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Can Expressive Arts Therapy Help Caregivers of Persons with ASD?: A Community Engagement Project Capstone Thesis

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Can Expressive Arts Therapy Help Caregivers of Persons with

ASD?: A Community Engagement Project

Capstone Thesis

Lesley University

May 5, 2020

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Expressive Arts Therapy

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Abstract

Taking care of persons with autism spectrum disorder is not easy, especially in a school setting where there are more rules and cultures to follow. There is high turnover among our staff. I have witnessed several staff leave our school because of the burden of the work. The experience made me disappointed. I am sure that our students feel the same way as I do; they just don't know how to express their feelings when they realize staff is no longer with them. They trust the staff and the staff leave, sometimes even without saying goodbye. I was sad each time I knew someone left us. And of course, I was frustrated that I could not help prevent losing them. I started thinking how I can support the staff with this burden in our work environment. I created an expressive arts therapy group among staff at the residential program for their well-being. I wanted to learn if staff can be happier before starting their shift. I had six direct care staff participate in the project and facilitated three expressive arts sessions. They created together and enjoyed a drum circle. They reported their life condition was elevated, and they had a good start on their shift each week. There are many studies about autism spectrum disorder, but they are not focusing on caregivers, and I believe it is important since as the population of those diagnosed with autism spectrum disorders is increasing, so are the number of caregivers.

Keyword: caregiver, burden, burnout, autism, ASD, EAT, expressive arts therapy, turnover, special needs education, education, teachers, caretaker, self-care, spectrum, stigma

Can Expressive Arts Therapy Help Caregivers of Persons with ASD?: A Community
Engagement Project

As autism spectrum disorder (ASD) populations are increasing so do caregivers of ASD. Since I have been working for students with ASD for 15 years, I've seen great and not-so-great caregivers/parents and families come and go. I was always curious about what makes them amazing or frustrated when dealing with taking care of persons with ASD. The challenges are posed by not only by persons with ASD, but also sometimes by the bureaucratic system at the site and society.

I interviewed some parents of children with ASD in Japan when I went home in 2019, where they mostly expressed their real struggle as parents. One of parents shared with me that she would almost kill her son and herself. She was exhausted and depressed. Nobody seemed to care about her struggles, as her son was often having panic attacks and consequently hitting his head on the wall. She couldn't sleep at night. She just wanted to rest and forget everything that others said to her. Fortunately, she did not kill anybody. She and her son are still alive and things around them are a little bit better as her son grows, even though his resources are still limited in his living area and she needs to figure it out what he can do.

I became curious about how the caregivers can feel better and become better caregivers, overcoming their hardships when working with persons with ASD. Since we sadly hear news sometimes about the neglected and abused children with ASD by caregivers, the most important thing is to do better self-care before burn-out. It may be difficult to take it seriously at the professional level because there is a stigma around it. I see cultural differences in my work environment. For instance, there are some cultures whose people, especially men, should not complain, and they do not realize that failure to recognize burn out or trauma at work is an issue

for themselves. They do not want to know that the stressful physical conditions can contribute to mental ones. One of my coworkers told me that he could not sleep well since he started working 11 months ago. He woke up 3-4 times at night and took a long time to fall asleep after that. I recommended him to see a therapist, but he did not like the idea. He says he does not want to think that is a big problem. He still thinks it is ok and he can deal with it. I sometimes have a stomach issue when I work with students with ASD. I believe it is from stress since the problem does not manifest itself on my days off. I believe if the caregivers take care of themselves well, they can in turn give better care to their clients with ASD. They will be more patient and confident while working in these high stress environments. Some of the incidents that happen can be linked to instances when caregivers are exhausted, frustrated, and unsupported.

