



SLAITS
State and Local Area Integrated
Telephone Survey



Methodological issues with adding questions quickly to an on-going survey of children with special health care needs

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Standard disclaimer



- The words and opinions expressed and represented herein are mine, and do not necessarily reflect the thoughts & opinions of:
 - Department of Health & Human Services (DHHS)
 - Centers for Disease Control & Prevention (CDC)
 - National Center for Health Statistics (NCHS)
 - State and Local Area Integrated Telephone Survey Mechanism (SLAITS)
 - Health Resources & Services Administration (HRSA)
 - Maternal and Child Health Bureau (MCHB)
 - National Opinion Research Center (NORC) at the University of Chicago



Agenda

Section 1

Random Digit Dial (RDD)

telephone surveys & disasters:

- Stimulate & broaden our thinking collectively
- What else *could* happen?
- RDD telephone surveys have been used successfully
 - Behavioral Risk Factor Surveillance System (BRFSS)
(9/11, Oklahoma City, flu vaccine shortages, mental health status post-disaster, emergency preparedness [M. Link presentation, 9th Health Survey Research Methods Conference, March 3, 2007, Atlanta])
 - mental health studies conducted in NYC after 9/11
(New York Academy of Medicine, Columbia University, Mt. Sinai School of Medicine, Florida State University, Medical University of South Carolina, SRBI, Inc.)



Section 2

Brief case study:

- Pre-event status
- Precipitating crisis
 - Calculation of population control totals



Section 3

Next steps:

- Take-home messages
- Must incorporate a multidisciplinary approach to ensure success
 - Statistics
 - Disaster research
 - Emergency / first responders
 - Bioterrorism / terrorism
 - Mathematics
 - Survey methodology
 - cognitive, social science aspects: survey participation, response formulation
 - sampling, statistics, modeling aspects: mandatory containment policies & how they impact availability, mode choice, staff availability, and survey response; social contact networks, attack rate, natural history of disease (for infectious agents), systems biology, etc.



Section 1

RDD telephone surveys &
disasters





Very little data...

- Almost all articles were topical in nature
 - Physical & mental health impacts of disaster: GI symptoms, heart attacks, PTSD, anxiety, depression, 'unexplained symptoms', coping with stressful events
- Not much at all re: survey methods
 - A few articles re: logistical aspects, ethics of post-disaster surveying (IRB concerns, approval)
 - A few articles on response to surveying post-disaster, still focused on mental health (mainly PTSD)
- More articles re: statistical applications
 - Modeling, simulation & infectious disease (pandemic flu, transmission models, etc.)



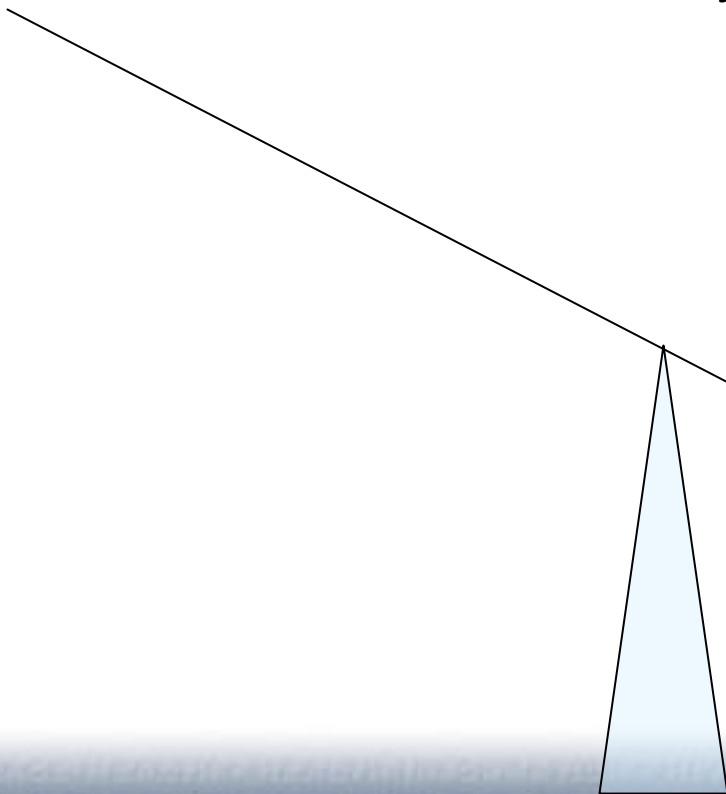
- “Continuity of Operations”
- “Continuity of Government”
 - Practical, but somewhat unsatisfying
 - Could develop elaborate plans to address all elements—is this realistic to refer to if it is a huge document?
 - Nothing re: data & surveys
 - Except they usually do recognize the need for and complexities of collecting data in strenuous conditions
 - Not much help re: how or how to adjust estimates
 - ‘Any data is better than no data at all (no matter how bad it is)?’



