Addressing the Challenges of Research Study
Recruitment among People Coping with HIV/AIDS and Cancer

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Conflict of Interest

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- No Conflict of Interest
The Scourge of HIV/AIDS

- 1981 CDC’s Morbidity & Mortality Weekly Report
  - Pneumocystis carinii pneumonia (PCP) and immune system problems
  - Associated Press, LA Times, San Francisco Chronicle cover MMWR
- Physicians flood CDC
  - Reports of opportunistic infections among gay men
  - Reports of aggressive Kaposi’s Sarcoma
  - By end of 1981, 270 cases of severe immune deficiency among gay men and 121 had already died.
- 1987 - AIDS Coalition to Unleash Power (ACT UP) founded
  - Activism to find ways to prevent and cure HIV/AIDS
  - Political model for other diseases

Rapid Progress against a Lethal Disease

- 1983 Montagnier reports discovery of retrovirus as possible cause of AIDS
- Today, Combined Antiretroviral Therapy (cART) has converted HIV/AIDS from a fatal to a more chronic disease
- Earlier administration of cART in the disease process has further enhanced survival
Today: PLWHA and Diseases of Aging Process

- People Living with HIV/AIDS (PLWHA) now living to encounter diseases of aging process
- Earlier onset, higher incidence, & lesser response of many cancers
  - Compromised immune system
  - Chronic inflammation
  - cART's stress prematurely ages the body
  - cART compromises organ systems

Today’s Research Needed to Resolve Treatment Challenges of Co-Morbidity

- RESULT: Clinicians caught off guard
- PLWHA sent to HIV/AIDS centers after initiation of cancer therapy endangers HIV/AIDS patients
- Co-morbidity treatments
  - cART cocktail + chemotherapy + radiotherapy + surgery
- Finding optimal combinations and doses
- Finding optimal therapeutic order
- Finding optimal management of sequelae
Surprisingly Slow Study Accrual for PLWHA

Today’s research participation rates for the community that set the legendary standards for scientific activism and engagement is suddenly looking like all other minority communities.

Goal of Current Qualitative Study

- Explore why PLWHA are not joining cancer research studies
  - What has changed among PLWHA?
  - Are old strategies failing? Not being used?
- What new strategies can we try?
  - Do today’s PLWHA need different recruitment strategies?
  - What new strategies can be tested?
- Define outcome measures to evaluate new strategies’ effectiveness in increasing accrual of PLWHA to cancer studies
7 Questions Guiding Focus Interviews & Groups

1. Accrual to HIV/AIDS studies has slowed. What explains this?
2. Recruiting PLWHA and cancer to research studies is especially challenging. What factors contribute to this?
3. What changes might increase accrual of PLWHA to cancer studies?
4. Have PLWHA changed their views toward research studies?
5. Have studies become less attractive?
6. What else should we know about PLWHA that would help us increase participation in cancer clinical trials?
7. Anything else we should know about this challenge?

Methodology (continued)

- Focus Interviews first
- Focus groups second
  - Recorded
  - Transcribed
  - Coded and analyzed with Dedoose software
- Participant recruitment
  - Word-of-mouth
  - Flyers in clinics
  - Calls from clinicians
- Participants IRB-consented for study and recording
Sample Description

- Unique study participants (N = 69)
  - Focus interviews with guided survey questions (n = 45)
    - HIV/AIDS alone (n = 20)
    - HIV/AIDS + cancer (n = 25)
    - Men (n = 43) + women (n = 2)
  - Focus groups (n = 45)
    - Retained original focus interview participants (n = 21)
    - New study additions (n = 24)
  - Cancer status
    - HIV/AIDS alone (n = 32)
    - HIV/AIDS + cancer (n = 13)

Results: Dedoose Cloud
### Surprise Examples of Lead Topic Categories

- HIV/AIDS patients’ poor accrual to cancer clinical trials due to:
  - “HIV is not a problem any more”
  - "PLWHA wish to avoid stigma of HIV/AIDS”
  - “Transportations issues”
  - “Insufficient education”
  - “Insufficient advertisements”

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### Next Steps: Community Partners Help Select Identified Issues to Address

- **Community's Issues**
  - Essential education and enlightenment for PLWHA
  - Essential education and partnerships with community oncologists

- **Researchers’ Issues:**
  - Transportation, cost, and incentive barriers
  - Privacy and stigma
  - Greater dissemination of open studies
  - New strategies are needed to reach today’s PLWHA

- **Clinicians’ Issues**
  - PLWHA are not typical cancer patients
  - Research partnerships with community oncologists
Conclusion

- Premature aging of the community of PLWHA makes this an issue of ultra high importance.

- It is one that must be resolved swiftly if we are to avoid an unnecessary additional burden of illness and distress.

Questions?

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