Slide 1

45th National Conference on Pediatric Health Care

Resources, Workload, and Care Coordination Hours Predict Depressive Symptoms in Parents of Children with Medical Complexity

Patricia R. Lawrence, PhD, RN, CPNP-AC &

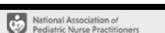Regena Spratling, PhD, RN, APRN, CPNP-PC, FAANP, FAAN

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Experts in pediatrics, Advocates for children. 1

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Speaker Disclosure
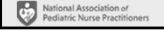
There are no disclosures

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Background and Significance

- Children with medical complexity (CMC) represent less than 1% of all US children (Berry, et al, 2014).
- CMC care costs account for between $50-110 billion in annual health care spending (Cohen et al., 2012; Lassman et al., 2014).
- CMC definition (Cohen et al., 2011):
  - One or more chronic conditions that is lifelong, such as critical congenital heart disease (CCHD)
  - Substantial health service needs
  - Functional limitations
  - High health care use

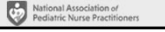National Association of Pediatric Nurse Practitioners

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Background: Parent Challenges

Workload Challenges
- Direct care (Mooney-Doyle & Lindley, 2020; Romley et al., 2017) and care coordination (Hofacer et al., 2019; Mooney-Doyle & Lindley, 2020)
- Time to attend appointments, hospitalizations (Cady & Belew, 2017; Cohen et al., 2012)

Capacity Challenges
- Overwhelmed, unprepared, little training (Barnert, et al., 2019; Ni et al., 2019; Nygard & Clancy, 2018; Spratling, 2017)
- Lack of resources needed to meet demands (Cady & Belew, 2017)

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Background: Parent Challenges (continued)

Financial Hardship
- Non-reimbursed costs, co-pays (Kuo et al., 2011; Mooney-Doyle & Lindley, 2019; Vessey et al., 2017)
- Financial strain due to lost income (Mandic et al., 2017; Mooney-Doyle & Lindley, 2019)

Social Hardship
- Isolation, little support from others, no time or energy for socializing (Caicedo, 2014; Thomson, 2016)

Mental Health Challenges
- Depression 35% in parents of children with chronic illness vs 19% in parents of healthy children (Cohn et al. 2020)

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Problem

- Research examining the impact on families of CMC and the mental health of their parents is very **limited.**

- Understanding factors that contribute to parental depressive symptoms is important given evidence for worse health outcomes and higher health care use in children of depressed parents (Brooks et al., 2015; Pierce et al., 2019).

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Purpose of the Study

Examine relationships among family resources, social support, parents' perceived workload to care for their children with medical complexity and their perceived ability to do the work necessary, and to examine how these variables are related to parental depressive symptoms, particularly when workload exceeds capacity.

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Theoretical Model
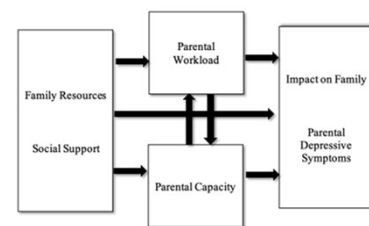
Integrated theoretical framework (Lawrence & Spratling, 2022) using Family Management Style Framework (Knafl et al., 2012) and the Cumulative Complexity Model (Shippee et al., 2012)

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Research Questions

In parents of CMC with CCHD:

1. What is the relationship of social support or family resources to parental workload or capacity?
2. What is the relationship between workload and capacity?
3. What is the relationship of workload or capacity to parental depressive symptoms, particularly when workload exceeds capacity?
4. What are the relationships among social support, family resources, workload and capacity, and depressive symptoms?
5. What are the relationships between commonly described workload challenges (such as care coordination) and depressive symptoms?
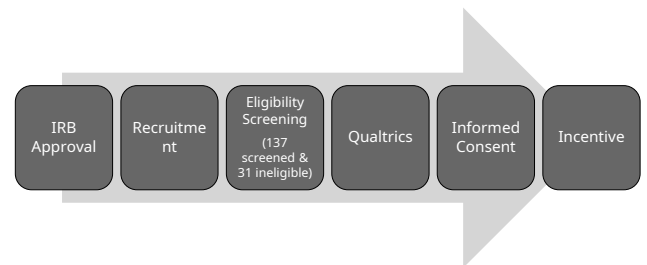
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Methods

