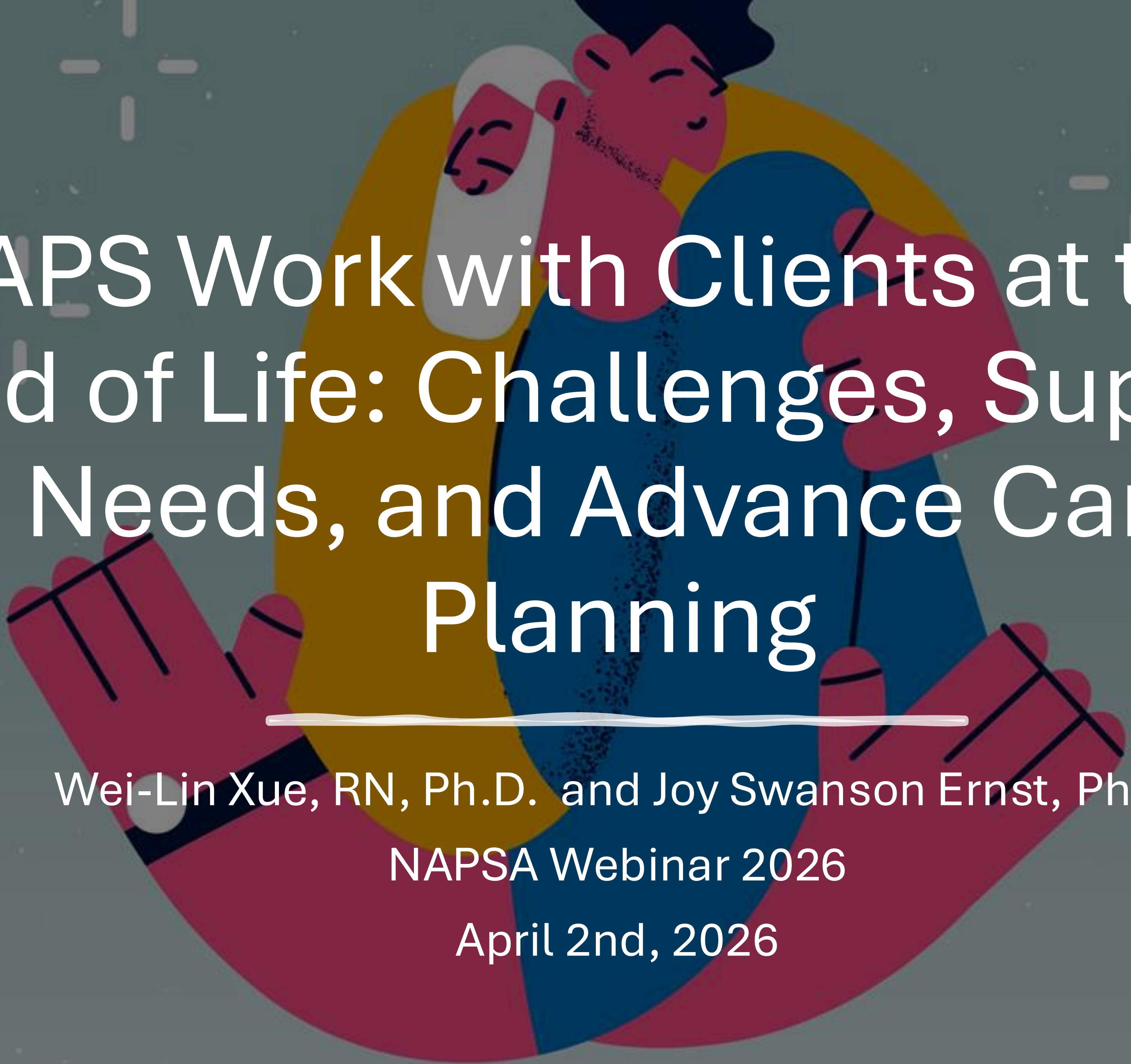

APS Work with Clients at the End of Life: Challenges, Support Needs, and Advance Care Planning

