Decision-making and goal-setting in chronic disease management: Baseline findings of a randomized controlled trial

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Abstract

Objective—Growing interest in collaborative goal-setting has raised questions. First, are patients making the ‘right choices’ from a biomedical perspective? Second, are patients and providers setting goals of appropriate difficulty? Finally, what types of support will patients need to accomplish their goals? We analyzed goals and action plans from a trial of collaborative goal-setting among 302 residents of a high-poverty urban region who had multiple chronic conditions.

Methods—Patients used a low-literacy aid to prioritize one of their chronic conditions and then set a goal for that condition with their primary care provider. Patients created patient-driven action plans for reaching these goals.

Results—Patients chose to focus on conditions that were in poor control and set ambitious chronic disease management goals. The mean goal weight loss −16.8lbs (SD 19.5), goal HbA1C reduction was −1.3% (SD 1.7%) and goal blood pressure reduction was −9.8 mmHg (SD 19.2 mmHg). Patient-driven action plans spanned domains including health behavior (58.9%) and psychosocial (23.5%).

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Contributors

N/A.

Prior presentations

The contents of this paper were presented as an oral presentation at the Society for General Internal Medicine National Meeting in Hollywood, Florida on May 11th, 2016.
Conclusions—High-risk, low-SES patients identified high priority conditions, set ambitious goals and generate individualized action plans for chronic disease management.

Practice implications—Practices may require flexible personnel who can support patients using a blend of coaching, social support and navigation.

Keywords
Patient-centered care; Chronic disease management; Vulnerable populations

1. Introduction

Patients of low socioeconomic status (SES) are less likely to receive patient-centered care: [1,2] providers tend to communicate with these patients in a narrowly biomedical, physician-dominated manner [3] characterized by low patient involvement in decision-making [4]. This lack of engagement can lead to mistrust, decisional conflict [5] and low adherence [2,6], particularly in the context of chronic disease management which requires a sustained patient-provider partnership and an active patient role in health behavior change [7].

Collaborative goal-setting is a structured form of patient engagement in which patient and provider discuss and agree on a health goal [8,9]. When applied to chronic disease management, goal-setting can have three distinct stages: first, patients use decision aids to choose a chronic disease (e.g. diabetes) or behavior (e.g. increasing physical activity) that they would like to focus on. Next, providers help patients to set a measurable goal for their chosen condition [8]. Finally, patients create concrete action plans for achieving this goal. Collaborative goal-setting has been shown to improve a number of chronic disease behaviors [10–14] and outcomes [15–19] and is now required by the National Committee for Quality Assurance Patient-Centered Medical Home recognition standards [20].

This growing interest has raised several unanswered questions about using collaborative goal-setting as a strategy for chronic disease management among low-SES patients. First, providers may feel reluctant to cede any decision-making to patients – particularly those with low education or health literacy – for fear that patients’ decisions may deviate from what providers would advise based on the biomedical perspective [21]. Few prior studies [13] have explored whether these concerns are justified. In one prior study [13], patients with diabetes used an interactive CD-ROM to assess their physical activity and diet, and then set behavior change goals. It appeared that patients did make the “right” decisions, choosing to work on a behavior for which they were at greatest risk. A second question relates to goal difficulty; a large body of goal-setting literature demonstrates the importance of setting goals that are challenging, yet attainable [22]. Very few studies [8] have examined the difficulty of chronic disease management goals to understand whether patients and providers are able to strike this balance. Finally, in most prior studies, action planning has been facilitated by providers or computerized programs focusing on narrow domains such as dietary change [23], physical activity [24] or recommended diabetes care [25]. Few prior studies [26] have asked patients to create action plans based on what they think will help them to reach chronic disease management goals. As a result, current approaches to collaborative goal-setting may not be as patient-centered as intended.
In this paper, we describe baseline findings from a randomized controlled trial of collaborative goal-setting versus collaborative goal-setting plus six months of support from a community health worker delivering the evidence-based IMPaCT intervention [27–29]. Our prior studies suggested that low-SES patients with multiple chronic conditions felt overwhelmed by their comorbidities and thought that they would do better if they focused on controlling one condition at a time [27]. Therefore, in this trial, patients used a low-literacy visual aid to choose one of their multiple chronic conditions to focus on during the study period. Patients then collaboratively set a chronic disease management goal for their chosen condition with their primary care provider. Patients randomized to a community health worker created patient-driven action plans to help them achieve their goals.

