"They make you pay"

How Fear of Retaliation Silences Residents in America's Nursing Homes

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National Consumer Voice for Quality Long-Term Care 47th Annual Conference

Source of image: Canva/Katarzyna Bialasiewicz

New Report

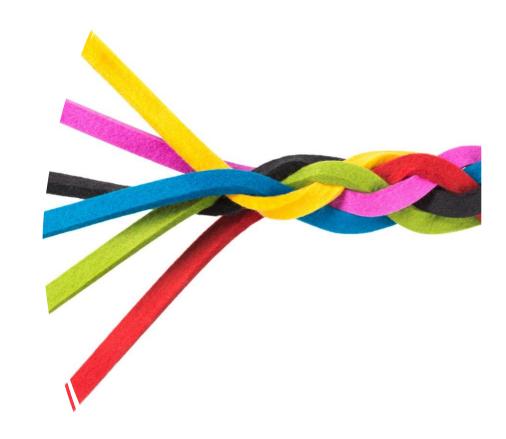


https://nursinghome411.org/retaliation/

USA Today (6.16.23): https://tinyurl.com/5fvh7rfd

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- Nursing Home Inspect (ProPublica) website: https://projects.propublica.org/nursing-homes/



CNAs and Nurses – Majority Are Caring

"We love working with the residents, it gives us joy that we can assist them in the evening of their lives. We truly care for the residents and that honest care shows in the work we do."



Source: Certified nursing assistants: The Foundation. Presentation on May 14, 2018 at the Annual Meeting of Massachusetts Alzheimer's Association, Marlborough, MA.

Fear

"An unpleasant often strong emotion caused by anticipation or awareness of danger"

Merriam-Webster Dictionary

Definitions

Fear of Retaliation

"A concern or feeling of vulnerability that one's actions may cause retaliation by another."

Retaliation

"An actual or perceived negative reaction of a person as a result of another person's action or behavior."

Source: Voices Speak Out Against Retaliation Instructor's Guide

Retaliation

Definition

"Acts of retaliation / revenge by facility staff in response to complaint to the facility, Ombudsman program, or state survey agency."

Complaint Code D06

Source: National Ombudsman Reporting System

Quote

"Fear of retaliation is not something you can look up in a dictionary but if you live in a setting where you depend on others to care for you, you know exactly what it is."

Ronnie, nursing home resident

Source: Voices Speak Out Against Retaliation training video (2010)

Nothing New

"Total Institutions"

Staff retaliation against people receiving care in psychiatric hospitals:

"Looping"

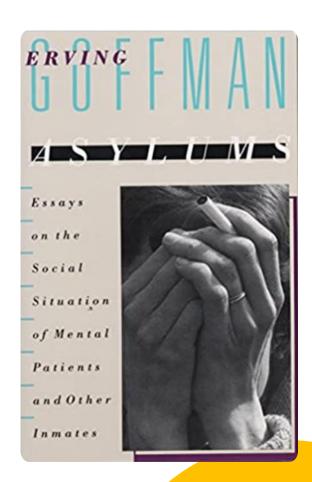
"Hectoring"

"Mortification of the self"

"Sanctioning"

"Errors of resistance"

"Conversion"



Half a Century Ago

Nursing Home

Staff Retaliation Against Residents – 1973 Study

- Resident abused for defecating on the floor or in a waste basket
- Residents' biting, punching, kicking or spitting at aides were, in the aides' minds, punishable behaviors
- Resident "mentally confused" who "did not know any better" was placed into a tub of hot water to punish him for cursing the orderly

Stannard, C.I. (1973). Old folks and dirty work: The social conditions for patient abuse in a nursing home. *Social Problems*, 20(3), 329-342. https://psycnet.apa.org/record/1973-29687-001



Nothing New

Nursing Homes

A resident in a nursing home in Ohio

Sustained severe lacerations on ear, skin tears, and bruising on his neck and hands.

When asked by staff who did it to him, he said,

"He'll beat me up again if I tell you."

Later, he identified a male aide who confessed to abusing him.



Source: U.S. House of Representatives (7.30.01). Abuse of Residents is a Major Problem in U.S. Nursing Homes

Media Report - Minnesota

In response for asking for her medications, a nurse came and slammed a phone against her chest so hard she almost passed out.

After her complaint to the state was not adequately addressed, she said:

"This is why no one knows about these crimes.

It's not because we don't have a voice.

It's because people in power deliberately choose not to listen."



80 y/o Marjory Aldrich
Photo credit: The Star Tribune

Fear of Retaliation

How Common?



Illustrator: Yuval Caspi



"We constantly hear about retaliation fears and actual harm to residents, families and staff.

This is a rapidly escalating problem that results in inconceivable suffering and it must be stopped."

