Disaggregating Latina/o Surveillance Health Data Across the Lifecourse: Barriers, Facilitators, and Exemplars

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Carmela Alcántara & Leopoldo J. Cabassa
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Outline

- Latina/o Health Data Disaggregation Team
- Project Aims
- Methods
- Major Findings
- Top Recommendations

Latino Data Disaggregation Team

- Carmela Alcántara & Leopoldo J. Cabassa
- Shakira Suglia
- Louise Falzon
- Irene Perez Ibarra
- Elliot McCullough; Talhah Alvi

- Advisory Board: Margarita Alegria; Dolores Acevedo Garcia; Larissa Aviles-Santa

Project Aims

- **Primary Aim:** To identify the barriers and facilitators that either prevent or promote the collection of disaggregated surveillance health data on US Latinos.

- **Secondary Aim:** To review exemplars of disaggregated surveillance health surveys to identify promising measures, approaches, and techniques.

METHOD

Systematic Review

- Peer-reviewed, English-language
- January 2006 to June 2016
- Adult outcomes:
    - cancer, heart disease, stroke, unintentional injuries, diabetes mellitus, any depression, any anxiety disorders, and insomnia.

- Child outcomes:
    - asthma, obesity, ADHD/developmental disabilities, autism, depression, anxiety, and conduct disorder.

RESULTS

Systematic Review Records

- 1801 unique records retrieved and screened
- 573 full-text articles assessed for eligibility
- 175 included in qualitative synthesis
- Results from 45 different surveillance health surveys

Systematic Review Findings

- Disaggregation was defined as to separate data from surveillance health surveys on US Latinos into subgroups.

Figure 2. Use of disaggregation in the included studies (N=175 studies).

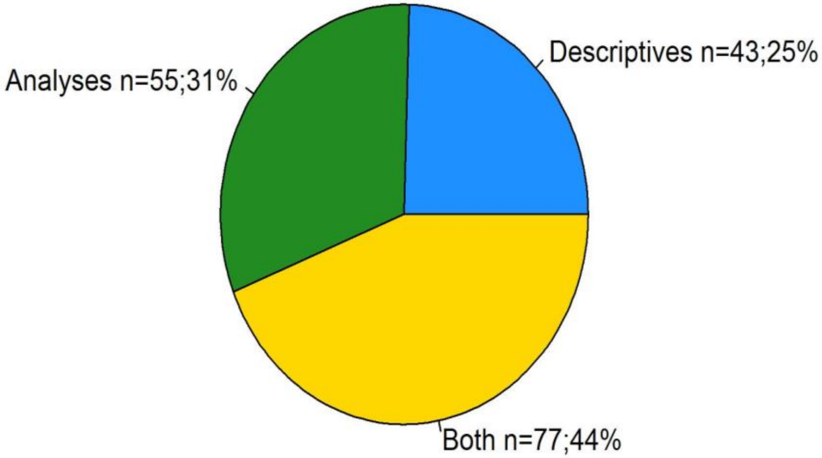


Figure 3. Number of articles published per year of publication from 2006-2016 (N=175).

Note: Grey line shows the mean number of publications. Total: mean = 15.9; sd = 6.3; Adult: mean = 12.1; sd = 5.2; Children: mean = 3.7; sd = 1.9.

