University Students' Experiences as Volunteers in Hospitals for Individuals with Autism Spectrum Disorder and Their Families: "Be My Hospital Friend"

Doç. Dr. Yeşim GÜLEÇ-ASLAN*

İstanbul Medeniyet University, Faculty of Education Science, Department of Special Education, İstanbul, TURKEY, yesim.gulec@medeniyet.edu.tr, ORCID: 0000-0003-0283-2129

Arş. Gör. Ayşe Büşra SUBAŞI-YURTÇU

İstanbul Medeniyet University, Faculty of Education Science, Department of Special Education, İstanbul, TURKEY, busra.yurtcu@medeniyet.edu.tr, ORCID:0000-0002-3257-4944

Doç. Dr. Özcan ERKAN AKGÜN

İstanbul Medeniyet University, Faculty of Education Science, Department of Computer Education and Instructional Technologies, İstanbul, TURKEY, ozcan.akgun@medeniyet.edu.tr,

ORCID: 0000-0002-6486-0486

Prof. Dr. İsmail GÜLEÇ

İstanbul Medeniyet University, Faculty of Arts and Humanities, İstanbul, TURKEY, ismail.gulec@medeniyet.edu.tr, ORCID: 0000-0002-0174-148X

Abstract

Parents of children with autism spectrum disorder (ASD) routinely visit healthcare institutions for medical examinations. Hospital visits can be a difficult experience because of core challenges of ASD, a general lack, or low level, of ASD knowledge

^{*} Sorumlu Yazar. Tel: +90 555 349 29 29

among healthcare providers and lack of volunteer services. This study investigates results of a program developed to overcome these problems. The program under the name of "Be My Hospital Friend" aimed to encourage university students to engage in volunteer services in health issues. The purpose of this qualitative study was to describe the experiences of participants via reflections. Also, student's levels of ASD knowledge were examined. The results show that the program was beneficial for participants' ASD knowledge and personal development. The results discussed in terms of implications for research and practices.

Keywords: Autism spectrum disorders; Hospital; Qualitative research; Volunteering.

Üniversite Öğrencilerinin Otizm Spektrum Bozukluğu Olan Bireylere ve Ailelerine Yönelik Hastane Ortamlarındaki Gönüllülük Deneyimleri: "Hastane Arkadasım Ol"

Öz

Otizm spektrum Bozukluğu (OSB) tanılı bireyler yaşadıkları çeşitli sağlık sorunları nedeniyle tıbbî kontrolleri için ailelerince sağlık kurumlarına düzenli olarak götürmektedirler. OSB've özgü temel güclükler, sağlık çalışanlarının OSB bilgilerindeki vetersizlikler ve bu sürecte aileve destek olacak gönüllülük hizmetlerinin eksikliği nedenleriyle, sağlık kurumlarına gidildiği günler OSB tanılı birey ve ailesi için zor bir süreç haline gelebilmektedir. Bu araştırma kapsamında, OSB tanılı bireylere ve ailelerine, sağlıkla ilgili süreçlerinde gönüllü destek olmak amacıyla üniversite öğrencileri ile yürütülen "Hastane Arkadaşım Olur musun?" adlı bir program başlatılmıştır. Bu nitel araştırmanın amacı, yansıtma formları ile toplanan veriler aracılıyla öğrencilerin bu gönüllülük çalışmasındaki deneyimlerinin incelenmesidir. Ayrıca, öğrencilerin OSB bilgi düzeyleri de niceliksel olarak incelenmiştir. Araştırma bulguları, programın öğrencilerin OSB bilgi düzeylerini ve kişisel gelişimlerini sağlama bağlamında faydalı olduğunu göstermiştir. Bulgular gelecekteki uygulama ve araştırmalar doğrultusunda tartışılmıştır.

Anahtar Sözcükler: Otizm spektrum bozukluğu; Hastane; Nitel araştırma; Gönüllülük.

Introduction

Autism spectrum disorder (ASD) is characterized by social communication impairments and restricted, repetitive behaviors (American Psychiat-

ric Association [APA], 2013). In addition to the core challenges of ASD (patterns of restricted, repetitive and aggressive behavior, difficulties with social skills, etc.), individuals with ASD frequently report co-morbid conditions such as attention deficit-hyperactivity disorder (ADHD), anxiety, depression, and such neurological issues as epilepsy, gastrointestinal, feeding, and sleep problems, sensory issues, aggressive behaviors, mental illness, and unhealthy weight.

Therefore, children with ASD experience more medical concerns than typically developing children or other children with special needs (Brachlow, Ness, McPheeters and Gurney, 2007; Bruder, Kerins, Mazzarella, Sims and Stein, 2012; Carbone et al., 2013; Cheak-Zamora and Farmer, 2015; Hall, 2012; Hyman and Johnson, 2012; Kamp-Becker, Schröder, Remschmidt and Bachman, 2010). As a result, their parents and families routinely have to take their children to healthcare institutions for medical examinations. While many children fear going to the doctor's office or other medical institutions, for children on the autism spectrum, their core challenges make such visits especially challenging. For example, they may display behavioral problems or tantrums in response to the crowded and noisy environment of the healthcare institution or to the disruption of their daily routines. Thus, health-related issues and time spent during hospital visits, a process that is unpleasant and scary enough even for typically developing individuals, can be a highly challenging process, during which undesirable experiences occur. Consequently, the health-related quality of life of individuals with ASD and their families might decrease (Carbone, Behl, Azor and Murphy, 2010; Carbone et al., 2013; Havercamp et al., 2016; Hyman and Johnson, 2012; Kamp-Becker et al., 2010).

