

Quantifying Public Perception of End-of-Life Care Policies

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Background

- In five states Alaska, Idaho, Pennsylvania, New Hampshire, and Tennessee - legislative officials passed default surrogate and durable power of attorney laws
- Each of the states found varying outcomes in end-of-life (EOL) care
- One possible explanation for the variation = the increase in media attention surrounding the passages led to an increase in knowledge in end-of-life care and possible course of actions, such as completing an advanced directive or living will, taken by members of the public.

Aims and Major Questions

- Examine the causes of state variations in EOL care outcomes. One
 potential mechanism explored is public discourse and perceptions
 of durable power of attorney and default surrogate law passages
 and its effects on end-of-life care outcomes.
- What is happening in the public during the time which EOL policies are enacted and put into effect?
- How can public perception be quantified?
- How do trends in public perception of end-of-life care policies affect EOL care outcomes?

Methods

Understanding Societal Context

Collected, read, and analyzed historical to present day newspaper articles from each of the five states to better understand public responses to end-of-life care policies



Researching the Research Efficacy of Google Trends in Papers

Conduct literature reviews on the effectiveness and various applications of Google Trends (GT) as a possible proxy for quantifying public perception and media attention



Data Collection

Collected relative search volume data of certain EOL care related search terms, such as, "living will", "default surrogate", and "durable power of attorney" from each of the five states

Time windows observed: 2004-present, 2 months before law passes + after law is in effect, 3 months before law passes + after law is in effect



