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Title

A dyadic study of advance care planning readiness among Black older adults with serious illness and their surrogates

Priority 1 (Research Category)

Geriatrics

Presenters

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Abstract

Context: Advance care planning (ACP) supports adults and surrogates in sharing personal values and preferences for medical care. Black older adults have lower ACP engagement, but the mechanisms behind this are understudied.

Objective: To examine readiness to engage in ACP as well as barriers and facilitators of engagement.

Study Design and Analysis: Mixed methods explanatory sequential design; dyadic and thematic analysis.

Population Studied and Setting: Black adults aged 60 and older and their surrogates enrolled from the heart failure and geriatric clinics at an academic medical center or a local predominantly Black faith community.

Intervention/Instrument: In the quantitative phase, surveys with validated instruments were used to measure personal values, readiness for ACP, and barriers and facilitators to engagement. A semi-structured interview guide was developed based on survey responses and included five domains: decision-making, communication with surrogate and medical team, exploring conceptions of “being a burden,” family and community support, and preferences and values.

Outcome Measures: Readiness, barriers, and facilitators of ACP engagement.

Results: Thirty older adults and eleven surrogates completed surveys and fifteen participants completed follow-up interviews. Most older adults and surrogates were confident that they could talk to their care partner (79% and 100%, respectively) and doctor (76% and 100%), but fewer endorsed readiness to talk to their care partner (50% and 82%) and doctor (43% and 64%). Lack of readiness to discuss ACP was related to self-perception of health status, though this perception was not always shared by surrogates. Older adults and surrogates were discordant in several ACP barriers and facilitators. When choosing a surrogate, older adults valued proximity, experience, and that the surrogate understood their values; they did not necessarily select the closest relative (and often chose a pastor). “Being a burden” was associated with care needs and decision-making; this was denied as a concern (“they care for you because they love you”) and frequently cited as a major fear.

Conclusions: ACP interventions that engage older adults and surrogates and address illness perception may improve care planning and health decision making. Choosing a surrogate is complex. Black older adults’ individual conceptions of “being a burden” may be helpful to consider in supporting ACP.