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NAPSA Webinar 2026

April 2nd, 2026

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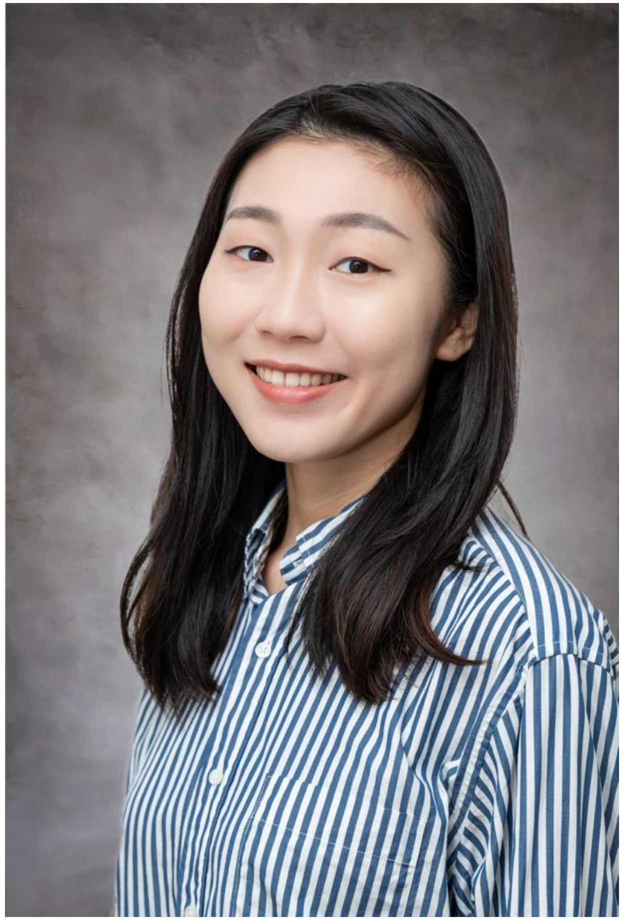

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Acknowledgements

- National Adult Protective Services Association
- Pi-Ju (Marian) Liu, PhD, Associate Professor. School of Nursing, Purdue University

Webinar Objectives

Explain	Explain the barriers and challenges for APS workers encountering and working with clients and families at the end of life.
Describe	Describe how APS workers communicate with clients about advance care planning and powers of attorney.
Propose	Propose strategies for improving training and supports for APS workers addressing the needs of clients at the end of life.

Background

- Abuse and neglect occurs in the context of advanced illness and death
- APS frequently works with individuals who are seriously ill or nearing the end of life
- Researchers’ interests
  - Wei-Lin’s experience as hospice nurse
  - Joy’s research on elder neglect in APS caseload

Definitions

Advanced illness: late-stage chronic illness, when one or more conditions become serious enough that general health and function decline and treatments begin to lose their impact – a state that progresses to the end of life

Advance care planning: discussing and preparing for future decisions about the medical care if individuals become seriously ill or unable to communicate their wishes