Since I am working closely with residential staff who work with persons with ASD, I would like to find ways in which we can be better caregivers for them. When the caregivers are happier, persons with ASD are happier too. In this capstone project I created a group of caregivers at the school residential program for children with ASD and conducted three expressive arts therapy (EAT) sessions with them as a community engagement project. I hoped to learn how EAT can help caregivers to reduce their stress and help them to do their best work performance for our students with ASD. EAT is still unfamiliar in our community and I feel it is a great opportunity for my colleagues to know what EAT is, how it can support them, and how we can use EAT at our site.

Literature Review

What is Autism Spectrum Disorder (ASD)?

According to DSM-5 (APA, 2013), ASD is one of the many neurodevelopmental disorders that can affect people. It displays “deficits in social-emotional reciprocity . . . , in

nonverbal communicative behaviors used for social interaction . . . , [and] deficits in developing, maintaining, and understanding relationships” (p. 50). It also has

restricted, repetitive patterns of behavior, interests, or activities, such as stereotyped or repetitive motor movements, use of objects or speech . . . , insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior . . . , highly restricted, fixated interests that are abnormal in intensity or focus . . . , [and] hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. (p. 50)

All of my students have ASD as a primary diagnosis. Some are very talkative, some of them are not verbal, but most of them understand what I say in one way or another. Some of the students keep moving their bodies, while other students sit still in the classroom. Some of them are picky eaters, some of them eat everything. Some of them communicate when they get the tiniest scratch on their finger. Another student hits himself until he gets a black eye without showing any pain. Although we can say they have ASD in general, each one is unique. They also have different styles of learning. Therefore, we, as educators, need to recognize the best way to reach out to each of our students. We need to try many ways to find the best teaching skill to educate each one of them. Nowadays, the number of children diagnosed with ASD is rising. “About 1 in 59 children has been identified with autism spectrum disorder (ASD), according to estimates from CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network” (“Prevalence,” 2020, para. 1). ASD is reported to occur in all racial, ethnic, and socioeconomic groups. ASD is about 4 times more common in boys than in girls. For example, we have 76 male students and 16 female students at the residential program where I work.

What is Caregiver Burden?

A caregiver is anyone who provides care for another person in need, such as a child, an aging parent, a husband or wife, a relative, friend, or neighbor. A caregiver also may be a paid professional who provides care in the home or at a place that is not the person's home (Office on Women's Health, 2019).

When I heard from one of my coworkers that she decided to leave our school, I was totally shocked. I was still new and learning everything from her. She took care of me as a new staff very well at work, and also in private. She was one of the best staff at the program and everyone liked her, including students' parents. She was very positive, optimistic, enthusiastic, wholehearted, and passionate to teach our students. Besides, she took care of her staff kindly, equally, and precisely as a master teacher. I felt safe whenever I worked with her, which was very rare for me at that time. She had some reasons to leave us but one of them was the burden. And, she was not the only person who had left from us in that way. I am not sure if our school keeps track of the rate of staff turnover, but I have seen various great staff leave us over the years.

It does not matter whether it is parents or professionals, caregiver burdens are the same for anyone taking care of persons with disabilities who cannot take care of themselves. Harvey-Knowles et al. (2018) state,

Physical and psychological manifestations of stress are not only unhealthy for caregivers; these maladies often complicate interaction processes between caregivers and cancer sufferers (Kim et al., 2008; Litzelman, Kent, Mollica, & Rowland, 2016). Comforting and supportive conversations have been deemed particularly important in illness contexts

as the provision and reception of comfort can impact both provider and recipient well-being. (p. 2)

I am a caregiver for students with ASD. My best friend was a caregiver for her father who suffered from his dementia. My mother is a caregiver for my father who got a cerebral hemorrhage 2 years ago and is paralyzed now in a wheelchair. We, three of us here, all feel the burden in different ways. In my case, I usually get a sign of burden as either headache or upset stomach. When I noticed that is a sign of feeling I am burning out, I would pause what I am doing and take a deep breath. If it is allowed at the situation, I would make art or just listen to music. One of them makes me calm down and helps me understand why I am upset and feeling burning out. I then go back to the moment from which I made a pause. I also have to talk to someone to review myself and the situation. It is important for me that I am able to know when I am overwhelmed and burning out, but there is always a possibility that I may miss the signal of burning out and just leave as it is. This can happen to anybody and it turns into serious burden for caregivers and becomes the cause of leaving a job or developing physical or mental health issues. We should not be alone as caregivers. If we isolate ourselves, the situation is going to worsen.

