Partnering with Families and Schools in Pediatric Research

Cynthia A. Gerhardt, Ph.D.
Families & Childhood Illness

- Up to 1/3 of children are affected by a chronic condition

- Stressors may increase risk for individual or family difficulties in multiple domains

- Research is needed to identify at-risk populations and inform interventions

- We’ve conducted studies on a variety of conditions and across the illness spectrum
Inclusion Criteria

- Families of children chronic illness
- 8-17 years of age
- In school without full-time special education
- Within 100 miles of hospital
Procedures

Parent permits school contact

Principal agreement

Teacher data collected

School data collected

Target family T1 & T2 home visit

Comparison family T1 & T2 home visit
Why do we conduct clinical research in the community?
Where to Collect Data?
Methodological Points

- **Recruitment**: Minimize ascertainment bias, maximize participation rates
- **Multiple informants**: Moms, dads, teachers, peers, siblings, nurses, doctors
- **Mixed methods**: Questionnaires, interviews, observations, physiological assessments
- **Retention**: Prospective, longitudinal, low attrition
- **Controls**: Demographically matched peers
Recruitment Strategies

• Identification from disease registries or patient list, not clinic or volunteer samples

• Initial study letter from physician or familiar provider, followed by phone call from study staff

• Schools are contacted about a specific child, mailed study information, and follow-up call

• Foot in the door technique, only agreeing to initial contact, then each phase of data collection separately
Multiple Informants

• Each informant has unique, valid perspective of participant

• Who is best suited to report on construct of interest?

• How do we make this easiest on the informant?

• GO TO THEM AT THEIR CONVENIENCE

• This means often school visits during planning period, home visits evenings or weekends
Mixed Methods

• Partnerships in the community allows for a wide range of data collection techniques

• In vivo home or classroom observations

• Longer term physiological assessments (e.g., actigraphy, salivary cortisol)

• Qualitative interviews

• Balance with sterile, controlled lab environment vs. naturalistic environment
Retention Strategies

• Families complete follow-up information forms with multiple, alternate contacts

• Holiday cards to track addresses

• Semi-annual newsletters with study progress and findings

• Offer schools in-services or classroom discussions about friendships, research

• Participation on STEM advisory boards, mentorship of student interns
Controls

- Schools and community sampling allows for selection of controls
- Matched from classroom, neighborhood, or snowball techniques
- Classroom controls have historically similar family/SES factors
- Allows for direct group comparisons
Results

- 85-90% of families permit school contact
- 80-85% of schools participate
- 90-95% of those who complete school visit agree to home visit
- 75% of fathers participate
- 85% first choice comparisons
- 75-80% retention up to 8 years
- Methods replicated across multiple sites
Interventions

- Families underutilize formal interventions
- Want care that is individualized or family-based
- Support groups viewed as stigmatizing or unhelpful
- Families do not want to come back to hospital, but few community resources
- Limited research on acceptability of technology-based approaches

(Cherlin et al., 2007; Lichtenthal et al., 2011)
NUTRITION 101

In the class you'll learn:
Blair’s rivalry toward Dorrie hits a new level. Dorrie has trouble making healthy choices since she doesn’t know the nutrition basics.

Start class

The Class Reacts!

"Personally I’ve never been that interested in nutrition and healthy eating. But lately Devin and Blair have been getting to me. Devin’s all about his sports and high performance."
- Shatrac

"You might call me ‘The Nutritionista’. My parents own the Green Grocer so I’m up on all the latest nutrition facts."
- Blair

"In sports season, I’m always hungry. When I’m not working out, I’m working on a meal. I know about protein, but not much else."
- Devin

"Chips, jelly beans, and chocolate covered pretzels...I can’t ever eat just one. I love junk food...especially when stressing."
- Dorrie

"I’m with Dorrie on the Junk food...it’s the first thing I reach for when I get home from school. But lately I’ve been watching some cooking shows and trying new foods."
- Molly

"Who has time to think about food? I’m lucky to get to first period with matching socks."
- Jessie

Welcome!
This week’s assignments!
- Check out the home page.
- Complete class.
- Record your activities in Keeping Track.
- Check out the other folders.

Previously on Health-e-teen
In the last class you learned about the health-e-teen program and met the cast...

Coach's latest blog
The coach gives a thumbs up to smoothies...

What do you think?
What is your favorite food?
- Pizza
- Burgers
- Fries
- Pasta

Submit
Conclusions

• Community-based approaches are feasible and produce ecologically valid research findings

• Strategies can be successful across research topics and social/physical environments

• Partnerships require effort, need to be grown and maintained over time
Acknowledgements

Thank you to the schools and families who generously participated in this work

Thank you to collaborators:
- Hospital for Sick Children
- Vanderbilt University
- University of Colorado
- Dana Farber Cancer Institute
- Cincinnati Children’s Hospital Medical Center
- University of Wisconsin-Milwaukee

The National Institutes of Health and American Cancer Society
Questions