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Outcomes that Matter: High-Needs Patients' and Primary Care Leaders' Perspectives on an Intensive Primary Care Pilot



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BACKGROUND: Quantitative evaluations of the effectiveness of intensive primary care (IPC) programs for highneeds patients have yielded mixed results for improving healthcare utilization, cost, and mortality. However, IPC programs may provide other value.

OBJECTIVE: To understand the perspectives of highneeds patients and primary care facility leaders on the effects of a Veterans Affairs (VA) IPC program on patients. **DESIGN:** A total of 66 semi-structured telephone interviews with high-needs VA patients and primary care facility leaders were conducted as part of the IPC program evaluation.

PARTICIPANTS: High-needs patients (n = 51) and primary care facility leaders (n = 15) at 5 VA pilot sites.

APPROACH: We used content analysis to examine interview transcripts for both a priori and emergent themes about perceived IPC program effects.

KEY RESULTS: Patients enrolled in VA IPCs reported improvements in their experience of VA care (e.g., patient-provider relationship, access to their team). Both patients and leaders reported improvements in patient motivation to engage with self-care and with their IPC team, and behaviors, especially diet, exercise, and medication management. Patients also perceived improvements in health and described receiving assistance with social needs. Despite this, patients and leaders also outlined patient health characteristics and contextual factors (e.g., chronic health conditions, housing insecurity) that may have limited the effectiveness of the program on healthcare cost and utilization.

This work was presented as a poster presentation entitled, "High-needs, high-cost patient perspectives on their experiences with VHA intensive primary care team" at Academy Health Annual Research Meeting, June 2018.

Received September 4, 2020 Accepted April 29, 2021 Published online May 13, 2021 **CONCLUSIONS:** Patients and primary care facility leaders report benefits for high-needs patients from IPC interventions that translated into perceived improvements in healthcare, health behaviors, and physical and mental health status. Most program evaluations focus on cost and utilization, which may be less amenable to change given this cohort's numerous comorbid health conditions and complex social circumstances. Future IPC program evaluations should additionally examine IPC's effects on quality of care, patient satisfaction, quality of life, and patient health behaviors other than utilization (e.g., engagement, self-efficacy).

KEY WORDS: intensive primary care; high-risk high-need; Veterans; qualitative effects; patient-centered outcomes.

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INTRODUCTION

In the USA, a small proportion of patients account for the majority of healthcare spending,^{1,2} primarily from hospitalizations.^{3,4} To address the complex medical and social needs of these patients (hereafter termed "high-needs patients"), healthcare systems, including Veterans Administration (VA), have piloted "intensive primary care" (IPC) programs.^{1,5–7} These programs facilitate care coordination, provide care management and additional social services, and aim to engage patients and caregivers in their healthcare. IPC programs have shown promise, but quantitative evaluations in both VA and non-VA settings suggest that few have reduced healthcare utilization, cost, and mortality beyond usual care.^{1,6,8–12}

It is likely, however, that patients may benefit from IPC programs in other ways. Limited qualitative research on

the perspectives of high-needs patients found improved healthcare experiences and relationships with their care team,^{13–15} as well as reduced barriers to self-care (e.g., medication education).¹⁶ In addition, providers reported improved patient engagement.¹⁷ Exploring patient and primary care facility leader perspectives can provide insight into other potentially beneficial IPC outcomes when considering the value of IPC programs.

Our study purpose was to explore the perspectives of patients and healthcare facility leaders to identify additional important outcomes that could augment utilization and cost studies of IPC programs for high-needs patients.

METHODS

We conducted patient and facility leadership telephone interviews as part of a mixed methods evaluation of a five-site pilot IPC program within VA. The pilot project and its evaluation are described in detail elsewhere.^{7,11,18} Briefly, in 2014, the VA Office of Primary Care funded five sites to develop and implement their own IPC programs. All five sites had interdisciplinary care teams including a physician lead, nurse, psychologist and/or psychiatrist, social workers, and, in some instances, a peer support specialist, preventive home visits, comprehensive patient assessment and evaluation, and care or case management.^{7,11} The national evaluation team identified eligible patients at each site at high risk for hospitalization (e.g., predicted 90-day risk of hospitalization in the \geq 90th percentile based on VA's Care Assessment Need (CAN) score¹⁹ and had a hospitalization or emergency department visit in the past 6 months); a random sample was invited to participate in the IPC program and the remaining patients received usual care in VA Patient-Centered Medical Home.¹¹

Sample and Recruitment

Patients were eligible to participate in study interviews if they had at least four encounters with the IPC team and at least one in the previous month (n = 138). We excluded patients with cognitive (e.g., dementia) or medical issues (e.g., hearing impairment) that would make it difficult to participate in a 20–30-min telephone interview (n = 25). We used stratified random quota sampling to obtain approximately 10 patients per demonstration site and recruited patients by mail and phone calls (n = 78) with a response rate of 81% (Appendix Table).