Age and Outcome Distribution

Age Distribution

- ☐76.0% adult
- ☐21.1% children
- ☐2.9% both

Top 5 Outcomes

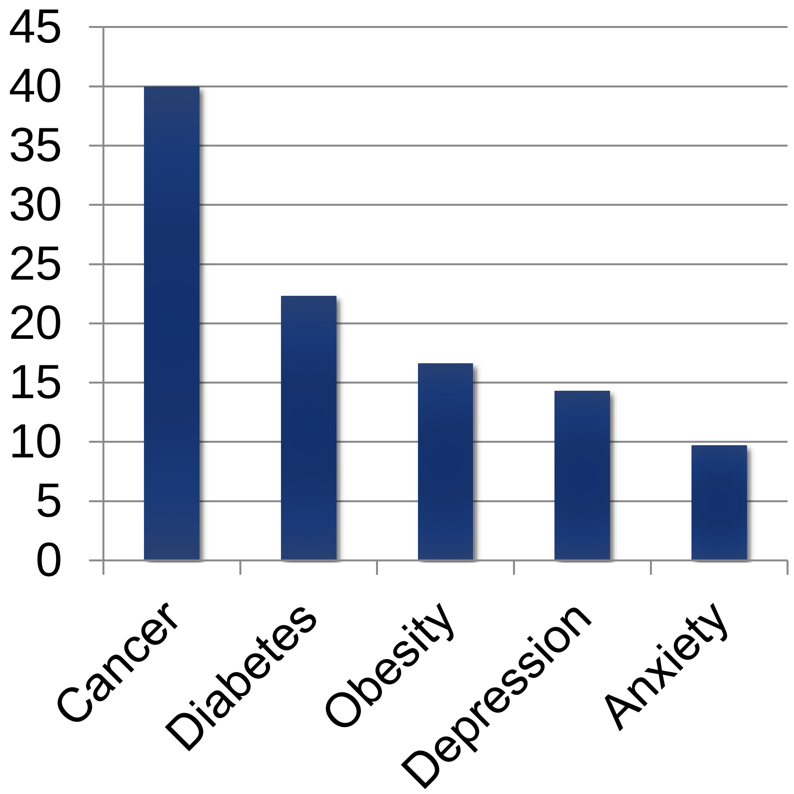
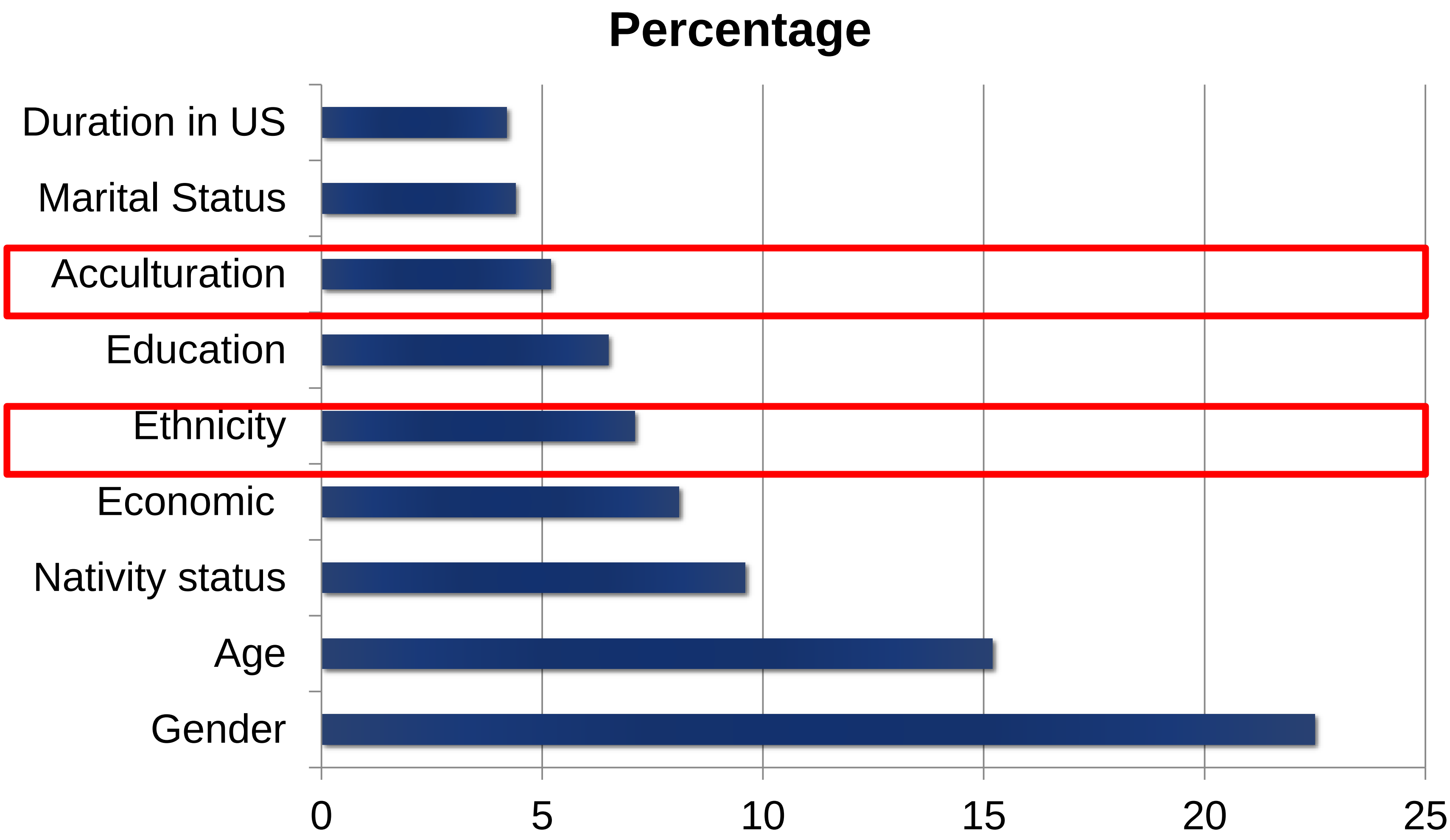


Table 2. Characteristics of the disaggregation* types in the total included studies (adult and child) (N=175).



Stakeholder Interviews

- **Aim:** To explore potential barriers and facilitators for disaggregating health data for the Latino population

- **Sample**: 12 stakeholder semi-structured qualitative interviews
  - 4nationally recognized Latino health researchers
  - 4 local representatives from departments of health or mental health
  - 4 national representatives

- **Data analysis**: Content analysis

Barriers

- Small sample sizes
- Lack of resources and funding
- Lack of cultural humility and cultural competence in data collection.
- Concerns regarding the validity of measures and lack of systematic measures to capture disaggregated data across multiple domains
- Lack of a strong economic argument for disaggregating data
- Lack of diverse faculty to inform the design, collection, and analysis of disaggregated health data

Facilitators

- Create guidelines for disaggregated data collection
- Promote an immigration or ethnicity lens
- Offer targeted funding to collect disaggregated health data
- Develop marketing campaigns
- Invest in mentoring and training programs
- Promote disaggregation through legislation
- Liberate data by making it publicly available
- Conduct mixed-methods research to advance the science of disaggregated health data

TOP RECOMMENDATIONS

Top Recommendations

Research

- Develop guidelines for ethnic health data disaggregation and a standardized survey items.
- Mandate the collection of Latino heritage, acculturation, and duration in the US in all publicly funded surveys.

Funding

- Invest in research training and mentoring programs at all stages of career development.
- Develop targeted funding announcements and opportunities to support disaggregation research.

Policy

- Develop a strong economic and scientific argument for Latina/o health data disaggregation.
- Develop a set of decision tools to help stakeholders determine when, how, and on what to disaggregate.

AREAS FOR FURTHER EXPLORATION

Politics of Disaggregation

- Complex and multi-faceted

- Need to address tensions resulting from competing demands (research vs. policy needs)

- Need for flexible and adaptable data collection systems that can capture changing demography.