

BRIEF REPORT

Patient Barriers to Accessing Referred Resources for Unmet Social Needs

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Introduction: Many primary care clinics screen patients for their unmet social needs, such as food insecurity and housing instability, and refer them to community-based organizations (CBOs). However, the ability for patients to have their needs met is difficult to evaluate and address. This study explores patient-reported barriers to accessing referred resources using a conceptual framework that identifies opportunities for intervening to optimize success.

Methods: Patients who participated in a social needs screening and referral intervention at a Federally Qualified Health Center (FQHC) were called 2 weeks after the clinic encounter. We conducted a directed content analysis across 6 domains of access to examine responses from patients who reported barriers.

Results: Of the 462 patients that were reached for follow-up, 366 patients reported 537 total barriers. The most frequent challenges related to resource availability (24.6%, eg, patients waiting for submitted application to process) and approachability (23.8%, eg, patients lacking information needed to contact or access resources). Barriers in the domains of acceptability (21.6%, eg, competing life priorities such as medical issues, major life events, or caretaking responsibilities) and appropriateness (17.9%, eg, resource no longer needed) largely represented patient constraints expressed only after the clinical encounter. It was less common for patients to identify accommodation (eg, physical limitations, language barriers, transportation barriers, administrative complexity) or affordability of community resources as barriers (11.2% and 0.9%, respectively).

Conclusion: Findings suggest opportunities for improvement across the access continuum, from initial referrals from primary care staff during the clinical encounter to patients' attempts to accessing services in the community. Future efforts should consider increased collaboration between health and social service organizations, and advocacy for structural changes that mitigate system-level barriers related to resource availability and administrative complexity. (J Am Board Fam Med 2022;35:793–802.)

Keywords: Communication Barriers, Community Health Centers, Follow-Up Studies, Food Insecurity, Health Services Accessibility, Housing Instability, Patient Navigation, Patient Reported Outcome Measures, Population Health, Referral and Consultation, Social Determinants of Health, Social Problems

Introduction

Compelling research has demonstrated the strong link between adverse social determinants of health

and poor health outcomes.^{1–4} This large body of evidence, coupled with recent value-based payment reforms, has resulted in growing interest to address individual-level, social needs in health care settings.^{5,6} Multiple medical professional associations across specialties, including the National Academies of Sciences, Engineering and Medicine, have recommended screening for social needs as part

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of routine clinical care.^{7–10} A cross-sectional survey found that 15% of primary care clinics and 30% of Federally Qualified Health Centers (FQHCs) nationwide assess patients for multiple social needs, including food insecurity, housing instability, utility needs, transportation needs, and interpersonal violence.¹¹ To respond to identified needs, many practices have also implemented interventions to connect patients with community-based organizations (CBOs) or government programs.^{12–15} Unfortunately, primary care clinics are often limited in their capacity to continue follow-up with patients to ensure needs are met, and patients are likely to experience barriers with receiving services once referred.^{14,16} This study aims to examine patient-reported barriers to accessing resources for social needs, and explore differences in barriers before and during the COVID-19 pandemic.

Methods

Program Description and Data Collection

From March 2019 to December 2020, clinic case managers at a Federally Qualified Health Center (FQHC) in North Carolina screened 1682 patients for unmet social needs using the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) tool as part of routine clinical care. Example domains from the PRAPARE tool include food, utilities, transportation, housing, employment, stress, social isolation, and domestic violence.¹⁷ Among patients who screened positive for an unmet need, 756 requested to receive resource referrals from case managers. Referrals ranged from clinic-based resources (eg, transportation van), CBOs (eg, food pantries), and government programs (eg, public housing). For patients given resource referrals, case managers offered additional telephonic follow-up support from trained student volunteer community resource navigators.

