

# Chapter 11

## Financial Hardship, Food Insecurity, and Forgone Medical Care



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### Introduction

Tremendous progress has been made in the fight against cancer. From its peak in 1991, cancer mortality in the United States has declined by 29% [1]. From 2007 to 2016, cancer mortality declined by 1.6% and 1.0% annually for Latino males and females, respectively [2]. However, socioeconomic disparities in cancer mortality

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are widening [3]. Progress has come at a considerable cost to society, the health-care system, and to patients and their families.

In 2020, it was projected that as much as \$200 billion dollars will be spent on cancer care in the United States [4]. The average price of new cancer drugs on the market today is \$14,000 per month, and cancer patients can expect to pay approximately \$5000 out-of-pocket in the first year following a cancer diagnosis [5, 6]. The high costs of cancer care contribute to widening socioeconomic disparities in cancer mortality. The age-adjusted cancer mortality rate is now 80% higher for males living in poverty and 55% higher for females living in poverty than for those with incomes that are 600% of the federal poverty level [3].

As the costs of cancer care skyrocketed over the past decade, new terms emerged to define the problems a patient may experience in relation to the cost of medical care: *financial toxicity* and *financial hardship*. Akin to physical toxicities, like nausea, neutropenia, and fatigue, financial toxicity makes it difficult for cancer patients to complete treatment [7]. Numerous studies have described financial hardships experienced by cancer survivors including debt, inability to pay medical bills, bankruptcy, and other financial sacrifices [8]. To cope with the high costs of cancer care, patients make financial sacrifices, shifting money that might have previously been budgeted for food to pay for medical care. In a study by Zafar et al., 46% of cancer patients reporting financial hardship stated that they coped with the cost of care by reducing spending on basic necessities, including food [9], raising concerns that cancer survivors may be at risk of food insecurity.

Food insecurity, defined as an inability to acquire enough food because of insufficient money or other resources, befell 37.2 million people in the United States in 2018 [10]. In 2020, the economic ramifications of the novel coronavirus (COVID-19) pandemic are projected to increase the number of people experiencing food insecurity by over 17 million, to approximately 54 million people [11]. Inextricably linked to income, the prevalence of food insecurity is highest among households with annual incomes below the official poverty line (35.3%); among households with children headed by a single woman (27.8%); and among households with non-Hispanic Black (21.2%) and Hispanic (16.2%) heads of household [10]. Food insecurity is increasingly recognized as a social determinant of health, with numerous studies finding strong associations between food insecurity and diabetes, hypertension, and hyperlipidemia [12–16]. Evidence from cross-sectional studies also suggests a high prevalence of food insecurity among cancer patients [13, 17–19]. In a small ( $n = 115$ ) sample of predominantly non-Hispanic white (85%) cancer patients in an academic medical center in Kentucky, Simmons et al. found 17% of patients to be food insecure [19]. Among a cohort of underserved oncology patients at New York City cancer clinics ( $n = 404$ ), Gany et al. reported a 56% prevalence of food insecurity and found that women were significantly more likely to be food insecure than men [17]. Food insecurity may be an early indicator of financial problems, as individuals make daily or weekly choices about purchasing food, whereas other bills can often be delayed longer [20]. Moreover, financial sacrifices made to cope with the high cost of cancer care may exacerbate existing food insecurity or cause new food insecurity for cancer patients. The precarious balance between

having enough to eat and affording medical care has been described in cancer patients [9, 13, 17, 19], and evidence supports a strong association between food insecurity and poor treatment adherence [19, 21, 22], inadequate symptom control [23, 24], and increased utilization of high-cost services [25].

Emerging evidence suggests that cancer-related financial hardship disproportionately affects Latinos. In a study of the Health and Retirement Study Cohort, a nationally representative longitudinal survey of more than 37,000 individuals over age 50, 60% of Latinos reported at least one financial hardship compared to 16% of non-Latinos [26]. Importantly, those in the study who reported at least one financial hardship had a higher risk of mortality than those who were financially stable, providing evidence of a link between financial hardship and disparities in mortality that has also been observed in cancer survivors filing for bankruptcy [27]. Data from the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium showed similar findings among cancer survivors, with 58% of Latinos and 45% of non-Hispanic whites reported financial hardship [28].

