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## Providing Resources to Caregivers of Pediatric Mentally Ill Clients and Assessing for Caregiver Burden

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PROVIDING RESOURCES TO CAREGIVERS OF PEDIATRIC MENTALLY  
ILL CLIENTS AND ASSESSING FOR CAREGIVER BURDEN

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Stacy Dee

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### Abstract

**Background.** Provision of educational and supportive resources to the caregivers of children with mental illness can help create an environment of advocacy and understanding between the child, caregiver, and provider. In depth and comprehensive learning about their child's mental illness cannot be accomplished in a one-hour new patient appointment or established patient appointment of 20 minutes. **Purpose.** The purpose of this practice improvement project was to facilitate educational and community support for caregivers of pediatric clients with mental illness and evaluate if caregivers require additional support due to burden. **Objectives.** (a) 100% of caregivers of pediatric clients who have appointments during the 10-week implementation period were contacted via telephone and offered the caregiver resource flyer and burden assessment by email, (b) 75% of the caregivers contacted during the 10-week implementation period were provided with the caregiver resource flyer and burden assessment via email, (c) 30% of the caregivers who were sent the resource flyer returned the burden assessment and demographic data sheet, and (d) 100% of caregivers identified as having severe burden were referred to social services. By meeting these objectives, it was expected that caregivers would have the opportunity to access resources available to further educate themselves and access local community groups for support to help lessen their burden. **Results.** Telephone callbacks to receive the resource flyer were imperfect with approximately 30% of the caregivers receiving the flyer via email. Further results will be presented during the SCMF Lecture. **Implications.** Other means of receipt for the resource flyer and burden assessment are needed to capture 100% of caregivers of pediatric clients at this private practice.

*Keywords:* caregiver burden, mental health, stigma, mental illness, caregiver resources, caregiver burden assessment

### **Providing Resources to Caregivers of Pediatric Mentally Ill Clients and Assessing for Caregiver Burden**

One in six children between the ages 6 and 17 years will have a treatable mental illness according to recent statistics (Devitt, 2019). The number of children in the United States with a mental illness is approximately 7.7 million or 16.5% of the population. A mental health professional will see half of this population, and the other half will be seen solely by their family provider (Devitt, 2019). Provisions of educational and supportive resources to the caregivers of children with mental illness can help create an environment of advocacy and understanding between the child, caregiver, and provider (Schiffman et al., 2015). Supporting these caregivers is essential in the management of children with mental illness. Caregivers who understand the disorder and have the ability to cope with the relationship strain the symptoms of the mental illness can invariably produce while continuously supporting the child is invaluable (Schiffman et al., 2015).

#### **Statement of the Problem**

Stigma is a genuine threat to those with mental illness and those caring for a child with a mental illness. The stigma of mental illness creates barriers for those suffering from these treatable illnesses (Muralidharan et al., 2016). Myths, inaccurate portrayal in the entertainment industry, and the dark history of “insane asylums” still linger in today's society as to what it is to have a mental illness. Parents of children with a mental illness are their advocates and closest allies. It is important that guardians are accurately educated in their children's illness and have a supportive network to cope with possible caregiver burden.

The clinic site for this quality improvement project currently does not provide resources for parents to educate and to discuss triumphs, setbacks, and emotional experiences that are

unique to caring for a child with a mental illness in a supportive community. The clinic does not routinely screen caregivers for burden either. Rectifying this missed opportunity to provide reliable educational resources and community support is a small step that will benefit the child and the provider. As their most prominent advocate, parents will be well versed in their child's illness and have support from a community with similar experiences.

### **Assessment**

The project site was a privately owned, nurse practitioner-led, mental health clinic in South Central Texas. The clinic services clients with insurance or the ability to pay out of pocket for visits. Socioeconomically, because of this requirement, the clients tend to be middle to upper middle class. The clinic has the capabilities for outpatient medication management only; there is no inpatient or crisis management available through this clinic. The nurse practitioner manages clients with varying mental illnesses and severity. The clients' ages range between 7 and 89 years old. The clinic is expecting another psychiatric mental health nurse practitioner within the year but currently staffs two counselors along with two front office personnel.

The clinic schedule is full daily. Medication management appointments are scheduled for 20 minutes, and new patients are scheduled for an hour. The time during appointments is spent interviewing the client and in the case of a child—the child and parent. The interview is lengthy, consisting of questions regarding signs, symptoms, behaviors, and trends regarding the child, current medication regimen, and the client's mental illness.

Previously, the pediatric client and guardian would check in at the front office, wait in the waiting room, be seen in the provider's private office during the scheduled visit, and would schedule a follow-up when leaving or call for a follow-up at another time. However, during the spring of 2020, "Stay at Home Orders" due to COVID-19 were issued in the state of Texas. The

clinic, to maintain continuity of care, began scheduling appointments telephonically.