- **Design:** Non-experimental, cross-sectional, correlational design
- **Sample:** Non-random, convenience and snowball sample of parents with CMC
- **Setting:** National recruitment
- **Recruitment efforts:** Digital flyer shared through local and national social media platforms for parents of CMC
- **Data collection:** Qualtrics
- **Power analysis:** 106 participants

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Inclusion Criteria

- Biologic, foster, or adoptive parent whose CMC fits definition by Cohen et al. (2011)
- 18 years or older and self-identifies as the primary caregiver of their CMC
- Read, speak, and understand English and have electronic access to Qualtrics
- CMC is singleton between 6 months through 5 years of age
- CMC diagnosis includes critical congenital heart disease

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Procedures

IRB Approval → Recruitment → Eligibility Screening (137 screened & 31 ineligible) → Qualtrics → Informed Consent → Incentive

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Instrument	Variable	Scoring	Cronbach's α
Revised Family Resource Scale (Van Horn et al., 2001)	Perception of available resources incl. financial resources	20 items Range: 20-100 ↑score=higher resources	.72 - .84
Management Effort Subscale of Family Management Measure	Time and work to manage chronic condition	4 items Range: 4-20 ↑score=more work/effort	.74 (mothers)
Management Ability Subscale (Knafl et al., 2011)	Ability and competency to manage chronic condition	12 items Range: 12-60 ↑score=greater ability	.72 (mothers)
Personal Resource Questionnaire (Weinert, 2003)	Perception of social support	15 items Range: 15-105 ↑score=more support	.87 - .93
Center for Epidemiological Studies-Depression (CES-D) (Radloff, 1977)	Screen for depressive symptoms	20 items Range: 0-60 ↑score=more depression	.78 - .89

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National Sample

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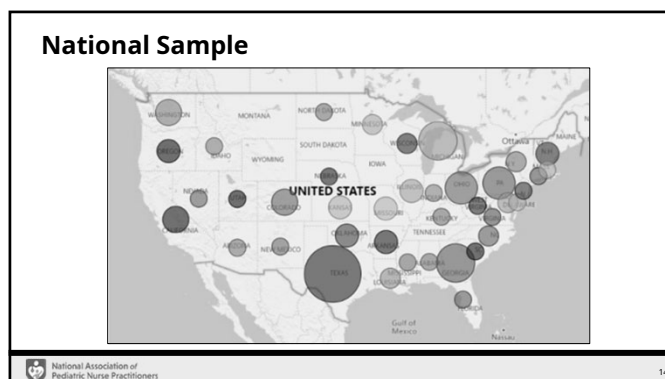
Sample

Parents (n=106)	Children (n=106)
Average age 32.95 years	Average age 33.7 months
98% mothers	Majority white (72.4%) males (59.4%)
86.8% married or partnered	46.2% with public health insurance
84.9% White, non-Hispanic Majority unemployed (49.1%) & college educated (37.7%)	40.6% with between 1-3 other health conditions
61.3% with income > $50,000	Average of 2.53 pieces of life sustaining equipment (Digestive 74.5%, Respiratory 49.1%)
49.1% Unemployed	Average of 5.67 daily medications
58.5% took LOA, 66% cut down hours to care for CMC	Majority (30.2%) had annual out-of-pocket medical expenses b/w $1000 and $5000; 25.5% > $5000 annually
61.3% with clinically significant depressive symptoms	52.8% had single ventricle physiology

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CMC Care Requirements

- Parents reported an average of 72 weekly hours to provide direct care
- Parents, on average, required 8.5 hours each week to coordinate care
- Parents traveled an average of 6.4 hours per week for CMC appointments
- CMC had, on average, just one unpaid caregiver
- CMC required an average of 25 specialty clinic visits per year, and had an average of 7 subspecialists to manage their chronic conditions
- 38.7% of CMC received paid weekly RN visits
- Mean of 18 hours of weekly RN visits

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Descriptive Statistics of Major Variables

