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Understanding the Acceptability and Effect of Psychiatric Care via Telemedicine as an Alternative Option for Patients Living with Intellectual Disabilities in Group Homes

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Cover Page Footnote

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Original Clinical Investigations

Understanding the Acceptability and Effect of Psychiatric Care via Telemedicine as an Alternative Option for Patients Living with Intellectual Disabilities in Group Homes

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Telemedicine has become a popular alternative to in-person clinic visits in the field of psychiatry, but few studies examine the impact of telemedicine mental healthcare provided to patients with intellectual disabilities living in group homes. Our study aims to fill this gap in the literature. A ten-question survey was designed to evaluate the effect of telemedicine services on access to care, quality of care, and patient and caregiver stress. This survey was distributed to caregivers of patients living in group homes who received care at the University of Alabama Medical Center. The majority of respondents indicated that telemedicine visits improved access to care, did not result in lower quality care compared to in-person visits, and adequately addressed the needs of the patient. Our findings suggest that telemedicine is an acceptable method of delivery of healthcare for a significant proportion of caregivers of patients surveyed.

INTRODUCTION

The COVID-19 pandemic created an unprecedented need for telemedicine services as many clinics closed for non-essential visits to prevent the spread of infection and redirect resources to critical care patients. The consequences of telemedicine-based health care are broad and often contrasting between patients: for some, telemedicine leads to increased access to care without the need for transportation or close physical proximity to the provider. For others who may struggle with use of or access to technology, telemedicine serves as a barrier to care. 1,2 Some patients prefer to receive care in the comfort of their home while others find telehealth visits to be impersonal and lacking in the level of care they hope to receive because they are not face-toface with the provider and a full-scale physical exam cannot be performed.^{1,3} Recently published studies show that psychiatric care delivered via telemedicine has greatly increased access to mental health care for those who otherwise struggled to access it through the creation of more available appointment slots, elimination of the need for physical proximity to an office, and more flexible insurance and out-of-pocket payment options through telemedicine platforms. 1,4 However, compared to the number of studies published that examine the efficacy of telemedicine in delivering general psychiatric care, relatively few studies specifically examine the impact of telemedicine on the population of patients living with intellectual disabilities.⁵ Even fewer studies specifically examine the efficacy of psychiatric care delivered via telemedicine to patients with intellectual disabilities living in the group home setting. Our

study aimed to fill this gap in the literature by examining the impact of telemedicine on the care provided to outpatient psychiatric patients with intellectual disabilities living in a group home setting.

Patients with intellectual disabilities living in group homes belong to a population with specific needs and a high degree of reliance on continuity of care. 3,6,7 Barriers to care commonly faced by patients in this population include lack of access to outpatient psychiatric clinics in the community, lack of transportation to and from appointments, and lack of continuity of care through the process of adjusting and optimizing pharmaceutical and behavioral interventions.^{3,5-7} Moreover, patients with intellectual disabilities may have difficulties with verbalization and communication, meaning they require a caregiver at their group home to be present at all appointments to act as an advocate and liaison between patient and doctor.6 The process of leaving the group home to attend in-person appointments with a psychiatrist can be traumatizing to the patient due to the potentially uncomfortable sensory environment of the vehicle and office itself.^{6,8} This creates strain for not only the patient, but also the caregiver and physician.^{7,8} Because telemedicine eliminates the need for the stressful process of traveling to the psychiatrist's office, 1,5 allows patients to establish care with clinics outside their own cities thus connecting individuals in areas without an adequate number of psychiatrists to provide care,⁴ improves continuity of care through easily scheduled telehealth appointments, 1 and facilitates the involvement of both the caregiver and patient in the appointment,^{3,5} we hypothesized that telemedicine would be the preferred option to access outpatient psychiatric care over in-person

clinic visits for the caregivers of patients with intellectual disabilities living in group homes.

Through a survey distributed to patient caregivers at group homes in Tuscaloosa, Alabama, we examined the perceived benefits and drawbacks of telemedicine care in the field of psychiatry. In our study, telemedicine visits included both medication management and psychotherapy for new and existing patients, as well as initial patient intake visits for new patients. We hoped to learn if caregivers perceived that telemedicine increases ease of access to care, lessened the burden of transportation that is placed on caregivers, created a sense of connection between patient and doctor, and allowed patients to maintain the same quality of care they would receive were they seen in-office, among other points of investigation. Our study aimed to understand the impact of telemedicine on the care of patients living with intellectual disabilities so as to optimize the platform and to provide the best care possible for a population that has historically been marginalized and denied adequate care.6,7

