

Understanding and developing approaches for addressing differential follow-up among Asian and Hispanic cancer cases

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Background

- Cancer survival and mortality statistics derived from population-based cancer registry data provide important measures for cancer control
- Quality of these statistics depend on completeness of follow-up data
- Follow-up has been documented to be less complete for some population subgroups, including Hispanic and Asians/Pacific Islanders (API)



Objectives

1. Develop a thorough understanding of current registry follow-up practices
2. Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics
3. Identify plausibly missed deaths and conduct subject tracing to track them
4. Develop recommendations to:
 - a) improve the quality of follow-up data, and
 - b) analytical approaches for addressing differential follow-up



Methods

- Study conducted in the context of the California Cancer Registry
 - 72% of SEER's Hispanic population
 - 66% of SEER's API population
 - 10 regional registries, 1 central state registry
- Specific methods described with each objective



Results: Objective 1- Develop a thorough understanding of current registry follow-up practices

- Administered Qualtrics survey to regional and central registries (N=5 operational units that cover 10 regional registries)
- Results:
 - Does registry perform active follow-up?
 - All responded YES
 - Types of active follow-up?
 - Calling physician offices, hospitals, and treatment centers for follow-up data, emphasis on pediatric cases;
 - Producing lists of delinquent patient follow-up for non-ACOS hospitals;
 - Coordinating follow-up data collection through physician office visits;
 - Including vital status information requests with SEER POC study communications to physician offices; and
 - Using subject tracing techniques as a last resort to find current information about a case.



Results: Objective 1- Develop a thorough understanding of current registry follow-up practices

- Results, continued:
 - Does registry perform additional linkages?
 - Most responded NO
 - Does registry receive follow-up info from research studies?
 - YES (n=2), NO (n=3)
 - Does registry conduct subject searching?
 - YES (n=2), NO (n=3)
 - Is registry experiencing challenges in data completeness relating to outpatient physician groups?
 - YES (n=4), NO (n=1)
 - Challenges include MDs who are reluctant to provide info, timeliness



Results: Objective 2- Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics

- Examine percentages (%s) and relative odds of patients lost to follow-up

Associations of race/ethnicity with incomplete follow-up, California Cancer Registry, cases diagnosed 2000-2009

Race/ethnicity	Total N patients	% with incomplete follow-up	Relative odds of incomplete follow-up
NH White	523,685	1.9%	1.0
Hispanic	134,082	8.9%	5.0 (4.8-5.1)
API	77,191	5.9%	3.2 (3.1-3.3)

Incomplete follow-up = cases who are alive and date of follow-up 2+ years or more prior to 12/31/2012



Results: Objective 2- Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics

Associations of race/ethnicity with incomplete follow-up, California Cancer Registry, cases diagnosed 2000-2009

Race/ethnicity	Total N patients	% with incomplete follow-up	Relative odds of incomplete follow-up
NH White	523,685	1.9%	1.0
Mexican	36,481	14.3%	8.5 (8.2-8.8)
South/Central Am	10,854	11.2%	6.4 (6.0-6.8)
Cuban	1017	1.2%	0.6 (0.3-1.1)
Puerto Rican	687	2.3%	1.2 (0.7-2.0)
Other Hispanic	85,043	6.5%	3.5 (3.4-3.6)
Filipina	21,990	5.8%	3.1 (2.9-3.3)
Chinese	21,321	5.9%	3.2 (3.0-3.4)
Japanese	8309	4.2%	2.2 (2.0-2.5)
Vietnamese	7196	4.9%	2.6 (2.3-2.9)
Korean	5944	6.3%	3.4 (3.1-3.8)
South Asian	4952	9.9%	5.5 (5.0-6.1)
Other Asian	7479	6.6%	3.6 (3.3-3.9)

Incomplete follow-up = cases who are alive and date of follow-up 2+ years or more prior to 12/31/2012

