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Health Literacy Among a Formerly Incarcerated Population Using Data from the Transitions Clinic Network

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Abstract Health literacy is increasingly understood to be a mediator of chronic disease self-management and health care utilization. However, there has been very little research examining health literacy among incarcerated persons. This study aimed to describe the health literacy and relevant patient characteristics in a recently incarcerated primary care patient population in 12 communities in 6 states and Puerto Rico. Baseline data were collected from 751 individuals through the national Transitions Clinic Network (TCN), a model which utilizes a community health worker (CHW) with a previous history of incarceration to engage previously incarcerated people with chronic medical diseases in medical care upon release. Participants in this study completed study measures during or shortly after their first medical visit in the TCN. Data included demographics, health-related survey responses, and a measure of health literacy, The Newest Vital Sign (NVS). Bivariate and linear regression models were fit to explore associations among health literacy and the time from release to first clinic appointment, number of emergency room visits before first clinic appointment and confidence in adhering to medication. Our study found that almost 60% of the sample had inadequate health literacy. Inadequate health literacy was associated with decreased confidence in taking medications following release and an increased likelihood of visiting the emergency department prior to primary care. Early engagement may improve health risks for this population of individuals that is at high risk of death, acute care utilization, and hospitalization following release.

Keywords Health literacy · Incarcerated · Prisoners · Health disparities · Healthcare utilization

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Introduction

Nearly 80% of individuals leaving prison have a chronic health condition that requires self-management and consistent primary care [1, 2]. The vast majority of incarcerated individuals will be released back to the community where they will face barriers to accessing health care and managing these chronic conditions. Recently released

individuals have many competing demands including finding food, housing, and employment, and these are often prioritized over personal health [3]. For those who do seek to engage with the community health system, there are often many barriers, including inexperience accessing health care prior to their incarceration, insurance eligibility and feelings of distrust, and stigmatization by the health system based on their criminal record [2, 4]. Little is known, however, about the degree to which health literacy is an additional barrier among this population and how inadequate health literacy may affect post-release chronic disease management.

Health literacy is defined as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[5] Health literacy is increasingly understood to be a mediator of chronic disease self-management and health care utilization [6–8]. Individuals need to be able to understand instructions, as well as educational materials related to disease prevention and management and signs and symptoms of disease. Being able to understand these items can help prevent new disease onset and improve outcomes of current health conditions [9]. Within the general US population, over one third of adults have low health literacy; and among racial and ethnic minorities, people with lower education attainment, and people who have limited English proficiency, proportional low health literacy is likely to be higher [10]. Individuals with low health literacy are more likely to take their medications inappropriately, have increased use of acute care services, and receive less of some preventive care [11]. Poor health literacy is also a barrier to achieving good health in the general population and has been shown to account for racial differences in medication adherence and health outcomes [12, 13]. As such, insufficient health literacy may contribute to the high risk for poor health outcomes among individuals who are released from incarceration, especially given the disproportionate incarceration of minority and low socioeconomic populations.

The relationship between health literacy, chronic disease management, and health care utilization for people recently released from incarceration has not yet been well described. Ramaswamy and colleagues reported health literacy scores on a small sample of jailed women in a qualitative study that explored cervical health in this population known to have disproportionately high rates of cervical cancer [14, 15]. Despite having baseline levels of health literacy that were adequate, they found that cervical health literacy was poor and may have contributed to women's receipt of inadequate follow-up after abnormal cervical screening results. There have been some larger studies examining overall literacy among individuals with a history of incarceration. In a 2003 National Assessment of Adult Literacy (NAAL) that included incarcerated persons, more than half of those surveyed (56%) had basic or below basic literacy levels and only 3% of the sample had proficient levels of literacy [16]. A small Canadian study among women incarcerated in prison documented feelings of shame among participants regarding their low levels of literacy. These participants reported that they often felt confused and intimidated when trying to access health care [17]. Research studies with larger sample sizes of criminal justice involved populations that specifically examine health literacy are lacking. Thus, we aimed to describe the health literacy in a national cohort of recently released individuals with chronic medical conditions and to explore how health literacy affects chronic disease management and health care utilization in the immediate post-release period.

