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Opportunity to inform social needs within a hospital setting using data-driven patient engagement

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ABSTRACT

Background High-risk patients account for a disproportionate amount of healthcare use, necessitating the development of care delivery solutions aimed specifically at reducing this use. These interventions have largely been unsuccessful, perhaps due to a lack of attention to patients' social needs and engagement of patients in developing solutions.

Methods The project team used a combination of administrative data, information culled from charts and interviews with high-risk patients to understand social needs, the current experience of addressing social needs in the hospital, and patient preferences and identified opportunities for improvement. Interviews were conducted in March and April 2020, and patients were asked to reflect on their experiences both before and during the COVID-19 pandemic.

Results A total of 4579 patients with 26 168 visits to the emergency department and 2904 inpatient admissions in the previous year were identified. Qualitative analysis resulted in three themes: (1) the interaction between social needs, demographics, and health; (2) the hospital's role in addressing social needs; and (3) the impact of social needs on experiences of care. Themes related to experiences before and during COVID-19 did not differ. Three opportunities were identified: (1) training for staff related to stigma and trauma, (2) improved documentation of social needs and (3) creation of navigation programmes.

Discussion Certain demographic factors were clearly associated with an increased need for social support. Unfortunately, many factors identified by patients as mediating their need for such support were not consistently captured. Going forward, high-risk patients should be included in the development of quality improvement initiatives and programmes to address social needs.

INTRODUCTION

Worldwide, a subset of patients account for a disproportionate amount of healthcare costs.[1] This group of patients, often referred to as, 'high-cost users', are defined as those at risk and to whom the highest 5% of healthcare costs can be attributed.[2] In Canada, roughly 65% of hospital and home care costs have been attributed to high-cost users.[2 3] High-cost users are also frequently referred to as 'high-risk' patients, and from here,

this term will be used synonymously. Studies seeking to characterise high-risk patients frequently demonstrate that these individuals are significantly more likely to have been diagnosed with multiple chronic conditions, which often require more costly services and long-term care.[2–4]

Care delivery solutions aimed at reducing use of high-risk patients have included a wide variety of interventions[5–7] including increasing care coordination before, during and after hospital admission; providing direct care in the community; and 'hotspotting',[8] whereby patients were also connected to social services during hospital admissions. These interventions have largely been unsuccessful in terms of reducing use.[5–8] Possible explanations for variable success include the lack of addressing underlying social determinants of health, more broadly referred to as 'social needs', as well as a lack of patient inclusion in determining what opportunities best meet their needs.

Social determinants of health, most notably homelessness, have been implicated in dramatically increasing healthcare use, risk of death, harmful substance use, poor mental health and suicide.[9 10] Similar findings have been reported in studies looking specifically at Toronto's population, whose residents often struggle to obtain healthcare that adequately meets their needs.[11 12] Yet social determinants of health are typically absent from algorithms used to determine level of risk when creating inclusion criteria for interventions that target high-risk patients.[13] Therefore, much work still needs to be done in order to determine how healthcare organisations can address patients' social needs in the development of interventions for high-risk patients. This study aimed to understand key needs and gaps as defined by high-risk patients to inform subsequent interventions.

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METHODS

This project used qualitative methods guided by administrative data within a network of two large academic hospitals in downtown Toronto, Canada, in early 2020. We defined high-risk patients as anyone with over four emergency visits or three inpatient admissions in the previous year. The objective was to delineate the first step towards developing a quality improvement initiative by uncovering opportunities for the hospital to address the social needs of its high-risk patients.

The project team used a combination of administrative data, information found in patient charts, and interviews with high-risk patients to understand these individuals' social needs and their experience related to addressing their social needs in the hospital, patient preferences and self-identified opportunities for improvement.

