Clinical observations

Supporting the Medically Fragile: Individualized Approach to Empowering Young Adults With Chronic Disease During the COVID-19 Pandemic

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Article history: Received May 1, 2020; Accepted June 17, 2020

Keywords: Young adults; Chronic disease; System navigation; Care fragmentation; Vulnerabilities; COVID-19; Pandemic Empowerment; Psychosocially complex; Emergency preparedness

ABSTRACT

Young adults with chronic and complex diseases face systemic barriers, care fragmentation, and increased vulnerabilities. Novel coronavirus pandemic has proven to further complicate care coordination for young adult patients with medical and psychosocial complexities. The BRIDGES Young Adult Program at Boston Children’s Hospital has 6 years of experience advocating for and empowering young adults with chronic medical conditions, and their families, through outpatient consults aimed to assist with subspecialty guidance and defragmentation of care during the time of transition from pediatric to adult care. Recently, the BRIDGES consult team developed a pandemic-responsive approach to facilitate individual emergency planning and empowerment of self-management for these high-risk patients. Through the use of a virtual platform, consults were conducted with a multidisciplinary team to support patients and families with system navigation, advance care planning, emergency preparedness, chronic care management, and coping during this time of crisis. BRIDGES aimed to equip patients and families with knowledge and resources, within a rapidly changing environment, to allow for optimal self-care and self-advocacy.

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assumed that primary care physicians spent time with our complex patients discussing advance care planning and COVID-19 preparedness; however, as a result of rapid changes in the health system, minimal time was allotted for these discussions. Our program filled that gap.

COVID-19 unmasked fragmentation of the health system, particularly the barriers preventing coordinated safe care for patients facing complexities. In response, our team created a pandemic-responsive approach through a virtual consult platform to address the needs of the medically complex. Moreover, in this evolving pandemic state, we hope to empower our high-risk patients and families by building on our existing multidisciplinary consult process to include individualized discussions on advance care planning, understanding risk and prevention of COVID-19, stress management, and emergency planning.

Virtual Visit Process

Patient demographics

Patients with at least one pediatric onset illness and at least three chronic morbidities met inclusion criteria. The referral process for BRIDGES consults remained the same; however, patients who had been seen by BRIDGES in the last 9 months were also offered a virtual visit via phone call. Of the initial cohort of patients, a subset of patients were non-native English speakers (30%), 80% of patients depended on private duty nursing or personal care attendants for medical care and activities of daily living, and 80% were medical technology dependent.

Preplanning

As hospital policies shifted for virtual visits in late March 2020, BRIDGES recognized its unique position to meet through virtual platforms. Patients were identified, and if interested, they were scheduled for a 1-hour visit with our multidisciplinary team through a phone call interaction or Zoom virtual platform. Before the scheduled appointment, the BRIDGES multidisciplinary team, including an attending physician, nurse practitioner, social worker, and nurse transition coordinator, would meet for 30 minutes to discuss details of the previously reviewed patient history.

During the visit

BRIDGES opened each visit with standard goal setting. Patients and families were asked to identify three concerns. Similarly, BRIDGES identified the following broad priorities: (1) emergency preparedness; (2) COVID-related questions; and (3) discussing advance care planning and health care proxy.

During the visit, the physician led the discussion with acute concerns related to COVID-19, health system navigation, and advance care planning. The nurse practitioner discussed care for chronic conditions during this time; the nurse transition coordinator reviewed durable medical equipment, medications, and primary care needs; and social work concluded with assessment of social supports, general well-being, and coping strategies.

BRIDGES response

Without BRIDGES support, patients who were unsuccessful in reaching providers, pharmacies, or medical supply companies may have presented to emergency departments to get needed medications or supplies. In one case, a patient was found to have new onset COVID-19 symptoms during the visit, the family did not know how to obtain testing, and BRIDGES spent time organizing testing for the patient and family. Given the patient's complicated history, this process needed to be carefully planned and appropriate providers notified.

Determining if a hospital was diverting patients, availability of testing and facility-specific admissions processes were considered for each patient to determine the best point of contact and subsequent entry should they need to seek care. Furthermore, BRIDGES advocated for patients to be equipped with a medical summary. Its utility is notably evident during this public health crisis, as our patients have rare pediatric onset disease and in the setting of an emergency could present to an adult emergency department where their condition is poorly understood. Moreover, necessary adaptations to care plans were made, examples include troubleshooting around obtaining medications and medical equipment, infection control, navigating virtual visits, and who to notify in the setting of new symptoms or exposures.

Given today's uncertainty and our complex chronic population, advance care planning was identified by our clinical team as an important item to address. BRIDGES used the Boston Children's Hospital Massachusetts Health Care Proxy form to provide education and documentation for assigning a health care proxy.

Most patients and caregivers identified a diversion from their typical routine, noted difficulty managing anxiety around the virus, and reported feeling isolated. As applicable, BRIDGES emailed interested patients and families free resources such as websites for virtual museum visits, exercise programs, meditation and mindfulness programs, and virtual support communities.

COVID-specific learnings

Similar to the needs of elderly patients, this patient population and these visits highlight the unique nature of this care. Specifically, as patients are in young adulthood, their parents are often older and, in the setting of COVID, are high risk themselves. Many families were facing lack of help; availability of home nurses and nonlicensed personnel were significantly reduced or null, and families were concerned about who would provide care if they were to become ill. Caregivers reported feelings of burnout and distress as a result.

Implications and Conclusions

This virtual visit process has allowed BRIDGES to tailor visits to the unique needs of our patient population. Given the unprecedented times, we were able to decentralize our approach beyond the normal confines of the health system. The need to further provide individualized support around symptom and chronic care management during the COVID-19 pandemic is apparent. The nature of chronic and complex
disease does not easily fit into a standardized process but rather requires high frequency of health system interface. Our response continues to have limitations, as many patients do not have access to virtual platforms and/or have disabilities that make such communication unfavorable. As COVID-19 has continued to unmask deep-seeded systemic fragmentation, we are tasked with providing innovative equitable solutions to those most affected by structural failures. The BRIDGES response supports patients and caregivers by meeting them exactly where they are to address the uniqueness of one’s diagnosis and social situation, including one's strengths, vulnerabilities, and barriers to achieve safe and responsive care in an ever-changing health care environment.

**Funding Sources**

This study was supported by Stuart and Jane Weitzman Foundation. The Foundation had no direct involvement in clinical case observations, writing of this report, or decision to submit for publication.