

Evaluating Educational Needs in Dementia Care: Insights to Guide Expansion of a Home Health Caregiver Curriculum



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Background

Home health and hospice providers play a critical role in supporting persons living with dementia and their caregivers as symptoms progress and care becomes more complex.^{1,6} Challenges such as incontinence, mobility limitations, behavioral changes, swallowing difficulties, and caregiver strain require skilled assessment and education.² Caregivers report little or no training in performing medical or nursing tasks; clinicians also often lack confidence in dementia care and caregiver education.⁴⁻⁷ Our team developed a home health caregiver curriculum to address such gaps. The current project aims to expand the curriculum for hospice / palliative care agencies in the state. A needs assessment survey was developed help adapt implementation for hospice providers.

Methods

- Hospice/palliative care agencies in WI identified through community partnerships.
- An anonymous REDCap survey was piloted with one agency.
- Respondents rated confidence for educating caregivers using statements “I am confident I can educate caregivers how to...” 1) prevent, 2) identify, and 3) manage, for dementia-related medical concerns, and other management strategies.
- Respondents rated agreement on a 5-point Likert scale of “Strongly Disagree” to “Strongly Agree. “Strongly Agree” and “Agree” were categorized as confident while “Neutral”, “Disagree”, and “Strongly Disagree” as not confident. Sum of ratings identified those with lower (<50 percentile) overall confidence.
- Demographics, dementia practices, resources, and requested priority topics for continuing education were also collected.

Results

- Surveys completed by N=29 hospice / palliative care staff; majority were White, female, nurses or social workers, with average of 10.9 years and median of 8 years of professional experience (range 0.5-39 years) (Table 1).
- Most respondents served rural communities and were familiar with their county Aging and Disability Resource Center (72.4%). Fewer knew about Dementia Care Specialists working through those centers (31.0%)
- Confidence ratings were generally high (means ≥3.6 on a 5-point scale); N=12 had lowest confidence (<50 percentile), more common among social workers but distributed across other characteristics, such as years in professional role, work setting and age (Table 1).
- Swallowing problems, weight loss, medication related changes, dehydration, pneumonia, and other infections were consistently among lower confidence areas (Table 2).
- Staff identified additional learning priorities: behavior changes, resources, caregiver role strain, cognitive changes, dementia basics, and communication changes (Figure 1).