Navigators attempted to reach 646 patients who agreed to follow-up support within 2 weeks of the clinical encounter when the initial referral(s) were made. Navigators were trained to remind patients about their referrals and motivate follow-through, provide specific information about accessing resources (eg, application process, resource location, hours of operation), and reconnect patients with case managers when needed per our escalation protocol. When patients reported not connecting

to 1 or more resource referrals, navigators asked, "Were there any reasons you were not able to connect with [the resource(s)]?" Navigators summarized and documented responses from patients as free text notes in a secure, REDCAP electronic database.¹⁸ Program details, including the screening instrument, workflows, and navigator training, are described in detail elsewhere.^{19–22}

On March 10, 2020, North Carolina declared a state of emergency for the COVID-19 pandemic. Due to pandemic safety precautions, between March 2020 and December 2020, case managers shifted from screening patients for social needs in-person to conducting proactive telephonic screening for the lowest income patients, identified through reports from the clinic's finance department. Navigators continued to follow-up with patients telephonically. During the pandemic, many CBOs closed due to stay-at-home orders or reduced capacity due to increased demand for services or inadequate staffing. New social services also emerged to meet community needs during the pandemic (eg, COVID-19 emergency financial assistance, drive-through meals at schools and food delivery programs).

Qualitative Analysis

We conducted a directed qualitative content analysis on responses from patients who reported barriers during follow-up. Codes were based on the 6 dimensions of access (approachability, acceptability, availability, accommodation, affordability, and appropriateness) adapted from Levesque et al.'s conceptual framework,²³ and subcodes were refined from the data itself (codebook with definitions in Appendix Table 1). Levesque et al.'s framework is widely-used in public and population health and can be used to operationalize determinants to access throughout the full process of obtaining health and social services. While the original framework includes both service-level (supply-side) and patient-level dimensions (demand-side) dimensions, we focused on conceptualizing barriers at the service-level. Such an approach allows researchers and practitioners to identify concrete improvement opportunities for health and social services across the access continuum rather than blaming or attributing barriers to patients themselves.

Two researchers (SS and LS) independently coded responses in Microsoft Excel; a third researcher (TL) reconciled discrepancies. We used Stata (Release 16;

Table 1. Characteristics of Patients Who Reported Barriers to Access (n = 366)

Patient Characteristic	Patient Sample, % (n)
Age, med. (Q1 – Q3)	51.4 (42.0–58.9)
Sex	
Female	66.2 (231)
Male	33.8 (118)
Race/Ethnicity	
Black, non-Hispanic	48.9 (163)
White, non-Hispanic	9.6 (32)
Hispanic*	41.2 (148)
Primary language	
English	62.0 (227)
Spanish	37.7 (138)
Other	0.3 (1)
Highest level of education	
Less than high school	36.7 (125)
High school or GED	37.0 (126)
More than high school	26.4 (90)
Work situation	
Full-time	14.7 (53)
Part-time	15.0 (54)
Unemployed, seeking work	41.0 (148)
Unemployed, not seeking work	29.4 (106)
Main insurance	
Uninsured	71.8 (262)
Medicaid	11.5 (42)
Medicare	11.2 (41)
Other public	4.7 (17)
Private	0.8 (3)
Unmet social needs documented	
Housing	44.3 (159)
Access to medicine or healthcare	41.9 (152)
Food	39.4 (143)
High stress	39.2 (142)
Social isolation	32.0 (116)
Transportation	22.7 (82)
Utilities	21.2 (77)
Safety at residence	6.9 (25)
Afraid of partner	3.9 (14)
Number of received referrals, med. (Q1 – Q3)	2 (1–3)
Category of received referrals	
Access to medicine or healthcare	49.7 (182)
Food	41.5 (152)
Financial assistance	35.8 (131)
Social or emotional health	22.7 (83)
Transportation	12.8 (47)
Housing	9.8 (36)
Other	11.5 (42)

*Continued***Table 1. Continued**

Patient Characteristic	Patient Sample, % (n)
Connection status with referral at 2-weeks	
Started services with a resource	19.8 (71)
In process of starting services with a resource	17.8 (64)
Contact attempted with at least one resource	15.3 (55)
Contact not attempted with any resources	47.1 (169)

