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Associations Between Perceived Financial Distress and Non-medical Out-of-pocket Expenses Among Caregivers of Critically Ill Children

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Disclosure Information

I have no relevant financial relationships with the manufacturer of any commercial product and/or provider of commercial services discussed in this CME activity.

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Critical Illness And Financial Health

- Financial Toxicity = objective burden and subjective distress
 - Indirect costs include non-medical out-of-pocket expenses (NMOOPEs) such as transportation, housing, childcare, meals
- Critical illness is a source of financial distress with negative long-term consequences
 - Associated with worse outcomes and decreased quality of life (adults with cancer)
 - Limits rehabilitation and recovery post-discharge (adults with ARDS)
 - Those with child-rearing responsibilities may suffer to a greater degree (adults with ARDS)

What We Know In Pediatrics

- Families with pre-existing financial and social hardships
 - Disproportionate burden from NMOOPEs
 - Highest risk for critical illness
- Despite this association, there are families in every income bracket who experience high financial distress

What is the distribution of perceived financial distress for families of critically ill children and its relationship to NMOOPEs?

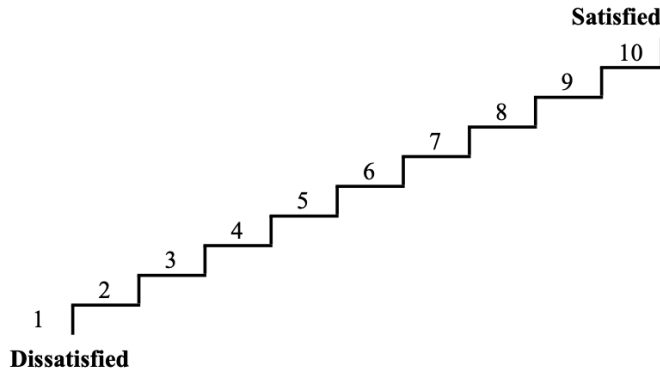
Objective

To compare the relationship of NMOOPEs relative to income and perceived financial distress in families of children admitted to the PICU.

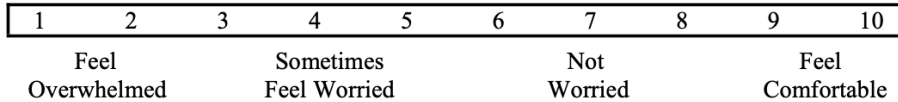
Methods

- Prospective cohort study; time of enrollment was at least 72 hours and no more than 120 hours
- Exclusion criteria: language other than English/Spanish, no permanent address
- Administered the validated InCharge Financial Distress/Financial Well-being (IFDFW) questionnaire, questions on demographics, social influencers of health, and NMOOPEs

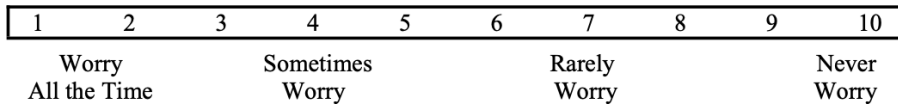
2. On the stair steps below, mark (with a circle) how **satisfied** you are with your **present financial situation**. The “1” at the bottom of the steps represents complete dissatisfaction. The “10” at the top of the stair steps represents complete satisfaction. The more dissatisfied you are, the lower the number you should circle. The more satisfied you are, the higher the number you should circle.



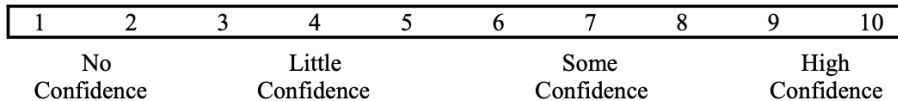
3. How do you feel about your **current financial situation**?



4. How often do you worry about being **able to meet** normal monthly living expenses?



5. How confident are you that you could find the money to pay for a **financial emergency** that costs about **\$1,000**?



