Urban, Low-Income, African American Well-Child Care: Parent Experiences and Expectations

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Robert Wood Johnson Foundation, Future of Nursing Scholars
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Learning Objectives

Participants will:
• Have a greater understanding of urban, low-income, African American parenting experiences and well-child care expectations
• Recognize the parenting struggles and challenges faced by this population
• Identify guiding strategies for improving well-child care quality for this population that improves a child’s life course trajectory for healthy development

Background

• Well-child care (WCC) is the foundation of pediatric primary care and health promotion

• #1 priority at every well-child visit => address parents’ concerns

• African American parents report lower overall quality of pediatric primary care

• This population also faces:
  • Increased risk for poor health
  • Increased risk for poor development
  • Multiple negative social determinants of health

• Healthy People 2030: eliminating health disparities and attaining health equity

• Well-child care has the potential to improve child health

One solution: High-quality WCC

Methods

DESIGN: Qualitative focus group study; St. Louis, Missouri and Milwaukee, Wisconsin

PARTICIPANTS: Purposive, volunteer sample recruited from focus group sites; one child aged birth to five, identified as AA, qualified for Medicaid, WIC, or Head Start

DATA COLLECTION: Four focus groups held at community sites; audio-digitally recorded

ANALYSIS: Conventional content analysis following professional transcription

Disclosures

There are no financial conflicts of interest to disclose.

Co-authors and dissertation committee

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Cynthia J. Peden-McAlpine, PhD, ACNS
Mary Chesney, PhD, APRN, CNP, FAANP, FAAN
Susan M. Mason, Ph.D., MPH
Participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>30</td>
<td>86%</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>14%</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>26</td>
<td>74%</td>
</tr>
<tr>
<td>Father</td>
<td>4</td>
<td>11%</td>
</tr>
<tr>
<td>Grandmother</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>Other relative</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Benefits utilized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>32</td>
<td>91%</td>
</tr>
<tr>
<td>Head Start</td>
<td>8</td>
<td>23%</td>
</tr>
<tr>
<td>WIC</td>
<td>14</td>
<td>40%</td>
</tr>
<tr>
<td>Age of children (n=49)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-12 months</td>
<td>6</td>
<td>12%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>9</td>
<td>18%</td>
</tr>
<tr>
<td>3-5 years</td>
<td>34</td>
<td>69%</td>
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</table>

Categories and Sub-Categories

Community Factors Impacting Parenting

Provider Implications:

- Acknowledge factors outside of the home that impact a child's life course trajectory: schools, safety, lack of resources, etc.
- Screen for SDH
- Invest in neighborhoods: public policy, grassroots involvement to promote neighborhood safety, school reform, and access to healthcare

Joys and Struggles of Parenting

- The easiest task of parenting – to love their children
- Challenges included providing for their children, not just financially, but childcare, food, and a safe home

Sources of Parenting Advice and Support

- Just Google it
- Previous health care experiences inform healthcare decisions

Provider Implications:

- In many ways, no different from all parents – family, the internet, natural remedies, providers
- Unique: role of past experiences in informing health behaviors
- Create a space where past experiences can be acknowledged and reframed

Health Care Systems Challenges

Provider Implications:

- A lot of politics and money to healthcare
- Private insurance is better than Medicaid
- 55% of African American children on public insurance
- Parents viewed the care as sub-standard
- Poor perception of care means small things can signal disrespect or decreased value
Challenges with the Provider
• Providers do stereotype
• Providers don’t really care, they come for the paycheck
• You see a new face every two weeks

Provider Implications:
• One’s perceptions can become one’s reality
• Trust has been violated historically
• Stereotypes, providers missing something, not listening, etc. lead to families seeking care elsewhere
• Avg. length of relationship: 6-11 mon.
  
• Increase trust, avoid stereotypes, use clear communication, consistent providers

Anticipatory Guidance Topics

Provider Implications:
• I like to know where they are (growth and development)
• Discipline is hard

What Parents Desire
• Know them like the back of your hand
• It’s all in who you trust

Provider Implications:
• All parents want reassurance and a chance to discuss their priorities with their child’s provider
• All parents would like a continuous relationship with one provider
• However, African American parents are less likely to have a medical home and less likely to be involved in decision making
• Providers in the community
• Increased diversity of providers

Limitations
• Transferable to like contexts
• Cities were selected for their similar characteristics
• Parents may have held back their opinions
• PI is not associated with any of the local clinics

