

# Telehealth in Genetics: The Genetic Counselor Perspective on the Utility of Telehealth in Response to the COVID-19 Pandemic in Wisconsin



Sarah H. Choi<sup>1</sup>, Marwat N. Salamin<sup>1</sup>, Catherine A. Reiser<sup>1</sup>, Lauren E. Rachow<sup>1</sup>, Michael Lasarev<sup>2</sup>, M. Stephen Meyn<sup>3</sup>, Elizabeth M. Petty<sup>1</sup>

<sup>1</sup>University of Wisconsin – Madison, School of Medicine and Public Health, Department of Pediatrics, 
<sup>2</sup>University of Wisconsin – Madison, Department of Biostatistics and Medical Informatics, 
<sup>3</sup>University of Wisconsin – Madison, Center for Human Genomics and Precision Medicine



# **BACKGROUND & RESEARCH GOAL**

- The COVID-19 pandemic prompted many genetics clinics across the country and globally to integrate telehealth modalities (telephone and/or videoconference) into their clinical practice to promote the safety of patients and clinic staff members.
- As it is expected that telehealth will continue to be utilized by genetic providers to meet patient needs in Wisconsin, and likely other regions, it is important to learn providers' perspectives of telehealth especially now that many have experience providing patient care via telehealth during the COVID-19 pandemic.
- Our study aimed to examine the providers' perspectives on the utility and effectiveness of telehealth in response to the COVID-19 pandemic in Wisconsin.

# **METHODS**

# Recruitment and Eligibility

- All members of the Wisconsin Genetic Systems Integration (GSI) Hub and the Wisconsin Genetic Counselor Association (WIGCA) were invited to complete an anonymous online survey via email.
- Eligibility was limited to clinical genetic providers who currently provide clinical care to patients in Wisconsin.
- Survey was open from October to November 2020.

### **Survey Instrumentation**

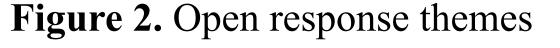
 39-item online survey included multiple choice, dropdown, slider, Likert scale, and open-ended response questions exploring genetic providers' experiences with telehealth providing clinical genetic services to their patients during the COVID-19 pandemic.

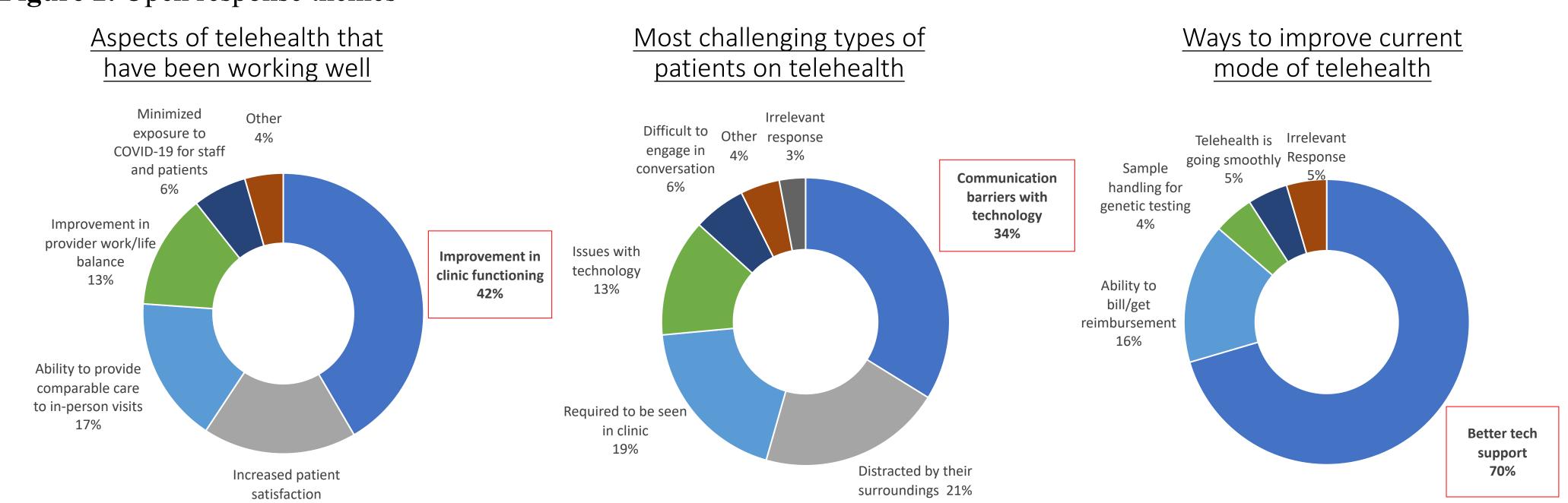
### Data Analysis

- Characteristics of the closed ended questions were summarized using basic descriptive statistical analysis (frequencies and percentages)
- An inductive thematic analysis was used for analyzing the open-ended questions following the five analysis phases: familiarizing with data, generating initial codes, reviewing themes, defining and naming themes, and producing the report. The intercoder percent agreement between the two coders was approximately 94%.

