

Exploring Social Determinants of Health in Primary Immunodeficiency Patients Undergoing Immunoglobulin Replacement Therapy

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BACKGROUND

- Primary immunodeficiency disorder (PIDD) is characterized by absent or dysfunctional antibodies, which impairs the body's ability to fight infections and increases the risk of autoimmune, autoinflammatory, and malignant conditions.¹⁻⁶
- The standard treatment for PIDD, immunoglobulin replacement therapy (IRT), is lifelong and addresses only one aspect of the patient's overall health. Individuals with PIDD often experience significant limitations in physical and mental health, as well as in academic and social activities.^{2,7}
- Social determinants of health (SDOH) including health behaviors, social and economic factors, environmental conditions, and clinical care play a significant role in health outcomes, accounting for up to 80%.^{2,5,6}
- Existing research primarily focuses on initiating therapy, with limited data on how SDOH affect ongoing treatment. This creates a crucial gap in understanding how social factors influence patient outcomes and therapy effectiveness over time.

PURPOSE

- This cross-sectional, descriptive study aimed to comprehensively identify and categorize the various facets and trends of social determinants of health (SDOH) within our primary immunodeficiency disorder (PIDD) population. The findings from this study will be used to guide the provision of appropriate, tailored resources to better support our patients.
- The primary objective is understanding the types of SDOH affecting our PIDD population.

METHODS

- Protocol for responding to and assessing patients' assets risks and experience (PRAPARE) is a validated survey tool to assess SDOH
- Inclusion criteria: electronic health records eligible participants, aged 18 years and older with specific immunodeficiencies (identified by ICD-10 codes), were recruited telephonically.

PRAPARE
Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences
Paper Version of PRAPARE for Implementation as of September 2, 2016

Personal Characteristics

1. Are you Hispanic or Latino?
Yes No I choose not to answer this question

2. Which race(s) are you? Check all that apply
Asian Native Hawaiian
Pacific Islander Black/African American
White American Indian/Alaskan Native
Other (please write) I choose not to answer this question

3. At any point in the past 2 years, has season or migrant farm work been your or your family's main source of income?
Yes No I choose not to answer this question

4. Have you been discharged from the armed forces of the United States?
Yes No I choose not to answer this question

5. Are you worried about losing your housing?
Yes No I choose not to answer this question

6. What address do you live at?
Street: _____
City, State, Zip code: _____

7. What is the highest level of school that you have finished?
Less than high school High school diploma or GED
More than high school I choose not to answer this question

8. What is your current work situation?
Unemployed Part-time or temporary work Full-time work
Otherwise unemployed but not seeking work (ex: student, retired, disabled, unpaid primary care giver)
Please write: _____
I choose not to answer this question

RESULTS

- We identified 193 patients we could possibly enroll in the study. Our goal population was 100 patients to participate. However, due to short data collection period 81 participants were selected.
- Data collection period: 2/24/25-3/3/25
- 116 patient responded; 81 chose to participate; 35 declined
- 77 patients didn't respond (send to voicemail)

- Excluded if <18y, not within IDC10 codes, deceased
- Excluded as the patients declined to participate (n=35)

RESULTS (continued)

TABLE 1. BASELINE CHARACTERISTICS OF PIDD PATIENTS
PATIENT CHARACTERISTICS (n=81, (%))

Race		Who is filling out the survey?	
Caucasian	79 (97.5)	Patient	77 (95.1)
Asian	1 (1.2)	Parent/ Guardian	4 (4.9)
African American	1 (1.2)	What language are you most comfortable speaking?	
Hispanic	0 (0)	English	80 (98.8)
Mean Age, years (SD)	51.4 +/-15.5	Chinese	1 (1.2)
Survey Participants			
Male	23 (28.4)		
Female	58 (71.6)		

SURVEY RESPONSES (n=81, (%))

What is your housing situation?

Has housing	81 (100)
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Are you worried about losing your housing?

Yes	4 (4.9)
No	77 (95.1)

What is the highest level of education that you have finished?

Less than high school	2 (2.5)
High school, GED	18 (22.2)
More than high school	61 (73.3)

Have you been discharged from the armed forces of the United States?

Yes	2 (2.5)
No	79 (97.5)

Has migrant farm work been your main source of income?