McDowell (2017) acknowledged:

The challenge...for both parents and professionals will be to find ways to carry out the legislative mandates for collaborative efforts to help children. Legislation alone cannot achieve this process. It is a human, psychological and educational process that must begin with people learning about one another. We must learn to appreciate the perspectives of others, learn to share with one another and learn how to learn from one another. (p.1)

Gallant and Connell (2003) pointed out that research on caregivers of individuals with other types of conditions such as dementia, stroke, and cancer has reported that caregivers high in neuroticism have been shown to have more depression. Since my father got his brain injury 2 years ago, my mother is the only one who takes care of him in my home country of Japan. She is truly his sole caregiver and feeling the burden consistently, because of numerous physical and emotional difficulties to provide him care. She had depression before and became free from the medication, but now she needs some of them to sleep at night. Unfortunately, I am an only child and living in a different country. They do not have any relatives in their neighborhood.

The cultural expectations can also contribute to caregiver burden. There is a strong stigma in my country, which is the family have to take care of their sick family members instead of relying on professional facilities. People talk about your family if you are not sacrificing to support them enough and not doing the right thing. Doing right means that everyone around you accepts your action. You need to be accepted by your neighbors, that is what my mother always feels. My mother doesn't want her neighbors to be annoyed and bothered by her and my father's situation. For example, she asked the ambulance not to make sounds when it came to get my father. She still hesitates to call 911 because of the noise, but it is obviously not safe! I am very worried, and I have to ask her neighbors to check with her sometimes. She was too scared to bother her neighbors. Her emotional status might be more fragile than before.

Caregiver Burden and ASD

What I have learned in my role as a caregiver for students with ASD, is that takes a lot of patience. It also requires caregivers to cooperate as a team to take care of them. We can't do it only by ourselves. "Parents are the child's natural teachers, and caregiver-implemented interventions have been documented to promote skill generalization and maintenance while also

potentially reducing parental stress and increasing quality of life” (Grofer Klinger, Ence & Meyer, 2013). Students with ASD need repetitive practices to master a task. Sometimes they can immediately understand it, but most of the time they need more experience to practice than others. They may be aggressive toward a caregiver when frustrated or when they are not ready to learn the task. Once they overcome their fear to challenge themselves new things, they can expand their understanding and their lifestyles. Caregivers for students with ASD must have a passion for helping students to challenge themselves because students with ASD strongly tend to stay in their comfort zone. They love routines and familiar people and do not like changes in staffing or environment. These fears can cause their life experiences to be limited and lacking in growth. It also causes their parents to be stressed out in having to maintain such consistent patterns.

“In terms of problem behaviors, research by Konstantareas and Homatidis (1989) found that self-injury was the strongest predictor of parental stress in a sample of 44 children with autism” (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009, p. 376). Some of our students have serious self-injury behaviors and their parents are constantly worried about them. They need more support than other typical families might. One of the parents is always anxious about her child and she often looks physically and emotionally overwhelmed when visiting our school. Some of our students with ASD have a heavy attachment to a particular caregiver. If the caregiver is not around them, the student becomes very unstable and usually has consistent meltdowns all day long. Caregivers struggle with feelings that they shouldn’t take a day off, or shouldn’t get sick, otherwise the students will have a hard time without the staff. It places a significant burden on caregivers. Claisen et al. (2005) explored the attachment of intellectually disabled children and their attachment toward their caregivers. It showed that particular

caregivers are essential and impossible to replace for some intellectually disabled children.

