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Psychosocial, Cultural, and Spiritual Health Disparities in End of Life and Palliative Care: Where We Are and Where We Need to Go

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Abstract

Background—Although health disparities are well documented, the extent to which they affect end of life care is unknown. Limited research funding leads to sparse and often contradictory palliative care literature, with few studies on causal mechanisms.

Purpose—The purpose of this article is to explore the psychosocial, cultural and spiritual health disparities existing in palliative and end of life care with the goal of identifying future research needs.

Method—To determine knowledge gaps related to health disparities in psychosocial, cultural, and spiritual aspects of end of life care we draw upon recent literature from multiple databases.

Discussion—Although there are few data, we do know minorities make little use of hospice, often because of lack of knowledge about hospice or palliative care, family-centered cultures, and preferences for more aggressive end of life care than hospice allows.

Conclusion—Future research should include a search for theoretical and causal mechanisms; prospective longitudinal investigations; diverse patients, conditions, contexts, and settings; methodological diversity and rigor; and interdisciplinary, culturally sensitive interventions.

Access to palliative and end of life care has improved over the last decade but certain diverse populations remain unserved (Cohen, 2008). Based on a presentation given at *The Science of Compassion: Future Directions in End of Life and Palliative Care Research*, sponsored by the National Institute for Nursing Research (NINR) in August 2011, this article summarizes selected references to psychosocial, cultural, and spiritual health disparities existing in palliative and end of life care, with the goal of identifying future research needs. Searches of CINAHL, PubMed, Social Sciences Index, and PsychInfo using the terms, health disparities, end of life care, palliative care, psychological, social, spiritual, and cultural, in combination with population groups representing various racial, cultural, and ethnic backgrounds, reveals little about the extent to which health disparities affect end of life care. Empirical studies are limited in number, scope, and geographic locations (Johnstone & Kanitsaki, 2009), and we know little about the demographics or use of hospice services by specific racial and ethnic groups (Cohen, 2008). Many studies fail to identify race, social class, and differences in environmental conditions of participants (LaViest, 2005). In addition, many investigators do not acknowledge the importance of psychosocial variables, or enroll sufficient numbers of minority group members to be able to compare minority to majority participants or examine differences among subgroups of minorities in large data sets (e.g., Hardy, et al., 2011). Automatic assumptions about the value of

autonomy may also preclude recognition of other types of effective decision-making models (Johnstone & Kanitsaki, 2009).

The literature from the last five to seven years on health disparities in psychosocial, cultural, and spiritual palliative care is limited, contradictory, restricted by methodological shortcomings, and complicated by sparse research resources (Welch, Teno & Mor, 2005). It emphasizes detection of health disparities, but sheds little light on underlying causal mechanisms (Rhodes, Teno & Connor, 2007). In addition, definition and measurement of the terms health disparities, race, ethnicity, and culture, vary across existing studies. In fact, ethnicity is often omitted, offering further restrictions (Ezenwa, Ameringer, Ward & Serlin, 2006).

One way to explore the existing descriptions of the causal mechanisms that underlie health disparities and end of life care, along with interventions aimed at reducing such disparities, is through a conceptual framework such as that used in the National Healthcare Disparities Report <http://www.ahrq.gov/qual/nhdr02/frame1.htm>. Their framework focuses on access to care, receipt of care and quality of care, and examining barriers; usage and costs of care; and effectiveness, safety, timeliness, and patient-centeredness.

What We Know: Access to Care

There has been little or no change in hospice utilization rates for African Americans or Hispanic/Latinos over the last five years (Bullock, 2011). These populations are family-centered and prefer to avoid disclosure of illness to patients, keep ill loved ones at home (Mazanec, Daly & Townsend, 2010), avoid advanced directives (Carr, 2011), seek aggressive treatment (Mack, Paulk, Viswanath & Prigerson, 2010), and distrust the health care system (Johnstone & Kanitsaki, 2009). Making life and death decisions is a tremendous burden across African American, Hispanic/Latino, and Anglo groups (Braun, Beyth, Ford & McCullough, 2008), where individual differences in beliefs and values, with-in group differences, and across-group differences exist (Crawley, 2005; Ezenwa et al., 2006; Johnson, Kuchibhatla & Tulskey, 2008). Additionally, the end of life experience is affected by acculturation in Hispanic/Latinos, with less acculturated families preferring feeding tubes and other more aggressive services (DeSanto-Madeya et al., 2009). Moreover, accurate information about hospice may not be available in Spanish (Coon et al., 2004) and families may be unable to get personal advice from other Latinos who have experienced its benefits, a major cultural strategy for information-gathering (Evans, Coon & Crogan, 2007).