Two sets of administrative data, one for patients with a high number of emergency department visits and one for patients with a high number of inpatient admissions, were obtained for high-risk patients from the previous year (2019). Data sets for inpatient admissions and emergency visits were not exclusive. Data included patient demographics, the diagnosis most responsible for the emergency department visit or for the inpatient admission and the length of stay. Demographics included age, sex, language and income level by quintile. International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10), codes (see online supplemental file 1) related to the visits and other markers, such as whether there was an address provided for the patient, a marker often used to classify those who are experiencing homelessness,[14 15] were used to flag visits as being related to homelessness, substance use, part of ongoing palliative care or as being avoidable, consistent with the commonly used Canadian list of ambulatory care-sensitive conditions.[16 17]

A sample of high-risk patient charts was reviewed in order to assess the current processes in place that aim related to address patients' social needs. Visit notes by various providers, as well as flags within the chart, were reviewed to see if, how and when social needs were captured—both those specific to the visit and those meant to give greater context to the patient's life and circumstance. Additionally, charts were reviewed to see if contact with a social worker occurred during the visit, whether referrals were made to community organisations that address social needs or if postdischarge follow-up specific to social needs was noted, as well as notes indicating a discussion around the existence of family and/or social support.

Patients whose charts were reviewed were also contacted for phone interviews. Interviews were conducted by phone because phone numbers are available through the patient charts, are low barrier to access and are more anonymous, and face-to-face interviews were not possible as interviews were conducted during the first wave of the COVID-19 pandemic. Semistructured interviews were conducted with patients over the phone by two

1. Can you tell me about a recent visit to the hospital? Did you feel comfortable talking to your healthcare team about social needs?
2. What are your thoughts on the hospital's role in helping people to make connections to social services in the community? Is this an appropriate location to have these conversations?
3. Thinking generally, what do you think is the best way to approach talking to patients about social needs in the hospital?
4. What was the most helpful part of your hospital visit? What is something that would have made it better?
5. Have you ever been connected with services in the community that address social needs? What has been the most helpful?

Figure 1 Guiding questions for patient interviews.

independent members of the project team (SH-G and CS) to discuss their experience and their opinions as to how the hospital could better identify and address their specific social needs, as well as those of other patients (figure 1). Interviewers were trained in health equity and had prior experience with interviews. Neither interviewer had any previous relationship with the patients being interviewed. When contacted, patients were informed about the purpose of the interview and given the opportunity to either consent or refuse to participate. Notably, interviews were conducted in late March and early April 2020, during the COVID-19 pandemic. Patients who had recent hospital visits were asked to reflect on hospital experiences both before and during the pandemic and were invited to provide feedback and suggestions for improving care. An interview guide was created by the project team and refined after the first five interviews were completed. Detailed notes were taken during the interviews, but they were not recorded.

Analysis

Descriptive analyses of patient visits and demographic data were used to describe the population of high-risk patients. The emergency department and inpatient data sets were analysed separately. Items of interest within charts were recorded as 'yes' or 'no', and detailed notes were made on any mention related to social needs. Following interviews with patients, charts were cross-checked with interview notes to determine consistency with patient accounts. Qualitative data from chart review notes and notes from patient interviews were coded and analysed by two independent members of the project team (SH-G and CS) using an iterative, constant comparative process that used descriptive and interpretive analyses, as well as open coding, thereby allowing themes in the data to be identified. The data were subsequently reviewed independently by four project team members (SH-G, CS, HS and AD; HS and AD were project interns) and then discussed to obtain consensus.

Patient and public involvement

This project was a component of a larger initiative guided by a multidisciplinary working group including a patient member and a public member. The working group was involved in the project design.