The objectives of this paper are to address critical knowledge gaps around collaborative goal-setting for chronic disease management. In particular, we sought to answer the following questions: if low-SES patients with multiple chronic conditions are encouraged to prioritize one of their conditions, which do they pick? How difficult are the chronic disease management goals patients set with their providers? What action plans do patients create for reaching these goals?

2. Methods

This study describes the baseline findings of a two-armed, single-blinded randomized controlled trial (ClinicalTrials.gov Identifier: NCT01900470) approved by the Institutional Review Board of the University of Pennsylvania.

2.1. Study setting and participants

Patients were recruited from two urban academic adult internal medicine clinics between July 11th, 2013 and October 15th, 2014 at which time the pre-specified sample size target was reached. Eligible patients: (1) had ≥ 1 visit in a study clinic during the prior year and an upcoming appointment; (2) lived in a high-poverty 5-ZIP code region in Philadelphia; (3) were diagnosed with 2 or more of the following chronic diseases: hypertension, diabetes, obesity, asthma/COPD with tobacco dependence. These diagnoses were defined using EMR ICD-9CM codes from the year prior to study enrollment, or in the case of obesity, by a Body Mass Index (BMI) of 30 or greater. Patients were excluded if they: (1) had previously worked with a community health worker or (2) lacked capacity to provide informed consent. During the study time period, Penn Medicine adopted the IMPaCT community health worker program as part of its system-wide population health management strategy for uninsured or publicly insured patients. In order to be consistent with inclusion criteria that were used at other sites across the health system, on April 30th, 2014, the study team added the following inclusion criteria: uninsured or publicly insured.

2.2. Patient enrollment

Research assistants (RAs) received a weekly list of patients meeting inclusion criteria and called patients with upcoming primary care appointments to explain the study and confirm eligibility (Fig. 1). When interested patients arrived to their scheduled primary care visit, the RA obtained written informed consent and initiated study procedures.
2.3. Procedures

2.3.1. Collaborative goal-setting—RAs used a 2-min script to explain a low-literacy visual aid designed to help patients choose a chronic disease to focus on during the study (Fig. 2). The aid listed patients’ chronic diseases and current level of control for each disease. It also described evidence-based health behaviors proven to benefit each chronic disease; this information was designed to inform patient choice, rather than to prescribe these specific strategies. Acknowledging the importance and difficulty of maintaining control of conditions, we allowed patients to choose any of their conditions, even those that were under control.

Patients brought the aid with them into the exam room and reviewed their choice with their primary care provider. The provider then helped the patient to set a chronic disease management goal for their chosen condition: a systolic blood pressure goal for hypertension, HbA1c goal for diabetes, weight goal for obesity, or smoking cessation for asthma/COPD and tobacco dependence. Patients and providers were allowed to set a maintenance goal (same as their baseline value). Any patients choosing to focus on tobacco dependence were asked to set a goal of complete cessation because we planned to monitor success with measurements of urine anabasine; these measurements are more reliable with cessation, not reduction [30]. The goal-setting discussion between patients and providers – which took about 3–5 minutes to perform – took place during scheduled primary care appointments, with no extra dedicated time. This decision was made in order to test the feasibility of the goal-setting process in a real-world, busy practice environment.

Primary care providers at study clinics underwent a 60-min training session on collaborative goal-setting, which reviewed principles of goal-setting theory [31], including the importance of setting realistic goals.

2.3.2. Baseline assessment and randomization—After setting a goal with providers, patients completed a brief baseline assessment with the RA. RAs recorded height, weight, blood pressure and HbA1C measured by clinic staff during the primary care visit. RAs then notified a member of the study team not involved with outcomes assessment, who assigned each patient to one of two study arms from a computer-generated randomization algorithm [32]. Patients randomized to collaborative goal-setting alone received usual care in accordance with guidelines at each site. Patients randomized to receive community health worker support met with their community health worker immediately after enrollment.

