religious activities, praying, and children's groups that may be sponsored by the religious entity (e.g., scouts).

Occupational therapy has had a strong focus on family participation and performance in meaningful occupations (DeGrace, 2004; Fingerhut et al., 2013), religious activities included. Occupational therapists who work with families of children with ASD should provide support and services that improve family functioning and well-being at home, school, and in the community (Fingerhut et al., 2013; Karst & Van Hecke, 2012).

Thompson et al. (2018) conducted a descriptive survey design to explore the attitudes and behaviors of occupational therapists concerning religious observance in clinical practice. Using a sample of 181 participants, the authors reported that most of the respondents felt that religious observance was an important occupation. Yet, most of the participants reported rarely or never addressing religious observance in their clinical practice because of issues including the work context and the sensitivity of the topic. Thompson et al. (2018) concluded that addressing religious participation as a part of routine clinical practice is an unmet need that occupational therapy should address.

To date, the literature is sparse regarding how occupational therapists can assist families of children with developmental disabilities with religious participation, in this case, individuals with ASD. Anecdotally, occupational therapy services are typically provided Monday through Friday in a school-based or private practice setting for school-aged children (5–12 years of age) in the rural community where the case report occurred. Occupational therapists do not provide pediatric therapy services on weekends or in religious settings in the area. Further occupational therapy services are funded through government funded or private insurance. Thus, the case report is novel regarding the type of service delivery, and the setting where the services were provided. The purpose of this case report is to document how occupational therapy assisted a family with a child who has ASD and their clergy to increase participation in activities in the religious context.

Background Information

Informed consent was provided by the client's parents to conduct and disseminate this case report. The case report did not meet the definition of research for the Human Subjects Committee at Rocky Mountain University of Health Professions. Katie (a pseudonym) is an 8-year 4-month-old female diagnosed with ASD. She has a history of receiving skilled therapeutic educational and therapy services (special education, developmental therapy, speech-language pathology, and occupational therapy) from her initial diagnosis to this case report's date. She comes from a home with two younger siblings and involved parents. The purpose of this case report is to document the process of occupational therapy providing consultations in a novel setting (religious) and addressing participation in related religious activities outside of structured educational or medically funded therapy services.

As part of an interdisciplinary evaluation team (Gee et al., 2016) housed in a public university in the western United States, occupational therapy services were offered to observe Katie and provide a free consultation to her family as well as the clergy where Katie's family were members and attended religious services. The goal of the observation and consultation was to provide support and strategies that may increase Katie's participation in the religious rituals and activities.

Per the parent report, concerns were raised as a part of the occupational therapy evaluation within the interdisciplinary evaluation team. Specifically, it was reported that Katie demonstrated difficulties related to elopement from religious classes on and off-site, indicated insufficient attention, and exhibited behavioral and verbal outbursts that impacted her ability to participate in meaningful religious activities.

The clergy (Bishop) and volunteer staff (Primary President and Primary Teacher) of the local religious organization consented to the observation and consultation after the parents and the occupational therapist provided them with information regarding the scope of the observation and consultation.

The occupational therapy observation occurred on a Sunday, with the aim to determine what type of modification(s) were needed during specific religious tasks in the physical and social contexts that would increase safety (reduce escaping behaviors and elopement) and increase participation without parental involvement. The observation included assessing Katie's participation and performance during small and large group religious classes. The small religious class, referred to as "Primary Class," included 11 children 9 to 10 years of age, two adult volunteer teachers, and two children who needed special attention (one was Katie). The observing occupational therapist used the Model of Human Occupation (MOHO) (Taylor, 2017) and the Coping Model of Pediatric Occupational Therapy (Cole & Tufano, 2020) as a loose framework to assess how Katie's performance capacity and the physical and social environment may have been barriers to participation in the structured and semi-structured religious classes (Cole & Tufano, 2020; Taylor, 2017).

At the time of the observation, the primary class was combined with another class (children 7– 8 years of age), but typically there are only five children in Katie's assigned class. The instructional media and activities included the teachers reading from a manual, asking the children questions, and waiting for responses. The teachers would occasionally ask the children to read from religious texts, present pictures that represented the content being presented, and then engage in fine motor coloring tasks of imagery from the lesson content. The typical duration of the class is approximately 40 min. However, the observation of the class lasted 25 min. During the small class experience, Katie demonstrated the following challenging behaviors and their associated frequency (see Table 1).

Table 1
Small Classroom Observations (Pre-Recommendations)

Type of Behavior	Description	Frequency
Verbalization	Katie engaged in verbalizations that were not consistent with the task (lesson) or the setting (church). However, these verbalizations were quiet enough to not overtly interrupt the lesson.	15
Verbal Outbursts (High Volume)	There were occasions when Katie exhibited loud outbursts that both interrupted the lesson and generated a startled or negative reaction from her classmates.	4
Excessive Movement	When seated next to an adult, there were occasions where Katie engaged in excessive movement beyond what would be expected of a child her age.	7
Self-Stimulatory Behavior	Katie engaged in self-stimulatory behaviors during the class that consisted of hand waving and finger flapping.	3

Children typically transition from their small primary class to a larger group session titled "sharing time," which includes prayers, talks by the children, a lesson, and music and singing. During the observation, Katie was required to transition from a small group class to a large group class located approximately 30 feet down a hallway. As a part of the transition, she became lost after going to the restroom and required assistance to help her transition back to the large group meeting. Katie's parents reported that she is a flight risk and, if left unattended, will leave the building.