METHODS

A ten-question survey was designed to describe the attitudes towards and perceptions of telemedicine visits as a more accessible, less stressful, and similarly efficacious option for delivery of psychiatric care to patients living with intellectual disabilities in group homes in Tuscaloosa, Alabama. Because the majority of patients living in group homes within our clinic's patient population are nonverbal and attend all clinic visits (whether in-person or via telemedicine) with caregivers employed by the group homes they reside in, it was necessary that the survey be completed by the patients' caregivers. Potential participants were identified as caregivers employed by group homes that housed patients with intellectual disabilities seen by psychiatrists at the University of Alabama Betty Shirley Psychiatric Clinic via telemedicine visit between March 2020 and August 2021. Thirty-three group homes met inclusion criteria. The primary caregivers at each group home were contacted by telephone, and informed consent was obtained from those who indicated they would participate in the study. The digital survey was distributed to participants via email and administered via Qualtrics.

The survey utilized a 5-point Likert scale (1 = "Strongly Disagree", 5 = "Strongly Agree"). The survey probed perceptions and attitudes about technology as a barrier to care, the stress of in-person compared to telemedicine visits for intellectually disabled patients, and quality of care. The survey was created on Qualtrics (Qualtrics, Provo, UT). Responses were anonymous and could not be traced back to participants. Invitations to complete the survey were sent via email, although participants were given the option to complete the survey over telephone call if preferred.

Results of the survey were collected using Qualtrics (Qualtrics, Provo, UT) and analyzed using R (R Core Team, Vienna, Austria).

The University of Alabama institutional review board approved this study. The authors have no known conflicts of

interest to declare. All authors certify their responsibility for the manuscript.

RESULTS

Of the 33 group homes contacted, 10 employees responded for a response rate of 30.3%. Of these, three respondents (30%) wrote qualitative comments in an optional free response text box, which are included in Table 2 below. Table 1 contains survey responses for each question included in the questionnaire as well as measures of central tendency for responses for each question. Table 3 contains the byitem proportion of survey responses.

In our survey, the majority of caregivers reported that telemedicine visits improved access to care (Tables 1 and 3; question 1) with 80% strongly agreeing that ease of access is improved by telemedicine. Most respondents endorsed that telemedicine reduced both patient and caregiver stress compared to in-person visits (Table 1, questions 2 and 3). The majority of respondents reported that access to technology for telemedicine visits did not act as a barrier to care during telemedicine visits (Table 1, question 6). All respondents expressed that telemedicine visits did not result in lower quality care (Table 1, question 7) and that telemedicine visits adequately addressed the needs of their patients (Table 1, question 10). In the results of our survey, 90% of respondents strongly disagreed with the statement that telemedicine visits fail to address the needs of their patients (Table 1, question 10). Zero respondents agreed with the statement that telemedicine visits are impersonal (Table 1, question 8), with 70% of respondents strongly disagreeing with the statement. 100% of respondents disagreed with the statement that it is more difficult to schedule telemedicine visits compared to in-person visits (Table 1, question 9), with 90% strongly disagreeing.

Although the majority of respondents indicated that telemedicine visits did reduce stress for the patients and caregivers, 80% of respondents disagreed with the statement that telemedicine visits decreased behavioral issues for patients (<u>Table 1</u>, question 4).

Caretakers held mixed opinions regarding their preference for telemedicine versus in-person visits for future appointments. 60% of respondents strongly agreed that they would prefer future visits to be conducted via telemedicine, but 30% strongly disagreed (Table 1, question 5). Table 2 displays several comments from caretakers who expressed interest in conducting future visits via telemedicine, but an option to hold in-person visits is preferred by a sizable minority of caregivers.

DISCUSSION

This study aimed to gather information describing the attitudes towards and perceptions of telemedicine visits as an accessible and similarly efficacious option for delivery of psychiatric care to patients living with intellectual disabilities in group homes in Tuscaloosa, Alabama. Overall, quantitative responses overwhelmingly supported the study's hypotheses, demonstrating that caregivers felt telemedi-

