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Palliative Care-Related Knowledge, Attitudes & Confidence in Home Health Care: Results From a U.S. Pilot Study

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BACKGROUND

- In the United States (U.S.), the rising use of home health care (HHC) services among people with multiple chronic conditions highlights a need for home-based palliative care.[1]
- However, only 7% of palliative care programs in the U.S. are operated by home health care (HHC) agencies.[2]
- Misconceptions and knowledge gaps often hinder palliative care uptake and effective implementation.[3-5]
- Integration of palliative care into the HHC setting could improve patient outcomes, but depends upon workforce readiness to provide services.
- Better understanding of HHC patient/caregiver receptivity to palliative care is also needed.

OBJECTIVE

- To develop and test two questionnaires assessing U.S. HHC clinician readiness for and patient/caregiver receptiveness to palliative care measured by knowledge, attitudes, and confidence.

METHODS

- Comprehensive literature review identifying existing palliative care-related survey questions and instruments.
- Development of 2 questionnaires by adapting existing items and creating new ones, capturing all eight domains outlined in the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines).[6]
- Sought expert feedback and conducted 20 cognitive interviews (10 patients/caregivers; 10 clinicians) for content validity and understandability.
- Refined questionnaires consisted of four sections, measuring knowledge, attitudes, confidence, preferences and experiences, with 79 items for patients/caregivers and 101 items for clinicians.
- Conducted pilot testing, using test-retest reliability, with 30 clinicians and 28 patients/caregivers from a large, urban HHC agency.
- Descriptive statistics were calculated in Stata 17 using the first survey timepoint.