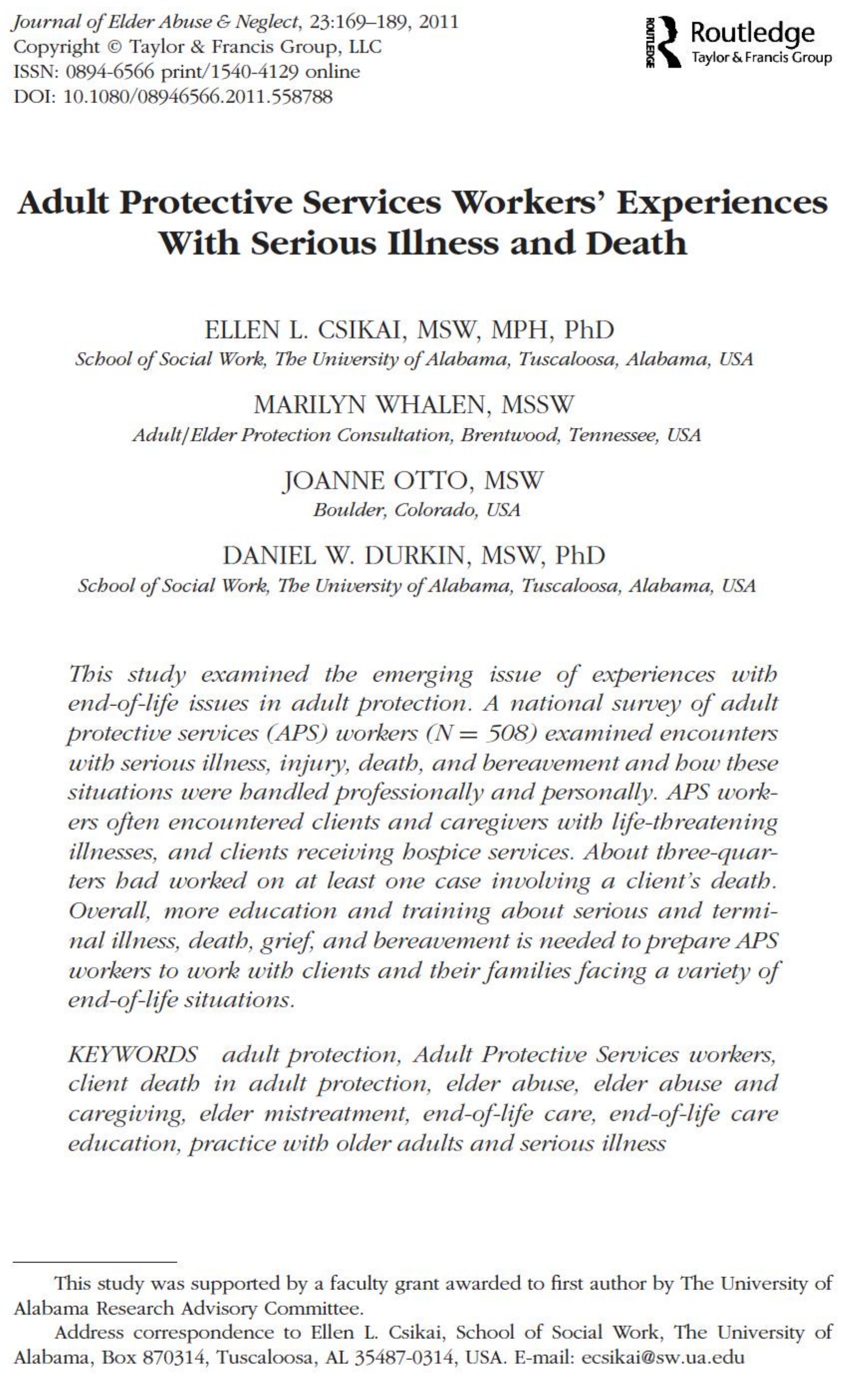
Advance directives: legal documents that provide instructions for medical care and only go into effect if an individual cannot communicate their own wishes

Research on Elder Abuse and Advanced Illness

- Studies of abuse and neglect in context of serious illness care in the community
  - Consequences of unmet needs for care "high need high cost" older adults (Beach et al., 2020)
  - Social workers encounters with victims and perpetrators of elder abuse (Goldblatt et al, 2018)
  - Nurses' encounters with self-neglect (Band-Winterstein, 2018)
- Studies of how abuse/neglect at EOL handled in health care settings
  - Underreporting and uncertainty about reporting (Liao & Jayawardena, 2009)

APS Workers' Experiences

- Survey of 508 APS workers in 2005
- Majority of workers reported frequent encounters with serious illness and death, including death of clients
- Workers also reported encountering caregivers with life-threatening illness or who had recently died
- Situations were difficult due to lack of experience and education, or lack of time to process issues
- Most used coworkers or supervisors for support



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Adult Protective Services Workers' Experiences With Serious Illness and Death

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This study examined the emerging issue of experiences with end-of-life issues in adult protection. A national survey of adult protective services (APS) workers (N = 508) examined encounters with serious illness, injury, death, and bereavement and how these situations were handled professionally and personally. APS workers often encountered clients and caregivers with life-threatening illnesses, and clients receiving hospice services. About three-quarters had worked on at least one case involving a client's death. Overall, more education and training about serious and terminal illness, death, grief, and bereavement is needed to prepare APS workers to work with clients and their families facing a variety of end-of-life situations.