**How to balance competing data priorities??
Are they all equal?
If not, which one should yield?**



Timeliness, relevance, utility



Accuracy
(sacrificed?), Look at the data first and ask questions later—ex.) methods reports/data users requests (in good times, much less the bad)



Concerns

- External & internal validity
- Reliability
- Security, confidentiality, privacy
- How might these issues vary across subpopulations?
- Burden of participation
 - Those who survived a disaster or disruption may constitute a small group, to then be targeted by multiple researchers?! Each with his/her own research question(s) of interest....



Additional concerns



- Sampling, recruitment
- Selection bias
- Data analysis, interpretation
- Generalizability?
- Small sample sizes?
- A 'new' nuance for the terms 'non-response', 'disposition codes', 'response rate calculations', 'resolution rate'?
- Bias
- All in the absence of well-defined 'norms' since a disruptive situation is not normal by definition



Additional concerns

- Labor intensive, time consuming, expensive anyway (even without a disruption)
- ERB & OMB clearances – logistics
- How do you plan for situations in which different parameters may be impacted at once, or different parameters may be impacted with each situation?
- Infrastructure damage, geographical distribution, dispersion of population in response
- How does one plan ahead to consider all possibilities re: adjustment?



Partial solution?

- Can statistics and survey methodology help ameliorate some of these issues??
- Decrease the vulnerability of survey systems to 'shocks', and ensure the production of reasonably sound statistics after an event?



The 2005 Gulf Coast hurricanes *were* *very important events..*

but other adverse events can disrupt your surveys—
are we prepared to deal with the survey disruptions?

- Focus on Katrina: massive storm, temporal issue
 - Logistical issues: not just disruptive to the respondents *but to the staff as well*





Potential survey disruptions



- Infectious disease outbreaks, biological hazards or release
- Deliberate or accidental transmission:
 - Pandemic / avian ‘bird’ flu
 - *E. coli*, *Ebola*, *Smallpox*, *Salmonella*, *Cryptosporidiosis*, Severe Acute Respiratory Syndrome (SARS), anthrax, West Nile Virus
 - Extreme Drug-Resistant Tuberculosis (XDR-TB) deemed ‘virtually untreatable’ by the World Health Organization



Potential survey disruptions



Natural disasters:

- Avalanche
- Drought
- Earthquake
- Extreme heat or cold
- Fire, wildfire
- Flood, flash flood
- High winds, sand storm
- Tropical storm
- Hurricane
- Glacier, iceburg
- Landslide, mudflow
- Snow, blizzard
- Thunderstorm, lightning
- Tornado
- Tsunami
- Volcano
- Famine



Potential survey disruptions



Technological, man-made disasters:

- Airplane crash
- Enemy attack, war, sabotage, strike, insurrection
- Building, structure collapse
- Chemical, hazardous materials / substance release
- Civil unrest, massive riots
- Critical infrastructure failure
 - Telecommunications
 - Computers / internet (cyberthreat)
 - Electrical power, gas, oil, coal, nuclear
 - Transportation (highways, airports, buses, trains)
 - Water supply, sanitation

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Potential survey disruptions



- Explosion (conventional, dirty bomb)
- Maritime
- Mass immigration or public gathering
- Mine collapse, explosion
- Radiological, nuclear release
- Terrorist attack (multiple methods)



The track record of RDD surveys in disasters....not bad!