Appointment times were verified the day before by the front office staff, and the provider called the clients from her office. While guidelines for opening up businesses have been put in place, this continues to be the current patient flow for the clinic at this time of writing.

The stakeholders at this outpatient clinic were the provider and the client and the client's parent or guardian in the case of a pediatric patient. The provider agreed that education was paramount for the clients and the caregivers. She graciously gave access to her electronic medical record and telephone systems to contact clients. A copy of a letter of support is noted in Appendix A. During the 10-week implementation of this project, the project coordinator contacted the caregivers of pediatric clients and offered the educational resource flyer (Appendix B) that also contained an assessment tool for caregiver burden (Appendix C). Sustainability for this project included transitioning to furnishing the caregiver educational flyer at the first visit. The provider had access to the flyer and contributed to its development. Sustainability appeared likely in some form, whether it was electronic delivery or paper delivery, as the provider was a contributor to the resources identified on the flyer.

### **Project Identification**

Educational and emotional support for the parents or guardians was superficial during these visits, often highlighting current signs and symptoms the child was experiencing and what to expect regarding medication. In-depth and comprehensive learning about their child's mental illness cannot be accomplished in the one-hour new patient appointment or an established patient appointment of 20 minutes.

Initially, this was not the trajectory of the project. The project coordinator had wanted to focus on caregiver burden. While caregiver burden is still significant, the focus changed when

the original project site barred students during the Stay at Home Orders issuance for the state due to COVID-19. The original project site catered to a very different population—adult clients who were underinsured or had no insurance. The original project site was also a larger entity that included a crisis center, case managers, and therapists. Identifying burden in the caregiver of an adult with severe mental illness on the day of a client’s appointment could be met with providing time with the case manager to discuss areas of support wanted by the caregiver.

Caregiver burden was not explicitly addressed at the current project site; however, the caregiver burden assessment tool originally to be used at the previous project site was sent out with the resource flyers to gauge burden in the pediatric caregivers at this clinic. The caregiver burden assessment was optional, and parents were given the same caregiver resource flyer regardless of completing the caregiver burden survey. Evaluation of caregiver burden changed the current practice policy of not evaluating for burden. The new manner of interviewing, socioeconomic status of the patient population, resources at the clinic, and practice population had a bearing on the shift of focus from caregiver burden assessment with referrals to educational and community resources for guardians to evaluating if the sample population had any burden.

### **Purpose and Objectives**

The purpose of this practice improvement project was to evaluate the burden experienced by caregivers of pediatric clients with mental illness and to facilitate educational and community support for these caregivers, thereby strengthening the children’s primary support system. The objectives of the project were: (a) 100% of caregivers of pediatric clients who had appointments during the 10-week implementation period were contacted via telephone and offered the caregiver resource flyer and caregiver burden survey by email, (b) 75% of the caregivers

contacted during the 10-week implementation period were provided with the caregiver resource flyer and caregiver burden survey via email, (c) 30% of the caregivers who were sent the resource flyer returned the caregiver burden survey and demographic datasheet, and (d) 100% of the caregivers identified as having severe burden were referred to social services.

### **Anticipated Outcomes**

By meeting these objectives, it was expected that caregivers would have the opportunity to access resources available to further educate themselves on the specific mental illness/es of the child and have access to local community groups for support at a place and time convenient to them. The evaluation of the caregiver burden assessments revealed no burden being experienced by these caregivers. However, should a significant amount of high burden be revealed, exploration of this topic during appointments with an assessment should be routinely done. Then if high burden is determined, appropriate referrals and encouragement of participation in local support groups should be initiated.

### **Summary and Strength of Evidence**

#### **Stigma Surrounding Mental Illness**

Mental health stigma is still a current topic; it has been studied extensively in children and adults. In this past decade, the push in research has changed from “Is there mental health stigma?” to “What is the best way to alleviate stigma?” The first nationally representative study regarding mental health stigma in children was performed in 2007, less than 15 years ago. The National Stigma Study-Children (NSS-C) surveyed adults using scenarios of children with attention-deficit/hyperactivity (ADHD) disorder and depression (Pescosolido et al., 2008). The researchers found that fewer adults could identify depression or ADHD from daily troubles. While depression was identified more often than ADHD, female children suffering from ADHD

were significantly less likely to be identified. The surveys revealed that only a third of respondents expressed ADHD to be serious, while the majority expressed depression to be serious. These data parallel that 32.9% of respondents believed that ADHD would improve on its own, and 17.4% of respondents believed depression would improve on its own.

The NSS-C findings supported the need to educate the public and caregivers regarding the perception of mental illness. It also suggested that depending on the mental illness diagnosis, there may be challenges regarding parents' participation in treatment (Pescosolido et al., 2008). The analysis from the study suggested that public health messages and parent-targeted psychoeducational materials should be aimed at the knowledge, beliefs, and attributes of those involved to prevent interferences for seeking help or adhering to the treatment regimen (Pescosolido et al., 2008).