KEYWORDS *adult protection, Adult Protective Services workers, client death in adult protection, elder abuse, elder abuse and caregiving, elder mistreatment, end-of-life care, end-of-life care education, practice with older adults and serious illness*

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Study design

- Qualitative design to hear from APS workers firsthand
- 7 online focus groups with APS-affiliated workers from diverse locations and settings
- Focus groups allow for interaction and elaboration on perspectives and experiences with difficult or sensitive topics (Barbour, 2018)

Participant Recruitment

Join Us for a Focus Group Discussion on Elder Mistreatment at the End-of Life

FOCUS GROUP

We would like to hear from Adult Protective Services (APS) workers to share their experiences and challenges assisting clients who experience abuse at the end of life.

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- Email and flyer that were sent to all NAPSA members
- 29 recruited via email
- 9 nurses in the NAPSA nurses’ group participated in their regularly scheduled monthly meeting
- 7 focus groups and 1 individual interview

Data Collection and Analysis

- Researcher-developed interview guide
  - Frequency of dealing with advanced illness and end of life issues with APS clients and/or their family members
  - Types of abuse encountered
  - Challenges or barriers in serving clients
  - Personal and professional effects
  - Use of advance care planning
- Used thematic analysis (Braun & Clarke, 2021)

Key themes:

Family Issues

- Family conflict
- Family financial need
- Family not equipped for home care

Client self-determination

- Client’s desire to die at home
- Dying clients refuse care

Clients cannot get needed care

Personal and professional impact

- Affected by client’s decisions and death
- Feel unprepared
- Empathy

Resources and support needed

- Collaboration with other agencies
- Peer support
- Trauma-informed organizational support

Family issues: Family conflict

Family members can disagree about appropriate EOL care (aggressive treatment vs. palliative care)

Conflict complicates efforts to provide effective support and services

Family conflict

“Sometimes the person at the end of their life . . . will just defer to the family because they're just like, well, **my family is going to be the one that's left**. . . and **I want to make them happy.** And just trying to because like those cases will get screened in for mental abuse too, and it’s . . a difficult situation to navigate. . . especially when somebody's decisional or even worse when somebody is like when that's in question.” (APS Investigator)

Family conflict

“ It's just everyone is so different and sometimes it's **the family not being in agreement with what the client wants or sometimes family is not ready to sign on to hospice, where the client is**. And sometimes it's that they know if other services start coming into the home, their people are going to see what's going on, and there's going to be investigations. **That's when the financial exploitation comes into play, and neglect.** That's when we see a lot of those.” (APS worker)

Family issues: Family financial need

Complicates APS efforts to ensure appropriate care

Families often prioritize home ownership or pooled family resources over nursing home care

Financial constraints can lead to unintentional neglect

Influence of cultural and religious beliefs

Family financial need – costs of care

“A big barrier and a concern for our patients is the cost. They want to go home because they don't know, they don't know much about what the costs would be to go to an assisted home or [a skilled nursing facility]. They don't know what those are going to be, so they don't want to think about it. . . **And the family is not prepared to take that burden on if mom or dad doesn't have the money, it's that's a tough one to negotiate.”** (APS investigator)

Families not equipped for caring

Denial and grief hinder decision-making and support provision

Insufficient resources complicate caregiving and affect client safety and quality of life

These factors are hurdles for APS

Readiness for care

"The family members are, I think, emotionally, not looking at the situation. **Their emotions are involved versus thinking rationally about what is the best interest** (of their family member) this situation." (APS investigator)

Client self-determination

Workers balance support for clients' choices with meeting clients' needs

Many clients want to die at home and decline at-home and institutional care

Service refusal is also tied to the need to preserve family resources and protect family members

Clients and referral sources often do not understand the limits of APS

Self-determination – desire to die at home

“(At times) you encounter someone at end of life, and **they're being abused, and they want to die at home regardless.** This has been their decision all along.” (Program Field Rep for APS)

