

Contextual factors and health among
multiethnic populations:
HPV and implications for primary care

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Overview of Session

- Background
- Description of research program
- Prior research
- Study results: Parents' preferred & actual sources of HPV information
- Overall conclusions

Bridging the Critical Chasm

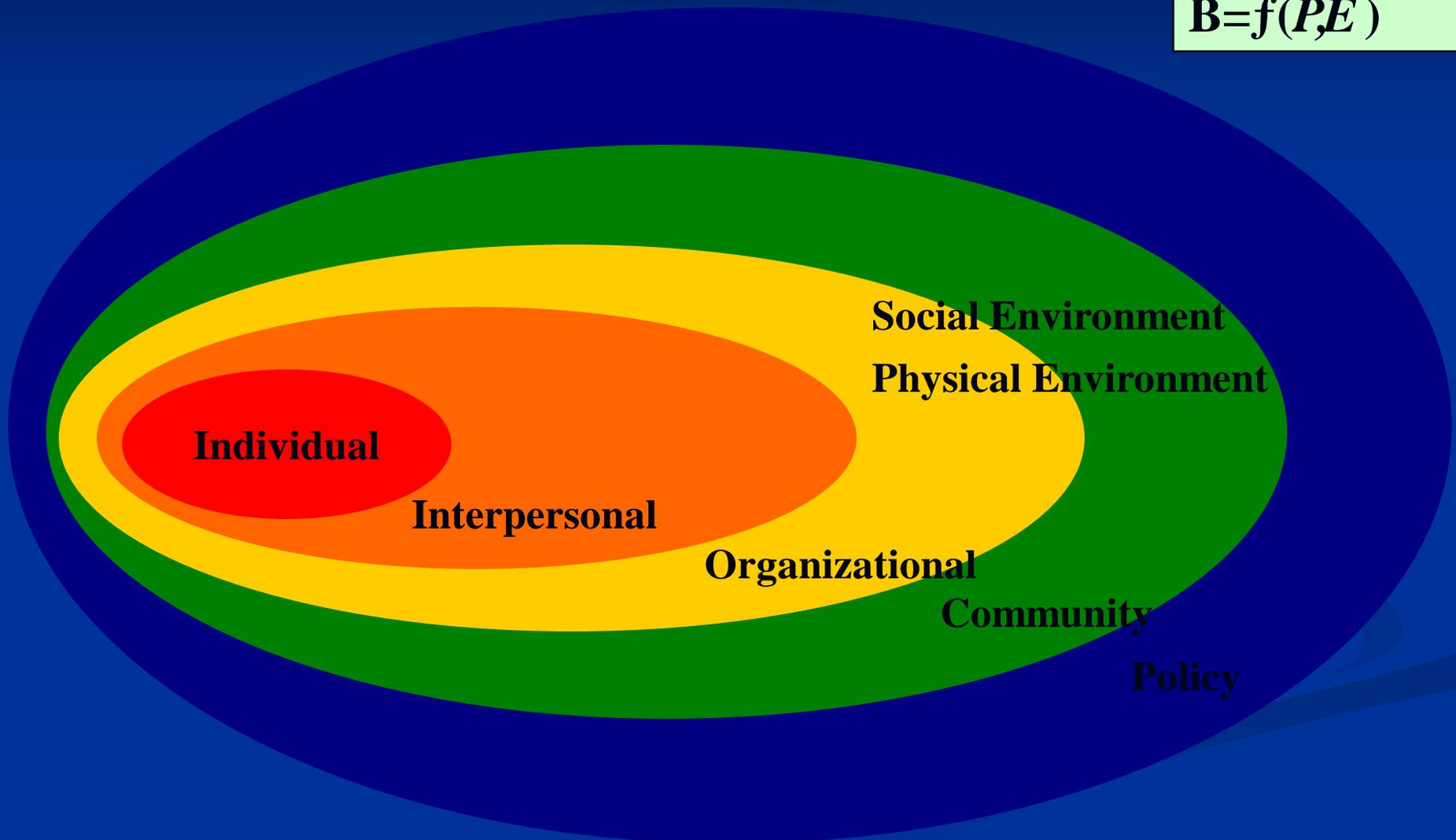


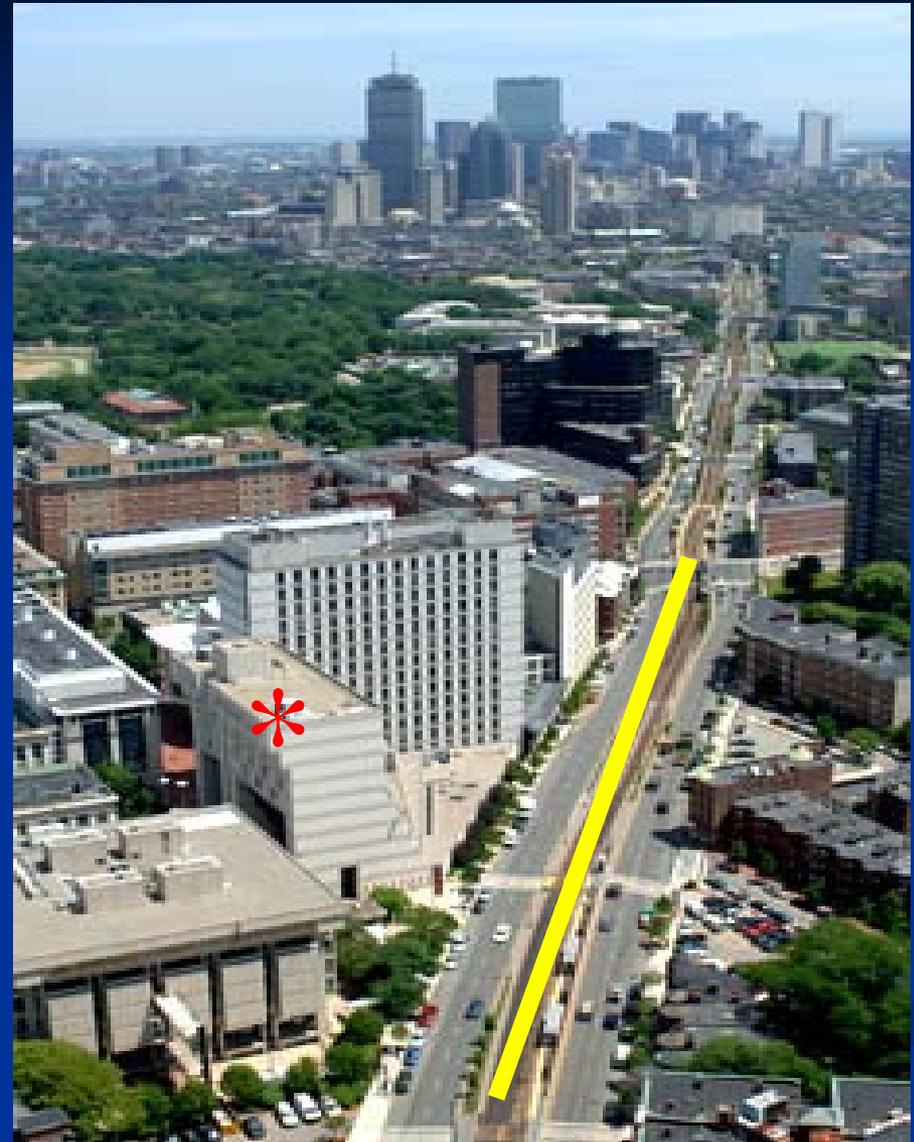
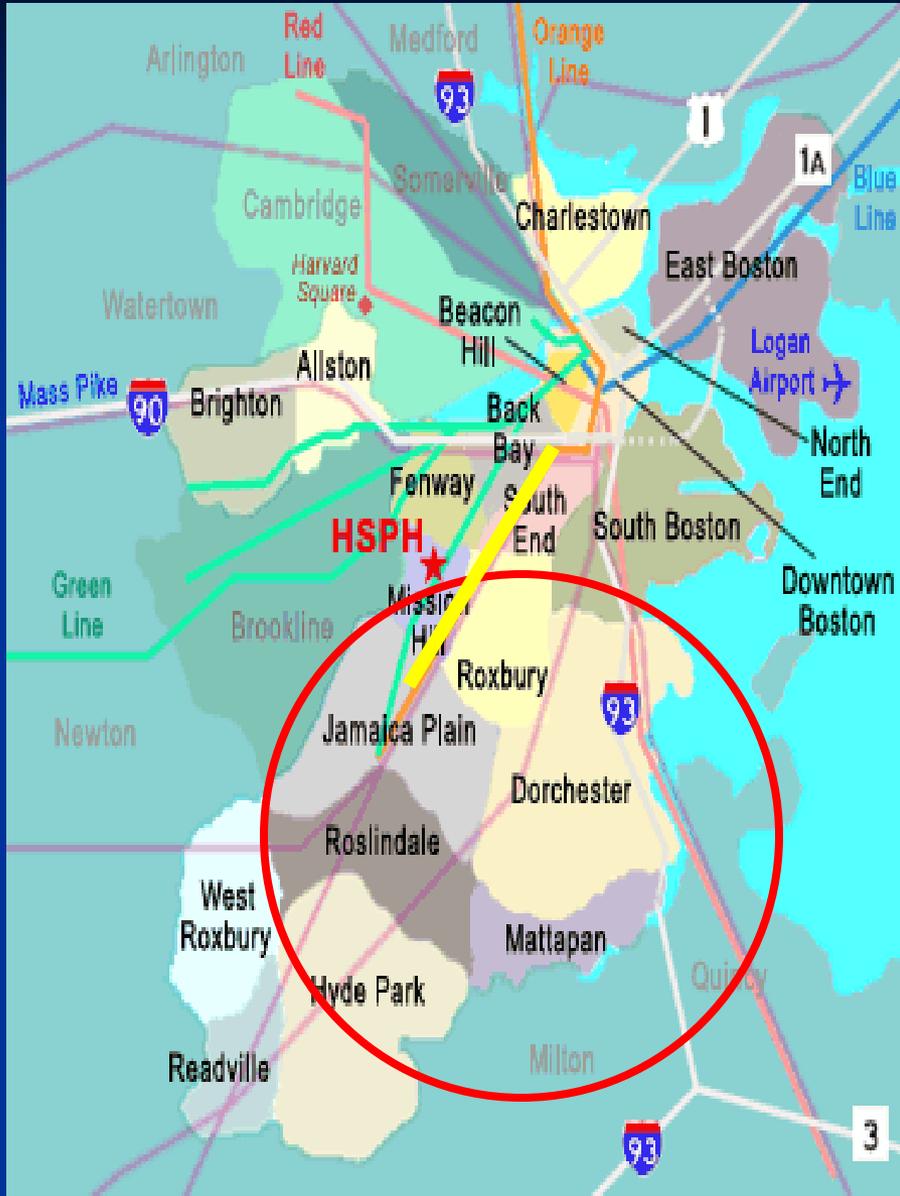
Research Program