Pescosolido et al. (2007) again used the NSS-C findings, but this time explored stigma associated with treatment and attitudes toward psychiatric medications for children. Nearly half of the sample believed "mental health treatment would make a child an outsider at school and suffer as an adult" (Pescosolido et al., 2007, p. 614). More than half also believed "the community knew, despite confidentiality protection, which children had been or were currently in treatment" (Pescosolido et al., 2007, p. 614). Furthermore, a third of the sample believed "getting mental health treatment for a child would make the parent feel like a failure" (Pescosolido et al., 2007, p. 614).

It appears apparent, but Pescosolido et al. (2007) were able to support those who perceived more mental health stigma were less likely to adhere to psychiatric medications for children. The majority of the sample agreed "that physicians overmedicate children with common behavior problems" and that "giving medication to children with behavior problems has

long-term negative, developmental effects” (Pescosolido et al., 2007, p. 615). They also believed that giving medication delays “dealing with their real problems” and medications blunt children’s personalities preventing families from “working out problems for themselves” (Pescosolido et al., 2007, p. 615). The researchers advocated for education, specifically regarding medication, and building relationships with the parents to alleviate the stigmas associated with child and adolescent mental illness, as noted above (Pescosolido et al., 2007).

Stigmas regarding medication and family dynamics also asserted the stereotype that mentally ill children are violent. The stigma of violence to others instills fear and fuels the perception that the mentally ill are a danger to society (Perry et al., 2007). A critical analysis of sample characteristics that perceived less mental health stigma included women, those with more education, full-time workers, and those who associated with a liberal religion; those who resided in the South found mental health treatment more stigmatizing (Pescosolido et al., 2007).

Education appeared to be a factor in destigmatizing mental illness and its treatment. Education at the individual or family unit level through family peer education programs showed the most significant improvement of reported burden and distress of family members and improved attitudes toward the families’ role as a caregiver (Kageyama et al., 2017; Schiffman et al., 2015). Education performed through technology-based platforms (Chu et al., 2018), parent training programs set in outpatient settings (Baumel, 2018), or distance delivered parent training through telephone or internet (Olthuis et al., 2018) all have shown improvement of parental distress, mental health literacy, and treatment adherence.

### **Caregiver Burden**

Caregiver burden is a seemingly old yet new concept of study. The care of the elderly in the home was commonplace 200 years ago, and it was unheard of to have a family’s elderly

cared for by anyone else but the elder's family. As communities grew, becoming more urban, institutions became available for the disabled, mentally ill, and elderly. Deinstitutionalization happened in the mid-20th century in most western countries, and the first study of caregiver burden was published. Grad and Sainsbury (1966) studied caregiver burden in two English villages with a sample of caregivers of mentally ill individuals with one village receiving community-based services and the other village receiving hospital-based services. Services in both villages proved to be statistically significant in decreasing severe caregiver burden.

Caregiver burden was extensively studied in the United States in various groups in the last 30 to 40 years.

Caregiver studies of individuals with dementia have shown increased burden, specifically, psychological distress for the caregiver (Razani et al., 2014). Individuals with dementia who have severe psychiatric and behavioral problems were also significantly associated with higher levels of burden for the caregiver (Mohamed et al., 2010). Elderly care with neurocognitive disease is a large population with caregivers; another population is that of younger individuals with spinal cord injuries.

Lazarus and Folkman (1984), researchers of stress and coping, found coping was the reaction to any stress. Reactions can be positive or negative; however, positive coping leads to healthy well-being (Lazarus & Folkman, 1984). When looking at the caregiver burden model (see Figure 1), one is essentially balancing the stress of providing for another individual with the caregivers' social resources (finances, social support) and psychological resources (coping). Caregivers with low burden had more positive coping skills and physical resources, while caregivers with high burden had negative coping skills and lower social resources (Vitaliano et al., 1991).

**Figure 1***Caregiver Burden Model*

$$\text{Distress (Burden)} = \frac{\text{Exposure to Stressors} + \text{Vulnerability}}{\text{Psychological Resources} + \text{Social Resources}}$$

Caregivers' resource availability can affect burden. Quasi-experimental and descriptive correlational studies have shown that burden was less when caregivers had resources available to them (Aylaz & Yildiz, 2018; Cw Lam et al., 2013). The type of illness an individual had also affected the amount of burden on the caregiver. Researchers have identified caregivers of individuals with dementia and adults with severe mental illness required more support and had considerably more burdens than caregivers of children or adults with physical disabilities (Oliveira et al., 2015; Stanley et al., 2017).