We identified primary care facility leaders (primary care chief or nurse executive, lead physicians, and nurse managers) from pilot sites from administrative records and contacted them by email, with follow-up phone calls and instant messaging.

Data Collection

Telephone interviews were conducted by a trained interviewer, lasting 10–40 min with patients and 30–60 min with primary care facility leaders. Interviews were recorded and professionally transcribed. This evaluation was designated as non-research evaluation to support VA operations and quality improvement under the authority of VA Office of Primary Care. An ethics committee was also specifically designed for this VA IPC pilot to provide QI-related ethnic guidance and monitor the project to ensure protection of participants.²⁰

For patients, we used a semi-structured interview guide (Appendix) designed to understand patient satisfaction and experiences with the IPC intervention as part of the quality improvement evaluation process. We asked patients about their perceptions of the IPC program and its influence on their health. We also used a semi-structured interview guide (Appendix) to ask primary care leaders about their perspectives on how IPC fit in with ongoing facility priorities and the value of IPC.

Analysis

We conducted qualitative content analysis to code transcripts for a priori and emergent themes. A priori themes included patient perspectives on the impact of IPC on patient health, and facility lead perspectives of the value of IPC. An initial codebook was developed with codes related to the effects of IPC on patient health, behavior, and interaction with VA. Codes were developed based on familiarity with the data and literature about high-needs patients' healthcare experiences.²¹ The codebook (Appendix) was refined through an iterative process of discussion with a secondary coder, before the entire sample was coded using Atlas.ti (version 8.0). The secondary coder reviewed transcripts and codes, and both coders met to resolve discrepancies in coding and develop themes based on a close reading of the transcripts. Finally, preliminary themes were shared with the larger study team, who were actively involved in study design and data collection, for feedback and discussion.

RESULTS

Study participants (n = 66) consisted of 51 patients and 15 primary care facility leaders. The average age of patients in our sample was 66 years; 84% were men, 49% were non-Hispanic White, and 37% were non-Hispanic Black; and half were previously married (Table 1). More than 70% of patients reported they were extremely satisfied with IPC, with no difference in satisfaction by site. We interviewed two to four primary care facility leaders at each site.

Table 2 summarizes key themes about patient and facility leader perspectives on IPC effects.

Table 1 Participant Characteristics

	Sample size $(n = 51)$	Mean (SD) or %
Patients		
Age (years), mean (SD) 51	65.6 (10.1)
Gender, %		
Male	43	84.3
Female	8	15.7
Race/ethnicity, %		
Non-Hispanic White	25	49.0
Non-Hispanic Black	19	37.3
Hispanic	2	3.9
Other	5	9.8
Marital status, %		
Never married	13	25.5
Currently married	13	25.5
Previously married	25	49.0
Urban/rural, %		
Urban	32	62.7
Rural	5	9.8
Missing	14	49.0
IPC locations, %		
Georgia	11	21.6
Ohio	10	19.6
Wisconsin	10	19.6
North Carolina	10	19.6
California	10	19.6
Satisfaction level, %		
Extremely satisfied	36	70.6%
Somewhat satisfied	12	23.5%
Not at all satisfied	2	3.9%
Could not answer	1	2.0%
Primary care facility lea	aders	
Location		
Georgia	3	20.0%
Ohio	2	13.3%
Wisconsin	3	20.0%
North Carolina	3	20.0%
California	4	26.7%

IPC's Perceived Effects on High-Needs Patients

Improved Experience of VA Care. Many patients emphasized the importance of relationships, communication with their

 Table 2
 Patient and Facility Leader Perspectives on IPC Effects and Potential Outcomes for Future IPC Evaluations

Perceived Improvement	Description
Experience of VA care	Strong relationship between patients and their IPC team: trust, feeling cared for Access to care team: reliable and timely access to care team
Motivation to care for health and increased engagement with care team	Increased motivation to care about their health Proactively engage with IPC team about health concerns
Health behaviors	Improved diet Increased physical activity Improved medication
Perceived physical and mental health and well-being	management Patient-perceived improvements in physical health, especially dia- betes and hypertension Patients described feeling less
Social needs	anxious and depressed Assistance with social needs: housing (e.g., eviction), food insecurity, and transportation

providers, and access to care and providers. Patients frequently reported feeling a sense of connection with their IPC team because they could trust their providers and rely on them for support with both health and non-health-related issues. Some patients directly contrasted these relationships to their previous experiences with other care teams. Patients used words like "love," "friend," "comfortable," and "good people" to describe the relationships that they formed with their IPC providers. In fact, one patient described, "I had a case worker with the IPC team and I really fell in love—what I call in love with this person...."