- Health disparities area
 - Community-based participatory research
 - Lower-income, multiethnic & immigrant communities
 - Local relevance of public health research
 - Aim of knowledge translation & elimination of health disparities
 - Influence of social contextual factors on health promotion, health decision-making, & health outcomes
 - Ecological models
 - Role of interpersonal, sociocultural, organizational, & community-level factors in shaping the health & health promotion participation of low-income ethnic populations

The Ecological Model

$$B=f(P,E)$$





HSPH, 651-677 Huntington Avenue

Overview of Prior Research

- Examining associations of interpersonal & neighborhood-level factors on perceived neighborhood safety¹
 - Low-income, multiethnic public housing residents
- Examining contextual barriers to health promotion²
 - Low-income Cape Verdean immigrant women in Boston neighborhoods
- Developing conceptual model of health promotion³
 - Low-income Cape Verdean health promoters



¹De Jesus, M., Shelton, R., Puleo, E., & Emmons, K. (under review). The role of social contextual factors in shaping perceptions of neighborhood safety among multiethnic low-income public housing residents.

²De Jesus, M. (in press). The importance of social context in understanding and promoting low-income immigrant women's health. *Journal of Health Care for the Poor and Underserved*.

³De Jesus, M. (in press). Mutuality at the centre: Health promotion with Cape Verdean immigrant women. *Ethnicity and Health*.

Lessons Learned

- Ethical considerations are not clear decision-making points, but ongoing processes throughout research collaboration
 - Power discrepancies – need to create contexts & structures that facilitate mutual sharing of power, information, & institutional resources
 - Entering community –need to develop credibility
 - Developing relationships over time –need to establish trust & reciprocity, clear community benefits
- Reflexivity –also iterative process
 - Awareness of how researcher shapes research process
- Community expertise
 - Valued resource & collaborators
 - Have extensive knowledge & experience of salient community issues

Information-seeking in a context of uncertainty: Preferred versus actual sources of HPV information among Black, Latino, and White parents



De Jesus, M., Othus, M., Shelton, R., Kokkinogenis, K., & Allen, J. D. (under review). Preferred sources of HPV information among Black, Latino, and White parents: Implications for primary care.

Background

■ HPV vaccine

- In June 2006, the US FDA licensed a prophylactic quadrivalent human papillomavirus (HPV) vaccine called Gardasil
- Against HPV types 6, 11, 16, & 18
- For use among girls & women aged 9 to 26 years old

■ Reaction to vaccine

- Enthusiasm & controversy
- Influence of pharmaceutical companies & other stakeholders

Factors impacting knowledge translation

- Multiple stakeholders ~ conflicting priorities
 - **Manufacturers**
 - Lobbied hard for expedited vaccine approval and compulsory vaccination
 - Undermined public confidence & created backlash among parents
 - **Policy makers**
 - Legislation pending in 41 states that addresses HPV vaccine (E.g., VA has implemented school mandates). Others, have financial resources set aside for educational efforts
 - **Providers**
 - Modest knowledge levels of HPV. Made into 2 bullets
 - Intention to vaccinate varies by level of HPV knowledge, attitudes about vaccination, physician age, gender & specialty
 - **Parents, young women, adolescents**
 - Intense direct media advertising & conflicting reports about the pros/cons of vaccination, as well as side effects

Parents: Reaction of uncertainty

- Public mistrust
 - Concerns about potential adverse effects
- Concern about impact on adolescent sexual activity
 - Potential to provide false sense of protection against STIs
- Social stigma
 - Vaccination is admission that one's daughter is sexually active
- Poor public understanding of HPV
 - Existing knowledge is low, but parents are highly motivated to access information
 - This bodes well for educational efforts

Why focus on parents & their preferred sources of HPV information?

- In this context of uncertainty & conflicting reports, parents & early adolescents hold much of decision-making burden
 - Need HPV information to make informed decisions
- *Gap in literature*
 - No information about where parents actually obtain HPV information & where they prefer to get this information

Aims

- Examine most common sources through which parents are being currently educated about HPV & their preferred sources of HPV information
- Examine whether reported relationship quality with their daughter's health care provider is associated with their preferred source of HPV information
 - Potential demographic confounders: race/ethnicity, education, and income level

Methods

- Eligibility criteria
 - English or Spanish-speaking parents
 - At least 1 daughter (9-17 years old)
 - Diverse socioeconomic & educational backgrounds

- Data collection: Mixed methods study design
 - Web-based survey
 - Random sample (N=476 parents)
 - Focus Groups (FGs)
 - White, Black, Latino parents recruited in collaboration with our community partners (8 FGs)

- Data analysis
 - Descriptive statistics & multivariate regression models
 - Thematic analysis