Table 1. Survey responses regarding attitudes toward telemedicine services

Likert scale value	(1)	(2)	(3)	(4)	(5)	
Corresponding response	Strongly Disagree	Slightly Disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	
Question	Frequency of responses for each Likert value					Mean (SD) Median [min, max]
Telemedicine visits have made it easier for my clients to access psychiatric services.	2	0	0	0	8	4.20 (1.69) 5.00 [1.00, 5.00]
Telemedicine visits are less stressful for my clients to attend than in-person visits.	1	0	2	0	7	4.20 (1.40) 5.00 [1.00, 5.00]
Telemedicine visits have reduced stress for group home caregivers.	2	0	1	0	7	4.00 (1.70) 5.00 [1.00, 5.00]
Telemedicine visits have resulted in decreased behavioral issues for my clients.	1	0	4	2	3	3.60 (1.26) 3.50 [1.00, 5.00]
5. I would prefer most future psychiatric visits to be telemedicine visits.	3	0	0	1	6	3.70 (1.89) 5.00 [1.00, 5.00]
Technology has been a barrier to receiving care via telemedicine.	8	1	1	0	0	1.30 (0.675) 1.00 [1.00, 3.00]
7. Telemedicine visits have resulted in lower quality psychiatric care for my clients.	8	2	0	0	0	1.20 (0.422) 1.00 [1.00, 2.00]
8. Telemedicine visits are impersonal.	7	3	0	0	0	1.20 (0.422) 1.00 [1.00, 2.00]
9. It is more difficult to schedule telemedicine visits than in-person visits for my clients.	9	1	0	0	0	1.10 (0.316) 1.00 [1.00, 2.00)
10. Telemedicine visits are not able to address my clients' psychiatric needs.	9	1	0	0	0	1.10 (0.316) 1.00 [1.00, 2.00]

Table 2. Qualitative responses from survey participants regarding telemedicine services

Respondent	Qualitative Response
Respondent 1	"I hope they become [a] mainstream option for my clients."
Respondent 2	"These visits are [awesome]this helps decrease the chances of behavioral acts especially in public"
Respondent 3	"The [telemedicine] visits are great for our individuals. It's extremely convenient for both client[s] and caregivers."

cine appointments increased access to care for their patients without sacrificing the quality of care. In terms of convenience and ease of access, 80% of respondents strongly agreed that telemedicine has made psychiatric care easier to access (Table 1, question 1) and 100% disagreed that telemedicine visits were harder to schedule than in-person visits (Table 1, question 9), findings in line with other published studies examining the attitudes and impacts of telemedicine on the field of psychiatry. 1,9,10 Respondents also indicated that telemedicine visits positively

impacted stress levels, with 70% of caregivers agreeing that virtual visits reduced visit-related stress for both caregivers and patients (Table 1, questions 2 and 3). When examining the results as a whole, the majority of respondents endorsed positive opinions of the telemedicine care provided at the Betty Shirley clinic across all 10 questions in the survey.

Four questions elicited unanimous answers from respondents, with 100% of caregivers disagreeing to varying degrees (either strongly or slightly) with the following state-

Table 3. By-item proportion of survey responses

Survey Questions and Selected Answers	Number of responses (response percentage)
1. Telemedicine visits make it easier for my clients to access psychiatric services.	
Strongly agree	8 (80%)
Strongly disagree	2 (20%)
Telemedicine visits are less stressful for my clients than in-person visits.	
Strongly agree	7 (70%)
Neither agree nor disagree	2 (20%)
Strongly disagree	1 (10%)
3. Telemedicine visits have reduced stress for group home caregivers.	
Strongly agree	7 (70%)
Neither agree nor disagree	1 (10%)
Strongly disagree	2 (20%)
4. Telemedicine visits have resulted in decreased behavioral issues for my clients.	
Strongly agree	3 (30%)
Somewhat agree	2 (20%)
Neither agree nor disagree	4 (40%)
Strongly disagree	1 (10%)
5. I would prefer most future psychiatric visits to be telemedicine visits.	
Strongly agree	6 (60%)
Somewhat agree	1 (10%)
Strongly disagree	3 (30%)
6. Technology has been a barrier to receiving care via telemedicine visits.	
Neither agree nor disagree	1 (10%)
Slightly disagree	1 (10%)
Strongly disagree	8 (80%)
7. Telemedicine visits resulted in lower- quality psychiatric care for my clients.	
Slightly disagree	2 (20%)
Strongly disagree	8 (80%)
8. Telemedicine visits are impersonal.	
Slightly disagree	3 (30%)
Strongly disagree	7 (70%)
9. It is more difficult to schedule telemedicine than in-person visits for my clients.	
Slightly disagree	1 (10%)
Strongly disagree	9 (90%)
10. Telemedicine visits are not able to address my clients' psychiatric needs.	
Slightly disagree	1 (10%)
Strongly disagree	9 (90%)

ments: "Telemedicine visits are not able to address my clients' psychiatric needs" (Table 1, question 10), "Telemedicine visits have resulted in lower quality psychiatric care for my clients" (Table 1, question 7), "Telemedicine visits are impersonal" (Table 1, question 8), and "It is more difficult to schedule telemedicine visits than inperson visits for my clients" (Table 1, question 9). The uniformity of these answers across all respondents further highlights benefits of telemedicine that are consistently perceived positively by caregivers and patients. On an organizational level, these responses suggest that the Betty Shirley Clinic is succeeding at providing group homes with virtual care that is easy to schedule and of a quality consistent with in-person care they have received.

