

UCLA

UCLA Previously Published Works

Title

Economic burden, financial stress, and cost-related coping among people with uncontrolled diabetes in the U.S.

Permalink

<https://escholarship.org/uc/item/6pr9v19n>

Authors

Patel, Minal R
Anthony Tolentino, Dante
Smith, Alyssa
[et al.](#)

Publication Date

2023-08-01

DOI

10.1016/j.pmedr.2023.102246

Peer reviewed



Economic burden, financial stress, and cost-related coping among people with uncontrolled diabetes in the U.S

Minal R. Patel^{a,*}, Dante Anthony Tolentino^b, Alyssa Smith^a, Michele Heisler^{a,c,d}

^a Department of Health Behavior & Health Education, University of Michigan School of Public Health, United States

^b School of Nursing, University of California, Los Angeles, United States

^c Department of Internal Medicine, Michigan Medicine, United States

^d U.S. Department of Veterans Affairs VA Ann Arbor Healthcare System, United States

ARTICLE INFO

Keywords:

Economic burden
Diabetes
Financial stress
Coping
Social determinants of health

ABSTRACT

Granular information on material deprivation including financial and economic well-being among people with diabetes can better inform policy, practice and interventions to support diabetes management. The purpose of this study was to describe in-depth the state of economic burden, financial stress, and coping among people with high A1c. Data came from the 2019–2021 baseline assessment in an ongoing U.S. trial that addresses social determinants of health among people with diabetes and high A1c who report at least one financial burden or cost-related non-adherence (CRN) ($n = 600$). Mean age of participants was 53 years. Planning behaviors were the most common financial well-being behavior, while savings was least frequently endorsed. Nearly a quarter of participants report spending more than \$300 per month out-of-pocket to manage all of their health conditions. Participants reported spending the most out-of-pocket on medications (52%), special foods (40%), doctor's visits (27%), and blood glucose supplies (22%). Along with health insurance, these were also the most cited as sources of financial stress and where assistance. Seventy-two percent reported high levels of financial stress. Maladaptive coping was evident through CRN, and less than half engaged in adaptive coping such as talking to a doctor about cost or using a resource to address their needs. Economic burden, financial stress, and cost-related coping are highly relevant constructs among people with diabetes and high A1cs. More evidence-generation is needed for diabetes self-management programs to address sources of financial stress, facilitate behaviors to enhance financial well-being, and address unmet social needs to alleviate economic burdens.

1. Introduction

Diabetes is one of the most prevalent chronic diseases in the U.S., with more than 30 million Americans reporting a diagnosis (American 2022). Over 30% of people with diabetes in the U.S. do not meet target glycemic or blood pressure goals (American 2022; Walker et al., 2014). Social determinants of health are increasingly recognized as key drivers of adverse diabetes outcomes and spending (American 2022; Walker et al., 2014; Patel, 2020 Nov 5).

Weida and colleagues have recently described financial well-being as an important measurable social determinant of health, where lack of financial well-being—or financial stress—serves as a root cause of other insecurities such as economic burden and vulnerability to other social risks (e.g. food insecurity) (Weida et al., 2020 May 18). Financial well-

being is distinct from the concept of financial literacy. While financial literacy is focused on understanding financial concepts and skills, financial well-being is the state of having a healthy financial outlook that mirrors daily financial activities: paying bills on time and in full (spend), having sufficient long-term savings (save), having a prime credit score (borrow) and planning ahead for expenses (plan) (Weida et al., 2020 May 18). Various domains of financial well-being have been linked to both physical and mental health outcomes and self-rated health (Kahn and Pearlin, 2006 Mar; Butterworth et al., 2009 Jul; Butterworth et al., 2009).

Friedline and others have attempted to create a temporal ordering of the causes and consequences of financial stress by grouping the literature into categories (Weida et al., 2020 May 18; Friedline et al., 2020 Jul 15). Those with inadequate income or debt may experience economic

* Corresponding author at: Department of Health Behavior & Health Education, University of Michigan School of Public Health, 1415 Washington Heights, Ann Arbor, MI 48109-2029.

E-mail address: minalrp@umich.edu (M.R. Patel).

<https://doi.org/10.1016/j.pmedr.2023.102246>

Received 18 September 2022; Received in revised form 2 January 2023; Accepted 11 May 2023

Available online 15 May 2023

2211-3355/© 2023 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

hardship that precipitates stress from trying to afford current and ongoing financial obligations. Individuals may use various strategies to cope with these circumstances, both adaptive and maladaptive. Much of the literature describing burden, stress, or coping driven by the financial and resource aspects of managing diabetes includes one or more of these areas based on data availability (Caraballo et al., 2020 Feb; Mszar et al., 2020 May 18; Shi et al., 2021 Jun; Blanchette et al., 2021 Aug; Patel et al., 2016 Aug). Among people with Type 1 diabetes, Blanchette et al. found that 21% of the variance in HbA1c is explained by greater financial stress (Blanchette et al., 2021 Aug). Using data from the National Health Interview Survey, multiple studies have shown high prevalence of food insecurity, inability to pay medical bills, financial stress, and cost-related non-adherence (CRN) behaviors among people with diabetes (Patel et al., 2016 Aug; Caraballo et al., 2020 Feb; Mszar et al., 2020 May 18). However, these national studies demonstrate associations between those with diabetes and disease-agnostic indicators of burden, stress, and coping behaviors. In our prior work, which included a small sample of people with diabetes who reported some indication of financial burden from diabetes ($n = 104$), we found that the most frequently reported burdensome components of diabetes included medications, followed by healthy food access, insulin pumps, and lost work time (Patel et al., 2018 Feb). Forty-percent reported having monthly out-of-pocket expenses over \$1,000 to manage their overall health, and 32% reported spending on average over \$100 out-of-pocket per month for their diabetes (Patel et al., 2018 Feb).

More granular information on financial well-being, economic burden, financial stress, and coping among people with diabetes can better inform policy, practice, and interventions to support diabetes management and mitigate adverse outcomes. Our baseline data from a randomized trial focused on addressing social determinants of health that impair diabetes management (Patel et al., 2020) provides a unique opportunity to address this significant gap in the literature in a sizable sample ($n = 600$). Accordingly the purpose of this study was to describe in-depth the state of economic burden, financial stress, and coping among people with high A1c and some indication of diabetes being impacted by economic burden.

2. Methods

2.1. Data source

This study is a cross-sectional, secondary data analysis of a larger study. Data are from interviewer-assisted patient surveys from the baseline assessment of a randomized controlled trial testing approaches to addressing unmet social risk factors in people with diabetes (Patel et al., 2020). All study procedures were approved by the University of Michigan Institutional Review Board and met ethical standards for research.

2.2. Sample

Between 2019 and 2021, potential participants were initially identified via the University of Michigan's Diabetes Research Registry and the electronic health record through Michigan Medicine. Study participants met the following criteria: 1) 18–75 years of age, 2) diagnosis of Type 1 or Type 2 diabetes with prescribed oral or injectable antihyperglycemic medication, 3) most recent (within the past 6 months) recorded HbA1c level of $\geq 7.5\%$ for individuals ≤ 70 years and greater than 8.0% for individuals between 70 and 75 years in age, 4) positive report of financial burden or cost-related non-adherence (CRN) such as taking less medications, skipping medication doses, delaying or deciding not to fill a prescription, or delaying or deciding not to see a healthcare provider (Pierre-Jacques et al., 2008; Burcu et al., 2015), and 5) access to a mobile phone. Exclusion criteria included significant cognitive impairment precluding individuals from completing the study as evidenced by inability to complete study intake procedures. Individuals

actively participating in another diabetes-related research study were also excluded.