Ethnic minority groups are less likely to use hospice services (Connor, 2007; Hardy et al., 2011). Differential use of hospice between rural and urban settings may occur because of the lack of dissemination of information about hospice rather than geographic proximity (Carlson, Bradley, Du & Morrison, 2010), or other factors such as a high supply of beds in an urban area, proximity to the hospital, access to trusted family and availability of few palliative care or residential care facilities (Lackan, Eschbach, Stimpson, Freeman & Goodwin, 2009).

What We Know: Receipt of Care

Although little research examines the African American family's end of life experience, we know the fear of denial of treatment, rooted in a long history of discrimination, exacerbates health disparities in the African American population. For example, despite a clear preference for more aggressive end of life care among African Americans, Anglo patients preferring intensive care are nearly three times more likely to receive it (Loggers et al., 2009).

Family-centered African Americans use only 8% of palliative and hospice services. They express lower caregiving stress and higher benefits than Anglos (Haley et al., 2004), emphasize faith and spirituality more than Hispanic/Latinos or Anglos and, because they view suffering as part of God's plan or as part of their generations of struggle, they are less likely than Anglos to discuss death, engage in advanced care planning, or utilize hospice to diminish that suffering (Braun et al., 2008; Bullock, 2011; Johnson, et al., 2008; Mazanec et al., 2010; Rhodes, et al., 2007). They are, however, more likely to desire life support and other aggressive treatments as a family unit (Bullock, 2011; Welch et al., 2005; Kwak & Haley, 2005; Johnson et al., 2008).

African Americans have less exposure to hospice information, are more likely to withdraw from hospice programs once enrolled (Johnson, Kuchibhatla, Tanis & Tulskey, 2008) and are less likely to return (Kapo, Macmoran & Casarett, 2005). Such decisions may be due to health literacy rather than race, with increasing health literacy resulting in greater acceptance of comfort care (Vollandes, et al; 2008).

Although we know little has been published about end of life interventions in African Americans or Hispanics/Latinos, one home-based palliative care intervention study with a largely African American sample (82.6%) has been published. Participants in this study were provided access to outpatient clinic appointments, providers trained in palliative and end of life care, and transition between levels of care, in order to avoid institutionalization (Holley, Gorawara-Bhat, Dale, Hemmerich & Cox-Hayley, 2009). More than two-thirds of enrolled participants died at home or in hospice and satisfaction with care were high. A second successful intervention offered unrestricted treatment choices and resulted in a 60% and 73% increase in African American hospice referral, compared to two usual care groups (Ciemins, Stuart, Gerber, Newman & Bauman, 2006).

Hispanic/Latinos also underutilize hospice but little is known about this phenomenon; they are more than 13 percent more likely to die in a hospital than Anglos (Lackan et al., 2009). In fact, little is known about caregiving in general in these families (Evans, Coon & Ume, 2011). They prefer family-centered, collective decision-making and fall between African Americans and Anglos in their attitudes toward life support (Kwak & Haley, 2005). Like African Americans, they view suffering as an act of faith, opt for more aggressive treatment, and do not complete advance directives, perhaps due to cultural beliefs and values but also to a fear of being denied treatment, particularly in certain regions of the country (Braun et al., 2008).

Hispanic/Latinos prefer informal care provided by family members, which may partially explain their reluctance to use hospice. They appraise caregiving as less stressful than Anglos and derive more satisfaction from it (Coon et al., 2004), use religious activities to cope, and avoid seeking assistance such as hospice because they fear other family members will see their use of hospice as an acknowledgment of burden, which is culturally unacceptable. Empowering these families to access end of life care through a patient navigator intervention (Fischer, Sauaia & Kutner, 2007) is underway. Although qualitative documentation and a cost-effectiveness analysis are complete, study results are not yet available.