“We’ve worked to get 24/7 services in. But she (the caregiver) bites a little bit, right? Like she feels like she should be providing care, but then she cannot change . . . the incontinence devices and then he sits and (it is) causing wounds. So yeah, **it's a very difficult time and you want to honor that, but you also want to make sure that they're safe and they have that dignity.**” (Asst. Director Adult and Aging Services)

Clients cannot get needed care

- Barriers include shortages of health care professionals, absence of community resources and skilled nursing facilities, and high cost of care
- Barriers result in substandard care, extended hospital stays, and abuse and neglect
- Financial burden on families

Clients cannot get needed care

"There's really no aftercare after that. We deal with these cases when we can't place a client and they're left home with no resources, minimal support. And we all know what the outcome is. They will eventually pass away in substandard conditions, and we are helpers. We are trained and it's embedded within us to help and save people. **And when you can't do that, it's not a good place to be."** (APS nurse)

"[State's name], probably for the last year or more, has been experiencing a **massive shortage in healthcare professionals. . . outside of family caregiver support**, I think one of the **biggest challenges right now is just finding the level of care that clients need."** (Adult protection caseworker)

Personal and Professional Impact:

- Affected by clients’ decisions and their deaths
- Feeling the lack of preparation to deal with these issues
- Empathy

Affected by Client’s decision and Death

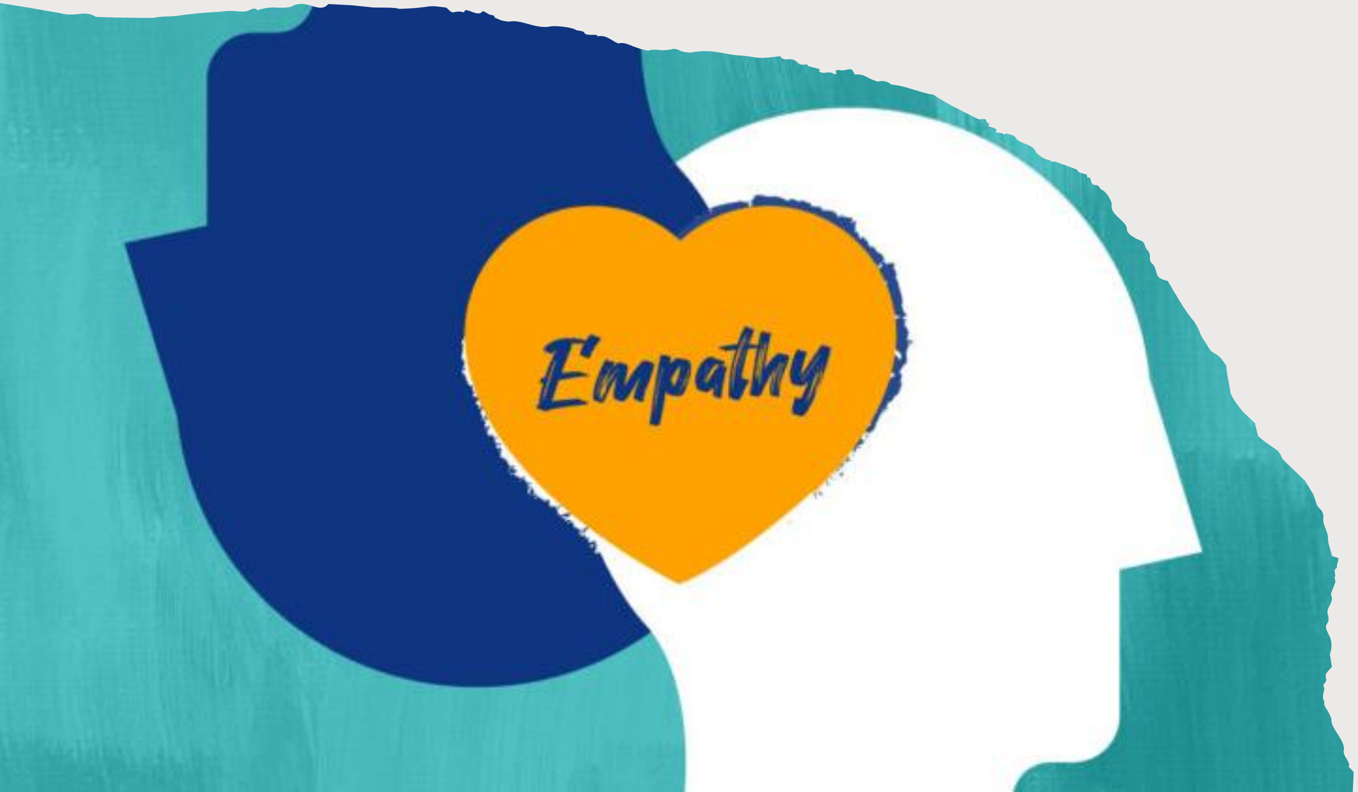
“**I'll never forget the first time I had a client die** and not while I was there, even you know. But when I heard about it shortly after we became involved, and **it wrecked me out for a little while. I was really upset about it**. And then you know this, that was five years ago or whatever. And then by the 4th or 5th time. It happens. You know it upsets me a little less.” (Adult Services Specialist)