Kristine Sundberg, Executive Director, Elder Voice Advocates

Survey

Atlanta LTC
Ombudsman
Program

"44% of the residents who had seen abuse of other residents did not report it."

Half did not report it due to fear of retaliation

Source: Atlanta Long-Term Care Ombudsman Program (2000). **The Silenced Voice Speaks Out**: A Study of Abuse and Neglect of Nursing Home Residents. Atlanta, GA: Atlanta Legal Aid Society; Washington, DC: National Citizens Coalition for Nursing Home Reform.

UConn Study

Connecticut LTC homes

Survey Question

Do you worry about retaliation if you were to report a complaint or concern?

23% of nursing home residents worried about retaliation if they were to report a complaint or concern

Additionally...

4% reported that they do not want to complain

1% reported not wanting to get people in trouble

Source: Robison et al. (2007; 2011)

Residents' Words

• "Yes, I heard a girl say that they know how to get even so I try to keep my mouth shut."

• "Oh yeah, always. That's why nobody makes a complaint. The administrator scares everyone and he's very belittling and yells at people."

• "Yes, there's a lot of retaliation."

Other Findings

Several residents completed in-depth interviews

Based on these interviews, the researchers found:

- Some instances of retaliation are **egregious** or highly visible, but **others** are more **subtle**.
- Many forms of retaliation may not even be recognized by residents or staff.
- Worry about potential retaliation was just as fearsome for some residents as the experience of retaliation itself.
- Those who felt conflicted about whether or not to report retaliation reported feelings of hopelessness and despair.

Study Conclusion

"Retaliation and the fear of retaliation is a reality in any supportive housing situation."

Robison et al. (2007; 2011)

Barrier for Reporting

Rights Violations,
Poor Care &
Mistreatment

"Fear of retaliation is one of the most common reasons residents do not want to pursue a complaint and disclose their identity.

Since residents live in a facility and rely on staff for their basic needs, their fear of retaliation cannot be overemphasized."

- The National Long-Term Care Ombudsman Resource Center (2018)

Residents' fears could be a factor leading to "underestimating neglect or abuse"

"The threat of retaliation not only terrifies residents..., it discourages them and their families from taking steps that would protect their rights or enforce public regulations"

- Chris Serres, Star Tribune, 2017



Identify the circumstances surrounding and manifestations of:

- 1. Residents' fear of staff retaliation
- 2. Residents' allegations of staff threats of retaliation
- 3. Residents' perceptions of staff retaliation
- 4. Actual (confirmed) staff retaliation

5. **Emotional consequences** of 1-4 above



Overarching Goals

1. Raise awareness to this phenomenon

2. Call for policy, practice, and research action to address it

* The study did *not* aim to identify solutions.

A follow up project is underway....

Barriers for Research on Mistreatment / Retaliation in Nursing Homes

- Administrators' reluctance to grant permission to conduct research (liability / adverse publicity)
- Informed consent for study participation (inc. assessment of residents' cognitive abilities)
- Residents' decline to participate in research such as due to physical disability or...fear of retaliation
- Prospective studies can be time intensive and expensive

One way to overcome barriers

Statement of Deficiencies and Plan of Correction (Form CMS-2567)

Department of Health & Human Services Centers for Medicare & Medicaid Services

Printed: 08/03/2023 Form Approved OMB No. 0938-0391

STATEMENT OF DEFICIENCIES AND PLAN OF CORRECTION	(X1) PROVIDER/SUPPLIER/CLIA IDENTIFICATION NUMBER: 415070	(X2) MULTIPLE CONSTRUCTION A. Building B. Wing	(X3) DATE SURVEY COMPLETED 05/15/2023
NAME OF PROVIDER OR SUPPLIER Crestwood Nursing & Rehabilitation Center, Inc		STREET ADDRESS, CITY, STATE, ZIP CODE 568 Child Street Warren, RI 02885	
For information on the nursing home's plan to correct this deficiency, please contact the nursing home or the state survey agency.			
(X4) ID PREFIX TAG	SUMMARY STATEMENT OF DEFICIENCIES (Each deficiency must be preceded by full regulatory or LSC identifying information)		
F 0600 Level of Harm - Immediate jeopardy to resident health or safety Residents Affected - Few Note: The nursing home is disputing this citation.	Protect each resident from all types of abuse such as physical, mental, sexual abuse, physical punishment, and neglect by anybody. ***NOTE- TERMS IN BRACKETS HAVE BEEN EDITED TO PROTECT CONFIDENTIALITY** 45263 Based on record review and staff interview it has been determined that the facility failed to protect and keep residents free from physical abuse relative to an incident that occurred between Resident ID #1 and Resident ID #2, resulting in the death of Resident ID #1. Findings are as follows: On [DATE] the Rhode Island Department of Health received a facility reported incident that states in part Just prior to the change in shift, the on-coming RN [Registered Nurse] went to check on the residents in room [room number redacted], d+[DATE] [secondary to] door being closed. Abuser [Resident ID #2] was found to be blocking entry into the room however upon gaining access, the RN noted the room looked like bed linens were spread around the room and general disorder. Victim [Resident ID #1] was in the bed but was noted to be motionless and pale. On closer assessment, the RN noted what looked like pillow stuffing inside the mouth of victim and that [s/he] had expired. Record review of the facility policy titled Abuse Prohibition last revised on [DATE] states in part, Policy: It is the policy of this facility to ensure all residents are treated with respect and dignity and that all residents are free from abuse. Definitions .Abuse: Willful infliction of injury, unreasonable confinement, intimidation, or punishment resulting in physical harm .H. Protection Immediate response to allegations and/or incidents may include as appropriate but not limited to .Increased supervision of the victim and others as needed-rooms changes .		