The purpose of this chapter is to describe financial hardship and food insecurity, and their relationships to accessing cancer care, using data from the recently completed Comprehensive History of Individual Cancer Experiences (CHOICE) Project with cancer survivors in New Mexico. Among New Mexicans, the term “Hispanic” is frequently chosen as a self-defined social identity term and will be used throughout the rest of this chapter to refer to individuals reporting Hispanic ethnicity in the CHOICE Project survey [29]. The research on financial hardship and food insecurity among Hispanic cancer survivors is limited. To address these gaps, we reflect on our own research and propose directions for future study.

## Methods

The CHOICE Project used a cross-sectional survey to quantify the prevalence of financial hardship and food insecurity among population-based Hispanic and non-Hispanic cancer survivors. Individuals from 21 through 64 years of age, diagnosed with a first primary, invasive breast, colorectal, or prostate cancer between 2008 and 2016 were identified from the population-based New Mexico Tumor Registry (NMTR). To be eligible for the study, cancer survivors at the time of their cancer diagnosis had to have private insurance, Medicaid, or have been uninsured with an income that was greater than \$24,000 (approximately 200% of the Federal Poverty Level for an individual [30]). In addition, they had to be able to speak English or Spanish and provide informed consent.

Participants were asked to complete a survey measuring their financial experiences. Available in both English and Spanish, surveys were web-based, computer-assisted telephone interviews or paper versions. Material financial hardship was measured using four questions from the Medical Expenditure Panel Survey Experiences with Cancer Supplement (MEPS-ECS) that asked participants: whether they had to borrow money or go into debt; make financial sacrifices (e.g., reduced

spending on vacation or leisure activities, delayed large purchases, reduced spending on basics, used savings set aside for other purposes, or made a change to living situation); whether they were unable to cover the cost of medical visits; or filed for bankruptcy because of their cancer, its treatment, or the lasting effects of treatment [31]. Food insecurity was measured using the two-item Hunger VitalSign™ food insecurity screening tool [32]. Participants responding “often true” or “sometimes true” to either of the following statements were classified as food insecure: (1) “Within the past 12 months, we worried whether our food would run out before we got money to buy more”; (2) “Within the past 12 months, the food we bought just didn’t last and we didn’t have money to get more.” In the survey, participants were asked to recall their situation at two timepoints: the 12 months prior to their cancer diagnosis and the 12 months after diagnosis. Food security status at each timepoint was combined to characterize participants as persistently food secure (i.e., food secure at both timepoints); newly food insecure (i.e., food secure prior to diagnosis and food insecure after diagnosis); persistently food insecure (i.e., food insecure at both timepoints); or newly food secure (i.e., food insecure prior to diagnosis and food secure after diagnosis). A single question from the MEPS-ECS was used to measure access to care, asking participants whether they ever had to delay, forego, or have to make other changes to any of the following cancer care because of cost: prescription medicine, visit to specialist, treatment (other than prescription medicine), follow-up care, or mental health services [31]. In addition, participants’ sociodemographic information was ascertained from the survey, and tumor type, stage, and treatments received were collected from NMTR records. Ethnicity was classified using survey data, indicating whether a participant self-identified as Hispanic.

Data were summarized with descriptive statistics including means, standard deviations, frequencies, and proportions. Differences between Hispanic and non-Hispanic participants were compared using t-tests for continuous variables, Pearson’s chi-square tests for nominal categorical variables, and nonparametric tests of trend across ordinal categorical variables. Polytomous logistic regression was used to estimate odds ratios (OR) and 95% confidence intervals (CI) that assessed the relationship between Hispanic ethnicity and food insecurity. Multivariable logistic regression models were developed to assess the association between Hispanic ethnicity and forgoing, delaying, or making changes to each type of medical care, adjusting for sociodemographic and clinical characteristics that differed between Hispanic and non-Hispanic cancer survivors at the  $P < 0.20$  level. Adjustment variables in the final models included food insecurity status, age at diagnosis, education, annual household income, insurance type at diagnosis, marital status, and cancer type. All analyses were conducted using STATA v.15.

