

## Table 1. Selected Studies on Care Decision Making for Patients, Family Caregivers, or Practitioners

Online-only content for “Informal Caregivers: Communication and Decision Making” by Carol Whitlatch, PhD, in the American Journal of Nursing September 2008 Supplement, p. 73-7.

Subjects and procedures	Study description and relevant findings
Biesecker AE, et al. <i>Am J Alzheimers Dis Other Dement</i> 1997;12(2):73-83.	
Telephone interviews were conducted with 104 family caregivers of persons with Alzheimer’s disease to explore their interactions and communication with physicians.	<ul style="list-style-type: none"> <li>• The semistructured interviews examined changes in caregivers’ interactions with physicians as their relative’s illness progressed, the caregivers’ reactions to those changes, and the types informational needs and advance directives that were discussed.</li> <li>• The results indicated that caregivers felt that physicians communicated more with the caregiver and less with the relative as the illness progressed.</li> <li>• Caregivers noted that they would have liked more information about what to expect as their relative’s illness progressed and about financial and legal issues, services, research, and their own needs.</li> </ul>
Carpenter BD, et al. <i>Fam Relat</i> 2006;55(5):552-63.	
Eighty adult child–older parent dyads were interviewed to determine how well the adult child knew the parent’s psychosocial preferences.	<ul style="list-style-type: none"> <li>• Adult children were found to be fairly accurate about their parent’s preferences, although the authors reported “variability across preference domains.”</li> <li>• Adult children underestimated the importance parents placed on continued enrichment and personal growth.</li> <li>• Adult children overestimated parents’ preferences for predictability, routine, and control.</li> <li>• The authors suggested that interventions must address contextual factors “to improve intergenerational knowledge and enhance the likelihood that parent preferences are considered in care planning.”</li> </ul>
Casarett DJ, et al. <i>J Am Geriatr Soc</i> 2004;52(11):1923-8.	
One hundred family members of deceased hospice patients were interviewed to examine what they knew about hospice prior to engaging the services.	<ul style="list-style-type: none"> <li>• Semistructured interviews were conducted with families who had enrolled in hospice services in Providence, Rhode Island; San Diego; and Fort Myers, Florida.</li> <li>• Nearly all family members (92%) reported knowing about hospice services prior to the patient’s illness. Seventy-one percent said that their relatives also knew about hospice prior to their illness.</li> <li>• Family members reported wishing they had known more about specific aspects of hospice sooner.</li> <li>• The interviews indicated that physicians play a key role as gatekeepers in the referral process and must be included in efforts to increase access to hospice.</li> <li>• The authors suggest that educational efforts about hospice need to begin earlier in the disease process and that future work should explore how hospice services can be tailored to help patients and families make more timely decisions.</li> </ul>