David Wright Director, Quality, Safety & Oversight Group, CMS

"It feels like a treasure hunt.

That form has been around since dirt. It is an old and hard to read form."

"Who is going to look through it in a nursing home?

We need to better compare information. People don't need to labor through it.

There are ways to do it more efficiently and transparently.

The more transparent we'll be, the more it will inform and guide our work."

Source: Wright & Tritz (November 4, 2016). Plenary session at the 40th Annual Conference of Consumer Voice, Arlington, Virginia

Lack of Centralized Tracking

• The aspects of retaliation examined in this study are not tracked by CMS in over 15,000 nursing homes.

• The National Ombudsman Reporting System does not track complaints related to "Fear of Retaliation" (it does track "Retaliation" with D06 Complaint Code).

Sometimes researchers can't wait for datasets to be created and become accessible...

More accurately, residents can't wait...

Nursing Home Inspect (ProPublica):

https://projects.propublica.org/nursing-homes/

Search keyword: "Retal"

Data

Initial Dataset

835 standard surveys and investigation reports (Form CMS-2567)

Final Dataset

- 100 standard surveys and investigation reports
- Completed by SSAs between June 9, 2017 and September 27, 2022
- 100 nursing homes in 30 states

Investigation Reports

Excluded

- Family fear of staff retaliation
- Staff fear of supervisors, managers, and co-workers' retaliation

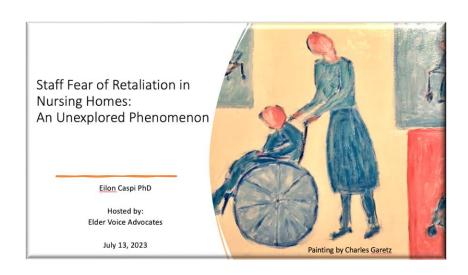
• Resident-to-resident retaliation

 Reports containing the word "Retaliation" but no relevant inormation beyond it

Staff Fear of Retaliation

Webinar (Elder Voice Advocates):

https://www.youtube.com/watch?v=Mutv1Pl7cf8&t=38s



- To read the report with fifty 1-page summaries, after logging on, scroll all the way down: https://tinyurl.com/33twcht7
- Berklan, J.M. (7.20.23). Many nursing home staff fearful of retaliation by superiors: Study.
 McKnight's Long-Term Care News. https://tinyurl.com/4njvjj6h
- Need for research on family fear of retaliation in long-term care homes

1-page Summaries

Template

• Title

Deficient practice(s) statement

 Brief background about resident(s) impacted (when available)

• Summary of *relevant* evidence

Background about the nursing home

1-page Summaries

Template

- Name of nursing home
- Federal provider ID

Date investigation completed

- Type of deficiency issued
- Severity level

- Overall Quality Star Rating
- Staffing Ratings

Findings



Illustration: Yuval Caspi

Residents' Lived Experience

In their own words

240 residents were found to experience fear of retaliation (conservative estimate)



"I prefer to stay quiet to prevent retaliation"

"I am afraid they are going to retaliate against me"

"They make you pay"

"No matter what you say, they will make you pay for it"

"Can't say their names. Don't want to pay the price."



"They will come at me"

"It backfires on you"

"Residents get chewed at when a concern is voiced"

"I feel like I am retaliated against when I complain"

"You did not want to be on the wrong side when it went off"

"I was worried that she would try to kill me by overmedicating me"



"It was like she was out for blood"

- Medication Aide describing verbally abusive retaliation by a CNA against a resident

"Never saw such evil"

– A staff member who witnessed cruel retaliatory physical abuse by a co-worker

A blind resident "put through hell" for reporting incorrect dosage of blood pressure medication

"If I told you what she has done to me, she would just make my life worse"

"I didn't like to complain because it would come back to haunt me, the staff would retaliate"



"They would just gang up on you like a pack of wolfs"

"Oh, it will come back on me. It would be abusive, It would be bad. She would figure out a way where I couldn't defend myself"

"I felt threatened for my life"

"Terrified of being evicted and feels powerless and helpless"

"This is my home. I do not want to live here, and I fear retaliation"



"I am literally afraid of her. She intimidates.
 Are you sure nothing is going to happen to me?"