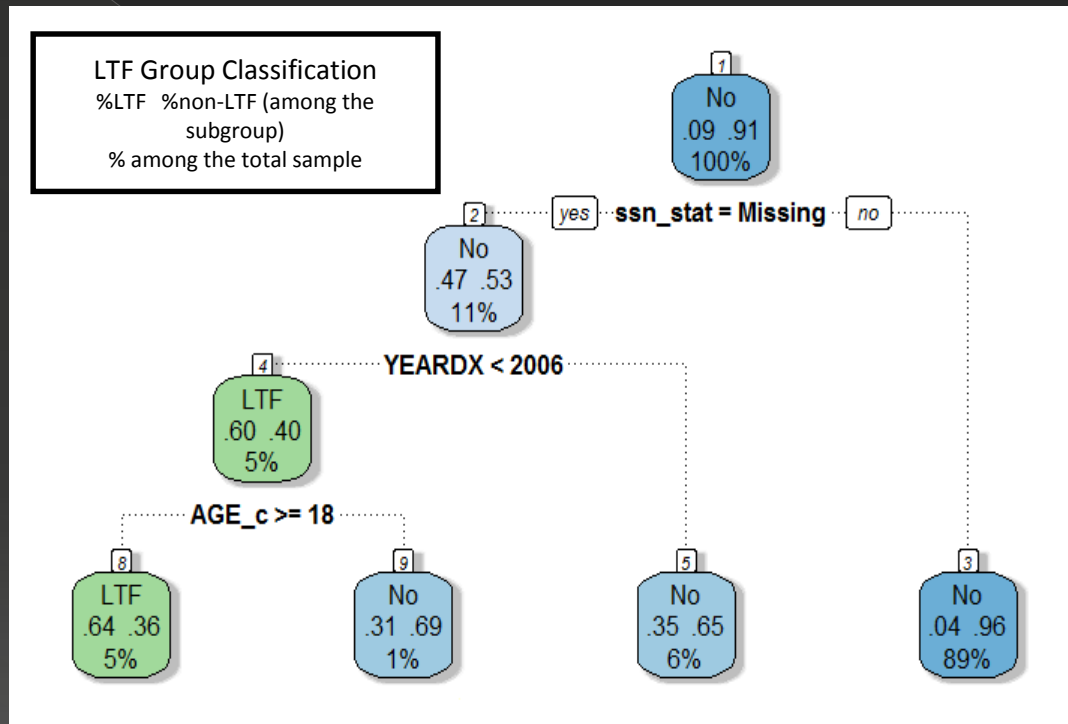
Results: Objective 2- Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics

- Multivariable model among **Hispanics**, incomplete follow-up associated with:
 - Unknown social security number (SSN)
 - Being Mexican and “other Hispanic”
 - Male
 - Foreign-born
 - Lower neighborhood SES
 - Residence in ethnic enclave neighborhoods
 - Unknown marital status
 - Payer source = uninsured, Medicaid, unknown
 - Advanced stage



Results: Objective 2- Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics

- Recursive partitioning analysis, **Hispanics**



Tree node/subgroup	% of total sample	% lost to follow-up
3. Known SSN	89%	4%
5. Missing SSN; yr dx 2006 or later	6%	35%
9. Missing SSN, yr dx prior to 2006, age < 18	1%	31%
8. Missing SSN, yr dx prior to 2006, age \geq 18	5%	64%

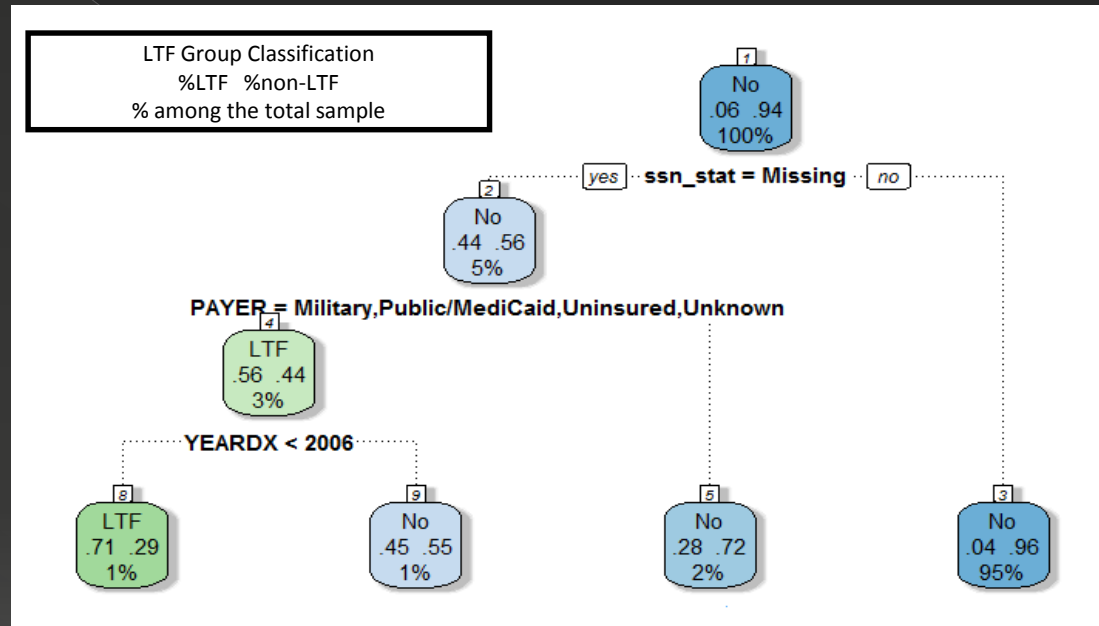
Results: Objective 2- Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics

- Multivariable model among **APIs**, incomplete follow-up associated with:
 - Unknown SSN
 - Being Japanese, South Asian, “Other Asian”
 - Foreign-born & unknown birthplace
 - Higher neighborhood SES
 - Unknown marital status
 - Payer source = uninsured, Medicaid, military/VA, unknown
 - Advanced stage



Results: Objective 2- Evaluate follow-up results by race/ethnicity, birthplace, and disease characteristics

- Recursive partitioning analysis, APIs



Tree node/subgroup	% of total sample	% lost to follow-up
3. Known SSN	95%	4%
5. Missing SSN; private, Medicare health ins	2%	28%
9. Missing SSN; military, public/Medicaid, uninsured, unknown health ins; yr dx 2006+	1%	45%
8. Missing SSN; military, public/Medicaid, uninsured, unknown health ins; yr dx<2006	1%	71%

Results: Objective 3- Identify plausibly missed deaths and conduct subject tracing to track them

- Cases diagnosed 2000-2009 in the Greater Bay Area Cancer Registry that were lost to follow-up
 - n=1,740 Hispanic
 - n=1,458 API

	N	% among traced cases
Traced cases	3198	100%
New info found	839	26.2%
Lexis-Diligence only	224	7.0%
MasterFiles only	327	10.2%
Lexis-Diligence & MasterFiles	288	9.0%
No new info found	2359	73.8%
Time spent tracking (min)		Mean min per case
Lexis-Diligence	3741	1.17
MasterFiles	3917	1.22

Results: Objective 4- Develop recommendations

- Active follow-up increasingly more difficult for registries
- Subject searching increasingly difficult given privacy guidelines, with little yield for rather intense effort
- Explored and developed recommendations for analytical approaches to address differential follow-up



Results: Objective 4- Develop recommendations

- We suggest a range of sensitivity analyses to examine the potential impact of differential follow-up on relative survival differences comparing foreign-born to US-born:
 1. In the group being compared (i.e., foreign-born), assume that all those lost to follow-up are deceased.
 2. Depending on the cancer site and mortality rates by stage, in the group being compared (i.e., foreign-born), assume that among all those lost to follow-up, only those with poor-prognosis stages are deceased.



Results: Objective 4- Develop recommendations

Sensitivity analyses – continued:

3. Assume that all cases who are lost to follow-up in all groups being compared (i.e., foreign-born and US-born) are deceased.
4. Assume that among all cases who are lost to follow-up in all groups being compared (i.e., foreign-born and US-born), only those with poor-prognosis stages are deceased.



Results: Objective 4- Develop recommendations

Sensitivity analyses – continued:

- Examine the range of relative survival estimates from the four scenarios above to the original survival estimates.
- We urge users of the data to be cautious about drawing conclusions without careful assessment of these biases.



Results: Objective 4- Develop recommendations

We further suggest that, in the context of linkages, it may also be worthwhile to:

1. explore strategies for linkages in the absence of an SSN; and
2. while deterministic linkage is the current standard, for cases lost to follow-up, take additional effort to manually review records of high probability in linkages (e.g., linked on several identifiers (names, date of birth)).

This work emphasizes the value of patient SSNs in cancer registry data, and provides support for its continued collection in reporting facilities.



Thank you!

Questions? Comments?



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