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hosts

Neglect Causing Suffering and Death in Long-term Care

Speaker: Eilon Caspi, PhD

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April 23, 2021

Painting by Charles Garetz

Neglect Causing Suffering and Death in LTC Homes

Eilon Caspi PhD

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April 23, 2021

UCONN

INSTITUTE FOR COLLABORATION ON HEALTH, INTERVENTION, AND POLICY (InCHIP)

Acknowledgments

Elder Voice Family Advocates: Debbie Singer, Anna Ostroushko, Anne Sterner, Kay Bromelkamp, Kris Sundberg, Jean Peters for assistance with this project

Lindsey Krueger & **MDH's** investigators for their dedicated work in investigating allegations of neglect in LTC homes

Chris Serres, The Star Tribune

Jennifer Segal for securing permission from Jeff Garetz to use image on 1st slide

Kate Goebel and **Cross** for assistance with this webinar

The majority of staff and nurses are dedicated, hard working, compassionate, and caring people

There are good LTC homes out there…

Definition of “Neglect” in Minnesota

(a) **Failure or omission** by a caregiver **to supply** a vulnerable adult (VA) with **care or services**, **including** but not limited to, food, clothing, shelter, **health care**, or **supervision** which is:

(1) Reasonable and **necessary to obtain or maintain** physical or mental **health or comfort**…of the VA

(2) **Not** the result of **an accident** or therapeutic conduct

(b) **…which a reasonable person would deem essential to** obtain or maintain the VA's **health, safety**, or comfort…of the VA

Physical Neglect

"**Failure to provide** the goods or **services necessary for optimal functioning** or **to avoid harm**."

– Lindbloom et al. (2007)

To "Neglect"

"To give **little attention or respect** to"

"**To leave undone or unattended** to especially through carelessness"

Disregard

"To treat as unworthy of regard or notice" – Webster dictionary

“I WANT TO KNOW THAT SOMEONE WILL BE THERE FOR ME WHEN SOMETHING HAPPENS TO ME.”

- An older woman living with Alzheimer’s disease in assisted living

Types of Neglect

- **Dehydration / Malnutrition**
- **Pressure Sores / Wound infections**
- Lack of monitoring or treatment of **complex health conditions**
- **Delays** in **emergency medical care**
- Inadequate **pain management**
- Left **soiled in urine and B.M.** for extended periods
- **Call lights** not answered for extended periods
- Unsafe **transfers**
- Inappropriate **use** of **medical equipment**
- **Medication Errors**
- **Lack of Supervision**

Neglect is Prevalent

Nursing Homes

- General Accounting Office, 1998
- Hawes, 2003
- Thompson, 2001
- Page et al. 2009
- Zhang et al. 2011

Assisted Living

- Hawes, 2003
- Page et al. 2009
- Magruder et al. 2019
- Phillips & Gau, 2011
- Philips & Ziminsky, 2012
- Breslow, 2013
- Schoch et al. 2013

MAJOR
CONTRIBUTING FACTOR

Inhumane & Unsafe People-to-People Ratios

Devastating Consequences

NHs

- Thompson, 2001
- Lindbloom et al. 2007
- OIG, 2014, 2019

ALRs

- PBS Frontline film: *Life & Death in Assisted Living*

- Schoch et al. 2013 – “Deadly Neglect“ (San Diego)
- NY Times: Rau, 2018; Anand, 2019; Span, 2019
- Elder Voice Family Advocates, 2019

Barriers for Reporting

- **Lack of awareness of the problem**
- **Lack of protocols** for detection / Poor recognition
- Lack of knowledge of **reporting processes**
- Concern it'll **reflect negatively on job performance**
- Concern about **disciplinary action**
- Concern about **regulatory issues** (e.g. citations)
- **Adverse publicity**
- **Fear of lawsuits**

– Friedman et al. (2017)

- Cognitive disability
- **Fear of retaliation**

RETALIATION

"I am literally afraid of her.

She intimidates.

Are you sure nothing is going to happen to me?"

– Resident speaking with OHFC investigator regarding allegations of maltreatment

Conditions that may Mimic Neglect in Elders

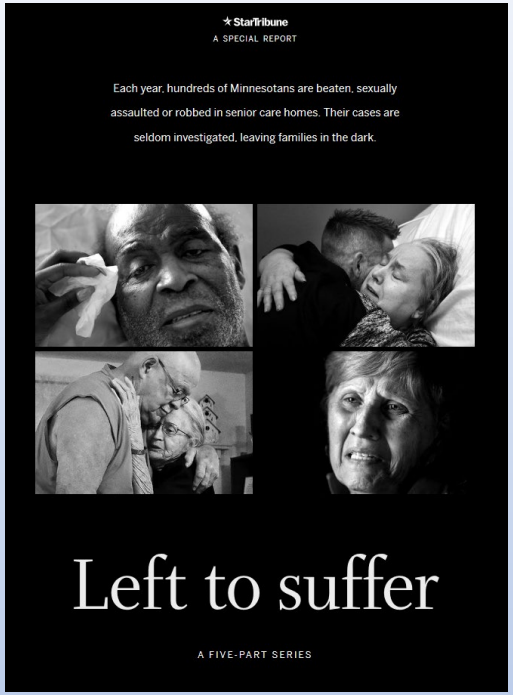
- **Constipation** from medications or hypercalcemia
- **Fecal impaction** (e.g. Chronic constipation)
- **Dehydration** secondary to medications
- **Diabetes**
- **Poor wound healing**
- **Urinary tract infection** (in women)
- **Vaginitis**