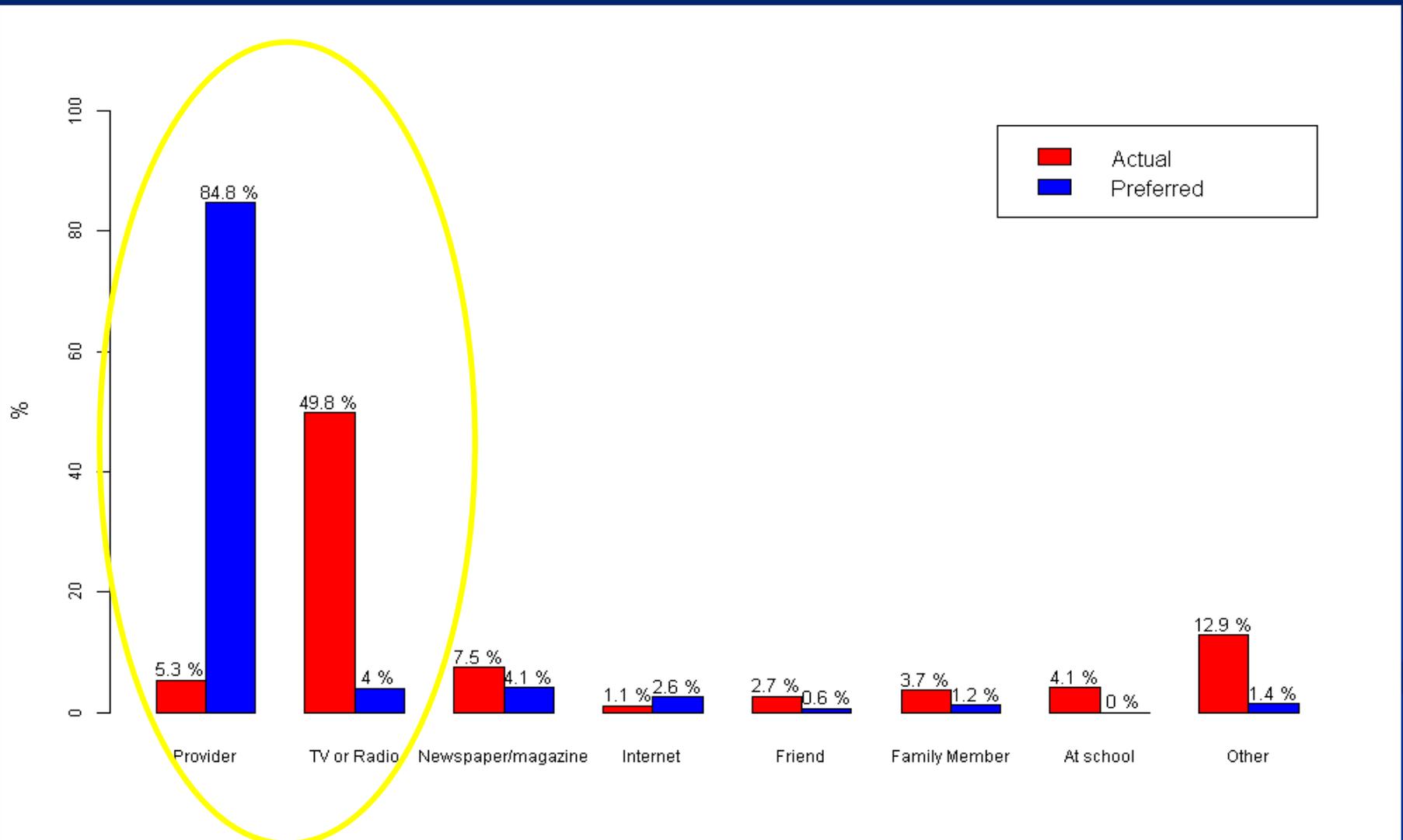
Selected Characteristics of Survey Participants (N= 476 Parents)

Race/Ethnicity		Heard of HPV before survey	
Black	29%	Yes	90%
Hispanic	20%		
White	51%		
Mothers		Heard of HPV vaccine before survey	
Fathers	8%	Yes	67%
	92%	No	26%
		Don't know	7%
Age (Mean)		Ever had HPV	
	41 years old	No	89%
Education		Know anyone who has had HPV	
HS or less	29%	No	77%
Some college	38%		
BA degree or higher	33%		
Income level		Daughter's healthcare insurance	
<\$25K	25%	Private insurance	58%
\$25K-\$50K	28%	Medicaid/Masshealth	20%