Yes	2 (2.5)
No	79 (97.5)

Were you unable to get any of the following when it was needed?

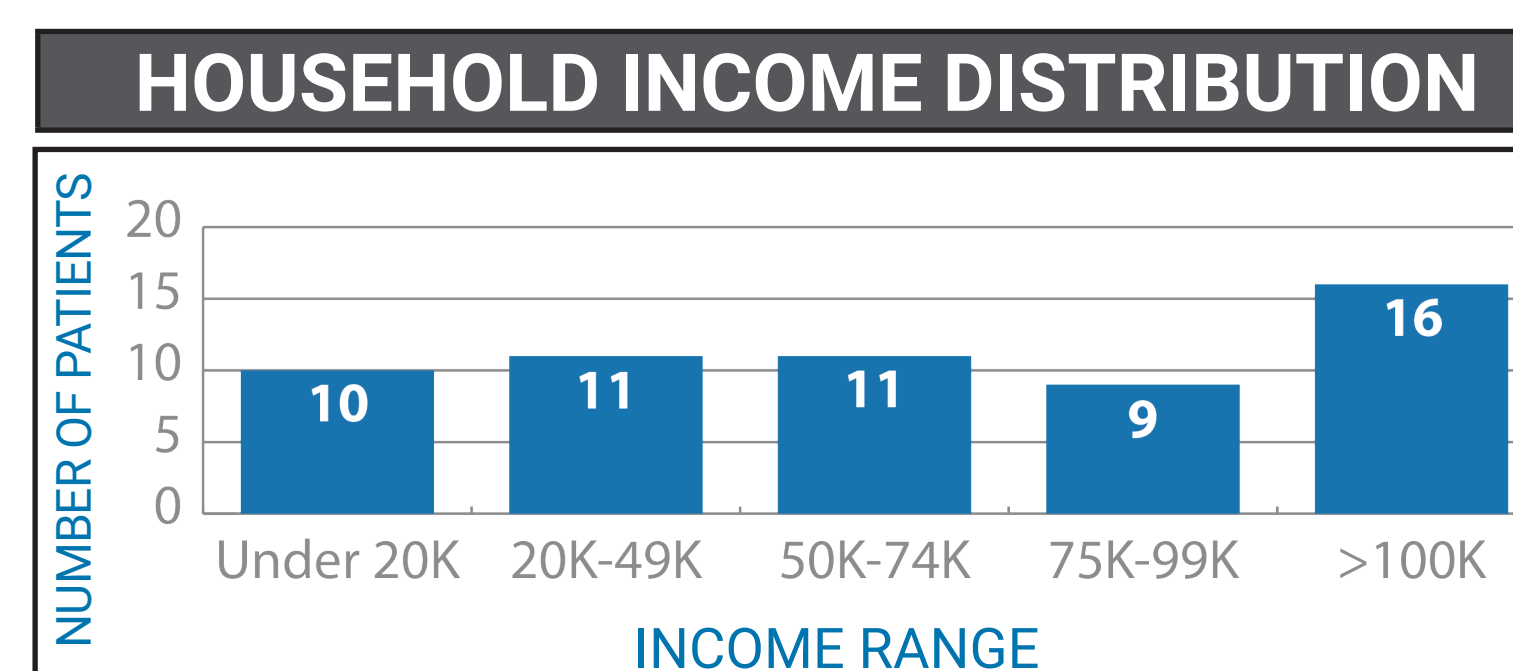
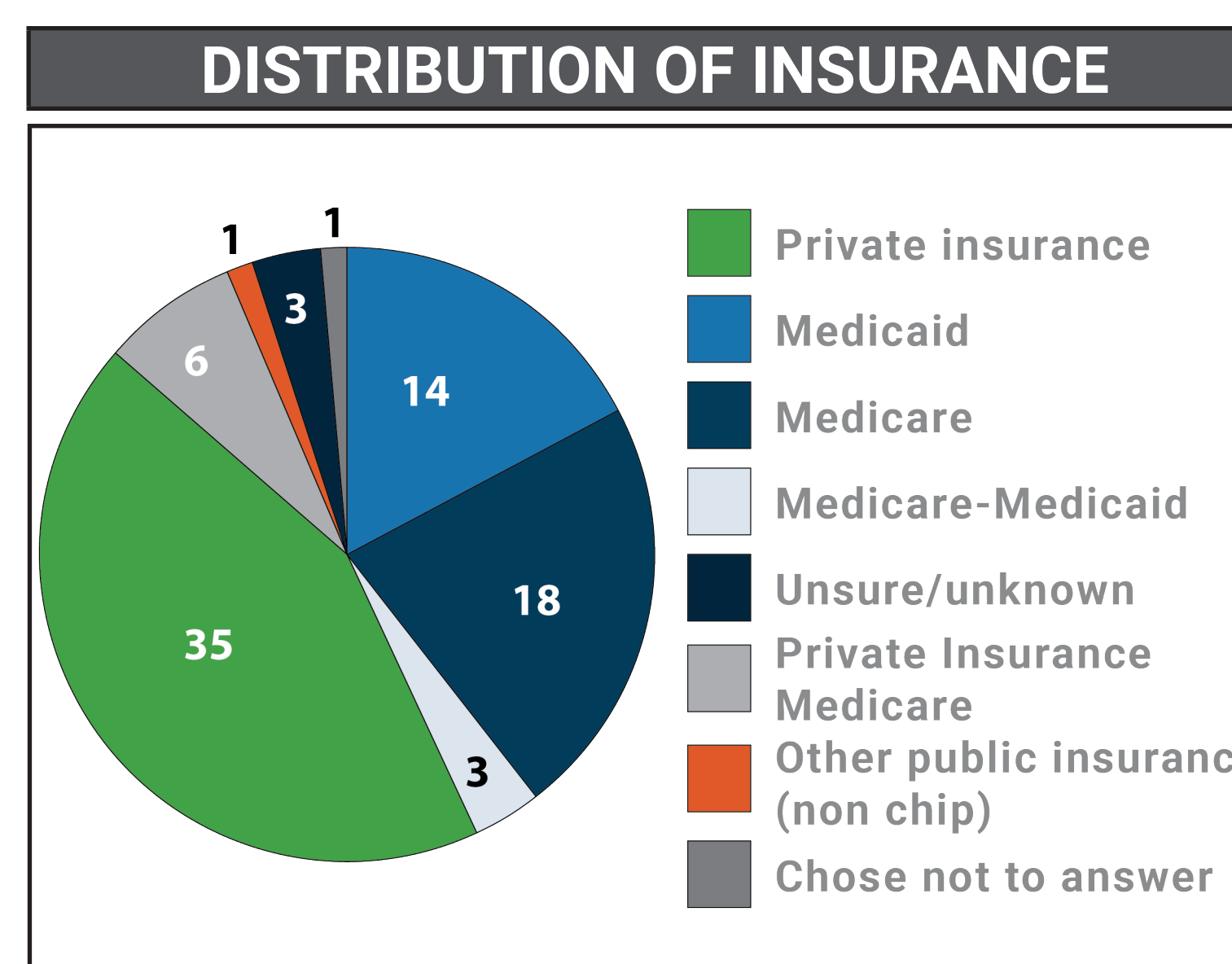