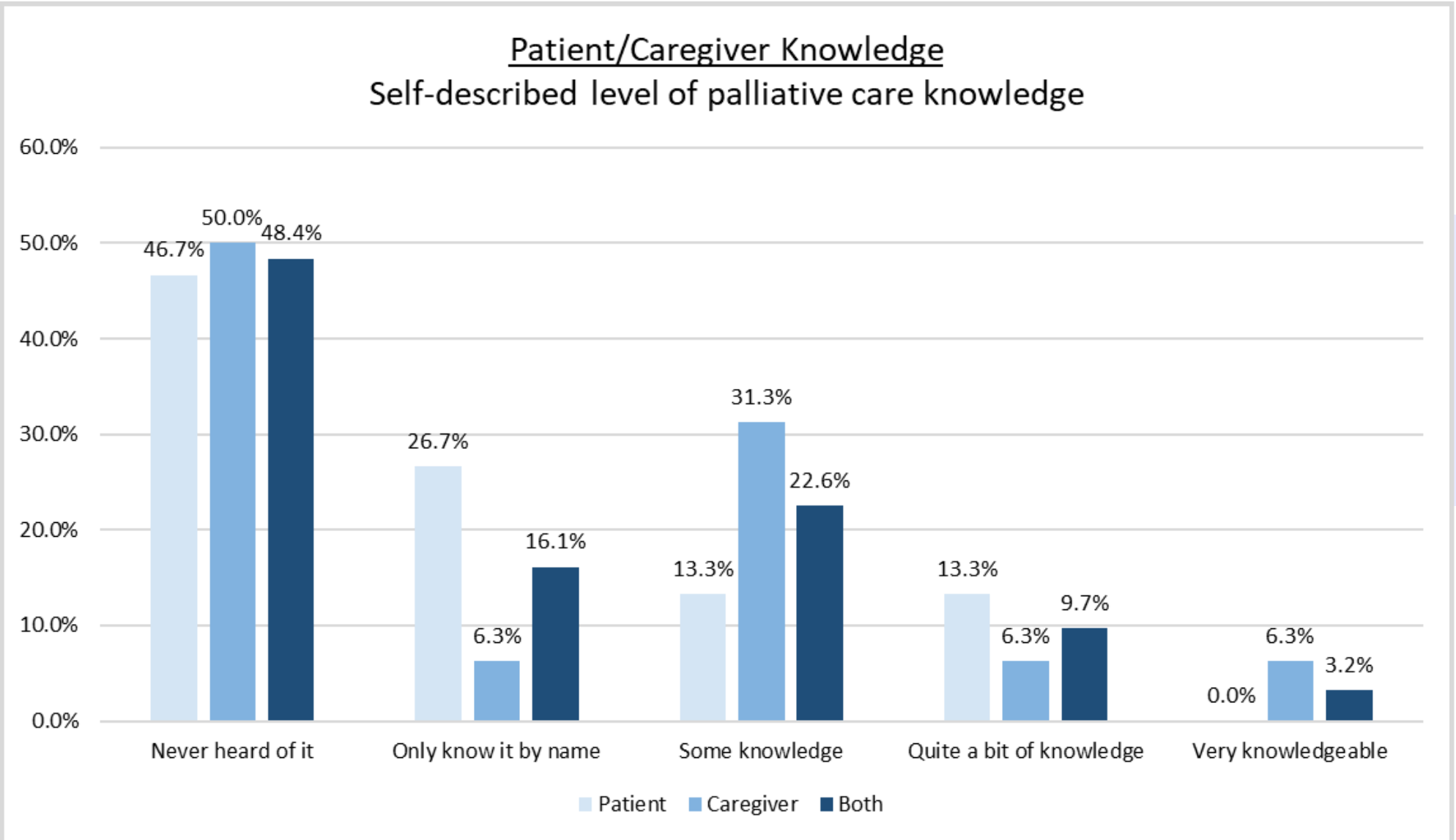
DISCUSSION

- Findings from this pilot study provide valuable insights into the current state of palliative care readiness and receptiveness among U.S. HHC clinicians, patients and caregivers.
- Significant knowledge gaps were identified, along with lower levels of confidence for certain aspects of palliative care.
- Despite this, attitudes towards palliative care were generally positive.
- Although integrating palliative care into HHC practice could lead to better patient outcomes, existing knowledge gaps could impede informed decision-making, resulting in unmet care needs, increased hospitalizations and higher healthcare costs.