Variable/ Instruments	M (SD)	Possible Range	Observed Range	Cronbach's Alpha
FRS-R	72.58 (12.34)	20-100	38-75	.91
PRQ2000	77.89 (17.91	15-105	15-105	.93
Perceived Workload (FaMM Effort)	16.75 (2.77)	4-20	10-20	.70
Perceived Capacity (FaMM Ability)	43.89 (6.56)	12-60	27.58	.71
CES-D	20.95 (12.01)	0-60	0-49	.93
IOF-R	45.21 (8.48)	15-60	18-60	.89

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Research Questions 1 and 2:

What is the relationship of social support or family resources to parental workload or capacity?

What is the relationship between workload or capacity?

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Research Questions 1 and 2:

	FRS-R	PRQ2000	Workload	Capacity	CES-D
1. FRS-R					
2. PRQ2000	.55***				
3. Workload	-0.47***	-0.12			
4. Capacity	.54***	.44***	-0.33***		
5. CES-D	-0.56***	-0.44***	.33***	-0.33***	
6. IOF-R	-0.60***	-0.29**	.69***	-0.44***	.45***

Note. *p<0.05. **p<0.01. ***p<0.001.

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Research Question 3:

What is the relationship of workload or capacity to parental depressive symptoms, particularly when workload exceeds capacity?

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Research Question 3:

Parental Depressive Symptoms, Regression

	Model 1			Model 2			Model 3		
	β	SE	Sig.	β	SE	Sig.	β	SE	Sig.
Parental									
Workload	.33	.40	<.001***				.25	.41	.010*
Capacity				-.33	.17	<.001***	-0.25	.17	.011*
Constant	-	6.81	.64	-	7.52	<.001***	-	11.94	.063
Adj. R²		.101			.099			.148	

Note. *p<0.05. **p<0.01. ***p<0.001.

Workload and capacity explained 14.8 % of the variance in depressive symptoms scores

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Creating a new variable to explore workload > capacity

- Part of the theoretical framework used for this study posits that poor health outcomes can occur when illness management workload outweighs the capacity to manage it. (Shippee et al., 2012)

- Z-scores for capacity and workload generated

  - Workload z-score ≤ Capacity z-score = 0
  - Workload z-score > Capacity z-score = 1

Influence on depressive symptoms when workload *exceeds* capacity

Parental Depressive Symptoms, Regression

	Model		
	β	SE	Sig.
Workload>Capacity	.46	2.09	<.001***
Constant	-	1.53	<.001***
Adj. R²		.203	

Note. *p<0.05. **p<0.01. ***p<0.001.

Workload > capacity explained 20.3% of the variance in CES-D scores

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Research Question 4:

What are the relationships among social support, family resources, workload and capacity, and depressive symptoms?

Research Question 4:

Parental Depressive Symptoms, Regression

	Model 1			Model 2			Model 3		
	β	SE	Sig.	β	SE	Sig.	β	SE	Sig.
Support									
Social Supp.	-0.44	.06	<.001	***				-0.21	.07	.038	*
Family Res.				-0.56	.12	<.001	***	-0.39	.18	<.001	***
Parental										
Workload								.13	.41	.172
Capacity								.02	.18	.871
Constant	-	4.73	<.001	***	-	7.41	<.001	***	-	13.67	<.001	***
Adj. R²		.183			.308			.324	

Note. *p<0.05. **p<0.01. ***p<0.001.

When all four predictor variables were included in the model, it explained 32.4% of the variance in CES-D scores, with family resources being the strongest predictor

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Research Question 5:

What are the relationships between commonly described workload challenges (such as care coordination) and depressive symptoms?

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Research Question 5:

Parental Depressive Symptoms, Regression

	Model		
	β	SE	Sig.
Sociodemographics			
Medications[a]	-0.01	.30	.909
Specialists[b]	-0.06	.41	.600
Care coord.[c]	.38	.16	<.001***
Direct care[d]	-0.05	.02	.605
Constant	-	3.3	<.001***
Adj. R²		.104	

Note. *p<0.05. **p<0.01. ***p<0.001.