“So, it's sometimes **I am not prepared to see what I'm seeing**, to see how people are living, and that's what they've chosen to do and the people that are living with them and a lot of times family members when they'll call me, they say I can't do anything about the way Dad wants to live.” (APS investigator)

Feeling the lack of preparation

“I had hospice experience and long-term care experience coming into this job. I'm prepared to deal with it. I didn't feel unprepared, but **not everybody on my team is prepared to handle this stuff**. **It's a very uncomfortable conversation, especially when you're coming into these situations as an APS investigator.** You know, it's gotten to a real bad place that nobody else could solve the problem. By the time we get in there and we're still dealing with people who are at the end of their lives, and we're still talking to family members that are grieving a loss. (APS Investigator)

Development of empathy



"I might not necessarily agree with those choices. **I might not necessarily think that they're making the best choices for themselves, but if they have the capacity, if they have the understanding of what they're doing, I can't stop them.** And that's probably one of the biggest struggles that I've had while working in the social work field is that we can't control what somebody else is going to do in their own personal life as long as it's not affecting, if they're not harming themselves or somebody else. " (Adult Services Resource Coordinator)

Resources and support needed

01

More collaboration between agencies

02

Peer support between workers

03

Trauma-informed organization support

More collaboration between agencies

“We need to work together here in this hospital environment—planning, collaborating in this safe place—so that when they leave, if they do leave, we’re continuing to move the ball forward. I would just say that our hospital system sometimes feels like we’re kind of stuck in that situation.” (Professor of family and community medicine)

“The staff at these (bank) branches, who witness the decline of their customers, could advocate for better preparation, such as establishing a trust, a will, or a power of attorney. This way, there isn't just one person who, as they decline, becomes vulnerable to financial abuse due to a lack of preparation or protection. Having a power of attorney or appointing someone else as a decision-maker can help protect those who, while still capable of processing some things, may struggle with managing numbers, for example.” (Social Worker)

Peer support for workers

“ **When we talk about it, you feel a little better, and you get support from others, along with some ideas on what you can do.** But we are also improving our self-care. **I think having some trauma awareness classes might be a good idea as well.**” (Director of Nursing, Community Division)

“What we typically do with our staff is, you know, **we listen, we support, and we try to give them the time to talk through what they're experiencing and feeling**. Most of the time, **it's a trauma response where a past bad experience is being triggered, and they need time to process it.**” (Director of Community Operations)