Trained recruitment staff made initial contact with potential participants via telephone and screened them for inclusion/exclusion criteria over the phone. Participants who met inclusion criteria consented via phone, prior to their baseline assessments. The consent described the voluntary and confidential nature of the study and that participants who agreed to participate will be randomly assigned to one of two groups who receive resources for better managing diabetes. All participants provided written informed consent, and received a modest monetary incentive for their participation.

From a total of 6,055 potential participants initially contacted, 997 were confirmed eligible. Of those, 666 (66%) consented to participate, and 600 provided completed surveys. This analysis is based on the sample of 600 completed surveys.

2.3. Measures

In-person interviewer-assisted surveys were conducted by trained staff prior to March 11, 2020, the same day the World Health Organization (WHO) declared the COVID-19 pandemic. Since then, surveys were administered over the telephone. All data were collected in Qualtrics.

2.4. Demographic and clinic characteristics

Standard demographic characteristics were collected, including age, gender, self-reported annual income, educational attainment, employment status, health insurance status, self-reported race/ethnicity, marital status, and monthly out-of-pocket expenses for managing diabetes. Using income and household information, participants were classified using percentiles relative to the US poverty level for 2019 (United States Census Bureau, 2019). Other data collected included the length of time since diagnosis with diabetes, number of chronic conditions, and type of diabetes (Type 1 or Type 2). Additional clinical measures included the 2-item validated Diabetes Distress Scale (Polonsky et al., 2005 March). Higher scores indicated greater distress. A1c was measured during the baseline survey using the DCA Vantage Analyzer for interviews conducted in-person (Szymezak et al., 2008). For participants surveyed via telephone, HbA1c's were collected by the A1c Now home test kit (Hirst et al., 2017 Feb 1). A1c was statistically calibrated to account for data collection method. Blood pressure was measured as systolic blood pressure/diastolic blood pressure in millimeters of mercury (e.g., 120/80 mmHg) with an automated blood pressure machine (Takahashi et al., 2022).

2.5. Financial Well-Being

We measured financial well-being using a modified version of the Financial Management Behavior Scale (FMBS) (Dew and Xiao, 2011). Seventeen items assessed spending (cash management), borrowing (credit management), savings and investment, and planning (insurance provision) on a 5-point Likert Scale (1-never to 5 always). Higher scores indicated better financial well-being in each sub-domain.

2.6. Economic burden

Economic burden was captured through three assessments related to their health: 1) self-report of out-of-pocket spending on diabetes in the past 30 days on eight indicators (medications, physical activity membership, doctor visits, home blood testing supplies, laboratory tests, transportation for healthcare visits, physical therapy, low carb or low sugar foods). Items were assessed on a four category scale (\$0, \$1–50, \$51–100, over \$100); 2) self-report of average, monthly out-of-pocket spending to manage all health conditions. Items were assessed on an 11-point Likert scale in \$50 increments between \$0–501; 3) self-report

of areas of needed assistance. Items were adapted from: the Accountable Health Communities Health-Related Social Needs Screening Tool, the Health Leads Social Needs Screening Toolkit, and the Kaiser Permanente Your Current Life Situation Questionnaire (Leads and Toolkit, 2018; Survey and Center, 2017; Billioux et al). Items assessed the presence of everyday needs over the past 12 months such as food, housing, energy/ utilities, income, employment, help with medical bills, and diabetes management needs (e.g. blood glucose supplies, medications/insulin, healthy food and meals, physical activity programs, and diabetes education and counseling). “Yes“ responses indicated an expressed need for resources related to diabetes management or other social risks.

2.7. Financial stress attributed to diabetes

Financial stress attributed to diabetes was captured through two assessments: 1) self-report of aspects of diabetes management endorsed as financially burdensome (e.g. health insurance, buying healthy food, medications, testing supplies, physical activity, etc.) assessed on a 5-point Likert scale (not at all – very much); 2) the 11-item COST-FACIT measure (Cronbach’s alpha = 0.84). Each item was measured on a 5-point scale (0: not at all – 4: very much), with recall based on the past 7 days related to their diabetes management (Patel et al., 2022). Lower scores indicated worse financial stress.

2.8. Coping

We assessed both maladaptive and adaptive coping behaviors. Maladaptive coping included cost-related non-adherence (CRN) behaviors for diabetes, measured by asking participants if they engaged in any of the following behaviors during the last 12 months due to financial burden from diabetes: took less medications, skipped medication doses, delayed or decided not to fill a prescription, and delayed or decided not to see a healthcare provider (4-point Likert scale: never - often) (Pierre-Jacques et al., 2008; Burcu et al., 2015). Behaviors were analyzed as dichotomous variables, with ‘never’ and ‘rarely’ indicating ‘no’ CRN, and ‘sometimes’ and ‘often’ indicating ‘yes’ to CRN. Adaptive coping strategies were captured through two assessments: 1) self-report of talking to doctor about out-of-pocket costs assessed as none vs. 1 or more times; 2) already using resources for areas of needed assistance (y/n).

2.9. Statistical analysis

Descriptive statistics were used to describe sample characteristics, mean scores of financial management behaviors component sub-scales, economic burden, financial stress attributed to diabetes, and coping behaviors. In sub-group analysis, ANOVA was used to examine demographic and clinical differences in financial well-being scores.

3. Results

3.1. Sample characteristics

A total of 600 participants were included in the analytic sample (Table 1). On average, participants were 53 years of age (standard deviation (SD) = 13), 55% (n = 334) were female, 35% (n = 210) reported non-white race, and 87% (n = 520) reported some college education or above. Twelve percent (n = 73) were classified as living on incomes less than 100% of the poverty level, 16% (n = 95) 100–200% of the poverty level, and 72% (n = 424) 201% or more above the poverty level. Mean number of baseline unmet social needs was 5 (SD = 5). Fifty-three percent of respondents (n = 318) reported not being in the workforce, and 98% (n = 589) reported having either public or private health insurance. Mean years living with diabetes was 15 (SD = 11), mean A1c was 8.2% (SD = 1.5), and mean systolic blood pressure was 133 mm/Hg (SD = 19). Participants on average were managing a mean number of 4 chronic conditions (SD = 2.3), and 46% (n = 273) reported taking 7 or

Table 1
Demographic and clinical characteristics of participants.

Factor	Full sample (N = 600) N (%)
Age (mean(SD))	53 (13)
<44	130 (22)
45–64	340 (57)
> 65	130 (21)
Gender	
Female	334(55)
Male	264 (44)
Other	2(1)
Race	
Non-Hispanic White	388 (65)
Non-Hispanic Black	101 (17)
Hispanic	31 (5)
Asian	23 (4)
Multiple Race	42 (7)
Other	13 (2)
	340 (57)
Married or partnered (% yes)	
Income as percent of poverty level	
<100%	73 (12)
100–200%	95(16)
201–400%	260 (44)
>400%	164 (28)
Education	
Less than High School	9 (1)
High School Graduate or GED	71 (12)
Some College	270 (45)
College Degree	250 (42)
Employment	
Employed: Full-Time	203 (34)
Employed: Part-Time	47 (8)
Unemployed	31 (5)
Not in work force	318 (53)
	589 (98)
Has health insurance (% yes)	
Health insurance type	
None	11 (2)
Private	260 (43)
Medicare	44 (7)
Medicaid	79 (13)
Medicare + Medicaid Supplemental	64 (11)
Medicare + Private Supplemental	140 (23)
Other	2 (1)
Average monthly out-of-pocket spending	
\$100 or less	161 (27)
\$101 - \$500	372 (63)
\$501 or more	54 (9)
Unmet social needs (mean (SD))	5 (5)
Type of diabetes	
Type 1	130 (22)
Type 2	470 (78)
Years living with diabetes (mean (SD))	15 (11)
HbA1c (mean (SD))	8.2 (1.5)
Systolic blood pressure (mean(SD))	133 (19)
Number of chronic conditions (mean (SD))	4 (2.3)
Number of medications	
1–2	51 (8)
3–4	113 (19)
5–6	162 (27)