**Caregiver Burden Scale**

The caregiver burden scale used for this project was the Zarit Burden Interview (ZBI) short form. The ZBI was an instrument used to determine the amount of burden an informal caregiver suffered from, and the assessment tool was a 22-item Likert scale and originally designed for caregivers of dementia patients (Zarit et al., 1985). The ZBI, since its inception, has been used across many caring populations to include pediatrics with disabilities, those with spinal cord injuries, and adults with severe mental illness; the ZBI has been translated into many languages (Bachner & O'Rourke, 2007; Gelkopf, 2014). The project coordinator chose this caregiving burden scale among 40 different options because of its available short form and screen form. The short and screen forms were later developed with 12 and 4 questions, respectively (Bedard et al., 2001). The appeal of the short form was the ability to assess for burden quickly and accurately in the clinical setting. The intent was to use the short 12-question

tool with the option to switch to the 4-question screen should caregivers refuse to participate due to the number of questions.

An additional benefit to using the ZBI was that the internal consistency was fairly constant across all three tool length versions. The 22-item assessment, most often used by researchers, had an internal consistency of between 0.83–0.89 with correlations to the short form between 0.92–0.97 and the screen version between 0.83–0.93 (Bedard et al., 2001; Gelkopf, 2014). The consistency of reliability and validity among all three ZBI forms was ideal should the project coordinator need to switch forms during the implementation period.

### **Project Intervention**

The project coordinator was given access to the provider's electronic health record. During the 10 weeks of intervention, the coordinator explored the previous week's appointments and identified the clients who were aged 17 years old and younger. Identifying pediatric clients ensured a caregiver. The current flow of patient appointments by telephonic appointments made identifying adult clients with caregivers difficult, thus adult clients with caregivers were excluded from the project. However, at the completion of the project, the provider supplied the resource flyer to whomever she determined had a need. The recipient could be a parent caregiver, an adult caregiver, or even a client.

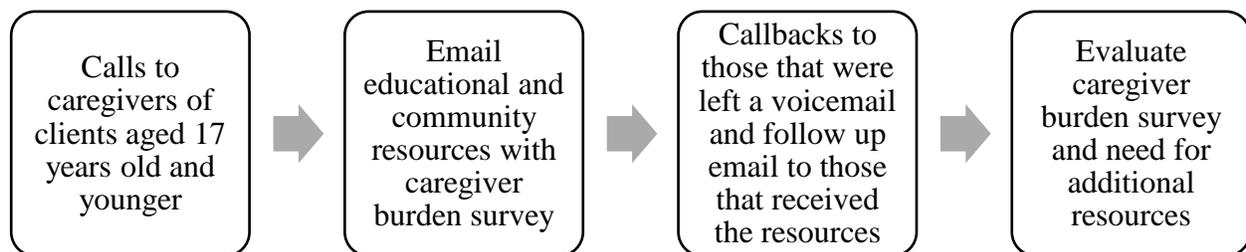
Once the clients under 17 were identified from the previous week, the project coordinator reached out telephonically. The coordinator, again, working very closely with the provider, developed a script regarding how to approach a parent regarding educational resources. A script was also used for telephone calls that ended with a voicemail (Appendix D). These scripts ensured the provider was aware of how the discussion evolved to the acquisition of personal email addresses of the caregivers for the provision of education materials and the surveys. The

provider also wanted the conversation to be clear that a student nurse practitioner working on her Doctor of Nursing Practice project was initiating the resources and that receiving or declining the flyer would have no bearing on the treatment regimen of the child.

The resource flyer was emailed to the parent or guardian on the day of the conversation. If the telephonic call resulted in voicemail, a message was left with a detailed reason for the call and a contact number should the individual desire the resource flyer and participation in the caregiver burden screening. Those calls that ended in voicemail were called again the following week. If the caller received a voicemail a second time, a message was not left and no further attempts to contact that caregiver were attempted. The week following the caregiver's receiving of the resource page, another email was sent with a reminder to fill out the caregiver burden surveys with additional webpages of legitimate mental health resources. The resource page was included again in the second email as well (see Figure 2).

## Figure 2

### *Flowchart of Project Intervention*



While the project coordinator did not have access to the families' socioeconomic status, by health insurance coverage or ability to pay out of pocket, one could assume the financial stability of these families. Demographics of the population were also limited, as race/ethnicity

was not generally identified in the provider's notes. The sample included male and female clients 17 years of age and younger with telephonic appointments with the provider during the 10-week implementation period.

Organizational barriers to project implementation included the recent appointment process changes due to COVID-19 restrictions. Appointments changed from in-person sessions to telephonic sessions. The provider also did not want to actively furnish the resource page during her telephonic appointments, preferring that the coordinator contact the parents at another time to promote the educational materials and surveys. Organizational facilitators included the provider's quick response to providing access to the electronic medical record and phone system. She also worked very closely in the development of the resource flyer, development of the phone scripts, and the wording of the demographic survey.

### **Evaluation Plan**

The objectives of this project were analyzed using the simple statistical method of percent change and are presented below. In addition, demographic data for the caregiver participants were gathered (Appendix E).