To aggravate the situation further, a general lack, or low level, of knowledge and skills about ASD among healthcare providers adds to the challenges those individuals with ASD and their families experience when seeking help to meet their health needs. Thus, among the limited research literature focusing on the levels of ASD awareness, skills, knowledge, and needs of healthcare providers and/or students of medicine and health sciences, findings indicate a need for specific training about ASD tailored to the needs of healthcare providers and/or students of medicine/health sciences or related disciplines. Such training would not only increase awareness, skills, and knowledge about ASD but also ensure that these healthcare providers

would feel competent to enhance the health-related quality of life of families of individuals with ASD. However, further research is needed (Bruder et al., 2012; Carbone et al., 2010; Carbone et al., 2013; Chiri and Warfield Erickson, 2012; Golnik, Ireland and Borowsky, 2009; Havercamp et al., 2016; Nolan, Walker, Hanson and Friedman, 2016; Shah, 2001).

In the meantime, to fill this gap, volunteers can play an important role (Carbone et al., 2010; Hall, 2012; Hyman and Johnson, 2012). For example, volunteers can make a major contribution to the quality of life for people with ASD and their families in their daily and social lives by (a) assisting with transportation and self-care, (b) providing social support, (c) spending time with people with ASD so that their families can take care of daily chores and/or take time for themselves, and (d) mounting public awareness campaigns (Gardiner and Iarocci, 2014; Nieto et al., 2015).

Beyond this day-to-day support of families, in health-related settings, volunteers can provide assistance with medical routines (e.g., helping families carry their personal belongings, taking care of the child with ASD when his or her parents deal with formal procedures, providing transportation assistance) as well as more formal procedures and/or paperwork, including making initial appointments, copying documents, getting documents signed, getting prescriptions filled and so on. Furthermore, they can arrange activities that make the wait time in healthcare institutions (waiting for examinations, waiting for official documents to be prepared, and so on) more enjoyable for children with ASD (painting pictures, reading, etc.) or, alternatively, share common medical information with healthcare providers (details about the patient's diagnosis, ASD, etc.). Throughout, volunteers can meet with families ahead of time to identify their needs and, as a result, offer customized help in accordance with those needs (Carbone et al., 2013; Chiri and Warfield-Erickson, 2012; Hall, 2012; Hyman and Johnson, 2012).

In short, volunteer services are of tremendous importance for ensuring the quality of life of individuals with ASD and their families. Yet, to date, no studies have explored volunteer services in the area of healthcare. Instead, existing studies have looked at volunteer services that provide support to individuals with ASD in their leisure time (Collier, Rothwell, Vanzo, Carbone, 2015; Nietto et al., 2015) and university students engaging in with their peers with ASD (Gardiner and Iarocci, 2014). In Turkey, volunteer service in the area of ASD, in general, is very limited and is usually con-

ducted by non-governmental organizations and some universities. However, there is no volunteer service or research pertaining to the healthcare needs of people with ASD and their families.

To fill this gap in the research, the present study, an Autism Volunteer Program (AVP), was initiated in a state university under the name of "Be My Hospital Friend." carried out with undergraduate and graduate students of the Faculty of Medicine and Faculty of Health Sciences. The program aimed to encourage university students to engage in volunteer services to provide assistance and support to individuals with ASD and their families in health-related issues and to spread public awareness about ASD. Another objective of the program was to raise students' levels of knowledge about ASD and create a volunteer team that was knowledgeable about ASD.

In this study, student experiences within the context of the "Be My Hospital Friend" program were analyzed. Specifically, the meanings of volunteering from the perspectives of participants are described. In addition, participants' levels of knowledge about ASD were analyzed quantitatively.

The study was expected to help future healthcare providers expand their knowledge on ASD during their academic life; that is, before entering their professional career. In addition, the study helped participants to assist people with ASD and their families and offered the students the opportunity to increase public awareness by means of ASD awareness campaigns. The literature as a whole includes few studies on the healthcare processes of individuals with ASD and their families, and the relevant Turkish literature on this issue is nonexistent; therefore, the findings of this study are expected to make contributions to the literature from a Turkish setting and, hence, also provide a cultural perspective on the literature in general.

Method

This qualitative study was conducted using a phenomenological research approach (Creswell, 2014; Smith and Osborn, 2004).

Participants

A total of 9 students (Woman) participated. One was first-year medical student, two were third-year medical students, and three were first-year students at the Department of Nursing of a Faculty of Health Sciences. The remaining three participants were master's-level students in the Department of Physiology of the Faculty of Health Sciences. Of these three, two worked

as nurses in a hospital. The age range of the participants was 20 to 37, with an average age of 24 years.

A purposeful sampling strategy was used to determine the sample (Creswell, 2014). In October 2016, announcements soliciting volunteers to participate were disseminated by various means, reaching a total of 543 undergraduate students (Faculty of Medicine=502, Department of Nursing of a Faculty of Health Sciences=41) and 231 postgraduate students from the Faculty of Medicine and Faculty of Health Sciences (Institute of Health Sciences: 22, Healthcare Management Program: 57, Medical Law Program: 152). Announcements included brief information about the AVP and Volunteering Intentions Scale (Gardiner and Iarocci, 2014; Hall and Minnes, 1999; Mahoney, 2008). The scale evaluates the behaviors of individuals who want to participate in volunteer work in order to measure their true intentions and willingness to volunteer. To that end, the scale includes an item that asks respondents to provide their contact information; those who are believed to have "the intention to volunteer" and, hence, are evaluated positively, as displaying an accurate sign of behavioral intent (Gardiner and Iarocci, 2014). In the present study, potential volunteers were asked to provide their e-mail addresses and/or phone numbers as a pre-registration procedure for the program. Fifteen pre-registered students were then invited to an introductory meeting, yet only 10 students showed up. However, three of the 10 students did not attend the following meetings due to busy schedules. Two other students were registered to the program after the introductory meeting. Finally, the project was carried out with nine students.