(continued on next page)

Table 1 (continued)

Factor	Full sample (N = 600) N (%)
7 or More	273(46)
Diabetes distress scale (DDS-2)	
No distress	152 (25)
Moderate distress	71 (12)
High distress	377 (63)
Depressive Symptoms	
None	259 (43)
Mild	175 (29)
Moderate	94 (16)
Severe	71 (12)

more medications. Twenty-eight percent (n = 165) reported moderate-severe PHQ 4 depressive symptoms, and 63% (n = 377) reported high diabetes-related distress.

Fifty nine percent of the sample reported financial stress based on a COST-Facit score of 20 or less, 73% of the sample reported economic burden based on greater than \$100 of out-of-pocket spending on diabetes in the past month, and 39% reported engaging in at least one cost-related non-adherence behavior in the past 12 months (Table 2). Financial stress, economic burden, and maladaptive coping (cost-related non-adherence) was highest for those 45–64 years of age, females, non-Hispanic Whites, those 201–400% of the poverty level, having some college education, not in workforce, those with government sponsored insurance, reporting \$100–500 out-of-pocket spending over the past month, type 2 diabetes, having 7 or more medications, and depressive symptoms in the mild-severe range. While financial stress was higher among those married or partnered (52%), participants who were single reported greater economic burden (59%), and cost-related non-adherence (53%).

3.2. Financial well-being

Among elements of financial well-being, planning behaviors were the most common behavior type (mean 3.83 (SD = 1.09)), followed by borrowing (mean 3.47 (SD = 1.10)), and spending (mean 3.06 (SD = 0.46)). Savings were the least frequent behavior (mean 2.48 (SD = 1.14)) (Fig. 1). Demographic and clinical differences in financial well-being were evident, with lower financial well-being scores among those 45–64 years in age (p <.001), females (p <.001), non-Hispanic Blacks (p = 0.03), not married or partnered (p <.001), income less than 100% of the poverty level (p <.001), less than a high school education (p <.001), not in the workforce (p <.001), government-sponsored health insurance (p <.001), average monthly out-of-pocket spending on diabetes \$100 or less (p = 0.02), taking 7 or more medications (p <.001), and mild-severe depressive symptoms (p <.001) (Table 2).

3.3. Economic burden

Aspects of diabetes management on which respondents spent over \$100 out-of-pocket in the past 30 days included medications (52%), followed by special low carb or low sugar foods for diabetes (39.5%), doctor's visits (27%), and blood glucose supplies (22%). The majority of respondents spent nothing out-of-pocket for lab tests, transportation for healthcare visits, physical therapy or gym or community memberships for physical activity (Fig. 2a).

In managing all of their health conditions per month, 11% of respondents reported spending \$0-\$50 on average out-of-pocket, 64% of respondents reported spending \$51-\$300 per month, 16% of respondents spent \$301–500 per month, and 9% of respondents reported spending \$501 or more (Fig. 2b).

The most frequently endorsed areas of needing assistance were healthy food and meals (45%), income support (39%), medications and/

or insulin (39%), general help with medical bills (38%), and physical activity programs (38%) (Fig. 2c). Nearly one-third of respondents endorsed areas of needing assistance with loans or debt, health care, carbohydrate counseling, blood glucose supplies, general diabetes education, government assistance programs, and housing and utilities.

3.4. Financial stress

The most prevalent aspects of health spending perceived as financial burdensome among respondents were health insurance (45% very much, 33% somewhat), buying healthy food (42% very much, 43% somewhat), medications (37% very much, 48% somewhat), testing supplies (30% very much, 41% somewhat), physical activity memberships (30% very much, 25% somewhat), and health care visits (19% very much, 45% somewhat) (Fig. 3a).

Lower Cost-FACIT scores indicate greater perceptions of financial stress (Patel et al., 2022). Seventy-two percent of respondents reported Cost-FACIT scores of less than 25 (range 0–40) (Fig. 3b).

3.5. Coping strategies

Maladaptive coping strategies included cost-related non-adherence behaviors. In the past year as a result of cost pressures, 25% of respondents reported delaying getting their prescription filled, 19% delayed seeing a healthcare provider, 17% decided not to fill a prescription, 16% took smaller doses of medicine, 14% skipped doses of medicine, and 11% did not see a provider (Fig. 4a).

Among adaptive coping strategies, 38% of respondents reported talking to their doctor about out-of-pocket costs (Fig. 4b). Use of resources was between 4 and 33% among 20 areas of social needs queried. Use of resources was highest for government assistance programs (33%), medications/insulin (32.5%), healthcare (31.5%), healthy food and meals (23%), general diabetes education (23%), and blood glucose supplies (21%).

4. Discussion

In this study, we used data from a sizable sample of predominantly insured people with diabetes to describe in-depth the state of economic burden, financial stress, and coping among people with high A1c who report some indication of their diabetes being impacted by economic burden. Demographic and clinical patterning of financial well-being, financial stress, economic burden, and maladaptive coping were consistent other work demonstrating vulnerability to these conditions (Butterworth et al., 2009 Jul; Walker et al., 2014; Patel, 2020 Nov 5; Weida et al., 2020 May 18; Kang et al., 2018 Sep; Herrick et al., 2021 Sep; Szanton et al., 2010 Jul) We found that planning behaviors were the most common financial well-being behavior type, while savings was the behavior least frequently endorsed by participants. Nearly a quarter of participants report spending more than \$300 per month out-of-pocket to manage all of their health conditions. Participants reported spending the most out-of-pocket on medications, special foods for diabetes, doctor's visits, and blood glucose supplies. In addition to health insurance, these are also areas where people most frequently endorsed areas of financial stress and needing assistance. One-third also want help with aspects of diabetes management (e.g. carbohydrate counseling, blood glucose supplies) and other social needs such as housing and utilities. In this sample, over half reported financial stress. Maladaptive coping was evident through cost-related non-adherence behaviors, and less than half of participants engaged in adaptive coping strategies such as talking to a doctor about cost or using a resource to address their needs.

We found that savings was the least frequent financial well-being sub-domain behavior reported in our sample. Savings play a protective role against financial vulnerability. For people with diabetes, especially those with private insurance, diabetes treatment supplies and therapeutics have demonstrated significant annual out-of-pocket

Table 2
Demographic and clinical differences in financial well-being, financial stress, economic burden, and maladaptive coping associated with diabetes.