## Results

Of the 1211 eligible individuals identified from the NMTR, 394 completed the survey (response rate 33%). Forty-two percent ( $n = 164$ ) of study participants identified as Hispanic (Table 11.1). Ninety-seven percent of both Hispanic and non-Hispanic cancer survivors identified as White race. Cancer survivors identified as Hispanic tended to be diagnosed with cancer at a younger age (mean 49.7 vs. 51.6,  $P = 0.01$ ), were less likely to have a college or professional degree (30% vs. 59%,  $P < 0.01$ ), were more likely to have an annual household income  $< \$30,000$  (44% vs. 24%,  $P < 0.01$ ), and were less likely to have private insurance (65% vs. 77%,  $P = 0.01$ ) compared with non-Hispanic cancer survivors.

### *Material Financial Hardship*

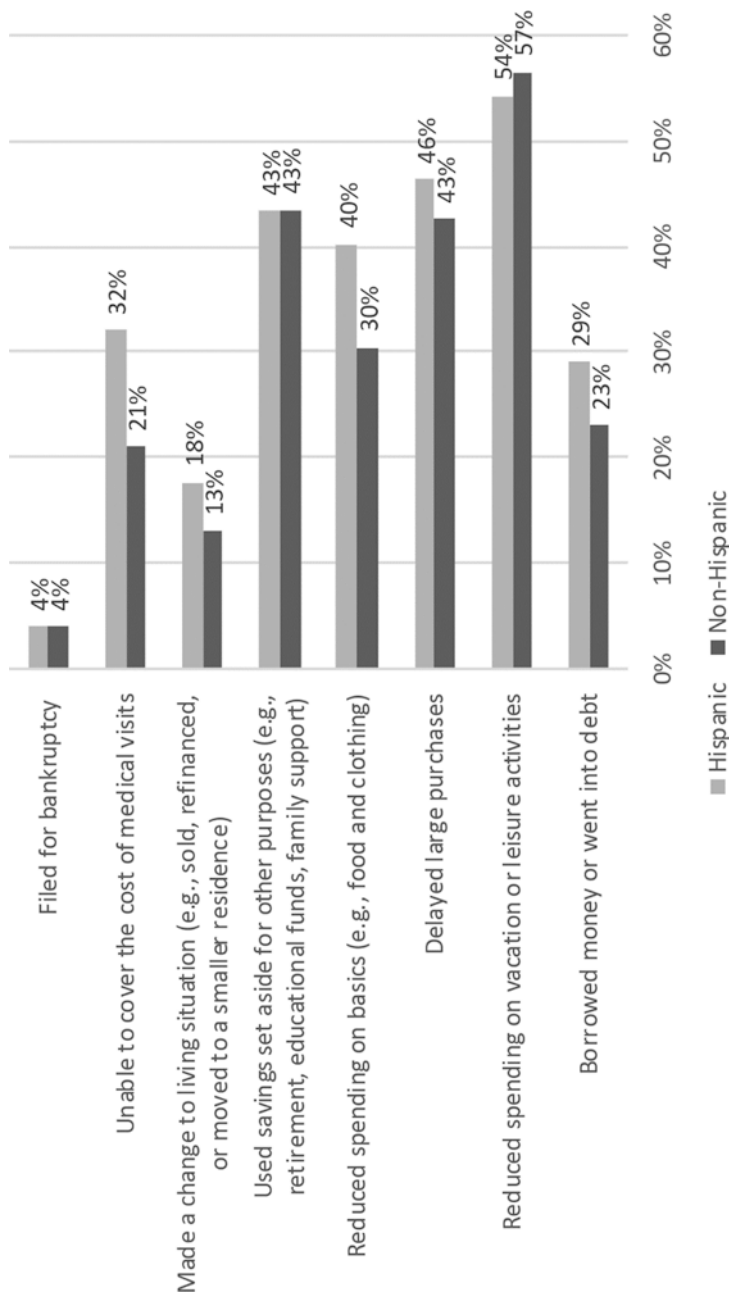
Hispanic cancer survivors were more likely to report being unable to cover the cost of their medical bills (32% vs. 21%,  $P = 0.02$ ) and more likely to reduce spending on basics such as food and clothing (40% vs. 30%,  $P = 0.04$ ) than non-Hispanic cancer survivors (Fig. 11.1). Hispanic cancer survivors were also slightly, though not significantly, more likely than non-Hispanics to make a change to their living situation (18% vs. 13%,  $P = 0.21$ ), delay large purchases (46% vs. 43%,  $P = 0.46$ ), and borrow money or go into debt (29% vs. 23%,  $P = 0.19$ ). Four percent of cancer survivors filed for bankruptcy, while more than half of all cancer survivors reported reducing spending on vacation or leisure activities, and no difference was observed by ethnicity for these types of financial hardship.