While telemedicine visits often remove barriers to access to care by eliminating the need for transportation or physical proximity to a medical practice, telemedicine can serve as a barrier to care in cases where patients do not have access to technology.8,10 Despite the fact that use of and access to technology has become increasingly widespread throughout America over the last decade, Americans living in rural areas like Tuscaloosa County remain less likely than urban Americans to own a smartphone or computer. 11 The digital divide between rural and urban/suburban America may prevent telemedicine from meeting the healthcare needs of patients living in rural communities. In our survey, 90% of caregivers disagreed that technology has been a barrier to care via telemedicine visits (Table 1, question 6). This finding is in line with several studies examining the benefits of group homes for patients with intellectual disabilities who are unable to live alone or with a relative. 12-14 Caregivers in group homes can help patients utilize technology that they otherwise would not have access to or be able to use without help.8,12 Telemedicine visits at the Betty Shirley Clinic were conducted via a secure video conference application designed specifically for the healthcare setting and only requires that patients/caregivers have access to either a camera phone or web camera. If a group home is adequately resourced and managed, it can realistically serve as a means of increased access to healthcare, whether in-person or via telemedicine, not a barrier.

While much of the survey data collected supported our initial hypothesis, the study did yield a few surprising results. Primarily, the study revealed mixed opinions about the desire for telemedicine to be employed as the main platform for future visits, with 70% agreeing that they would prefer telemedicine in the future and 30% strongly disagreeing (Table 1, question 5). Some caregivers used the qualitative response section to express the desire for an option to schedule future visits as telemedicine rather than in-person. This distinction further underscores the need for flexibility in access options for caregivers and their patients.

In past studies, caregivers and clinicians have identified behavioral challenges such as verbal and physical outbursts as a possible barrier to access care for some patients with intellectual disabilities. ^{15,16} Calming and possibly restraining an upset patient can be physically demanding and emotionally distressing for the patient, caregiver, and physi-

cian. 15,16 Behavioral challenges are often exacerbated by changes in a patient's physical environment, especially when the environment the patient travels to is unfamiliar, such as a clinic. 15,17,18 Thus, it was hypothesized that telemedicine visits might help overcome this barrier if behavioral challenges were triggered by visiting the clinic. In designing our survey, we hoped to investigate this via question 4. However, only 50% of caregivers agreed that telemedicine visits reduced their patients' behavioral challenges with 10% strongly disagreeing and 40% neither agreeing nor disagreeing (Table 1). In the optional qualitative response portion of the survey, one respondent expressed that telemedicine visits did reduce the occurrence of outbursts related to travel, writing, "These visits are [awesome]...this helps decrease the chances of behavioral acts, especially in public" (Table 2, response b). In retrospect, we feel that our question was vaguely worded and ultimately failed to probe respondents about behavioral challenges in the specific context of clinic appointments rather than behavioral challenges as a whole. If this study is repeated or replicated on a larger scale, we plan to amend this question to improve its clarity and specificity.

Our study has several strengths. Perhaps most importantly, our study takes steps towards addressing an existing gap in published literature. While many studies have examined the impact of telemedicine on patient care. 1,2,9,19 few have specifically probed its impact on patients with intellectual disabilities and still fewer on the subset of those patients who live in the group home setting. The importance of addressing barriers to care for these individuals is underscored by the fact that this population has been historically marginalized. 16,18 This study was designed in collaboration with a physician who primarily provides care for patients with intellectual disabilities living in group homes. The significant degree of continuity of care within the clinic and experience and depth of knowledge of the physician provides an expert's perspective to the primary issues, barriers, and concerns of patients and caregivers that should be addressed by our study.