	Financial Well-being ^a (n = 600)	P-value	Financial Stress ^b 59% (n = 351)	Economic Burden ^c 73% (n = 426)	Cost-related non-adherence ^d 39% (n = 234)
Age		<0.001			
<44	2.89 (0.58)		78 (22)	87 (20)	48 (21)
45–64	2.87 (0.65)		213 (61)	242 (57)	148 (63)
> 65	3.11 (0.63)		60 (17)	97 (23)	38 (16)
Gender		<0.001			
Female	2.82 (0.59)		222 (63)	240 (56)	135 (58)
Male	3.05 (0.68)		129 (37)	185 (44)	99 (42)
		0.03			
Race					
Non-Hispanic White	2.94 (0.65)		217 (62)	279 (66)	138 (59)
Non-Hispanic Black	2.76 (0.59)		70 (20)	60 (14)	53 (23)
Hispanic	3.11 (0.59)		17 (5)	25 (6)	13 (6)
Asian	2.98 (0.80)		14 (4)	20 (5)	9 (4)
Multiple Race	3.07 (0.54)		23 (6)	30 (7)	15 (6)
Other	2.79 (0.53)		9 (3)	10 (2)	5 (2)
Married or partnered		<0.001			
Yes	3.02 (0.68)		181 (52)	174 (41)	110 (47)
No	2.80 (0.56)		170 (48)	252 (59)	124 (53)
		<0.001			
Income as percent of poverty level					
<100%	2.45 (0.45)		68 (20)	36 (9)	28 (12)
100–200%	2.63 (0.54)		73 (21)	63 (15)	51 (22)
201–400%	2.87 (0.57)		153 (44)	199 (48)	106 (46)
>400%	3.38 (0.58)		52 (15)	120 (29)	45 (20)
		<0.001			
Education					
Less than High School	2.62 (0.39)		6 (2)	5 (1)	3 (1)
High School Graduate or GED	2.68 (0.60)		50 (14)	37 (9)	34 (15)
Some College	2.86 (0.60)		165 (47)	190 (45)	103 (44)
College Degree	3.08 (0.66)		130 (37)	194 (45)	94 (40)
		<0.001			
Employment					
Employed: Full-Time	3.08 (0.63)		90 (26)	146 (34)	78 (33)
Employed: Part-Time	2.84 (0.60)		25 (7)	34 (8)	19 (8)
Unemployed	2.93 (0.64)		22 (6)	23 (5)	13 (6)
Not in work force	2.83 (0.63)		213 (61)	222 (52)	124 (53)
		<0.001			
Health insurance type					
Private	3.11 (0.61)		124 (36)	198 (47)	104 (46)
Government sponsored	2.57 (0.52)		218 (64)	220 (53)	124 (54)
		0.02			
Average monthly out-of-pocket spending on diabetes					
\$100 or less	2.85 (0.69)		74 (22)		45 (20)
\$101 - \$500	2.94 (0.61)		234 (68)		154 (68)
\$501 or more	3.12 (0.66)		35 (10)		28 (12)
Type of diabetes		0.35			
Type 1	2.97 (0.61)		69 (20)	87 (20)	42 (18)
Type 2	2.91 (0.65)		282 (80)	339 (80)	192 (82)
		<0.001			
Number of medications					
1–2	2.98 (0.57)		20 (6)	31 (7)	21 (9)
3–4	3.09 (0.63)		58 (17)	80 (19)	47 (20)
5–6	3.01 (0.65)		90 (26)	118 (28)	57 (24)
7 or More	2.80 (0.63)		182 (52)	197 (46)	109 (47)
Depressive symptoms		<0.001			
None	3.15 (0.61)		102 (29)	184 (43)	84 (36)
Mild	2.86 (0.64)		106 (30)	127 (30)	63 (27)
Moderate	2.75 (0.60)		77 (22)	68 (16)	49 (21)
Severe	2.52 (0.46)		65 (19)	47 (11)	37 (16)

a. p-value generated by ANOVA.

b. Financial stress was defined as COST-FACIT scores less than or equal to 20.

c. Economic burden was defined as average monthly out-of-pocket spending greater than \$100.

d. cost-related non-adherence was defined as a positive response to at least one of five measures in the past 12 months: took less medications, skipped medication doses, delayed or decided not to fill a prescription, and delayed or decided not to see a healthcare provider.

burden, as demonstrated in our data and other studies (Chua et al., 2020 Jul 1; Glied and Zhu, 2020). Other aspects of diabetes management such as specific foods are not covered by health plans, thus making people vulnerable to financial insecurities that savings can assist in buffering.

Economic burden and perceptions of financial stress in our sample are consistent with findings from other studies among people with

diabetes and are largely driven by the cost of medicines and health insurance. For example, the list price of insulin in the U.S. has soared over the past 20 years (Herman and Kuo, 2021 Sep; Herman and Kuo, 2021), creating significant economic burden and perceptions of financial stress among those who rely on this medicine to regulate their diabetes (Carballo et al., 2020 Feb; Shi et al., 2021 Jun) In a recent survey of 2,000

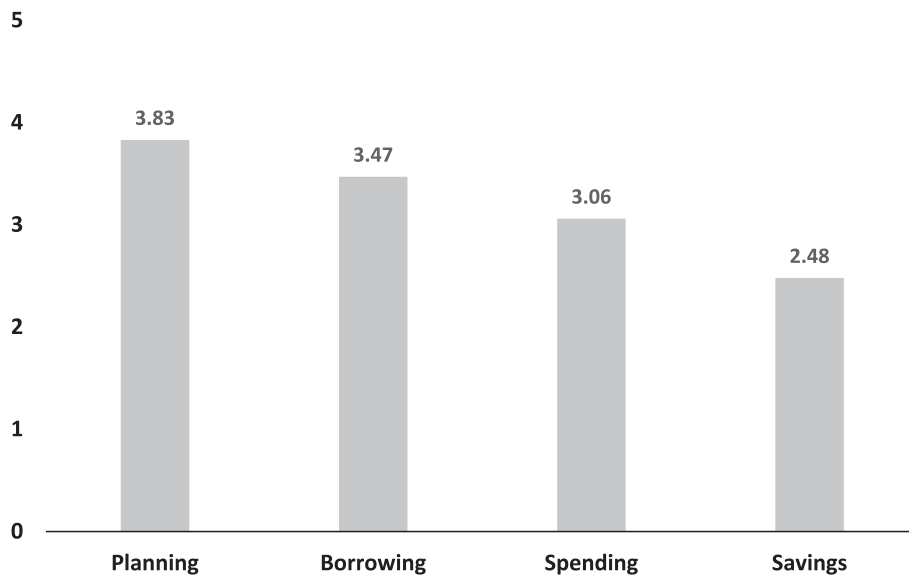
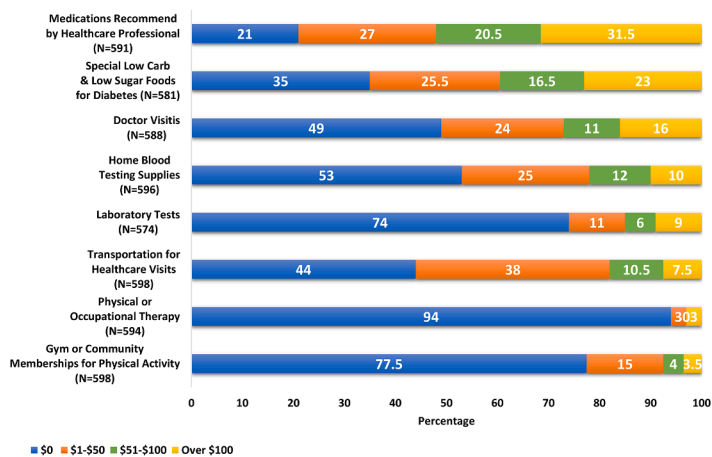
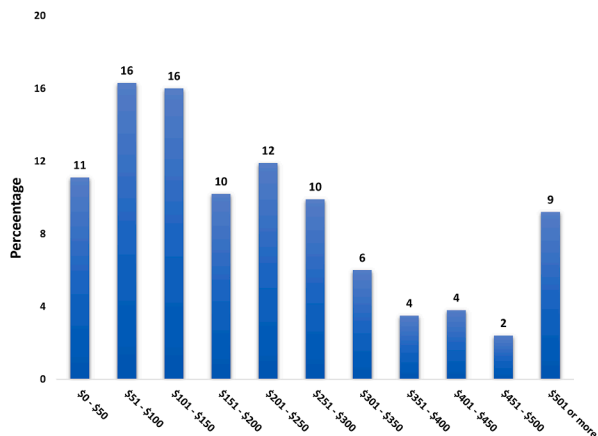


Fig. 1. Financial well-being.