“Study by Bowlby (1969/1982) states that from infancy, children are proved to have some kind of attachment to their carers’, this helps in maintaining the stability and also the prevention of stress” (Kurian, 2018, p. 8). Because of the intellectual disability, they don’t understand the fact that they may not have the particular caregiver all the time and they don’t have flexibility to adjust themselves with another caregiver.

Interventions for Caregivers/Professionals

In my home country, it is popular for parents of children with ASD to have additional therapeutic education. The truth is that it is not easy to get into the programs since the facilities are not capable of dealing with the numbers of children diagnosed with ASD. They usually need to wait for a time from a few months to years to enroll the program. “Results suggested that child therapeutic education during preschool was effective in not only child growth and development but also the mother’s mental health” (Yamada, 2010, p. 176). Once they can get into the program and their mothers can see children with ASD’s growth, the mother’s mental health can also begin to get better.

Hartley, Dorstyn, and Due (2019) did a meta-analysis of 10 independent studies, and found that “caregivers, children and adults who received mindfulness all reported significant gains in subjective wellbeing immediately post-intervention” (p. 1). I use some of the mindfulness techniques for students with ASD in my art classes and caregivers can also participate in the activities. I personally like to see if the caregivers will try it because I know they also need the relaxation and release provided. I think it helps students and staff to focus more on each step. They calm down with the mindfulness prompts and can be ready for the art class.

Harvey et al. (2018) conducted the study that caregivers for cancer survivors would do creative writing and it showed the caregivers wellness became better.

The most compelling findings suggest that expressive disclosure and benefit finding might help caregivers struggling with depressive symptoms. It is also possible, however, that time management writing could improve caregiver stress, particularly for individuals who report higher than average stress levels. These forms of writing are cost-effective and can be completed at participants' homes. As such, practitioners may wish to consider recommending expressive writing for individuals experiencing difficulty pertaining to the cancer experience. (p. 831)

I think the most important part of taking care of caregivers is letting them know that we are caring for them. And they need to know they are cared by certain people. Because they have a tendency to be isolated themselves. I believe it can be the first step to avoid caregivers' burden and expressive arts therapy is the one of the most efficient process to do that. It can be any art form and each caregiver can choose how they want to express themselves in a comfortable way.

Method

I asked my supervisor at work if I could have some staff to have a group for my community engagement project. He recommended a staff who had a brother with ASD. I accepted his recommendation and chose five other people from our residential program. Staff A started to work in our school within three months. He was originally from Kenya and had a challenging student in his group. Staff B had been working for six years and he was from the United States. Staff C was originally from Japan and she had a brother with ASD. She was working with our students for about two years. Staff D was working for almost a year and he was originally from Japan. Staff E was from Sierra Leone and working at our school for five years.

He also had some challenging students in his group. He shared that his sister might have ASD but she was not diagnosed in her country. He had seen her struggle with being different than others while growing up together. Since he started working for students with ASD, he had an idea that his sister may have ASD. Staff F was introduced by my supervisor and she had been working for five years. She had a brother with ASD and was from the United States. I have six people in total for my group, two women and four men of different ages. I talked to each one of them about my project and got permission from them to participate on two to three separate sessions for expressive arts therapy. I set the date and time weekly from 2:30 p.m. to 3:25 p.m. on three Thursdays.

According to Dietrich-Hartwell (2017) “the space itself should be inviting, comfortable, and preferably consistent and unchanging” (p. 5). I decided to use my art room I usually used for our students; therefore, it was not a new place for each participant. The room had enough open space to move around and many windows could get beautiful sunlight. When I closed doors, the space could be secured.

First Session

I appreciated each participant for their time from the bottom of my heart. I explained what expressive arts therapy was and what I wanted to learn from the project. I shared the following group rules in the beginning:

- Show respect to everyone
- What is said in this group...Stays in this group
- “PUT UPS” only – No put downs
- Be polite and listen when others are speaking
- Participation is encouraged but you have the right to pass

- Always be kind (Teachers Pay Teachers, n.d.)