In the large group meeting each small class sits in their assigned rows (based on their class age group) and has a lesson, singing time, and other social activities. The age range typically is from 7 to 11 years of age. There were 17 to 18 children in sharing time with the adult teachers, one sitting with each small class, and other adult teachers leading the lessons and music. Sharing time's typical duration is 40 min, and the occupational therapist was present to observe the entire duration. It is important to note that

Katie demonstrated the highest degree of attention and task participation during music time that involved verbal and motor imitation (singing a song concurrent with American Sign Language). During the sharing time meeting, Katie demonstrated the following behaviors with their associated frequency (see Table 2).

Table 2
Large Group Classroom Observations (Pre Recommendations)

Type of Behavior	Description	Frequency
Verbal Outburst (High Volume)	Katie engaged in verbalization that was inconsistent with the task (lesson) or the setting (church). Though these verbalizations were quiet enough to not overtly interrupt the lesson.	9
Wandering	Katie left her seat and wandered around the large classroom room with approximately 50% of the occurrences being disruptive to the group activities.	5
Fidgeting	While seated, Katie demonstrated a decreased amount of movement but fidgeted with different objects.	6

MOHO was a guiding theory as structured domains focused on a system approach (Cole & Tufano, 2020; Taylor, 2017). The sub systems in MOHO that included volitional, habituation, performance capacity, and environmental components (physical and social) helped frame the recommendations toward increasing her participation. Throughout the engagement with Katie, her parents and the clergy and support staff, the observing occupational therapist internalized and reflected on the core assumptions of MOHO that included occupational engagement as the dynamic interaction of volition, habituation and performance capacity (Cole & Tufano, 2020; Taylor, 2017). Further, the therapists used explicit strategies from the Coping Model of Pediatric Occupational Therapy with its postulates of grading tasks and the environments (social and physical), supporting self-efficacy, and providing appropriate feedback to support enhanced coping skills in the religious classroom contexts. In this case, using the tools that supported Katie's occupational performance participation in other settings (home, school, clinic) enhanced her participation in the meaningful religious activities. Further, the therapist aimed to capitalize on the influence of the physical and social environments to support her participation in the large and small classroom-based structure and activities, recognizing similar structure and pedagogy (Cole & Tufano, 2020; Taylor, 2017).

The holistic and systems approach of MOHO embodied Katie's developmental level, diagnosis, significant background with therapy and educational support, and her parental competencies in navigating the opportunities and challenges to participation in community family-based activities (religious activities included) (Cole & Tufano, 2020; Taylor, 2017). Thus, the subsystems of MOHO (Cole & Tufano, 2020; Taylor, 2017) and the postulates of the Coping Model of Pediatric Occupational Therapy were used as guides in generating or adapting the strategies below and how those strategies were justified to the family and clergy.

In addition, some of the recommended strategies were modified strategies from what the parents indicated had worked in the school-based setting, strategies used by the treating occupational therapist and speech language pathologist who were treating her at a local clinic. Of interest, the strategies were recommended without knowing exactly how Katie would accept them in a religious context. Furthermore, it was unknown regarding the type and number of resources that can and should be allocated to Katie to increase her participation in the aforementioned religious activities. Finally, it is also important to note that all the adults who provided instruction as a part of the primary service are volunteers and have no additional training on how to help with chronic behavioral and emotional challenges.

Recommended strategies for clergy and staff to implement as a part of small classroom instruction:

- Reduce the number of children in Katie's class (physical and social environment).
- Consider Katie's developmental age versus her chronological age for Katie's class learning activities (performance capacity).
- Consider using books with pictures and visual resources (picture books, comic books, etc.) as a part of Katie's instruction. Katie had a strong interest in visual resources and storytelling through comic books (volitional).
- Assist Katie with predicting future class activities by creating a visual schedule for each part of the lesson (e.g., prayer, reading, activity, questions/discussion, closing activity, prayer, etc.) (volitional and habituation).
- Provide Katie with movement breaks every 10 min (e.g., jobs to help the teacher or other teachers, leaders of the children's organization) (performance capacity).
- Consider adding some assistants to help Katie (e.g., adolescents who may be transitioning to college or proselytizing service) (performance capacity and social environment).
- Increase expectations for Katie by considering what she can do to participate and help instead of what she cannot do (performance capacity).
- Identify members of the congregation (other than the parents) with whom Katie has a positive relationship to help with the class (social environment and performance capacity).
- Use metaphors (e.g., Zones of Regulation) that may help Katie regulate when she becomes loud or aggressive (performance capacity).
- Consider using more audio-visual teaching tools with Katie that may be more motivating and developmentally appropriate for her age (volition and performance capacity).
- Consider modifying the curricula so that they may align with Katie's interests and developmental level (e.g., she prefers comic book-style characters) (volition and performance capacity).

