

Transitioning to telehealth during the coronavirus disease 2019 pandemic: Perspectives from partners of women with cystic fibrosis and healthcare providers

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Abstract

Objectives: Cystic fibrosis is a chronic, genetic disease that primarily affects the respiratory system. The coronavirus disease 2019 pandemic has altered how people with cystic fibrosis receive healthcare. This paper explores the perceptions of cystic fibrosis healthcare providers and partners of women with cystic fibrosis regarding the use of telehealth in routine cystic fibrosis healthcare in the US.

Methods: As part of a larger study examining fertility counseling for women with cystic fibrosis, we conducted qualitative, semi-structured interviews. Participants included partners of women with cystic fibrosis ($n = 20$) and cystic fibrosis healthcare providers ($n = 20$). We completed the interviews before and during the global coronavirus disease 2019 pandemic. We analyzed the data using thematic analysis.

Results: When in-person healthcare could not be achieved safely, partners and healthcare providers found new value in telehealth. Three themes emerged: (1) increased connection between healthcare team and family, (2) increased efficiency of healthcare appointments, and (3) improved interdisciplinary collaboration. Partners found that telehealth allowed for more engagement in their significant others' healthcare. Providers reported enhanced efficiency and opportunities for collaboration across specialties that improved healthcare delivery and care coordination.

Discussion: Results from this study highlighted the positive value of telehealth. Telehealth

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presents as a potential alternative to delivering outpatient care for people with chronic illnesses beyond the pandemic

Keywords

Cystic fibrosis, telehealth, technology, family-centered care, innovation

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When the novel coronavirus disease 2019 (COVID-19) abruptly disrupted typical patterns of society, life was drastically altered. These disruptions were wide felt, especially within the healthcare setting. For some patients with chronic illnesses, the need to quarantine became a matter of life or death. This was especially true for patients with cystic fibrosis (CF). CF is a chronic, lifelong, genetic disease that primarily affects the respiratory and gastrointestinal systems.¹ Due to these patients' susceptibility to lung infections and potential for being immunocompromised, the COVID-19 pandemic has temporarily transformed the way they receive their regular CF healthcare, shifting their visits from in-person to a remote, telehealth platform to safely obtain care.

Integration of telehealth

Telehealth is defined as, 'the delivery of health care, health education, and health information services via remote technologies.'² For the purpose of this study, the use of remote technologies includes video conferencing using web-based platforms to communicate. Telehealth is not a new care delivery system; however, historically in the United States, telehealth is widely underutilized.³ Prior to the COVID-19 pandemic fewer than 0.01% of US healthcare visits were delivered via telehealth.³ In contrast, during the pandemic, the rates of telehealth visits increased to over 50% of total healthcare visits.⁴ This rapid shift to a telehealth format to accommodate the widespread quarantine guidelines was

made possible by the quick innovation of the healthcare sector as well as increasing coverage by the Centers for Medicare and Medicaid (CMS) for telehealth options.⁵ The purpose of this study was to explore perceptions of incorporating telehealth into routine CF healthcare by CF healthcare providers and partners of women with CF. It is important to capture the perspectives of partners of women with CF because they have a pivotal role in decision-making and chronic care, yet they are largely neglected as stakeholders in research and clinical care.

Methods

As part of a larger mixed-methods study examining the current state of fertility preservation counseling for women with CF, we conducted qualitative, semi-structured interviews. Participants included partners of women with CF ($n=20$) and CF healthcare providers ($n=20$). For this project, we estimated the need for approximately 20 participants from each group based on previous qualitative work of a similar nature. Determining the sample size in qualitative research is a matter of judgment and experience in evaluating data collected and guided by content saturation.⁶ To enroll partners of women with CF, we recruited participants from one CF clinic in the Southeastern region of the United States, through social media, and via snowball sampling. To recruit CF providers, we contacted CF foundation-accredited CF clinics throughout the US. We shared IRB-approved information sheets with interested individuals. We also recruited CF providers through listservs and snowball sampling. Each participant was offered \$20 as compensation for their time to

complete the interview. Prior to conducting the interviews, we read a consent document to each participant and asked if they gave consent for the interview. All participants gave verbal consent to be interviewed. We conducted the interviews between September 2019 and July 2020, before and during the national shutdown due to COVID-19. The interviews were conducted in person (before COVID-19) in a private office at the university where the research was conducted or via telephone and lasted an average of 45 min. The PI of the larger mixed-methods study conducted the first five interviews (SL) and trained a research assistant (CC) to conduct the remaining qualitative interviews for this study. Neither researchers (SL) nor (CC) had any prior relationship with the participants. The interview guide that was used was developed to measure concepts related to fertility and fertility preservation topics to better understand the current state of fertility preservation knowledge, preferences, experiences, and concerns. However, because of the COVID-19 pandemic and the semi-structured nature of the interviews, participants expounded on their experience with telehealth and how it had utility for patients with CF and possibly patients with other chronic conditions. We did not change the interview guides from the inception to closing of the study. The interviews were audio recorded and then transcribed verbatim. The university institutional review board approved this research protocol.