Conclusion
• Equalizing maxim: All parents want the best for their children
• Race, and socioeconomic status, and other social determinants of health impact the ability of parents to give their children the best
• By providing high-quality parent education and health services, providers can help parents to provide their best and counter the toxic stress of racism and poverty

Conclusion
• Parent expectations are not very different between races and income levels
• However, results reveal ongoing disparity in the experiences and perception of care
• Changing that perception to one of health care helping parents and children requires the commitment of all providers
• Change must occur in the exam room, but also through:
  • Advocacy
  • Political action
  • Community Engagement
References


Thank you!
Questions?
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Parental Perceptions of Adolescent Connectedness and the Primary Care Provider

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Center for Pediatric Nursing Research & Evidence-Based Practice

Disclosures
The author has no conflicts of interest to disclose.

Learning Objective
• To open a dialogue about the primary care provider’s role in supporting adolescent connectedness, based on findings from a nurse-led study

Clinical Problem
• Adolescents
  • Suicide rates – climbing since 2007
  • Rising hopelessness
  • PHQ-9
• Primary care
  • Time
• Mental health providers
  • Referral network
  • Insurance
  • Waiting lists
  • Logistics (e.g. transportation)

Advanced Practice Provider Research Fellowship
Children’s Hospital of Philadelphia
Center for Pediatric Nursing Research & Evidence-Based Practice
The Study
Exploring Parental Perceptions of Adolescent Connectedness and the Role of the Primary Care Provider

Background
• Adolescent depression and suicide is on the rise\(^1,2\)
• Connectedness to adults, schools, and peers is protective\(^3-7\)
• Literature gap regarding role of primary care provider (PCP) in supporting connectedness
• Conceptual Frameworks
  • Positive Youth Development\(^8\)
  • Bronfenbrenner’s Ecological Systems Theory\(^9\)

Objectives
• To describe parental perceptions of:
  • opportunities for community connectedness for adolescents
  • the barriers to accessing opportunities for adolescent connectedness
  • the potential role of the PCP in fostering adolescent connectedness to their communities

Methods
• Prospective qualitative study
• Semi-structured interviews
• Pediatric primary care practice 2.5 miles outside of Philadelphia
• Exempt status by IRB at Children’s Hospital of Philadelphia

Recruitment (November 2018 – April 2019)
• Two methods:
  • EMR randomization
  • In-person solicitation at time of office visit

Recruitment Realities

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
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<tbody>
<tr>
<td>Verbal proficiency in the English language</td>
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<tr>
<td>Parent/legal guardian of adolescent 11-18 years who receives primary care at study site</td>
</tr>
<tr>
<td>Parent/legal guardian of adolescent residing in one of the top 4 zip codes served by study site</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Exclusion Criteria</th>
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<tbody>
<tr>
<td>Parent/legal guardian of adolescent (being discussed) who has been a patient of the lead investigator</td>
</tr>
</tbody>
</table>

285 charts randomized

14 eligible participants

14 ineligible

20 interviews scheduled

14 cancellations/no shows

11 completed interviews
Analysis (January – May 2019)

• Interviews were audio-recorded and transcribed
• NVivo software used to manage the study data
  • Content analysis
    • Directed content analysis
    • Conventional content analysis
    • Inductive and deductive coding
  • Iterative process
    • Independent coding, team meeting, re-coding
    • Constant comparison

Results: Selected Demographics

<table>
<thead>
<tr>
<th>Relationship to adolescent, No. (%)</th>
<th>Participant Response (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>9 (82)</td>
</tr>
<tr>
<td>Father</td>
<td>1 (9)</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1 (9)</td>
</tr>
</tbody>
</table>

Co‐parent the adolescent, No. (%)

| Yes                              | 7 (64)                    |
| No                               | 4 (36)                    |

Employment status, No. (%)

| Full‐time                        | 8 (73)                    |
| Part‐time                        | 1 (9)                     |
| Not employed outside the home    | 2 (18)                    |

Educational attainment, No. (%)

| Graduate school, completed       | 3 (27)                    |
| College graduate                 | 1 (9)                     |
| College, partial completion      | 3 (27)                    |
| High school graduate             | 3 (27)                    |
| High school, partial completion  | 1 (9)                     |

Country of origin, No. (%)

| USA                              | 8 (73)                    |
| Bangladesh                       | 1 (9)                     |
| Mali                             | 1 (9)                     |
| Nigeria                          | 1 (9)                     |

Results: Qualitative Analysis

• Analysis yielded 22 codes and 9 themes

Results: Themes

• Perception of opportunities for connectedness:
  1. Most formal activities occur at school
  2. Most informal activities center on family and friends
  3. Others are influential for involvement
  4. Participation in activities is viewed as positive
• Barriers:
  5. Parental/caregiver discretion; demand of the activity
  6. Logistics
• Role of PCP
  7. Parent/caregiver do not recall discussing connectedness
  8. Discussing with PCP would be helpful
  9. Parent/caregiver understanding of health

Results: Opportunities for Connectedness – Theme 1 & 2

“She very recently was in a play at her school. Um and she is now moving on to track at her school.”

