

Capstone for Impact Submission | GY2019

Project Title: Pediatric palliative care patients who have chronic complex conditions transitioning from

pediatric providers to adult providers

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Advisor Names(s): Kenneth Pituch

Branch: Systems & Hospital Based Care

Path of Excellence: Scientific Discovery

Handover/Transition:

If this project can be continued by another UMMS student, you may contact them at the following email address/phone number (N/A if project cannot be handed over): ncremer17@gmail.com

Summary:

I interviewed 6 pediatric palliative care patients who have chronic complex conditions who are between the ages of 18 and 23 about their personal experiences transitioning from pediatric providers to adult providers. We discussed their fears, concerns, what went well and what didn't, and how as a health care system, we can make transitions a smoother process. We summarized our findings in an article and are planning to publish it.

Methodology:

In person interviews and summary of findings

Results/Conclusion:

The transition from pediatric providers to adult providers is challenging for any patient, but for patients with chronic complex medical conditions there are several additional challenges. These challenges include the personal connection that these patients and their families have with their pediatric providers, the lack of support services while inpatient on the adult side (i.e. therapeutic activities such as art), and the fact that many chronic complex care patients are not at the same level as their peers socially and developmentally.

Reflection/Lessons Learned:

I learned how valuable it is to talk face-to-face with patients about their health care experiences. So often as a medical student, I focused on the diagnosis and treatment and didn't stop to think about things that really mattered to the patient like their hospital experience and relationships with their health care providers.