Outcome and Exposure

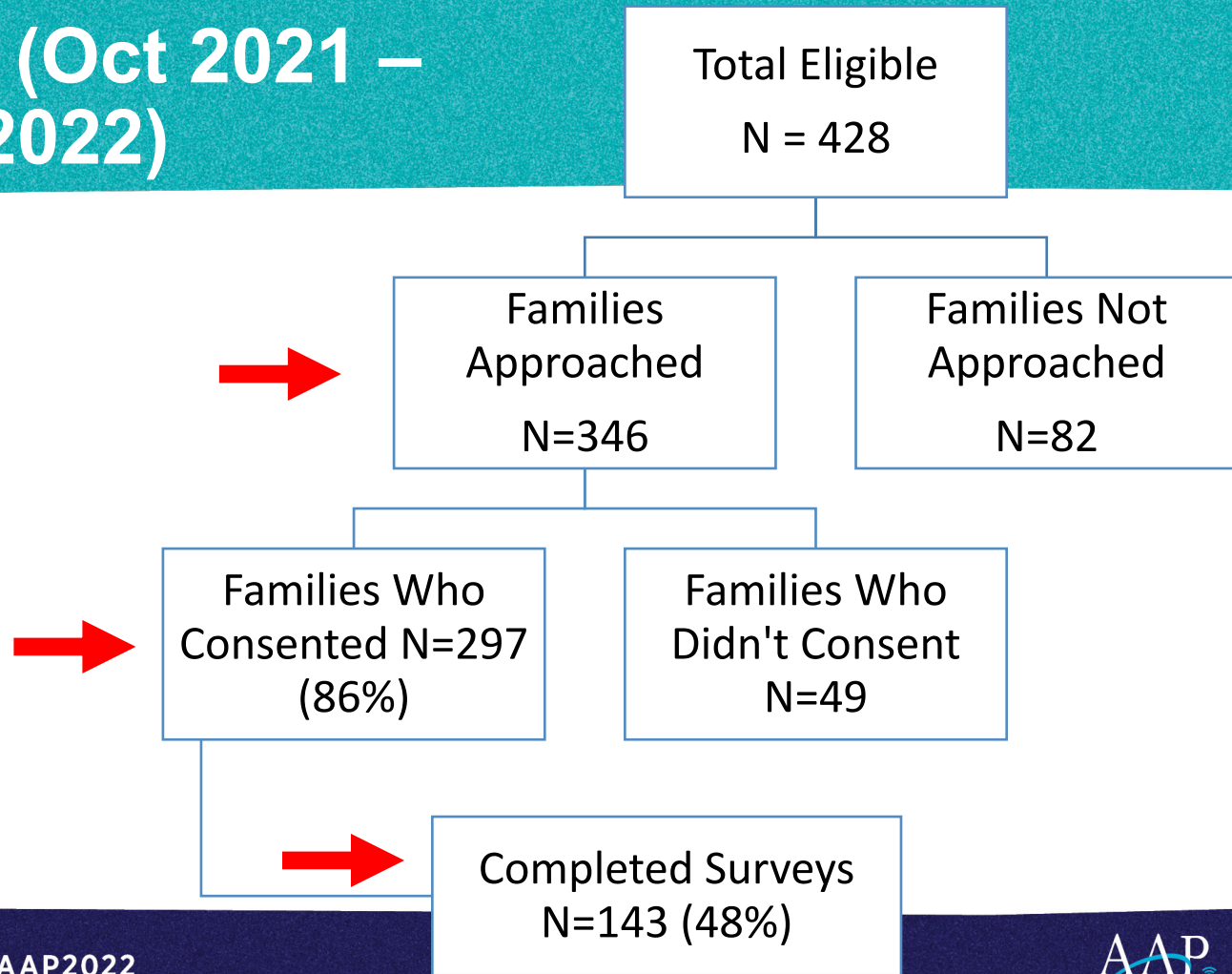
Exposure

- Non-medical Out-of-pocket expenses
 - Costs associated with transportation, meals, childcare, housing
 - Accrued in the last 3 days of the current ICU admission
 - Reported as proportions of the participant's weekly income

Outcome

- Family experience of financial condition using the InCharge Financial Distress/Financial Well-being (IFDFW) tool
- Trichotomized outcome
 - High financial distress/low financial well-being (score 1.0-4.0)
 - Average financial distress/average financial well-being (score 4.1-6.9)
 - Low financial distress/high financial well-being (score ≥ 7.0)

Recruitment (Oct 2021 – July 2022)



	Total Cohort (N = 143)	Financial Distress			P-value*
		High Distress (N= 40)	Average Distress (N= 68)	Low Distress (N= 35)	
Education (%)					
Up Through High School	23.1	37.5	19.1	14.3	0.031
Some college or more	76.9	62.5	80.9	85.7	
Insurance (%)					
Private	52.4	27.5	54.4	77.1	p <0.001
Public	39.9	62.5	38.2	17.1	
No Insurance or Other	7.7	10.0	7.4	5.7	
Marital Status (%)					
Single	26.6	47.5	23.5	8.6	0.001
Partnered	72.7	52.5	75.0	91.4	
No Response	0.01	0	1.5	0	
Race (%)					
Asian	22.6	24.3	24.2	17.6	0.001
Black/African American	15.3	21.6	15.2	8.8	
Hispanic/Latino	19.7	32.4	21.2	2.9	
White	42.3	21.6	39.4	70.6	