Methods

Setting

Data for this study came from patients of the Transitions Clinic Network (TCN), which has previously been described [18–20]. In brief, the TCN is a network of community health clinics that serve as primary care medical homes for people with chronic medical conditions returning from incarceration. During the period of data collection reported here, the TCN included 12 community health centers in 6 states and Puerto Rico, which were focused on improving transitions of care for individuals released from prison [18]. All TCN sites employ community health workers (CHW) with personal experiences of incarceration to engage people with chronic medical diseases in primary care upon release [5, 6].

Participants

Baseline data from 12 TCN programs were included in the current study. Over 2000 new patients returning from prison were served by the TCN between May 2013 and February 2015; however, only 1311 were screened for study inclusion given the variability in obtaining

institutional review board approval at each of these locations. Patients were excluded from participation if they did not have a chronic health condition ($n = 93$);already had an established primary care location that they planned to attend post-release ($n = 171$) or had been out of prison for more than 6 months ($n = 69$). Additionally, 227 individuals who were screened refused to participate; thus, the overall participation rate was 57% of the total number screened (77% among individuals who were not excluded). Eligible patients were recently released from prison (within 6 months): had at least one chronic health condition or age 50 years and older, were able to provide consent in English or Spanish, and planned to live in the TCN clinic area for at least 12 months. Patients who had a primary care provider prior to incarceration were excluded from participation. Participant enrollment ranged from 20 to over 200 across the sites, and in all, 751 patients consented to participate in the study. During or shortly after the first clinic visit, trained research assistants (RAs) assisted study participants to complete an in-person computer-assisted interview that lasted about 45 min. All data were collected on a HIPAA compliant web-based platform, Salesforce, and were immediately accessible to the coordinating center at Yale School of Medicine. The data coordinating center conducted quality checks weekly when sites first started entering data, and then monthly. Each TCN site could only access its clinic's participant data.

Study Measures

Independent Variable

We administered the Newest Vital Sign (NVS) at baseline to assess health literacy [21]. NVS assesses literacy skills for both numbers and words, has been validated against a previously validated measure of health literacy (the TOFHLA), [22] and has been shown to take approximately 3 min to administer. NVS scores are reported in a range from 0 to 6, with scores of 0–1 indicating limited health literacy, 2–3 indicating possible limited health literacy, and 4–6 indicating adequate health literacy. For this study, we dichotomized the variable into adequate health literacy [4–6] and inadequate health literacy (0–3), as previously reported [21]. We chose the NVS as our primary independent variable because it is the current best practice in assessing health literacy, which is the primary focus of our analysis for this manuscript.

Dependent Variables

Our main outcomes were confidence in taking medications, utilization of the emergency department (ED) prior to first TCN clinic visit, and time to first primary care appointment. Of patients who reported being told that they should take medications regularly and were released with medications, we ascertained confidence in taking medications after release by asking whether participants were not confident, somewhat confident, or very confident in taking these medications correctly at home. We combined those that were not confident or somewhat confident into the "not confident" group. ED utilization between prison release and the first clinic visit was assessed by self-reported frequency of ED visits. Lastly, participants reported their release dates allowing for calculation of the time between prison release and initial clinic engagement.