Participants signed an agreement that specified the rules of the program, responsibilities of the participants, and the researchers' roles, to signify their willingness to participate in the program on a voluntary basis. Furthermore, participants were asked to provide a clean criminal record, personal identity card, letter of reference, student identity card, and a clean bill of health.

Finally, a statement of ethical approval of the study was issued by the University Board of Research and Publication Ethics.

AVP Procedure

The current study covered the AVP process between October 2016 and July 2017. In accordance with the research objectives: (a) participants provided volunteer assistance to individuals with ASD and their families

related to health-related issues after receiving training and consulting services from the researchers; and (b) participants carried out public awareness work about ASD. The training and consulting services as well as the volunteer work itself were meant to equip participants with skills and knowledge about ASD.

Participants' areas of responsibility within the context of this study were as follows: (a) providing assistance to the individuals with ASD and their families related to health issues. These included making initial appointments with healthcare institutions on behalf of patients, dealing with formal procedures at the healthcare facility, getting prescriptions filled at pharmacies, organizing transportation in addition to helping families carry/move heavy belongings such as strollers; (b) making the commuting process as well as the time spent in the health care institution more enjoyable for the child with ASD by means of a variety of activities, for example, playing with the child while waiting for an appointment; (c) organizing events for public awareness about ASD; and (d) preparing informative booklets.

The steps followed during these procedures are explained in following paragraphs.

Step 1: Researchers organized a two-hour introductory meeting for the participants. After the participants introduced themselves, detailed information about the planned work was given. In the meeting, the research participants also shared their opinions about the concept of volunteering (what is volunteering, why is it important, etc.) (November, 2016).

Step 2: The researchers designed an eight-hour training program consisting of two sessions to teach participants the basics of ASD and problem behaviors; specifically, the characteristics of ASD, basic applied behavior analysis techniques, including possible reasons for problem behaviors and basic ways to deal with them. Participants were also informed about the problems they might encounter in healthcare institutions and ways to deal with them so that they could build effective communication with individuals with ASD and their families.

The training sessions were organized in a lecture format in which verbal instruction was complemented by PowerPoint presentations. Case studies were presented (videotaped examples, etc.), and volunteers received

written copies of training materials and a list of additional resources (November, 2016).

In addition, the volunteers visited two organizations where they could observe individuals with ASD. One of these organizations was a secondary school that enrolled mostly children with typical development but that also served four autistic students (Autistic Children Education Center [ACEC] with special education classes for students with autism opened within the general education schools as part of inclusive education). The visit to the school was made under the supervision of the first researcher and lasted two hours. The other organization was a special education center for people with ASD (ACEC for only Individuals with Autism [ECIA]). During the two-hour long visit here, volunteers observed students in different classes under the supervision of the second researcher. The volunteers were able to ask ASD-related questions to the teachers of the classes they visited (November, 2016).

Step 3: Announcements were released via different channels (social media, public announcements at schools and healthcare institutions, etc.) about the volunteer services offered (October, 2016). Families that wanted to receive volunteer assistance with regarding to the health-related issues were asked to submit an application. Researchers informed the families who applied about the program either face-to-face or via phone calls. Subsequently, the first researcher met with the families that wanted to participate in the program to identify their needs. For this purpose, the families answered questions about the challenges faced at hospitals and the type of support they required. After the families' needs were identified, two volunteers were assigned to each family. Availability of the volunteers' schedules as well as the congruence between families' needs and volunteers' interests and/or capabilities were taken into consideration when assigning volunteers to families. For example, nurses were assigned as volunteers to assist families that had difficulty when their children had to have their blood drawn, for example.

After the volunteers were assigned, the volunteers and families met with the researchers to plan the services to be delivered. A face-to-face meeting was also organized at the school or home of the child. The objectives behind this meeting were to introduce volunteers, families, and the child to each other, to inform the families about the process, and to finalize the plan based on the feedback from the families.

A total of eight families and their children received volunteer services. A range of services were offered in accordance with the special needs of families. For example, making appointments with hospitals on behalf of the patients; providing assistance when families were dealing with the formal procedures at the healthcare institution; accompanying them and their children when commuting to and from a hospital; asking municipalities to allocate a vehicle for traveling to the hospital; spending time with the children while waiting for appointments; informing healthcare professionals about autism and the specific condition of the child; assisting healthcare professionals, in accordance with their directions, during injections, anesthetic EEG measures or similar medical procedures, and taking care of the child while their parents were meeting with doctors; taking care of children while their mother was examined by the doctor if the mother had to visit a doctor herself and did not have anyone to care for her child; and helping mothers who did not have sufficient knowledge of the Turkish language to communicate effectively. In accordance with their needs, different services were delivered to families on different days. Although one day was enough for some families, others requested assistance for more than one day a week. For example, one of the families received help for five days.

Following their services, volunteers were invited to meetings to talk about their experiences. Volunteers shared both negative and positive experiences, challenges and other details concerning their voluntary work in the reflection form that is the qualitative data collection method of this study. Feedback was subsequently given by the first and second researchers in terms of the strategies to cope with the challenges they had faced. Besides, the volunteers who were assigned to deliver services got together with other participants to share their experiences.

