2020 Tamkin Symposium Lecture

Why is Elder Abuse Research So Hard? A Veteran of Science of Service Shows Off His Battle Scars

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Director of Geriatrics, The New York Presbyterian Healthcare System

Disclosures

- I am a low tech geriatrician with, sadly, little or nothing to sell
- I do not believe I have conflicts of interests relevant to this presentation
- I have served as an EA expert witness providing testimony in
 - Civil Cases of Elder Abuse
 - Criminal Cases of Elder Abuse
 - Before the United States Senate Committee on Aging
- I serve the board of The American Federation for Aging Research
- I will show off my battle scars as promised, this is an intensely personal talk
- I will not show off my tattoos: it ain't pretty the presentation is rated PG
- However, there will be some bawdy videos to make my points

A Road Map of My Presentation

- My/Your first exposure to elder abuse and the naiveté it engendered in me (and maybe you)
- The many (well meaning) but problematic studies this has led to (and we're not alone)
- Why is Elder Abuse Research So Hard?
- It's the dawn of a new exciting era and I'll give some examples (without scooping others)
- IMO, the the next series of important challenges will fall into two buckets:
 - Creating a pipeline of highly trained scientists who can do this work (ideally clinicians)
 - Giving them tools to bring to bear advances from both (a) gerontology and justice theory and (b) research methodology to create and evaluate evidence base interventions to see if they actually work
- I'm an translational guy, this is a translation symposium, so I'll give translational examples
 - Elder Abuse Multidisciplinary Teams
 - The Use of Nursing Homes as Elder Abuse Shelters

My First Elder Abuse Case

- Moonlighting in the Yale ER to support my student loan habit
- I was a Robert Wood Johnson Clinical Scholar and Geriatrics Fellow
- The Clinical Scholars Program: Medicine and Societal Problems
- I saw an 86 year old woman with cigarette burns on her chest
- In the days before EMR we used to call down to medical records
- This poor woman had a 50 year history of domestic violence and had been repeatedly misdiagnosed as malingering and histrionic
- Actually Led to a study funded by the John A Hartford Foundation in which I looked at the ER use of APS Physical Elder Abuse Victims

My Responses

- Emotional: Outrage and Empathy
- Intellectual: What do we know about this problem circa 1988
- Support: Is there anyone working in this field I can contact?



Review

> Clin Geriatr Med, 9 (3), 665-81 Aug 1993

Recognizing Elder Abuse and Neglect

M S Lachs ¹, T Fulmer

Affiliations + expand

PMID: 8374864

> Arch Fam Med, 2 (4), 371-88 Apr 1993

Diagnostic and Treatment Guidelines on Elder Abuse and Neglect

S C Aravanis, R D Adelman, R Breckman, T T Fulmer, E Holder, M Lachs, J G O'Brien, A B Sanders PMID: 8130916 DOI: 10.1001/archfami.2.4.371

Journal of the American Geriatrics Society



A Prospective Community-Based Pilot Study of Risk Factors for the Investigation of Elder Mistreatment

Mark S. Lachs MD, MPH, Lisa Berkman PhD, Terry Fulmer RN, PhD, Ralph I. Horwitz MD

First published:February 1994 | https://doi.org/10.1111/j.1532-5415.1994.tb04947.x | Citations: 86

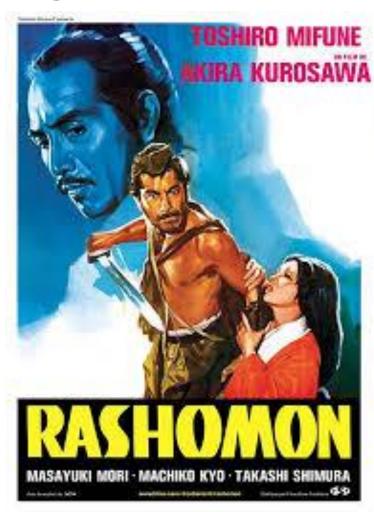
Supported in part by the National Institutes on Aging, contract number N01-AG-0–2105, Established Populations for Epidemiologic Studies in the Elderly (EPESE).