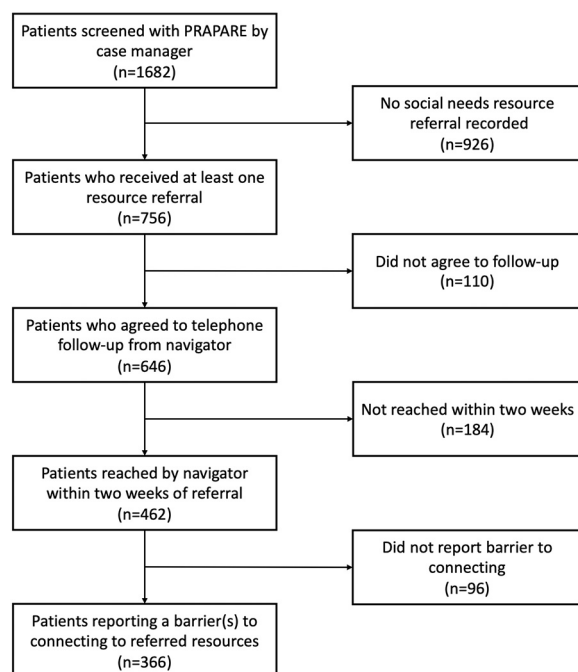
*Missing data for race was observed.

StataCorp LLC, College Station, TX) to calculate the frequency of patient-reported reasons by access dimension and compared frequencies before and after the state of emergency declaration in North Carolina (March 10, 2020) using Fisher's exact test. This project received exempt approval from the Duke Health Institutional Review Board.

Results

Of the 462 patients that were reached for follow-up, 366 patients reported a barrier to connecting to a referred resource and were included in our analysis (Figure 1). Patients who reported barriers were middle age, 41.2% Hispanic (37.7% Spanish as primary language), 48.9% Black non-Hispanic, 70.4% unemployed, and 71.8% uninsured (Table 1). Patient demographics of our sample largely mirrored the broader population served by the FQHC as reported in 2020 to the Health Resource and Services Administration (eg, 92% minority, 75% female).²⁴ Only 19.8% had started services with a resource within 2 weeks of the referral. Figure 2 displays the distribution of 537 barriers to accessing referred resources. The access dimensions availability (24.6%), approachability (23.8%), and acceptability (21.6%) represented the greatest number of barriers. Availability barriers included resources being unresponsive to contact attempts from patients (8.2%), and patients waiting for submitted application to process (9.1%). Approachability barriers presented when patients lacked information needed to contact or access resources (19.0%), or forgot about resources or scheduled appointments (4.8%). Acceptability barriers included competing priorities for patients (eg, medical priorities, life disruptions from hospitalization or death in the

Figure 1. Flow diagram of patients included in qualitative analysis. Abbreviation: PRAPARE, Responding to and Assessing Patients' Assets Risks and Experiences.



family, caretaking or childcare responsibilities) (14.2%), and patient distrust or prior negative experiences with resources (2.8%).

Compared with before the pandemic, patients screened after March 2020 more frequently reported barriers related to resources' capacity (eg, not able to take new clients or closed altogether) ($P=.004$), COVID-19 related concerns ($P=.049$), and language access ($P=.043$); it was less common to report competing family or health priorities as a barrier than before the pandemic ($P<.001$) (Appendix Table 2).

Discussion

This study is among the first to explore barriers that primary care patients face when accessing referred resources for social needs. Patients in this study were racially and ethnically diverse, mostly uninsured, and reported high levels of social risk (eg, housing instability, food insecurity, and poor access to medicine and health care). Our findings represented all service-level dimensions of access from Levesque's conceptual framework²³, and the most frequent barriers were related to resources' approachability, acceptability, and availability.