2.3.3. Creating action plans with the community health worker—Community health workers conducted an in-depth semi-structured interview anchored on the open-ended question: “What will you need in order to reach the health goal you set with your doctor?” Patients could answer broadly and were not limited to select the evidence-based strategies presented in the goal-setting decision aid (Fig. 2). Community health workers and patients used this conversation to create individualized action plans for reaching their chronic disease management goal.
2.4. Measures

RAs collected the following baseline data: age [33], gender [33], race [33], ethnicity [33], employment [33], severity of illness (ACG score) [34], household income and size [33], unmet or delayed need for medical care [35], number of emergency room visits and hospital admissions in the prior twelve months [35], and usual source of care [35]. The baseline questionnaire also included the SF-12 survey [36], the Patient Activation Measure (which assessed patients’ confidence in managing their health) [37], the ENRICHD Social Support Instrument [38], the Single-Item Literacy Screen [39], the Trauma History Questionnaire [40], a Single-Item Drug Screening [41], a Single-Item Alcohol Screening [42], perceived stress [43], and questions assessing homelessness and food insecurity [44]. In addition, the baseline questionnaire included an assessment of commitment and self-efficacy for achieving the collaboratively chronic disease management goal [45]. For patients assigned to community health worker support, community health workers documented action plans and detailed encounter notes.

2.5. Analysis of baseline data

The goals of the analysis are to: (1) describe the chronic disease that patients chose to focus on and examine associations between baseline characteristics and chronic disease choice, (2) describe the difficulty of chronic disease management goals relative to baseline values, and (3) describe the types of action plans that patients and community health workers created for reaching these chronic disease management goals.

We performed bivariate analyses using $\chi^2$ tests for categorical variables and $t$ tests and the Wilcoxon rank sum test for continuous variables. We created logistic regression models to determine associations of baseline characteristics with choice of each chronic condition during collaborative goal-setting. Four models were created, one for each condition; for instance, the first model was restricted to patients with diabetes and had the binary outcome of choosing diabetes as their focal condition (yes/no). For each of these logistic regression models, we included predictors that had a bivariate association with the outcome using $p<0.20$ as the threshold.

3. Results

Of the 524 eligible patients screened, 302 (57.6%) provided written consent and were randomized. Those who declined were older than participants (65.3 vs. 56.3 $p<0.0001$). The most common reasons for declining were: (1) being too busy (54, 24.3%); (2) not wanting to participate in any research (26, 11.7%); (3) not having enough time on the day of their scheduled clinic visit for study enrollment (28, 12.6%), and 4) not wanting a community health worker (21, 9.5%).

The mean age of the cohort was 56.3 (SD 13.1) years, 75.5% were female, 94.7% were black, 55.6% had an annual household income less than $15,000 and 96.3% had a history of a traumatic event on the 24-item Trauma History Questionnaire (Table 1). Participants had an average of 1.9 (SD 4.4) emergency room visits and 0.9 (SD 2.6) hospital admissions in the prior 12 months.
Participants had an average of 2.5 of the eligibility chronic conditions: 279 (92.4%) had a diagnosis of hypertension; 235 (77.8%) were obese; 175 (58.0%) had a diagnosis of diabetes and 55 (18.2%) had tobacco dependence with asthma/COPD (Fig. 3).

3.1. Choice of chronic condition

The most popular choice of condition to focus on during the study was obesity (chosen by 62.1% of obese patients), followed by tobacco dependence (chosen by 56.4% of smokers), diabetes (chosen by 42.3% of patients with diabetes) and hypertension (chosen by 18.3% of patients with hypertension) (Fig. 3).

Patients who chose to work on their obesity had a BMI of 39.7 versus other obese patients who had a mean BMI of 38.1 (p=0.17). Patients who chose to work on diabetes had a higher mean HbA1C than other diabetic patients (8.9% vs. 7.0, p<0.0001). Patients who chose to quit smoking used on average 9.3 cigarettes per day versus 10.8 for smokers who chose not to quit (p=0.94). Patients who chose to work on their hypertension had a higher baseline systolic blood pressure than other hypertensive patients (143.8 mmHg vs. 129.6, p<0.0001).

Multivariable models also revealed associations between patients’ baseline characteristics and their choice of chronic disease (Fig. 4). The choice of obesity as a focal condition was inversely associated with poor control of other conditions – elevations in systolic blood pressure (OR 0.78, 95% CI 0.66, 0.93) and HbA1c (OR 0.79, 95% CI 0.66, 0.95) – suggesting that patients weighed relative control of their conditions as they made prioritization decisions.

