Real Life Example: Nueva Vida Intervention

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Outline
1. Community-Academic Partnership: Nueva Vida Intervention
2. Engagement through Communities: Short and Long-term Benefits
3. Lessons Learned to Maximize Community-Academic Partnerships

Evolution of ‘Engaged’ Partnership

• Community-Based Organization: Nueva Vida
  – Successful program to address needs and improve quality of life of Latina Survivors and Caregivers
  – Trusted relationship with Latino families
• Academic Partner: Georgetown
  – Successful prior research with Latina breast cancer survivors
  – Significant interest in intervention research and engaging patients and families

Engaging Community-Based Organizations in Research

• Understand common goals
  – Improving quality of life
• Allow relationships to grow
  – First met in 2009
  – Submitted proposal in 2012
• Recognize expertise of community-based organizations from project inception

Team: Leveraging Connections

• Built upon existing relationships
  – SHARE (NY, NY)
  – Gilda’s Club New York City (NY)
  – Latinas Contra Cancer (CA)
• Recognize community expertise and input throughout process
  – Team, Design & Implementation
  – Engagement & Dissemination

Community-Based Organization Involvement
Proposal and Design Logistics

- Patient and Community partners involved in:
  - Formulating research questions & study design
  - Identifying eligibility criteria of participants
  - Making decisions about comparators and interventionists
  - Participating in and monitoring conduct of project
  - Helping to plan dissemination of results
  - Establishing reciprocal relationships, co-learning, trust, transparency

- Outcomes
  - Outcomes of common interest to patient partners, community organizations and research team

- Lead Time Critical
  - Biosketches, Review of documents, Budget

Nueva Vida Intervention

- Comparison (randomized controlled trial) between
  - Nueva Vida Intervention
  - Usual Services

- Focus to improve quality of life among Latina breast cancer survivors as well as their caregivers

Study Aims

Nueva Vida Intervention

- Survivor Group
  - Caregiver Group

  Gather together / Discuss topics

Implementation: “Research Democracy”

- 8 “talleres” (workshops)
  - 2 per month
  - 5 core topics
  - 3 topics: “Research Democracy”

  Stress Management
  Improving Communication
  Spirituality and Cancer
  Balancing Physical and Emotional Needs
  Anger Management
  Intimacy after Cancer
  Trauma and Cancer
  Role Changes
  Understanding Distress
  Myths and Cancer

  Including Others in Helping Caregivers
  Putting Our Lives in Order

Engagement & Dissemination: Equal Input

- Engagement Strategies:
  - Phone calls, scheduling
  - Birthday cards, postcards
  - Twice monthly site check-ins
  - Monthly team phone meetings
  - Annual in person team meetings
  - “Think aloud” technique
  - Polls / Surveys

- Dissemination:
  - Community Meetings
  - Newsletters
  - Webinars
  - Post-Intervention Parties
Benefits of Partnerships

- **Short-term:**
  - Greater relevance
  - More likely to address true needs
  - Increased awareness of a community’s:
    - Strengths / Expertise
    - Services / Resources
  - Greater proposal appeal
- **Long-term:**
  - Increased capacity
  - Greater likelihood for dissemination / impact
  - Expanded (and strengthened) collaborative relationships

Challenges to Partnerships

- **Implementation subtleties / less “internal validity”?**
  - Greater external validity / real-world research
  - Rich diversity in patients and caregivers
- **Ready to listen carefully and share decisions?**
  - Recognize greater salience to patients, family & community
  - Provide infrastructure support and training as needed
  - Plan on additional effort that may be needed for reaching some participants (e.g., caregivers)

Lessons Learned: Researcher

- Recognize value of community-based organizations in generating, partnering and sustaining research.
  - Be receptive to what is already being done by patients or in the community.
  - Keep needs of patients and families as a priority.
- Use a democratic approach to decision-making.
- Set a culture of open communication.

Lessons Learned: Researcher

- Spend time educating team members about the study process.
- Offer training that meets partners’ needs.
- Be prepared for a potentially higher administrative burden.
- Be flexible.

Lessons Learned & Taught: Community

- Appreciate the time and focus needed for research, including IRB.
- Practice patience (we want answers yesterday, but research provides important information).
- Stay involved in the entire process (not just learning the results).

Lessons Learned & Taught: Community

- Learn how to bring topics, ideas back to the team (relevant on both sides)
- Remind all involved to keep in mind the ‘whole picture’ and ‘whole patient.’
- Be willing to listen, even if something seems ‘minute.’
Lessons Learned & Taught: Community

• Appreciate that research truly helps move things forward.
• Experience increased joy to see how the researchers ‘get it.’
• Create a community so that all perspectives are elicited and respected.

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Research Plan Decisions

• Participant Eligibility (decision = broad)
• Design / Methods
  – Many phone calls to discuss:
    • Usual Care (decision = typical services offered)
    • Intervention (decision = compromise delivery schedule)
    • Interventionist Qualifications (decision = broad)
• Outcomes
  – Outcomes of common interest to patient partners, community organizations and research team