COMMUNITY ENGAGEMENT TO HELP SUPPORT CANCER SURVIVORS IN COLORADO

Examples in two rural Colorado communities

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Engaging Communities in Education and Research Conference
October 14, 2016
OBJECTIVES

- Describe how Boot Camp Translation has facilitated community engaged research/interventions

- Review 2 case studies of how BCT has been used in community-academic partnerships at UCD to enhance translational research
RURAL EASTERN COLORADO: ¡SURVIVE
Goal: develop, implement and evaluate a curriculum to educate primary care practices about emerging knowledge in cancer survivorship.

Especially important in rural communities, where fewer cancer-specific resources are available.

Early in grant writing process, PI team approached the High Plains Research Network (HPRN) leadership: Is this feasible/of interest?

- Rural, primary care Practice Based Research Network in Eastern Colorado
- 16 counties (64 total in state)
- Strong tradition of academic-community partnership and projects in health
THE HPRN COMMUNITY ADVISORY COUNCIL

- Existing partnership of individuals, all from communities in eastern Colorado
- Not necessarily health backgrounds: farming, ranching, small business, teachers, retired…….
  - Experts in their communities
- Discuss important health topics/concerns in their communities
- For this cancer survivorship project, core group added few more members with relevant experience (ie individuals with a history of cancer, those who work with cancer patients (ie chaplain))
STEPS TO PARTNERSHIP

- Idea presented to the HPRN-- known prior work with colon cancer testing
- HPRN C.A.C. agreed the project could meet a need for practices/patients in their communities
- Letter of support from HPRN C.A.C. in grant submission process
  - Grant submission includes specific consultant roles for HPRN “Working group”
  - Budget line item
- Once funding awarded (2012), primary care PI (Dr. O) attended HPRN meeting to present details/refresh memories
  - PI learns more about HPRN/communities, interests in topic on a more granular level
- Cancer Survivorship C.A.C. formed (see previous slide)
  - Include PCP, oncology nurse, cancer survivor, chaplain
PARTNERSHIP IN ACTION!

・“Boot Camp Translation” implemented in 2013-2014
・Multiple opportunities to meet in person and over the phone
・C.A.C. members develop expertise in cancer survivorship
・Didactics + Interactive discussions
・Took place as curriculum just starting to be developed
・This was a primary modality by which key messages and themes developed

Question: What do you believe the primary care practices in your community need to know to better support individuals with a history of cancer? What themes resonate with you/your community?
PARTNERSHIP IN ACTION--RESULTS

A. New **identify** for the project: iSurvive

B. Key **themes and messages** *identified as learning points* to be included, along with research-based evidence

C. In-person **case vignette scripts modified**:
   - Brief case details (no jargon!), followed by discussions:
     1) “Patient perspective”
     2) “Provider/practice perspective”
     3) “What the evidence tells us”

D. There needs to be a **resource for the patients!**........
iSURVIVE SERVICE MANUAL

- Messaging and content selected by C.A.C.
- Initial message/letter from the C.A.C.
- Call-outs for patients and for providers
- Based on concept of car/tractor manual
THE SAN LUIS VALLEY: “GREEN IS THE COLOR OF HOPE”
Completion of ACS Study on Cancer Survivorship in the SLV, June 2015

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In person mtg, March 2016
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- Hiatus.................

In person mtg, July 2016
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- In person mtg, Sept 2016.............
Cancer Survivorship is important, from multiple perspectives

Resources: “We have that resource here, but…”

The “Black Hole” of Medical Information Transfer

TS/SCPs are a good idea, but not sufficient alone

Issues of stigma

There are many strengths in the SLV that could be leveraged!
OUR BCT KICK-OFF THEMES

- Cancer is a trigger for changes in relationships---with others, with providers, with self
- Information is important, but needs to be tailored/made meaningful to all users
- Resources available may not be “one size fits all”
- Logistical/practical barriers are ever present
- How do we promote a sense of “volunteerism” and community support—*not just money, but time*
- It’s important to know what to expect (over time); people may begin to lose confidence in what is normal versus what is “abnormal”
- Spiritual influences highly acknowledged

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HONING IN ON ISSUES:

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Individuals need to know what to expect next in their journey.

Important to know who to call after the visit—empower survivors to cope/troubleshoot.

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Trustworthy sources of cancer information:
- Books
- CDs
- Support Groups/Counseling resources
- Financial information
- Blank, lined journal
- Phone numbers
- Medical liaison as source of information—concept of triage line emerges

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1) Phone numbers/who to call
2) Listing of books/resources to read
3) “Next steps”/what to expect symptom wise
4) Treatment options
5) Prognostic information/success rates of treatment—gives hope
6) Transportation info
7) Cost/financial information
8) Listing of holistic resources, info on supplements
9) Listing of supportive/counseling resources/caregiver resources
10) Nutrition support
**HOW DO WE PUT THIS INTO ACTION?**

- **Main themes:**
  - Team approach is necessary
  - Document needs to be a *living document*
  - Education: patients and providers

**Timeline:**

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WHAT IDENTITY DO WE WANT FOR THIS WORK?

EXAMPLES:

- “There is Hope for Tomorrow for Cancer Survivors”
- “Cancer Care for the SLV: Your Regional Guide to Living and Surviving Cancer”
- “You, Hope and Cancer in the SLV”
- “Survivorship Guide to Help You Cope with Cancer”

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San Luis Valley Cancer Companion: Hope for Tomorrow
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My San Luis Valley Cancer Companion: Hope for Today

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NEXT STEPS

- Getting feedback/vetting on guiding concepts
- Create a mock up of Cancer Companion
  - “El verde es el color de la esperanza”
- What does the process look like to get to patients?
  - Who customizes the information for patients?
WHAT COMMUNITY ENGAGEMENT ADDS

- In R25, in-person curriculum format was significantly changed; title itself changed!
- Additional resource (Service Manual) for primary care practices in HPRN practices; preparing a Companion Guide for those living with cancer in the SLV
- Increasing community expertise around topics of interest
  - Community support
- Language that is understandable, concepts that are relevant
THANK YOU!!

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