When all four predictor variables were included in the model, it explained 10.4 % of the variance in CES-D scores, with care coordination being the strongest predictor

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Discussion: Family Resources

More perceived family resources were associated with:

- higher capacity
- less workload and impact on the family
- fewer depressive symptoms (family resources had the *greatest* individual influence)

Financial challenges have a significant impact on parents of CMC (Kuo et al., 2011; Mooney-Doyle & Lindley, 2019; Mandic et al., 2017; Thomson et al., 2016)

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Discussion: Social Support

More social support was associated with higher capacity, less depressive symptoms and less impact on the family.

- Social support improves self-efficacy, decreases burden and depressive symptoms (Leahy-Warren et al., 2012; Tak & McCubbin, 2002).

Social support did not influence perceived workload.

- When social support exists, it allows parents to care for their CMC (Foster et al., 2022).

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Discussion: Workload and Capacity

As capacity decreases, perceived workload increases.

- Parents often feel unprepared and describe a lack of resources needed to meet demands (Cady & Belew, 2017)
- Burden on parents of CMC is enormous (Caicedo, 2014; Kuo et al., 2011)

The number of direct care hours was not predictive of perceived workload or depressive symptoms.

- Parents enjoy caring for their CMC (Rehm, 2013)

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Discussion: Depressive Symptoms

61% of parents reported CES-D scores concerning for clinical depression.

Higher than:
- 19% of parents of children with chronic conditions (Brooks et al., 2015)
- 40% of parents of technology dependent children (Toly et al., 2012)
- 25-50% of parents of children with CHD (Woolf-King et al., 2017)

A lack of family resources strongly predicted parental depressive symptoms.

- Well-established links between socioeconomic status and depression (Freeman et al, 2016; Lorant et al., 2007)

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Discussion: Influence of Care Coordination

Time required for care coordination efforts predicts depressive symptoms.

- Care coordination required by parents is associated with greater caregiver burden (Golden & Nageswaran, 2012)
- Medical homes that include care coordination are associated with greater parental satisfaction (Mosquera et al., 2014; Avritscher et al., 2019) and fewer depressed days (Yu et al., 2020)

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Limitations

- Cross-sectional design
- Representativeness of the sample
- Self-reported measures
- Influence of COVID-19

Strengths

- National sample
- Target sample reached
- Little or no missing data
- Instruments had adequate internal consistency reliability

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Implications

- Increase awareness of high levels of depressive symptoms, and the delicate balance between workload and capacity
- Consistently screen for social support, family resources, and depresspive symptoms
- Assist families with referrals for mental health and financial support
- Expand medical home models that provide care coordination support

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Future Research
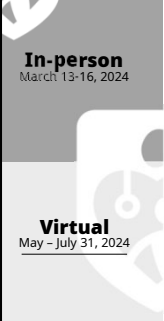
- Include diverse sample
- Explore factors that buffer and explain parental depressive symptoms
- Develop objective measures of workload and cognitive workload (information management) for parents
- Develop and test interventions that minimize workload and enhance capacity

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References

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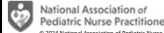
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Adolescent Connectedness During the COVID-19 Pandemic

Melissa Christie, MSN, CPNP-PC[1, 2],
Cynthia M. Kropp, MSS, LCSW[2], & Elizabeth B. Froh, PhD, RN[2, 3]

[1]University of Colorado School of Medicine
[2]Children's Hospital of Philadelphia
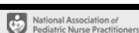[3]University of Pennsylvania School of Nursing

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Speaker Disclosure

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Slide 3

Acknowledgements

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Slide 4
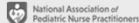
Learning Objectives

- To understand the research methodology and results of a nurse-led research study about adolescent connectedness during the COVID-19 pandemic

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Definition: Connectedness (CDC)

- "A sense of being cared for, being supported, and belonging"[1]
  - School
  - Family
  - Individuals
  - Organizations

The Research

Background

Connectedness is protective

- Adolescent connectedness to adults, schools, and peers is a protective factor for adolescent development (robust evidence base).[2-8]
- Many adolescents connect with others through school & community-based activities

… & then came the pandemic

- Public health restrictions greatly disrupted school-and community-based activities for adolescents.
- Large & growing body of evidence reporting the negative impact of the COVID-19 pandemic on adolescent mental health.[9-16]
- Very little data exists to highlight the adolescent experience of the pandemic, in their own words.