– Collins (2006)


PART 1

ABUSED, IGNORED ACROSS MINNESOTA

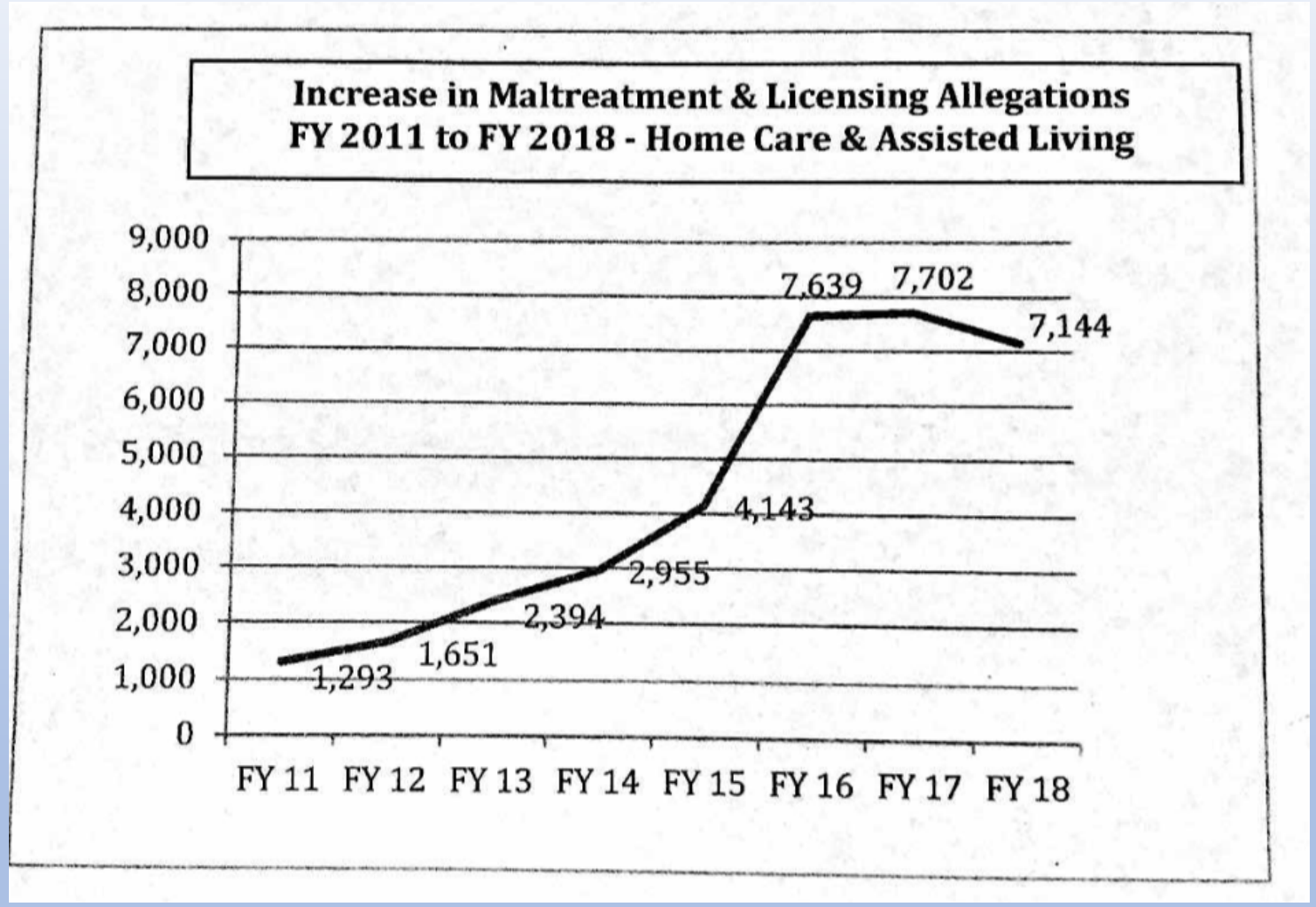
Story by Chris Serres • Photos by David Joles • Star Tribune • NOVEMBER 12, 2017



Background on Neglect in Minnesota

5.5-fold increase in allegations in Assisted Living

FY 11 → FY 18



“Zero Tolerance”

“Senior living providers and the dedicated caregivers who serve Minnesota’s growing population of aging citizens have **zero tolerance** for maltreatment of vulnerable adults”

– Patti Cullen, Care Providers of MN, 2.28.18

Why Focus on Neglect?

NEGLECT IS THE MOST PREVALENT FORM OF MISTREATMENT IN MN

BOTH AT THE ALLEGATION AND SUBSTANTIATION LEVELS

Governor Dayton

"Although [MDH] is partially to blame, **the real responsibility falls on each and every one of the care providers** in the state's facilities."