# Supporting Family Caregivers

Subjects and procedures	Study description and relevant findings
Connell CM, et al. <i>Gerontologist</i> 2004;44(4):500-7.	
<p>Separate focus groups were convened with 52 family caregivers and 39 physicians to examine their attitudes towards assessing for, diagnosing, and disclosing the diagnosis of dementia.</p>	<ul style="list-style-type: none"> <li>• Topics discussed with the caregiver groups included the process, advantages, and disclosure of the diagnosis, as well as caregivers' first reactions.</li> <li>• Topics discussed with the physician groups included the challenges to providing, advantages of, and caregivers' first reactions to the diagnosis.</li> <li>• Caregivers reported having a negative emotional response to disclosure, while physicians reported that "families handled the information well."</li> <li>• Future research should include families who have not sought a diagnosis and pair family members with physicians to discuss the "unique experiences" of the same interaction.</li> </ul>
Hansen L, et al. <i>J Gerontol Nurs</i> 2005;31(11):28-35.	
<p>Semistructured interviews were conducted with 17 family caregivers whose relatives had died within the previous eight months. Content analysis was used to analyze the transcribed interviews and full agreement across coders was achieved through discussion (92.2% interrater agreement).</p>	<ul style="list-style-type: none"> <li>• The Family Caregiving Process in Making Life-Sustaining Treatment (LST) Decisions for Elderly Ill Relatives framework was developed as the analyses proceeded. Four roles were found to be associated with strain and ease in making LST decisions: caregiver, elderly ill relative, other family members, and health care providers.</li> <li>• Caregivers knew their relatives' LST preferences and, as a result, some caregivers felt more relieved as they were making these decisions. Many caregivers noted that making the decision to place their relatives in a long-term care facility was more difficult than making decisions around LST.</li> <li>• Practitioners can make LST decision making easier for family caregivers by "being available to answer questions and by providing the information caregivers need." Caregivers could be helped by understanding "what symptoms their relative might experience when treatments are withdrawn or withheld."</li> <li>• The findings point to the important role practitioners have in helping families to identify and communicate their preferences and expectations for care.</li> </ul>
Menne HL, et al. <i>Gerontologist</i> 2007;47(6):810-9.	
<p>Data were collected from 215 family caregiver-individual with dementia dyads as part of a larger ongoing study of stress and well-being in families dealing with chronic physical and cognitive health conditions.</p>	<ul style="list-style-type: none"> <li>• Dyads were from the Family Caregiver Alliance in San Francisco; the Community Services Division of the Benjamin Rose Institute in Cleveland, Ohio; and the University Memory and Aging Center in Cleveland.</li> <li>• Separate structured interviews were completed with both members of the dyad. Parallel measures were often used to capture the stresses and strains of the care situation and the perceived well-being of each member.</li> <li>• The results revealed that the individuals with dementia who were more involved in decision making were younger, female, more highly educated, cared for by a nonspouse, and more recently diagnosed; had less depressive symptoms and fewer problems performing activities of daily living; placed more importance on autonomy and self-identity.</li> <li>• The discussion focuses on how interventions that help people with dementia participate in decision making early on in the diagnosis may lead to positive outcomes, such as a better quality of life. Early involvement in decision making can enhance autonomy and help practitioners and family members understand more about the identity and preferences of the individual with dementia.</li> </ul>

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Subjects and procedures	Study description and relevant findings
Robinson L, et al. <i>Aging Ment Health</i> 2005;9(4):337-47.	
<p>Nine couples in which one partner has early stage Alzheimer's disease were interviewed to examine the couple's psychological reactions to receiving the diagnosis.</p>	<ul style="list-style-type: none"> <li>• Married couples between 65 and 85 years old were recruited from memory centers in North London.</li> <li>• Joint interviews explored topics related to the couple's experiences with acknowledging that one partner had memory difficulties and receiving the diagnosis of dementia, as well as how the diagnosis affected their relationship.</li> <li>• Two themes emerged: making sense of and accepting the gradual changes associated with dementia, and developing coping strategies as individuals and as a couple.</li> <li>• The findings suggest that practitioners might best support couples by helping them create a "joint construction" of the experience that can help them make sense of the situation, find ways to adjust to role changes and new identities, and "manage the losses they face in the early stages of dementia."</li> </ul>
Whitlatch CJ, Feinberg LF. <i>Alzheimer's Care Quarterly</i> 2003;4(1):50-61.	
<p>One hundred eleven people with cognitive impairment and their family caregivers were interviewed using parallel instrumentation that explored decision making in everyday care from the perspective of the caregiver and the care receiver. The respondents were primarily black (59%) and caregiving adult daughters (33%) or wives (33%).</p>	<ul style="list-style-type: none"> <li>• The interviews examined issues such as who would make decisions for the care recipient when she or he was no longer able to make those decisions and how well caregivers understood their relative's daily care and nursing home wishes.</li> <li>• The results indicated that family caregivers were not always aware of and often underestimated the importance of their relatives' values and preferences for care.</li> <li>• The results also indicated that both the caregiver and the care recipient believed that the other person's best interests were more important than their own.</li> <li>• The findings point to the important role practitioners have in helping families to identify and communicate their preferences and expectations for care.</li> </ul>