A) Amount spent out-of-pocket on diabetes in the past 30 days



B) Average Monthly, out-of-pocket spending to manage all health conditions



C) Areas of needed assistance

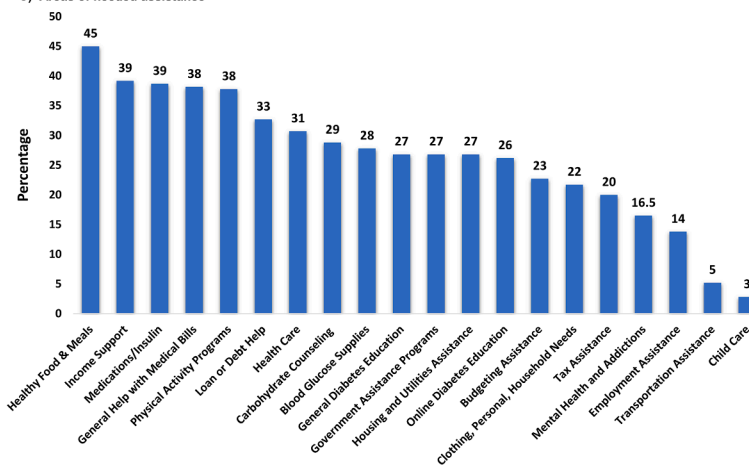
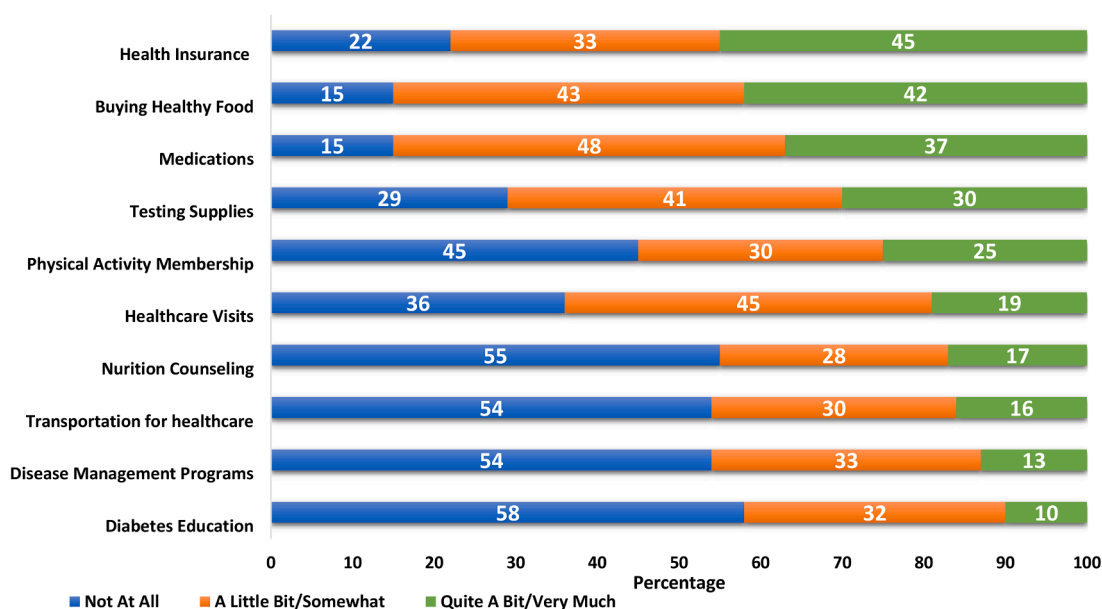
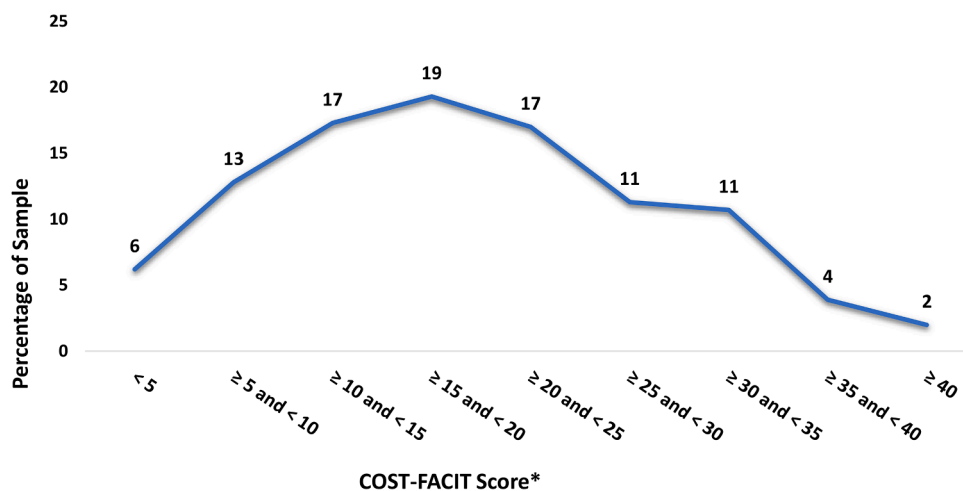


Fig. 2. Factors contributing to Economic Burden.

a) Aspects of health endorsed as financially burdensome



b) Financial stress based on COST-FACIT Scores



*Lower scores indicate greater financial stress

Fig. 3. Financial stress attributed to diabetes *Lower scores indicate greater financial stress.

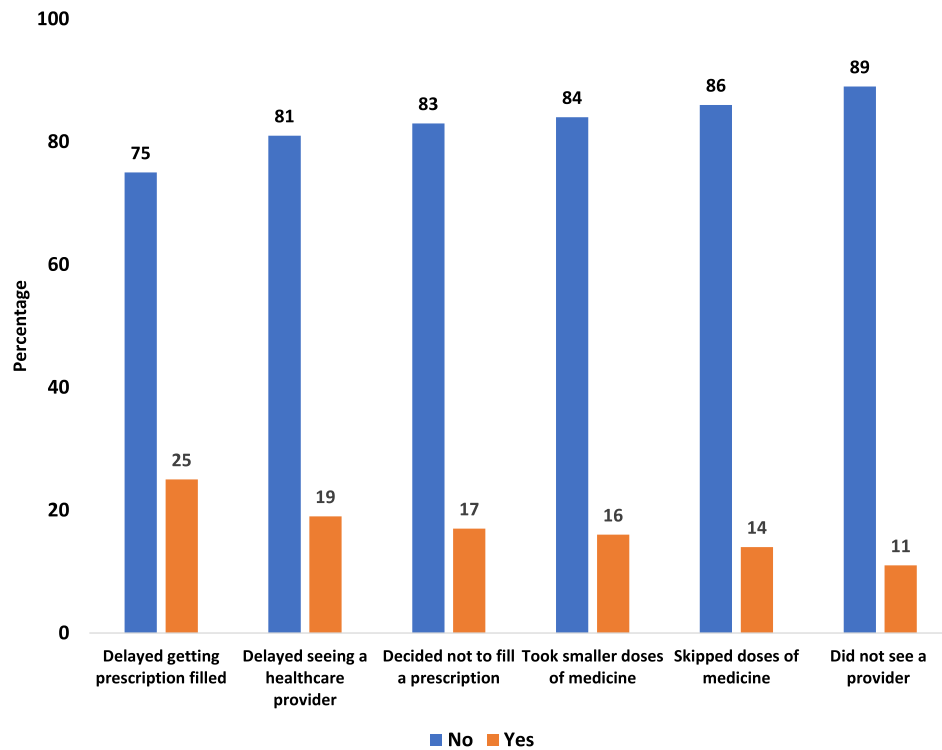
U.S. adults with diabetes, 79% of U.S. adults who have diabetes or care for someone with diabetes say paying for insulin has created financial difficulty; four out of five reported having taken on credit card debt to cover those costs, with the average credit card debt reaching \$9,000; and of those surveyed who have struggled financially due to the cost of insulin, 83% said they were afraid of not being able to pay for living expenses as a result (CharityRx. The financial burden of U.S. insulin pricing on the American diabetic community. Accessed September 2, 2022). Those who are often shielded from high out-of-pocket burden with insulin are those in low-deductible, copayment-only health insurance plans (Glied and Zhu, 2020).