### *Food Insecurity*

Both new and persistent food insecurity were significantly more common among Hispanic cancer survivors than non-Hispanics (Table 11.2). Thirteen percent of Hispanic cancer survivors and 7% of non-Hispanic cancer survivors were newly food insecure in the 12 months after their diagnosis (OR = 2.59, 95% CI: 1.29–5.19), while 34% of Hispanic cancer survivors were persistently food insecure compared to 20% of non-Hispanics (OR = 2.61, 95% CI: 1.61–4.21). Combining both newly and persistently food insecure individuals, the overall prevalence of food insecurity in the 12 months after cancer diagnosis was 47% for Hispanic cancer survivors and 27% for non-Hispanic cancer survivors in this study.

**Table 11.1** Characteristics of survey participants by ethnicity,  $N = 394$ 

	Hispanic ( $n = 164$ )		Non-Hispanic ( $n = 230$ )		$p$ -value
	$n$ or mean	% or SD	$n$ or mean	% or SD	
<i>Age at diagnosis (years)</i>	49.7	7.3	51.6	6.3	0.01
<i>Time since diagnosis (years)</i>	5.7	2.2	5.9	2.5	0.44
<i>Sex</i>					0.38
Female	118	72%	156	68%	
Male	46	28%	74	32%	
<i>Race</i>					0.81
White	159	97%	222	97%	
Non-White	5	3%	8	3%	
<i>Education</i>					<0.01
≤High School	113	70%	93	41%	
≥College	49	30%	132	59%	
<i>Annual household income</i>					<0.01
Less than \$30,000	71	44%	56	24%	
\$30,000–\$69,999	33	20%	35	15%	
\$70,000 or more	59	36%	139	60%	
<i>Marital status</i>					0.11
Married	64	40%	72	32%	
Not Married	97	60%	154	68%	
<i>County of residence</i>					0.87
Urban	109	67%	152	66%	
Rural	54	33%	78	34%	
<i>Insurance type at diagnosis</i>					0.01
Private	107	65%	176	77%	
Medicaid	43	26%	47	20%	
Uninsured	14	9%	7	3%	
<i>Cancer type</i>					0.14
Breast	104	63%	134	58%	
Colorectal	34	21%	41	18%	
Prostate	26	16%	55	24%	
<i>Cancer stage</i>					0.52
I	66	40%	105	46%	
II	69	47%	91	40%	
III	29	18%	34	15%	
<i>Cancer directed surgery</i>					0.17
Yes	149	91%	197	86%	
No	15	9%	31	13%	
<i>Radiation therapy</i>					0.65
Yes	56	34%	84	37%	
No	105	64%	144	63%	
<i>Chemotherapy</i>					0.78
Yes	69	42%	90	39%	
No	93	57%	138	60%	



**Fig. 11.1** Proportion of individuals experiencing material financial hardship

**Table 11.2** Association between Hispanic ethnicity and food insecurity

	Hispanic ( <i>n</i> = 164)		Non-Hispanic ( <i>n</i> = 230)		OR	95% CI
	<i>n</i>	%	<i>n</i>	%		
Persistently food secure	74	45	155	67	1.00	Reference
Newly food insecure	21	13	17	7	<b>2.59</b>	<b>1.29–5.19</b>
Persistently food insecure	56	34	45	20	<b>2.61</b>	<b>1.61–4.21</b>
Newly food secure	6	4	7	3		
Missing	7	4	6	3		