- Educational initiatives and training programs can help address misconceptions and low confidence levels.

CONCLUSION

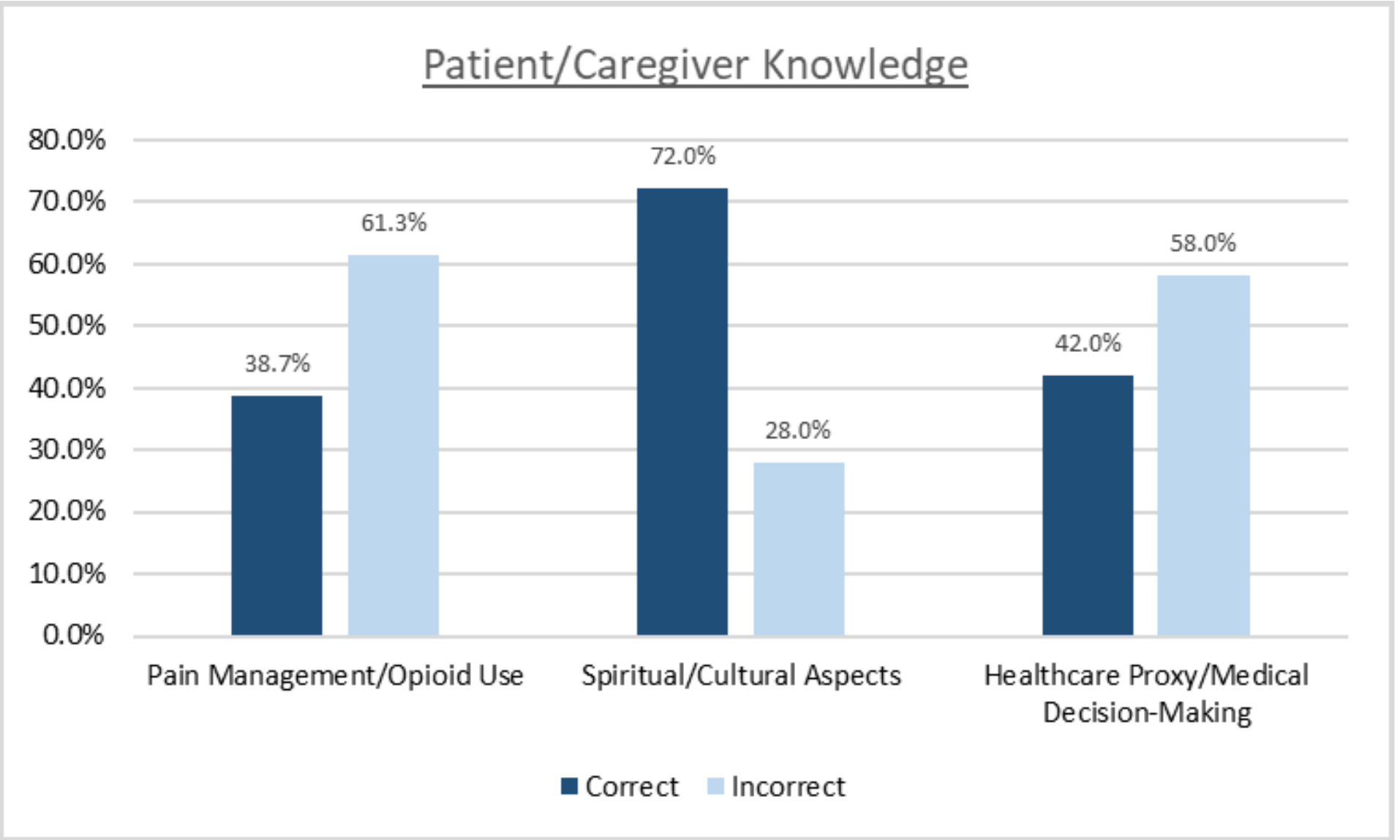
- Here, we developed and tested the first HHC setting–specific questionnaires measuring palliative-care related knowledge, attitudes and confidence among clinicians, patients and caregivers.
- Broader dissemination of our questionnaire would help identify additional training and educational needs in the U.S. HHC setting.
- In the future, questionnaires could also be adapted for different cultures and countries to enhance the global applicability of the findings and to support widespread palliative care integration into HHC practice.