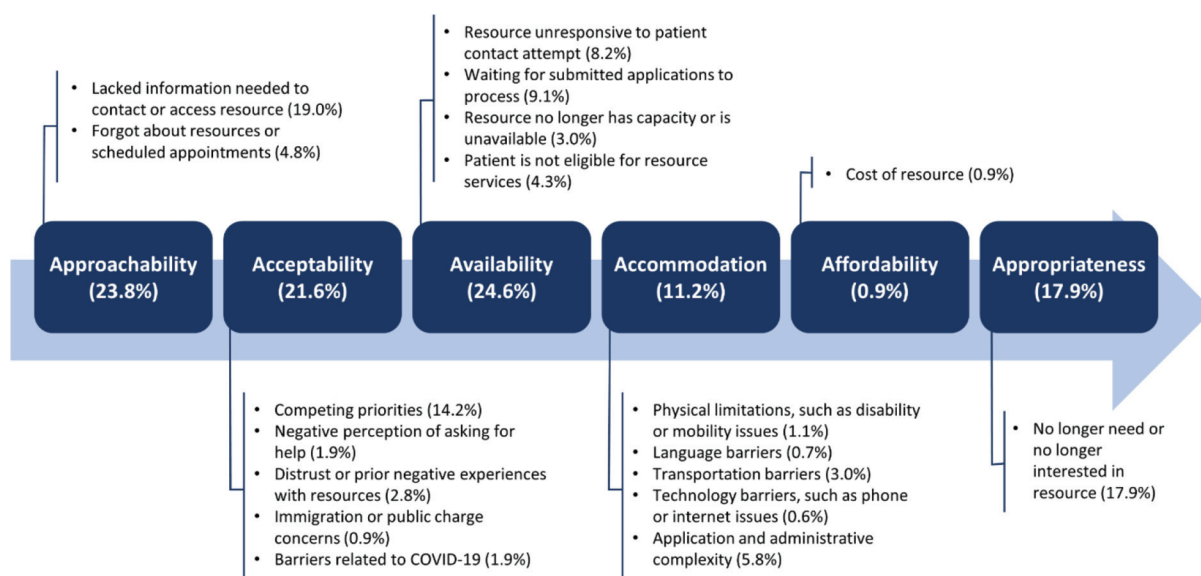
Mapping strategies to these barriers can guide opportunities to intervene during the clinical encounter, between clinic providers and CBOs, and for services directly supporting patients in the community to ultimately address unmet needs and support better health.

Nearly a fifth of reported barriers related to lacking information about resources, which calls attention to how referrals are presented to patients. This type of barrier to approachability may be prevented through better-designed, literacy-sensitive resource handouts, and information provided via multiple mediums (ie, article, e-mail, text), depending on patient preferences. A recent trial comparing the effect of 2 social risk interventions on the number of self-reported social risk factors and child and caregiver health suggested that high-quality, up-to-date written handouts, that specify contact names for services and highlight most relevant resources, could increase effectiveness.²⁵ Given that patient educational materials often do not reflect national guidelines for readability and suitability,²⁶ communication and education specialists could provide useful expertise for designing and testing strategies to address this critical gap.

Clinic staff must also consider how to increase referral appropriateness. Nearly a fifth of barriers related to patients no longer needing or being interested in a resource, indicating inadequate relevance of referrals to patients, or poor timeliness of the resources to provide assistance. Since the PRAPARE screening tool asks broadly about social needs over the past year, incorporating additional questions related to urgency, priority, and desire for assistance may result in more patient-centered referrals. More immediate follow-up and reminders, such as text messages or calls from staff and volunteers, can nudge patients to access resources closer to the clinic encounter. While our study focused on examining barriers for patients who accepted referrals, future research should also examine why many patients who screen positive for social risks are not interested in receiving assistance.²⁷

Overcoming barriers related to resource availability, acceptability, and accommodation may require collaborative action across sectors to address delays, complexities, distrust, and physical barriers. Existing models of collaboration between health and social services organizations are likely inadequate to fully address patients' social needs. Solutions may include colocation, standardized referral processes, and

Figure 2. Distribution of 537 patient-reported reasons for not accessing referred resources according to Levesque et al.'s conceptual framework for health care access^{a,b}.