Other models revealed a similar pattern: patients weighed relative control of their conditions and chose to focus on those in poorer control. The choice of diabetes as a focal condition was associated with elevated HbA1c (OR 1.7, 95% CI 1.35, 2.2) and inversely associated with elevated BMI (0.92, 95% CI 0.87, 0.96). The choice of tobacco cessation was inversely associated with elevated HbA1c (OR 0.63, 95% CI 0.41, 0.98). The choice of hypertension was associated with baseline systolic blood pressure (1.05, 95% CI 1.32, 1.97) and age (OR 1.4, 95% CI 1.10, 1.86), and inversely associated with elevated HbA1c (0.60, 95% CI 0.44, 0.83).

3.2. Difficulty of goals

The mean weight loss goal for patients focusing on obesity was −16.8 pounds (SD 19.5), mean goal HbA1C reduction was −1.3% (SD 1.7%), and mean goal blood pressure reduction was −9.8 mmHg (SD 19.2 mmHg). Patients focusing on tobacco were assigned a cessation goal for measurement reasons.

Patients’ self-rated commitment to achieving these goals was high: 4.9 (SD 3.0) on the Kanfer goal commitment scale ranging from 3 to 24, where 3 is highly committed. Patients’ self-efficacy for goal achievement was also high: 3.8 (2.4) on the Kanfer self-efficacy scale ranging from 3 to 16, where 3 indicates the highest level of self-efficacy.
3.3. Action plans

Patients and community health workers created an average of 4.59 (SD 1.9) action plans for reaching chronic disease management goals. These action plans most commonly related to health behavior change (e.g. “start a weight-loss contest with my overweight daughters”) (58.9%) and psychosocial issues (e.g. “join a recreation center to help me cope with my brother’s death”) (23.5%). Fewer action plans related to health system navigation (e.g. “meet with pharmacist for medication teaching”) (8.5%), resources for daily life (e.g. “find low-income housing”) (8.0%), and medical issues (e.g. “talk to doctor about foot pain that limits my exercise”) (1.2%).

4. Discussion and conclusion

4.1. Discussion

We conducted this study in order to answer three key questions about collaborative goal-setting. First, are patients making the ‘right choices’ from a biomedical perspective? Second, how difficult are the goals that patients and providers are setting? Finally, what types of support will patients need to accomplish their goals? This study has three main findings that answered these questions and may inform the use of collaborative-goal setting as a strategy for chronic disease management among low-SES patients.

First, patients chose to work on conditions that were in poor control. They appeared to weigh relative control of their multiple conditions and made choices that were rational from a biomedical perspective, even though they were not explicitly asked to do so. This may be reassuring to providers who may worry about patients making irrational choices or ‘taking the easiest route’.

Second, patients and providers set chronic disease management goals that were ambitious compared to reports of what can be achieved with behavioral interventions. For instance, a recent meta-analysis of 37 studies of behavioral interventions for obesity found a mean weight loss of −6.2 pounds (95% CI −7.9, 22) at 12 months [46]; in our study, high-risk patients and providers aimed for a −16.8 pound weight loss in 6 months. A meta-analysis of lifestyle interventions for diabetes control found an average HbA1c reduction of −0.29% (95% CI −0.61, 0.03%), at 6 months [47]. In our study, the average HbA1c reduction goal was −1.3%. Finally, a meta-analysis of lifestyle interventions for blood pressure reduction found an average systolic blood pressure reduction of −6.74 mmHg (95%CI: −8.25, −5.23) [48]; the systolic blood pressure reduction goal in our study was −9.8 mmHg.

Despite these discrepancies, patients in our study had high commitment and self-efficacy for achieving their chronic disease management goals. These findings may reflect a phenomenon of goal-setting exuberance [31]: individuals may be more likely to set ambitious goals at the outset of an endeavor, before they have the experience of trying to reach the goal and the attendant feedback of how difficult the goal may be [22,31]. This exuberance would suggest that providers need to encourage patients to set more realistic goals, or revise their goals on an ongoing basis. However, the final randomized controlled trial results – which will measure goal attainment (yes/no) as well as incremental
improvements towards the goal – are needed to understand whether such ambitious goals were motivating or self-defeating.