RESULTS

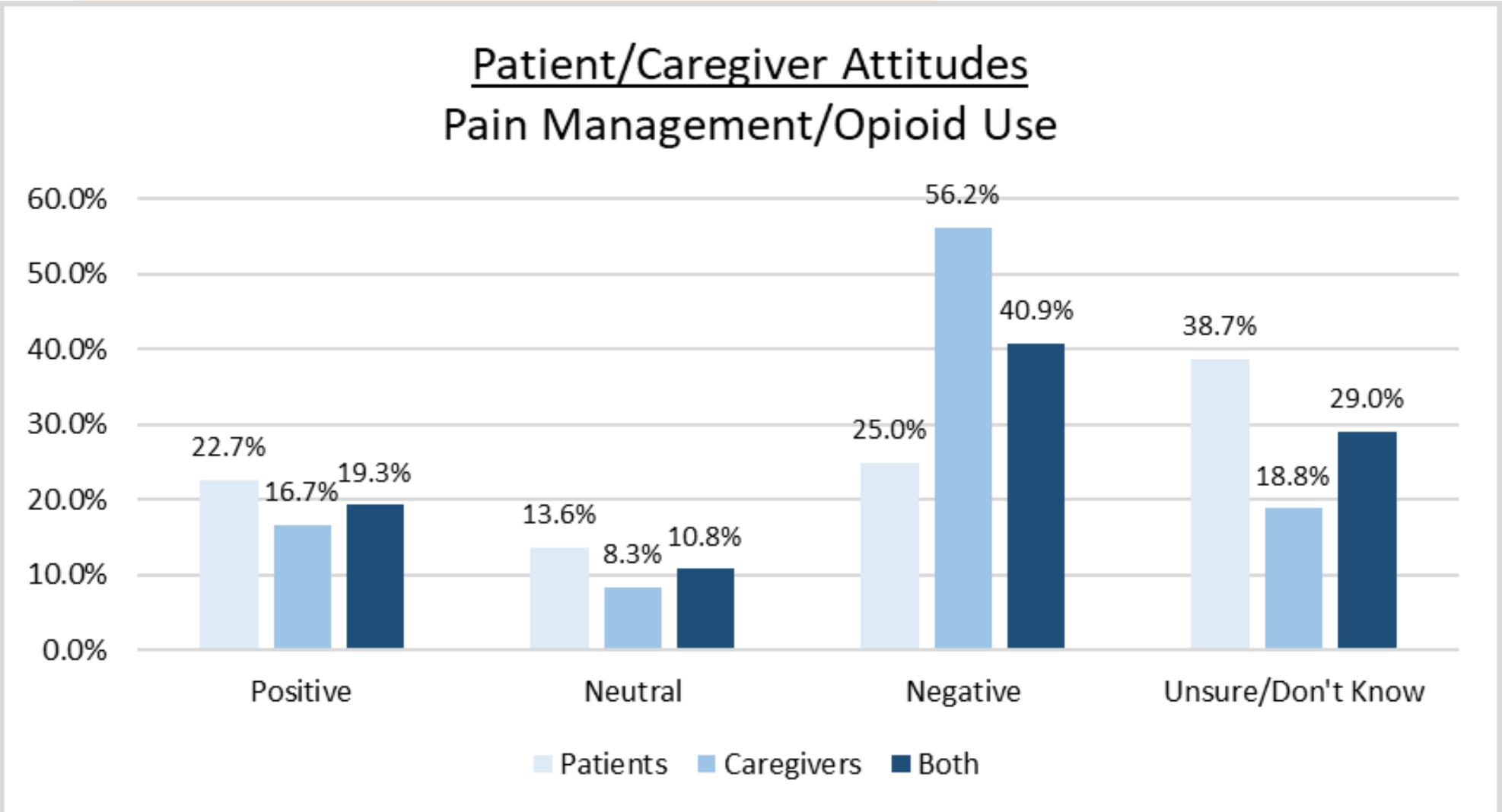

Patient/Caregiver Knowledge
Self-described level of palliative care knowledge

Overall, 48.4% of patients/caregivers were unaware of PC. However, 31.3% of caregivers indicated they had some knowledge.

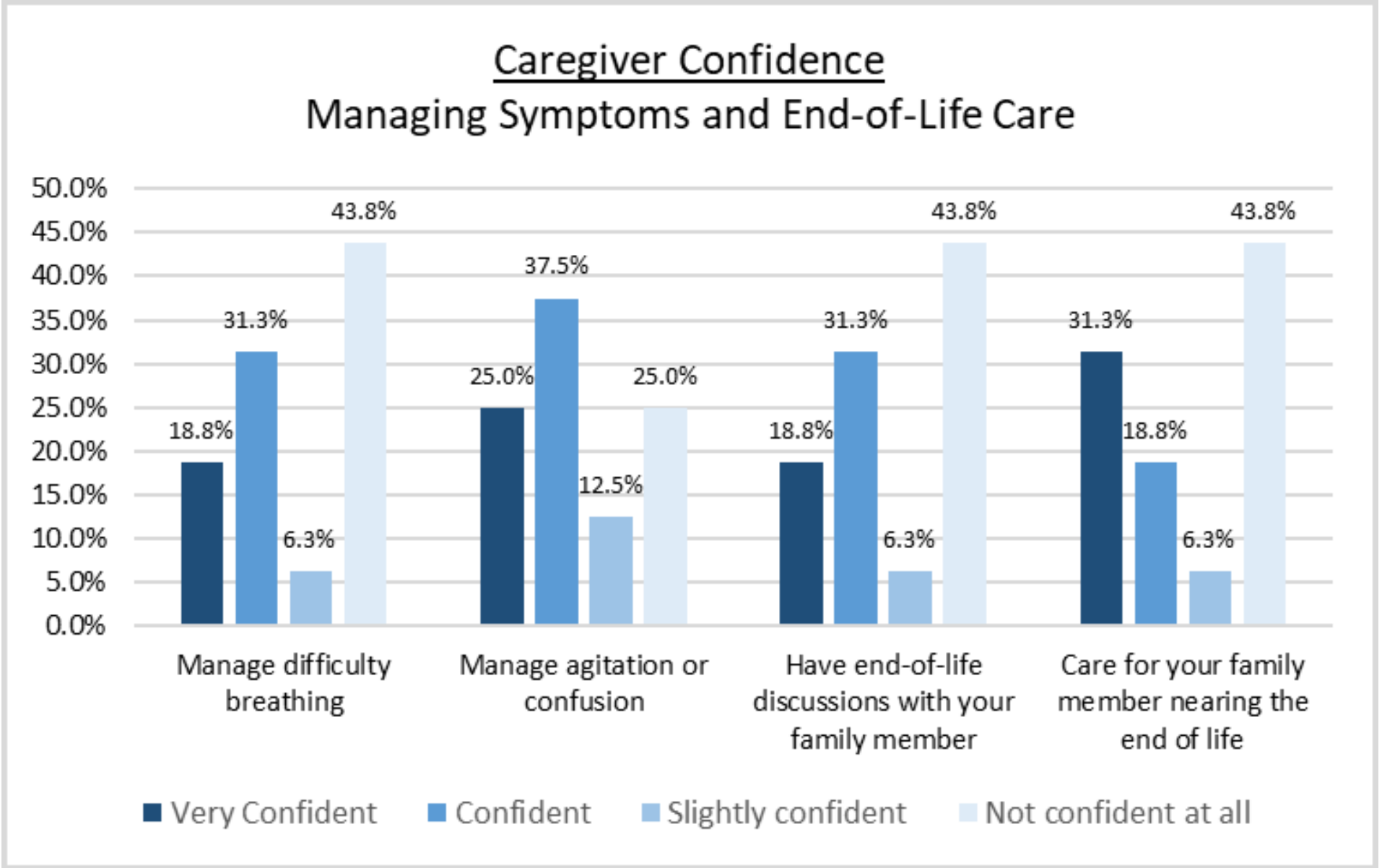
Among patients/caregivers, knowledge gaps existed regarding pain management/opioid use, as well as spiritual/cultural and ethical/legal aspects of palliative care.