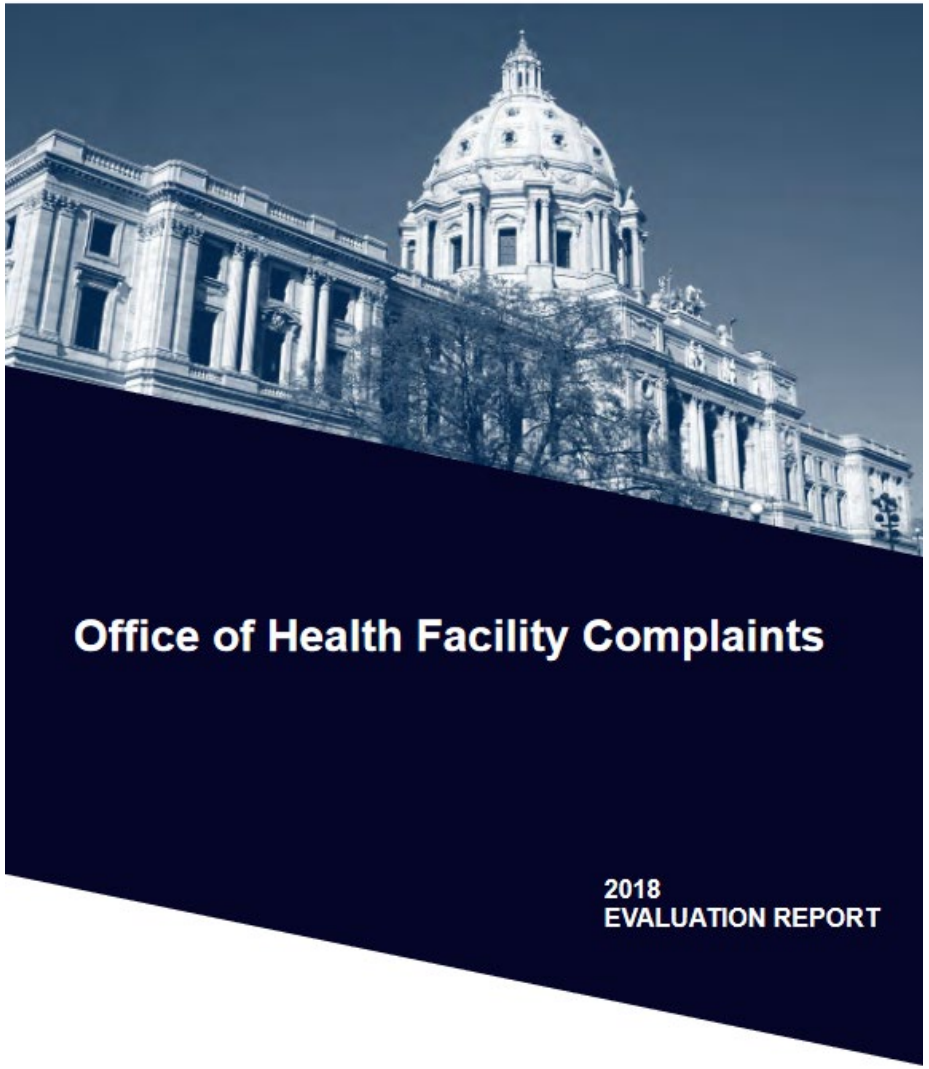
"They need to **fix the problems**, **stop breaking state laws**, and **follow moral codes**"

– Channel 5 ABC Eyewitness News, 2.22.18

Analyze Investigative Data

"We strongly agree with the evaluation's findings regarding better use of complaint and investigation data for prevention”

– Commissioner of Health



SHIFT TO PROACTIVE DATA-DRIVEN PREVENTION

"We spend 98% of our efforts responding to issues rather than prevention…and I mean it literally"

– Commissioner of Health, 2.18.19

Historians of Bad Care

MN Historical Society

“Nested” Neglect

Old F-Tag System

F224

“Prohibit mistreatment/Neglect/Misappropriation”

New F-Tag System

F600

“Free from Abuse and Neglect”

Aims

Identify:

1. Sequence of neglectful events ("Trajectories") resulting in harm

1. Patterns underlying neglect

2. Preliminary directions for prevention

Methods

Initial Dataset

429 MDH investigation reports substantiated as Neglect in NHs and AL

De-identified public records

Excluded 129 not Serious Bodily Injury (SBI)

Final Dataset

300 investigation reports resulting in SBI or death

Time period: 2013 – early 2020

Serious Bodily Injury (SBI)

Definition

- An injury involving **extreme physical pain**;
- involving **substantial risk of death**;
- involving protracted **loss or impairment of the function of** a bodily member, **organ**, or mental faculty;

or

- **requiring medical intervention** e.g. **surgery**, **hospitalization**, or physical rehabilitation

Preliminary Analysis

Step 1. **Qualitative reviews** of 300 investigation reports

Step 2. **Abstraction** of narratives **into Trajectories**

Step 3. **Identification of patterns**

Investigations Substantiated as Neglect Resulting in SBI and Death

	Subtotal	SBI	Death
Assisted Living	138	72	66
Nursing Homes	162	89	73
Total	**300**	**161**	**139**