In response to the COVID-19 pandemic, clinical genetic counselors in Wisconsin <u>showed strong</u> <u>interest</u> in utilizing telehealth in their clinical practice, especially as a way to increase access of genetic services for patients. <u>Better technology</u> <u>support</u> is needed in order to optimize genetic services via telehealth for patients and providers.

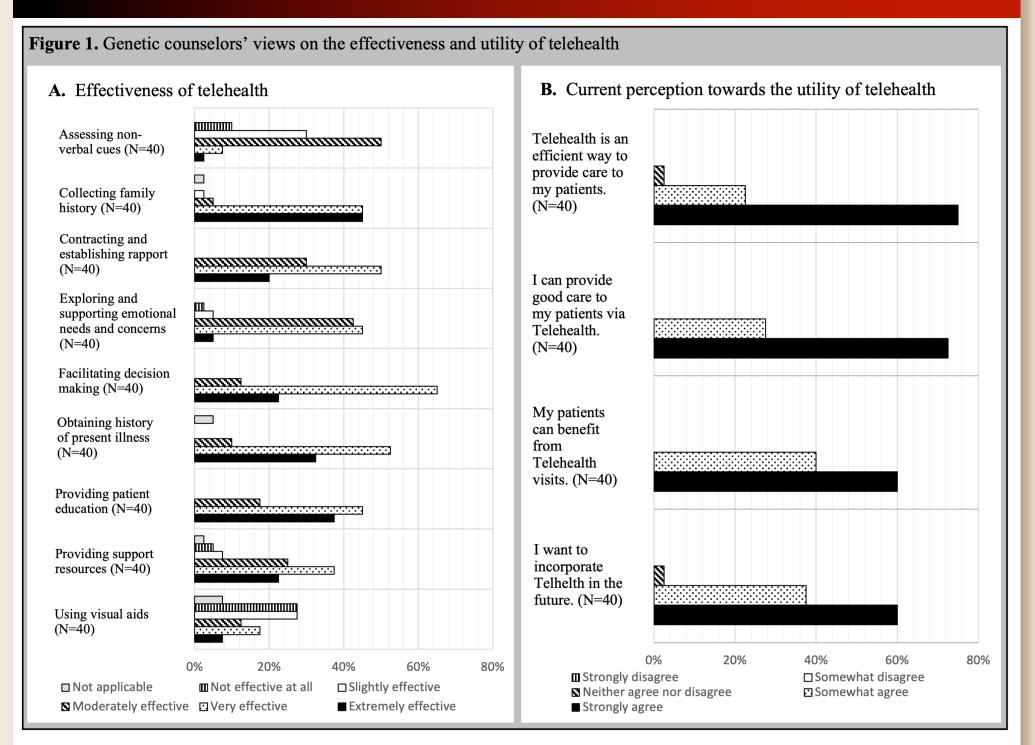
# RESULTS





The most common aspect of telehealth that went well for the counselors included improvement in clinic functioning (42%, n=47/113) that was most related to increased access for patients (e.g., people who live far away or cannot travel due to health complications) (32%, n=15/47). Many counselors found it difficult to counsel patients who had communication barriers (34%, n=23/68) via telehealth. Specifically, they had challenges providing quality care to patients with low health literacy or learning difficulties (35%, n=8/23) as well as those who are not proficient in English and required interpreter services (30%, n=7/23). When asked about ways to improve the current mode of telehealth utilized in their clinical practice, 70% (n=31/44) of the responses were related to better technology support from their institutions. Thirty percent (n=9/31) of these responses specifically commented on better equipment and device support that have video capabilities.

### RESULTS CONT.



# **CONCLUSION & ACKNOWLEDGEMENT**

### Conclusion

- Clinical genetic counselors in Wisconsin generally reported positive experiences integrating telehealth into their patient care during the COVID-19 pandemic.
- Provider experiences improved as the pandemic progressed.
- Virtually all genetic counselors have now had experience with telehealth, which may be an asset for ongoing delivery of timely genetic counseling services.
- While in person visits will certainly need to be available for patients who are required to be seen in clinic, with better technology support from their institutions, many genetic counselors wanted to utilize telehealth in their clinical practice especially as a way to increase access of genetic services for patients.

### <u>Acknowledgement</u>

The authors acknowledge the Wisconsin Genetic Systems Integration (GSI) Hub and the Wisconsin Genetic Counselor Association (WIGCA) for their assistance in distributing the study survey to their members. We also acknowledge the support for a summer research award from the Herman and Gwendolyn Shapiro Foundation to author MNS. Lastly, the authors would like to thank Sara Zoran, MS, CGC for providing valuable comments on the survey instrument and Jessica Scott Schwoerer, MD for offering insightful feedback on the manuscript.

This study met criteria for exemption, which was determined by the Education and Social/Behavioral Science IRB at the University of Wisconsin-Madison (IRB#2020-1253).

## Sarah H. Choi, MGCS

UW-Madison, SMPH 1500 Highland Ave | Madison, WI 53705 shchoi5@wisc.edu