Selected Characteristics of Focus Group Participants

Characteristic	% (n=67)
White male: 1 group (8 men)	12%
White female: 2 groups (16 women)	24%
Black male: 1 group (12 men)	18%
Black female: 2 groups (19 women)	28%
Hispanic male: 1 group (6 men)	9%
Hispanic female: 1 group (6 women)	9%
Have insurance	99%

Actual vs. Preferred Source of HPV Information



Multivariate Regression Predicting Preferred Source of HPV Information

Quality of relationship and preferred source of HPV information

	Parents	
	Unadjusted	Adjusted ¹
	OR (95% CI)	OR (95% CI)
Quality of relationship		
Good	2.09 (0.89, 4.85) <i>p</i> -value: 0.09	1.91 (0.83, 4.43) <i>p</i> -value: 0.13
Poor	REF	REF

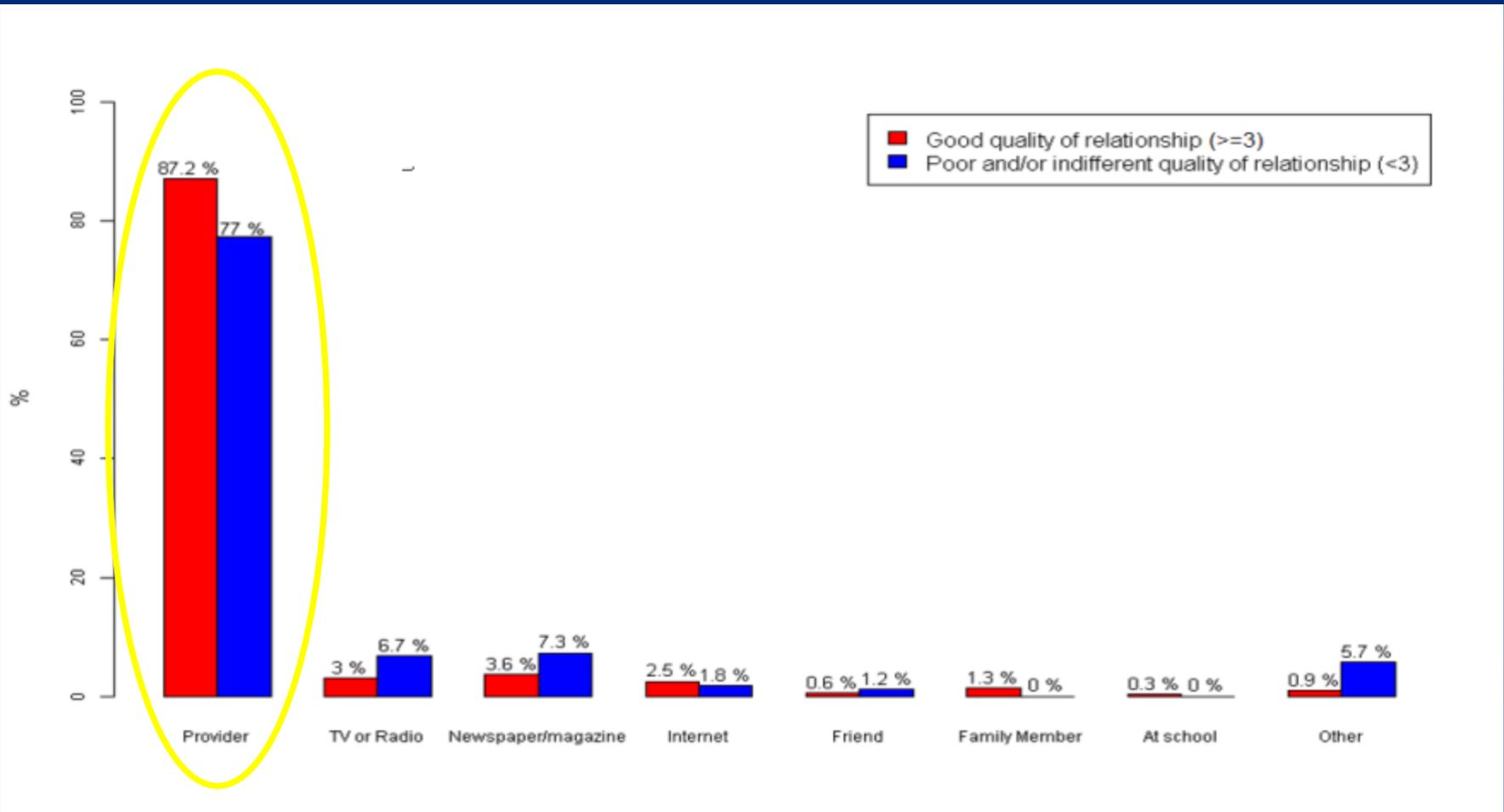
¹ Final multivariable logistic regression was adjusted for race/ethnicity, education, and income.