Analysis plan

This qualitative study utilized Braun and Clarke's six steps to thematic analysis to analyze the qualitative data: (1) familiarize with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) define themes, and (6) write-up analysis.⁷ QSR International's NVivo 12 qualitative data analysis software was used to organize and manage the qualitative data.⁸ Two team members independently coded each qualitative interview and then met several times to discuss

the emerging themes. After consensus about themes was reached between coders, the findings were written.

Results

At a time when in-person healthcare visits could not be achieved safely, CF partners and healthcare providers found new value in telehealth visits. The themes of 'increased connection between healthcare team and family', 'increased efficiency of healthcare appointments', and 'improved interdisciplinary collaboration' emerged from the interviews. Partners found that telehealth provided them the opportunity to be more engaged in their significant others' healthcare, whereas providers reported enhanced efficiency and opportunities for collaboration across specialties that improved healthcare delivery and care coordination.

Increased connection between healthcare team and family

The utilization of telehealth due to COVID-19 has increased the connection between the CF healthcare team and the patient's family. Partners of women with CF discussed how, prior to the COVID-19 pandemic, they were unable to attend their significant others' clinic visits. One partner shared, 'wasn't on those [visits]... that would have been pre-pandemic, so she [wife] would have been in the office for those appointment with her CF team, and I wasn't there (partner 19).' Given the new telehealth format, partners were able to be more involved and feel more connected to the CF healthcare team. Another partner reported, 'I don't typically go with my wife to those [CF] appointments. I have joined a couple of them recently because they've been done virtually (partner 20).'

On the other hand, providers discussed how the integration of telehealth has improved connectedness between the provider, patient, and

partner. A provider discussed how their team encourages patients with CF to include their partners and families during appointments using telehealth. The provider described, ‘... we’re always inviting people for those adult conversations to yes, bring your partner, or I’ve had I think one who recorded their conversation with me so they could take it home to their partner. I’ve people FaceTime or video call their partner if they’re not in the clinic (provider 13).’ Another provider discussed how the telehealth format can allow patients and partners to feel more relaxed and connected in their home environment during visits, especially when discussing sensitive topics. The provider said, ‘Maybe with people using and becoming more comfortable with telehealth... where the person is in their home environment, and it feels less sterile to them to see the person from their team discussing this [sensitive topics]. Maybe that person’s in their office or even at home, maybe making it seem more relaxed, more comfortable (provider 15).’ Telehealth has the potential for improving connectedness between the healthcare team and family especially for patients with chronic conditions who utilize healthcare frequently.

Increased efficiency of healthcare appointments

For patients with complex, chronic illnesses, healthcare appointments can be very long and require extensive planning, travel, and wait times. Partners discussed decreased transition times between healthcare visits and discussed their partners telehealth visits as more efficient than in-person visits. One partner reported, ‘The CF team was great. I also really like how they approach it and sort of that team mentality, and it may actually be more efficient—it’s kind of funny, just bouncing from person to person on Zoom and different parts of the team, but, yeah, they’ve been really helpful (partner 20).’

With the introduction of telehealth, providers can schedule a time to meet virtually with patients reducing wait times by removing external variables such as traffic and childcare. Healthcare providers can also schedule telehealth conferences that are geared toward specific content to provide their patients with more comprehensive knowledge about their illness and long-term trajectory. One provider said, ‘There’s so much we go over with them... if we start doing more telehealth visits, like we’re doing now, that would allow us more time to do other topics, because...if we don’t have a room [in clinic] available right away, they’re late to their appointment. We’re backed up. We may feel rushed and won’t be able to handle all the topics we’d wanna talk about (provider 17).’ When discussing setting up a separate telehealth visit to discuss health promotion and disease management, a provider shared, ‘That would allow us maybe more time in a telehealth visit to do some of this basic education that we don’t have the luxury in a clinic setting to do (provider 17).’ Both partners and CF healthcare providers discussed that telehealth could be a more efficient way to discuss sensitive topics and provide needed health education.

Improved interdisciplinary collaboration

The value of interdisciplinary collaboration was discussed by both healthcare providers and partners. Partners discussed the increased ability to integrate additional specialists into a healthcare visit when needed due to the current telehealth platform. One partner said, ‘Right now, everything is done for the most part virtually, so that would be pretty easy to coordinate adding someone onto the team in the shuffle of doctors and experts (partner 20).’

