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PC-FACS (**F**ast **A**rticle **C**ritical **S**ummaries for Clinicians in **P**alliative **C**are) *provides hospice and palliative care clinicians with concise summaries of the most important findings from more than 100 medical and scientific journals. If you have colleagues who would benefit from receiving* PC-FACS*, please encourage them to join the AAHPM at aahpm.org. Comments from readers are welcomed at pc-facs@aahpm.org.*

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Summaries With Commentary

Information Sharing Preferences of Older Patients and Their Families

Background. Elders and their family caregivers face multiple challenges as decision-making roles shift with advancing age.[1-3] What are the best ways to facilitate health information communications while respecting elderly parents' wishes?

Design and Participants. To determine how elders prefer to share health information with proxies, focus groups were conducted between October 2013 and February 2014 with Boston-area elders age >75 years ($n = 30$) and family members assisting in elder care ($n = 23$). The elders represented the continuum of independent living to skilled long-term care. Professionals moderated five groups of elders and five of spouses and adult children caring for a relative age >75 years. Each interview was audiotaped, transcribed, and analyzed inductively using the immersion/crystallization technique to identify themes. For the last three elder focus groups, the discussion guide was revised to place greater emphasis on discussion of privacy preferences and personal health information governance, including via patient portals using secure websites.

Results. Most elders were age ≥81 years (87%, $n = 26$); female (87%, $n = 26$); white (97%, $n = 29$), and had a college degree or higher (67%, $n = 20$). A third used the Internet rarely; 60% used it almost daily. Two themes emerged from the data: (1) consequences of information sharing and (2) dynamic control issues affecting the process. Elders and caregivers disagreed on how much disclosure was "enough." Unintended consequences included increased caregiver stress and elders feeling "spied on" or "second-guessed." Elders wanted control, retention, and transfer of decision-making to be individualized, maximizing their autonomy. Co-ownership of information should change gradually as the elder's functional and health status changed. The authors also concluded that simple proxy portal access may not, as currently structured, adequately handle changing dynamics of health information communications between elders and proxies, particularly in acute situations.[4-6]

Commentary. In response to CMS's Electronic Health Records Incentive Program, 30% of US hospitals and 10% of ambulatory practices reported the use of patient portals by the end of 2012. In palliative care, patient portals provide tantalizing potential for

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improving advance care planning and adherence to patients' wishes, reducing fragmentation during care transitions and increasing adherence and care coordination.[7,8] In addition, patient portals with online support tools can benefit all palliative care patients and promote communication between elderly patients and busy adult children.[9] However, these desirable outcomes have been hampered by a lack of uptake, discrepancies in perception among different stakeholders, and lack of evidence-based research. It is also unclear whether patient portals are useful to those with lower literacy, less education, and lack of Internet access.

Bottom Line. The advent of computers, mobile platforms, and patient portals should be combined to promote optimal end-of-life care, support patient autonomy, and reduce caregiver stress; but to ensure their usefulness, portals must be patient- and caregiver-centered, barriers must be identified, and access must be widely promoted.

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Source. Crotty BH, Walker J, Dierks M, et al. Information sharing preferences of older patients and their families. JAMA Intern Med 2015;175:1492-1497.

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African Americans and Hospice Care: A Narrative Analysis

Background. Hospice utilization is disproportionately low among African Americans.[1-3] What is the experience of African-American caregivers and hospice patients?[4-6]

Design and Participants. To gain insight into population-specific barriers to hospice usage, in-depth interviews were conducted in-person with adult African Americans who were hospice patients or the primary caregivers of a current or recently deceased hospice patient. No diagnosis or form of hospice was excluded. Interviews were recorded, transcribed, and then analyzed using a modified narrative typology[7] and comparison process[8] to identify major themes and reiterative stories. Ten patients and 16 caregivers were interviewed regarding their perceptions of and experiences with hospice; most were interviewed at least twice (range 1-4 times).

Results. Patients were six females, six males; mean age 70 (range 29-81); mean hospice stay 85 days (range 11-368); 37% with cancer diagnosis; all Christian/ Protestant. Caregivers were nine females, seven males; mean age 46 years (range 34-76); mostly Protestant. Their relative's hospice stay averaged 35 days (range 3-120). Three groups of narratives emerged: satisfaction, regret, and ambivalence. Eight patients and seven caregivers expressed satisfaction that hospice aligned with their perceptions and spiritual, cultural, and family values. Compassionate caregiving exceeded expectations. Four patients and four caregivers expressed regrets regarding physician referrals and hospice knowledge coming "too late" and misunderstanding about whether hospice was a final or flexible decision. Two patients and five caregivers expressed ambivalence in liking hospice but experiencing conflict with family or friends who accused the caregivers of abdicating their obligations. This heritage of "we take care of our own" caused self-doubts and prolonged relational estrangement.

Commentary. This qualitative analysis, derived from narratives that are rich in meaning, provides insight into the experiences of African-American caregivers and hospice patients with a single hospice provider in one southeastern US city. This analysis highlights how important it was for families to link their cultural