Table 1 High-risk patients and visit characteristics

		Emergency patients (n=3853)		Inpatients (n=726)	
		n	%	n	%
Number of visits (emergency patients) or admissions (inpatients)	Average/patient	6.79		3.68	
	Minimum/patient	4		3	
	Maximum/patient	183		20	
	Average for top 100	37.97		7	
	Average for top 50	52.32		8	
	Total visits	26 168	100	2674	100
Most responsible reasons for visits	Visits for substance use	2343	8.95	15	0.56
	Visits for mental health	1796	6.86	4	0.15
	Visits for palliative care	28	0.11	21	0.79
	Visits for homelessness	91	0.35	1	0.04
	Visits categorised as avoidable	1799	6.87	354	13.24
Cumulative length of stay/patient	Average	n/a		61.004	
	Minimum	n/a		31	
	Maximum	n/a		414	
Comorbidities/patient	Average	n/a		6.35	
	Minimum	n/a		0	
	Maximum	n/a		19	
No fixed address		349	9.06	1	0.14
No family doctor		875	22.7	43	5.92
Sex	Male	2108	54.71	403	55.51
Age	Under 18	4	0.10	–	0
	18–39	1105	28.68	87	11.98
	40–64	1392	36.13	301	41.46
	65–79	862	22.37	244	33.61
	80 and above	490	12.72	94	12.95
Language	English	3412	88.55	620	85.40
Income quintile	1—lowest	1106	28.70	178	24.52
	2—medium low	770	19.98	141	19.42
	3—medium	648	16.82	224	30.85
	4—medium high	445	11.55	154	21.21
	5—highest	465	12.07	120	16.53
	Missing	46	1.19	5	0.69
	Blank	373	9.68	4	0.55

RESULTS

There were a total of 4401 high-risk patients who had a combined total of 26 168 visits to the emergency department and 2674 inpatient admissions. The patient lists included 3853 patients with four or more emergency department visits and 726 patients with three or more inpatient admissions. Although 178 patients appeared on both lists, the lists were treated as separate data sets. The average number of emergency department visits was 6.79, but this number increased dramatically for the top 100 and top 50 high-risk patients (table 1). A large percentage of high-risk patients visiting the emergency department had no fixed address or family doctor, but the same was not true for the high-risk patients with inpatient admissions. High-risk patients visiting the emergency department were also younger than their inpatient counterparts.

Chart review and interviews

A sample of 74 high-risk patient charts were reviewed, evenly split between the emergency department and inpatient data sets. The samples were randomly generated, with 30 charts from each sample of taken from the top 100 high-risk patients, and the remaining seven randomly sampled from the bottom 100. The inpatient
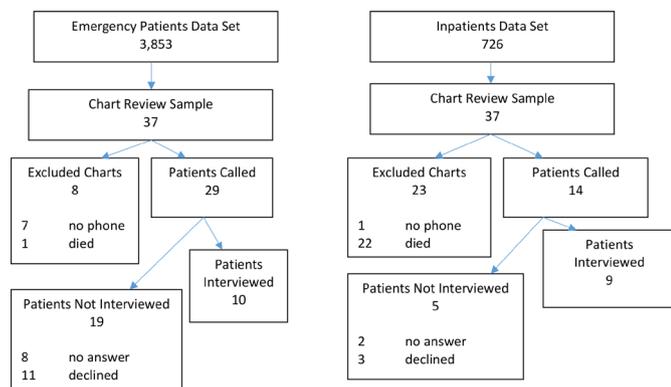
Figure 2 Patient interview inclusion flowchart.

and emergency department data sets were sampled separately.

A review of charts from patients in the emergency department data set revealed frequent mention of substance use and mental health challenges as the reason for the visits; considerably more than were found using the ICD-10 codes and other flags. Furthermore, many patients had behavioural warnings noted in the chart, but social worker involvement was mentioned infrequently. Charts from the inpatient data set, on the other hand, included more frequent mention of discussions about social needs and meetings with social workers, most of which were found within consult notes recorded during patient visits with specialist physicians. In general, there was no clear and consistent process for documentation of social needs.

Every patient whose chart was reviewed, who had a phone number listed and was not identified as deceased was called for an interview (see figure 2). In total, 19 patients were interviewed—10 from the emergency department data set and 9 from the inpatient data set. Interviews were approximately 30 min long. Many patients who had phone numbers listed were not reachable due to their numbers being no longer in service or due to the phone number belonging to a shelter or a drop in centre. Additionally, 14 patients declined to participate due to lack of interest or due to feeling too unwell at the time of the call. Notably, interviews highlighted a lack of social needs documentation within patient charts. Of the seven patients who, during their interview, specifically mentioned that they had met with a social worker while in hospital, four had no mention of such a meeting in their charts.

Interviews resulted in three themes related to social needs and three opportunity areas for the hospital to intervene (tables 2 and 3). The themes related to social needs included (1) the interaction between social needs, demographics and health; (2) the hospital's role in addressing social needs; and (3) the impact of social needs on experiences of care. Themes related to experiences before and during COVID-19 did not differ.