I checked with each one of them and everyone agreed to the rules without question. I then gave them 13 questions to start a dialogue among us to lead the group into a deeper conversation for everyone:

1. Do you like taking care of children/adults with ASD?
2. Why did you start working at our school? How long ago?
3. Why are you still working here?
4. What is your motivation to work here?
5. Do you have someone who you can share your struggle with at work?
6. Can you share your worst moment with your students?
7. Can you share your best or funny moment with your students?
8. Do you have anything you want to change at work?
9. Have you ever thought of leaving from our school? What made you think of it?
10. What do you appreciate at work?
11. What is your hope for your students and work?
12. How do you refresh your mind when you are frustrated at work?
13. Can you share what you do for self-care?

After one person read these questions for everyone, I asked them to pick some questions they wanted to talk about. After the unlimited dialogue about our work, I asked them what kind of arts they wanted to try together. I gave them three options, which include ceramics, painting, and flower arrangements. They said everything sounded good to them. Therefore, I chose painting and ceramics for the second session, and flower arrangements for the third session.

Second Session

I gave my appreciation to all of the participants in the beginning. I then showed them a sheet of paper which had many positive words on it and asked them to find one or two words which they liked. Staff A chose “Consistency.” Staff B was not at the second session. Staff C chose “Hope” and “Inspire.” Staff D chose “Challenge.” Staff E chose “Change.” Staff F chose “Positivity.” I asked them to share why they chose the word, and they all shared their reason. They were happy to share, and no one hesitated to share why they chose the word. It was under a warm-hearted atmosphere, with a lot of joking, laughing, smiling, giggling, great conversations, and positive energy in the group. I put a canvas on the table and gave everyone a roll of tape. I asked each one of them to put a piece of tape anywhere they wanted on the canvas to make a pattern. After that, each participant chose some colors and painted on the canvas together. They then picked a spot for their chosen word and glued it on. Figure 1 shows the piece I created in response.



Figure 1. My Response Using the Same Materials as They Created Together in Group

We then moved to the ceramic’s studio at our site. Since we had only 30 minutes left, we needed to hurry, but they did an awesome job making an individual heart with clay. I also gave the participants alphabet pasta so that they could put their chosen words on the heart as a

reminder. Participants would then choose colors for glazing after firing. They would be able to receive their own heart with their chosen word within 2 weeks. Figure 2 shows the heart I made in response.



Figure 2. My Response Using the Same Materials as They Created Together in Group

Third Session

I started with expressing my appreciation to each participant from the last session with me. Staff F was absent due to her vacation time. I asked a week ago that one of participants to lead the drum circle as a warm-up since she was a music therapist. She agreed to do it and prepared for them beforehand. We then followed her program.

[Drum Circle program]

- Choose the instrument that you want to play and have a seat.
- Play music “Al’s Bossa” by Alan lazar & “Rolling Drum” by Godfrey Mgcina for the background.

- Start from basic beat (4 beat), chanting (call and response), play faster, hands up and stop, play with your fingers, quiet and loud.
- Finish with rolling and hands up.

[Calm Down Part]

- Play music “Bali” by Isato Nakagawa for the background.
- Pass rainsticks and play as you feel.
- Put down the rainsticks on the floor.
- Close your eyes if you are comfortable with.
- Inhale and exhale three times.
- Open your eyes when you are ready.

The instruments used included: Conga (3), Bongo (1), Cowbell (2), Flog Guilo (1), Maraca (1), Rainsticks (4), and Thumb Piano (1). Participants chose and played instrument to release their internal energy. They tried drumming and vocalizing devotedly.