Covariates

Baseline data included age and self-reported sociodemographic characteristics, including race and ethnicity, gender, and education. We also included non-health-related variables, such as housing status and incarceration history, because these variables have been associated with health care utilization previously among this population [23, 24]. We assessed housing status by asking respondents where they were living at time of interview, and responses were grouped into five categories: homeless or shelter, own place (home owner or renting), staying with family or friends, other residential facility, and other. We asked participants about the number of times they had been convicted as an adult, and they could select from one or two, three or more, or refuse to answer. We also asked participants whether they had been arrested before age 16. Health-related variables included self-reported health, depression, chronic disease, and comorbidities. Health status was determined by asking respondents to rate their overall health from poor to excellent [25]. Depression was assessed using a validated instrument, asking questions about symptoms in the past 2 weeks. Respondents were also asked if they had previously received a diagnosis of a list of common chronic disease conditions from a health care provider [26]. Finally, we collected data on patterns of prior health care utilization for routine issues by asking patients about the source of care before their most recent incarceration and responses included

doctor's office, clinic or health center, emergency room, or some other place.

Data Analysis

Data were cleaned and coded in MS Excel and analyzed to characterize the sample using descriptive statistics and SAS 9.0. We determined the proportion of participants with adequate and inadequate health literacy according to NVS scores. We then explored factors associated in bivariate analyses with health literacy by using chi-square, student's *T* test or Mann-Whitney tests. Next, we built a multivariable logistic regression model with confidence taking medications as an outcome measure (dichotomous, yes/no) and a Poisson regression model with ED visits (count variable). Sociodemographic covariates that were associated with health literacy ($p < 0.10$) were then included in the multivariable regression model. We excluded the past incarceration variables from the final models because they did not significantly impact our main outcome estimates. We included general health but excluded comorbidities from the final models because they were significantly correlated. We also adjusted for time to first clinic in our Poisson model. The Yale School of Medicine Human Investigation Committee, Institutional Review Boards at all TCN sites that participated in our study, and the Office for Human Research Protections in the U.S. Department of Health and Human Services approved the study.

Results

Of the 751 participants, the mean age was 46.1 ± 11.2 years; participants were mostly male (85%), non-white (47% black, 30% Hispanic), and had not graduated from high school (59%). About a quarter (23%) were homeless at TCN engagement and another 68% were unstably housed (either living in an institution or with family and friends). Over half of the participants (59%) had been convicted three or more times as an adult and 39% were arrested before age 16 (Table 1). Over two thirds (68%) of the participants had 3 or more comorbid conditions and 46% reported health to be poor or fair. At first clinic visit, 100/751 (13%) of participants had used the ED and 449/751 (60%) were released with medications for their chronic condition, of which 404/449 (90%) were confident about taking their medications correctly.

Sixty percent of the participants had inadequate health literacy. Individuals with inadequate health literacy on average were older (47 vs. 45 years, $p = 0.02$), reported three or more convictions as an adult (62 vs. 54%, $p = 0.01$), and had lower educational attainment ($p < 0.01$) compared with those with adequate health literacy. In bivariate analyses, among those taking medications upon release, individuals with inadequate health literacy were less likely to be confident managing their medications (87 vs. 94%, $p = 0.01$) and to have more ED visits following release (1.8 vs. 1.1 visits, $p = 0.001$) compared with those with adequate health literacy. The mean length of time between prison release and engaging in primary care was not significantly different by health literacy status (Table 2).

In multivariate analysis, after adjusting for patient age, education, and general health, inadequate health literacy was associated with decreased odds in confidence with medications (adjusted odds ratio, AOR 0.43, 95% CI 0.21–0.89) among individuals released with medications. The relative risk of using the ED before first primary care visit after prison release was higher for individuals with inadequate health literacy (AIRR = 1.59, 95% CI 1.10–2.30) compared to those with adequate literacy. None of the sociodemographic covariates was significantly associated with our outcomes in the adjusted models (Table 3).

Discussion

In a large multi-site study of individuals recently released from prison, we found that almost 60% of the study population has inadequate health literacy. These rates are consistent with past studies of low-income populations with chronic conditions, which have shown high rates of inadequate health literacy that range from 47 to 86% [27–32]. Similar to past studies, we found that individuals with less education and a higher burden of chronic health conditions had lower health literacy [7, 11, 33–35].