My Responses

- Emotional: Outrage and Empathy (grandparents saved my life)
- Intellectual: What do we know about this problem circa 1987
- **Support:** Is there anyone working in this field I can contact?
- Career Ambition: I need to make this my career
- Advocacy as a Doctor Who Fixes Things: Elder Abuse Victims Can and Must be Swiftly and Surgically Removed From the Harmful Environments and Their Abusers Punished to the Fullest Extent
- Community Service: I Became a APS volunteer physician as I did not have the athletic ability to become a vigilante Marvel Superhero

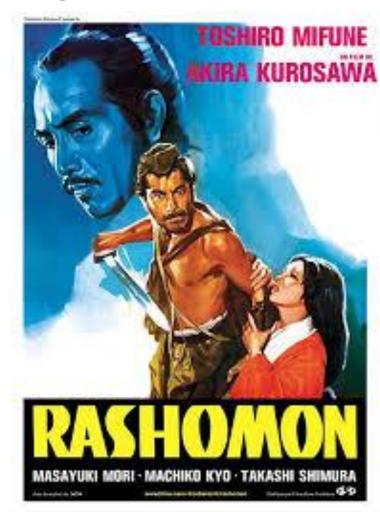
My Field Experience With Adult Protective Services Changed Everything

- It turns out this is a tad more complicated than I figured
- Who Knew? Elder Abuse is in the Eyes of the Beholder
- In fact, many victims did not want to be rescued (or they were, at the least, ambivalent about it)
- Many reminded me of Michael Palin of Monty Python who was held hostage in "The Castle of Anthax" by the maidens



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- Many reminded me of Michael Palin of Monty Python who was held hostage in "The Castle of Anthax" by the maidens
- The "Perpetrators" were even more complicated
- My "surgical excision" fantasies were perhaps unrealistic
- Maybe I needed to rethink my "Nazi Hunter" Mode



Can You Relate?

- What was your first experience when you saw or heard about elder abuse?
- Have you ever asked yourself what attracted you to this field?
- It turns out there is a literature about who works in Domestic Violence:
 - Those who have been victims at some point in their lives
 - Those who have come from traumatic childhoods in other ways

Open access Research

BMJ Open Is a clinician's personal history of domestic violence associated with their clinical care of patients: a cross-sectional study

Elizabeth McLindon, ^{1,2} Cathy Humphreys, Kelsey Hegarty ^{1,2}

Intimate Partner Violence and Abuse Among Female Nurses and Nursing Personnel: Prevalence and Risk Factors

Michele Irene Bracken

, PhD, WHNP-BC, Jill Theresa Messing, PhD, MSW, Jacquelyn C. Campbell, PhD, RN, Lareina N. La Flair, MPH & Joan Kub, PhD, MA, APHN, BC

Can You Relate?

- What was your first experience when you saw or heard about elder abuse?
- Have you ever asked yourself what attracted you to this field?
- It turns out there is a literature about who works in Domestic Violence:
 - Those who have been victims at some point in their lives
 - Those who have come from traumatic childhoods in other ways
- Higher prevalence of mental health disorders from such childhoods such as depression, anxiety, low self esteem, and personality disorders
 - This often begets angry young men (and woman) who are on the side of justice
- So is choosing to work in this field that such a bad thing?
 - For direct service providers its probably an excellent form of sublimation
 - For people in policy and research it may be a mixed bag, especially non-clinicians

What Happens When Well Meaning, Big Hearted People Attempt Research and Policy in Elder Abuse Without Training

- Policy and Dissemination without Data, for instance:
 - Mandatory Reporting Laws
 - Criminal background checks of nursing home residents as well as staff
- Research driven by stories and not data, for instance:
 - Focus on nursing home abuse by staff and not other residents
 - Bruises can be dated (no they cannot be)
 - Prevalence studies all over the map because of different definitions