Third, when community health workers asked patients the open-ended question, “What will you need to do in order to reach the health goal you set with your doctor?” the answers were mostly non-clinical. Even health system navigation – e.g. obtaining appointments or referrals – was a relatively infrequent topic of patient-driven action plans (8.5%). This is interesting given that patient navigation and care coordination are central to many programs aimed at this population. Our findings suggest that when given the flexibility to do so, patients think broadly about the actions they will need to take in order to achieve chronic disease management goals, and may require support beyond the traditional domains of navigation and resource referral.

This study has several limitations. First, a conceptual issue is whether asking patients to select a disease is the best starting point. An alternate approach might be to ask patients their overall health goals (e.g. “I would like to be able to play with my grandchildren without feeling short of breath”) and then work with providers to select a disease or health behaviors that best help achieve that goal. The benefits of having patients select a disease a priori are that it requires less time and influence from busy provider who might be more prescriptive than collaborative given time constraints and the complexity of the decision. A second limitation of this study is that patients choosing to work on their tobacco dependence were asked to set a complete cessation goal. This goal may have dissuaded heavy smokers, and could explain why smokers who chose to work on tobacco dependence smoked slightly, though not significantly, less than those who were unwilling to quit. Third, while community health workers were open-ended in asking patients about their action-plans, patients may have been influenced by the prompts on the goal-setting decision aid and fact that community health workers were facilitating the conversation. Fourth, although this study suggests that our approach to collaborative goal-setting and action planning was feasible in a real-world practice, the final randomized controlled trial results are needed to evaluate effectiveness of this approach. Finally, this trial was designed to compare whether the community health worker support adds more collaborative goal-setting with the primary care provider. Since there is no placebo control arm, we will not be able to determine the effect of collaborative goal-setting versus usual care.

4.2. Conclusion

Helping high-risk patients achieve better control of their chronic conditions is a major goal of the health care system. Our study shows that when high-risk, low-SES patients are engaged in collaborative goal setting – they are able to self-identify high priority conditions, set ambitious goals and generate creative and individualized action plans. These lessons that underscore the importance of engaging low-SES patients in the management of their chronic conditions and should reassure providers that these patients can handle being in the driver’s seat.
### 4.3. Practice implications

This article describes use of collaborative goal-setting among a very high-risk population: predominantly minority, low-income patients with multiple chronic conditions, high rates of trauma and significant hospital utilization. Patients were able to use a low-literacy visual aid to rationally prioritize one of their multiple chronic conditions, and collaboratively set challenging chronic disease management goals with their providers in a busy primary care clinic. Patients created action plans for reaching these goals that spanned domains suggesting that practices may require flexible personnel who can support patients using a blend of coaching, social support and navigation.

### Acknowledgments

#### Funders

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### References


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Fig. 1.
Study Procedures.
Mrs. Jones has tobacco dependence, hypertension and diabetes:

- She reads about behaviors that are proven to help with each of her conditions.

- She has been smoking more since the recent murder of her son and doesn't think she can set a quit date now. She's already started the DASH diet and feels good about maintaining her blood pressure. But she does want to meet a nutritionist and commit to taking her insulin.

- Mrs. Jones explains to her PCP that she would like to work on her diabetes. They set a goal to lower her HbA1C from 9.5% to 8.5% over 6 months.

Fig. 2.
Collaborative goal-setting aid.
Fig. 3.
Prevalence, choice and baseline control.
Fig. 4.
Association between baseline characteristics and choice of condition.
Table 1

Baseline characteristics.