Bold values represent statistical significance at the 2-sided  $P < 0.05$  level

**Table 11.3** Proportion of participants forgoing, delaying, or having to make changes to cancer care because of cost

	Hispanic ( <i>n</i> = 164)		Non-Hispanic ( <i>n</i> = 230)		<i>p</i> -value
	<i>n</i>	%	<i>n</i>	%	
<i>Did you ever delay, forego, or have to make other changes to any of the following cancer care because of cost?</i>					
Prescription medicine	23	14	31	13	0.88
Visit to specialist	27	16	40	17	0.81
Treatment (other than prescription medicine)	19	12	24	10	0.72
Follow-up care	28	17	38	17	0.89
Mental health services	23	14	13	6	<0.01

### ***Forgoing, Delaying, or Having to Make Changes to Cancer Care Because of Cost***

No significant differences by ethnicity were observed in the proportion of cancer survivors forgoing, delaying, or having to make changes to cancer care because of cost, with the exception of mental health services (Table 11.3). However, Hispanic cancer survivors were more than twice as likely to forgo, delay, or make changes to mental health services compared with non-Hispanic cancer survivors (14% vs. 6%,  $P < 0.01$ ). Upon adjustment for multiple sociodemographic and clinical factors (Table 11.4), the association between Hispanic ethnicity and forgoing, delaying, or having to make changes to mental health services persisted (OR = 2.67, 95% CI: 1.11–6.45). In addition, new and persistent food insecurity was strongly associated with forgoing, delaying, or having to make changes to cancer care because of cost.



**Table 11.4** Multivariable models for the association between Hispanic ethnicity and forgoing, delaying, or making changes to medical care because of cost

	Prescription medication		Treatment other than prescription medication		Specialist visits		Follow-up care		Mental health services	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<i>Ethnicity</i>										
Non-Hispanic	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
Hispanic	0.68	0.32–1.40	0.97	0.44–2.15	0.62	0.32–1.21	0.77	0.40–1.48	<b>2.67</b>	<b>1.11–6.45</b>
<i>Food security status</i>										
Persistently food secure	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
Newly food insecure	2.37	0.80–7.05	<b>5.54</b>	<b>1.79–17.1</b>	<b>4.45</b>	<b>1.67–11.9</b>	<b>4.45</b>	<b>1.72–11.5</b>	<b>3.90</b>	<b>1.15–13.3</b>
Persistently food insecure	<b>3.14</b>	<b>1.34–7.33</b>	<b>6.23</b>	<b>2.38–16.3</b>	<b>3.90</b>	<b>1.78–8.55</b>	<b>4.45</b>	<b>2.04–9.72</b>	<b>5.13</b>	<b>1.82–14.4</b>
<i>Age at diagnosis (years)</i>	1.00	0.95–1.05	1.04	0.98–1.09	1.00	0.96–1.04	1.00	0.96–1.05	0.98	0.93–1.04
<i>Education</i>										
≤High School	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
≥College	0.60	0.28–1.29	<b>3.19</b>	<b>1.32–7.69</b>	0.92	0.46–1.83	1.61	0.80–3.21	<b>3.12</b>	<b>1.16–8.40</b>
<i>Income</i>										
Less than \$30,000	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
\$30,000–\$69,999	1.99	0.70–5.67	1.46	0.48–4.44	<b>2.78</b>	<b>1.10–7.05</b>	2.06	0.81–5.22	2.68	0.83–8.73
\$70,000 or more	2.38	0.74–7.66	1.13	0.34–3.82	1.86	0.65–5.33	1.73	0.62–4.84	1.65	0.40–6.84
<i>Insurance</i>										
Private	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
Medicaid	1.05	0.39–2.83	0.39	0.12–1.28	0.97	0.39–2.37	0.79	0.32–1.96	1.06	0.34–3.35
Uninsured	<b>4.96</b>	<b>1.20–20.6</b>	2.62	0.56–12.3	2.09	0.49–8.93	2.42	0.61–9.63	2.01	0.35–11.7
<i>Marital status</i>										
Married	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
Not married	0.52	0.25–1.09	0.82	0.37–1.81	1.21	0.61–2.41	1.09	0.56–2.14	0.67	0.27–1.62
<i>Cancer type</i>										

(continued)

Table 11.4 (continued)

	Prescription medication		Treatment other than prescription medication		Specialist visits		Follow-up care		Mental health services	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Breast	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference	1.00	Reference
Colorectal	1.06	0.45–2.49	1.14	0.45–2.89	1.64	0.78–3.45	1.58	0.77–3.24	0.87	0.31–2.46
Prostate	0.73	0.27–1.97	0.49	0.15–1.56	0.80	0.33–1.95	0.38	0.14–1.06	–	–

