

The PaCER Perspective

July 2020

Who are we?

Our inter-generational, diverse team brings together parents of IBD patients, siblings of IBD patients, patients themselves and various professional voices to coalesce into an effective research group able to empathize with IBD patients. We understand the emotional and physical implications of receiving an IBD diagnosis and thus provide a non-clinical, supportive experience for IBD patients who wish to participate in qualitative research.

Despite being a large group of seven, spanning ages 25-61, we were effective due to our common goal of wishing to improve IBD outcomes. We shared our personal experiences, whether they were negative or positive and learned from each other, all the while being sensitive to each team members' needs, strengths, and weaknesses.

What was it like to be a patient leading a research project?

As patient researchers, we believe we share a unique bond with our patient participants. We recognize the importance of bringing the patient voice/perspective to research. We have shared experiences which allow for an insightful, empathetic experience. We were mindful of not allowing our biases and personal healthcare experiences to cloud a situation but to clarify. The PaCER motto "by patients with patients and for patients" is very fitting.

How much time did you commit to this research project and PaCER certification?

The PaCER certification program consists of three consecutive courses spanning one-year culminating in a research project and paper. The amount of time needed to complete the first two course deliverables varied from a few hours a week to 10 hours per week. The hours required during the last course were more concentrated within blocks of time due to focus group, interview, and data analyses requirements. As expected, writing the research project paper required collaborative team sessions and sustained effort by all team members over several weeks.

What did you learn going through the research process?

As we were all narrative research novices, PaCER provided the framework. We incorporated PaCER methodology to progress through the program utilizing the SET, COLLECT and REFLECT focus groups and individual interviews to formulate a qualitative research project derived from patient stories. We learned how to facilitate focus groups, take flip chart notes and process notes as well as conduct semi-structured and narrative interviews. We used both in person and a variety of online programs and platforms to facilitate our interactions with one another and with our study participants. Data analysis of narrative research required grouping information into categories, clear definition of these categories and disclosure of our biases. We learned the difference between quantitative and qualitative research.

What challenges did you experience and how did you navigate them?

An anticipated challenge was due to our large group size of seven. A large group can be unwieldy and cumbersome. However, due to strong leadership and our diversity of experience and strengths, we coalesced into an effective group which projected goodwill and mutual respect. As we are in different life stages, team members were able to support each other, and collaborate to allow a team member to excel, build upon their strengths and learn new skills. We managed the workload to ensure that each member made a valuable contribution. We complemented each other!

An unanticipated challenge was due to mentors needing to step back due to illness. We were assigned three different mentors, which in retrospect, enriched the experience despite being frustrating at the time. We referred to our online learning materials, problem solved amongst ourselves and reached out only when needed for guidance and clarification from our current mentor being respectful of her health challenges. Given the fact that we have all witnessed these struggles and setbacks with our own, our children's' and/or our siblings health, we were flexible, understanding and patient.

A surprising challenge was due to the nature of PaCER where the narrative drives the research question. Due to this our team, at times, struggled with the purpose of our research as we were most familiar with research that starts with a hypothesis. Journaling, talking to our mentors and seeing the appreciation expressed by our participants helped us with that challenge.

Can you tell us about your results?

Our research focused on what was important to patients immediately following their diagnosis. Patient participants shared stories of their experiences post diagnosis, including what went well and what could be improved upon. These experiences fell into one overarching category and three distinct categories of which one, based on patient participant ranking, became the primary category. The research paper is in the final draft with the academic reviewer.

Prior to the COVID – 19 pandemic we had submitted abstracts to three conferences, ABSPORU 2020, IIQM Thinking Qualitatively and CAHSPR 2020. ABSPORU 2020 is postponed with no new date set, IIQM Thinking Qualitatively is postponed to July 2021 and our abstract was not accepted in CAHSPR 2020 due to the large number of submissions.

What advice do you have to patient who would like to get engaged in health research?

Enter the process with an open mind. Accept that your contribution, despite you having little or no research background or limited IT skills, will be valuable. Be prepared for a rewarding, but challenging experience that will force you to self-reflect and grow as an individual, embrace concepts outside your comfort zone, meet new people, work as a team, and recognize and solve conflicts. The reward is being able to contribute to improving patient outcomes with “just your unique patient experience”.

One of our team members is preparing a manuscript for the purpose of publishing. More to come...

Thank you to our mentors, teachers, and sponsors:

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