

Health Priorities of Multi-Morbid Ambulatory Patients in New York City During the COVID-19 Pandemic: A Qualitative Analysis

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Abstract: During the COVID-19 pandemic, adults with chronic conditions delayed or avoided seeking preventative and general medical care, leading to adverse consequences for morbidity and mortality. In order to bring patients back into care, we, in this qualitative study, sought to understand the foremost health-related needs of our multi-morbid ambulatory patients to inform future outreach interventions. Via a telephone-based survey of our high-risk patients, defined using a validated EPIC risk model for hospitalization and ED visits, we surveyed 214 participants an open-ended question, “What is your top health concern that you would like to speak with a doctor or nurse about?”. We found 4 major themes: 1) primary care matters, 2) disruptions in health care, 3) COVID-19’s impact on physical and mental health, and 4) amplified social vulnerabilities. Our results suggest that interventions that reduce barriers to preventative services and disruptions to healthcare delivery are needed.

Keywords: health priority, primary care, multi-morbidity, ambulatory patients

Introduction

Several recent studies have found that during the COVID-19 pandemic, adults with chronic conditions and non-COVID-related medical complaints have delayed or avoided seeking preventative health services and general medical care.¹⁻³ Possible reasons for this include early stay-at-home orders, ambulatory care clinic closures, fear surrounding exposure to coronavirus, among many others. However, this has adverse consequences for chronic disease management, morbidity, and mortality.¹⁻³ To elucidate the top medical needs of multi-morbid patients in our ambulatory practice during the COVID-19 pandemic, we conducted a qualitative study to elicit their health priorities. Findings could inform future outreach efforts and interventions to meet patient needs and bring them back into care.

Materials and Methods

This qualitative study was part of a larger telephone-based survey with mixed quantitative and qualitative components conducted from 5/2020 to 3/2021 at a large, academic, hospital-based primary care practice in New York City. The telephone-based survey, which included novel and validated questions, was intended to understand and address the health-related needs and challenges of multi-morbid high-risk patients at our ambulatory practice during the COVID-19 pandemic. The novel questions were guided and informed by the Andersen and Aday model of factors influencing health services utilization. The validated questions included selected questions from the Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) Screening Tool. The results of the quantitative components of the survey are reported in a separate investigation.⁴ Demographics such as age, sex, race, ethnicity, and insurance type were also collected. We defined high-risk patients using a validated Epic risk model for hospitalization and emergency department (ED) visits, which is based on 55 variables such as number of chronic medical conditions, medication burden, and prior

health care utilization.⁵ Trained medical students and care managers administered the survey. We included an open-ended question at the end, “What is your top health concern that you would like to speak with a doctor or nurse about”, which was the focus of this study.

We performed a thematic analysis of the data collected from this open-ended question. First, two investigators (D. B. and D.M.) independently coded the first twenty responses. Next, one investigator (P.B.L.) reviewed the codes, reconciled discrepancies, and consolidated them into a codebook. The codebook was applied to the remaining responses and the process was repeated. Two investigators (A.C.M. and M.R.S.) reviewed the final codebook. As a team, codes were consolidated into categories and themes, by censuses. To ensure that our thematic analysis was rigorous and of high quality, we followed the Braun and Clarke 15-point Checklist for Thematic Analysis.⁶ Data saturation, or the point at which no new themes emerged, was achieved the 160th interview. Additional interviews were conducted as part of a practice wide quality improvement initiative and coordinated outreach effort to identify patient needs.

Verbal informed consent was obtained with each participant during the telephonic interview at the height of the COVID-19 pandemic. The protocol (20–06022217) was approved by The Weill Cornell Medicine Institutional Review Board (IRB) and was determined by the IRB that the study protocol does not constitute human subjects research as the intent solely pertains to quality improvement and quality assurance activities. All patient data collected was anonymized which has not distorted the scholarly meaning.

Results

Two hundred and ninety-nine high-risk patients were identified for outreach based on inclusion criteria. Eighty-five patients were excluded because they were unreachable by phone ($n = 59$), declined to participate ($n = 12$), were seeking primary care elsewhere ($n = 7$), and had passed away ($n = 7$). A total of 214 high-risk ambulatory patients participated in the study. The majority were over 60 years old (75.7%), 66.4% were female, 25.7% were Black, 30.4% were Hispanic/Latino, 66.4% had Medicare (Table 1). Four major themes emerged, which are outlined in Table 2.

Theme I: Primary Care Matters

Participants described a need for their chronic conditions (such as coronary heart disease, diabetes, and chronic pain) to be managed at our practice and to address non-COVID-related medical issues to avoid worsening of health outcomes. Additionally, despite the restraints imposed by the pandemic, many voiced a desire to receive routine preventative care,

Table 1 Characteristics of Study Participants

Characteristics	Overall (n=214) n (%)
Demographics	
Age	
Under 60	52 (24.3%)
60–79	113 (52.8%)
80 or older	49 (22.9%)
Female	142 (66.4%)
Race	
Other	83 (38.8%)
Mixed	6 (2.8%)
Black	55 (25.7%)
White	70 (32.7%)
Hispanic/Latino	65 (30.4%)
Insurance	
Other	35 (16.4%)
Medicare	142 (66.4%)
Medicaid	37 (17.3%)

Table 2 Summary of Major Themes and Subthemes

Major Themes	Sub-Themes
Primary Care Matters	Desire for preventative care
	Managing chronic conditions
	Managing acute non-COVID related symptoms
	Gateway to other providers
Disruptions In Health Care	Difficulty getting medical, diagnostic, and therapeutic appointments
	Communication challenges about medical care
	Delays in medications and medical equipment
COVID-19's Impact On Physical And Mental Health	COVID precautions and best-practices
	Mental Health
	Fear of COVID impact on health
Amplified Social Vulnerabilities	Housing instability and food insecurity
	Uncertainty regarding home care services

including receiving routine immunizations and cancer screenings like mammograms. Another function of primary care that was remarked upon was the role of primary care to connect patients to needed sub-specialty services through referrals. With impaired services to primary care, some felt their access to sub-specialty services was also limited.