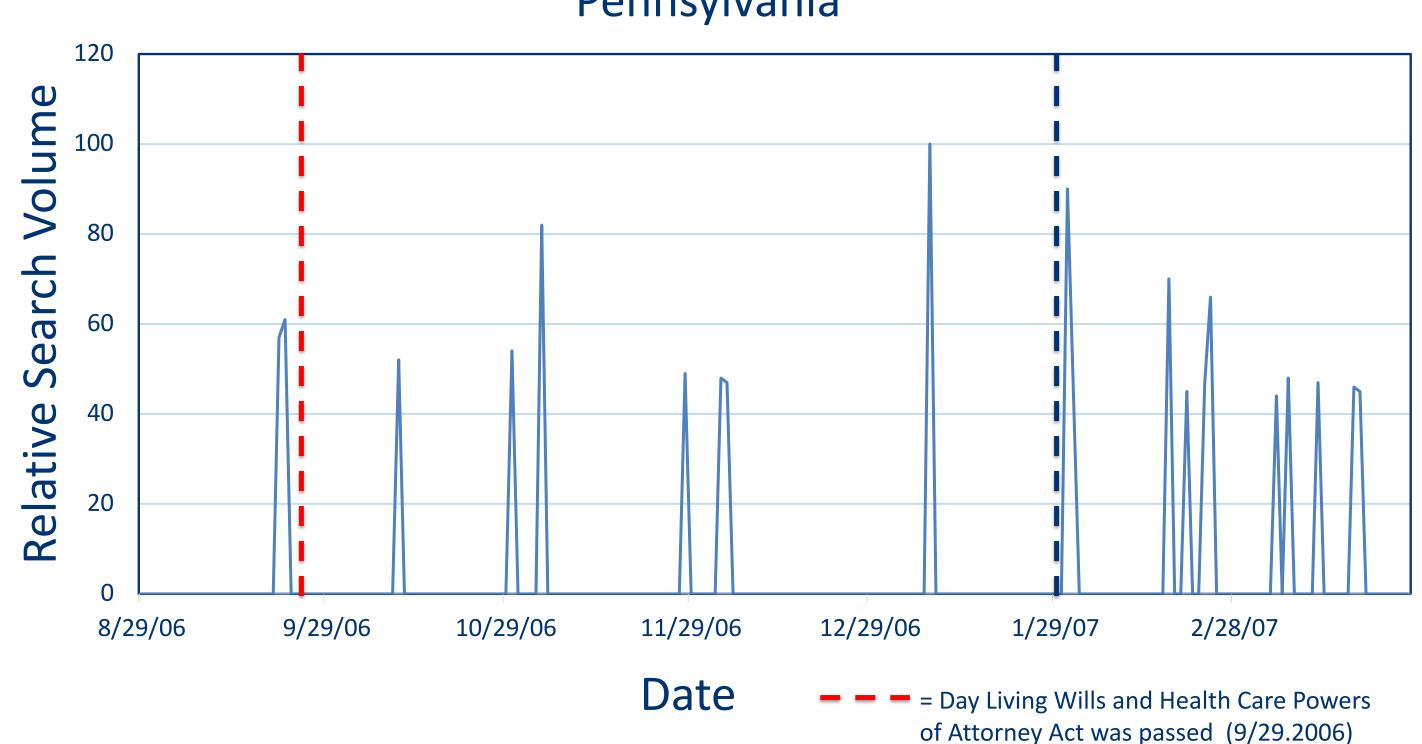
Next Steps

Explore how to incorporate GT data into statistical models or how to use Google Trends descriptively as a potential explanation for the variation in the effectiveness of laws

Results

Google Trends

Fig. 1. Relative Search Volume for "Living Will" in Pennsylvania



= Day Living Wills and Health Care Powers of Attorney Act came into effect (1/29.2007)

On September 21 and 22, 2006, 8 and 7 days before the passage of the Living Wills and Health Care Powers of Attorney Act was passed, there is a peak in RSV (57% and 61%, respectively). Further, on January 30, 2007, 1 day after the law came into effect, there is a 90% peak in RSV. More research needs to be conducted to understand the relationships between the law passages, media attention, and EOL outcomes.

Societal Context

Alaska: 54 articles read (1986-2021)

- 2019 Dialogue about pregnancy negating a living will¹
- 2009 Sarah Palin criticizes Obama administration for "death panels" – suggesting that bureaucrats would have the power to decide whether seniors and disabled people were worthy of care²

Idaho: 29 articles read (2007-2021)

- 2005 Dialogue about pregnancy negating a living will³
- 2018 Idaho sued for pregnancy clause⁴

New Hampshire: 41 articles read (1990-2021)

 Most articles present with an informational or supportive tone regarding EOL policies, suggesting a lack of dissent

Pennsylvania: 86 articles read (1990-2021)

- Margaret Lowenthal: "Act 169 generated a great amount of media attention and controversy over the inclusion of statements on hydration and artificial nutrition."
- Some criticism from the public: Herb Denenberg: "The forms are frankly pathetically deficient."⁶

Tennessee: 80 articles read (1987-2020)

- Similar to NH, most articles present with an informational or supportive tone regarding EOL policies, again suggested a lack of dissent
- Articles concerning the death of Terri Schiavo were found for each state

Conclusions

- Google Trends is a viable means to capture public discourse by focusing on relative search volume data, but brings several limitations in its provision of data, for example:
 - In Alaska and Pennsylvania, there was a lack of RSV data for several EOL related terms such as durable power of attorney, living will, and advance directive, particularly in the time leading up to and after the passages of legal statutes of concern
 - Google Trends only provides data post 2004, creating difficulty in analyzing public discourse regarding passages enacted before 2004
 - Certain peaks in RSV can be directly related to Terri
 Schiavo and thus unrelated to EOL policies

Skills Acquired

- Reading comprehension skills obtained from literature reviews for projects such as: instruments for educational attainment, racial disparities in long term care, and differences between Medicare Advantage vs. Traditional Medicare in the provision EOL care
- Data visualization skills in Excel and R

References

¹Wetsman, Nicole. 2019. *Doctors can ignore your DNR order if you're pregnant.*

²Petrillo, Laura. 2014. What you can do today to pull the plug on Sarah Palin's "death panel" myth. GeriPal: Geriatrics & Palliative Care for All Healthcare Professionals.

³mataliandy. Updated: Pregnant? No Living Will for You. 2005 [cited Aug 6, 2021]. Available from

https://www.dailykos.com/story/2005/3/23/101465/-.

⁴Boone, Rebecca. 2018. Idaho sued over pregnancy exclusion in advance directive law. *AP News*.

⁵Lowenthal, Margaret. 2007. Act 169: Pennsylvania's New Advance Directive Law: Implications for Health Care Providers. *Pennsylvania Nurse* 62, no. 4:22-23.

⁶Denenberg, Herb. 2004. A good deal of thought is required before selecting health-care plan. *Reading Eagle (PA)*31.

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