To obtain feedback from the participating families, the first researcher held either phone or face-to-face interviews with the mothers to explore families' satisfaction with the services, the challenges they might have experienced and any recommendations they had. The families' feedback was also communicated to the volunteers. Finally, both the families and the volunteers were asked to fill in evaluation forms both before and after the service process.

Further, a one-hour meeting was organized with volunteer students, the first researcher, and 25 parents from ECIA, one of the schools visited initially, upon the request of a teacher from that school. During the meeting, volunteers asked families a range of questions regarding the aspects they were curious about ASD, and families' questions regarding hospital appointment systems and ways to cope with the barriers and challenges they had experienced at hospitals were answered. Following the meeting, two families from that group requested volunteer assistance during upcoming hospital visits for their children (December, 2016-July, 2017).

Although the research has ended, our volunteer team still assists families in response to their requests, and there are still ongoing activities and attempts to grow the volunteer team which will carry on the voluntary service.

Step 4: During March-July 2017 activities were arranged. For example, during the Autism Awareness Month, volunteers organized awareness-raising activities under the guidance of the researchers. In April, two conferences were held at the university open to participation by any interested persons outside the university. In one of those conferences, the mother of an autistic child gave information about ASD on the basis of her personal experiences. In the second conference, an ASD professional presented information about educational opportunities for autistic individuals. Furthermore, volunteers shared information about autism at booths set up at the university and via social media (preparing and handing out fliers about important aspects of ASD, recommending books to read, etc.). Volunteers and researchers prepared two booklets that included some basic information about ASD and useful tips that might facilitate the hospital-related processes of individuals with ASD and their families. The booklets were distributed free of charge to relevant institutions (schools, etc.) and individuals (teachers, etc.).

Apart from the introductory meetings, 20 meetings, each lasting two hours, were organized throughout the research process. During those meetings, the aforementioned processes and activities were planned and feedback on the completed program steps was exchanged in a group environment.

Data Collection

The reflections of participants were main qualitative data collection method. Participants wrote brief reflections (100-250 words) comprising their opinions about their experiences with the research process, the volunteer services they delivered, and the effect of voluntary work on their about

personal, professional, and academic lives. In addition, we examined the changes in participants' levels of ASD knowledge quantitatively. The Knowledge about ASD Test was developed by the researchers based on the relevant literature (e.g., APA, 2013; Gardiner and Iarocci, 2014; Mavropoulou and Padeliadou, 2000; Swiezy et al., 2005) to assess and evaluate the volunteers' basic knowledge of ASD. The instrument consisted of 25 questions and was checked for validity by three area specialists. The highest possible score on the scale was 100 points. It was administered both before and after the ASD training.

Data Analysis

The data were analyzed inductively, beginning with organizing all raw data to construct themes (Creswell, 2014; Yin, 2003). The reflection forms were read and examined as to create initial categories. The initial categories were reviewed by a specialist familiar with qualitative method and ASD, and were subsequently refined based on her suggestions and feedback. The categories were then examined to create initial themes. The initial themes and categories were examined by another specialist familiar with special education and qualitative method, who confirmed the consistency between the initial themes and the categories. The researchers finally identified themes and subthemes.

After all the data had been divided into themes, a second group of specialists examined the consistencies between themes and data, and the researchers and specialists discussed the consistencies between the themes and the data until agreement was obtained. All themes and subthemes were finally reported using descriptions and quotations in the context of the research goals (Creswell, 2014; Yin, 2003).

During qualitative data collection and analysis, the following strategies were used to establish trustworthiness (Brantlinger, Jimenez, Klingner, Pugach and Richardson, 2005; Creswell, 2014): member checking, triangulations in data collection, peer debriefing in data coding and theme development, researcher reflexivity, and ethical behavior.

The quantitative data were analyzed descriptively in accordance with relevant qualitative data-analysis methods.

Findings

Qualitative Data

The findings were interpreted and presented via three themes: perceived benefits of the AVP, suggestions for the AVP and understanding volunteering from the volunteers' perspective. In addition to these findings, we also give findings of views of families, benefiters from AVP, in order to making more qualified suggestions to conduct better AVP processes by including not only service givers views but also service takers views, although this was not a direct goal of this study.

Perceived Benefits of the AVP

As presented in Table 1, all volunteers reported that the AVP brought a variety of benefits to their lives. These benefits were examined in two subthemes as follows: "Understanding ASD: Knowledge and Awareness" and "Personal Satisfactions."

Suggestions for the AVP

All the research participants (%100) put forward some similar suggestions about the program. They suggested accepting new participants and continuing the program in the following years as well. Another suggestion was that similar programs should become widespread and that more people with ASD and their families should benefit from these services. Finally, they believed it would be good to include a higher number of healthcare providers or providers-to-be in similar volunteer programs. Some quotes from volunteers' comments are as follows: "I expect the project to be continued and thus, to be of help for families and children." (V1), "I hope the number of similar programs increases and in this way, it becomes possible to see people with ASD more in social life. By means of these programs, we, healthcare providers can become more knowledgeable about the issue and offer more help to autistic people and their families." (V3), "Public awareness about autism would increase by means of similar volunteering projects and organizations and in return, people might help autistic individuals and their families. However, more volunteers are required to achieve this." (V6), "If volunteer programs of this type increase in number and become more widespread, families and children will not feel lonely or hopeless. They won't have difficulty at hospitals or in other settings. I believe many healthcare providers should engage in voluntary work." (V8).

Understanding Volunteering From The Volunteers' Perspective

The theme "Understanding volunteering from volunteers' perspective" was examined under two subthemes: definition of volunteering and motivations for participating in the AVP. Table 2 includes themes, subthemes, and sample quotes.