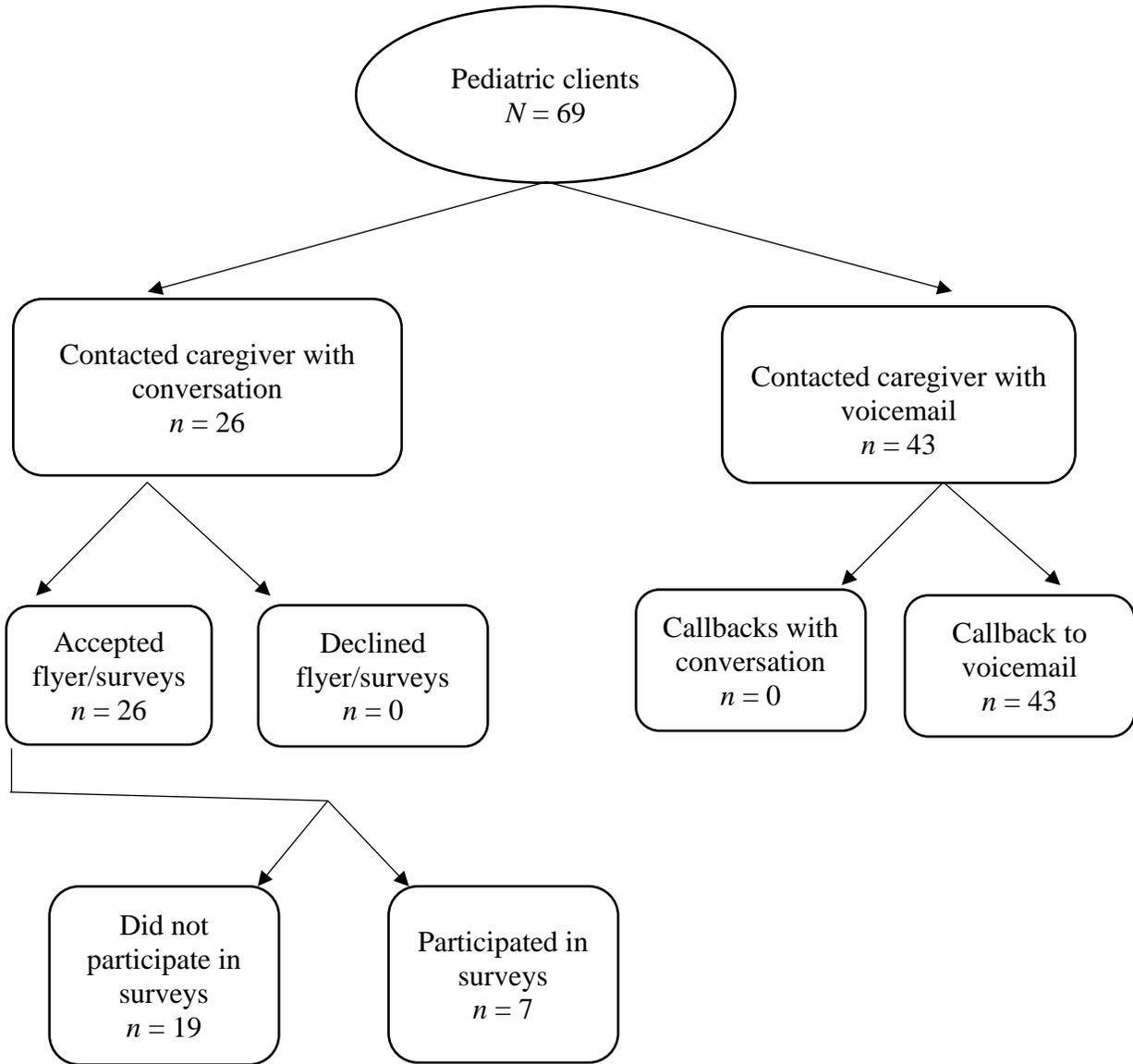
### **Project Results**

#### **Objective 1**

This objective can be broken down into two scenarios, as presented in Figure 3. One hundred percent of the guardians were contacted via telephone; however, only 26 caregivers contacted resulted in a conversation with the caregiver. Voicemails were left for the remaining 43 caregivers, and callbacks the next week did not result in conversations with the remaining caregivers. No callbacks resulted in conversations during the implementation period. The project coordinator successfully had conversations with 38% of the sample.

**Figure 3**

*Flowchart of Caregiver Communication*



**Objective 2**

The second objective was that 75% of the caregivers contacted would receive the resource flyer and the burden assessment. As stated in the previous paragraph, 26 phone calls resulted in a conversation with a caregiver. These caregivers were able to verbalize they did or did not want the resources delivered to them through email. All the caregivers who were engaged directly by the project coordinator opted to receive the resource flyer. This resulted in 100% of the sample receiving the resource flyer and burden assessment, therefore, meeting the second objective that 75% of the caregivers contacted would receive the resource flyer.

