



Mixed-method Design in Community-Based Participatory Research

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Community-Based Participatory Research (CBPR)

CBPR grew from a long tradition of Participatory Action Research (PAR). According to Larry Green and colleagues, PAR is a "systematic investigation with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change."



CBPR developed because of research efforts that did not reflect the voices of those who were affected by the problem.

Family Nurse Care Coordination Partnership (FNCCP)

One of first Community-Based Participatory Research (CBPR), NIH funded grants

CBPR partnership is a diverse group of parents, nurses, and researchers who formed in response to the grant announcement, but had previously been involved in other community groups that addressed Children with Special Health Care Needs (CSHCN)

Study designed by the committee; partners articulated the research question, designed the intervention, and participated in the research.

Research Question: How do families get needed services for their children?

Goals are to improve care coordination among parents of children with special health care needs and nurses and teach parents how to navigate systems of care

Qualitative design supported the need for funding

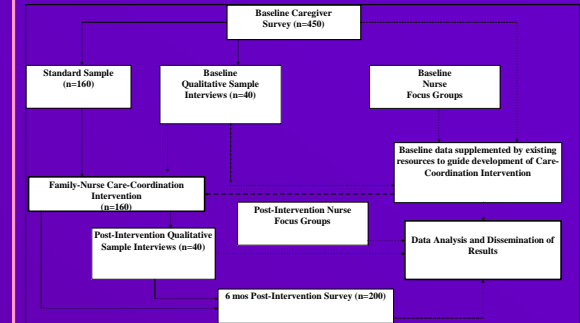
Building the Intervention

Intervention Development Team (I-Team) began in 2005 (pre-grant). Members built trust through open, honest communication. Both nurses and parents shared stories in a small group, semi-structured environment.

Nurse Focus Groups were small, informal, structured discussions about the basic tenants of family-centered care. Questions were identified by the I-Team and themes from analysis assisted in the development of the *Family Baseline Survey*.

Family Baseline Survey was a 25 question, phone survey which gathered data on how parents coordinated care for their child. SPSS data analysis was used to facilitate the development of a peer educator intervention, including teaching parents skills they reported not having.

Study Design



CBPR Partners

Natural group, who knew each other prior to coming together on grant

Investigators:

Parent and Advocate (Arc-Jacksonville)
Medical Anthropologist (DCHD/UNF)
Regional Nursing Director (CMSN)
Nurse and former care coordinator (UNF)
Research Associate (DCHD)

Stakeholders:

Parents of children with special health care needs

Nurses:

Care Coordinators with CMSN from 4 regional offices in Northeast Florida

"Families can navigate any system they have the opportunity to learn"

C. Temple, 2005

Intervention

Products

- Care Notebook
- Navigating Guide
- Peer-parent and nurse training series
- Resource Guide

Methods

- 90 minute semi-structured, pre-intervention parent interview
- 90 minute peer-parent visit
- Nurse Care Coordinator telephone follow-up

Evaluation

Intervention

- Nurse follow-up after peer-parent visit
- Nurse and peer-parent focus groups
- Post-intervention interviews with families
- Follow-up survey with families

Partnership Evaluation

- 30-60 minute, face-to-face interviews
- Partners were interviewed using 6 domains
- Asked to evaluate overall effectiveness of the CBPR process
- Will be used to evaluate future partnerships

CBPR: What did it do?

Improved the quality and validity of research

Enhanced the relevance and usefulness of research data for all partners

Joined together partners with diverse skills, knowledge, and expertise

Strengthened the research and program development capacity of partners

Aims to improve health and well-being of communities