Opportunities and Challenges of Conducting Oncology Research in Appalachia

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Discuss opportunities/value of conducting research in Appalachia
Describe key challenges in conducting research in Appalachia
Examine ways to address key challenges from an oncology study
What is the value of conducting research in Appalachia?

• Access to a unique underserved population
• Opportunity to address great health disparities
  • Cancer illness and death rates in Appalachia exceed US averages
• High prevalence of chronic disease and co-morbidities support sample availability
  • Hazardous work environments, unhealthy lifestyle, nutritional deficits
• Opportunity to create knowledge that addresses a real-life need
What is the value of conducting (oncology) research in Appalachia?

- High prevalence of poor health habits
  - Limited knowledge at baseline
    - room to improve
- Limited access to care are significant in rural areas, including Appalachian cancer care
  - Underutilization of health services
    - can focus on increasing use
- Health Professions Shortage in many areas
  - can show impact of providers
- Statewide clinical trials networks - implemented with electronic medical record connections
Challenges: Research in Minority Populations

1. Reluctance to participate in research - trust issues
2. Difficult access in (rural) communities
3. Technology barriers in (rural) communities
4. Cultural-related issues
5. Low (health) literacy
6. Possibility of receiving placebo or adverse side effects
7. Time commitment & fear of costs
Reluctance to participate in research - trust issues

• Patients and families needed more than one visit from research nurses - wanted us to talk with “key” family members
  - Did not want to “bother” others
  - Perception did not need as had “family”

• Solution: Cards with information printed and left with patient; nurse introduced researchers to patient; research nurses made return visits when family would be present; involved family in monitor use/eval; enrollment of patients through cancer center nurse introduction
Difficult access in (rural) communities

- Finding homes (mountains esp. difficult)
  - rural areas had gravel/mud roads without street signs
  - little availability of Global Positioning System (GPS) mapping directions
  - navigable only by 4-wheel drive vehicles

- Solution: obtain detailed directions from patients at time of consent - essential
Technology barriers in (rural) communities

- Patient homes with landline phone connections had successful transmission of data - less than half of eligible sample
- Originally-provided telemonitor GPRS system had limited data service
  - only able to connect from an urban/suburban setting

Solution: Newer telemonitors - new carrier with greater service coverage : connected from remote rural mountain areas.
Cultural-related issues

• Patient (and family) perception ≠ Physiologic data
  - Participants perceived oxygenation to be less severe than indicated by pulse oximeters
  - Symptoms of pain, appetite, and dyspnea changed rapidly - “not complaining/bother”

• Solution: Monitors collected symptom data as well as physiological data;
  - Use of motivational interviewing/nurse coaching - use more often if they identified changes at times other than scheduled
Low (health) literacy

- Majority of participants were not able to complete study survey forms
  - Illness limited stamina
  - Health literacy limitations

Solution: Standardized nurse-administered verbal data collection for diary records was instituted; alternate sources of information were identified and used to validate data (health records, family, Medicare EOB)
Possibility of receiving placebo or adverse side effects

• Drop-out rate higher in control group after randomization
  - First visit in hospital for consent and then T1 data collection
  - 2nd visit in home for data collection and informed as to usual care with 3 more visits or telemonitor to be left in home for 14 days

• No direct solution - did obtain consent from most of the patients who dropped out to allow continued access to record data
Time commitment and fear of costs

- Less willingness to participate among eligible rural patients living in poverty as indicated by Medicaid as primary payer -
  - There seemed to be no financial benefit or improved care without telemonitor
  - Worry about replacement of damaged (e.g., dog) equipment

- Possible solution: consent changes/insured; graduated incentive payment system to offset financial limitations for patient participation
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