^aEach access domain precedes the following 1 as a linear pathway to service utilization, from seeking care to reaching care to benefiting from care (eg, the resource referral must first be perceived as acceptable before issues of service availability are fully relevant to patients).

^bLevesque et al.'s original dimension of "availability and accommodation" was split into separate domains of "availability" and "accommodation" due to the large number and diversity of barriers represented in each domain.

community navigators.⁷ North Carolina is implementing a statewide technology platform that facilitates closed-loop referrals across health and social services.²⁸ The platform can also help identify resources that meet patients' accommodation needs, such as language preferences or physical limitations. Evaluation of this technology is still needed to assess its utility and effectiveness. These and other strategies need further investment as the COVID-19 pandemic has highlighted critical gaps in the social safety net, digital equity, and trust in communities.²¹

In addition to strengthening collaborations with CBOs to better support individual patients, health care providers should also consider how they can partner with CBOs to advocate for upstream policy changes at the system level. For example, health providers can advocate for policies to increase investment in social care resources, or advocate for reduced administrative burden of applications to social services.^{29,30} This is consistent with the implications found in a recent retrospective cohort study conducted at the same FQHC that found that a simplified, 'direct-access', and less complicated process for applying and receiving services was associated with a statistically significant increase in the

odds of successfully connecting with a referred resource.²² Additional qualitative research conducted with patients participating in the same social needs intervention at our FQHC also revealed that policy and societal level determinants related to resource availability and application processes were major barriers to referral success.²⁹

This study has several limitations. First, while we reached 72% of patients referred to follow-up by phone, it is possible that the distribution of barriers may change when accounting for patients not reached, particularly as patients reached were more likely to be referred to resources for food, financial assistance, and medicine and health care. Second, although our patient sample is large and diverse, this study is limited by the type of data we analyzed, obtained as written notes from navigators rather than verbatim responses recorded directly from patients. While we already conducted semistructured interviews to elicit more in-depth responses²⁹, future efforts may consider using structured surveys using our adapted framework to capture more quantitative data to test our qualitative findings and improve generalizability. Third, given our sample is limited to 1 FQHC in a midsized city, translation of our findings should be considered carefully by clinical and

community contexts. Larger studies are needed to study patient barriers across more diverse primary care contexts, including non-FQHC practices serving low-income populations and clinics in rural areas.

Our findings reveal the breadth of patient-reported barriers to connecting with referred resources for unmet social needs across the access continuum. Challenges begin with how primary care staff present referrals to patients during the clinical encounter, continue when patients attempt to access services in the community, and are further compounded by patients' individual contexts and previous experiences with social services. Our findings are consistent with previous reports describing intersecting systemic and personal barriers to accessing social services.^{31–33} While previous efforts have focused on social risk screening^{34,35}, continued innovation and investment are needed at each stage of the downstream process of assisting patients with their social needs to overcome patient barriers and optimize social care interventions.

To see this article online, please go to: <http://jabfm.org/content/35/4/791.full>.

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Appendix Table 1. Codebook for Patient-Reported Reasons for Not Connecting to a Referred Resource