**Objective 3**

The third objective was to have a 30% rate of return for the burden assessment and demographic sheet from the caregivers sent resources via email. During conversations with the caregivers, they were informed that a caregiver burden assessment and demographic survey would be included in the email. Participation in the surveys was optional, as was receiving the resource flyer. The project coordinator received 27% participation in completing these surveys, almost meeting this objective.

**Objective 4**

Evaluation of the caregiver burden assessments revealed this private practice sample population did not suffer from caregiver burden (see Table 1).

**Discussion**

As the project coordinator implemented the practice improvement project, it was not difficult to correctly execute the planned intervention. Assessment of receipt of the resource flyer and surveys was determined by a lack of “failure to deliver” emails when the resource flyer was sent electronically. Active participation was not evaluated in the websites provided for

educational and community support groups; these resources were provided for the caregivers to use at their convenience. Participation in the surveys was also encouraged but not required to receive the resource flyer.

**Table 1**

*Caregiver Burden Scale Scores*

	Score
Caregiver 1	16.0
Caregiver 2	8.0
Caregiver 3	19.0
Caregiver 4	1.0
Caregiver 5	13.0
Caregiver 6	9.0
Caregiver 7	5.0
<i>Mean</i>	10.1

*Note.* Mild-to-moderate burden score  $\leq 20$ , severe burden score  $> 21$ .

The change of project site and appointment process because of COVID-19 restrictions significantly changed the original intent of this project, which was to assess caregiver need with subsequent provision of resources during an office visit. This altering of the focus of the project changed the direction of the project to educational and community support the caregivers could access while at home. However, the project coordinator was still able to explore the possible burden at this private practice clinic. The returned surveys indicated the sample did not have

collective burden. The demographic survey revealed the participants did have many protective factors for burden such as financial stability, family support, and gender as seen in Table 2.

**Table 2***Returned Survey Demographics*

Baseline Characteristics	<i>n</i>	%
Age of Caregiver (years)		
Youngest	33	
Oldest	52	
<i>Mean</i>	44	
Race of Caregiver		
Black	1	14
Hispanic/Latino	3	43
White	3	43
Gender		
Female	7	100
Male	0	
Relation to child		
Mother	7	100
Share caregiving role with		
Father	4	58
Stepfather	1	14
Other	1	29
Employed		
Yes	6	86
No	1	14
Employment		
Full-time	4	57
Part-time	2	29
Stay at home parent	1	14
Employment during COVID-19		
Unchanged	2	29
Work from home	3	43
Not working	1	14
Stay at home parent	1	14

### **Limitations**

The most significant limiting factor for this project was the multiple changes that were made from the project's inception to how the project was ultimately completed. As mentioned previously, this project had initially been designed to evaluate the burden of caregivers for adults with severe mental illness at a facility with a population sample that was not insured or underinsured. This facility was a larger entity in South Central Texas and required multiple approvals within the system through a presentation of the project to a review committee. The presentation to the board took place in early March 2020, resulting in approval of the initial project.

Unfortunately, COVID-19 precautions were put in place the following week. Thus, students were barred from the sites, and appointments with providers became telephonic. This made carrying out the original project impossible, requiring a re-envisioning of the project and change in project site as the project was built off the clinic process for the larger organization before COVID-19. The initial project interventions were to (a) identify caregivers of adults with severe mental illness at the front desk during check-in, (b) administer the Caregiver Burden Scale to the caregiver while the client waited to be seen, (c) evaluate of the tool by the provider during the appointment, and (d) refer the caregiver to the case manager if the score indicated severe burden on the same day. The telephonic appointment schedule changed how and when clients would see the provider and case manager during the appointment. The difficulty of implementing a caregiver assessment and follow up with a case manager in an appointment process that was changing on a weekly basis proved unfeasible.

The search for a new project site began, and a smaller nurse practitioner-led private practice became the new site for the project. The nurse practitioner had already transitioned to

telephonic appointments. She was the only provider along with two therapists. However, she did not have a case manager or social worker on staff. The change of the project site and the lack of a case manager required the project to be altered. Discussions with the provider suggested she did not feel caregiver burden was an issue at her practice; however, she agreed a project to evaluate for burden would be useful. The electronic medical record did not indicate which clients had caregivers, but a population change to pediatrics ensured a caregiver. Thus, a new project was developed that focused on evaluating caregivers of pediatric clients with mental illness for burden and providing education and community support resources for these caregivers.

Limitation for the new project included the project mentor/provider was not willing to assess burden or provide resources during a telephonic visit. Also, the project coordinator, instead of a clinic staff member, contacted guardians to communicate and distribute the resource flyer. Additionally, the majority of phone calls ended with a voicemail. Therefore, the coordinator did not have an opportunity to develop a rapport with the caregivers, so reaching out via telephone did not illicit a callback or later communication between the caregiver and coordinator.