Patients commonly described that the process of obtaining VA care was easier through the program: they could readily contact their IPC team and often received care more expediently because the team could facilitate care coordination. For example, one patient described, "they found out that I got arthritis in my back, stenosis....And immediately, they got me a consult....They got me hooked up to—I got the physical therapy now... they really got it done." Patients also found that their IPC program staff were "easier to reach because they are always available," unlike their VA primary care providers, which usually resulted in "phone tag."

Increased Motivation to Care for Health and Increased Engagement with Care Team. Several patients noted that their positive relationships with IPC team members increased their motivation and their sense of accountability to take care of their health. For example, one patient described, "I feel that they care about me and I should care about myself if they do too, probably do the things I need to do that keep me...being able to do what I got to do." Some patients similarly described feeling more autonomous, confident, and empowered to manage their health. As one patient explained, "they teach you how to be self-reliant and just to know that you can do it." Several primary care leaders also concurred that high-needs patients seemed to become more involved in their self-care through IPC. One leader described changes in patients' attitudes as "an awakening in our patients" where patients were "more in tune to their care."

Some patients described that trusting relationships with and reliable access to their IPC team led them to proactively checkin with and call their IPC team when health concerns arose. One primary care leader noted how patients became more engaged, "[patients] are asking questions. They're listening." One patient also described, "whenever I find my situation is kind of questionable...or something that worries me, I just call them." The teams often directed patients to appropriate care, such as by scheduling appointments on behalf of patients. In a few instances, patients said that they called their IPC team for help instead of going to the emergency department and their IPC team facilitated necessary care. For example, one patient said, "As old people...you're going to go run and see the doctor the minute you feel a slight ache....If I do need to get in, he knows somebody that can get me an appointment in the primary care so I don't have to go to ER (emergency room)."

Improvements in Health Behaviors. High-needs patients commonly cited improvements in their health behaviors, especially lifestyle changes and medication adherence, as one of the effects of the program. One patient described, "I'm a diabetic....They've been working with me on my diet and giving me suggestions on different things I can do... I'm actually eating better." Patients often attributed changes in their diet to their increased motivation to care for their health, and the IPC team "clearly [making] everything so understandable," "[setting] goals," and tailoring their suggestions to patients' circumstances. One primary care facility leader noticed increased physical activity among patients due to IPC coaching: "We are encouraging them to do a little bit more exercise... and we're seeing some improvements."

Several patients also described improvements in their ability to manage their medications. Patients who had multiple medications found it helpful that their IPC team explained the purpose of their medication and gave them pill boxes to keep track of their medication. As one patient described it: "The team has helped me to realize certain things... [my medication] is not a cure, because if it was a cure, then I would take it and wouldn't have to take it anymore. But I still have to take my medication."

Improvements in Perceived Physical and Mental Health and Well-being. Some patients noted physical improvements in health, particularly with chronic conditions such as diabetes, due to IPC-facilitated improvements in medication management and health behaviors. One patient stated, "My health, believe it or not, has gotten a little better since they took over because they got me on the right prescriptions, the right medications, and...they showed me the proper foods that I need to eat for my diabetes." A primary care facility leader also described, "[IPC] is definitely a tool that can help diabetics that are uncontrolled, kind of a multidisciplinary approach can help lower A1Cs and I think that is certainly a med center priority." Some patients also mentioned that they thought their health would be worse without IPC.

Patients also frequently described feeling less anxious and depressed during the pilot and often attributed this improvement to having better relationships with their providers. They valued "knowing someone cared" and being able to rely on their IPC team for emotional support. As one patient said, "That [call/check-in on patient] is helpful in the way that you don't feel so alone. The average person doesn't understand what I'm going through because they haven't been through it....But they [IPC team members] know that it's a very stressful time and they try to let me know if there's anything that I can think of that I need...to let them know and they would help me." Assistance with Social Needs. A few patients noted facing challenges posed by social needs, such as transportation, housing, and food. These patients valued the IPC team's help with addressing these issues by providing information and contacts for local assistance. One patient described that someone on the IPC team, "helped with our public transportation, signing me up for different things." Another patient noted assistance with food and housing, "Now she has helped me locate food banks so I can go and get food. She tried to help me, my trailer is not in the best of repair so we've reached out to different organizations." Patients appreciated how help with their social needs made it "easier for the Veteran's day-to-day life."