"Data" is not the plural of "Anecdotes"

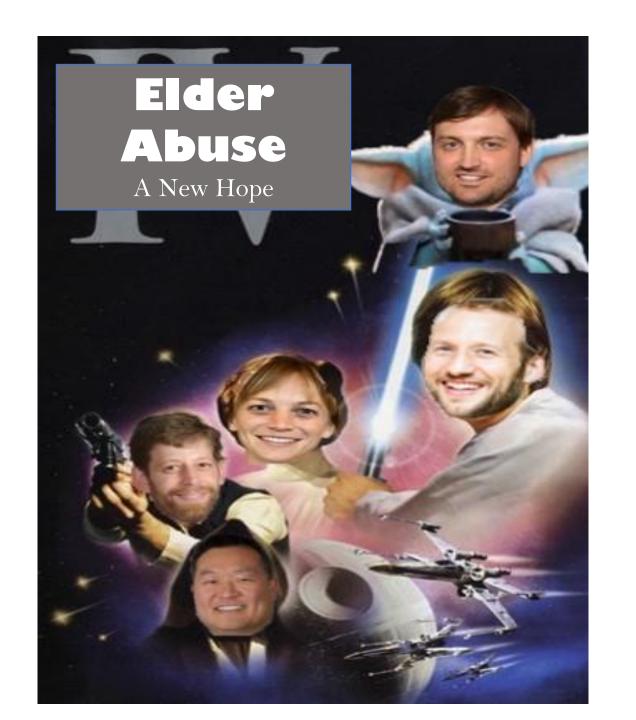
So Why Is Elder Abuse Research So Hard?

- Difficult to access populations, even harder to follow up on
- The high prevalence of cognitive impairment (prevalence studies)
- Definition Problems
- "Lumping" and 'Splitting"
- Incredible Heterogeneity of Subjects: medical and social comorbidity
- Poorly Characterized Interventions, no measures of fidelity
- Multi-Modal Interventions
- Outcome measures:
 - Poorly created and tested (if they are tested at all)
 - Outcomes Important to researchers but not victims (my surgical excision fantasy)
 - No adjustment for baseline state, no adjustment for the intensity of the abuse

Imagine a Cancer Study in Which

- Patients with a small cancerous lump in the breast were pooled together with patients that have advanced metastases to brain and bone, given the same chemotherapy, and then compared head to head for survival or cure rates
- Two patients with the same extent of pancreatic cancer, one of whom decides to take a less toxic single medicine chemotherapy, the other choosing toxic 5 drug therapy and radiation, who are then compared head to head for survival or cure rates
- This is exactly was has been happening in elder abuse

Do Not Despair; There is Hope!



Dr. Anthony Rosen Identifying Diagnostic Injuries Of Elder Abuse

- For decades it was thought/taught that bruises could be dated and be used to definitively diagnose elder abuse
- There are Pathognomonic Injuries of Child Abuse
- We do not know if this is so for elder abuse
- Many false positives and false negatives because of chronic illness
- Dr. Tony Rosen to the Rescue

Tony Rosen

- Trained in Geriatric Emergency Medicine
- GEMSTAR and Beeson Awards in Elder Abuse
- Attempting to Discern Accidental Injuries from Elder Abuse Injuries by comparing injury patterns in ER Fallers vs DA office elder abuse victims
- Other projects
 - Photography protocols for elder abuse documentation
 - Created a database of injury types and locations with hundreds of fields
 - Machine learning to detect those at high risk in ERs

Dr. Timothy Platt-Mills Screening For Elder Abuse in the ED

- An ideal place to screen; victims otherwise isolated
- Done for other forms of domestic violence (child abuse)
- Challenging For Many Reasons
 - ER are Hurried Environments
 - Victims may be cognitively impaired
 - Abusers may accompany them
 - Even if cognitively intact, victims may conceal abuse
- Dr. Timothy Platt-Mills to the rescue!