Suffering even when not SBI…

Example I

Camera Footage

Resident with severe cognitive impairment requiring complete assistance with ADLs

Staff unsafe transfer → Fall

Crawling on floor w/o underwear on hands and knees with BM…

Staff walk by w/o acknowledgment, watch TV, read magazine, leave area several times…

No attempt to assist resident off floor and change adult depends…

Another employee assisted resident after **3 hours and 49 minutes!**

Perpetrator falsely documented incident and care provided…

Suffering even when not SBI…

Example II

- Resident with history of stroke, diabetes, depression & obesity
- Staff assigned to assist resident with toileting during night shift
- Resident **goes to the bathroom** at **2am**
- Over-the-toilet commode too small; commode legs gave out
- Resident became **wedged on toilet**; could not get up
- Pushed her **call pendant** and **screamed for help**
- Another resident went to find staff
- Staff member asleep

Suffering even when not SBI…

Example III

"Memory Care" Unit

Resident with cognitive impairment

Required hourly checks and assistance with ADLs

Not provided

Repeatedly found soaked in urine; sometimes feces

"So bad the mattress had to be replaced"

Developed UTI and Hospitalized

“Unsubstantiated” Neglect Allegation

77-year-old resident attacked by roommate → Brain injury

MDH:

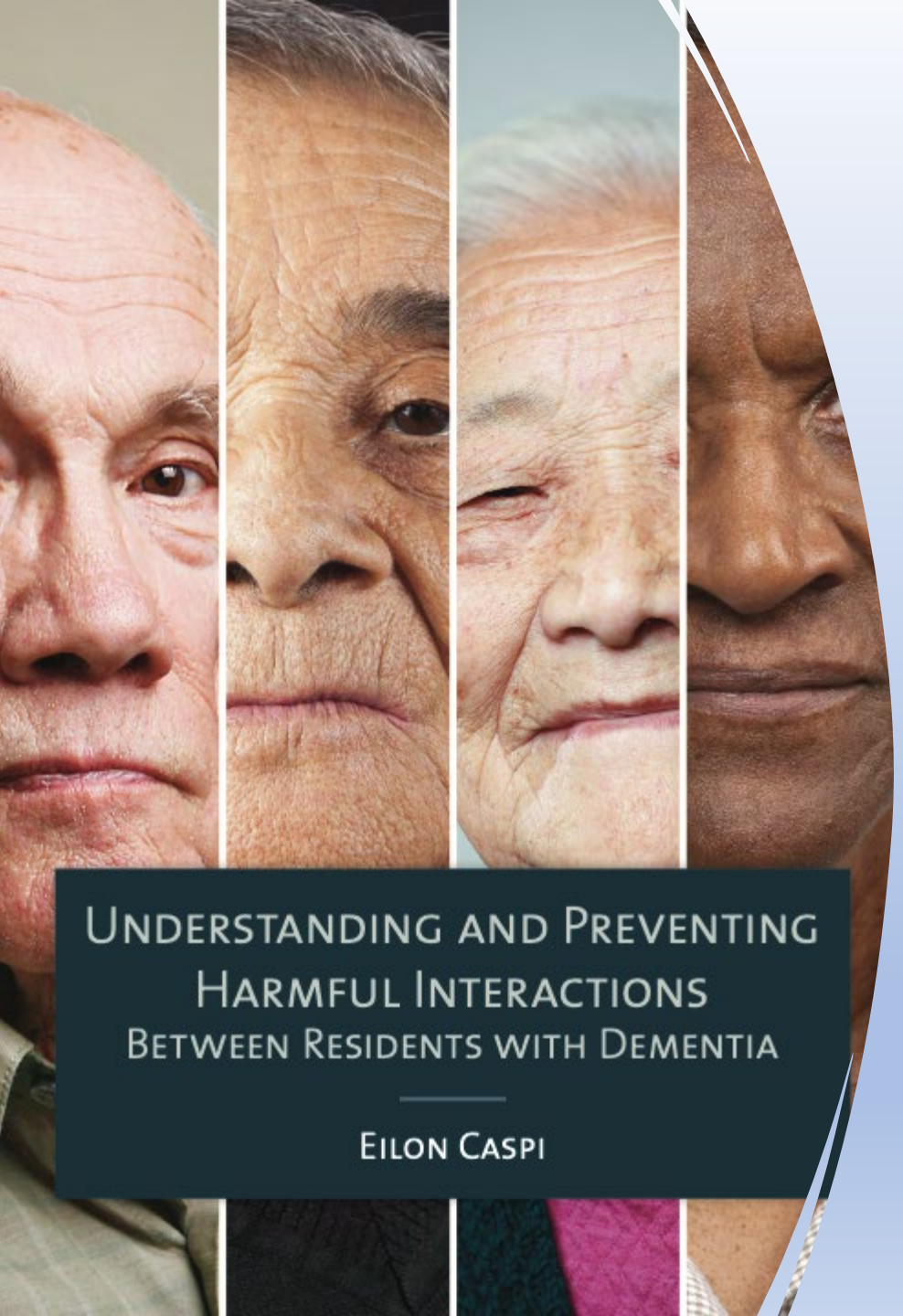
"Based on a preponderance of evidence, the allegation of neglect is not substantiated. Two residents had been roommates for over one month with no history of altercations... Staff could not have anticipated the unexpected and sudden altercation.”