Our findings also built on prior literature by demonstrating other

factors critical to diabetes management endorsed frequently as financial burdensome in this sample such as diabetes monitoring supplies and healthy food access. While food is typically not covered or reimbursable through health insurance plans, coverage for diabetes monitoring supplies is variable due to fragmented health policies regarding insurance (Chehal et al., 2022 Jul).

We found that less than half of participants reported using adaptive coping strategies such as using resources to address a social need. Although screening and resource linkages for unmet social needs are burgeoning in healthcare, our findings align with national trends of less than half of people taking up offered resources (Swavely et al., 2019; Martel et al., 2018; Tong et al., 2018; De Marchis et al., 2020; Bottino

a) Maladaptive coping strategies



b) Adaptive coping strategies

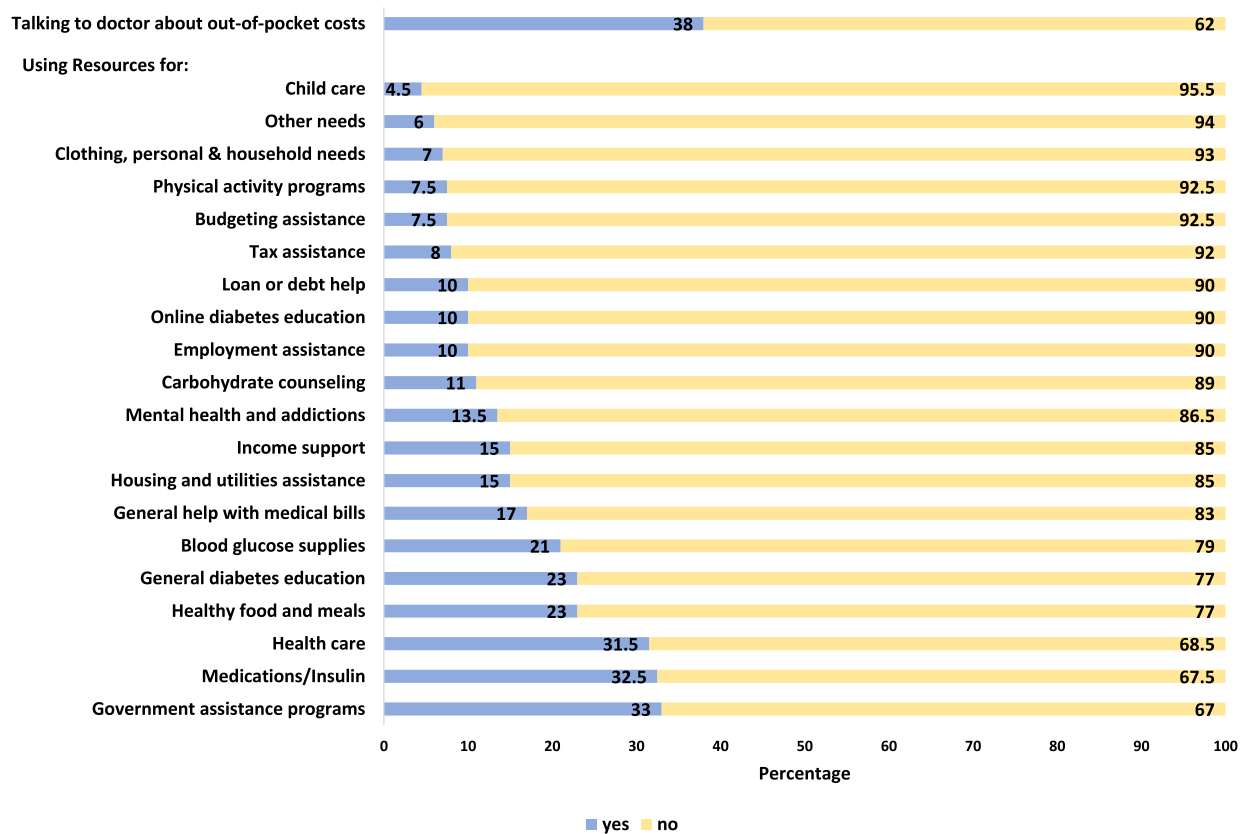


Fig. 4. Coping strategies.

et al., 2017; Knowles et al., 2018; Schickedanz et al., 2019; Uwemedimo and May 2018; Garg et al., 2010; Byhoff et al., 2019; Sokol et al., 2021; Cullen et al., 2021; Cohen et al., 2022 Sep) While there is more emphasis on supporting medical and community linkages to support diabetes management (Tung and Peek, 2015 Jul; Gunter et al., 2021 Dec), our study is among the first to document the prevalence of actual resource use.

There are limitations to our study that should be noted. The sample in this study consisted of adults with diabetes, high HbA1cs, and some indication of unmet social needs who had been recruited to an intervention study in one health system. This therefore limits the generalizability of our findings. Although our sample was heterogeneous in terms of race/ethnicity, further work is warranted to assess the financial well-being, economic burden, financial stress, and coping strategies across people with diabetes and varying levels of glycemic control and reported unmet social needs. Our study was limited to the types of coping strategies assessed and available in our data. We did not collect information on financial literacy, but this information would be important in future studies to further examine relationships between elements of financial literacy, financial well-being, and associated outcomes.

Notwithstanding these limitations, our findings have important implications. Health policies at all levels must seek to effectively address the economic burden that diabetes places on individuals and families (Glied and Zhu, 2020; CharityRx. The financial burden of U.S. insulin pricing on the American diabetic community. Accessed September 2, 2022; Chehal et al., 2022 Jul) Community resources to assist vulnerable patients are often decentralized, and difficult to navigate therefore greater attention to changing this infrastructure to optimize uptake is critical. The 2021 National Clinical Care Commission report on improving federal diabetes prevention and treatment programs made several recommendations to urge Congress to make diabetes medicines more affordable to people and strengthen coverage of services vital to managing diabetes (National Clinical Care Commission Writing Group et al., 2022). Having insurance plans better meet the financial needs of managing complex chronic conditions like diabetes is an important policy reform priority. Health system and health plan interventions aimed at improving diabetes clinical outcomes show promise with targeted, multicomponent designs addressing diabetes self-management and non-medical needs (Hessler et al., 2019 Apr 29). However the evidence remains limited and necessitates more evidence-testing of intervention components that target social determinants. Our findings illustrate areas of economic burden and financial stress that should be targeted in future interventions.