Views of the Families

All of the mothers (%100) told that 'they were very satisfied by volunteer service and volunteers' style of management in the processes, and they got enough support, and they did not face with any handicap, according to feedback results, to take views of families about the management of the processes, their satisfy levels and suggestions.

Tablo 1. Perceived Benefits of the AVP

Subtheme Subtheme 1: Understanding ASD: Knowledge and Awareness (N=7, %78)

Sample Quotes

"As a healthcare provider, I was aware that children with ASD and their families might experience difficulties, but I didn't know that their lives were a lot harder than I imagined. Families have a range of problems to deal with and have to meet their children's various needs. They are not fully understood in many social settings. I have seen that it is really hard for them to handle such issues as, transportation, the procedures to be carried out at hospitals and making appointments although they all seem to be very easy from an outsider's point of view. Families do not receive much help at hospitals. To the contrary, we met people who displayed aggressive, insensitive and unpleasant behaviors towards those children and their families. In this regard, healthcare providers must be more sensitive and helpful." (V1)

"Although I'm a healthcare provider, I had no knowledge of ASD before the program. Thanks to the program, however, I have gained knowledge about ASD. The program has contributed to my professional development. I, now, know how to approach to autistic children and their families thanks to the training I received and to the voluntary services I delivered to those children and families. I know how I can make their lives easier. From now on, I will be standing by them not only in hospital settings, but also in all the other areas of life." (V2)

"I feel prepared for situations I can experience in my professional life and for the likelihood of having an autistic child myself or for my neighbors' and relatives' likelihood ofhaving a special child. I was interested in the subject of "epilepsy and neurophysiology" in the area of medical physiology. "Autism" might now be another area of interest for me and I guess I'm more prepared for any problem that might arise in hospital settings that I will observe while writing my thesis." (V4)

"The best part of the program for my personal life is that it has helped me gain "awareness". It has become a primary responsibility of mine to do something for people with ASD and to touch their lives instead of just watching their sorrow and in return, feeling sorry for them. I am sure that from now on, I will be able to understand them better both in my professional and social life. This has been a "project of enlightenment" for me. I would like to instill the same awareness in other people wherever I go, be it a school or a hospital. I would like to encourage them to visit the nearest school and ask how they can help and what they can do for autistic people." (V5)

Table 1 (cont.). Perceived Benefits of the AVP

Subtheme

Sample Quotes

Subtheme 1: Understanding ASD: Knowledge and Awareness (*N*=7, %78) "I believe my awareness has grown with this program. I mean, due to my major, I encounter a variety of diseases and disorders. My everyday life is full of disorder cases. But, in this program, I have gained the opportunity to see autism from another perspective, namely from the perspective of a patient, not only from the perspective of a doctor or a student. Before this program, I had never been that close those people. This was a really meaningful experience for me. Their hospital procedures are hard and they are, therefore, in need of help. We need to empathize with them and should help them as much as we can." (V6), "This program enabled me to see individuals of a different, yet special group whom I hadn't noticed before. I have understood how special autistic people are and that they live in a world of their own. I have learnt how to communicate with them. It has been a great pleasure. I have learnt their special attributes. I have seen how a mother whose child has not even once been able to call her "mum" could raise her child with affection. I have seen that educating people with ASD is overall a very long process which demands a great deal of patience." (V7)

Subtheme 2: Personal Satisfactions (*N*=7, %78)

"I feel really lucky to participate in this project. We will meet all kinds of people due to our occupation, and now, I have an idea about how to approach autistic people and their families. I am now fully aware that we share the life with autistic children and their families." (V9), "I found spiritual satisfaction in the satisfaction of families." (V1), "I am glad due to the services I delivered. We were of help both for the children and their families. By participating in the project I did a good job. It was a great pleasure to assist families to overcome the challenges they faced and to finish their work in shorter times. For example, one child threw a tantrum in the hospital. Sometimes, some healthcare providers were not well-informed and caused difficulty. Families had difficulty dealing with these problems and we helped both them and healthcare providers." (V2), "It was really exciting and

enjoyable to meet those families and their children. I'm glad that both the children and their families were satisfied. I was really happy." (V3), "I need to express my happiness about being part of this program. What I feel now is the happiness that comes from contributing to the solution of a social problem." (V4), "I felt spiritual joy. I was happy that a little patient could hold my hand. He was not scared of me and we walked together on the way to the hospital." (V6), "I developed emotionally. Offering voluntary help made me feel competent." (V7), "I derived a spiritual pleasure from this work. I was happy." (V8), "What I have gained and being able to help children and their families is a great emotional satisfaction." (V9).

 Table 2. Understanding Volunteering From the Volunteers' Perspective

Subtheme **Sample Quotes** Subtheme 1: "Volunteering is like feeling you serve a purpose, because mere existence in the world does not always have a meaning. Touching other Definition of people's lives, especially those of special people brings meaning to our Volunteering existence in the world." (V1) (N=7, %78)"Volunteering resembles a tree, because you feed people benevolence." "Volunteering is casting your bread upon the waters. Here, the point is offering as much help as possible without expecting anything but happiness." (V3) "Volunteering is like motherhood, because it requires empathy, affection and sacrifice of highest possible extent." (V4) "Volunteering is similar to inspiration, because it comes from the heart." (V6)Subtheme 2: "Volunteering is like having a good mood, because making someone happy helps one feel a sense of spiritual well-being." (V7) Motivations "Volunteering is like realizing yourself, because it tells me who I am, for what I need and how I can feel better." (V5) **Participating** "Volunteering is like light, because when one helps others, he/she enin the AVP lightens their lives." (V8) (N=7, %78)"Volunteering is like the second wing of a bird, because it is not possible to fly on one wing. Our second wing, namely volunteering must always be present in our lives." (V9) "I'm a medical student and despite my heavy course load and extensive theoretical studies, I would like to take close care of these patients who are subject to peculiar societal attitudes. I don't only want to be cognizant of their situation, but I want to live with them and learn how they see us. I believe I can learn this by means of this program." (V6) "The reason for which I have participated in the program is that I want

people around me to feel better. I know that I will be happy, because I

"I participated in the program to be an individual with higher sensitivity to their environment and to increase my personal awareness. I would

help people." (V7)

like to feel spiritual satisfaction and help humanity. It is important to offer some relief to those people." (V5)