But…

There *were* warning signs prior to attack:

“I told them that if I have to spend one more night with this man, then I would kill myself. They still ignored me.”

Daughter**:** “How many times were we supposed to warn them?”



Film & Book on Prevention of Resident-to-Resident Incidents

"Fighting for Dignity" (Terra Nova Films; CEUs)

https://tinyurl.com/13oft42e

Book (Health Professions Press)

https://tinyurl.com/6kk8esfm

“Understatement”

Citations issued by SSA at severity level lower than it should be…

GAO (2008); GAO (2009); OIG (2019)

LTCCC’s Elder Justice “No Harm” Newsletter:

https://nursinghome411.org/news-reports/elder-justice/

Gloria Throndrud

Neglect Not investigated

90 y/o woman with Alzheimer's in assisted living "memory care" unit

One evening, while in bed, **called for help 99 times** over 39 min → Fell off bed

On floor, **called and cried out for help 143 times**

"Please help me Lord."

Total: called for help **242 times** over **1 hour & 38 min**

Permission to use the image was received from Gloria's daughter

Daughter's voice was heard…

"**Something is fundamentally wrong with the system that allows an elderly woman**, anyone elderly, **to be disregarded**"

"**My goal** is to obtain the **basic dignity, safety** and care **my Mom deserves**"

FOX 9 TV segment: https://tinyurl.com/59rvm7a2

Alleged Neglect During the Pandemic

Resident with Lewy Body Dementia in assisted living “memory care”

- **March 18**: Family visits not allowed

- Lost a lot of weight; heavily soiled; disheveled; facial hair; toenails ingrown & painful
- Six falls in less than 2 weeks; unable to walk on his own; required two-staff transfer

- **June 10:** Daughter decides to take him home. **WHAT SHE SAW WHEN SHE ARRIVED**:
- Shaking uncontrollably; saturated in sweat; bruised head to toe; moaning in pain
- “His genitalia was bright red and the skin was sloughing off”

Fraud

“The act of deceiving or misrepresenting”

– Merriam Webster dictionary

Daughter's Reflections

"I think it comes down to the **isolation**, the **loneliness**, and ultimately the **neglect**."

"**Our loved ones are dying** not due to COVID-19 but **due to isolation and neglect** that is going on behind the scenes."

"This was **one of the most painful and excruciating experiences of our lives** that will forever have a lasting impact on us."

KARE 11: https://tinyurl.com/y3c2s5pt You Tube: https://tinyurl.com/y54a6bco

103 COVID-19 Deaths in a Single Nursing Home

Special report

"Death was everywhere." How a Minnesota nursing home fell into a COVID-19 black hole. *Star Tribune*, 12.13.20

Shall we disregard it and grant this nursing home legal immunity?

A Perfect Storm (ChangingAging): https://tinyurl.com/53j96r8x

PRELIMINARY FINDINGS

Vulnerable and Frail Population

Nearly half of the 300 residents had some level of **cognitive impairment**

Dozens of others had conditions such as **stroke, Parkinson's** disease, & **TBI**

Many…

Medically dependent due to various **complex healthcare conditions**

Physically dependent on staff for **extensive assistance with ADLs**

Primary Consequences

- **PSYCHOLOGICAL SUFFERING**
- **E.R. VISITS & HOSPITALIZATIONS** (including substantial healthcare costs)
- **DECLINE IN PHYSICAL CONDITION**
- **MOVE TO HIGHER LEVEL OF CARE** (e.g. AL to NH and/or hospice)
- **TRAUMATIC PHYSICAL INJURIES**
- **DEATHS**

Cost of replacing a single care employee

Employment of many staff was terminated…

Others resigned…

Estimated:

Between $2,200 and $4,000

Unknown human cost of perpetrator “crossing the street” to work in a different care home…

Responsibility Determination

(*n*=300)

- **LTC Home: 77%**

- Both LTC home & Individual: 8%
- Individual: 14%
- Unknown: 1%

Trajectories

Sequence of neglectful events resulting in harm

Most prevalent forms of Neglect:

1. Neglect of Healthcare

1. Neglect of Supervision

NEGLECT OF HEALTH CARE – Assisted Living

- **Wellness Checks** required → Not done → Several residents found injured and dead many hours / two or more days later

- Resident with dementia → Falls at night → Arm fracture → Calls for help using **pendant** at 1:55am → **Left unanswered for six hours** → Found on floor at 8am

- **Lack** of **fall-risk assessment/prevention** → Injurious falls (hip fracture) → **No post-fall assessment**

- **Unsafe manual & mechanical lift transfers** against Service Plan → Several injurious falls & deaths

- Resident with TBI & stroke → **Repositioning not done** → 10 cm x 10am pressure sore → No intervention → **25cm x 25cm pressure sore** → Septic shock → Died