- Same reasons we use them in non-disaster situations: efficient, timely, representative samples, centralized call centers (usually—problematic with a disease outbreak though...), flexibility with sample ‘replicates’—can turn on and off in a localized manner if needed
- RDD surveys have successfully been used in ‘urgent’ situations in the past...
 - Australia: food-borne disease outbreaks (*Salmonella*), ‘BRFSS-like’ survey
 - used to find and maintain a bank of control cases for case-control studies
 - Kirk M, Tribe I, Givney R, Raupach J, Stafford R. Computer-assisted telephone interviewing techniques. *Emerging Infectious Diseases* 2006;12;4:697-6983.
- BRFSS:
 - Kansas: Acute infectious disease outbreak
 - Fox LM, Banez Ocfemia MC, Hunt DC, Blackburn BG, Neises D, Kay Kent W, Beach MJ, Pezzino G. Emergency survey methods in acute *Cryptosporidiosis* outbreak. *Emerging Infectious Diseases* 2005;11;5:729-731.
 - 9/11, mental health impacts
 - Influenza vaccination shortage
 - California Earthquakes, mental health impacts



Section 2: CASE STUDY

2005 – 2006

National Survey of Children with
Special Health Care Needs





NS-CSHCN

- Second iteration (first conducted: 2001)
 - Prevalence of children with special health care needs (CSHCN)
 - 0 to 17 years in each state & DC
 - Characterizes:
 - health and functional status
 - types of services they need and use
 - shortcomings in the system of care (unmet needs)
- Basis for Federal and State program planning efforts





Methodology

- RDD telephone survey, complex design
- National Immunization Survey (NIS) sampling frame
 - State and Local Area Integrated Telephone Survey mechanism (SLAITS)
- Fielded April 2005 – February 2007
- Sample = 850 CSHCN/state & DC; referent sample of 6,000



Methodology

- KP (parent/guardian) reported data
- Detailed questionnaire administered to KP about one randomly selected child per HH

Household telephone survey of parental reports of health status and behaviors *without medical record or administrative data validation re: the NS-CSHCN portion*



Why we ♥ this survey

(a few selected examples)



- ***No other data source can provide this breadth of information at these levels***
- Provides **uniform comparable** CSHCN data allowing multiple levels of comparison (state, region, national)
- Critical subpopulation of interest



