

# Developing and Adapting an Instrument to Measure the Impact of the COVID-19 Pandemic on Pediatric Hematology and Oncology Patients and their Families

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**RESEARCH QUESTION:** How does one develop an instrument to measure the effects of the COVID-19 pandemic in a heterogenous population?

## BACKGROUND

According to the American Academy of Pediatrics and the Children's Hospital Association, as of August 6<sup>th</sup>, pediatric COVID-19 cases represent 9.1% of all total cases in the U.S.<sup>1</sup> More importantly, 179,990 new child cases were reported from 7/9-8/6 (from 200,184 to 380,174), a 90% increase in child cases over 4 weeks<sup>1</sup>. As numbers continue to rise, everything possible must be done to keep children safe, especially immunocompromised populations. Although limited data from NYC suggests that pediatric cancer patients may not be more vulnerable than other children to infection or morbidity resulting from COVID-19,<sup>2, 3</sup> especially if there is no other underlying comorbidity beyond the cancer diagnosis,<sup>3</sup> other data suggests that the presence of underlying conditions places children at greater risk of COVID-19-associated hospitalizations.<sup>4</sup> Additionally, it has been clear that the supportive care of immunosuppressed cancer patients has been impacted by changes to everyday life, and by the challenges that their families have undergone. It also cannot be ignored that, overall, Hispanic and non-Hispanic black children have had higher cumulative rates of COVID-19-associated hospitalizations compared to non-Hispanic white children.<sup>4</sup> Reasons for these disparities are not fully understood and must be investigated further, although they are likely tied to sociodemographic factors. This research is motivated by these disparities and by the need for more information in order to develop better guidelines on the management of care of pediatric cancer patients during this infectious epidemic.

## OBJECTIVE

This study is part of a larger study that is intended to collect retrospective and prospective data in order to understand how COVID-19 has affected pediatric and young adult hematology and oncology patients and their families. My summer contribution involved working with a multiethnic and multidisciplinary team to help develop, adapt, and launch a survey instrument for this study. Prior to this research, no such instrument existed. At the moment, the study is still in the initial interviewing stage and is ongoing.

## STUDY POPULATION

The targeted population is ethnically and sociodemographically diverse. The survey was administered by phone to the parents/guardians of patients, ages 0-18+, who are treated by the Division of Pediatric Hematology, Oncology, and Stem Cell Transplant, and who live in the tri-state area (NY, NJ, and CT).

## METHODS

- As this was a new study, it required the development of a new team, whose members were intentionally chosen for their backgrounds. It included myself, a medical school student, and 3 public health students who are studying population/family and global health, epidemiology and health policy, and urban planning and emergency disaster response, respectively. These team members bring their relevant interests and skills in contact tracing, data analysis, and how the built environment affects communities. Other persons on the team included my mentor, one of the principal investigators of this substudy, her coPI, the study coordinator, the lead research assistant, and other members of the MaNE research team.
- Next, we (the student members of the team) had to familiarize ourselves with the study, its objectives, and its relevance given the effects of COVID-19 in NYC and the tri-state area. Careful consideration was given to the study population. This helped determine the adaptation of the questions included in the survey.
- We then worked remotely, meeting daily in subteams and as a whole group over Zoom, to work on the adaptation and implementation of the survey.
  - This involved discussing and learning about why questions had to be modified in specific ways, such as to always be sensitive to the study population.

## PROCESS/RESULTS

The survey questions were adapted from multiple instruments designed either for low-literacy, Spanish-speaking immigrants, or for high-literacy, English-speaking US natives. Questions adapted from Spanish instruments were translated to English.

New survey questions were translated from English to Spanish.

Revised the survey to clarify and expand upon questions, add questions, delete others, simplify language, and ensure a logical order of questions. \*Later revisions were fewer and more minor.\*

Each team member practiced administering the survey more than 7 times, both amongst ourselves, as well as with research assistants experienced in working with other low-literacy populations. The survey was practiced in both English and Spanish.

Launching of survey with families.



## LIMITATIONS/CHALLENGES

Challenges to scheduling interviews:

- Participant phone numbers not active/working
- Participants may be hard to reach if their child (patient) is in hospital
- Participants very busy, especially during weekdays

Challenges during interviews:

- Background noise/distractions
- Sensitive/personal questions
- Although all participants were fluent in either Spanish or English, these were not always their first/native languages and lead to the need for additional clarification/simplification of questions

## IMPLICATIONS & LESSONS LEARNED

This research may inform the multidisciplinary care of pediatric cancer patients, in order to ultimately improve their health outcomes.

**Lessons learned about survey development, interviewing, and the overall study**

- Survey development is an iterative process and will likely involve numerous revisions.
- Tailor the language to the audience. The simpler, the better.
- Importance of being attuned to participants' tone, pauses/silences, environment, etc.
- Importance of using neutral, non-charged, and non-leading language while still showing empathy when appropriate
- Importance of interviewing consistency among interviewers to ensure reliable results
- Much of the project also involved learning about the ins and outs of a study and how to work together to ensure all project tasks are completed efficiently. This required constant and clear communication and coordination between all team members, who had different perspectives to offer based on their respective fields of interest.

## REFERENCES:

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