Code #	General Category	Specific Barrier	Definition/Description	Exclusion(s)	Example
1.0	Approachability of Resources		Any description that implicitly or explicitly identifies an individual's ability to "identify that some form of services exists, can be reached, and have an impact on the health of the individual;" Any description that implicitly or explicitly refers to a patient's ability to be aware of and effectively utilize a service		
1.1		Lacked information needed to contact or access resource	Any description where a patient lacked complete information for resource (e.g., missing phone number, address, hours information); information gap		"did not receive public pantries handout;" "[patient] lost [resource] handout;" "[patient] never received info in the mail"
1.2		Forgot about resources or scheduled appointment	Any description where a patient did not remember referred resource		"patient did not remember the referrals;" "Patient was not aware that [patient] was provided or referred to these services"
2.0	Acceptability of Resources		Any description of an individual choice or circumstance that influenced the patient's decision to accept or seek a service or affected their perception of the appropriateness of seeking a service	Any description where patient forgot about resource	
2.1		Competing Priorities	Any description where the patient was too busy, experienced competing medical priorities, life disruption (e.g., hospitalization, death in the family), or caretaking or childcare responsibilities		"also has to manage schedules of son and grandson;" "patient wasn't feeling well, so did not reach out;" "[patient] has not had time . . . will try again after sister gets out of the hospital"
2.2		Negative perception of asking for help	Any description where a patient did not want to use services unless absolutely necessary or felt uncomfortable seeking/receiving help/assistance		"has not attempted to use [resources] because [patient] feels that others need it more"
2.3		Distrust or prior negative experiences with resources	Any description where a patient did not think resource would be able to help them or was skeptical about utility of resource, especially given previous experience with social services		"[patient] has also tried things before, but they didn't really do anything;" "patient has previously had bad experiences with [resources]"
		Immigration or public charge concerns	Any description where a patient did not feel comfortable accessing a resource due to fear related to immigration or public charge		"worried about public charge;" "wondering if [resources] will ask for papers/documentation"
		Barriers related to COVID-19	Any description where a patient did not feel comfortable accessing a resource due to COVID-19 related barriers (e.g., safety concerns of interacting with the public)		"was concerned about going due to rising cases;" "wants a cleaning, but is waiting for Corona to end"
3.0	Availability of Resources		Any reference where a resource lacks capacity to meet a patients' needs, is unable to do so in a timely manner, or patient is unable to make complete contact	Any reference where resource met some of the patients need but was not able to fully meet the entire demonstrated need	
3.1		Resource unresponsive to patient contact attempt	Any description where a patient attempted contact and resource never answered/called them back, patient was unable to make complete contact with resource		"called but nobody picked up;" "[patient] went to [resources] and most were closed"
3.2		Waiting for submitted applications to process	Any description where a patient has submitted an application for a resource but has not heard back yet/has not begun receiving resource/has yet to learn of eligibility for services		"waiting to hear back from [resource]"
3.3		Resource no longer has capacity or is unavailable	Any description where the resources were not able to take new clients or closed altogether		"[referral] no longer accepting patients;" "programs ran out of funds"
3.4		Patient is not eligible for resource services	Any description where a patient is ineligible to receive help from a resource (e.g., income, insurance status)		"[patient] was told that [patient] did not qualify because [patient] was also receiving aid from [other resource];" "patient has a felony on [patient] record from 10 years ago, disqualifying [patient] from [resource]"

(Continued)

4.0	Accommodation of Resources		Any reference to a resource's inability to accommodate patients' need in order to successfully connect	Any reference to general patient limitations that were not tied to ability to successfully connect (i.e. patient complains of chronic pain separately from reporting barriers)	
4.1		Physical limitations (e.g., disability, mobility, chronic pain)	Any reference to a resource's inability to accommodate a patient's physical status resulting in a patient's inability to successfully access or utilize a resource		"patient tried to use [resource] but said she wasn't able to because [patient] was disabled;" "has been immobile; so difficult to connect"
4.2		Language barriers	Any reference to a resource's inability to provide appropriate language services resulting in a patient's inability to successfully access or utilize a resource		"found [resource] to be useful but not great to use because of the lack of Spanish speakers;" "patient had not contacted the resources on the [resource sheet] because it was in English"
4.3		Transportation barriers	Any description where a patient was unable to access a resource because they did not have access to transportation and were physically unable to get to the physical location of the resource		"patient doesn't have transportation to services"
4.4		Technology barriers (e.g., phone, internet)	Any description where a patient was unable to access a resource or application for a resource due to a lack of necessary technology		"patient had not done the application, do not have access to internet;" "due to [patient] phone not working, [patient] hasn't been able to schedule another appointment to obtain more medication"
4.5		Application and administrative complexity	Any description where a patient needed help completing application (e.g., patient needed CM assistance with completing or scanning application forms)		"patient got proof of income for [resource] application. Will be bringing completed application at [clinic at next appointment];" "patient does not feel comfortable completing application online"
5.0	Affordability of Resource		Any description that implicitly or explicitly identifies cost or financial situation as a barrier to successfully connecting with and receiving a service		
5.1		Cost of resource	Any description where a resource's pricing exceeded a patient's capacity or ability to pay		"patient mentioned she does not have the money for the copay required by [resource];" "[resource requires] \$2000 down for a house, [patient] doesn't have that"
6.0	Appropriateness of Resource		Any reference to a "fit between services and [patient] needs" or timeliness of the referral and its fit		
6.1		No longer need or no longer interested in resource	Any description where a patient found another method of meeting need or otherwise stated that they were no longer interested		"[patient] was not interested in connecting to [resource];" "[patient] said [patient] was doing very well at the moment and did not need [resource]"