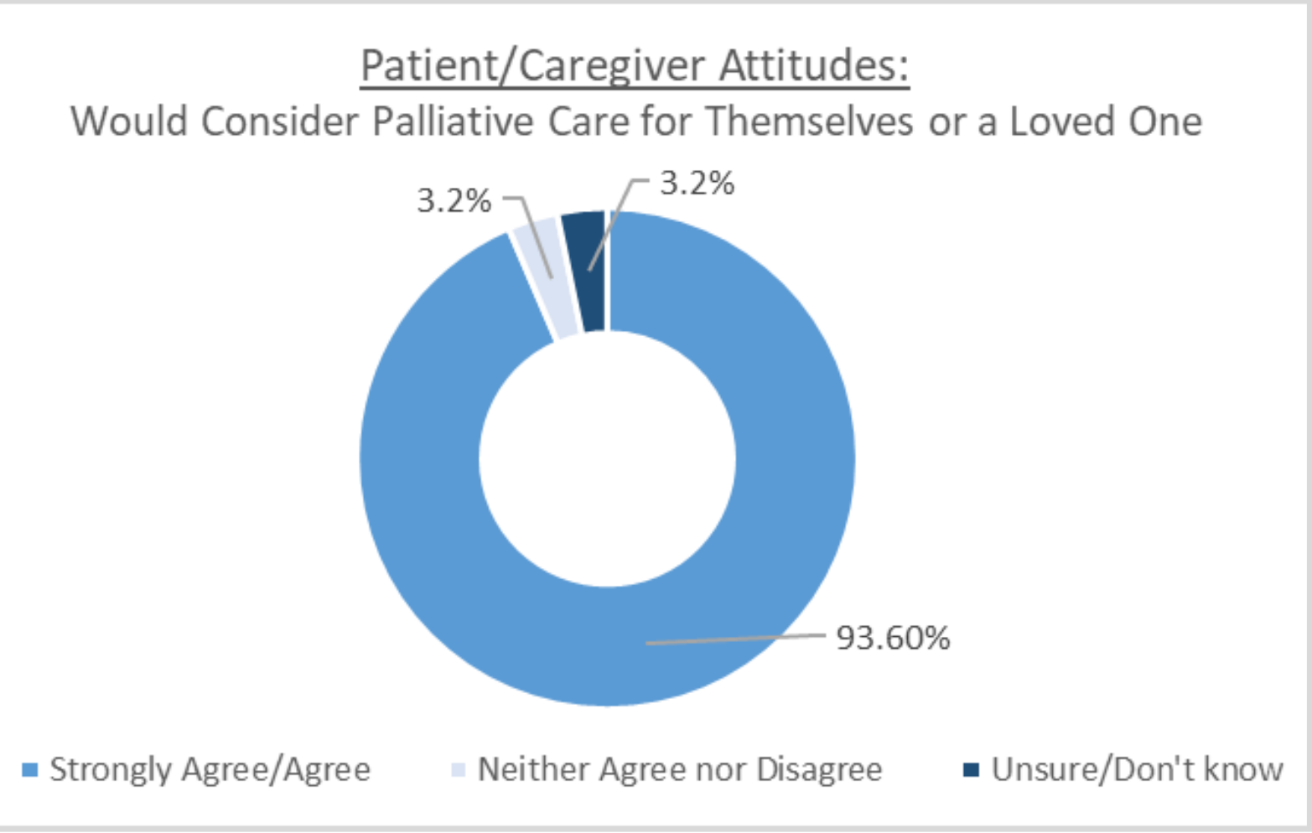

Patient/Caregiver Knowledge

Attitudes on pain management/opioid use varied among patients/caregivers.


Patient/Caregiver Attitudes
Pain Management/Opioid Use

Caregivers were less confident in managing difficulty breathing and agitation, engaging in end-of-life (EOL) discussions or providing EOL care.