After that, I introduced a flower arrangement to the participants. Its benefits were to develop wellness, gratitude, love, stillness, connection to nature, stimulating all senses, and so forth. They had two choices of white mugs as a container. They would be able to drink a cup of tea or coffee with it after enjoying their flower arrangements. I thought it would be a small gift from me to them for participating in my project. They chose a mug which they liked and the flowers as well. I demonstrated how to cut the stems at an angle. After that, I chose to let them do this totally freely instead of instructing them as I had done with ceramics. I thought it was important for participants to be fully free to express themselves in the moment with those materials.

Results

Sharing thoughts and hardships with a small group of people at work could change a person's life. In addition, making arts together with the group could make an even bigger change. Each participant stated they had a good time and wanted to keep our sessions weekly even after my project ended. They were happy to meet every session and I could see smiles on their faces more frequently.

First Session

Although I told them they did not have to answer all of the questions, most of them talked about most of the questions. They wanted to speak about themselves and hear each other. They needed to share what they were thinking about their work. They also made connections with one another in the group. After the dialogue, everyone appeared more relaxed and open.

Second Session

It was a satisfying moment according to the participants. Following my instruction, they seemed to be enjoying the process with each step to form the clay in a reflection of their own hearts. Kneading and wedging clay could let people focus and calm down. Rolling to make clay flat and by cutting it into a heart could give participants courage and confidence. By smoothing the surface of clay heart using a cheesecloth and their palm and fingers gave participants an opportunity to calm their minds and slow them down. One of participants said to me after the session that he had tryphobia and it was difficult for him to put the alphabet pasta into the clay to make the word. He completed the task without letting anyone know about it, but stated later that he was really struggling. I felt bad after hearing this and appreciated his openness to share it with me. I learned that I need to be mindful of what types of challenges each participant might have.

Third Session

Each individual could enjoy playing instruments and release their internal energy by drumming and vocalizing enthusiastically. They seemed slightly confused when we started drumming, but then turned into self-focusing and attuning with the others by playing the drum. At the vocalizing part, I saw more smiles on each individual's face.

When we started the flower arranging, I heard them having meaningful conversations as they worked on flowers. I saw that they were relaxing, laughing, smiling, and looking at each other while focusing on arranging flowers. Each person appeared to be pleased and happy. After everyone completed arranging flowers, I asked them to stand up and walk around to see each other's flower arrangements. It was just like an exhibition at a museum. They noticed that every arrangement was different even though there were from the same materials. This could help people to understand and respect each other even though everyone's opinion and background were not the same. Since our workplace can sometimes feel like a melting pot, with people from many different cultures, this can be a reminder that we are all different and that is a good thing. Our students with ASD are also all unique in personality and background. Staff need to respect that and understand that students also have the right to express themselves in their own ways.

Discussion

Caregiver's burden is real. Continuous emotional exhaustion can damage people seriously. It can happen to anyone. The stress it can cause creates critical conditions, the worst-case scenario being death. I learned that it had not been rare for people in Japan to have homicidal tendencies because of the burden from taking care of person in need. Miyamoto, Mitsuhashi, and Nagashima (2013) shared their study about high murder rates in regard to family caregivers through 37 criminal cases. The study showed that the stress all related to their

conditions of disability, financial struggles, lack of social support services, anxiety for the future, anger to the system, giving up one's will to live seemed easier for them than maintaining caregiver's mental health issues.

For years there have been many questions that have gone through my mind about how these dire situations could have been prevented. When I listened and watched the news of these kinds of incidents, I wonder what kind of help these people could have received to prevent this need to give up hope and choose to kill.

When I was working as a residential instructor just like the participants for this project, I rarely smiled at work for the first few years. There was a stressful situation. Working with people from different cultures, language barriers, teaching students with challenging behaviors and lack of support put me in a tough setting. I didn't have a supervisor who I could truly trust. I did not want to think about the work when I was not working, but I was living in the staff dormitory at the same building where students lived. When some serious emergency situations such as fire alarm going off occurred, I had to go to support students even it was a middle of the night. Therefore, it was difficult for me to shift my mind between on and off.