"What am I supposed to do when you leave?
 I still must live here. I don't want to talk anymore"

When Speaking with Surveyors



Ombudsman:

"How come you won't let us address these things?"

Resident:

"You get to go home. I have to stay here all weekend. And once you go home, everything changes."

Source: Interview with Mairead Painter, March 16, 2023

Interview with Surveyor

A resident stated that an aide pulled a mechanical lift harness roughly behind her.

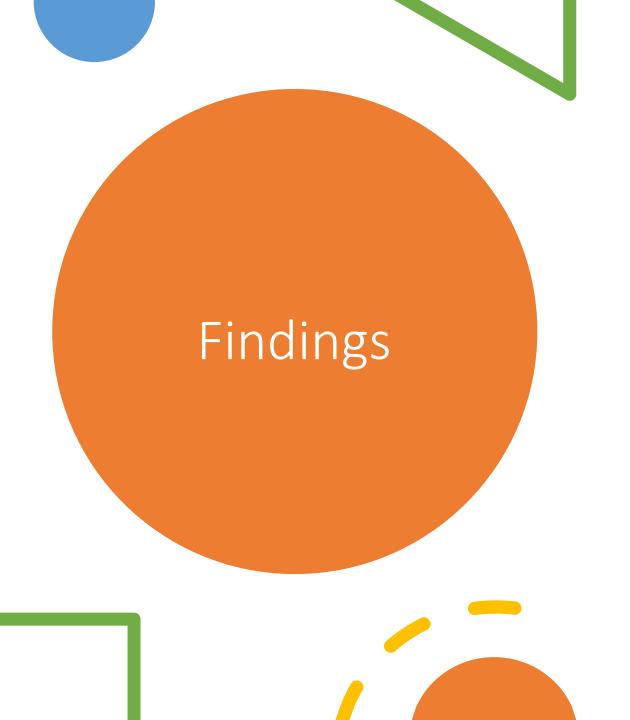
The resident didn't report it due to fear of retaliation.

She told her family to **stay quiet** about it.

"You have to be careful of what you say around here, it will come back to you."

When asked if she has ever been hurt, the resident wouldn't answer, turned her head to the door, and said, "They are out there, they are listening to everything."

When her family spoke, she said: "You don't understand, you have to keep your mouth shut."



1. Fear of Retaliation

Fear of Retaliation

Many residents were...

- Convinced their reporting on rights violations, poor care, and mistreatment will result in retaliation
- Fearful (some terrified) for their safety if they were to speak up about care concerns and mistreatment
- Many chose to remain anonymous when reporting concerns and mistreatment to employees and state surveyors
- Some chose not to identify the alleged perpetrators for fear of retaliation
- Others chose not to speak at all about the violations of their rights, care, and mistreatment

Fear of Retaliation



She "kept saying she felt threatened, her life was in danger" due to physical abuse the night before.

She didn't report it due to fear of retaliation from aide.

To protect herself during the night, she kept her reacher by her side in the bed out of fear of the abusive aide.



Fear of Retaliation

One resident stated that a CNA slapped him on his head...

He didn't want to say anything about it; adding the CNA "was bigger than him"

Another resident was fearful due to an incident in which a CNA allegedly wrung a towel soaked with hot water on her private parts.

Some were so afraid of retaliation that they didn't report mistreatment.

They remained mistreated and neglected (e.g., stayed in soiled adult depends for hours) to avoid retaliation by a particular employee.

Quote

"Fear is very powerful. It can paralyze some people to the point where they'll let just about anything happen without reporting it."

Ronnie, nursing home resident



Source: Voices Speak Out Against Retaliation training video (2010)

Giving Up

• Some residents gave up trying to voice grievances after their grievances were continuously ignored or resulted in retaliation.

One resident:

"Filing grievances was pointless as staff back each other up when asked about a situation and then become total terrors."

"It was just part of being in a nursing home"

An anonymous resident said that agency staff were too rough, so mean, yelled at the resident and other residents, and did not care about the residents.

They began to cry and felt like they just had to let things roll under the rug, because it was just part of being in a nursing home.

The resident felt it did not do any good to tell anyone, because they kept bringing more and more agency staff, and if the residents did tell someone, the staff would just treat you worse.

The resident knew other residents felt the same way.