"I participated in the program to achieve personal development. Besides, I would like to get to know patients of autism." (V8)

"I'm curious about how people with autism perceive and see us and their environment. I would like to learn how to approach children with autism." (V9)

Quantitative Data

In addition to the qualitative data, we gathered some quantitative data to enrich the findings to make better predictions about the effects of the study on participants. Specifically, we asked the participants to complete the Knowledge About ASD Test (KASDT) to compare pre- and post study scores with regarding to the participants' knowledge about ASD. We used the Wilcoxon signed-rank test for comparisons, because the multi-variable distribution of the data violated the normal distribution assumption of t test. The descriptive statistics are presented in Table 3. As illustrated, the posttest means and medians were higher and the standard deviations were lower than the pretests for both instruments.

Table 3. Descriptive Statistics of KASTDT

	N	Mean	Std. Deviation	Median	Minimum	Maximum
KASDT Pretest	9	52.7778	13.01708	48	36.00	75.00
KASDT Posttest	9	95.3333	5.65685	100	88.00	100.00

According to Wilcoxon signed-ranks test results KASDT (z=2.675, p<.05), the posttest scores are significantly higher than the pretest scores (see Table 4). There is no negative rank for comparison. This means that the posttest scores were higher than the pretest scores for all participants. Thus, we can conclude that the activities performed in this study positively and significantly affected participants' knowledge about ASD. As a result, we accomplished our goal of helping the participants gain skills and qualifications about people with disabilities and ASD within the scope of the study.

 Table 4. Wilcoxon Signed-Ranks Test Results for KASTDT

		N	Mean Rank	Sum of Ranks	Z	p
KASDT Posttest -	Negative Ranks	0^{d}	.00	.00	-2.675 ^b	.007
KASDT Pretest	Positive Ranks	9e	5.00	45.00		
	Ties	0^{f}				
	Total	9				

Discussion and Conclusion

The present study reported on an Autism Volunteer Program (AVP),

"Be My Hospital Friend," aimed to encourage university students to engage in volunteer services to provide assistance to people with ASD and their families in health-related issues and to carry public ASD awareness efforts. The meaning of volunteering from the perspectives of the participants and their experiences with the program were analyzed and described. In addition, participants' attitudes towards individuals with special needs and levels of knowledge about ASD were analyzed quantitatively.

The qualitative findings of the study pointed that the AVP was beneficial for the volunteer students. Students indicated that they gained knowledge and skills about ASD thanks to the training they received, the observation processes they joined, and the services they delivered. They also reported that their awareness regarding people with ASD and their families increased and that the program brought some additional personal benefits to them (spiritual satisfaction, increased self-esteem, etc.). The quantitative data also revealed that volunteer students' levels of knowledge about ASD increased. The relevant literature indicates that a variety of activities about ASD (training, etc.) organized for current and future healthcare providers raise those individuals' levels of skills, and knowledge about ASD and promote their personal development (feeling more competent in relation to ASD, etc.) (Chiri and Warfield-Erickson, 2012; Havercamp et al., 2016; Hyman and Johnson, 2012; Shah, 2001). It is very important for healthcare providers to gain knowledge, skills and competence about ASD in order to leverage them to give health services individuals with ASD and their families properly when they come to hospital. Increasing vocational competences of healthcare staff results in developing better attitudes and behaviors towards individuals with ASD and their families, and this ascend their life quality (Bruder et al., 2012; Havercamp et al., 2016; Hyman and Johnson, 2012). Therefore, it can be said that this kind of studies to improve healthcare staff are essential. They can increase their knowledge and skills and serve better by participating these studies.

Participants also offered specific suggestions regarding the AVP, including accepting new participants into the program and continuing it with growing number of volunteers; and making similar programs available elsewhere so that more individuals with ASD and their families could benefit from these services. All these comments imply that volunteer students understood the importance of these programs and the support of healthcare

providers for people with ASD and their families and that they began to reflect on what they could do in relation to ASD. This finding is consistent with the relevant literature, which emphasizes that when current and future healthcare providers are given the opportunity to take part in ASD-oriented programs, their motivation to develop positive attitudes towards people with ASD and their families and to deliver appropriate services increases (Havercamp et al., 2016).

