

Webinar Title

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

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Summary of Research (500 word max)

This study examines the experiences of Adult Protective Services (APS) professionals working with clients who are seriously ill or nearing the end of life, a context in which abuse and neglect often occur alongside advanced illness and death. APS professionals frequently encounter these situations, yet limited research has explored their experiences and support needs in this context. Using a qualitative design, this study conducted seven focus groups and one individual interview with APS-affiliated professionals from diverse roles and settings across the United States. Data were collected using a researcher-developed interview guide and analyzed using thematic analysis. Findings highlight that APS workers frequently navigate complex and difficult situations involving (1) family conflict, (2) client self-determination, (3) personal and professional impact and (4) resources and support need.

First, family conflict is a common challenge, particularly when family members disagree about care decisions or are not prepared to support end-of-life care. Financial concerns also play a significant role, as the cost of care can influence decisions and contribute to neglect or financial exploitation. In addition, families are often emotionally unprepared, which affects their ability to make decisions in the client's best interest. Second, client self-determination presents another key challenge. APS professionals must balance respecting clients' wishes, such as the desire to remain at home, with concerns about safety and adequacy of care. At the same time, many clients face barriers to accessing needed services due to shortages of healthcare providers, limited community resources, and high costs of care. These barriers can result in substandard care, prolonged hospital stays, and increased risk of abuse and neglect. Third, APS professionals also reported significant personal and professional impacts. Workers described feeling unprepared to handle end-of-life situations, particularly without prior experience or training. They are often affected by clients' decisions and deaths and must navigate emotionally difficult interactions with clients and families. Despite these challenges, many workers described developing empathy and striving to respect client autonomy. Finally, participants identified several key support needs, including improved collaboration between agencies, stronger peer support, and trauma-informed organizational practices. While some resources are available, they are not always accessible. The role of APS in ACP is shaped by agency policy, worker experience, and available resources.

Advance care planning (ACP) and advance directives (ADs) emerged as an important but inconsistent area of practice. Involvement in ACP varies widely, and multiple challenges were identified. Workers, clients, and families often lack understanding of the purpose of ACP, including the roles and responsibilities associated with advance directives and power of attorney. Resistance to ACP discussions is common and may be influenced by denial, timing issues ("too early or too late"), or prior trauma. Additionally, questions remain about whether ACP can effectively prevent abuse or reduce APS involvement. Participants emphasized the need for greater education, clearer communication about directives, and stronger involvement from medical professionals in explaining end-of-life options.

Overall, the findings demonstrate that APS professionals play a critical role in supporting vulnerable adults at the end of life, but face significant challenges that require enhanced training, collaboration, and system-level support.

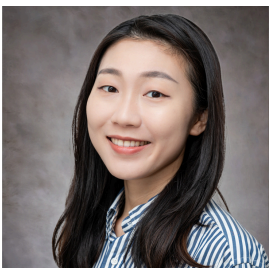
Practice & Policy Implications (e.g.: How can this research inform the Adult Protective Services field? What additional data is needed? What may be possible next steps?) (500 word max)

This study highlights several concrete implications for APS practice, policy, and future research. APS professionals need more targeted preparation to manage end-of-life cases, including training on navigating family conflict, assessing caregiver capacity and financial stress, and balancing client self-determination with safety concerns. Advance care planning (ACP) should be more clearly integrated into APS practice. Workers should be equipped to explain advance directives and power of attorney, recognize appropriate timing for ACP discussions, and collaborate with healthcare providers to support these conversations. At the same time, findings indicate that ACP should not be viewed as a standalone solution, as it does not necessarily prevent abuse or reduce APS involvement, particularly in the presence of family conflict, denial, or limited resources.

The findings also point to the need for earlier and stronger interagency collaboration. APS is often involved late, after situations have escalated. Improved coordination with hospitals, hospice providers, home health services, and financial institutions and during hospital discharge, may help identify risks earlier and reduce crisis-driven APS involvement. System-level barriers remain a major challenge. APS professionals frequently encounter situations where needed services are unavailable or unaffordable, including limited access to in-home care, shortages of skilled nursing facilities, and high costs that delay care decisions. Policy efforts should focus on expanding access to affordable services and strengthening community-based resources to support end-of-life care.

In addition, APS professionals experience significant emotional strain due to repeated exposure to client refusal to care, death, and complex family situations. Agencies should implement structured peer support, trauma-informed training, and access to mental health resources to support workforce well-being and retention. Future research is needed to better understand how ACP is used in APS settings and whether it improves outcomes such as reduced family conflict or better alignment of care with client preferences. Studies examining differences across agencies and resource environments would also be valuable. Next steps include developing clearer guidance for APS roles in ACP, integrating APS into healthcare coordination processes, expanding workforce training, and increasing public education on advance directives and early planning.

Further Reading

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This research summary is part of a series sponsored by the NAPSA Research to Practice Interest Group. The purpose of this research summary is to provide direct access to findings in order to enhance practice and clarify policy choices.