Theme 2: Disruptions in Health Care

Due to COVID-19, patients reported difficulties with appointment cancellations and scheduling new appointments with primary care providers, subspecialists, and health centers (including dialysis and infusion centers). They were unclear how to best respond to cancelled appointments with subspecialists, for procedures, surgeries, and imaging. The described diminished capacity for clear patient education and communication led to uncertain management of chronic conditions as perceived by the patient. They also voiced frustration with delays in obtaining test results, medications, referrals, durable medical equipment, and procedures.

Theme 3: COVID-19's Impact on Physical and Mental Health

Participants expressed difficulty with balancing their fears of COVID-19 exposure with the need to seek in-person care for acute or chronic medical issues. This was especially a concern for those who perceived their chronic disease portended to worsen health outcomes if they contracted COVID. Additionally, social distancing heightened feelings of isolation, anxiety, and sadness. This was compounded by the lack of access to mental health services and placed an increased reliance on primary care services.

Theme 4: Amplified Social Vulnerabilities

Furthermore, several participants explained that COVID-19 adversely affected their financial stability, including their ability to maintain housing, help at home, and food. Patients who relied on home care workers worried about their caretakers, if found to be positive for COVID, would be pulled out of the workforce and unable to care for them because of isolation needs. As such, a top health concern was to obtain help with social services.

Discussion

This qualitative study expands our understanding of the perspectives of multi-morbid patients in primary care and their health-related needs one year into the COVID-19 pandemic. Early in the pandemic, most institutional priorities were, rightfully so, to ensure the safety of our patients from exposure to COVID-19 and thus shifted focus to urgent infection control concerns. However, during that time, we found that primary care was still a priority for patients, both its ability to manage existing chronic conditions, but also to provide preventative health services which may have been delayed or missed. Despite a desire for healthcare and healthcare services, healthcare delivery interruption made obtaining care challenging. Participants also shared that COVID-19 took a toll on their emotional and financial health and supports. Of the individuals with social vulnerabilities prior to the COVID-19 pandemic, those vulnerabilities only amplified during this time. These findings are important because as practices reopen and reimagine primary care's role in future pandemics, an understanding of patients' top health priorities should be sought to provide patient-centered care. The myopia of reactionary medical care should be avoided. Resources should be devoted to keep our patients' healthy over the long term, thus staying true to the tenets of primary care: ongoing patient monitoring, early detection, and prevention.

Our participants' concerns mirror the reality noted in the dramatic decline in preventative screening and monitoring of chronic disease during the pandemic.⁷ The overall risk incurred due to such declines has yet to be defined, however models suspect there will be longer-term population-based consequences to the delays in detection, prevention, and treatment of chronic disease. Moreover, it is well understood that the patient's health status and chronic disease burden contribute as major risk factors of COVID-19 disease severity.⁸ Practices should be aware that, based on our study, even in a pandemic when practices may assume that preventative care is a lower priority, patients still want preventive screening and chronic disease management. Additionally appropriate management of chronic disease may reduce the disease burden if patients were to contract COVID-19. Registries of patients with these gaps in care should be created and targeted outreach should be made to individuals with these disparities in care.

Additionally, reports of excess morbidity and mortality from non-COVID related complaints emerged – such as heart disease, diabetes, and stroke⁹ paralleling our study participants' worries. Our study participants highlighted that at all levels of healthcare, from primary care to subspecialty, from medications to procedures, disruptions were experienced. The findings suggest that changes to chronic care services to address urgent COVID-19 concerns were not adequately balanced with recognition of the persistent high priority chronic disease management needs of our high-risk ambulatory patients.

Study limitations include a small sample size and an inability to generalize the findings beyond a single academic practice. Additionally, the majority of our study population was over the age of 60. This may confer additional vulnerable needs as compared to a younger population. Our interviews also took place over the course of the first year into the COVID-19 pandemic. With evolving therapeutics and preventative strategies like vaccinations available at differing time points, it may be difficult to aggregate all the data. However, our chosen end point of this study took place prior to vaccinations being available for all adults in the United States (April 2021), which thus highlights the early pandemic priorities of our study participants.

Conclusion

In conclusion, our results suggest that patients highly value the contributions of primary care, even during a global pandemic where the assumption may be to focus on the acute over the chronic medical issues of individuals. Interventions that reduce barriers to preventative services and disruptions to healthcare delivery, like maintaining care gap registries and performing proactive telehealth outreach efforts to multi-morbid patients by a multi-disciplinary, are warranted. Additionally, policies which can address the financial and social vulnerabilities of patients, like expansion of local, state and federal social safety net programs, are needed in this unique time of COVID. Future studies examining the impact of programming that factor in patients' priorities, such as the ones described here, are welcomed.

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Disclosure

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