### **Recommendations**

Recommendations to continue this project and capture more caregivers would include a different mode of contact for the caregivers. Contacting caregivers by phone allowed the possible conversations to be directed to voicemail. While the project coordinator did leave detailed voicemails regarding the purpose of the call, there was no response from those caregivers during the 10-week implementation period. Understandably, during the COVID-19 Stay at Home orders, all contact with the project site and the caregivers/clients was via telephone. Capturing pediatric caregivers during scheduled or initial intake appointments may prove to be a better

avenue of approach. While there is no time during the appointment to provide in-depth education or supportive resources, the provider can inquire about an email to send the material to or provide the material as part of the initial intake process of first-time clients, thereby promotion of the materials does not deter from precious appointment time. The project site has also updated the clinic website to include web-linked resources. During phone appointments or face-to-face appointments, the provider can also refer caregivers to the resource page on the website.

It is also unclear how receptive caregivers who received a voicemail from a Doctor of Nursing Practice student they had never met regarding educational materials and community support resources affected the response to participate. If that was an issue, the above recommendations would also be helpful. The provider was the person they interacted with regularly. Receiving information from a person they had a rapport with may provide the confidence to put aside the vulnerabilities regarding their lack of knowledge about the mental illness and possible struggles as a caregiver.

### **Implications for Practice**

Education and community resources available for caregivers is an area often overlooked in the mental health arena. While mental health stigma campaigns in the last 20 years have helped alleviate some barriers to seeking treatment for individuals, it is essential to note that pediatric clients are not able to seek out treatment without the involvement of a caregiver. Education on mental illness and supportive community resources that provide peer encouragement are important for the pediatric client's most essential ally. The current project site was a mental health clinic; however, half of the children with treatable mental illnesses were seen by their primary care providers. Primary care providers typically do not have community connections to mental health resources that are readily accessible to mental health providers.

Reaching out to pediatric primary care or family practice clinics to begin the implementation of a resource flyer at their practice could greatly benefit those pediatric caregivers as well. Educating the primary care providers regarding burden and various burden assessments can also prove helpful. Caregiver burden is not contained to pediatrics with severe mental illnesses, but many different populations. Providing a primary care clinic with education regarding caregiver burden and assessment tools to evaluate for burden could help provide relief to caregivers of a variety of clients.

As a doctoral-prepared psychiatric mental health nurse practitioner, it is well within the role to seek out, collaborate with, and educate other providers on the importance of providing education and supportive measures to pediatric caregivers outside of the mental health realm, as not all children are treated by a provider with a psychiatric background. Researching the vast articles and data, translating the evidence to provide the best delivery specific for a clinic/ population, and presenting that process to providers/administrators of the clinic were an appropriate use of a doctorally-prepared nurse practitioner's education. She was capable of treating and managing psychiatric illnesses while also changing processes at various clinics to provide the best possible outcomes for all clients with treatable mental illnesses by supporting her primary care peers.

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**Appendix A**

**Letter of Support**

**Appendix A:** Letter of Support

Date: April 20, 2020

**Re: Letter of Support from Alamo Elite Wellness**

To Whom It May Concern:

This letter confirms that that I, as an authorized representative of *Alamo Elite Wellness*, allow the DNP student access to conduct project related activities at the listed site, as discussed with the DNP student and briefly outlined below, and which may commence when the DNP student provides evidence of IRB approval for the proposed project.

- **Project Site(s):** *Alamo Elite Wellness, 4242 Woodcock Dr., Unit 201, San Antonio, Tx, 78228.*
- **Project Purpose:** *Provide educational and community support resources to pediatric caregivers.*
- **Project Activities:** *Providing educational and community resources to pediatric caregivers by email, as well as an optional anonymous caregiver burden and demographic survey link in the email.*
- **Project Enrollment:** *Pediatric clients with appointments with the clinic from March 30, 2020 to Jun 5, 2020.*
- **Project Support:** *The site agrees to provide space to conduct project activities, authorize DNP student to access electronic schedule and health records to identify persons who might qualify for the project and distribute teaching materials to qualifying participants. The site also agrees to allow the DNP student to access the site's telephone system to contact possible participants.*
- **Data Management:** *Access to electronic health record will be granted to DNP student and the student will comply with HIPAA laws.*
- **Anticipated End Date:** *June 2020*

We understand that this site's participation will only take place from April to June 2020. No IRB review is required for this project. I understand that any activities involving Personal Private Information or Protected Health Information may require compliance with HIPAA Laws and Rutgers Policy.

The organization agrees to the terms and conditions stated above. If we have any concerns related to this project, we will contact the DNP student. For concerns regarding IRB policy or human subject welfare, we may also contact the UIW IRB.