Patients identified demographic factors such as being an immigrant, having a disability and being a caregiver for other family members as factors that influenced their social needs. Additionally, poverty, having to care for others at home and needing additional support at home were identified as the most significant social needs. Moreover, patients recognised that their own medical and health needs made financial security both more difficult and more important. One patient commented that losing their home would equate to their death because of their extreme health needs. Patients noted that these factors also impacted their ability to afford medications, successfully arrive at follow-up appointments and manage other basic necessities, both in and out of hospital.

Although many patients had concerns about their social needs, many felt well cared for at the hospital and considered their social needs to be part of their home life, separate from any care they received from the hospital. Most felt that the hospital addressing social needs was a foreign concept, except for inpatients who had experience in a particular clinic where social needs were regularly addressed. Patients with such experience all commented on how helpful having these needs addressed in hospital had been. In general, though, patients felt that their support for social needs came mostly from family and friends outside of the hospital, with a few mentioning that a strong relationship with their family doctor was also a helpful support. Other patients found support at community organisations but noted that finding community organisations that were a good fit could be very difficult.

Several people interviewed associated their social needs or demographics with stigma experienced both in the emergency department and as an inpatient, when they felt their explanations for why they had sought care were not trusted and were subsequently not treated with respect. It was noted that such treatment sometimes resulted in them needing to return to the emergency department shortly after their initial visit. Many patients felt coming to the emergency department added stress and anxiety due to difficulty getting there, not feeling fully respected or worries about catching an illness from other patients.

Three opportunity areas (table 3) were identified for hospitals to help improve care for patients related to addressing their social needs: (1) training for staff related to social determinants of health, stigma and trauma; (2) improved documentation of social needs; and (3) programmes that connect patients to navigation and support in the community. In particular, patients mentioned that they wanted to be connected to family doctors with whom they could have a good relationship, as well as receive navigation and support related to poverty and receiving support in the home.

DISCUSSION

The combination of data, chart review and interviews helped paint an illustrative picture of the current patient experience, which also served to highlight opportunities for improvement in addressing social needs within the hospital setting. According to patient interviews, certain

Table 2 Summary of qualitative themes

Theme	Paraphrased input from patient consultations
Interaction between social needs, demographics and health	Patients identified specific demographic factors (eg, being an immigrant) impacting social needs. Medical complexity was described as a factor that both increases and impacts the effects of social needs.
The hospital's role in addressing social needs	Patients generally viewed social needs as separate from the hospital and are mostly supported through family, friends and community organisations.
Impacts of social needs on experiences of care	Patients associated their social needs with stigma and poor experiences of care in the hospital.

demographic factors were clearly associated with an increased need for social support. Unfortunately, many of the factors identified by patients as mediating their need for such support were not consistently captured in the data or physician chart notes.

This study found differences between high-risk patients visiting the emergency department compared with those who have multiple inpatient admissions. In particular, many high-risk patients visiting the emergency department have no fixed address and no family doctor, both factors that have been tied to higher rates of emergency department visits.[18 19] These differences are corroborated by the chart review and interviews as well as other studies,[20] which showed higher levels of social complexity for high-risk patients visiting the emergency department and higher rates of medical complexity for high-risk patients with multiple inpatient admissions.

Findings such as those mentioned in this paper have been corroborated by other studies, which have shown that inadequately addressed social needs that systemically marginalise patients, most notably poverty and homelessness, can dramatically impact healthcare quality indicators and are commonly associated with high-risk patients.[8 21] For instance, McGilton et al[22] analysed the social needs of older adults with chronic conditions and found that socioeconomic status was an important factor affecting access to information and care coordination.

Moreover, unaddressed social needs have been associated with higher use of acute care, including both emergency department visits and hospital admissions.[9 10] This difference in rates of healthcare use among high-risk patients and the majority of healthcare users is especially pronounced when comparing those with and without a mental health disorder.[23 24] Such findings also serve to illustrate the importance of addressing another often-overlooked and systemically marginalising social need: substance use disorders, which was also found to be a frequent reason for emergency department visits by high-risk patients in the present study. Indeed, more than 50% of the patients in the study conducted by Rentas et al[23] had an ongoing substance disorder.