“We like to go out to eat, um, restaurants, um we go to church services together, we go to the movies, um, different cultural events.”

“Now that he is into video games, and um Facetiming friends, and a lot of things that have to do with technology, um, books not so much. Um, so he spends a lot of time on video games, talking to friends, and sleeping.”

Results: Opportunities for Connectedness – Theme 3

“The wrestling coach actually came to him. And um, because it was a teacher of his, and was like, ‘Oh you know, I, I’m the head of the wrestling program, you should really do wrestling’.”

“I try to let him have something active to go to. ‘Do you like soccer? Do you like soccer, or tennis, or something?’ He picked basketball.”

“I think the personality of this friend this year is always encouraging her. And also asking her to participate with her. So I think it was kind of, more or less a buddy system.”
Results: Opportunities for Connectedness – Theme 4

“Um, he—he’s like a hibernating bear. So being in something outside of school, you would think he would come home more tired, but I think the adrenaline rush—he interacts with us differently. He’s not zooming right past the dinner table going upstairs to do his own thing. He’s kinda telling us about locker room talk, uh, plays, ‘Oh, I was supposed to sit down but the coach played me because I did so well,’ you know, things of that nature, so I think it gives him, um, a sense of purpose.”

“I know for a fact, her knowing that she’s got something to do, it’s more excitement. I know she’s not depressed.”

“The body lose the weight.”

Results: Barriers in Accessing Opportunities – Themes 5 & 6

“It got to be too demanding. And then it took away from her doing her school work.”

“There’s been a lot of times when she wanted to like, join a different like, tennis and stuff like that, but because of my work schedule it was hard for me to get someone who can pick her up on a daily basis and would drop her off.”

Results: Role of the PCP in Connectedness – Theme 7

“Um [long pause] [sighs]. I don’t know if this might be the only time, to be honest.”

“No, I haven’t.”

“Nope, it’d be very little.”

“No.”

“Not yet.”

Results: Role of the PCP in Connectedness – Themes 8 & 9

“She definitely has doctors that she definitely bonds closer to with, ya know. And I think that if it comes from that specific doctor, I think she’d be more inclined, she’d be like, oh yeah maybe you know what, that is, maybe that is something I’d be interested in, like you know, thank you for letting me know of that.”

“I would just say to continue—if it—there is something going on whether there are bulletins posted in the office, you know. Um, or even askin’ me, ‘Is he involved?’ because maybe if he’s not I’m gonna now seek it, you know what I mean?”

“So I wanna say she’s always been a pretty healthy kid. You know, um, unlike my oldest daughter [laughs], asthma and all this stuff. Um, she pretty much, was born on time, well maybe 2 or 3 days late, um, (pause) I don’t know. There’s no real correlation I don’t think. I mean, unless there is another way to ask the question?”

Discussion

- Highlights gap in patient-parent-provider communication about the importance of connectedness
- Potential impact of PCP in promoting connectedness
- Future research is needed to explore the most effective ways to hold these conversations

Thank You

- Elizabeth B. Froh, PhD RN
- CHOP Center for Pediatric Nursing Research & Evidence-Based Practice
- CHOP PeRC
- CHOP Care Network Drexel Hill
- CHOP Research Institute
- University of Pennsylvania School of Nursing students

... and last but not least, our participants for sharing their stories with us


Learning Objectives

- Discuss outcomes of a national study of pediatric nurse and nurse practitioner roles in health care transition planning, and the impact of knowledge and perceived importance on key elements
- Identify key elements of Health Care Transition Planning validated in the Nursing Roles in Health Care Transition Planning (NR-HCTP) Tool
- Consider future practice implications on the basis of study results

Purpose

The purpose of this national research study was to address a gap in current knowledge specific to pediatric nursing professionals’ roles and responsibilities in Health Care Transition Planning (HCTP)