It is important to consider the limitations of the study in addition to its strengths. First, although all group homes served by the Betty Shirley Clinic were contacted to participate in this study (n=33), responses were provided by 10 homes, or approximately 30% of the group homes contacted, which was a smaller sample size than desired. Due to the small sample size, the risk of both response and non-response bias increases.²⁰ Because the survey was only administered online, caregivers who are more comfortable using technology might have been more likely to submit responses than those who are less comfortable with an online platform. Additionally, caregivers who are more comfortable using technology might consequently possess a greater level of familiarity with or more favorable view of telemedicine compared to those who are less comfortable with technology. This could potentially result in a high proportion of responses endorsing positive views of telemedicine that is not truly representative of the caregiver population. In terms of generalizability, both the small sample size and the geographic homogeneity of the surveyed population decreases how applicable this study's findings may be to clinics in other parts of the world. ²⁰ While our study specifically aimed to examine the acceptability and perceptions of telemedicine within our local patient population, we recognize that clinics located in different regions serve unique patient populations with needs that may differ from those of the Betty Shirley clinic. This underscores the need for further research, perhaps via a similar study performed on a larger scale that includes clinics from around the country in order to gather readily generalizable results.

The patient population of individuals with intellectual disabilities that the Betty Shirley clinic serves is primarily nonverbal, and for this reason, patient caregivers were asked to answer questions about patient experience as well as personal experience as a caregiver. Because patients could not directly reply to survey questions, responses are biased towards the caregiver's perspective, which is necessarily removed from the patients themselves. We believe that the continuity of care and high degree of interpersonal interaction between the caregivers and patients should result in survey responses that accurately depict both the caregiver and patient experience, but responses to patientcentered questions should be interpreted with this context in mind. Furthermore, detailed information about group homes and respondents was not collected in order to maintain survey anonymity and brevity as well as to discourage attrition. The research team also chose to omit demographic questions from the survey instrument to provide respondents an additional layer of protection, as patients with intellectual disabilities are a historically vulnerable population.¹⁸ This limited the analysis able to be performed to descriptive statistics.

The study findings contribute to understanding the various ways telemedicine can be a useful tool for healthcare providers to address barriers to care for vulnerable populations, such as patients with intellectual disabilities. With telemedicine booming in the early days of the COVID-19 pandemic out of necessity, many expressed concerns that virtual visits would sacrifice quality of care and limit the connection between patients and doctors. 2,4,10 The present study suggests that telemedicine visits at an outpatient psychiatric clinic could help address barriers to care without sacrificing quality of care for patients with intellectual disabilities. Furthermore, while not the primary aim of the study, the results also contributed to research regarding telemedicine's impact on caregiver strain. Group homes evaluated often face understaffing issues, and the patient populations present in group homes can pose particular physical and psychological challenges for caregivers. 21,22 Survey results showed that 70% of respondents strongly agreed that telemedicine reduced caregiver stress (Tables 1 and 3, question 3), suggesting the potential for the use of telemedicine as a tool to improve caregiver wellbeing.

Future studies should aim to broaden the scope of this study by surveying a greater number of caregivers and patients at group homes in a wide variety of geographic regions. Additionally, studies could evaluate the specific factors, patient needs, and barriers that make telemedicine ideal on a clinic-to-clinic basis.

CONCLUSION

Our study supports the findings of previously published research that suggests telemedicine not only increases patient access to psychiatric care, but also serves as an effective alternative to in-person psychiatric care both within the general patient population and the sub-population of patients with intellectual disabilities. Our study highlights the general acceptability of telemedicine visits for caregivers and their patients. While generally acceptable, our study did not find that telemedicine visits were always preferable to in-person visits. This supports the importance of offering telemedicine visits as an option rather than as a replacement for in-person visits. In addition, we believe there is a clear need for a study similar to the one we detail in this paper to be conducted on a larger scale in order to prioritize high-quality, easily accessible mental healthcare within this historically marginalized population. While this study was limited by a small sample size and the inability to directly survey patients, it is useful to inform future patient care and clinic management strategies within our practice, emphasizing the importance of offering mental health care via telemedicine as a choice for patients with intellectual disabilities living in the group home setting.

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ETHICS APPROVAL

This research study was conducted retrospectively from survey data obtained for research purposes. We consulted extensively with the IRB of The University of Alabama who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of The University of Alabama.

CONSENT TO PARTICIPATE

Informed consent was obtained from all individual participants included in the study.

The survey and output data for this paper were generated using Qualtrics software, Version XM of Qualtrics. Copyright © 2021 Qualtrics. Qualtrics and all other Qualtrics product or service names are registered trademarks or trademarks of Qualtrics, Provo, UT, USA. https://www.qualtrics.com

The statistical analysis for this paper was performed using R. R Core Team (2013). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL http://www.R-project.org/

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