*Pearson Chi-Square or Fisher's Exact Test used to determine significance based on the N within each cell

	Total Cohort (N=143)	Financial Distress			P-value ^a
		High Distress (N= 40)	Average Distress (N= 68)	Low Distress (N= 35)	
Proportion of weekly income spent on NMOOPEs (%) ^					
Total NMOOPEs		36.4	12.8	5.10	p <0.001
Food		3.5	1.7	1.4	p <0.001
Childcare		6.7	0	0	0.002
Transportation		6.8	3.5	1.6	p <0.001
Miscellaneous		5.8	0.8	0.3	0.007
Families concerned for having their utilities discontinued (%)					
Yes	18.3	41.0	10.3	8.6	p <0.001
No	81.7	59.0	89.7	91.4	
Families unable to afford health care (%)					
Yes	16.8	32.5	11.8	8.6	0.011
No	83.2	67.5	88.2	91.4	
Families concerned about housing instability (%)					
Yes	13.3	30.0	8.8	2.9	0.001
No	86.7	70.0	91.2	97.1	

^aData was not-normally distributed, so Kruskal-Wallis test used for preliminary analyses

[^]Weekly income determined by dividing approximate income by 52 weeks

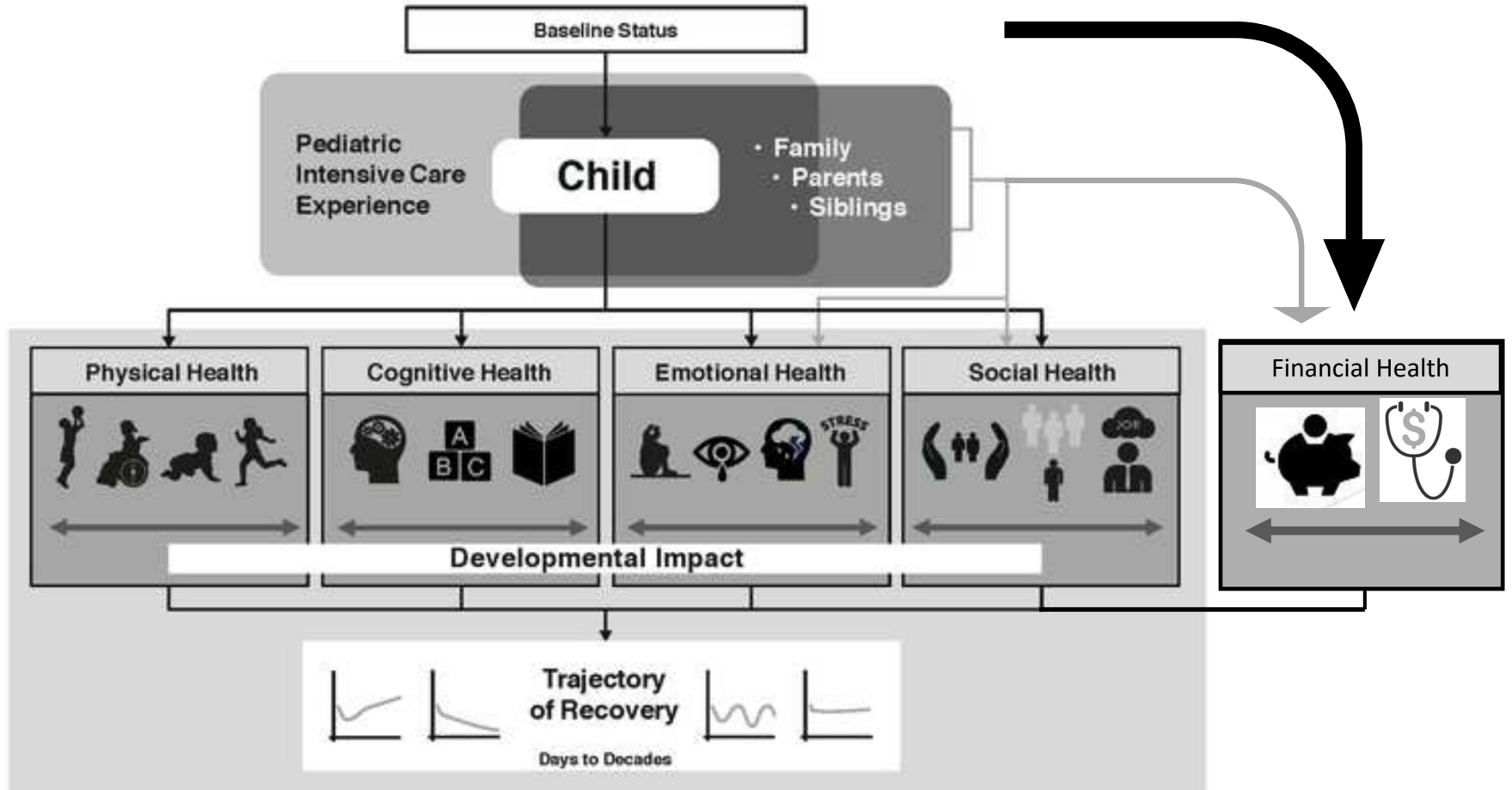
Why Should We Care?