Very little is known about hospice use for cancer in Asians, with immigrant Asians being more than 18 percent more likely to die in a hospital than Anglos (Lackan et al., 2009). There are too few studies to identify general patterns, but in every ethnic subgroup, Asian families are less likely to enroll in hospice than Anglos, although Filipino Americans are more likely to enroll in hospice earlier and stay longer (Kwak & Haley, 2005; Ngo-Metzger, Phillips & McCarthy, 2008). Enrollment by Asian families may be precluded by lack of

knowledge, cultural beliefs that talking about death may cause it, and potential feelings of failure if they allow someone else to care for their aging parents (Kwak & Haley, 2005). In Korean Americans, one study found that more than half of the sample had heard of hospice and nearly three-fourths would consider using it (Jang, Chiriboga, Allen, Kwak & Haley, 2010).

Although there are few end of life palliative care interventions employing an Asian sample, there is one randomized controlled trial with sites in Hawaii and Colorado (Brumley et al., 2007). Overall, 37% of the sample (N = 298) were ethnic minorities, with 13% Hawaiian and 18% Asian/Pacific Islanders; 63% of participants in Hawaii were minorities compared with 10% in Colorado. Families participated in an interdisciplinary, multidimensional intervention that provided 24/7 in-home palliative care services and coordinated care across settings, thereby increasing patient satisfaction, reducing use of medical care, and reducing costs, but results were not reported in terms of ethnic variation.

What We Know: Quality of Care

There is documented evidence of disparities in almost every area of health for African American and Hispanic populations. Associated with such disparities is conscious or unconscious racism based on ignorance of race as a social construction, and the conflation of race with misunderstood concepts of culture, ethnicity, and indicators of socioeconomic status (Crowley, 2005). Although controversy exists, distrust stems from broad knowledge of the Tuskegee study, reinforced by daily societal mistreatment and experiences with the health care system that include inadequate pain management due to discrimination or stereotyping and inability to access opioids from community pharmacies (Bullock, 2011; Ezenwa et al., 2006), fewer referrals for pain management (Green, Todd, Lebovits & Francis, 2006), and past denial of opportunity for aggressive, disease-oriented treatment (Loggers et al., 2009). It also is thought that, like African Americans, Hispanic/Latinos receive inadequate pain management and maybe unable to access opioids from neighborhood pharmacies (Bullock, 2011; Ezenwa et al., 2006).

Concerns with patient-physician communication remain in regard to treatment and support when a family member is dying (Welch et al., 2005). It is unknown whether or not provider race, ethnicity, or concordance affects prescription of pain medication (Cintron & Morrison, 2006); few African Americans have experience with physicians of their own race and ethnicity or with other culturally competent providers (Braun et al., 2008). Like African Americans, Hispanic/Latinos tend to have little contact with ethnically concordant physicians and they wish for improvements in patient-provider communication (Braun et al., 2008).

What We Have Yet to Understand: Future Research

Longitudinal, prospective, theoretically driven designs (uncommon in end of life research with diverse populations) offer opportunities to examine and interpret causal mechanisms and directions, along with exploration of mediators and interaction effects (Radina & Barber, 2004; Stajduhar, et al., 2010). Differences in end of life care across settings must be explored and individualized assessment of caregiver needs, as opposed to inaccurate assumption of common needs, could increase recruitment and intervention precision. We also must address unclear definitions and general methodological limitations in health disparities and end of life research, including lack of theoretical frameworks, use of cross-sectional designs and convenience samples, and self-developed measurement scales which seldom take race or ethnicity into account (Haley et al, 2004; Kwak & Haley, 2005).