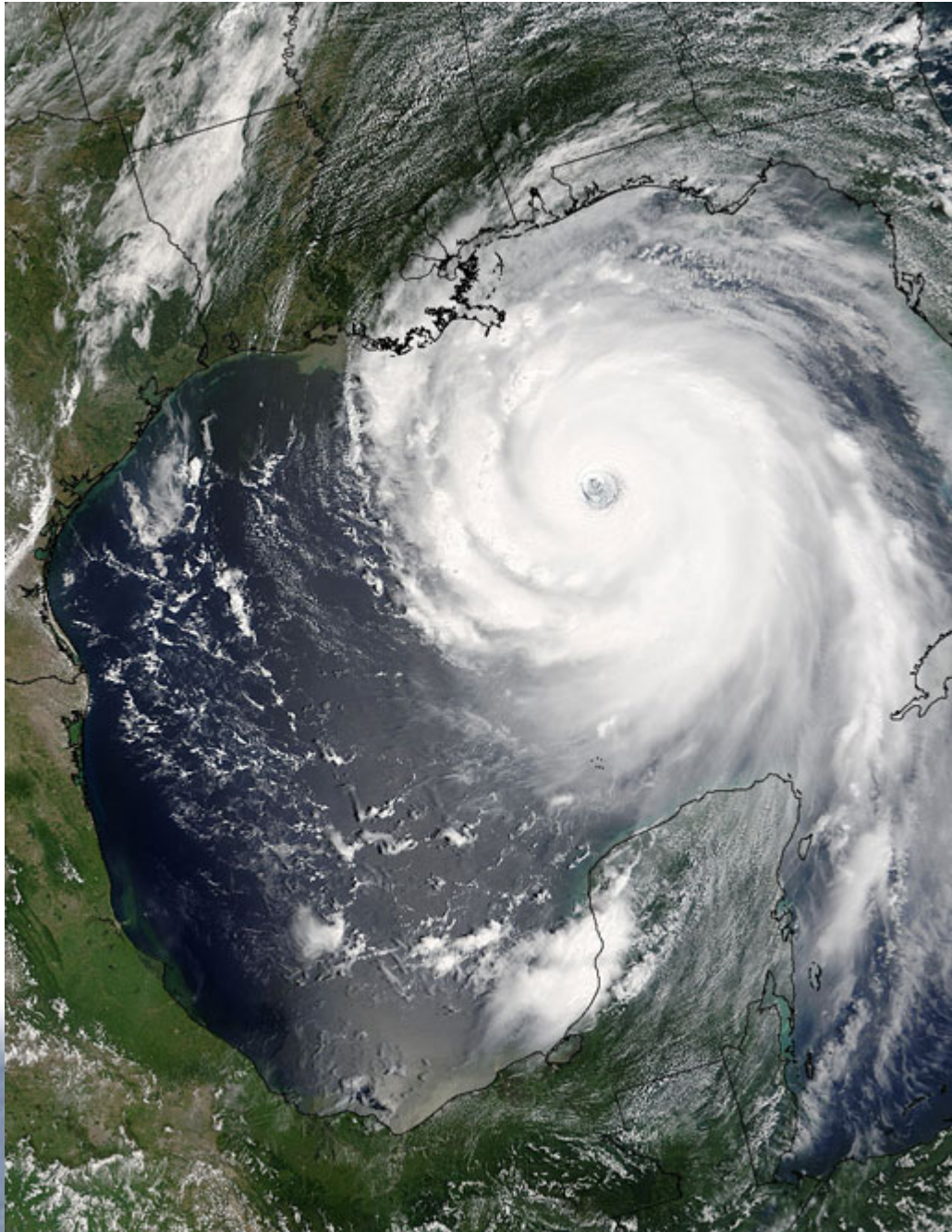


Things were fine until....