The CF healthcare providers also discussed how the COVID-19 pandemic has increased interdisciplinary collaboration within the CF healthcare team. One provider said, ‘We organize a teleconference on that day so we can all have some discussion (provider 18).’ Another

provider discussed how telehealth has increased her awareness of what other members of the CF healthcare team are discussing with the patients. This provider said, ‘We walk into the room and have a telehealth thing there. It made it so we’re all informed of what’s going on, not only on the nutrition side but I know the social work person is talking to the patient about and what the nurse practitioner is focusing on (provider 9).’ Utilizing telehealth allows for additional providers, who have needed expertise, to be added to the interdisciplinary healthcare team more easily. When discussing the possibility of adding additional team members through telehealth to enhance interdisciplinary collaboration, one partner offered, ‘Actually, that would probably be—I mean, that would be sufficient because they’re gonna have access to medical records and documents and any test results. A lot of that stuff can be ordered and done remotely, and they can have the results, be more of a consultant type thing, which could totally be done virtually (partner 20).’ The telehealth format allows for easier interdisciplinary collaboration and communication among members of the healthcare team. Interdisciplinary collaboration is vital for patients with chronic illnesses that may impact several body systems and require visits to several specialists. Telehealth may increase the feasibility of this collaboration.

Discussion

The results of this study identify a unique perspective in considering the value of telehealth visits in the future. From the perspectives of CF partners and healthcare providers, telehealth increased the connection between the healthcare provider and family, increased efficiency of healthcare delivery, and improved interdisciplinary collaboration. This is consistent with the emerging literature discussing the rapid integration and possible benefits of telehealth during the COVID-19 pandemic for the obstetric,⁹ psychiatric,¹⁰ and oncologic¹¹

patient populations. In the obstetrics population, telehealth visits decreased barriers to receiving care by decreasing the need for travel and child-care.⁹ The same increase in efficiency has been seen among various patient populations.^{10,11} Our findings are consistent with previous literature that the integration of telehealth may increase the efficiency of visits for patients during the COVID-19 pandemic.^{9–11}

Family and healthcare provider perspectives of utilizing telehealth during the COVID-19 pandemic have been reported in the intensive care setting (ICU),¹² but perspectives of the integration of telehealth are less understood for patients with chronic illnesses in the outpatient setting. In the ICU setting, telehealth was used to discuss the patient status and was viewed as an acceptable alternative when in-person communication was impossible.¹² Our study moves beyond discussing the acceptability of provider–family communication and highlights the value of utilizing telehealth to promote the connection between the family and provider in an outpatient setting.

Prior to the pandemic, in 2014 a qualitative study of healthcare providers in the United Kingdom found conflicting results regarding provider perspectives of the use of telehealth for patients with chronic conditions.¹³ These findings included the idea that telehealth affords an opportunity to either empower or burden patients. Telehealth opportunities, technology, and circumstances have advanced considerably since 2014, it may not be surprising that our participants discussed only positive aspects of telehealth given the current pandemic situation and necessity of integrating telehealth into outpatient healthcare. We acknowledge that there are considerable challenges to integrating telehealth into chronic illness management,¹³ but our participants discussed the positive aspects of integrating telehealth without discussing the barriers to telehealth likely because for several months telehealth was the only option to see patients who are likely immunocompromised and have respiratory system disease.

Strengths and limitations

To our knowledge, this is the first study to describe experiences related to the integration of telehealth during the COVID-19 pandemic from the perspectives of CF healthcare providers and families in an outpatient setting. Since CF is a chronic disease that primarily affects the respiratory system, the perspectives from this group are especially important. The use of multiple coders to independently examine the qualitative data is another strength of this study. Limitations of this study include that it has a relatively small sample size, albeit consistent with qualitative research studies, and may not be generalizable to other chronic conditions that do not impact the respiratory system. Additionally, our participants chose to discuss telehealth integration positively and did not discuss any barriers to telehealth integration while we know that literature shows there are barriers to telehealth integration in healthcare.^{14,15} Unfortunately, we were unable to capture the patient's perspective as it related to the integration of telehealth during the COVID-19 pandemic. We acknowledge that as a limitation of this study.

Implications for future

While future study is necessary to fully determine the most effective and efficient methods to deliver telehealth visits, the perspectives from the CF partners and healthcare providers demonstrate that the use of telehealth and its full capability in function and role show promise, especially for patients with chronic illnesses who require frequent, complex healthcare appointments. Telehealth has the potential to be utilized even after the global COVID-19 pandemic.

Conclusion

Results from this study highlighted the positive value of telehealth from the perspectives of CF partners and healthcare providers. Future

research is necessary to fully determine the most effective methods to implement telehealth visits for the CF population and others with chronic conditions. Telehealth holds promise as a potentially more cost-effective, efficient, and comprehensive alternative to delivering care even beyond the current pandemic.

Contributorship

JC and CC researched literature and conceived the study. SL was involved in protocol development and gaining ethical approval. CC was involved in patient recruitment and data analysis. JC and CC wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

This study does contain human subjects and we received university IRB approval to conduct this study.

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Guarantor


JC

Informed consent

We obtained verbal informed consent from each participant prior to their participation in this study.

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Trial registration

Not applicable, because this article does not contain any clinical trials.

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