Caregiver Confidence
Managing Symptoms and End-of-Life Care

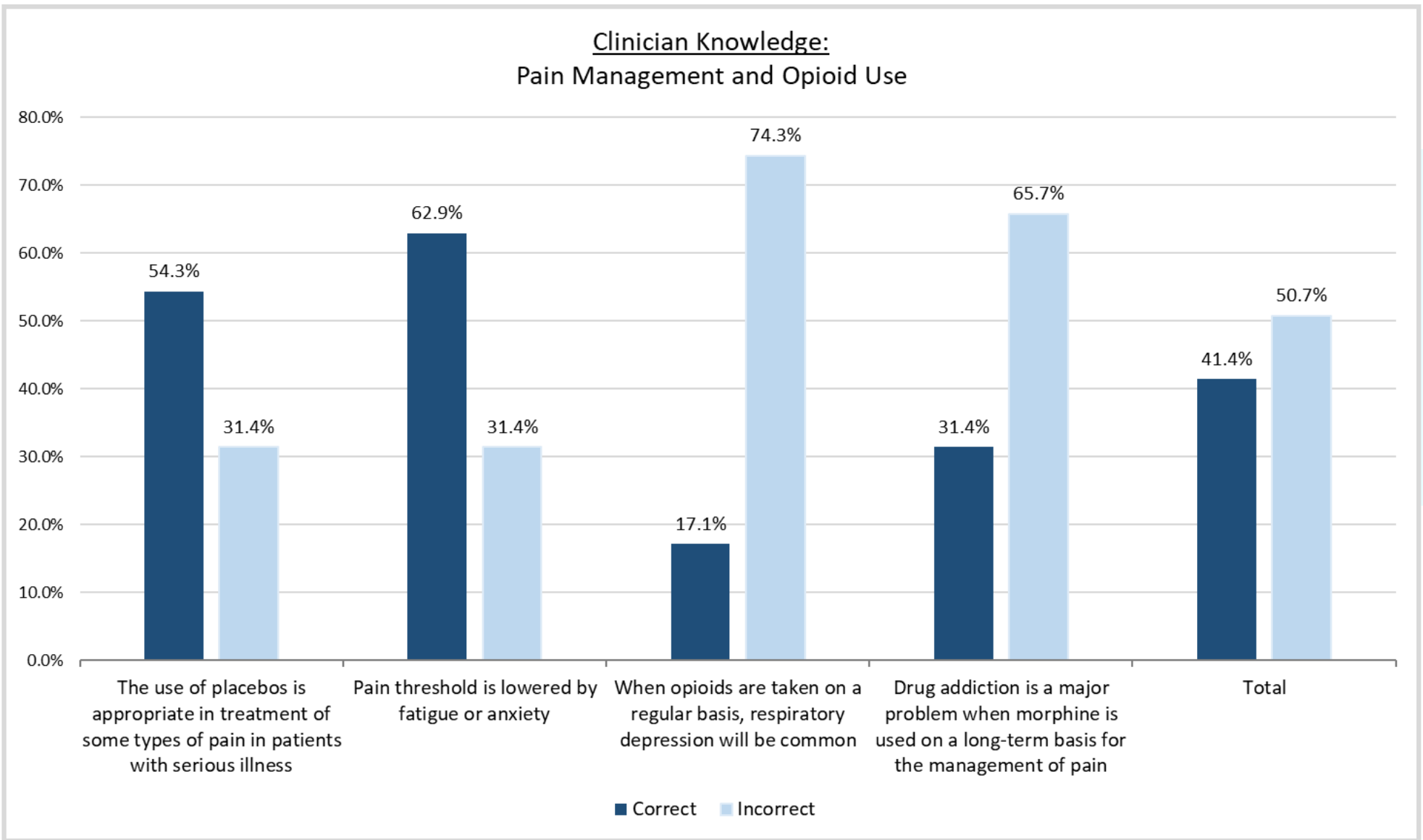

Patient/Caregiver Attitudes:
Would Consider Palliative Care for Themselves or a Loved One

Despite knowledge gaps and varying attitudes and confidence levels, 93.6% of patients/caregivers would consider palliative care for themselves or a loved one.