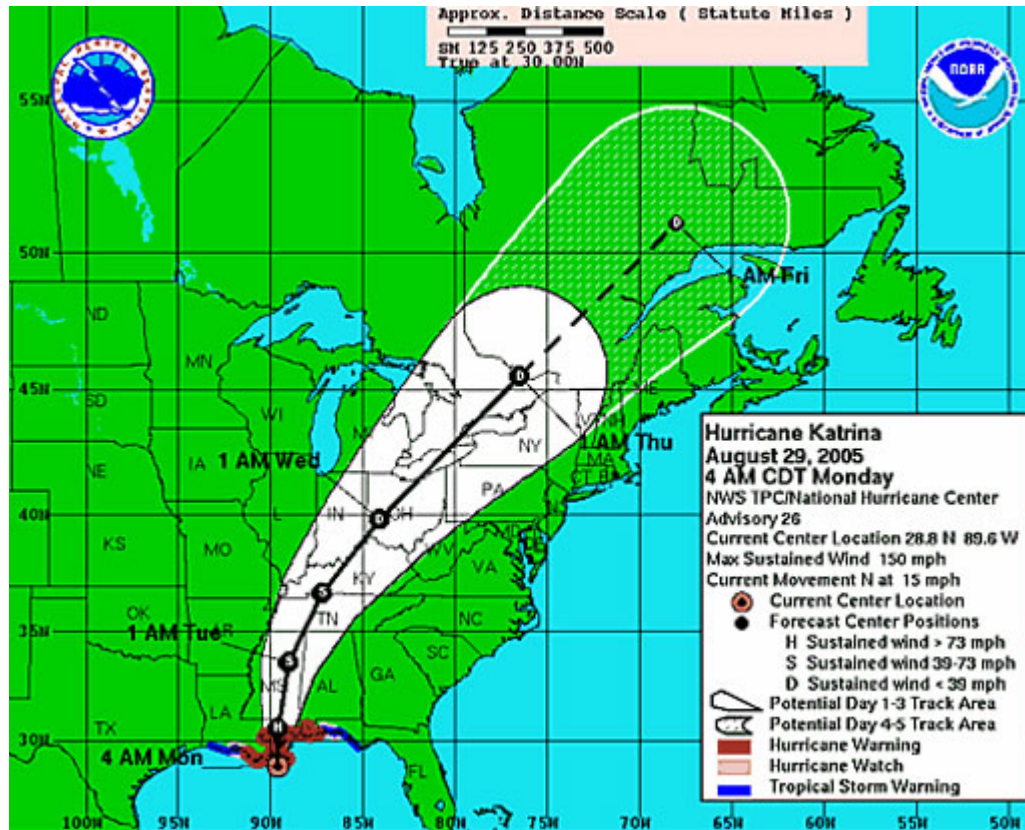
Hurricanes Katrina & Rita stopped by
the Gulf Coast
&
overstayed their welcome





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Crisis!



- Survey funder called upon to provide essential direct health care services to people in need as this cohort scattered throughout the US
- started to field complaints directly from evacuated families
 - Had difficulty during the evacuation because of the child's special health care need(s)
 - Problems obtaining durable medical equipment (DME) during and after the evacuation



To get some perspective....
(2004 Florida hurricanes, not Katrina)



**Janet Baggett, Deputy Chief, Bureau of Chronic Disease
Prevention & Health Promotion
Florida Department of Health (Tallahassee)**

Baggett J. Florida disasters and chronic disease conditions [letter to the editor]. *Prev Chronic Dis* [serial online] 2006 Apr. Cited March 15, 2007. Available from URL: http://www.cdc.gov/pcd/issues/2006/apr/05_0230.htm





“Florida had five hurricanes during 51 days beginning on August 12, 2004...more than 9 million people were evacuated...

Not broadly publicized was the way people with chronic diseases were affected..”.



“...Florida provides special-needs shelters to meet the needs of people with chronic diseases and disabilities during times of disaster...”

“Most people in these shelters needed oxygen, special diets, and medication. Many were unable to make their way to the bathroom without help, could not sleep lying flat, or could not breathe well without oxygen.”



“...People often arrived at our shelters without vital medications....people in our shelters were often unable to recall personal, medical, and insurance information...the entire infrastructure of some communities disappeared entirely”.



New 'Hurricane' questions



- Added as Section 6D
 - located immediately after family-centered care and transition issues questions, but before health insurance questions
- Goals:
 - Assess unmet health care needs and DME access among CSHCN, appropriate shelter
 - where they received health care services to improve delivery and level of services



New contributions

- We might be able to examine these data by the nature of the SHCN and various health conditions (pending sample size considerations)
- Will allow:
 - MCHB to examine and refine disaster planning efforts for CSHCN
 - calculation of more precise state-level estimates of key health indicators by allowing states to exclude the evacuees
 - What impact, if any, did this migration have on key state-level health and health services indicators for the evacuating and receiving states?
 - What is the impact of excluding this migratory population from the calculation of key indicators of receiving states?

