

Finding sexual minorities with cancer: What are the options?

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How do we identify disparities in cancer?

- SEER is the basis
- Other registries growing in importance
- Together form a “national” picture of cancer incidence, treatment, outcomes
- Recent disparities examples include language preference among minority cancer patients, follow-up quality by race/ethnicity

Why cancer disparities in sexual minority women and men?

- Hints in the literature that disparities exist
- Most data from surveys, imperfect
- Good stage to bring these hypotheses to light

Example: SMW and breast cancer

- Evidence that breast cancer risk factors differ among SMW categories
- May lead to incidence differences
- Culprits include both primary and secondary prevention
- Little known about treatment factors, but hypothesize poorer care

Registries not likely aid

- Most registries do not contain sexual orientation
- Sexual orientation not included in most medical records
- Hard to quantify incidence without this

Holly et al., 2002

- Creative use of existing data for nonparticipants
- Homosexual definition = HIV positive, single, age less than 55, living in gay neighborhood
- Adding “homosexual” nonresponder men identified underreporting

Kavanaugh-Lynch, et al, 2002

- Used existing case-control study to compare breast cancer risks between lesbians/heterosexuals
- Lesbian defined as no male sexual partners ever; never married and not using contraceptives; not currently married and no contraceptives
- Risk higher in all three “lesbian” types

Dibble & Roberts, 2000

- Comparison of heterosexual and lesbian cancer rates over time at community clinic
- Found higher incidence among lesbians
- Sample non-population based, with major demographic differences between groups

Critique of this literature

- Not exact definition
- No “disease” for women
- Clinics not population based

Where are we?

- Need for good methodology is clear
- Opportunity to collect sexual orientation data and compare incidence
- What are the problems here?

Barriers to SO collection

- Do we have measures of this variable?
- Will women complete items?
- Do we have adequate means of data storage/protection?

Valid measures? Maybe...

- Three pronged definition of SO (behavior, label, desire)
- Work at NCHS to improve question wording, phrasing
- Use in national surveys

Women can and will complete items

- Large national sample of older women (n=150K), measured behavior, found risk factor differences (Valanis et al, 2002)
- Large national sample of women (n=90K) measured label, found some differences (Case et al 2004)
- Small probability sample surveys (Diamant 2000, Bowen, 2004) measured both, found risk factor differences
- Minor missing data in all studies

Next research steps

- Special study for SEER
- Inclusion of SO in standard medical record demographics
- Inclusion of SO into ongoing research projects and surveys
- Tracking of sexual minorities in studies

Next research questions

- Risk factor comparisons among SO categories
- Estimates of incidence, prevalence
- Comparisons of treatment decisions, care, follow-up, and survival