Patient-Level Factors that Mitigated IPC's Impact on Decreasing Program Cost and Utilization

Both patients and primary care leaders described patient-level factors *apart from the IPC program* that could impact high-needs patients' health and healthcare use.

Severity of Patient Health Status. Patients and primary care leaders both recognized that high-needs patients have multiple and complex health needs, many of which are chronic physical and mental health conditions that required continual management. Some patients described their health status by using phrases such as "serious illnesses," "all these problems with my body," "chronic issues," and "really sick." While patients acknowledged that they "may not get better," they also emphasized that IPC still "made it a lot easier though from dayto-day." Several patients also expressed that they "need all the help [they] can get" and envisioned needing continual support from their providers to manage their complex health conditions.

Patients and primary care leaders also noted that many highneeds patients previously "fell through the cracks," sustaining delays in care that might have contributed to their current serious health needs. One high-needs patient noted, "A lot of people are just falling through the cracks.... I know I'm one of them if it weren't for [this] team." For these patients, IPC was able to coordinate overdue care. As one primary care leader explained, "We've found some patients who they've kind of fallen through the cracks and we have been able to go into those patients' records and see a condition or a diagnosis or something was identified years ago and it just wasn't followed up on. And now here we are five or eight years later...we're able to pick it up now and try to address it and get the patient the help that they need. We've had several cases like that."

Patients' Social Circumstances. Patients' difficult social circumstances may limit the effect of the IPC pilot by preventing patients from participating, regardless of IPC efforts and services. As one patient stated, "I understand that

my health is important but...I'm having problems dealing with life as it is." Housing issues were common. For example, one patient described, "I've had problems with flooding in my house for the past two years...Everything has just been on my mind about my house so I haven't really been able to participate [in IPC] the way I should." A few primary care facility leaders also stated that their patients' challenging social circumstances limited their ability to participate in IPC: "you kind of go in thinking, 'Well, as long as we provide them the level of service they need, then they all will do better.' But, unfortunately, a lot of these patients are in the situation they're in because [of]... the chaotic life they have lived with this."

DISCUSSION

We identified potential outcomes, besides cost and utilization, that future evaluations of IPC programs may consider. While published quantitative analyses on IPC programs' effects on reducing healthcare costs, unnecessary utilization, and mortality have been mixed, 1,6,8-12 our qualitative evaluation found strong evidence for improved patient experience, engagement, and even quality of care. Patients perceived improvements in their experience of VA care, including improved patientprovider relationships and access to their healthcare team. Patient and primary care leaders also observed greater proactive engagement with their IPC team, increased motivation for health behavior change and self-care, and improvements in patient health behaviors, physical and mental health, and social needs. Our interviews also provided clues as to why previous evaluations of IPCs might not have found cost and utilization reductions. Some patients, especially those with chronic health conditions and life circumstances that make participation challenging, might require non-healthcare services not provided by IPCs, while patients who had previously "fallen through the cracks" might initially have higher utilization upon IPC enrollment.

Our study is consistent with previous work; surveys have shown improved patient experience and satisfaction with IPC, particularly trust in providers and patient-centeredness,²² and that relationships with and access to care teams are important dimensions of patient experience that .¹⁶ High-risk patients in our sample described a sense that their IPC team reliably and genuinely cared for them. Patients also found their entire IPC team to be reliable and accessible, which improved the process of seeking and receiving care in the VA system. Future IPC evaluations should consistently evaluate changes in patient experience.

Improved patient self-efficacy and engagement may be better measures of IPC success than decreased utilization. In fact, utilization may initially increase for some patients, and this may actually benefit some previously disengaged highneeds patients. Both patient and primary care leaders described that, with IPC, patients seemed to care more about their health and proactively engaged with their care team. This is consistent with qualitative work from Federally Qualified Health Center IPC that highlighted the importance of patient engagement, including patient self-care behaviors and interaction with their care team.¹⁷ An unintended consequence of increased patient engagement is that it may lead to more patient interactions with the healthcare system, including hospitalizations, as other case management studies have shown.^{8,12} In some situations, though, these interactions may re-direct patients from acute care settings (e.g., Emergency Departments) to less resource-intensive settings in ambulatory care (e.g., appointments with primary care providers or specialist) for unexpected acute care needs.²³ In our previous randomized multi-site evaluation and a similar single-site VA evaluation of IPC, we found higher outpatient primary care utilization and non-significant decrease in hospitalizations,¹¹ but an increase in telephone and overall primary care visits,²⁴ among IPC patients as compared with usual PCMH care, supporting the trend of increased patient interactions.