Table 1. Questionnaire Structure for HHC Clinicians, Patients and Caregivers

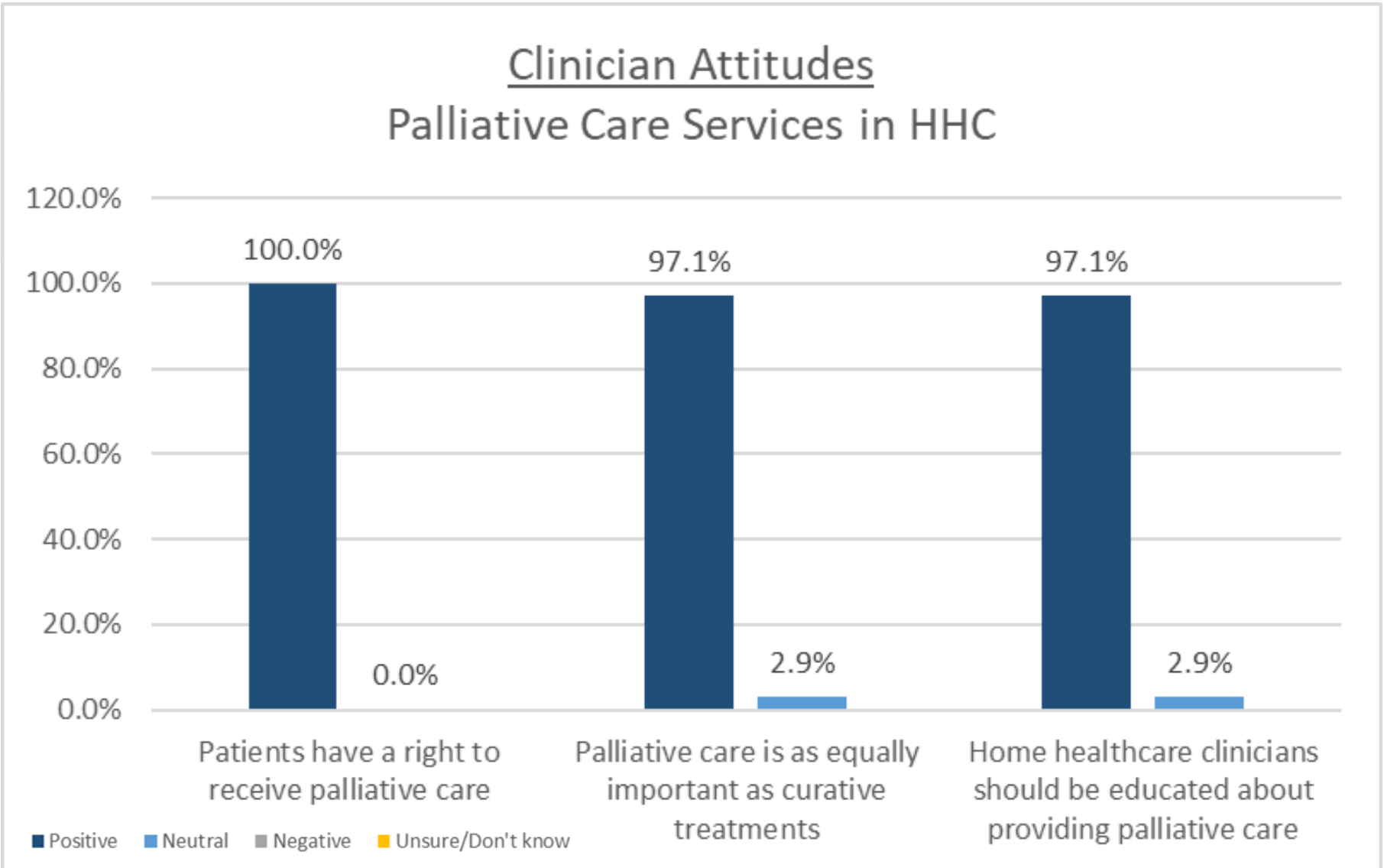
Concept/Audience	Knowledge		Attitudes		Confidence		Preferences/ Experiences	
	Patient/ Caregiver	Clinician	Patient/ Caregiver	Clinician	Patient/ Caregiver	Clinician	Patient/ Caregiver	Clinician
NCP Guideline Domain	**Number of Questions**							
Structure and Processes of Palliative Care	19	5	5	9	1	4	13	6
Physical Aspects of Care	4	19	5	2	2	5	1	0
Psychological and Psychiatric Aspects of Care	1	6	3	1	1	1	2	0
Social Aspects of Care	0	2	0	3	0	1	3	0
Spiritual, Religious, and Existential Aspects of Care	1	2	0	2	1	1	2	0
Cultural Aspects of Care	2	2	2	3	2	1	0	0
Care of Patients Nearing the End of Life	2	5	3	10	1	2	2	0
Ethical and Legal Aspects	1	5	0	3	0	1	0	0
Total	**30**	**46**	**18**	**33**	**8**	**16**	**23**	**6**
Role-Specific	0	8-RN, 2-P/O/ST	1-PX	0	5-CG	6-RN, 1-SW, 1-P/O/ST	0	0