Quality of Relationship with Daughter's Health Care Provider

Quality of relationship ¹	% (N=476 parents)
Have a good relationship	80.6%
Always willing to answer my questions	87.7%
Trust medical recommendations	85.2%

¹ Cronbach's alpha for 3 items= 0.88

Preferred Source of HPV Information By Relationship Quality (N= 476)



Focus Group Findings:

An overview of six salient themes

- Lack of HPV information

“I imagine that if it’s a virus...I don’t know if it’s the same as cancer.”

- Received HPV information from TV

“I only found out about it through the commercials on TV.”

- Health care providers are preferred source of HPV information

“I made an appointment for the purpose of obtaining information from her doctor.”

- Importance of comprehensible written health material

“Put it in a brochure or a pamphlet ... at a level we can discuss.”

- Language barriers: Interpreters & materials needed for non-English parents

“It’s not very easy to find information in Spanish.”

- Family-oriented decision-making related to daughter’s health

“It’s a family thing. The more opinions, the better the decision you can make.”

Strengths & Limitations

■ Strengths

- Lack of studies examining parental actual & preferred sources of HPV information
- Informs medical practice and research
- Informative quantitative & qualitative data

■ Limitations

- Limited measure of quality of provider-patient relationship
- Lack of variability in quality of relationship variable

Implications for decision-making related to HPV vaccine

- Shifting paradigms of decision-making
 - Movement away from paternalistic model (i.e., doctor-centered) to shared decision-making or informed decision-making
 - More involvement in health care decisions
 - IOM 2001 report*: “patient-centered care” involves shared decision-making– requires patients/parents to be informed
 - Provide the information, communication, & education that people need & want
 - Respect patients’ values, preferences & expressed needs

**Crossing the Quality Chasm: A New Health System for the 21st Century*

Conclusions: Implications for primary care practice & research

- Disconnect between actual vs. preferred source of HPV information
- Education for parents from daughter's health providers needed
 - Parents are hungry for information from trusted sources
 - Need to know more about specific information needs for parents and daughters
- Provider education
 - Communication skills, strategies & guidance to address parental & patient concerns