If the residents said anything about it, it just comes back on them.

Learned Helplessness – Definition

"A phenomenon in which repeated exposure to uncontrollable stressors results in individuals failing to use any controls options that may later become available.

Essentially, individuals are said to learn that they lack behavioral control over environmental events, which in turn, **undermines the motivation to** make changes or **attempt to alter situations.**"

Dictionary of Psychology, American Psychological Association

"The act of giving up trying as a result of consistent failure to be rewarded in life, thought to be a symptom of depression"

Collins English Dictionary

Quote

"If you don't think anything is going to change and you don't see positive outcome in any way, that's when people give up.

Once people become hopeless – despair and hopelessness – is when we see the most impact. That's what is most difficult for me to see residents going through."

- Mairead Painter, CT LTC Ombudsman, March 16, 2023

Mistreatment Perpetuated

- Fear of retaliation led to lack of reporting or delayed reporting of poor care and mistreatment
- Rights violations, poor care, and mistreatment often remained uninvestigated
- In several cases, alleged perpetrators were allowed to have continued access to fearful residents

Gross Asymmetry of Power

- Extensive evidence of power imbalance in the context of residents' fear of retaliation
- Many residents were physically dependent on extensive staff assistance with ADLs
- Study by Robison et al. (2011) found:

Residents with worse health were more likely to express fear of retaliation

• Review of dozens of studies (Hirt et al. 2022) recognized:

"The imbalance of power b/w residents not being able to draw attention on their experience of abuse and staff members probably not reporting abuse in order to protect themselves or their colleagues."



Quote

"Whenever you talk about any type of abuse, there's **a power dynamic**. The person is using that to isolate. They start to carve
the person out. They keep them alone. They keep them in fear.

So, when you align with someone, you **break some of that dynamic down**.

That is what we would really encourage people to do and where the role of the Ombudsman comes in as well."

– Mairead Painter, March 16 2023

2. Residents' Allegations of Staff Threats of Retaliation

Residents reported experiencing various types of staff threats of retaliation:

- Threats to delay or not provide services and care
- Threats to neglect and abuse residents
- Threats of physical violence
- Threats of retaliation if a resident will report on being sexually abused
- Threats to discharge residents

Threat to Resident

A resident stated that staff:

Threatened the resident and his/her roommate if they complained to survey team

Said once the Surveyors were gone, things would go back to the way they were...

Threat to Family

A family member asked why the resident had not been showered, had his teeth brushed, and had his adult depends were soiled (left unchanged)

CNA:

"You better not call state (regulatory services) or it will be worse for the residents."

Threat of Discharge

Friday at 4 PM

Without advance notice...

Residents were told "We're moving you" to an all-men secure care unit

Against their will

Refuse to move?

Director of Nursing: "That's where the 5-day [discharge] letter comes in"

"They came one day and said, 'We're moving you' without any warning. I said, 'No' and the Administrator said he would kick me out, so I moved."

Media Report - Minnesota

An 84 y/o woman lived with her husband in a senior home.

She had a "pulmonary condition so severe that her doctor ordered her to avoid smoke."

When she complained about smoking, which the care home rules prohibited:

The administrator threatened to evict them for "misbehaving" and "stirring up trouble."

"We were petrified. We were being labeled as troublemakers and had nowhere else to go."

The couple could no longer live with the threat of eviction and the breathing difficulties from the exposure to smoke. They eventually moved to a different assisted living...

The woman asked:

"How would you like to be forced out of the home where you've lived for 12 years?"

SPEAK UP, AND RISK EVICTION



State lacks laws to protect seniors from retaliation

Fourth in a five-part series by CHRIS SERRES . Photos by DAVID JOLES . Star Tribune staff

3. Residents' Perceived Staff Retaliation

- Delays in care
- Neglect
- Psychological abuse (yelled at, cursed at, mocked, & received silent treatment)
- Confronted aggressively ("You reported me")
- Physical abuse
- Forcing residents to do things against their will
- Harassment through intrusive one-on-one 24/7 supervision
- Other right violations

Perceived Staff Retaliation

An anonymous resident told an LPN that something seemed off with their medications.

The LPN then became mean to them and one day:

The LPN came up behind the resident, leaned over to give them a hug, but then whispered in their ear:

"She could beat the s*** out of me, and no one would know how she did it."

"I was terrified."

The resident was afraid to say anything, but finally had to when she noticed multiple medication discrepancies.

Feces on Nose

A resident alleged that an agency staff took a towel with feces and placed it on her nose

The reason?

The resident did not want the aide to use paper towels to clean her

She wanted her to use a towel

"Can you believe that?"

"A while back I had to poop on myself because there was a wash basin with urine in it sitting on my toilet."