Dr. Timothy Platt-Mills Screening For Elder Abuse in the ED

- Trained in Emergency Medicine, also a leader in the field
- Vice Chair of his Program, Chief of ER research
- Extensive NIH funding
- Has conducted the largest screening EA project in the world
- Many other studies in Elder Abuse and Emergency Medicine
- Much of his work serves as the basis for the Hartford Foundation's Collaboratory in Elder Abuse



The National Collaboratory To Address Elder Mistreatment:

A COLLECTIVE IMPACT APPROACH



Members of the National Collaboratory











Education
Development
Center
Rebecca Stoeckle
and Kristin Lees
Haggerty

Massachusetts
Executive Office of
Elder Affairs
Alice Bonner and
Bree Cunningham

University of Texas Medical School Carmel Dyer and Jason Burnett University of
Southern
California, Keck
School of Medicine
Laura Mosqueda,
Bonnie Lipton and
Theresa SiversTeixeira

Weill Cornell
Medical College,
Mark Lachs and
Tony Rosen

The Collaboratory is supported by The John A. Hartford Foundation, The Gordon and Betty Moore Foundation, and The Health Foundation of Western and Central New York

Other Young Superheroes

- **David Burnes** (University of Toronto): Creation of Better Outcomes Measures including severity scales and Goal Attainment Scaling
- Duke Han (USC) unraveling the neuroscience of elder financial exploitation and vulnerability using sophisticated neuroimaging
- Kristin Lees (EDC): running to (instead of from) elder abuse in patients with Alzheimer's Disease and related dementias) unlike the lemmings

What do these remarkable young people share and what can we learn from them?

- Excellent Scientific Taste
- Risk Taking
- Using Theory from other fields as I've Outlined
 Using research Methodology from other fields as I've suggested

We Can Learn From Their Examples

- Intervention is the next frontier
- We don't know what works
- Lets bring Theory and Methodology from other fields to Evaluation
 - Advances in Legal Justice theory: Restorative Justice
 - Advances in Clinical Research Methodology
 - Improvements in Clinical Trial Design and Alternative Methodologies
 - Better Process and Outcome Measures
 - Statistical and Analytic Advances

Restorative Justice

- Another approach to crime and punishment
- Distinct alternative to and/from "Retributive Justice"
 - Serves as the basis for American Criminal Law
 - Derives from the code of Hammurabi ("An eye for an eye")
 - Also called "Retaliatory Justice"
 - From the Latin: Lex Talionis of (Law of Retribution)
- Highly Relevant to Elder Abuse

An Example of Restorative Justice

- Elderly woman with advanced dementia brought to the US from Central America by her two daughters to provide care for her
- All undocumented aliens
- One prior trip to an ER two years earlier for a UTI
- Medical Bill Left them Nearly Destitute and fearful of deportation
- Near her mother's death, they called their local priest for last rites
- At the funeral home mortician noticed extensive bedsores
- Police were called and urged the DA to press elder abuse charges
- No criminal history or brushes with the law on the part of daughters

Restorative Justice

- Considers the vantages of all stakeholders
 - The victim (what does he or she want)
 - The community (does this person pose a threat?)
 - The abuser (do we can to incarcerate the disabled?)
 - Funders and Taxpayers: Is this how we should be spending limited community resources?
 - Law enforcement (An opportunity to educate)

Advances in Clinical Research

- Better measurement of medical and social comorbidity at baseline so that subjects are comparable; statistical matching
- Better characterization of the exposure (elder abuse)
 - Types
 - Severity Measures
- Better Outcome Measures, by stakeholder, victim specific
- Acknowledgement that interventions may not only not work, but that they could actually be harmful, however well intentioned
 - Adverse Events
 - Data Safety Monitoring Boards
 - Stopping Rules

When Well Intentioned Ideas Harm

- Countless Examples from Medicine
 - Cholecystectomy (gallbladder removal) for asymptomatic stones
 - Tonsillectomy for sore throats and ear infections
 - Thalidomide to Prevent Miscarriage
- But From the Social Sciences Too
 - Mandatory arrest of DV perpetrators leading to murders
 - DARE program to prevent youth drug use actually increased it

Does the DARE Program Work?