NEGLECT OF HEALTH CARE – Assisted Living

- Resident in “memory care” home → **Catheter not draining** → E. Coli → Septic shock → Hospital → Nursing home → Died
- Residents with diabetes → High **blood sugar levels** (540 & 765 mg/dL) → Deaths
- Resident with large bulge on stomach → Moaning in pain → Delays in recognition → **Strangulated hernia** → Death of small intestine → Died
- Resident cognitively impaired → In pain → **Metal object found in heel** → Infection → Foot amputated → Died
- **Medication errors** (e.g. fentanyl patches; blood thinner; antibiotics; antipsychotic meds) → Several deaths

NEGLECT OF SUPERVISION – Assisted Living

- Resident with dementia using wheelchair on "secure" unit → **Left via unsecured door** by the dining room → Fell off a flight of stairs → Severe injuries → Died
- Resident w dementia → **Exits via 2nd floor door** → Fell on stairs → Subdural hematoma → Died 15 days later
- Resident with dementia → **Wellness checks not done** → Left → Found dead in a pond
- Staff **unaware** resident with dementia **moved into "Memory Care" unit for 18 hours** → Found with head wedged b/w toilet & wall → Died
- Resident with Alzheimer's → Neck **entrapped** b/w bed & transfer pole → Died

NEGLECT OF SUPERVISION – Assisted Living

- Three residents with dementia → **Cleaning detergent**/supply **left unattended/ unlocked** → Ingested→ Severe burns → Died

- Resident requiring **monitoring for suicide attempts** → No staff supervision at night → Broke into locked meds cabinet → Ingested 85 dosages in an attempted suicide

- Resident with Alzheimer's "up most nights" → Walks at night in common area → **Staff asleep on sofa** (caught on camera) → Fell → Femur fracture → Died

- Resident with dementia and heart failure → Failed to plug **heart pump** at bedtime → Batteries depleted → Died

- Residents with dementia engaged in repeated **altercations** → Lack of supervision and intervention → Several physical injuries (e.g. hip fracture, head injury)

NEGLECT OF SUPERVISION – Assisted Living

Resident with borderline personality disorder & intellectual disability

→ Must be ”visible to staff at all times” due to long history of self-injurious behavior

→ **Hammers two nails into her skull** with a shoe

→ Ongoing complaints of headaches & swelling on forehead → Not addressed

→ Nearly a month later.....CAT scan: 2 nails (4.8 cm & 6.2 cm) in her frontal lobe

→ Surgical removal, 3 days in ICU, and six weeks of IV antibiotics…

Report

April 22, 2019

Funded by:
Stevens Square Foundation

Link: https://tinyurl.com/y6zorqzu

STATE + LOCAL

Report highlights abuses, preventable deaths in Minnesota's assisted-living facilities

Report of state data shows a surge in accusations of neglect, poor conditions.

By Chris Serres Star Tribune | APRIL 11, 2019 — 3:58PM

GLEN STUBBE – STAR TRIBUNE

Kristine Sundberg, president of Elder Voice Family Advocates, second from left, led a group to meet with legislators. Also there are Jane Overby, Kristine Sundberg, Kay Bromelkamp, Brenda Roth and Bonnie Wenker.

NEGLECT OF HEALTH CARE – Nursing Homes

- Resident with heart failure & diabetes → **Change in condition since 4pm** → *"Help me God."* → **Delays in calling 911 (8:48pm)** → Septic shock → Died next day

- Resident with COPD on low flow oxygen (retains CO2) → Nurse turns up oxygen flow due to low oxygen saturation levels → **CO2 poisoning** → Unrecognized →Continued to titrate oxygen flow up despite critical CO2 levels → Unresponsive → Died

- **Unsafe transfers** (against Care Plan) → 16 injuries and 16 deaths

- Resident **requiring foot pedals on wheelchair** during transfers → Foot pedal not used on way to dining room → Fell forward → Fractured vertebrate & neck → Died

NEGLECT OF HEALTH CARE – Nursing Home

- Resident with stroke → Mechanical ceiling lift transfer to commode → **Left unsupervised while attached to ceiling lift** (against manufacturer's guidelines) → **Wheels unlocked** → Commode rolls away → Fell → Legs fractured → Severe pain → ER → Died days later

- Resident with memory loss → **Shower chair wheel defective** → Didn't notify maintenance → Two weeks later → Wheel broke → Fell → Subdural hematoma (brain bleed)

- Resident with dementia → Fell → Hip fracture → **Unrecognized for 18 hours** (despite pain & 5cm x 5cm bruise) → Physician not notified → Family visit → Hospital → Died 5 days later

- Resident with cancer and chronic pain → **Prescribed 30 mg pain med** (for pain 10 out of 10) → **Administered 600 mg (20x higher dose)** → Found dead

NEGLECT OF HEALTH CARE – Nursing Homes

- Resident with "difficulty expressing needs" → Requiring gastric tube feeding → **Tube positioned incorrectly** → Vomited formula → **No emergency medical treatment** → Found unresponsive 3 hours later → Died

- Resident with severe cognitive impairment → **Failed to assess skin under post-surgical immobility boot** → Routine provider visit → Discovers 3 unstageable pressure sores → Hospital → Sepsis → Died

- Resident w severe cognitive impairment → **Enters unlocked laundry room** → **Enters cement basin** (155-degree water) → 2nd degree **burns** → Died