"I had to urgently poop but first had to urgently move the basin filled with urine and it took too long and I ended up pooping on myself."

After cleaning himself up, he took the wash basin, placed it on the desk at the nursing station, and told staff why he did that.

Shortly after...

He smelled urine in his bedroom for two days...

He found the same basin with urine in it inside his bedside drawer

4. Actual (Confirmed) Staff Retaliation

Verbal / Psychological Abuse

- Harassing
- Intimidating
- Yelling
- Cursing

Actual (Confirmed) Staff Retaliation

Physical Abuse

- While in bed, staff forcefully pulled her neck forward towards her feet causing pain and c-2 displacement requiring hospitalization
- Grabbing his pinky finger and bending it backwards toward his wrist until he screamed
- Shower scalding
- "Reflexive" slapping / punching

5. Emotional Consequences

- A wide range of negative emotional consequences
- While the severity varied, many residents suffered tremendously and were emotionally devastated
- Frustration, anxiety, fear, anger, sadness, depression, and helplessness
- Felt disregarded, ignored, belittled, infantilized, humiliated
- Some residents felt isolated and trapped (e.g. like "a prisoner in jail")





All Day Worry

Resident's concern about abrupt repositioning by night aide

He "worried all day about what will happen at night."

"When I get up in the morning, my biggest concern is what will happen in 12 hours when I go to bed at night."

He declined to identify the aide due to fear of retaliation.

Scared

Residents worried about their security and safety

- "I got scared the whole day" after staff verbal abuse
- Terrified after staff threats of physical abuse / violence
- A resident had "terror in their face" when recounting RN's verbal abuse and physically injurious abuse. She said, "They almost broke me in half"
- Some feared for their lives (e.g. "Scared to death")
- Helplessness due to inability to defend themselves from abuse / retaliation
- Worrying about the safety of other residents (e.g. roommates) and employees

Visibly Shaking

Resident A with moderate cognitive impairment had a bowel movement accident

Resident B stated that, a CNA responded by screaming at resident A for at least 10 minutes:

"G..... it man!

You're too old for this s...!

I can't believe you s... yourself again, you're a f..... baby man!"

Resident A (the victim) was "so angry" and "visibly shaking" after the verbal abuse

Worry About Other Residents

A resident (cognitively intact) stated he was left soiled in urine & B.M. for over 30 minutes...

"Out of frustration of reporting issues or complaining, I prefer to stay quiet, to prevent retaliation."

"My complaining is mostly for those who cannot advocate for themselves...

Because while being cognitive and verbal, I get this kind of treatment, it saddens me even thinking about the kind of treatment those who cannot speak and are not cognitive are getting."

Feeling Dehumanized

Residents felt treated as:

"Less than a person"



Painter: Charles Garetz

"Lowest form of life"

 "Staff acted like we were non-people. They don't even acknowledge that we are human"

• "I'm not a piece of meat, I'm not a pile of dirt."
I have rights."

• Dozens of direct resident quotes indicate:

The dignity of many residents was at risk or violated

• Dignity:

Indignity

"The quality or state of being worthy, honored or esteemed"

- Merriam-Webster Dictionary

Residents have a federal right to:

"Dignified existence" (F550)

"Be treated with respect and dignity" (F557)

Retaliation Causing Physical Pain

- A resident was pushed forcefully in her bed causing a c-2 dislocation requiring hospitalization
- Having one's pinky finger bent backward toward their wrist until they screamed
- Being scalded during a shower
- One resident alleged that a staff member banged his head against the side rail ("really hard") and that he/she then took a urinal and smashed it against his genitals over and over ("really hard")
- An aide pressed a metal tray against a resident's face (causing swelling and redness beneath eye)
- Being punched in the face (causing a bloody nose and mouth)

Retaliation Causing Physical Pain

A resident with moderately impaired cognition was masturbating in a small room connected to the nursing area...

An RN went up to him, grabbed his penis, and screamed,

"If you don't stop that, I am going to rip that thing off."

Staff witness: The resident screamed because the RN grabbed it so hard...

Quote

I asked Mairead Painter, Connecticut State Long-Term Care Ombudsman:

You went through the list of emotional consequences identified in my study.

As a State Ombudsman, what is your reaction to that in general?

Mairead:

"It is sickening, and it just shows we need to do a lot more education and outreach."

Source: Interview held on March 16, 2023

Other Findings

Overall Quality Star Rating

(Scale 1-5)

Average (n=98): 2.80 / Somewhat below state average

Distribution:

1 Star (n=22)

2 Stars (n=25)

3 Stars (n=18)

4 Stars (n=16)

5 Stars (n=17)

Preliminary evidence suggests:

The phenomenon exists in NHs across all Overall Quality Ratings

Staffing Ratings

(Scale 1-5)

Average (n=96): 3.01 / At state average

Distribution:

Preliminary evidence suggests:

The phenomenon exists in NHs across all Staffing Ratings

Conclusion



 A source of resident suffering and harm remains inadequately addressed and understudied.