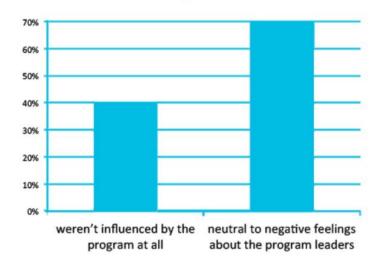
Home → Drug Addiction → Does the DARE Program Work?



D.A.R.E. is an acronym that stands for Drug Abuse Resistance Education. Developed by both law enforcement and school officials in 1983, the program was provided to youths as a formal way of introducing drug use information to young people in attempts to lower the rate of substance abuse down the road. Whether or not the program has been successful remains a controversial topic.

Proponents of the program claim youths retain the information learned and carry it onward into their developmental years. Others tout the efficacy of the D.A.R.E. program, citing poor statistics that don't back up the claims the organization promotes. One such figure stems from a survey conducted by the California Department of Education in which 40 percent of student respondents claimed they weren't influenced by the program at all, and almost 70 percent cited having neutral to negative feelings about the program leaders.^[1]

Students' Response to D.A.R.E.



Unintended outcomes evaluation approach: A plausible way to evaluate unintended outcomes of social development programmes ★

Sumera Jabeen △ 🖾

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https://doi.org/10.1016/j.evalprogplan.2017.09.005

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How Might We Employ this Paradigm? Two Examples

- Elder Abuse Multidisciplinary Teams (MDTS)
- Use of Nursing Home Beds for Shelters for EA Victims

Potential Evaluation Matrix For Elder Abuse Multidisciplinary Teams

Stakeholder	Merits/Metrics	Concerns
Victims	 Integrated/coordinated approach; services are not fragmented. Aversion of mortality and injury, improved depression and anxiety, treatment of unaddressed medical conditions, improvement in functional status. Safety. Reduction of risk. Civil, legal, and housing outcomes. Goal attainment scaling or similar methods to elicit victim specific preferences. Cost per case. Scalability, especially if this is high. 	 Team members to do not provide direct service to victims; interventions are therefore predicated on the "lens" of the provider. Small numbers directly served in teams (2-4 cases typically discussed per MDT meeting). Must have a critical mass of EA providers
Families of Victims	• Solace in knowing that loved one is safer. Reduced family distress. For family abusers, referral to resources (e.g. mental health).	 Families usually interface only with the MDT team member providing direct service.
Team Members	 Support from other team members who treat victims in isolation. Lower burnout. Professional pride and advancement by developing specific expertise in elder abuse and aging. 	 Team members may be unfamiliar with the professional culture and customs of other team members and reticent to provide input
Parent Organizations of Team Members	 Professional development of team member employees. Improved risk management as cases have now been vetted through several professionals should adverse outcomes occur. 	 Cost to employer of MDT members who are providing "in kind" support. MDT members while in that role are not providing direct service.
Referring Providers	 Single source of discrete referral The existence of an MDT may attract other professionals into a regular role with MDTs, "deepening the bench" of professionals in elder abuse. 	 Referring providers from fields like medicine may have unrealistic expectations about the referral process which is unlike the process of referring a patent for subspecialty consult. HIPPA and other privacy laws may be preclude sharing of information.
Communities	Identification of service gaps and redundanciesIdentification of serial community perpetrators.	 How to finance the MDT coordinator position which is the "glue" that makes MDTs possible.