Also, we found that having inadequate health literacy was associated with decreased confidence in taking medications following release from prison. These findings mirror those found in other populations [5, 7, 11, 36–38] but bear further consideration given how individuals who cycle in and out of the criminal justice system engage with the health care system behind bars and upon release. Approximately 40% of individuals are diagnosed with a new chronic medical

Table 1 Participant characteristics by health literacy status

Characteristics	All participants		Adequate literacy		Inadequate literacy		*p* value
	N (mean)	% (sd)	*N* (mean)	% (sd)	*N* (mean)	% (sd)	
Age, years; mean (sd)	46.1	± 11.2	44.9	± 11.1	46.9	± 11.2	0.02
Race							
African-American/Black	352	46.9%	137	45%	215	48%	0.14
Hispanic	227	30.2%	94	31%	133	30%	
White	134	17.8%	62	20%	72	16%	
Other	38	5.1%	10	3%	28	6%	
Gender							
Male	640	85.2%	253	83%	387	86%	0.27
Female	111	14.8%	50	17%	61	14%	
Education							
Less than HS	227	30.2%	61	20%	166	37%	< 0.001
Graduate equivalency degree	213	28.4%	80	26%	133	30%	
High school graduate	121	16.1%	49	16%	72	16%	
Some college/college graduate	184	24.5%	111	37%	73	16%	
Unknown	6	0.8%	2	1%	4	1%	
Housing							
Homeless or shelter	172	22.9%	68	22%	104	23%	0.61
Own place	53	7.1%	26	9%	27	6%	
Other residential facility or institution	299	39.8%	124	41%	175	39%	
Staying with family/friends	208	27.7%	79	26%	129	29%	
Other	18	2.4%	6	2%	12	3%	
Unknown	1	0.1%					
Three or more prior convictions							
No	295	39.3%	136	45%	159	35%	0.01
Yes	440	58.6%	163	54%	277	62%	
Unknown	16	2.1%					
Arrested before age 16							
No	449	59.8%	194	64%	255	57%	0.09
Yes	290	38.6%	107	35%	183	41%	
Unknown	12	1.6%					
General health		0.0%					
Fair to poor	346	46.1%	127	42%	219	49%	0.06
Good to excellent	403	53.7%	175	58%	228	51%	
Unknown	2	0.3%					
Moderate to severe depression							
No	536	71.4%	212	70%	324	72%	0.48
Yes	215	28.6%	91	30%	124	28%	
Chronic disease conditions							
Diabetes or high blood sugar	133	17.7%	63	21%	70	16%	0.07
HIV/AIDS	48	6.4%	15	5%	33	7%	0.18
Hypertension or high blood pressure	283	37.7%	113	37%	170	38%	0.86
Chronic lung disease	81	10.8%	34	11%	47	10%	0.75
Heart disease	31	4.1%	12	4%	19	4%	0.85

Table 1 (continued)

Characteristics	All participants		Adequate literacy		Inadequate literacy		*p* value
	N (mean)	% (sd)	*N* (mean)	% (sd)	*N* (mean)	% (sd)	
Drug dependence	310	41.3%	116	38%	194	43%	0.17
Alcohol dependence	205	27.3%	93	31%	112	25%	0.09
Comorbid conditions							
1 to 2	189	25.2%	84	28%	105	23%	0.04
3 to 4	194	25.8%	74	24%	120	27%	
5 to 6	154	20.5%	52	17%	102	23%	
7 or more	163	21.7%	64	21%	99	22%	
None	51	6.8%	29	10%	22	5%	
Source of regular care before incarceration							
Doctor's office	111	14.8%	58	19%	53	12%	0.05
Clinic or health center	226	30.1%	85	28%	141	31%	
Emergency room	39	5.2%	14	5%	25	6%	
Some other place	10	1.3%	3	1%	7	2%	

condition while incarcerated [39]. Their experience of incarceration uniquely impacts the management of chronic conditions, as individuals typically are not permitted to manage their own medications or use devices to monitor their own diseases while incarcerated [40]. Regardless of an individual's health literacy, the correctional health system manages chronic disease and assumes control and responsibility. Thus, release from correctional facilities may expose an individual to new situations which challenge self-efficacy with respect to chronic disease management, including having to navigate a pharmacy system, administering daily medications, and monitoring disease status. This, in turn, could lead to individuals with inadequate health literacy using the emergency department more frequently following release from prison.