Bold values represent statistical significance at the  $P < 0.05$  level  
OR odds ratio, CI confidence interval

## Discussion

The results of the CHOICE Project highlight important differences in the prevalence of financial hardship and food insecurity between Hispanic and non-Hispanic cancer survivors. Hispanic cancer survivors were significantly more likely to report being unable to cover the cost of their medical bills and to reduce spending on food and clothing because of their cancer, its treatment, or the lasting effects of treatment. The struggle to afford medical care and food contributed to the substantially higher prevalence of both new and persistent food insecurity among Hispanic cancer survivors. Overall, 47% of Hispanic cancer survivors in the CHOICE Project experienced food insecurity in the year following their cancer diagnosis. This is alarmingly high compared to the overall prevalence of food insecurity in the CHOICE Project of 36% and far exceeds the 11% prevalence of food insecurity for US adults [10, 18]. Although few prior studies of financial hardship have had large numbers of Hispanic cancer survivors, those that report on the prevalence of financial hardship by ethnicity find similar disparities [27, 28]. These results provide justification for the need to develop interventions designed to address social needs, including financial hardship and food insecurity, among all cancer survivors.

The factors influencing the development of financial hardship and food insecurity following a cancer diagnosis occur within a dynamic system comprising multiple levels of contextual influence, including the individual patient, provider, social support networks, and the local community, state and national environments [33]. Sociodemographic characteristics of the individual, such as age, income, education, occupation, health literacy, and insurance, are all strongly associated with financial hardship [34–37]. To the extent that these characteristics differ between Hispanic and non-Hispanic cancer survivors, these factors may explain the high prevalence of financial hardship observed in the CHOICE Project. The interplay between the individual and the other levels of the socioecological framework often determines the degree to which financial hardship contributes to negative health outcomes. Communication between patients and providers, social support from family and larger social networks, availability of culturally appropriate patient support services within oncology clinics, and state and national policies shaping insurance, reimbursement, and access to financial and food resources can all serve as barriers to, or facilitators of, receiving timely appropriate cancer care among patients experiencing financial hardship. Factors at each of these levels thus contribute both to the risk of financial hardship and to the downstream negative effects of financial hardship, including food insecurity.

A cyclic model exists to explain the relationship between food insecurity and chronic disease in which the inability to access enough healthy food leads to compensatory strategies, including skipping meals and reducing caloric intake in times of food shortage and systematic overconsumption in times of food adequacy [23]. Stress, constrained dietary options, and eating patterns of food insecure individuals lead to medication nonadherence, postponement of needed health care, and impaired self-management capacity, ultimately increasing health-care expenditures for food

insecure individuals [23, 25, 38]. In the CHOICE Project, the relationship between food insecurity and forgoing, delaying, or making changes to medical care was strong, and did not appear to differ for Hispanic and non-Hispanic cancer survivors. While little research has directly addressed the problem of food insecurity among cancer survivors, there is a rich body of literature documenting the experience of food insecurity and health disparities among Hispanic communities in the United States [20, 39, 40]. Issues of food access and agency among Hispanic households are intertwined with structural inequality and economic development, but the intersection with personal experience often reveals nuanced cultural meanings and practices around food and times of food shortage [20]. Given the disproportionate burden of food insecurity among Hispanic cancer survivors identified in the CHOICE Project, strategies to address food insecurity will likely benefit from community-based approaches that seek to understand the lived experience of food insecurity in Hispanic households.

Evidence-based financial hardship and food insecurity screening tools exist. The COST-FACIT Measure of Financial Toxicity has demonstrated reliability and validity for identifying financial hardship in cancer patients [41]. The Hunger VitalSign™ food insecurity screening tool is also widely endorsed for the use in clinical settings [32]. Integrating these tools into oncology practice in a culturally appropriate, sustainable, and effective way to improve cancer outcomes remains a critical area of future research.

In summary, the CHOICE Project highlights persisting ethnic disparities in financial hardship and food insecurity. The strong relationship between food insecurity and cancer care access supports future research to address this social determinant of health to address cancer disparities and achieve health equity.

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