NEGLECT OF SUPERVISION – Nursing Homes

- Cognitively impaired resident→ **On pureed diet** due to risk of aspiration → **Frequently tries to take food from other residents** → **Tray with sandwich left 3 feet away for 90 min** → Eats it → **Chokes** → Died

- Cognitively impaired → Found with "heavy, labored breathing" (**Oxygen 78%)** → Suppl oxygen → **Never above 89%** → Physician not notified → Prepared for unrelated appointment → Didn't recheck vital signs & respiratory status → Van driver asks if should be on oxygen during ride → "No" & "Will be alright" → Arrives 2.5 hours later with "No pulse" → ER → Died

NEGLECT OF SUPERVISION – Nursing Homes

- Resident with Alzheimer's on hospice unable to communicate needs → **Air mattress overlay added** → 4 days later, 1st fall off bed→ No assessment to determine safety of using side rails → 2nd fall off bed (1 month prior to death) → 3rd fall → **Entrapment** → **Found dead** sitting on floor with **head & neck b/w mattress and side rail**

- Resident with dementia → Found with **foot on top of heat register** by bed → 1st, 2nd, & 3rd degree **foot burns** (5cm x 4cm) → Change in condition → Septic shock → Died

- Resident with Alzheimer's → **History of spilling liquids "at risk of burns"** → **Served hot soup** → Spilled → 1st, 2nd, & 3rd degree burns on thigh (20cm x 20 cm)

- Several residents with dementia → **Left unattended on toilet (against Care Plan)** → Injurious falls

Ventilator-related Deaths

- Resident with ALS dependent on ventilator for breathing (oriented but unable to reattach ventilator tubing) → Unable to speak due to tracheostomy and ventilator → **Ventilator disconnected for 11 minutes** → 2 alarms sounded. **Nurse assistant works alone** on unit (nurse on break) → No response → Found dead

~~~

- Resident with quadriplegia & respiratory failure → **Removed from ventilator 2 hours too early** (not following physician's orders) → Unresponsive → Died next day

- Resident ventilator dependent 24/7 in vegetative state → **Ventilator tubing detached & alarmed** → Not discovered until one hour later → Died

- Resident with respiratory failure → **Ventilator alarm activated for 39 min** → Understaffed & Nurse assisting on another wing → No response → Returned → Died
~~~

Overarching Theme

The vast majority of the psychological suffering, physical traumas, and deaths…

COULD HAVE BEEN PREVENTED

Care Professionals:

”The trauma & hospitalization could have been prevented with earlier intervention”

“When in doubt, call”

“Why didn’t they call the ambulance sooner?”

“Somebody should have said something. It would have prolonged his life“

Contributing Factors

- **Lack of or Inadequate Nursing Assessment**
- **Omissions of or Inadequate / Unskilled / Unsafe Actions**
- **Communication Problems / Breakdowns**
- **Dangerous Delays**
- **Organizational Factors** (e.g. Unsafe staffing levels; Lack of nurse manager supervision)

Preliminary Patterns

- LACK OF **BASIC NURSING and RISK ASSESSMENT**
- LACK OF **THOROUGH & TIMELY INTERNAL INVESTIGATION**
- FAILURE TO **RECOGNIZE WARNING SIGNS** & SIG **CHANGE IN CONDITION**
- DELAYS IN SEEKING **EMERGENCY MEDICAL CARE**
- LACK OF **BASIC CARE ASSISTANCE & TIMELY INTERVENTIONS**
- LACK OF, INADEQUATE, OR NOT FOLLOWING **CARE PLANS**

Preliminary Patterns

- LACK OF **SUPERVISION**
- **“SECURED” DEMENTIA CARE HOMES**…NOT SECURE
- LACK OF **NURSING / MANAGERS’ SUPERVISON OF CARE STAFF**
- **COMMUNICATION BREAKDOWNS** (Not notifying nurse / physician)
- **FAMILIES LEFT IN THE DARK**
- **DISCOVERIES DURING FAMILY / PROVIDERS’ VISITS** OR **OUTSIDE APPOINTMENTS**
- NOT HAVING OR FOLLOWING **INTERNAL POLICIES & PROCEDURES**

Conclusion

Disregard to the fate and suffering of vulnerable and frail elders in a *subgroup* of LTC homes in Minnesota

Conclusion

Break the silence and **dangerous normalization** of elder neglect

Would we accept these horrific incidents in child care settings?

Hold owners and **administrators** of neglectful LTC homes **accountable**

Conclusion

“A watershed moment”

– Gayle Kvenvold, President & CEO, LeadingAge MN, 2.28.18

”**Assisted living** settings – where the majority of our elders and vulnerable adults now live – **aren’t regulated at all**… and that’s **a big hole in the system**.”

– Commissioner of Health, 8.9.18

“Our protections in law are only as good as the enforcement capabilities.”

– Commissioner of Health, 11.5.18

Ensure Agencies Investigate Alleged Neglect

- MDH OHFC
- Ombudsman for LTC
- Law enforcement
- Medicaid Fraud Control Unit
- Medical Examiner / Coroner

Detection & Reporting

- N.P. / Physician
- Nursing Assistant Registry
- Board of Nursing
- Hospitals
- EMS
- Fire Department
- Funeral home directors

Report “Reasonable Suspicion of a Crime” in NHs

Affordable Care Act

“If the events that cause the reasonable **suspicion result in serious bodily injury**,

the **report must be made to [MDH] & Law Enforcement immediately after** forming the suspicion (but **not later than 2 hours** after forming the suspicion).