I accidentally broke a finger when one of my students went off to grab another student, and I had to be out of work for about a month. It turned out a good opportunity for me to stay back, refresh, and pick myself up. Looking back, I had been on the edge of burnout. I was being punched on my nose almost every day from one of my students. And I didn't have an enough support for the situation. I should have had someone to share my struggle with. I saw various noble staff leave our school due to burnout and find a better job for themselves. In this community project, I wanted to know how we could keep great staff in our school. Students need the great quality of education which depends on us as a staff. Students with ASD do not have

choices of staff, and staff needs to be responsible for each student. If the staff was experiencing burnout, it would be difficult for students to have a good experience with them at school. Every staff at our school had a lot of work and was very busy every single day. It was not easy to care for coworkers unless the person obviously showed something wrong or they are personally close as friends. We might miss a sign for someone who was burning out from our heavy workload. That is why I feel it is important that someone check with each staff consistently so we can support the staff and may avoid losing high-end staff for our students. It was not easy to get and nurture a great staff quickly.

Maslach and Jackson (1981) pointed out that persons with burnout can evaluate oneself negatively in regard to one's work with clients and feel unhappy about themselves, dissatisfied with their accomplishment on the job. I think most of caregivers were doing good in the beginning of taking care of the person in need, but after a period of time burnout would start. They would start losing confidence at the job and looking outside to find another way for living.

I am working for students with ASD and have opportunities to talk to the parents. They are seeking help for their child and for themselves, but also it might depend on the personality of the parents. Some parents still hesitate to ask for help even though their conditions were extremely challenging. It seems important to reach out from our side and check on them, so that they would know we are concerned about their family, as they are the caregivers. It is good to show that we are not only concerned about the person with ASD.

I also work closely with direct care staff for our students with ASD. They are hard workers. Many of them work overtime regularly. "However, increased caregiving hours significantly related to increased burden" (Morimoto, Schreiner & Asano, 2003, p. 219). They need to be well cared for providing a high quality of education to our students with ASD. That is

why I wanted to try using expressive arts therapy to support our direct care staff in their ability to give our students with ASD a high quality of life and education. It is important that we are able to keep our high-quality staff for our students to keep providing them a stable high-end education. Hanyu and Tokunaga (2011) pointed out that caregivers could improve their specific skills for working with their clients and they made the caregivers feel better and get confidence. After a few months or years, the caregivers do not feel the burden as heavily. After creating the momentum, caregivers can enjoy working with their clients without feeling extremely overwhelmed. I believe the part can be supported by expressive arts therapy at our site. Because of expressive arts therapy, clients can seize self-awareness, self-confidence and wisdom through various arts form. In my personal experience, I overcame several difficult moments at work with my faith and creativity. I would be very happy to be able to share more of my skills with my hardworking co-workers.

Right now, we are in the middle of the worldwide pandemic due to COVID-19. People are confused, frustrated, and have anxiety for their future. People have lost their jobs. It is reported the domestic violence rate is increasing due to staying home more than ever. Amanda Taub (2020) said on the New York Times, “The United Nations called on Sunday for urgent action to combat the worldwide surge in domestic violence” (para. 3). Frustration and anxiety make people burnout or/and aggressive. There is nowhere to be safe since we cannot see the virus. Hospital and clinic workers are burning out. Patients are dying in front of them and they also have a possibility to die from the same virus. In our school, the day program needed to be shut down due to the government’s order, but the residential program is still open since students are living there. Students are slightly less in number than usual, but we are the essential staff and we are at risk at work every single day. They said that we need to check our temp before

checking in, but they do not currently have enough medical thermometers to check all employees.

What I can do is to create a safe spot for the staff who need to express themselves. I would recommend that any staff can come into my art classroom or another designated space and make any art before working with students. It may sound inane for some people at this time, but hopefully they will know how making art helps people calm down. Most of us have not experienced a worldwide critical pandemic like this before and it is fine for everyone to be upset about it. It is important for us to not only see the massive amount of information which we can easily get overwhelmed by, but to also see ourselves. Expressive arts therapy is the one great tool to look at ourselves.