As part of the study, we also explored participants' meaning of volunteering. Thus, the volunteers described the concept of volunteering by existential and affective statements within the context of the value it brought to their own and others' lives. In this regard, therefore, volunteering, which includes serving people without expecting anything in return, is a concept that finds its meaning in existential and spiritual contexts (Caissie and Halpenny, 2003; Von Essen, 2016). Findings of this study indicated that there were some social, personal, professional, spiritual and existential motives behind volunteers' participation in the AVP. Participants described their motivation within the context the AVP program via those factors. In other words, students' participation was motivated by both intrinsic rewards (e.g., spiritual satisfaction, happiness) and extrinsic rewards (gaining knowledge related ASD). Besides, the desire to help oneself and others was also a source of motivation for the volunteers. Again, this is consistent with current literature, suggesting that volunteer work is motivated not only by intrinsic and extrinsic rewards, but also by the desire to help (oneself and/or others) (Caissie and Halpenny, 2003; Von Essen, 2016). When we consider this findings and related literature (e.g. Caissie and Halpenny, 2003), this study is an opportunity and is a first step for participants to gain insight and values for their on site work and real performance in future by understanding what is volunteering and how it is important not only for a person for personal development but also a developed society and civilization. Regarding the facilitating and satisfying effects (Carbone et al., 2013; Chiri and Warfield-Erickson, 2012; Hall, 2012) of outputs of volunteer services and volunteering on persons with ASD and their families, we can say that this study is very important and beneficial for this target audience.

The current study helped students of the Faculty of Medicine and Faculty of Health Sciences as future healthcare providers raise their knowledge about ASD and provide assistance to people with ASD and their families in health-related issues. As part of the program, a team of volunteers, which

consisted of individuals knowledgeable about ASD, was formed at the university where the research was conducted. Therefore, this study may be considered to be the initial research, which has contributed not only to the participating students' lives, but also to the lives of individuals with ASD and their families. Furthermore, the results of the study are expected to contribute to the relevant literature, which currently is very sparse on volunteering processes or promoting healthcare providers' competence concerning ASD and assisting people with ASD and their families in healthcare processes. Our findings are also expected to make contributions to the literature from a Turkish setting and, hence, to bring a cultural perspective to the literature.

Nevertheless, the study has some limitations. In particular, participants consisted of only nine volunteers studying at the Faculty of Medicine and Faculty of Health Sciences at one university. Although the project was widely publicized via different platforms, only nine people participated in the program. Therefore, we have information about only these students. The data were collected through other data collection methods (interview, etc.). It is important that future research be carried through different data collection methods. In order to serve AVP properly and well-qualified, we took the views of not only service givers but also families as benefiters. The families declared that they were satisfied by AVP and there was an enormous need for such services. These views were also highlighted by the literature (Chiri and Warfield-Erickson, 2012; Hall, 2012). But the purpose of this study was not directly investigating the families and their views. Therefore, we did not analyze families data in detail, this may realize in further studies. Collecting data of that kind would be beneficial in that it would make it possible to evaluate the services provided by volunteers and to improve the quality of those services

In conclusion, on the strength of the findings, we offer the following recommendations for improving current practice: (a) Provide training opportunities aimed at raising current and future healthcare providers' levels of awareness, skills, and knowledge about ASD; (b) train current and future healthcare providers about how to assist individuals with ASD and their families in health-related issues; (c) encourage the government to take measures to reduce the barriers and challenges individuals with ASD and their families' experience in health-related issues; and (d) increase volunteer services aimed at helping individuals with ASD and their families in num-

ber, accessibility and diversity.

Recommendations for future studies may be summarized as follows: (a) Comprehensive qualitative and quantitative research should be conducted on a larger sample by using different data collection methods; (b) the study can be repeated with participants from different cultures so as to arrive at some intercultural comparisons; (c) efficiency and effectiveness of the training and education that current and future healthcare providers receive may be analyzed; and (e) factors that have an influence on participation in volunteer work (gender, personality, etc.) may be examined.

Author's Note

We would like to thank volunteer students for their participation in the study and individuals with ASD and families. Also, we would like to present our gratitudes to specialists for trustworthiness study.

This work was supported by the Research Fund of İstanbul Medeniyet University. Project Number: S-GAP-2017-971.

This article was presented as a poster with preliminary data at the 28. National Special Education Congress held in Eskişehir Osmangazi University and the poster was published in the conference proceedings. This article includes a rich and in-depth review of this poster (Güleç-Aslan, Y., Subaşı Yurtçu, A. B., Akgün, Ö. E., Güleç, İ., Dilbaz, E., Narman, T., Bartan, M., Aslan, E., Malkoç, B., Koyuncu, S., Handemir, T., Erkaplan, B. ve Aksu, S. (2018). Hastane arkadaşım olur musun?: Üniversite öğrencilerinin otizm spektrum bozukluğuna yönelik bir gönüllülük çalışması deneyimleri. M. A. Melekoğlu, (Ed.), 28. Ulusal Özel Eğitim Kongresi Tam Metin Bildiri Kitabı (s. 8-17) içinde. Eskişehir. ISBN: 978-605-80966-0-8).

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Brachlow, A. E., Ness, K. K., McPheeters, M. L. and Gurney, J. G. (2007). Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs. *National Survey of Children's Health. Archives of Pediatrics & Adolescent Medicine*, 161, 399-405.
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M. and Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, 71(2), 195-207.
- Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J. and Stein, N. (2012). Brief report: The medicalcare of adults with autism spectrum disorders: Identifying