Our findings highlight an opportunity for intervention. Prior to release, correctional facilities could identify those with low health literacy and target services to ensure they have the necessary tools to seek and secure the healthcare they need to manage their illnesses and to avoid emergent care. Given that over half the incarcerated population may have inadequate health literacy, correctional health systems should consider translating the concrete goals and strategies detailed by the National Action Plan to improve health literacy in the general population to assist those under their supervision [41]. These include efforts to improve communication, shared decision-making and access to services in correctional health services, self-management support programs, use of health educators and, given the results of this study, well-coordinated discharge planning, and linkage to primary care services before discharge from corrections.

Table 2 Bivariate comparison of main outcomes

	Adequate literacy		Inadequate literacy		*p* value
	N (mean)	% (sd)	*N* (mean)	% (sd)	
Time to first clinic visit (days)	43.2	± 41.9	44.9	± 43.8	0.62
Number of ED visits	1.1	± 0.4	1.8	± 1.4	0.001
Confidence taking medications					
No	11	5.8%	34	13.1%	0.01
Yes	179	94.2%	225	86.9%	

Table 3 Multivariate models for confidence taking medication and number of ED visits

Characteristic	Confidence taking medications		Number of ED visits	
	AOR	95% CI	AIRR	95% CI
Inadequate literacy	0.43	(0.21–0.89)	1.59	(1.10–2.30)
Age at first visit	1.01	(0.98–1.04)	1.02	(0.99–1.03)
Education				
Completed GED or less than high school	0.76	(0.34–1.69)	1.09	(0.72–1.64)
High school graduate	0.55	(0.22–1.34)	0.75	(0.45–1.25)
College graduate	1.52	(0.54–4.31)	0.81	(0.50–1.32)
Unknown	0.19	(0.02–2.28)	0.86	(0.12–6.47)
Fair/poor health	0.7	(0.36–1.35)	1.17	(0.83–1.64)
Time to first clinic visit	1.59	(1.10–2.30)	1.00	(0.99–1.003)

AOR adjusted odds ratio, *AIRR* adjusted incidence rate ratio

Future research is urgently needed in order to evaluate best practices with respect to implementation of these efforts to bolster health literacy among individuals involved in the criminal justice system.

This study has noted limitations. We used data from a population of individuals with chronic conditions who were engaged in primary care. These data may not be generalizable to the larger population of individuals who are under the supervision of the criminal justice system. However, understanding health literacy is particularly salient among those with chronic medical conditions. Secondly, these data are cross-sectional, so we are unable to ascertain directionality of these data. We also did not include other important factors including discrimination and racism in these analyses that are associated with acute care utilization.

Conclusion

Our results indicate that inadequate health literacy is associated with a lack of confidence in taking medications appropriately and increased acute care utilization in the immediate post-release period. In the context of the high rates of chronic conditions among the millions of individuals who are released from the correctional facility, more studies are needed to understand the impact of inadequate health literacy on health outcomes in the months and years following release. Preventing negative consequences of inadequate health literacy should be a high priority for clinicians and policymakers. Future areas of research should include further understanding the role of health educators and community health workers in implementing strategies to improve health literacy and health communication with individuals prior to their release from incarceration, with a goal of improving health and health care utilization for this population. Finally, more research is needed regarding how structural factors within the criminal justice system may exacerbate existing health conditions and individuals' self-efficacy to manage these conditions.

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