Table 1: Survey Respondents

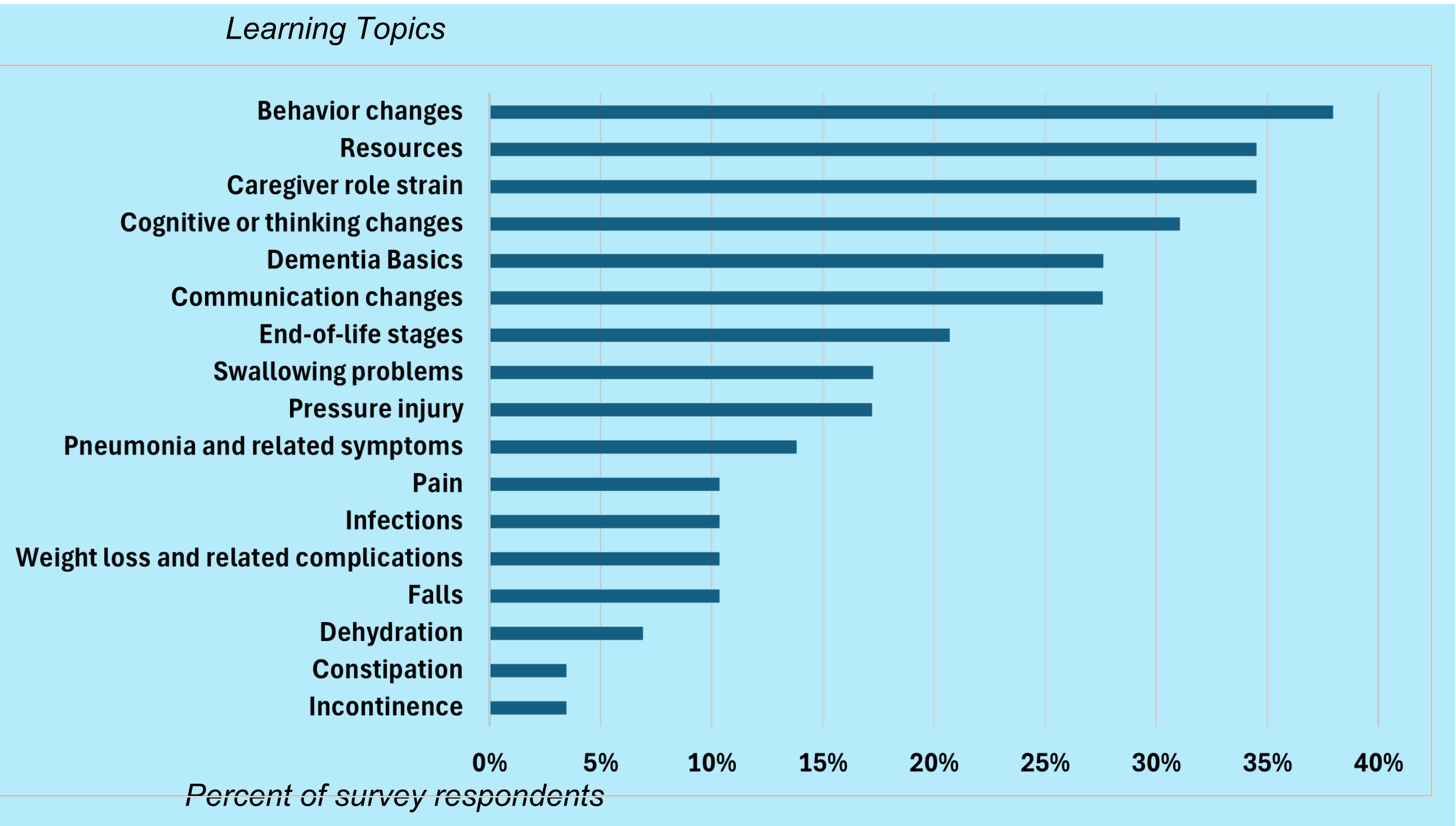
Characteristic	Overall	Confidence
	N (%) (N=29)	<50 percentile N (%) (N=12)
Professional Role		
Nursing	18 (62.1%)	25.0%
Social Worker	8 (27.6%)	58.3%
Chaplain	2 (6.9%)	16.7%
Missing	1 (3.4%)	-
Years in Professional Role		
<5 years	9 (31%)	33.3%
5–10 years	8 (27.6%)	25.0%
>10 years	12 (41.4%)	41.7%
Work Setting		
Rural community	22 (75.9%)	66.7%
Underserved community	9 (31.0%)	25.0%
Primary care	5 (17.2%)	8.3%
None of the above	7 (24.1%)	33.3%
Age		
18–25 years	6 (20.7%)	16.7%
26–35 years	12 (41.4%)	33.3%
36-45 years	-	-
46–55 years	2 (6.9%)	8.3%
55–65 years	7 (24.1%)	33.3%
66+ years	1 (3.4%)	-
Missing	1 (3.4%)	-
Gender		
Female	28 (96.6%)	91.7%
Male	1 (3.4%)	8.3%
Race/Ethnicity		
White	28 (96.6%)	100%
American Indian/Alaska Native	1 (3.4%)	-

Table 2: Conditions with Lower Confidence

Confident I can educate caregivers how to... the following in one with dementia	Prevent	Identify	Manage
	% not confident		
Pressure injury			27.6%
Incontinence and risk factors	32.1%		
Stages of dementia & complications		27.6%	
Behavior changes	39.3%		
Swallowing problems	39.3%		37.9%
Weight loss & related complications	39.3%		41.4%
Conditions changes with medication		41.4%	41.4%
Dehydration	21.4%	28.6%	34.5%
Pneumonia & related symptoms	42.9%	41.4%	31.0%
Other Infections	32.1%	37.9%	34.5%

Results

Figure 1: Topics for Learning Identified by Hospice Staff



Conclusion

Findings highlight critical gaps in clinician confidence and awareness of dementia-related resources in hospice settings and a potential value in role specific training. Respondents requested training on behavioral changes, caregiver strain, communication, and dementia basics.

Guided by these findings, we have begun partnering with interested agencies and recently launched the first hospice trainings using the refined curriculum. Ongoing implementation will strengthen staff knowledge, caregiver support, reduce burden, and enhance care quality for PLWD across Wisconsin.