Study Aim

- To understand adolescents' perceptions of their lived experiences of connectedness to others during the COVID-19 pandemic

Methods: Design & Setting

- **Study Design:** Prospective qualitative descriptive study using semi-structured 1:1 interviews
- **Study Setting:**
  - CHOP Primary Care Delaware County (Greater Philadelphia area)
    - FY21, providers had 3,296 well visits with patients aged 12 to 15 years old
    - Standard of care for well adolescent visits included PHQ-9 administration[17]
    - Conversations about connectedness were not part of the standard of care
  - Interviews took place virtually on Microsoft Teams (HIPAA-compliant platform)

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Methods: Recruitment

- November 2021 to May 2022
- Direct outreach (email or phone)
  - EMR data set query by CHOP Department of Biomedical and Health Informatics
  - 2,629 potential participants; randomized
  - REDCap study introduction email or phone call
- Passive outreach (study flyer)
  - Designed by CHOP Research Institute
  - Hung in CHOP Primary Care Delaware County waiting rooms & exam rooms; handed to families at check-in
- Recruitment ended when data redundancy was achieved

10

Methods: Recruitment

Inclusion Criteria

- Age 12 to 15 years
- Up-to-date with well child care at the primary care practice study site
- Parent/legal guardian permission to participate
- Access to WiFi or cellular hardware capable of videoconference
- Consent to audio-recording of virtual interview

Exclusion Criteria

- History of an office visit with the lead investigator (M. Christie)
- Cognitive impairment/developmental delay

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Methods: Study Visit

- Informed consent with parent/legal guardian present
- Demographics with parent/legal guardian present
  - *re-asked gender identity when 1:1
- Qualitative Interview
  - Semi-structured, 1:1
  - Gathered information about who they felt connected to during the pandemic, the impact of connectedness/lack of connectedness on their health, and the support they needed from adults moving forward
  - Deductive interview guide (open ended + series of probes targeting study aims and reflecting 5 C's Model of Positive Youth Development (competence, confidence, connection, character, caring).[18, 19]

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Methods: Data Analysis

- Digital recordings were uploaded to CHOP secure research drive
- Recordings transcribed by NVivo Transcription (artificial intelligence)
- Study team reviewed & verified AI transcription for accuracy and privacy
- Verified transcripts uploaded to NVivo Pro 11 for data management and coding

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Methods: Data Analysis

- Analyzed using conventional content analysis with inductive + deductive coding
- This generated a description of the study objectives with presentation of themes

1. LI & PI independently coded transcripts in NVivo (January – June 2022)
2. Team meetings to review coding (PhD RN, CPNP, LCSW, undergraduate student)
  → multidisciplinary input, final coding decisions made
3. Second-level coding & thematic analysis by LI and PI together (in-person & virtual meetings) (June – September 2022)

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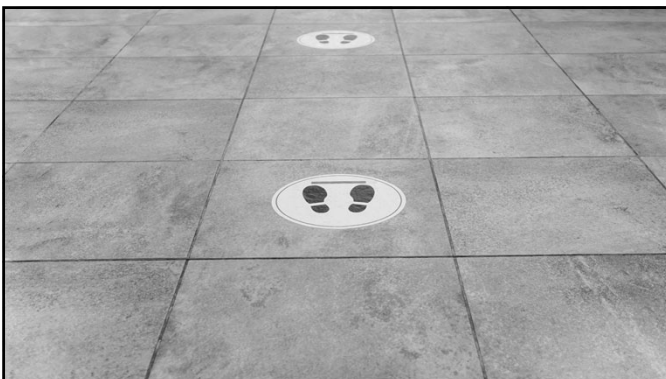
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Results

Please contact melissa.christie@cuanschutz.edu
directly for results; data has not yet been published

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Demographics Table[A]