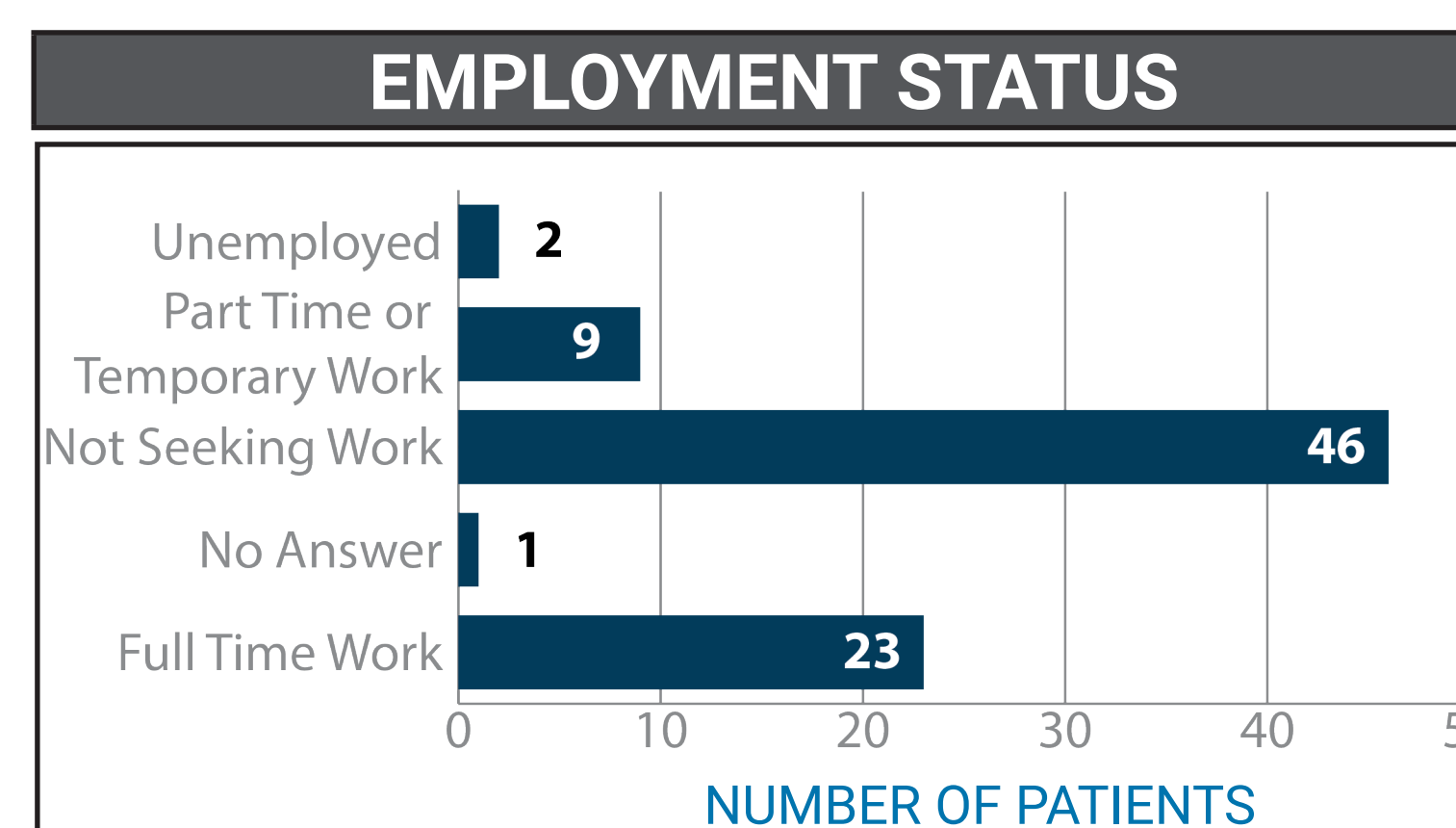
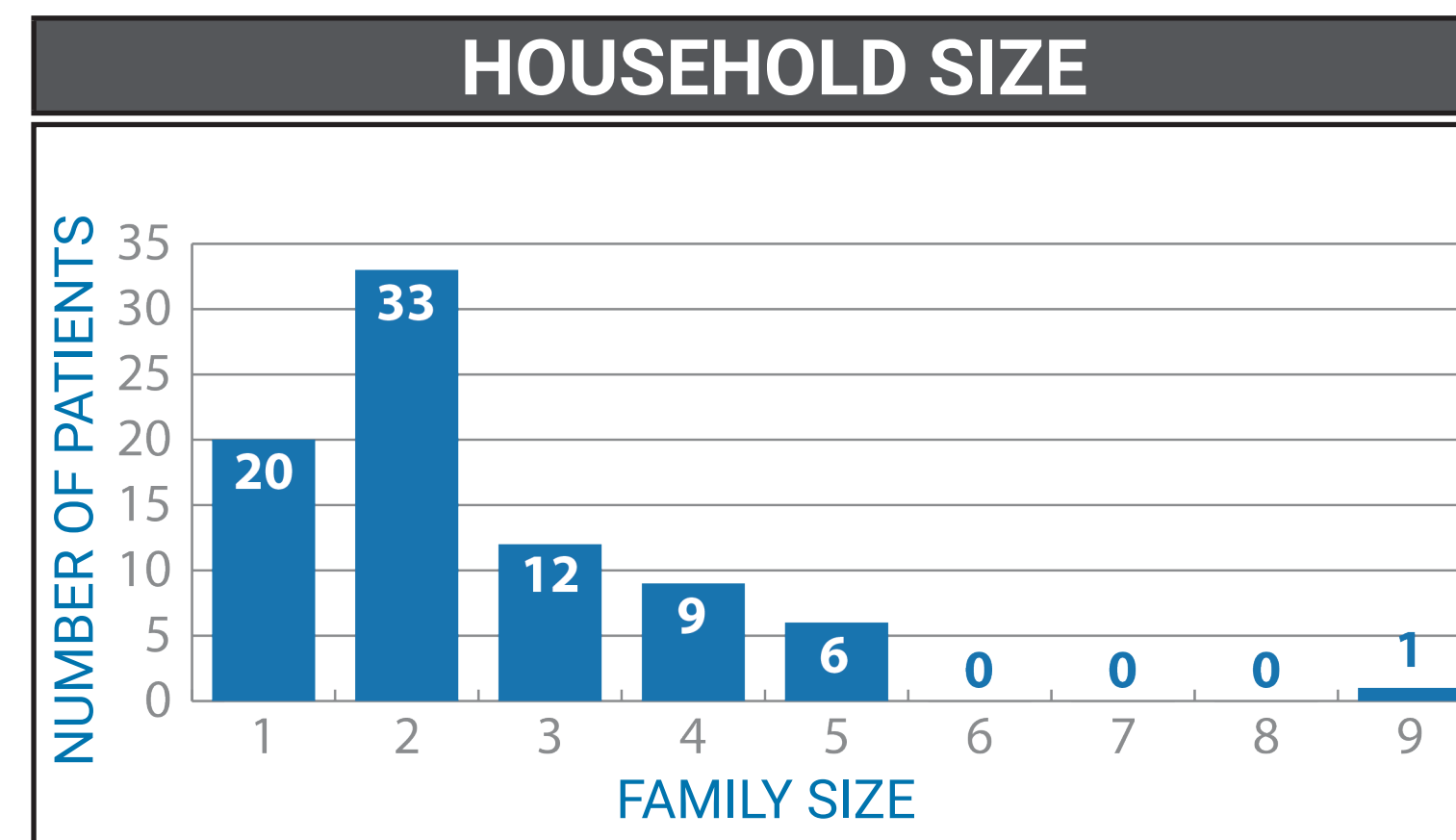
Medicine, healthcare (dental, mental, vision)	13 (16)
Food	4 (4.9)
Utilities	1 (1.2)
Phone	1 (1.2)