Longer-term evaluations of IPCs can potentially detect changes in health behaviors, including diet and exercise, and in chronic disease metrics, such as for diabetes, hypertension, or congestive heart failure. Patients and facility leaders in our interviews not only described health behavior changes that are important for managing chronic conditions, but some even noted improvements in chronic conditions themselves, especially lower blood pressure and hemoglobin A1c levels. While we did not verify these changes in their medical records, quantitatively examining changes in chronic disease metrics-even small changes in a limited number of patients-and whether patients can sustain these improvements are valuable for high-needs patients, especially those with poorly managed chronic conditions or multiple chronic conditions. To date, only a few IPC evaluations, conducted over short time frames and with small samples, have included these outcomes, and they found no changes in medication adherence^{8,25} or depression.²⁶

Exploring IPC effect on patients' quality of life may also be reasonable given that quality of life is more modifiable than function, health status, or mortality, and is an increasingly important healthcare metric.²⁷ IPC may improve patients' quality of life by improving patients' perceived physical and mental health,²⁷ and by helping to address patients' social needs, such as housing, food, and transportation.^{28,29} An IPC evaluation found improvements in health-related quality of life.³⁰ Helping patients to meet fundamental social needs is in itself a worthy goal, especially for high-needs patients, who often experience complex social circumstances. Addressing social needs among high-needs patients may have added importance for healthcare systems, since social needs commonly pose barriers to care and addressing them may improve the quality of life for their patients,

In addition to identifying outcomes for future evaluation, our results also suggest potential reasons for why previous IPC evaluations have had mixed effects on healthcare utilization.^{1,6,8–12} High-needs patients are heterogeneous in health conditions and social circumstances. We found that some patients perceived their health status as being serious, chronic, permanent, and requiring continual management, consistent with studies that have found some complex patients are persistently high-needs.^{31,32} Additionally, both patients and providers expressed that some patients may not be ready to participate due to life circumstances.^{31,32} IPC programs may have limited ability to modify cost and utilization for these high-needs patients, because these patients may require nonhealthcare social services that an IPC cannot reasonably provide. Prior IPC evaluations have not differentiated between these groups patients.³³ Additionally, patients and leaders both recognized that IPC reconnected patients who had previously "fallen through the cracks," leading to increased utilization-and thus cost-upon IPC enrollment as they get connected to VA care and receive care they had previously deferred.¹² However, by continuing to coordinate and engage high-needs patients, IPCs may prevent future inpatient and emergency department use in the long term. Finally, some patients had complex social circumstances that took precedent over their health needs, regardless of IPC efforts. IPC provided some assistance with social needs for some patients (e.g., identifying food banks), but for those with more complex social circumstances, addressing them may require partnerships with entities outside the healthcare system.

This study had several limitations. Our findings may not be generalizable across all VA and non-VA settings. There could also be selection bias among IPC patients who agreed to be interviewed; however, our use of stratified random quota sampling and our high response rate should have minimized the impact of any self-selection bias. Our findings may not be generalizable to all IPC participants, as our interview selection criteria required a minimum level of engagement with the IPC team. In addition, our results suggesting improved patient health behaviors were based on patients' and facility leaders' subjective perceptions and not on objective health outcomes; it may be subject to reporting bias. Finally, we did not interview family/ caregivers, another group that may have experienced improved outcomes from IPC.

Our study also has several strengths. Our study is among the first to identify outcomes besides cost, utilization, and mortality to evaluate IPC programs. Our rich qualitative data provide insight into the "why" and "how," often not captured in quantitative outcomes data. Because VA's high-needs population may be sicker and more socially complex than high-needs patients in the general population,^{34,35} our findings provide perspectives from the most vulnerable and highest-need patients.

CONCLUSION

Although previous quantitative evaluations of VA and other IPC programs found little evidence of cost and utilization savings,^{1,6,9–11} more recent IPC evaluations have begun to examine other outcomes and found improvements in patient experience and quality of care.^{22,36} Our findings identify other outcomes that are important to patients and healthcare system leaders that future IPC evaluations may want to consider. These include patient experiences, patient engagement and motivation, patient health behaviors (especially diet and physical activity), long-term chronic disease metrics, and patient quality of life. Healthcare systems will have to determine whether improvement in other outcomes justifies continuing a resource-intensive program that may not yield reductions in cost and utilization.

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Declarations:

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