Recommended strategies for clergy and staff to implement as a part of larger group instruction - sharing time:

- Consider using a visual schedule for sharing time, where Katie can check what is coming next and what has been completed (volitional and habituation).
- Provide Katie with fidgets that she can wear and use.
- Instead of questions from adults, such as, "do you want to go and sit?" consider providing Katie with directives, such as "let us go sit and sing like the other children" (performance capacity).
- Provide Katie with more jobs and tasks where she might hold pictures, read, etc., either with the older or younger sharing time groups (volitional and performance capacity).
- Consider how well Katie does with 1:1 support; possibly a transitioning young adult who can provide that level of support (social environment and performance capacity).
- Consider using consistent rules and expectations that work for Katie at home and school to implement at church under the direction of the caregivers and church volunteers' support (habituation).
- Provide Katie with positive reinforcement for desired behaviors that she exhibits, such as "I like how you are sitting" or "Thank you for helping hold the picture" (volitional and social environment).

- Consider changing where Katie sits in the large classroom. Katie may attend and participate more if she is closer to the front of the room (physical environment and volitional).

All strategies were discussed with the caregivers, clergy, and staff to allow for questions, elaborations, and some modeling by the therapists or the caregivers.

Two weeks after the observation, a summary of the observation and recommendations were provided during a follow up meeting held between the family, clergy, staff, and the occupational therapist. It was recommended that no more than three strategies be implemented in a given month for the primary class and sharing time to see if the changes in the environment or the tasks would increase Katie's participation. The strategies could be the same for both the primary class and sharing time, or they could be different. Follow up observations occurred 3 months after the consultation meeting with family, volunteer clergy, and staff. This observation mirrored that of the initial observation. The occupational therapist conducted observations that tracked the behaviors listed in Tables 3 and 4.

Table 3

Small Classroom Observations (Post Recommendations)

Type of Behavior	Description	Frequency
Verbalization	Katie engaged in verbalizations that were not consistent with the task (lesson) or the setting (church). Though these verbalizations were quiet enough to not overtly interrupt the lesson.	10
Verbal Outbursts (High Volume)	There were occasions where Katie exhibited loud outbursts that both interrupted the lesson and generated a startled or negative reaction from the classmates.	3
Excessive Movement	When seated next to an adult there were occasions where Katie engaged in excessive movement beyond what would be expected of a child her age.	4
Self-Stimulatory Behavior	Katie engaged in self-stimulatory behaviors during the class which consisted of hand waving and finger flapping.	2

Table 4

Large Group Classroom Observations (Post Recommendations)

Type of Behavior	Description	Frequency
Verbal Outburst (High Volume)	Katie engaged in verbalizations that were not consistent with the task (lesson) or the setting (church).	4
Wandering	Katie got up and wandered around the large classroom room with but was not disruptive.	2
Fidgeting	While seated, Katie demonstrated a decreased amount of movement.	3

Table 5

Small Classroom Observations Change Values

Small Classroom			
Type of Behavior	**Pre Recommendations Frequency**	**Post Recommendations Frequency**	**Difference**
Verbalization	15	10	5
Verbal Outbursts (High Volume)	4	3	1
Excessive Movement	7	4	3
Self-Stimulatory Behavior	3	2	1
Large Classroom			
Type of Behavior	**Pre Recommendations Frequency**	**Post Recommendations Frequency**	**Difference**
Verbal Outburst (High Volume)	9	4	5
Wandering	5	2	3
Fidgeting	6	3	3

Summary

As a result of the occupational therapy observations, the consultative session, and the implementation of the recommended strategies, Katie demonstrated anecdotal decreases in behaviors that may have prevented her ability to take part in the various religious activities meaningful to her family. Specifically, notable changes in the frequency of all undesirable or disruptive behaviors during structured religious activities (verbalizations, outbursts, movement, and self-stimulatory behaviors). However, the notable changes may not be the sole result of the occupational therapy consultative process with this case. Occupational therapy was the only discipline providing consultative services for Katie's barriers to participation in a religious context, which is a limitation, as having speech language pathology and clinical psychology involved may have created a more holistic approach.

Implications for Practice

Occupational therapists have a role in addressing the challenges that may prevent children with ASD from participating in meaningful religious activities valued by families and their communities. Moreover, religious clergy may be presented with families who have children with ASD and do not have the support needed to ensure meaningful participation in religious activities and rituals. The strategies recommended as a part of this consultative process represent strategies commonly used in the home, community, and school-based settings (Grajo et al., 2020; Weaver, 2015). However, this case report highlights the application of MOHO and contextual recommendations in religious contexts. Minimal differences are observed in the type and application. Finally, many funding sources may not reimburse for consultative or direct interventions that occur as the child takes part in religious activities, settings, and contexts. However, the impact on the family's quality of life may be more significant than addressing basic and instrumental ADLs, leisure exploration, or educational needs.

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