- the needs. Journal of Autism and Developmental Disorders, 42, 2498-2504.
- Caissie, L. and Halpenny, E. (2003). *Volunteering for nature: Motivations* for participating in a biodiversity conservation volunteer program. *World Leisure*, 45(2), 38-50.
- Carbone, P. S., Behl, D. D., Azor, V. and Murphy, N. A. (2010). The medical home for children with autism spectrum disorder: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders*, 40, 317-324.
- Carbone, P. S., Murphy, N. A., Norlin, C., Azor, V., Sheng, X. and Young, P. C. (2013). Parent and pediatrician perspectives regarding the primary care of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 964-972.
- Cheak-Zamora, N. C. and Farmer, J. (2015). The impact of the medical home on access to care for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 45(3), 636-644.
- Chiri, G. and Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Journal of Maternal and Child Health*, 16(5), 1081-1091.
- Collier, V., Rothwell, E., Vanzo, R. and Carbone, P. (2015). Initial investigation of comfort levels, motivations, and attitudes of volunteers during therapeutic recreation programs. *Therapeutic Recreation Journal*. *3*, 207-219.
- Creswell, J. W. (2014). *Educational research: planning, conducting, and evaluating quantitative and qualitative research.* Upper Saddler River, N.J.: Pearson.
- Creswell, J. W. and Plano-Clark, V. L. (2011). *Designing and conducting mixed-methods research*. Thousand Oaks, CA: Sage.
- Daley, T. and Sigman, M. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32, 13-23.
- Desai, M. U., Divan, G., Wertz, F. J. and Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, 49(3-4), 613-637.
- Gardiner, E. and Iarocci, G. (2014). Students with autism spectrum disorder in the university context: Peer acceptance predicts intention to volunteer. *Journal of Autism and Developmental Disorders*, 44(5), 1008-1017.
- Golnik, A., Ireland, M. and Borowsky, I. W. (2009). Medical homes for children with autism: A physician survey. *Pediatrics*, *123*(3), 966-971.
- Hall, H. and Minnes, P. (1999). Attitudes toward persons with downsyndrome: The impact of television. *Journal of Developmental and Physical Disabilities*, 11(1), 61-76.
- Hall, H. R. (2012). Families of children with autism: Behaviors of children, community support and coping. *Issues in Comprehensive Pediatric Nursing*, 35(2), 111-132.
- Havercamp, S. M., Ratliff-Schaub, K., Navas Macho, P., Johnson, C. N., Bush, K. L. and Souders, H. T. (2016). Preparing tomorrow's doctors to care for patients with autism spectrum disorder. *Intellectual and Developmental Disabilities*, 5(3), 202-216.
- Hyman, S. L. and Johnson, J. K. (2012). Autism and pediatric practice: Toward a medical home. *Journal of Autism and Developmental Disorders*, 42,

- 1156-1164.
- Kamp-Becker, I., Schröder, J., Remschmidt, H. and Bachman, C. J. (2010). Health-related quality of life in adolescents and young adults with high fuctioning autism-spectrum disorder. *Psycho-Social Medicine*, 31(7), 1-10.
- Lancee, B. and Radl, J. (2014). Volunteering over the life course. *Social Forces*, 93(2), 833-862.
- Lovaas, O. I. (2003). Teaching individuals with developmental delays: Basic intervention techniques. Austin, TX: Pro-Ed.
- Mahoney, D. (2008). *College students' attitudes toward individuals with autism*. Unpublished doctoral dissertation, University of North Carolina at Chapel Hill, NC.
- Mazurik-Charles, R. and Stefanou, C. (2010). Using paraprofessionals to teach social skills to children with autism spectrum disorders in the general education classroom. *Journal of Instructional Psychology*, *37*(2), 161-169.
- McCabe, H. (2008). Autism and family in the People's Republic of China: Learning from parents perspectives. *Research and Practice for Persons With Severe Disabilities*, 33(1-2), 37-47.
- Mandell, D. S. and Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110-115.
- Mavropoulou, S. and Padeliadou, S. (2000). Greek teachers' perceptions of autism and implications for educational practice: A preliminary analysis. *Autism*, 4(2), 173-183.
- Nieto, C., Murillo, E., Belinchón, M., Giménez, A., Saldaña, D., Martínez, M.-Á. and Frontera, M. (2015). Supporting people with autism spectrum disorders in leisure time: Impact of an university volunteer program, and related factors. *Anales de Psicología*, 31(1), 145-154.
- Nolan, R., Walker, T., Hanson J. L. and Friedman, S. (2016). Developmental behavioral pediatrician support of the medical home for children with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics*, 37(9), 87-693.
- Nougaret, A. A., Scruggs, T. E. and Mastropieri, M. A. (2005). Does teacher education produce better special education teachers? *Exceptional Children*, 71(3), 217-229.
- Robinson, S. E. (2011). Teaching paraprofessionals of students with autism to implement pivotal response treatment in inclusive school settings using a brief video feedback training package. *Focus on Autism and Other Developmental Disabilities*, 26(2), 105-118.
- Samuel, O., Wolf, P. and Schilling, A. (2013). Corporate volunteeering: Benefits and challenges for nonprofits. *Nonprofit Management and Leadership*, 24(2) 163-179.
- Shah, K. (2001). What do medical students know about autism? *Autism*, 5(2), 127-133.
- Smith, J. A. and Osborn, M. (2004). Interpretative phenomenological analysis. In J. A. Smith, (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). London, UK: Sage.
- Swiezy, N., Fairbanks, J., Stuart, M., Ashby, I., Ables, E. M. and Stone, W. (2005).

- Autism knowledge survey. Indianapolis, IN: Christian Sarkine Autism Treatment Center, HANDS in Autism.
- Volunteer Opportunities in Boston. (n.d.). Retrieved from http://www.childrenshospital.org/ways-to-help/volunteer-services/volunteer-in-boston#
- Von-Essen, J. (2016). On the meaning of volunteering: A study of world views in everyday life. *Foundations of Science*, 21(2), 315-333.
- Yin, K. R. (2003). Case study research. London, UK: Sage Publications.
- Yuker, H. E., Block, J. R. and Young, J. H. (1970). *The measurement of attitudes towards disabled persons*. New York, NY: Institute at Human Resources Center.