Otherwise, the report must be made **not later than 24 hours after** forming the suspicion”

CMS Memo: https://tinyurl.com/y6a923z8

Train Staff in Recognizing Signs of Neglect

- **Elder Assessment Instrument** – E.R.

– Fulmer et al. (2000)

Try This (Hartford Institute for Geriatric Nursing): https://tinyurl.com/y5q9rqbw

https://www.ncbi.nlm.nih.gov/pubmed/11015061

- **Clinical Signs of Neglect Scale** (Hospital; Pre-screener)
  – Friedman et al. (2017)

https://www.ncbi.nlm.nih.gov/pubmed/28829244

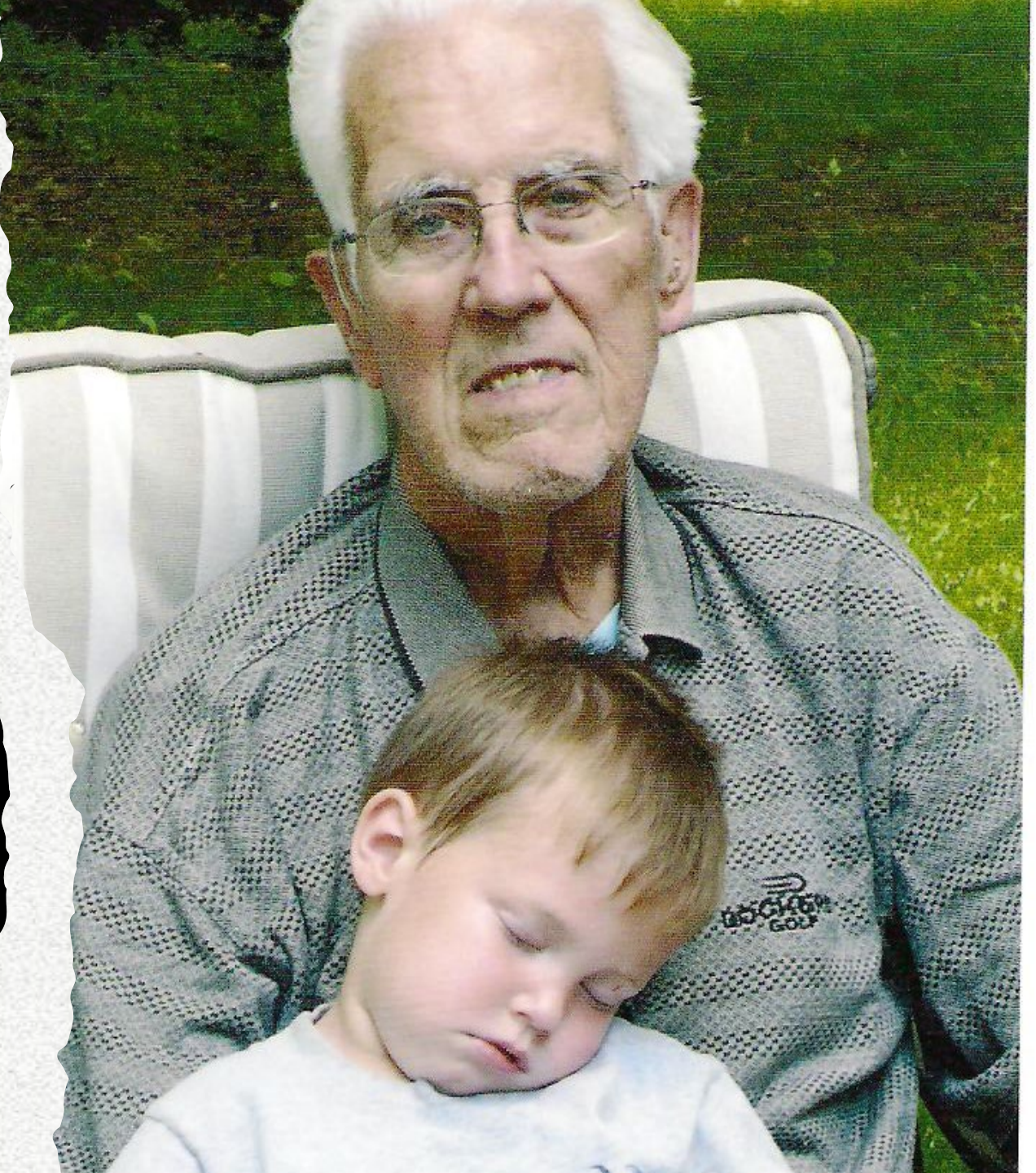
86-year-old Werner Allen

Poem – The Promise

ChangingAging:

https://tinyurl.com/8xrhwjvj

Permission to use image received from Werner's daughter



Questions & Discussion

IT IS THE HUMAN RIGHT OF ELDERS TO LIVE IN SAFE CARE HOMES

84-year-old Jacqueline Hourigan

Permission to use the image received from daughters

elder voice

Family Advocates

Thank you for joining us!

Together we give our elders a voice

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