The voice of many residents remains silenced.

• It is time to break the silence (literally) and dangerous normalization of this phenomenon.

Quote

"This is a human rights issue.

Vulnerable adults with complex medical issues are being retaliated against for the simple act of speaking up.

Someone needs to take the lead here and stop the practice."

– Cheryl Hennen, State LTC Ombudsman, Minnesota

Source: Serres (2017)

Develop, deliver, and evaluate educational / prevention programs

Educational programs are needed for:

- All care employees (direct & indirect), grievance officers, managers, owners
- Residents

Practical Implications

- Family members / Friends
- LTC Ombudsman Programs
- State Survey Agencies
- Law Enforcement
- EMS
- APS (in applicable states)
- Medicaid Fraud Control Units
- Medical Examiners / Coroners
- Other agencies?

Empower and encourage residents to speak up

 Develop "clear and confidential reporting mechanisms that protect residents' anonymity, thereby alleviating fears of retaliation."

- Cerulli (2023)

 Be aware that in certain situations, encouraging residents to speak up – even anonymously without strong and timely protections in place could sometimes end up harming them...

• "The staff were not stupid and could figure it out."

Policy Implications

CMS needs to...

- Strengthen oversight / protections / deterrence / enforcement
- Educate residents and families about their rights and reporting procedures
- Strengthen identification of "psycho-social harm" (CMS Memo, 2016): https://tinyurl.com/tn5khw9r
- "Reasonable Person Concept" guidance to surveyors (mid-late stages dementia)
- Centrally track all violations related to this phenomenon
- Launch a data-driven national campaign to address residents' fear of retaliation

Connecticut's Law

April 16, 2012

"An Act Concerning Fear of Retaliation Training in Nursing Home Facilities"

Requires

Annual in-service training on residents' fear of retaliation in nursing homes

https://www.cga.ct.gov/2012/FC/2012SB-00137-R000419-FC.htm

Other states need to pass a similar law

Ensure new law will also be applicable to assisted living residences...

Policy Implications

Retaliation in Assisted Living



Source of image: Canva

Resident living with paralysis of all 4 limbs (quadriplegia)

Became upset about staff handling of his mechanical lift transfer

Said he's going to report it to management

Staff member overheard and responded by:

Physically threatening, harassing & humiliating him

MDH investigation substantiated as Emotional Abuse:

https://www.health.state.mn.us/facilities/regulation/directory/ohfcfindings/hl20455015m.pdf

When crafting new legislation, prepare for push back

"The premise of this bill is that, somehow, those of us who have dedicated our lives to caring for the frail elderly will now "retaliate" against them. It is an outrageous premise, frankly..."

Martin Sbriglio, President, CEO, Ryder's Health Management
 March 8, 2012, five weeks prior to the bill's passage



Quote

"I am surprised that this is the culture.

I am not aware that residents are afraid of voicing concerns..."

Nursing Home Administrator

Ultimate Goal

Restore residents' trust and confidence that they and their families would never fear staff or managers' retaliation when speaking up about rights violations, care concerns and mistreatment in LTC settings – their home.

Ensure that their voice is heard and respected

Conclusion

"Creating an environment where residents feel secure reporting abuse is **critical for building trust**, promoting **accountability**, and maintaining the overall **safety** and well-being of senior care residents."

Source: Cerulli (9.25.23): https://tinyurl.com/2p9bf7w2

Reminder I

The nursing home complaint process is:

"The front-line system for addressing consumer concerns"

U.S. Office of Inspector General (2006)

"A critical safeguard to protect vulnerable residents"

– U.S. Office of Inspector General (2017)





Reminder II

Federal nursing home regulations state:

"The resident has a right to be free of interferences, coercion, discrimination, and reprisal from the facility in exercising his or her rights and to be supported by the facility in the exercise of his or her rights."

Source: CMS (2023)



Rights policy - Example Nursing Home, Corpus Christi, Texas

"You, the resident, do not give up any rights when you enter a nursing facility. The facility must encourage and assist you to fully exercise your rights.

Any violation of these rights is against the law.

It is against the law for any nursing facility employee to threaten, coerce, intimidate or retaliate against you for exercising your rights."



Reminder III

Deficiency Citation F585. Grievances

"The resident has a **right to voice grievances** to the facility or other agency or entity that hears grievances without discrimination or reprisal and **without fear of** discrimination or **reprisal**."