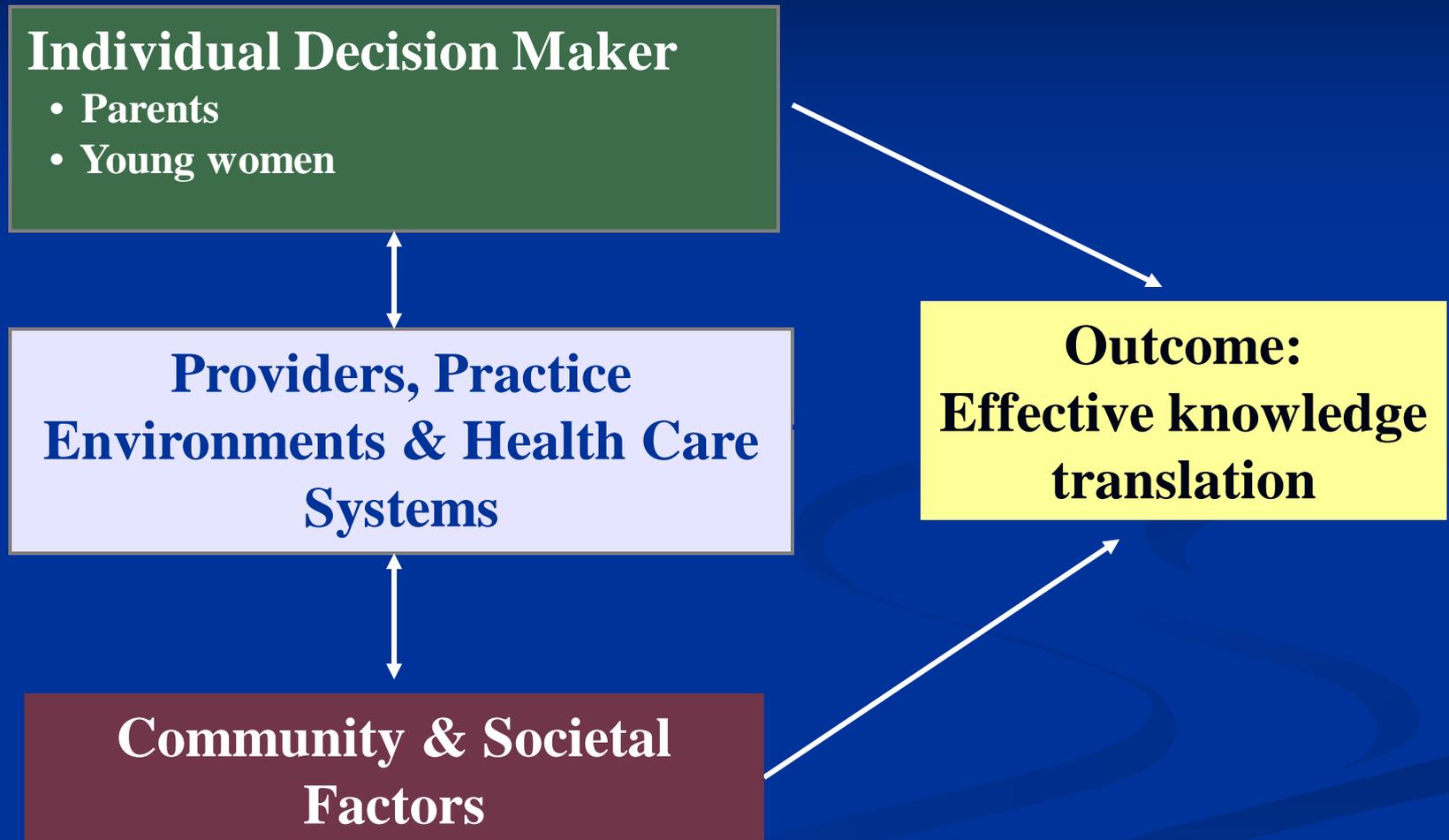
Educational materials for parents

- Cognitive testing of educational pamphlet
- Refining & translating pamphlet (English & Spanish)
- Disseminate materials to community health partners
- Write-up of research
- Apply for future funding

Knowledge translation efforts will be facilitated by...

- Data regarding salience of individual, interpersonal, institutional & societal factors that impact knowledge translation
- Information from members of medically underserved & ethnically diverse populations

Model for Knowledge Translation



Overall Conclusions

- Contribute to health disparities research by:
 - Examining factors across multiple levels of influence
 - With focus on lower-income multiethnic populations
 - Using community-based research approaches
- Elucidate important interpersonal & system-level factors & their influence on health decision-making that can impact interventions & policies
- Importance of physician-researcher-community partnerships

Acknowledgments

- Karen M. Emmons, PhD (CCBR & HSPH)
- David R. Williams, PhD (HSPH)
- Jennifer Allen, ScD (CCBR & HSPH)
- Elaine Puleo, PhD (CCBR & Umass Amherst)
- CCBR colleagues
- Community partners (Cape Verdean Unido, Bowdoin Street Health Centre, Multicultural Coalition, Whittier Street Health Centre)
- Community collaborators
- Parents