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How to Deal With the Conversation Hog

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Potential Evaluation Matrix For Elder Abuse Nursing Home Shelters

Stakeholder	Merits/Metrics	Concerns
Victims	 Aversion of mortality and injury, improved depression and anxiety, functional status Treatment of unaddressed medical conditions Safety. Civil, legal, and housing outcomes. Cost per shelter victim served; scalability. Goal attainment scaling to elicit victim preferences. 	 Loss of community dwelling status for those who remain after mistreatment risk ends; Loss of non-abusing community supports. Fear of permanent institutionalization, "Transfer Trauma". PTSD. Resident to resident elder mistreatment (20% per monthly) resulting in re-traumatization. Abuse by nursing home staff.
Families of Victims	 Solace in knowing that loved one is safe. Reduced family distress. For family abusers, referrals to resources 	 Distinguishing intentionally abusive caregivers from unintentionally abusive ones when victims' desire visits/contact. How are these supervised? Who determines who can visit?
Other Nursing Home Residents and families Staff	 A source of potential support to cohabitating victims by other residents and their families which may be another emotionally meaningful activity Increasing job satisfaction / personal fulfillment in caring for this vulnerable population. 	 Exposure of vulnerable nursing home residents and non-shelter families to domestic violence and potentially menacing abusers. Ease of visits for other families (restraining orders) Potential confrontation with perpetrators and exposure to violence, safety; psychological distress from seeing victims of elder abuse.
Nursing Homes Attempting to Replicate	 Important Mission; community reputation. Potential new source of philanthropy 	 Reputational risk from explosion in nursing home ligation; facilities adopting the shelter model may become bigger litigation targets Inability to replicate the model in facilities without philanthropy.
Referring Providers	 Avoidance of "social admissions Resource for community-based providers who believe that a victim needs immediate protection 	 Increased identification leads to an explosion of cases that cannot be accommodated by shelters so hospitals become expensive shelters. If victims requiring protection aren't eligible for shelter or can't be accepted quickly/off hours another option must be identified.
Communities	 Educational programs offered by shelters to increase community awareness 	Duplicative in communities that already have such programs.
Payors	 Cost savings to Medicare/Medicaid as prevention may result in better downstream victims' health. Acceptance rate by insurance, citizenship, diagnoses 	 Premature nursing home placement leading to increased costs. Inflation of "shelter days" after risk is mitigated as Medicare or Medicaid now paying for services misattributed to shelter activities.

Resident to Resident Abuse in Nursing Homes

R-REM Occurrence and Type	Adjusted Value [95% CI], n (%)*
Residents involved in R-REM over the observation period	407 (20.2 [18.1-22.5])
Primary subtype of incident	
Verbal	184 (9.1 [7.7-10.8])
Physical	104 (5.2 [4.1-6.5])
Sexual	12 (0.6 [0.3-1.1])
Other	107 (5.3 [4.4-6.4])
Other subtype of R-REM incident	
Inappropriate caregiving	7 (0.3 [0.2-0.7])
Menacing gestures or facial expressions	18 (0.9 [0.6-1.4])
Invasion of privacy	80 (4.0 [3.2-5.0])
Other	2 (0.1 [0.0-0.4])

R-REM = resident-to-resident elder mistreatment.

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Our Interventions are Expensive And Intense

- As a research project they would likely never get past an Institutional Review Board Without Pilot Data and a Safety Monitoring Plan
- They May Work
- They May Not Work
- We need evidence, not stories
- (except for fundraising but only if they work, stories are AOK then)
- Caution about dissemination (a lesson from the business world)
 - Errors scales quickly and easily
 - Good evidence based practice is difficult to scale

Summary

- It's time to up our game in the world of elder abuse evaluation
- People are suffering, we don't know what works or even what harms
- We can draw from diverse fields to improve our methods and theories
 - Legal Justice
 - Clinical Research
- Equally Important is growing the pipeline of well trained researchers who can make use of these tools who also work with clients
- I am interested in mentoring anyone committed to this:

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