Trauma-informed organization support

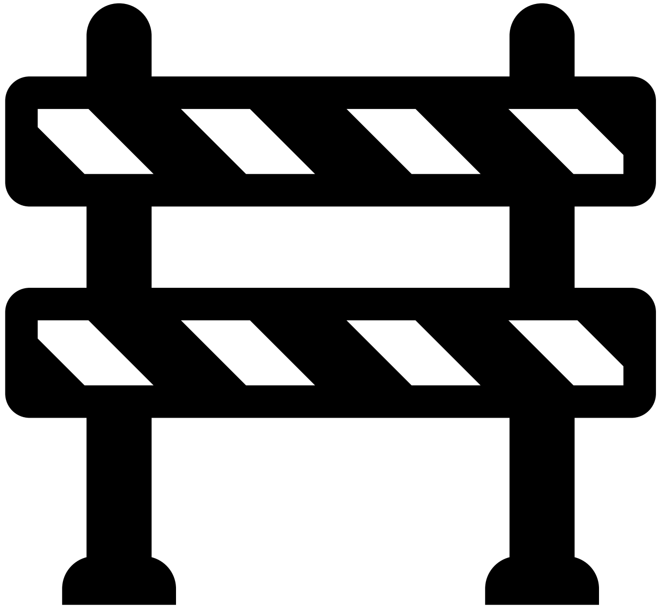
"We've been having many discussions about self-care and managing secondary trauma. **We conducted a training session on this, not just for APS, but for our entire staff, because in the field of aging, everyone is likely to encounter situations like this. We're also planning to provide training on trauma-informed care to help address these issues further."** (Asst. Director Adult and Aging Services)

Advance care planning (ACP) and advance directives (ADs)

- Involvement in ACP and ADs varied
- Challenges and barriers
- Resources and supports needed
- Does advance care planning prevent abuse?

Challenges and barriers

- Lack of understanding
  - Workers, clients, caregivers, and other family members do not understand purpose of ADs or the rights, duties, and responsibilities of a POA
- Client or family denial
  - “You’re either too early or too late”
  - Resistance to discussing advance care planning is linked to history of trauma in the family
  - People with capacity have the right to refuse medical care and other assistance



Challenges and barriers: Client capacity

"The client's ability to make decisions hasn't been officially assessed as lacking capacity yet, but it fluctuates. We struggle to determine if the client's signature reflects their true wishes and decisional ability at the time. There's medical and legal terminology regarding capacity, but we also have our own assessments of decisional ability. When someone is in advanced illness or end-of-life stages, these decisions are often not straightforward."(APS Program Supervisor)

"One of the things we've seen with end-of-life decisions is that when the client doesn't have the capacity to consent to hospice services, we've been contacted to involve APS for consent. However, even if we're guardians, we cannot consent to certain actions, like removing life-sustaining treatment. . . it creates a challenge for clients at the end of life who don't have anyone else to consent for them." (APS Program Supervisor)

ACP support needs

- Education for workers
- Community resources for clients
    - Explain different types of directives
    - Explain POAs
    - Medical professionals need to explain EOL options
- Everyone should be involved
- Does ACP prevent APS involvement or abuse?
    - ”I don’t know that it will fix any problems”

Summing up:

- APS workers frequently deal with clients or family members with advanced illness and nearing the end of life
- Workers must navigate complex and difficult situations involving family conflict, a family's ability to provide care, and financial exploitation
- Commitment to client self-determination is often difficult to reconcile with a client's need for better care
- Workers are often deeply affected by their clients' situations
- Though resources and support for workers are available, they can be difficult to access
- Appropriate roles for APS in advance care planning and advance directives are determined by agency policy, worker skill and experience, and existence of resources within and outside the agency

Discussion

- Do our findings resonate with your own experiences in APS? In what ways?
- What are strategies for improving training and supports for APS workers addressing the needs of clients at the end of life?

Thank you!

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Adult Protective services work with clients at the end of life: challenges and support needs

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Affiliations + expand

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Abstract

Adult Protective Services (APS) professionals frequently interact with clients who are seriously ill or dying as they investigate cases of elder abuse and self-neglect. This study explored the unique challenges and support needs of APS workers in these end-of-life contexts. Seven focus groups and one individual interview with APS professionals and individuals working closely with APS were conducted. Thematic analysis identified two overarching domains: (1) challenges - including family conflict, limited caregiver preparedness, client self-determination, challenges to service access, and emotional strain on professionals; and (2) support needed - such as improved interagency collaboration, peer and organizational support. Participants emphasized the emotional toll of witnessing client decline and death, and highlighted gaps in training, coordination, and workplace support. Findings highlight the need for targeted policy and practice reforms to better equip APS professionals addressing elder abuse and self-neglect at the end of life.

Keywords: Adult protective services; elder abuse; end-of-life; self-neglect.

https://pubmed.ncbi.nlm.nih.gov/40932788/

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