- There is an association between attributable out-of-pocket expenses and family distress
- Additional costs for an institution to address some of these concerns could be relatively small
- Such assistance could potentially have significant impact on family well-being

Next Steps

- Further insight into the nature of these expenses and their effects
 - Multi-center study
 - Considering other units such as NICU or CICU
- Opportunities for institutional and community policy interventions
 - Legal advocacy, community referrals, in-hospital counseling
 - IFDFW could be one outcome measure
- Optimize post-discharge outcomes

Post Intensive Care Syndrome - Pediatrics (PICS-p)



Thank you

- Denise Goodman
- Erin Paquette
- Carolyn Foster
- David Aaby
- Anna Chorniy



References

For more information on this subject, see the following publications:

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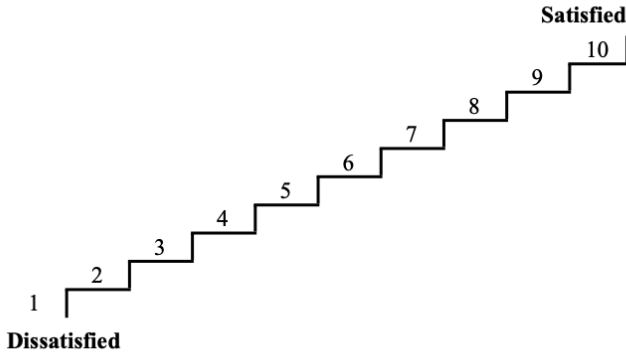
InCharge Financial Distress/Financial Well-Being Scale©

Directions: Circle or check the responses that are ***most appropriate*** for your situation.

1. What do you feel is the ***level*** of your ***financial stress today?***

1	2	3	4	5	6	7	8	9	10
Overwhelming Stress			High Stress		Low Stress		No Stress at All		

2. On the stair steps below, mark (with a circle) how ***satisfied*** you are with your ***present financial situation.*** The “1” at the bottom of the steps represents complete dissatisfaction. The “10” at the top of the stair steps represents complete satisfaction. The more dissatisfied you are, the lower the number you should circle. The more satisfied you are, the higher the number you should circle.



3. How do you feel about your ***current financial situation?***

1	2	3	4	5	6	7	8	9	10
Feel Overwhelmed		Sometimes Feel Worried			Not Worried		Feel Comfortable		

4. How often do you worry about being ***able to meet*** normal monthly living expenses?

1	2	3	4	5	6	7	8	9	10
Worry All the Time		Sometimes Worry		Rarely Worry		Never Worry			

5. How confident are you that you could find the money to pay for a ***financial emergency*** that costs about **\$1,000?**

1	2	3	4	5	6	7	8	9	10
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No
Confidence

Little
Confidence

Some
Confidence

High
Confidence

6. How often does this happen to you? You want to go out to eat, go to a movie or do something else and ***don't go because you can't afford to?***

1	2	3	4	5	6	7	8	9	10
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All the time

Sometimes

Rarely

Never

7. How frequently do you find yourself just getting by financially and living ***paycheck to paycheck?***

1	2	3	4	5	6	7	8	9	10
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All the time

Sometimes

Rarely

Never

8. How ***stressed*** do you feel about your personal finances ***in general?***

1	2	3	4	5	6	7	8	9	10
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Overwhelming
Stress

High
Stress

Low
Stress

No Stress
at All

Phone vs In- Person Recruitment