5. Conclusion

Economic burden, financial stress, and cost-related coping are highly relevant constructs among people with diabetes and high A1cs. More evidence-generation is needed to inform diabetes self-management programs that effectively address perceptions of financial stress, facilitate behaviors under the financial well-being domain, and address unmet social needs.

CRedit authorship contribution statement

Minal R. Patel: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization. **Dante Anthony Tolentino:** Conceptualization. **Alyssa Smith:** Data curation, Formal analysis, Project administration, Software, Visualization. **Michele Heisler:** Conceptualization, Funding acquisition, Investigation, Methodology.

Declaration of Competing Interest

The authors declare that they have no known competing financial

interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

Acknowledgements

This study was supported by the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health (R01 DK116715-01A1) and (P30DK092926) (Michigan Center for Diabetes and Translational Research). The funder had no involvement in the study design; in the collection, analysis and interpretation of data; in the writing of the report; or in the decision to submit the article for publication. The authors are grateful to study staff and participants who made this work possible. The authors have no conflicts of interest to disclose.

References

- American Diabetes Association.: Standards of Medical Care in Diabetes-2022. *Diabetes Care*. 2022; 45(Supplement 1).
- Billoux AK, Verlander SA, & Alley D. Standardized screening for health-related social needs in clinical settings: The accountable health communities screening tool. 2017. Discussion Paper, National Academy of Medicine, Washington, DC.
- Blanchette, J.E., Toly, V.B., Wood, J.R., 2021 Aug. Financial stress in emerging adults with type 1 diabetes in the United States. *Pediatr Diabetes*. 22 (5), 807–815.
- Bottino, C.J., Rhodes, E.T., Kreatsoulas, C., Cox, J.E., Fleegler, E.W., 2017. Food Insecurity screening in pediatric primary care: Can offering referrals help identify families in need? *Acad. Pediatr.* 17 (5), 497–503. <https://doi.org/10.1016/j.acap.2016.10.006>.
- Burcu, M., Alexander, G.C., Ng, X., et al., 2015. Construct validity and factor structure of survey-based assessment of cost-related medication burden. *Med. Care* 53 (2), 199–206.
- Butterworth P, Rodgers B, Windsor TD. Financial hardship, socio-economic position and depression: results from the PATH Through Life Survey. *Soc Sci Med*. 2009 Jul;69(2): 229-37.
- Butterworth, P., Rodgers, B., Windsor, T.D., 2009 Jul. Financial hardship, socio-economic position and depression: results from the PATH Through Life Survey. *Soc. Sci. Med.* 69 (2), 229–237.
- Byhoff, E., De Marchis, E.H., Hessler, D., et al., 2019. Part II: A qualitative study of social risk screening acceptability in patients and caregivers. *Am. J. Prev. Med.* 57 (6 Suppl 1), S38–S46. <https://doi.org/10.1016/j.amepre.2019.07.016>.
- Caraballo, C., Valero-Elizondo, J., Khera, R., Mahajan, S., Grandhi, G.R., Virani, S.S., Mszar, R., Krumholz, H.M., Nasir, K., 2020 Feb. Burden and consequences of financial hardship from medical bills among nonelderly adults with diabetes mellitus in the United States. *Circ. Cardiovasc. Qual. Outcomes*. 13 (2), e006139.
- CharityRx. The financial burden of U.S. insulin pricing on the American diabetic community. Accessed September 2, 2022 from: <https://www.charityrx.com/blog/the-financial-burden-of-u-s-insulin-pricing-on-the-american-diabetic-community%E2%BF%BC>.
- Chehal, P.K., Selvin, E., DeVoe, J.E., Mangione, C.M., Ali, M.K., 2022 Jul. Diabetes and the fragmented state Of US health care and policy. *Health Aff (Millwood)*. 41 (7), 939–946.
- Chua, K.P., Lee, J.M., Conti, R.M., 2020 Jul 1. Out-of-pocket spending for insulin, diabetes-related supplies, and other health care services among privately insured US patients with type 1 diabetes. *J. Am. Med. Assoc. Intern Med.* 180 (7), 1012–1014.
- Cohen, A.J., Isaacson, N., Torby, M., Smith, A., Zhang, G., Patel, M.R., 2022 Sep. Motivators, barriers, and preferences to engagement with offered social care assistance among people with diabetes: A mixed methods study. *Am. J. Prev. Med.* 63 (3 Suppl 2), S152–S163.
- Cullen, D., Abel, D., Attridge, M., Fein, J.A., 2021. Exploring the gap: Food insecurity and resource engagement. *Acad. Pediatr.* 21 (3), 440–445. <https://doi.org/10.1016/j.acap.2020.08.005>.
- De Marchis EH, Hessler D, Fichtenberg C, et al. Assessment of Social Risk Factors and Interest in Receiving Health Care-Based Social Assistance Among Adult Patients and Adult Caregivers of Pediatric Patients. *JAMA Netw Open*. 2020;3(10):e2021201. Published 2020 Oct 1. 10.1001/jamanetworkopen.2020.21201.
- Dew, J.P., Xiao, J.J., 2011. The financial management behavior scale: Development and validation. *J. Financ. Couns. Plan.* 22 (1), 19–35.
- Friedline, T., Chen, Z., Morrow, S., 2020 Jul 15. Families' Financial stress & well-being: The importance of the economy and economic environments. *J. Fam. Econ. Issues*. 42 (Suppl 1), 1–18.
- Garg, A., Sarkar, S., Marino, M., Onie, R., Solomon, B.S., 2010. Linking urban families to community resources in the context of pediatric primary care. *Patient Educ. Couns.* 79 (2), 251–254. <https://doi.org/10.1016/j.pec.2009.10.011>.
- Glied, S., Zhu, B., 2020. Not So Sweet: Insulin Affordability over Time. *Commonwealth Fund*, Sept <https://doi.org/10.26099/xbne-tj76>.
- Gunter, K.E., Peek, M.E., Tanumihardjo, J.P., Carbre, E., Crespo, R.D., Johnson, T.W., Rueda-Yamashita, B., Schwartz, E.I., Sol, C., Wilkinson, C.M., Wilson, J.O.,