The importance of documentation of health equity data, namely, demographic factors and social needs, is another finding supported by the literature. An American study by Navathe et al[25] analysed documentation of social needs within physicians' notes comparing this documentation to the standard use of International Classification of Diseases codes and other administrative flags. As in the present work, Navathe et al[25] found significant discrepancy between physician electronic health record notes and International Classification of Diseases, Ninth Revision, codes, which identified a patient's lack of social support in 16% of the data reviewed vs only 0.4%, respectively. In response to these findings, the authors recommended exploring options for automated analysis of notes, or the creation of standardised tools to adequately and accurately capture such data. Other studies have noted that interventions are less successful because of this lack of documentation and resultant lack of understanding regarding patients' social needs.[21] Consequently, identifying and properly documenting which of those patients is experiencing poverty, for instance, may confer considerable benefit to patients.[21] Navigation support was another opportunity recommended by high-risk patients, which

Table 3 Patient-identified opportunities for the hospital to address social needs

Opportunity area	Paraphrased input from patient consultations
Training for staff related to social determinants of health, stigma and trauma	Patients noted wanting hospitals to know that visits to the hospital often add stress and that building capacity for trauma-informed care and social determinant of health would help reduce stigma and in turn improve patient experience.
Improved documentation of social needs	Patients identified that it would be helpful if there were a mechanism for the hospital to see if people are on social assistance so they can know whom to help without the patients having to ask.
Programmes that connect patients to navigation and support in the community	Patients discussed a need for advocacy and help with system navigation outside of the hospital, especially in connecting to financial support and family doctors with whom they would have a comfortable relationship.

has been explored elsewhere. For instance, a research study asking high-risk patients for their ideas for reducing use also identified care coordination and additional at-home services as potential solutions.[26] A systematic review of general navigator programmes found that the majority of the navigator programmes were based in the community, and although there were trends supporting an improvement in adherence to care, use outcomes varied.[27]

Limitations and next steps

This study aimed to conduct consultations with patients with the highest risk. Although 75% of our interviews were with patients in the top 100 in terms of use, they did not include patients without access to a phone. Additionally, the scope of our study did not include interviews with caregivers. This, too, is a limitation, as caregivers represent an important aspect of high-risk patients' social needs. Future investigators may consider focusing on consultations with patients who do not have access to phones as well as their caregivers.

CONCLUSION

In light of our findings, it is abundantly clear that more work needs to be done to address patients' social needs and that hospitals can play an important role. For next steps, we intend to continue the quality improvement process by working with hospital staff (eg, physicians, technicians and administrators) and high-risk patients alike by employing codesign methods in the implementation of the solutions identified in this study

Furthermore, we are optimistic that by emphasising staff training around addressing social needs, designing policies and strategies aimed at improving documentation of health equity data and social needs, and the creation of more fulsome care navigation programmes, patients will feel confident that both their physical and social needs will be addressed.

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Supplemental material

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ICD 10 Codes and Other Markers

Category	ICD 10 codes or flags used for identification
Avoidable visit	G40-G41, J41-J44, J47, J10.0, J11.0, J12-J16, J18, J20-J22, J45, E10.0, E10.1, E10.63, E10.64, E10.9, E11.0, E11.1, E11.63, E11.64, E11.9, E13.0, E13.1, E13.63, E13.64, E13.9, E14.0, E14.1, E14.63, E14.64, E14.9, I50, J81, I10.0, I10.1, I11, I20, I23.82, I24.0, I24.8, I24.9
Visit related to substance use	F10-F19, F55, L27, R78, T38, T42.0, T45.1, T46.0, T80.2, T80.9, T80.8, T88.4, T88.6, T88.7
Visit related to mental health	F20-F25, F28-F34, F39-F45, F48, F60, F63-F66, F68-F69, X60-X84
Palliative visit	Z51, Z54
Visit related to homelessness	Z59
Patient with no fixed address	Postal code starting with U or X