Thank you for your cooperation and participation,

Signature 	Date 7-7-20
Full Name Christina Wei	Job Title managing director

## Appendix B

### Caregiver Resources

#### **National Alliance on Mental Illness (NAMI):**

**Non-crisis phone:** 1-800-950-NAMI (6264) M-F 8am to 4pm

**Websites:** <https://nami-sat.org/> San Antonio webpage  
<https://www.nami.org/> National webpage

**Non-crisis local phone:** 210-734-3349

The above websites are excellent for caregivers, such as yourself, as they are specifically geared for mental illness education and support. These are great resources to “bookmark” or “star” for quick access to browse at your leisure. I would like to highlight the available free classes that have transitioned to online forums during COVID-19. These classes are local to San Antonio and will connect you with others that are also navigating the role of caregiving to someone with a mental illness.

#### **American Psychiatric Association:**

**Website:** <https://www.psychiatry.org/patients-families/helping-a-loved-one-cope-with-a-mental-illness>

The above link brings you to a specific page on the American Psychiatric Association webpage. This is also a great resource for education on the particular mental illness of your loved one. I linked you to this page specifically, as the resources at the bottom are particularly useful as they are books and articles regarding how to be a supportive caregiver for your loved one.

#### **Depressive and Manic-Depressive Association:**

<https://www.dbsalliance.org/support/>

#### **Anxiety and Depression Association of America:**

<https://adaa.org/understanding-anxiety/suicide-resources>

#### **Substance Abuse and Mental Health Services Administration:**

<https://www.samhsa.gov/families>

The above websites cater to specific mental illnesses that may also provide education and resources for you and your loved ones.

**National Suicide Prevention Lifeline:** <https://suicidepreventionlifeline.org/>  
**1-800-273-8255 (TALK)**

**Crisis Text Line:** <https://www.crisistextline.org/>

**Appendix C**

**Zarit Burden Interview Short Form**

Form A: to be completed by the caregiver

**ZARIT BURDEN INTERVIEW**

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your relative?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Total for each column \_\_\_\_\_

Total Score \_\_\_\_\_

## Appendix D

### Telephone Scripts

Good morning/afternoon. I am calling on behalf of Christina Wei. She has identified you as a potential recipient of caregiver resources. I am Stacy Dee, a University of Incarnate Word psychiatric mental health nurse practitioner student, and I am offering to email resources for caregivers who may want to connect with other caregivers, read more about ways to alleviate possible stress from caregiving, and cope with your role as a caregiver. It is simply an arsenal of resources that you can browse or participate in at your leisure, especially during this time as we shelter in place. These resources are good now and when our society returns to some familiarity before the pandemic. The resources will also come with a survey through survey monkey. I would like to assess for caregiver burden. The survey is completely optional and consists of 12 questions. You will receive the resources regardless of your participation in the survey and participation does not change or alter appointments with Christina. The goal of the project is to give caregivers resources they can use and provide information regarding how we can support our caregivers. Would you like for me to email you the resources?

**If they say no:** Thank you very much for your time, Christina and I appreciate you taking the time for my phone call. Have a beautiful day and stay healthy.

**If they say yes:** Thank you, you will receive an email from sdee@student.uiwtx.edu. The links to resources and the survey monkey will be in an email entitled RESOURCES FOR CAREGIVERS. Can I have an email address that you check regularly? Thank you. Please be on the look-out for the email today. Have a beautiful day and stay healthy.

**Should I have to leave a message:** Good morning/afternoon, I am calling on behalf of Christina Wei, she identified you as a potential recipient for caregiver resources. The resources are web

links to various local and national supportive organizations for caregivers. If you would like further information, please call me: Stacy Dee at 210-882-7694. Thank you, have a beautiful day and stay healthy.

**Appendix E****Demographic Questionnaire**

1. What is your age?
2. What is your race ethnicity?
  - a. White or Caucasian
  - b. Black or African American
  - c. Hispanic or Latino
  - d. Asian or Asian American
  - e. American Indian or Alaska Native
  - f. Native Hawaiian or Pacific Islander
  - g. Another race
3. What is your sex?
  - a. Female
  - b. Male
  - c. Other
4. Are you the clients?
  - a. Mother
  - b. Father
  - c. Grandmother
  - d. Grandfather
  - e. Brother
  - f. Sister
  - g. Son
  - h. Daughter
  - i. Other (Specify)
5. Do you share the caregiving role with the client's?
  - a. Mother
  - b. Father
  - c. Grandmother

- d. Grandfather
  - e. Brother
  - f. Sister
  - g. Son
  - h. Daughter
  - i. Other (Specify)
6. Do you have employment?
- a. Yes
  - b. No
7. If yes, are you employed?
- a. Full-time
  - b. Part-time
  - c. Stay at Home Parent
  - d. Not Applicable
8. What is your occupation status during COVID-19?