- Loehmer, E., Chin, M.H., 2021 Dec. Population health innovations and payment to address social needs among patients and communities with diabetes. *Milbank Q.* 99 (4), 928–973.
- Herman WH, Kuo S. 100 years of Insulin: Why is Insulin So Expensive and What Can be Done to Control Its Cost? *Endocrinol Metab Clin North Am.* 2021 Sep;50(3S):e21-e34.
- Herman, W.H., Kuo, S., 2021 Sep. 100 years of insulin: Why is insulin so expensive and what can be done to control its cost? *Endocrinol. Metab. Clin. North Am.* 50 (3S), e21–e34.
- Herrick, C.J., Humble, S., Hollar, L., Chang, S.H., Hunleth, J., McQueen, A., James, A.S., 2021 Sep. Cost-Related medication non-adherence, cost coping behaviors, and cost conversations among individuals with and without diabetes. *J. Gen. Intern. Med.* 36 (9), 2867–2869.
- Hessler, D., Bowyer, V., Gold, R., Shields-Zeeman, L., Cottrell, E., Gottlieb, L.M., 2019 Apr 29. Bringing social context into diabetes care: intervening on social risks versus providing contextualized care. *Curr. Diab. Rep.* 19 (6), 30.
- Hirst, J.A., McLellan, J.H., Price, C.P., English, E., Feakins, B.G., Stevens, R.J., Farmer, A. J., 2017 Feb 1. Performance of point-of-care HbA1c test devices: implications for use in clinical practice - a systematic review and meta-analysis. *Clin. Chem. Lab Med.* 55 (2), 167–180.
- Kahn, J.R., Pearlman, L.I., 2006 Mar. Financial strain over the life course and health among older adults. *J. Health Soc. Behav.* 47 (1), 17–31.
- Kang, H., Lobo, J.M., Kim, S., Sohn, M.W., 2018 Sep. Cost-related medication non-adherence among U.S. adults with diabetes. *Diabetes Res. Clin. Pract.* 143, 24–33.
- Knowles, M., Khan, S., Palakshappa, D., et al., 2018. Successes, challenges, and considerations for integrating referral into food insecurity screening in pediatric settings. *J. Health Care Poor Underserved.* 29 (1), 181–191. <https://doi.org/10.1353/hpu.2018.0012>.
- Health Leads. Social Needs Screening Toolkit. 2018. <https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/>.
- Martel, M.L., Klein, L.R., Hager, K.A., Cutts, D.B., 2018. Emergency department experience with novel electronic medical record order for referral to food resources. *West J. Emerg. Med.* 19 (2), 232–237. <https://doi.org/10.5811/westjem.2017.12.35211>.
- Mszar, R., Grandhi, G.R., Valero-Elizondo, J., Caraballo, C., Khera, R., Desai, N., Virani, S.S., Blankstein, R., Blaha, M.J., Nasir, K., 2020 May 18. Cumulative burden of financial hardship from medical bills across the spectrum of diabetes mellitus and atherosclerotic cardiovascular disease among non-elderly adults in the United States. *J. Am. Heart Assoc.* 9 (10), e015523.
- National Clinical Care Commission Writing Group, Conlin PR, Greenlee C, Schillinger D, Lopata A, Boltri JM, Tracer H, Albright A, Bullock A, Herman WH. The National Clinical Care Commission Report: Improving Federal Programs That Impact Diabetes Prevention and Care. *Ann Intern Med.* 2022 Apr;175(4):594-597.
- Patel, M.R., 2020 Nov 5. Social determinants of poor management of type 2 diabetes among the insured. *Curr. Diab. Rep.* 20 (11), 67.
- Patel MR, Zhang G, Heisler M, Song PXX, Piette JD, Shi X, Choe HM, Smith A, Resnicow K. Measurement and validation of the Comprehensive Score for financial toxicity (COST) in a population with diabetes. *Diabetes Care.* 2022 Nov 1;45(11):2535-2543.
- Patel, M.R., Piette, J.D., Resnicow, K., Kowalski-Dobson, T., Heisler, M., 2016 Aug. Social determinants of health, cost-related nonadherence, and cost-reducing behaviors among adults with diabetes: Findings from the national health interview survey. *Med. Care.* 54 (8), 796–803.
- Patel, M.R., Resnicow, K., Lang, I., Kraus, K., Heisler, M., 2018 Feb. Solutions to address diabetes-related financial burden and cost-related nonadherence: Results from a pilot study. *Health Educ. Behav.* 45 (1), 101–111.
- Patel, M.R., Heisler, M., Piette, J.D., Resnicow, K., Song, P.X.K., Choe, H.M., Shi, X.u., Tobi, J., Smith, A., 2020. Study protocol: CareAvenue program to improve unmet social risk factors and diabetes outcomes- A randomized controlled trial. *Contemp Clin. Trials.* 89, 105933.
- Pierre-Jacques, M., Safran, D.G., Zhang, F., Ross-Degnan, D., Adams, A.S., Gurwitz, J., Rusinak, D., Soumerai, S.B., 2008. Reliability of new measures of cost-related medication nonadherence. *Med. Care* 46 (4), 444–448.
- Polonsky, W.H., Fisher, L., Earles, J., Dudl, R.J., Lees, J., Mullan, J., Jackson, R.A., 2005 March. Assessing psychosocial distress in diabetes. *Diabetes Care* 28 (3), 626–631.
- Schickedanz, A., Sharp, A., Hu, Y.R., et al., 2019. Impact of Social needs navigation on utilization among high utilizers in a large integrated health system: a quasi-experimental study. *J. Gen. Intern. Med.* 34 (11), 2382–2389. <https://doi.org/10.1007/s11606-019-05123-2>.
- Shi, L., Fonseca, V., Childs, B., 2021 Jun. Economic burden of diabetes-related hypoglycemia on patients, payors, and employers. *J. Diabetes Complications.* 35 (6), 107916 <https://doi.org/10.1016/j.jdiacomp.2021.107916>. Epub 2021 Mar 22.
- Sokol, R.L., Mehdipanah, R., Bess, K., Mohammed, L., Miller, A.L., 2021. When families do not request help: Assessing a social determinants of health screening tool in practice. *J. Pediatr. Health Care.* 35 (5), 471–478. <https://doi.org/10.1016/j.pedhc.2021.05.002>.
- Your Current Life Situation Survey. Kaiser Permanente Care Management Institute Center for Population Health. 2017. www.thepermanentjournal.org/files/2018/18-189-Suppl.pdf Accessed April 18, 2019.
- Swavely, D., Whyte, V., Steiner, J.F., Freeman, S.L., 2019. Complexities of addressing food insecurity in an urban population. *Popul. Health Manag.* 22 (4), 300–307. <https://doi.org/10.1089/pop.2018.0126>.
- Szanton, S.L., Thorpe, R.J., Whitfield, K., 2010 Jul. Life-course financial strain and health in African-Americans. *Soc. Sci. Med.* 71 (2), 259–265.
- Szymezak, J., Leroy, N., Lavalard, E., Gillery, P., 2008. Evaluation of the DCA Vantage analyzer for HbA 1c assay. *Clin. Chem. Lab Med.* 46 (8), 1195–1198.
- Takahashi, H., Saito, K., Yakura, N., 2022. Validation of Omron HEM-9200T, a home blood pressure monitoring device for the upper arm, according to the American National Standards Institute/Association for the Advancement of Medical Instrumentation/International Organization for Standardization 81060–2:2013 protocol. *J. Hum. Hypertens.* 36 (4), 416–419.
- Tong, S.T., Liaw, W.R., Kashiri, P.L., Pecsok, J., Rozman, J., Bazemore, A.W., Krist, A.H., 2018. Clinician experiences with screening for social needs in primary care. *J. Am. Board Fam. Med.* 31 (3), 351–363.
- Tung, E.L., Peek, M.E., 2015 Jul. Linking community resources in diabetes care: a role for technology? *Curr. Diab. Rep.* 15 (7), 45.
- United States Census Bureau, 2019. Poverty Thresholds. Accessed at: <https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html>.
- Uwemedimo OT, May H. Disparities in Utilization of Social Determinants of Health Referrals Among Children in Immigrant Families. *Front Pediatr.* 2018;6:207. Published 2018 Jul 24. [10.3389/fped.2018.00207](https://doi.org/10.3389/fped.2018.00207).
- Walker, R.J., Smalls, B.L., Campbell, J.A., Strom Williams, J.L., Egede, L.E., 2014. Impact of social determinants of health on outcomes for type 2 diabetes: a systematic review. *Endocrine* 47 (1), 29–48.
- Weida, E.B., Phojanakong, P., Patel, F., Chilton, M., Ewen, H.H., 2020 May 18. Financial health as a measurable social determinant of health. *PLoS One* 15 (5), e0233359.