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Advance Care Planning Shared Decision-Making Tools for Non-Cancer Chronic Serious Illness: a Mixed Method Systematic Review

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Disclosure

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Objective and Key Questions

- To evaluate effectiveness and implementation of interventions for integrating palliative in ambulatory care for care for adults with serious, life-threatening illness and their caregivers.
- We evaluated interventions addressing identification of patients, patient and caregiver education, shared decision-making tools, clinician education, and models of care.
- For each of the key questions, we address three parts:
  - 3a. What is available?
  - 3b. What is the effectiveness?
  - 3c. How is it implemented?

Key Questions

- We addressed five questions about the integration of palliative care in ambulatory care for patients with serious life-threatening chronic illness or conditions other than cancer:
  - KQ1: How can we identify those patients who could benefit from palliative care in ambulatory care settings?
  - KQ2: What educational resources are available for patients and caregivers in ambulatory care about palliative care?
  - KQ3: What palliative care decision-making tools are available for clinicians, patients, and caregivers in ambulatory care?
  - KQ4: What educational resources are available for nonpalliative care clinicians about palliative care in ambulatory settings?
  - KQ5: What are the models for integrating palliative care into ambulatory settings?

Effectiveness

KQ3b. What is the effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

- 6 RCTs (1,567 patients and 58 caregivers)
- ESRD, COPD, multiple serious illnesses
- All addressed advance directives or goals of care communication

Results:

- Palliative care shared decision-making tools may improve patient satisfaction with communication (SOE: Low).
- Palliative care shared decision-making tools may increase advance directives documentation (SOE: Low).
- We could not draw conclusions about the effect of shared decision-making tools on caregiver satisfaction or patient symptoms of depression, and no studies addressed other critical outcomes.

Implementation

KQ3c How have palliative care shared decision-making tools been implemented for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers? What is the evidence for how, when, and for which patients and caregivers they could best be implemented in care?

- 5 qualitative studies on advance care planning and documentation
- 18 patients, 38 caregivers, 21 non-palliative care ambulatory clinicians
- COPD, ESRD, heart failure

Results:

- Patients and caregivers preferred advance care planning discussions grounded in patient and caregiver experiences of illness, rather than general conversations about the end of life
- Patients and caregivers reported timing of advance care planning conversations should be individualized to the specific patient and caregiver
- Clinicians preferred advance care planning shared decision-making tools that were time-efficient and included structured scripting

KQ3. Key results: Overall integrative synthesis for shared decision-making tools (websites, qualitative, quantitative, key informants)

Factors for implementation	Summary findings
Intervention and implementation characteristics	<u>Intervention:</u> Content: Qualitative evidence emphasized grounding in patient and caregiver experiences of illness; this was a key component of several shared decision-making tools evaluated for effectiveness Structure: Although qualitative evidence emphasized that interventions should be time-efficient, specific and succinct, effectiveness studies also included more lengthy interventions conducted by additional staff outside routine workflow <u>Implementation:</u> Timing: Although qualitative evidence from patients/caregivers emphasized individualizing timing to preferences, effectiveness studies provided interventions to all eligible patients or based on clinical triggers

Conclusions/ Limitations

- Shared decision-making tools limited to advance care planning and goals of care communication
- All studies used outside funding and did not address sustainability/ dissemination
- Shared decision-making tools may increase patient satisfaction and advance directive documentation

Study Implications

- **Research**
  - Extend research focus to specifically address health equity or disparities as part of the intervention
  - Future Investigations is critical to patient-provider care in ambulatory settings and culturally appropriate intervention research
- **Policy**
  - Promote legislation to improve healthcare system and payment structures to enhance palliative care coordination of care
- **Practice**
  - Determine how to integrate interventions efficiently into workflows
  - How to more rigorously evaluate impact on such outcomes as caregiver satisfaction, concordance with patient wishes, anxiety, and depression.

Opportunities to Partner with Communities for Culturally Appropriate Intervention in Shared-Decision Making In Ambulatory Care

Question	*Response*	*All No. (%) N = 930*
Have you ever cared for someone who has a lot of health problems or who is near the end of their life?	Yes	652 (70%)
Is good end-of-life care important to you or someone you love?	"Very important"	781 (84%)
	"Important"	121 (13%)
	"No opinion"	19 (2%)
	"Not important"	9 (1%)
	"Not at all important"	0%
	Missing data	0%
Have you ever talked to someone about who makes decisions for you if you are too sick to make them for yourself?	No	372 (40%)
Would you like more information about end-of-life care for you or someone you love if it were available at our church?	Yes	865 (93%)

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Brief Reports

Church-Based Health Promotion Focused on Advance Care Planning and End-of-Life Care at Black Baptist Churches: A Cross-Sectional Survey

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Thank you! Questions?