Are these concerns still current?

Yes	11 (13.6)
No	70 (86.4)

Are you willing to share you household combined income?

Yes	57 (70.4)
No	24 (29.6)



RESULTS (continued)

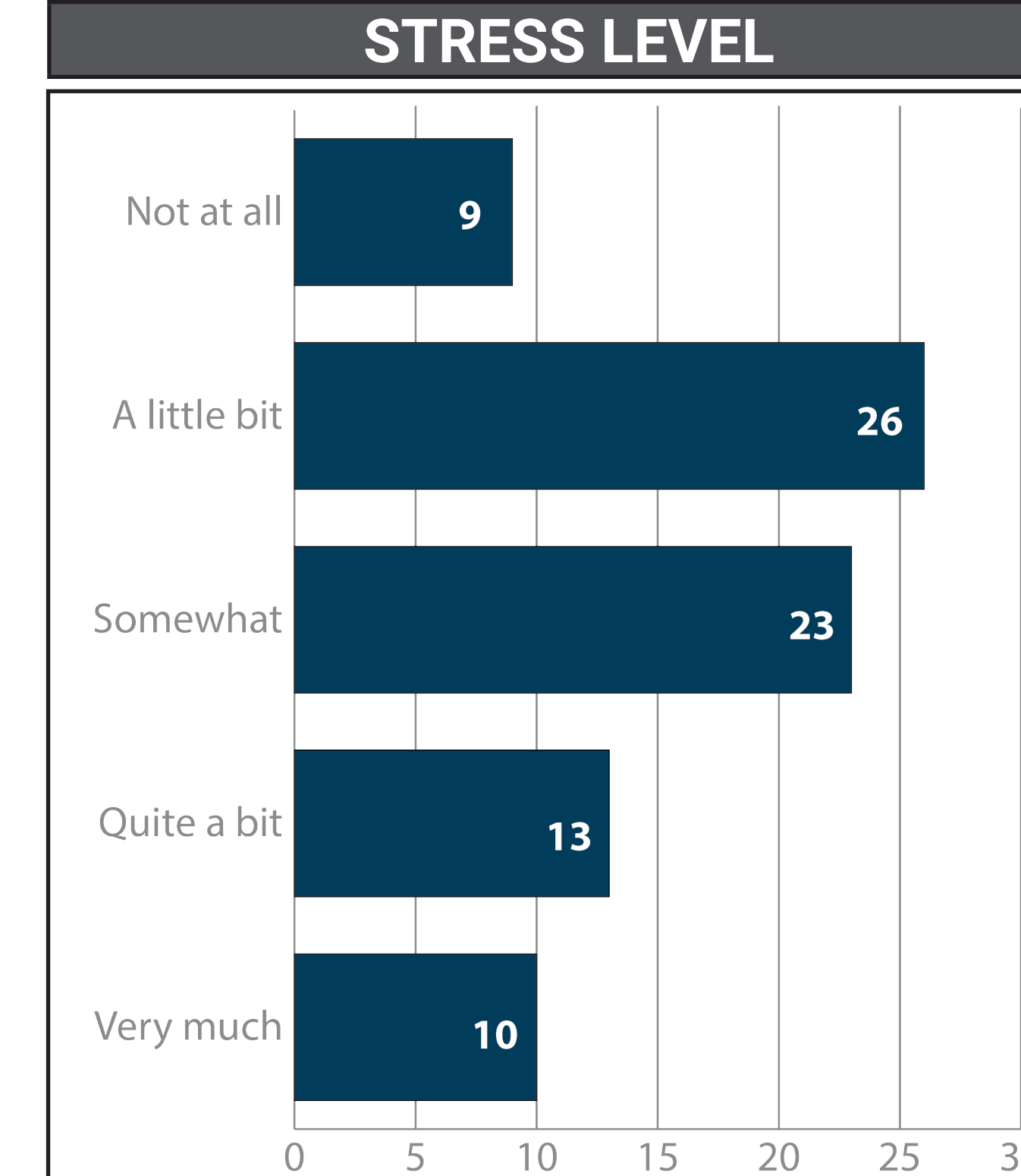
SURVEY RESPONSES (n=81, (%))

How often on a weekly basis do you see or talk to people that you care about and feel close to?

<1 weekly	7 (8.6)
1-2 a week	14 (17.3)
3-5 a week	19 (23.5)
>6 weekly	41 (50.6)

Has a lack of transportation kept you from appointments work or daily needs for living?

Yes, from medical appt	1 (1.2)
Yes, from medical appt, work, daily needs	0 (0)
Both	2 (2.5)
No	78 (96.3)



DISCUSSION

- Among our patient population, 43% reported having private insurance as their primary coverage, and 50.6% indicated that they speak with loved ones at least six times per week. A small portion (2.5%) reported lacking access to transportation, while 23.5% lacked essential resources for daily living, such as medical supplies, utilities, or food. Stress levels appeared to be low to moderate, with 32.1% reporting 'a little bit of stress' and 28.4% reporting being 'somewhat stressed.' Although 56.8% of patients were unemployed and not actively seeking work, 73.3% had attained more than a high school education.

CONCLUSION

- The findings of this study contribute to a greater awareness of ongoing SDOH and demonstrate the potential for implementing this survey across a broader patient population. Given its brevity and ease of administration, the survey could be incorporated into the initial phase of clinical visits or used throughout the continuum of care to help identify barriers contributing to patient nonadherence. This, in turn, could support the development of protocols for timely connection to appropriate resources—ultimately promoting improved health outcomes. Of the 193 patients contacted, we achieved a response rate of 60.1% (n=116), with 42% (n=81) of patients actively participating. Future studies should consider extending the study period and including a larger, more diverse population to yield more robust and generalizable findings.

- Study Limitations:**
 - Small sample size
 - Limited data collection timeframe
 - Potential for interpretation bias

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