Adapted from: Levesque, J. F., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International journal for equity in health*, 12, 18. <https://doi.org/10.1186/1475-9276-12-18>

Appendix Table 2. Frequency of Patient-Reported Reasons for Not Accessing Referred Resource Before and During COVID-19 Pandemic

On March 10, 2020, the state of North Carolina declared a state of emergency for the COVID-19 pandemic. The “COVID-19” subsample of patients are all those who were screened on or after March 10, 2020

The association between the prevalence of a barrier and the patient’s screening date (before or after the onset of the COVID-19 pandemic) were assessed using Fisher’s exact test.

Barrier to Connection	Barriers of Patients, pre-COVID (% N=292)	Barriers of Patients, COVID (% N=245)	P-Value	Percent of Total Barriers Reported (% N=537)
Approachability of resources	21.2 (62)	26.9 (66)	0.128	23.8 (128)
Lacked information needed to contact or access resource	16.1 (47)	22.4 (55)	0.077	19.0 (102)
Forgot about resources or scheduled appointments	5.1 (15)	4.5 (11)	0.841	4.8 (26)
Acceptability of resources	26.3 (77)	15.9 (39)	0.004*	21.6 (116)
Competing priorities	19.2 (56)	8.2 (20)	<0.001*	14.2 (76)
Negative perception of asking for help	2.4 (7)	1.2 (3)	0.358	1.9 (10)
Distrust or prior negative experiences with resources	3.8 (11)	1.6 (4)	0.189	2.8 (15)
Immigration or public charge concerns	0.3 (1)	1.6 (4)	0.183	0.9 (5)
Barriers related to COVID-19	0.7 (2)	3.3 (8)	0.049*	1.9 (10)
Availability of resources	24.7 (72)	24.5 (60)	1.000	24.6 (132)
Resource unresponsive to patient contact attempt	7.9 (23)	8.6 (21)	0.875	8.2 (44)
Waiting for submitted applications to process	11.3 (33)	6.5 (16)	0.070	9.1 (49)
Resource no longer has capacity or is unavailable	1.0 (3)	5.3 (13)	0.004*	3.0 (16)
Patient is not eligible for resource services	4.5 (13)	4.1 (10)	1.000	4.3 (23)
Accommodation of resources	11.0 (32)	11.4 (28)	0.891	11.2 (60)
Physical limitations (e.g., disability, mobility issues)	1.7 (5)	0.4 (1)	0.227	1.1 (6)
Language barriers	0.0 (0)	1.6 (4)	0.043*	0.7 (4)
Transportation barriers	2.4 (7)	3.7 (9)	0.450	3.0 (16)
Technology barriers (e.g., phone, internet)	0.3 (1)	0.8 (2)	0.594	0.6 (3)
Application and administrative complexity	6.5 (19)	4.9 (12)	0.463	5.8 (31)
Affordability of resources	1.0 (3)	0.8 (2)	1.000	0.9 (5)
Cost of resource	1.0 (3)	0.8 (2)	1.000	0.9 (5)
Appropriateness of resources	15.8 (46)	20.4 (50)	0.176	17.9 (96)
No longer need or no longer interested in resource	15.8 (46)	20.4 (50)	0.176	17.9 (96)