How can the burnout be avoided or slowed down in this current situation? It is important to output ourselves in safer ways. Since we have a lot of inputs but not so much opportunities to output. Our environment is tremendously narrower and limited than before. This current situation makes me think much deeper about my project and I need to appreciate the situation in a positive way.

Mantie-Kozlowski, Mantie, and Keller (2018) state, “Caregivers expressed that the sing-along sessions provided opportunities for rewarding interactions in an enjoyable activity” (p. 16). Even though caregivers with their clients participated the sing-along sessions together, they could get rewarding opportunity and could enjoy themselves. Expressive arts therapy had a lot of potential for helping caregivers in many ways. When I have art classes to lead at the residential program, I often see the staff enjoying their art making process besides supporting students. They said they could relax and enjoy with their students.

We had three sessions to meet together as my project. The group had six residential direct care staff for students with ASD. The dynamic of the group was very diverse with people of many nationalities. They were happy to meet every session and created artwork together. They could share their thoughts and struggles during these creative sessions. They made a collaboration art piece by finding inspirational and positive words with colored paints. They also created individual ceramics hearts with the positive words they chose. In another session, they experienced a drum circle and made a flower arrangement. They wanted to continue these sessions after the project. One of them told me that it was a motivation to come to work. Another staff told me that the session gave them a positive energy through the week.

A weakness of my project was that it was very limited because I had only six caregivers to participate and had only three sessions as a community project. I would like to expand the project to more participants of direct care staff in the residential program, and also try it among parents' group in the future. Another weak point on my project was that it might be difficult to find the best resource for each caregiver. For instance, I did not know one of my participants had a phobia as I shared in previous pages, and I made the caregiver uncomfortable without knowing during my session and it should be avoided.

In my future sessions of expressive arts therapy for caregivers, I would like to use the Zarit Burden Interview or The Sense of Competence Questionnaire: Consequences of Involvement in Care for the Personal Life of the Caregiver in the beginning and ending of the term. It would be helpful to know essentially about the caregivers' conditions and what more I would need to consider beforehand. Currently I have recommended to my supervisor that residential staff have an opportunity get into the support group at work. It should be in their paid hours and kept confidential. Mochizuki-Kawai, Kotani, Mochizuki and Yamakawa (2018)

mentioned in their study that they would examine their program's effect on caregivers' mental health and on relationship between patients and caregivers. It would be interesting to expand the research about the relationship between our students and caregivers. I would like to have them all meet in a support group. We could assess the number of meltdowns, self-abusive behaviors or sleeping patterns, eating habits, and concentration on activities.

I would also suggest examining the relationship between caregivers who attend expressive arts therapy sessions and the turnover rate. It would be interesting and useful for our school.

Ezzat, Bayoumi, and Samarkandi (2017) recommended caregivers for ASD to recognize coping strategies, find suitable ways to support family adaptation, and establish collaborative group with clinical team members and other professionals (p. 38). These recommendations are truly basic and essential. Caregivers are still struggling even though they trying to follow these recommendations. In addition, there are the limitations of getting enough support from those professionals. That is why caregivers should get additional support and expressive arts therapy is the one of them I believe.

As I conducted my project, I felt very fortunate to have an amazingly supportive supervisor who gave me an opportunity to lead my project at our school. I really appreciate to the six residential direct care staff who cooperated with me and devoted themselves to my project. I also appreciated the participants' divisions for letting them come to my project, even though the division needed them for preparation of the daily operations.

As a conclusion, caregivers need to have the consistent opportunity to express themselves. Expressive arts therapy is necessary to help caregivers for persons with ASD to

perform better to give our students high quality of life and education. This is just the one way to implement improving caregivers' life conditions.

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THESIS APPROVAL FORM

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In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

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