<table>
<thead>
<tr>
<th></th>
<th>Overall (n=302)</th>
<th>Goal-setting alone (n=152)</th>
<th>Goal-setting plus CHW (n=150)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>228 (75.5)</td>
<td>113 (74.3)</td>
<td>115 (76.7)</td>
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<tr>
<td>African American</td>
<td>286 (94.7)</td>
<td>144 (94.7)</td>
<td>142 (94.7)</td>
<td>0.98</td>
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<tr>
<td>Hispanic</td>
<td>8 (2.7)</td>
<td>4 (2.7)</td>
<td>4 (2.8)</td>
<td>0.28</td>
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<tr>
<td>Employed</td>
<td>42 (14.0)</td>
<td>12 (8.0)</td>
<td>30 (20.1)</td>
<td>0.002</td>
</tr>
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<td>Household Income&lt;15 K*</td>
<td>135 (55.6)</td>
<td>72 (58.5)</td>
<td>63 (52.5)</td>
<td>0.34</td>
</tr>
<tr>
<td>Trauma History †</td>
<td>290 (96.3)</td>
<td>144 (94.7)</td>
<td>146 (98.0)</td>
<td>0.13</td>
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<tr>
<td>Low Social Support</td>
<td>59 (19.6)</td>
<td>30 (19.7)</td>
<td>29 (19.5)</td>
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<td>Public insurance</td>
<td>248 (82.1)</td>
<td>128 (84.2)</td>
<td>120 (80.0)</td>
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<td>Delayed Health Need</td>
<td>115 (38.5)</td>
<td>56 (37.1)</td>
<td>59 (39.9)</td>
<td>0.62</td>
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<tr>
<td>Unmet Health Need</td>
<td>46 (15.4)</td>
<td>22 (14.6)</td>
<td>24 (16.2)</td>
<td>0.69</td>
</tr>
<tr>
<td>Lack of basic needs</td>
<td>90 (29.8)</td>
<td>48 (31.6)</td>
<td>42 (28.0)</td>
<td>0.50</td>
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<tr>
<td>Alcohol overuse</td>
<td>64 (21.4)</td>
<td>33 (22.0)</td>
<td>31 (20.8)</td>
<td>0.80</td>
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<td>Drug use</td>
<td>34 (11.3)</td>
<td>14 (9.3)</td>
<td>20 (13.4)</td>
<td>0.26</td>
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<tr>
<td>Age, y</td>
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<td>56.1 (12.6)</td>
<td>56.6 (13.6)</td>
<td>0.69</td>
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<tr>
<td>Mental Component</td>
<td>44.8 (13.2)</td>
<td>45.1 (13.3)</td>
<td>44.5 (14.8)</td>
<td>0.71</td>
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<td>Physical Component</td>
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<td>0.19</td>
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<td>Patient Activation Measure</td>
<td>60.9 (13.5)</td>
<td>61.8 (13.7)</td>
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<td>0.34</td>
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<tr>
<td>Perceived stress</td>
<td>5.9 (3.8)</td>
<td>5.8 (3.9)</td>
<td>5.9 (3.7)</td>
<td>0.82</td>
</tr>
<tr>
<td>Health Literacy</td>
<td>2.2 (1.3)</td>
<td>2.2 (1.3)</td>
<td>2.1 (1.3)</td>
<td>0.56</td>
</tr>
<tr>
<td>ER visits in prior 12 mos</td>
<td>1.9 (4.4)</td>
<td>2.1 (4.2)</td>
<td>1.7 (4.5)</td>
<td>0.31</td>
</tr>
<tr>
<td>Admissions in prior 12 mos</td>
<td>0.9 (2.6)</td>
<td>1.0 (2.7)</td>
<td>0.8 (2.4)</td>
<td>0.21</td>
</tr>
<tr>
<td>Severity of illness</td>
<td>3.6 (0.8)</td>
<td>3.6 (0.8)</td>
<td>3.5 (0.8)</td>
<td>0.21</td>
</tr>
</tbody>
</table>

Values are expressed as n (percentage) or mean ± SD unless otherwise indicated. Scales from 1 to 100 unless otherwise indicated.

* For all variables, there is <5% missing data, except for Household Income which has 19.5% missing data.

Scales:

Trauma: Any item endorsed on the 24-item Trauma History Questionnaire which assesses a range of trauma events in three areas: (a) crime-related events (e.g., robbery, mugging), (b) general disaster and trauma (e.g., injury, disaster, witnessing death), and (c) unwanted physical and sexual experiences.

Basic Needs: Shelter, food, wash, bathroom, transportation, telephone. Scores ranged from 4 to 16, score ≥ 5 threshold for some difficulty.

Perceived stress: measured on scale of 0 (low) to 16 (high).

Health literacy: measured on a scale of 5 (low) to 1 (high).

Severity of illness: measured by ACG score of 0 (low) to 5 (high).