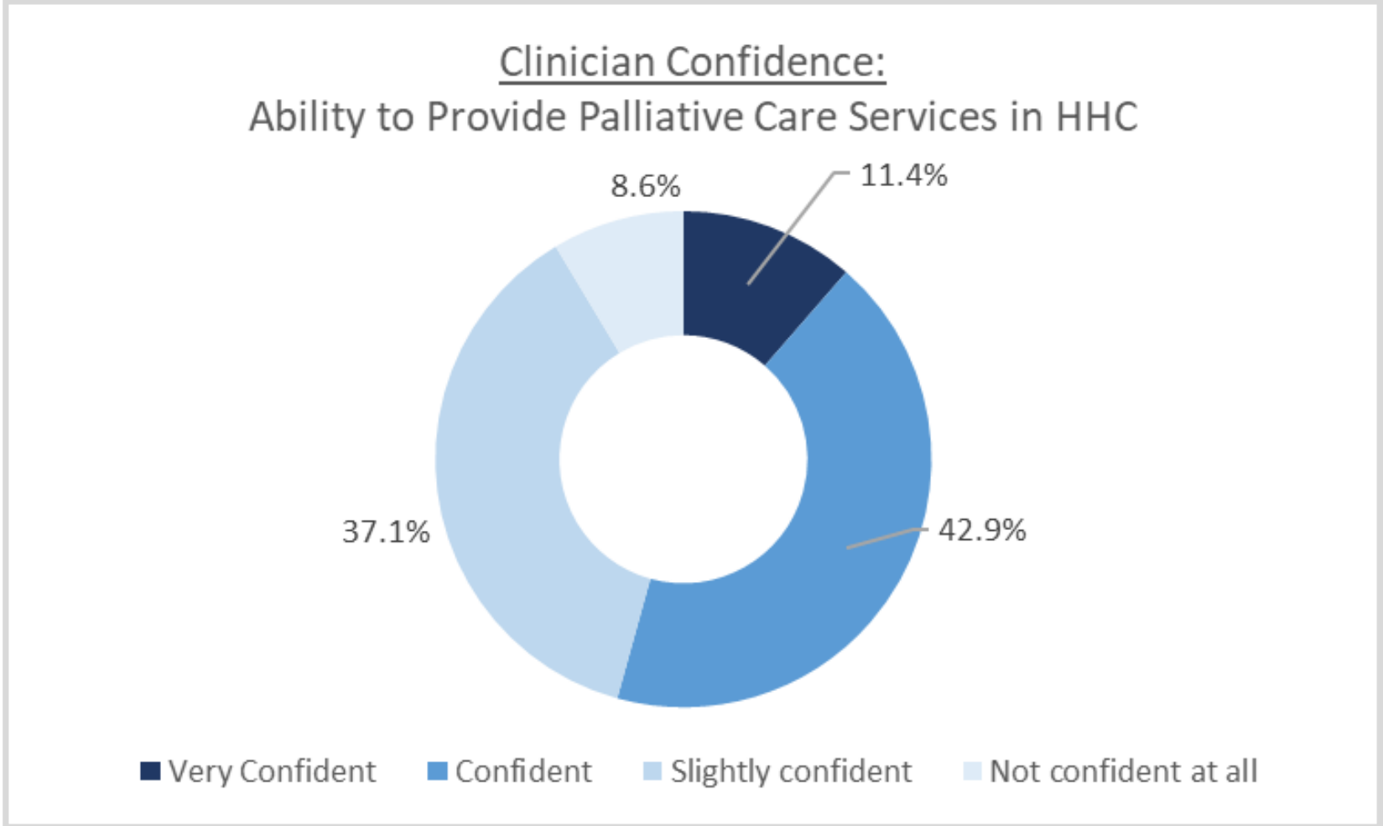
Note: RN: Registered Nurse; SW: Social Worker; P/O/ST: Physical, Occupational, or Speech Therapist; PX: Patient; CG: Caregiver


Clinician Knowledge:
Pain Management and Opioid Use

Overall, clinicians demonstrated adequate knowledge. However, several questions about pain management/opioid use and ethical/legal aspects of PC were answered incorrectly by >40% of clinicians.

HHC clinicians generally held positive attitudes towards palliative care.


Clinician Attitudes
Palliative Care Services in HHC


Clinician Confidence:
Ability to Provide Palliative Care Services in HHC

HHC clinicians had varying levels of confidence regarding palliative care service provision.

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