Background and Significance

- YAY with long-term conditions face numerous challenges in transitioning from pediatric to adult health care
- Estimated that 90% of YAY with long-term conditions now enter adulthood
- HCTP has emerged as a nursing practice priority for this vulnerable population who face M&M related to gaps in care
- 2018 Clinical Report from AAP/AAFP/ACP highlights evolution of HCT as more interdisciplinary and inclusive of nursing/SW
- Society of Pediatric Nursing Position Statement (Betz, 2017)
- NAPNAP Position Statement coming in 2020 (JPHC)

Research Questions

1. Determine to what extent nurses are involved in HCTP for YAY with CID
2. Identify the activities that nurses engage in when providing HCTP
3. Examine associations among selected professional demographics with the provisions of HCTP activities; including assessing YAY self-management abilities (SMA).
Theoretical Framework

The Health Care Transition Model proposed by the international and interdisciplinary Health Care Transition Research Consortium includes four domains specific processes, variables, and potential mediators affecting HCT outcomes:

1. Individual
2. Family/social support
3. Environment
4. Health care systems

Methodology

- Quantitative descriptive
- Validated investigator-designed survey questionnaire: Nurses’ Role in Health Care Transition Planning (NR-HCTP)
- Thirteen HCTP activities relating to communication, education, collaboration, and advocacy were explored through statements probing:
  - Pediatric nursing roles
  - Job description
  - Level of knowledge
  - Ratings of importance.
- Subscale in the NR-HCTP: 9-item Assessment of Self-Management Abilities (SMA)

Sample Characteristics n = 1814

- Permission obtained and participants recruited from:
  - Pediatric Nursing Certification Board (PNCB) n = 1647 (15.2% of opened surveys)
    - Certified Pediatric Nurse (CPN)
    - Pediatric Nurse Practitioner (CPNP-PC), (CPNP-AC) or dual PC/AC
    - Individual emails sent to certificants who had agreed to 3rd party email
  - Society of Pediatric Nurses (SPN) n = 167 (% of total opened unknown)
    - Announcement sent to membership containing a description and invitation to participate
    - Survey accessed by link; also posted on SPN website
  - Data gathered between June → December 2016

Results

Activities
- 63% of respondents performed HCTP activities related to speaking with families and other health care professionals about complex health needs, whether listed in JD (49%) or not (14%)
- Knowledge
  - While only 18% (n = 332) reported having specialized training in HCTP, the respondents reported being knowledgeable about all 13 HCTP activities (M = 41.8, SD = 12.2, Range 13-65, p < .001)
- Perceived importance
  - Overall, the 13 HCTP activities were reported to have high perceived importance; with “educating YAY about self-management abilities” ranking highest (M = 2.56, SD = .79, Range 0-3)
Results → HCTP Activities Performed by Nurses

Results

Correlation Analysis

Moderate to strong positive associations between

- Number of “job skills” (out of the 13 listed) and “total importance” of those skills to the RN/NPs current role
  \( r = 0.448, n = 1184, p < 0.01 \) and the “total knowledge” pertaining to those activities \( r = -0.506, n = 1186, p < 0.01 \)

- “Total knowledge” pertaining to the 13 HCTP skills and “Total importance” \( r = 0.466, n = 1206, p < 0.01 \)

Results

Regression Analysis

Predictors that were NOT significant:
- Education level
- Work setting
- Practice certification
- Having “transition” in job title

1. HCTP activities performed by pediatric nursing professionals in the US focused on education, advocacy, and support; and align with current standards of nursing practice pertaining to the care of YYA with complex health needs of all ages.
2. Pediatric nurses are more comfortable with the assessment of condition management that involves direct patient care, such as assessing and teaching YYA about daily management of their treatment regimen and health care needs.
3. There is a need for educational programs specific to supporting future HCTP role development among pediatric RNs and NPs.
Study Limitations

1. Purposive sample of pediatric NPs and Nurses who obtained National Certification (CPN, CPNP) –> highly motivated group of professionals
2. May not be generalizable to nurses who were not part of the study group
3. School nurses not included; discussions with NASN occurred

Practice, Research and Education Implications

• Study adds to other published evidence about the need for HCT education for RNs and NPs working with YYA with CID. Supported by both SPN Position Statement (2017) and NAPNAP Position Statement (in press, 2020)
• This study clarified the elements of the pediatric nursing role that are important in helping YYA and families successfully transition to adult care
• Separate analysis of the frequency that nurses assess self-management abilities, and the types of activities
• APRN, leadership roles, clinical and academic educator roles and researcher data being pulled out for separate analysis –> initial review indicates that average knowledge score was 5.35 points higher and average total perceived importance was 3.37 points higher than staff RN responses.

References


QUESTIONS??

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Cecily Betz, PhD. & Jennifer Mannino, PhD