"Retaliation by staff is abuse, regardless of whether harm was intended, and must be cited"

- CMS (2023)



"If you are afraid of anything...I don't care how little or how big it is, you should be able to tell somebody. Whether it be for yourself or for someone else."

Mary (in video Voices Speak Out Against Retaliation, 2010)

"None of this will happen overnight.

You must hold on to your ideas
and always have the courage to speak your mind."

Carol A. Rosenwald (the driving force behind the first CT VOICES Forum in 1997)



Embroidery by Anne Sterner

Carol "envisioned a time when the voices of nursing home residents would be heard beyond the walls of their facilities"

Amy Porter, Commissioner, CT Department of Aging and Disability Services, 2021

Empower and Assist Residents

Residents could seek support and assistance from:

- Close family / friends
- Other residents
- Trusted CNAs and nurses
- Indirect care staff members
- Social worker / psychologist
- Recreation Therapists
- Grievance officer
- DON
- Administrator
- Owner

- Resident Council
- Family Council
- LTC Ombudsman
- State Survey Agency
- Law Enforcement
- Media



Poem

Without the Voice of Elders:

https://changingaging.org/blog/without-the-voice-of-elders/

ChangingAging, February 9, 2021



Woodcarver: Eilon Caspi

Thank you

Q&A



Photo credit: Ofir Ben Natan, ESHEL



24 unique Ftags (157 citations)

The phenomenon is documented by Surveyors under a broad range of regulatory violations

Most common Ftags identified:

- F600. Free from Abuse and Neglect (n=43)
- F585. Grievances (n=19)
- F550. Resident Rights / Exercise of Rights (n=15)
- F610. Investigate/Prevent/Correct Alleged Violation (n=15)
- F607. Develop/Implement Abuse/Neglect, etc. Policies (n=15)
- F609. Reporting of Alleged Violations (n=14)
- F565. Resident/Family Group and Response (n=7)

Severity Levels (n=100)

- "Minimal Harm or Potential for Actual Harm" (n=67)
- "Actual Harm" (n=14)
- "Immediate Jeopardy" (n=12)

- "Actual Harm" and "Minimal Harm or Potential for Actual Harm" (n=5)
- "Immediate Jeopardy" and "Minimal Harm or Potential for Actual Harm" (n=2)

Caveats

 The "type of deficiency issued" was often not directly relevant to the 4 aspects of retaliation examined in this project

 The "severity level" determination was often not directly applicable to the suffering and harm reported by residents

Caution is needed when interpreting the findings re these data elements

Call for Research

- Improve understanding of risk and protective factors
- Develop and evaluate staff / resident / family training programs
- Identify full spectrum of emotional & physical consequences on residents & families
- Examine leadership's role in addressing the phenomenon
- Study the phenomenon among residents with dementia (at all stages)
- Develop and evaluate screening and assessment tools

Call for Research

- Study the phenomenon among families and friends of residents
- Study staff fear of supervisors, managers, and co-workers' retaliation
- The role of the LTC Ombudsman Program need to be examined
- Evaluate the role of assistive technology in early detection / reporting
- Study the phenomenon also in assisted living residences

Resources

Connecticut Voices Speak Out Against Retaliation:

https://portal.ct.gov/LTCOP/Trainings/Voices-Speak-Out-Against-Retaliation

Voices Speak Out Against Retaliation **Training Video** (2010):

https://www.youtube.com/watch?v=feoQjlW3_bc

Voices Speak Out Against Retaliation Instructor's Guide:

https://portal.ct.gov/-/media/LTCOP/PDF/InstructorGuidepdf.pdf

Connecticut Long Term Care Ombudsman Program VOICES Forum:

https://portal.ct.gov/LTCOP/Content/Voices-and-Forums/Voices-Main

Fact Sheets

Nursing Home Residents' Rights (National Consumer Voice for Quality LTC):

https://theconsumervoice.org/uploads/files/long-term-care-recipient/CV NHrights factsheet final.pdf

Resident Grievances (Long Term Care Community Coalition):

https://nursinghome411.org/wp-content/uploads/2017/05/LTCCC-Factsheet-Resident-Complaints-1.pdf

UConn Study

Robison et al. (2007). Connecticut long-term care needs assessment: Connecticut Long Term Care Ombudsman Program. University of Connecticut's Health Center.

https://health.uconn.edu/dev-aging/wp-content/uploads/sites/102/2017/03/ombudsman_program.pdf

Robison et al. (2011). Community-based versus institutional supportive housing: Perceived quality of care, quality of life, emotional well-being, and social interaction. *Journal of Applied Gerontology*, 30(3), 275-303.

https://journals.sagepub.com/doi/10.1177/0733464810369810

Journal Article - Upcoming

Caspi, E. Residents fear of retaliation in America's nursing homes: An exploratory study.

Journal of Applied Gerontology