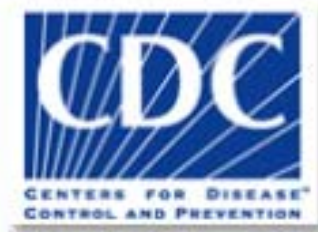


What else happened?

- Immediately ceased data collection in impacted areas
- Used 'FEMA line' to manage and control field work in the immediate aftermath
- Achieved approximately 750 completed interviews in LA post-disaster (higher than we expected)
- Very lucky that data collection was spread over two years
- Pre-Katrina cases will not be on the public use file, will only be available internally at NCHS
- Assumed pre and post-disaster CSHCN cases were different



Tricky issues...



- What do these post-Katrina cases represent?
- What about cases from Northern Louisiana collected pre-Katrina? Why drop all of these interviews because of the event? Should we?
- Zero weight Katrina cases (drop them entirely from the file)?



Preparation of population control totals

- Birth counts (Vital Statistics data)
- Infant mortality (National Vital Statistics Reports)
- Foreign immigration (Public-Use Microdata Samples, 2000 Census)
- Migration between states (Census estimates, 2006 Louisiana Health and Population Survey [LHPS])
- Orleans Parish migration (FEMA data, reported mailing addresses of Katrina aid applicants, assigned migrants to IAP areas proportionally to the # of applicants)
 - **Orleans Parish out-migration** (cases that left Orleans Parish)
 - **Katrina in-migration** (where to move the migrated cases)



Section 3

Take-home messages





Take-home messages



We need to expand our thinking about survey disruptions and the impact(s) on surveys and estimates, especially those that are trended and population-based...

Can we afford to be reactive instead of proactive?





- RDD surveys have been used successfully in disasters (pending infrastructure status)
- Recognize current limitations in forecasting & simulation
- Think critically to develop new methods for adjusting survey estimates & procedures
- (Sadly) it's just a matter of time before we get to test these new 'methods' again



- New area of survey methodology & statistical research that **MUST** be addressed
- Consider practical & logistical issues too: OMB & IRB reviews of 'crisis-ready' surveys and procedures, interviewer/staff issues
- Interesting problems; need to be flexible and creative in our solutions
- We **MUST** conduct additional workshops such as this!



Multidisciplinary



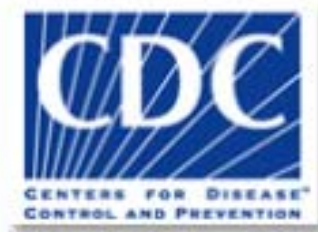
- Advances in Psychiatric Treatment
- American Journal of Psychiatry
- Annals of Epidemiology
- Annals of Internal Medicine
- Anxiety, Stress, and Coping
- Archives of Internal Medicine
- Australia & New Zealand Journal of Sociology
- Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science
- CNS Spectrums
- Emerging Infectious Diseases
- Environmental Health Perspectives
- Families, Systems, & Health
- Hispanic Journal of Behavioral Sciences
- Industrial Crisis Quarterly



- International Journal of Epidemiology
- Journal of Epidemiology and Community Health
- (The) Journal of Nervous and Mental Disease
- Journal of Psychiatry
- Journal of the Royal Society of Health
- Journal of Traumatic Stress
- Journal of Occupational & Environmental Medicine
- Natural Hazards Review
- PLoS Medicine
- Preventing Chronic Disease
- Proceedings of the National Academies of Sciences
- Psychological Science Agenda



- BRFSS
 - CDC, Michael Link, Ph.D. (Sr. Survey Methodologist)
- Disaster Research Centers
 - University of Michigan School of Public Health (Sandro Galea, MD, DrPH, director)
<http://www.sph.umich.edu/drem/>, or
www.disasterresearch.org
 - University of Delaware
- Florida State University
 - Traumatology Institute
- Center for Biosecurity
 - University of Pittsburg Medical Center



“In the middle of difficulty lies opportunity.”

Albert Einstein





On behalf of the SLAITS team,
thanks for your interest!



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