Characteristics	Participant Response (n = 12)	Characteristics	Participant Response (n = 12)
Age, range (mean)	12-15 years (13)	Has younger siblings, No. (%)	
		Yes	8 (67)
Gender, No. (%)		No	4 (33)
Female	8 (67)		
Male	4 (33)	Speaks languages other than English at home, No. (%)	
Non-binary/third gender	0 (0)	Yes	0 (0)
Prefer to describe	0 (0)	No	12 (100)
Prefer not to say	0 (0)		
		Has public transit pass, No. (%)	
Race, No. (%)		Yes	0 (0)
African American/Black	3 (25)	No	12 (100)
Caucasian/White	7 (58)		
Mixed	1 (8)	COVID-19 vaccination status, No. (%)	
		Yes, partially vaccinated	0 (0)
Type of School, No. (%)		Yes, fully vaccinated	11 (92)
Middle school, public	6 (50)	No, not vaccinated	1 (8)[B]
Middle school, charter	1 (8)	Prefer not to say	0 (0)
High school, public	4 (33)		
High school, private	1 (8)		
Has older siblings, No. (%)			
Yes	6 (50)		
No	6 (50)		

[A]Self-reported demographic characteristics
[B]Upcoming COVID vaccination scheduled at time of interview

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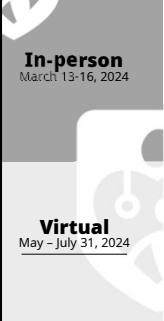19. The 5 Cs model of positive youth development. Explore SEL. – Harvard University. Available at http://exploresel.gse.harvard.edu/frameworks/52. Accessed September 23, 2022.

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Thank you

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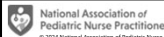National Association of Pediatric Nurse Practitioners

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In-person
March 13-16, 2024

Virtual
May – July 31, 2024

45th National Conference
on Pediatric Health Care

Examining Needs and Preferences
for a Cooking Skills Education
Program among Adolescents from
Low-income Families

By: Cassandra Duran, DNP, RN, FNP-BC

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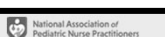© 2024 National Association of Pediatric Nurse Practitioners

Experts in pediatrics, Advocates for children. 1

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Speaker Disclosure

• No financial disclosures

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Learning Objectives

• Better understand the needs and preferences for food and
cooking skills education in older high school students in a public
charter school serving low-income students.

• Examine student demographics, food security status, dietary
intake, cooking self-efficacy, and preferences for intervention
programming.

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Background and Methods

• Modern teenagers have limited access to food and cooking
education.

• A needs-based assessment of high school adolescents was
conducted

• A questionnaire was conducted examining the following:
  • demographics, food insecurity, dietary intake, cooking self-efficacy, and
    preferences for intervention programming.

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Results

Table 1: Characteristics of student survey respondents (n=82)	
Female	56 (68.3%)
Age (Mean, SD)	16.34 (1.53)
Race/Ethnicity	
Black/African American	40 (48.8%)
Hispanic white	26 (31.7%)
Other	18 (19.6%)
US Born	75 (91.5%)
Primary Language at home is English	45 (54.9%)
Food Insecure	32 (39.0%)

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Results

Table 2: Diet and cooking self-efficacy among survey respondents. N (%)

Daily vegetable intake
- ≤ 1 cup 58 (70.7%)
- >1 cup 24 (29.3%)

Daily fruit intake
- ≤ 1 cup 33 (40.2%)
- >1 cup 49 (59.8%)

Weekly fast food intake
- ≤ 1 time per week 28 (34.1%)
- ≥ 2 times per week 51 (62.2%)

Cooking Self Efficacy (I Can...) Mean (SD)

Make a snack with fruit or vegetables	3.66
Can cook using a recipe	3.63
Can cook without a recipe	3.11
Can make my family a meal	3.13
Make a salad	3.66
Cut up / prepare ingredients	3.76
Measure ingredients	3.60
Shop for groceries / help shop for groceries	3.70

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Conclusion

- Mobile clinics provide a unique solution to reach underserved youth

- Mobile clinic collaboration with under-resourced schools may be key factor

- Widespread implementation would be beneficial for teens that are transitioning into adulthood

- More research is needed to understand how to optimize programs like this

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Questions?

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