We must strenuously avoid assumption of autonomous decision-making models across minority groups, employing collective models to decrease bias and reflect respect for the influence of families, local healers, and larger social networks (Carr, 2011; Johnstone & Kanitsaki, 2009). Also, although not commonly accomplished, consideration of socioeconomic, cultural, geographic, and political contexts is imperative when exploring health disparities, along with the culturally-specific negotiations surrounding the voluntary or involuntary nature of the caregiving experience, utilization of formal support services, and quality of life (Radina & Barber, 2004; Rhodes et al., 2007). Researchers need to recruit adequate numbers of minority participants for meaningful analyses; look within- and across-groups for similarities and differences; and oversample racially, ethnically, and culturally diverse participants (Carr, 2011; Hardy et al., 2011). We can enhance recruitment by employing racially and culturally concordant research staff, drawing on previously established relationships between participants and a welcoming institution, and decreasing economic constraints (Johnson, Elbert-Avila, Kuchibhatla & Tulsy, 2006). Finally, we must design culturally sensitive interventions targeting specific minority groups that use supportive, partnering communication to promote trust in culturally competent health care professionals, including lay health workers (Bullock, 2011; Hebert & Schulz, 2006).

We need interdisciplinary research teams to address a multitude of patient and family issues, provide caregiver education and support, and answer questions about optimal dose and delivery of culturally sensitive end of life interventions based on appropriate health literacy levels (Hardy et al., 2011; McNeill, Reynolds & Ney, 2007; Volandes et al., 2008). Unrestricted choices in treatment may be a vital component of these interventions for some minority groups (Ciemens et al., 2006). These teams should investigate patient conditions other than cancer; different settings; different types of caregivers; caregivers who are receiving services as opposed to those who are not; and caregivers who care for dying family members as opposed to those who care for chronically ill family members. Researchers must also disentangle patient and caregiver data (often integrated in results), so that details of the caregiving experience are preserved (Cohen, 2008; Hardy et al., 2011).

End of life care would profit from randomized controlled interventions, quasi-experimental studies, and rigorous qualitative research (Crawley, 2005; Mazanec et al., 2010). While retrospective qualitative accounts may be colored by a variety of factors, the caregiver's own perception or interpretation of the experience is precisely the data needed to formulate supportive, tailored interventions (Welch et al., 2005), particularly in bereavement, which is also under studied. Additionally, triangulation with archival data, documents, and observation or the use of mixed method studies, guided by a theoretical framework (Evans et al., 2011), can provide a richer picture of the caregiver experience. Additional diversity in methodological approaches could also add to the literature; grounded theory is by far the most common approach but narrative inquiry, ethnography, and phenomenology could add significantly to the discussion.

Previous inquiries have been confined largely to documenting the existence of health disparities, with few studies actually exploring underlying mechanisms and end of life issues. Consequently, we are now at a crossroads where we have "a sound understanding of *what* is happening, but not of *how* or *why*" (Walshe et al., 2009, p. 909; italics author's). What we do in the next decade will greatly influence not just the reduction, but the elimination of health disparities in end of life care (Healthy People 2020, 2010; National Research Council, 2004). Researchers must no longer merely describe patterns of hospice and palliative care use in minority populations, but must actively turn to disparity reduction, using yet-to-be created innovative, culturally-sensitive models for eliminating disparities in end of life care (Fischer, Sawaia & Kutner, 2007). Disparity reduction requires actions such as those proposed at the NINR interdisciplinary summit on End of Life and Palliative Care:

a search for theoretical and causal mechanisms; prospective longitudinal investigation of more diverse patients, conditions, contexts, and settings; methodological rigor and diversity; and interdisciplinary, culturally sensitive interventions.

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References

- Braun UK, Beyth RJ, Ford ME, McCullough LB. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of General Internal Medicine*. 2008; 23(3):267–274. [PubMed: 18172738]
- Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, Gonzalez J. Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society*. 2007; 55(7):993–1000. [PubMed: 17608870]
- Bullock K. The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*. 2011; 7(1):83–98. [PubMed: 21391079]
- Carlson MDA, Bradley EH, Du Q, Morrison RS. Geographic access to hospice in the United States. *Journal of Palliative Medicine*. 2010; 13(11):1331–1338. [PubMed: 20979524]
- Carr D. Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable? *OMEGA--Journal of Death and Dying*. 2011; 63(1):1–20.
- Ciemins EL, Stuart B, Gerber R, Newman J, Bauman M. An evaluation of the advanced illness management (AIM) program: increasing hospice utilization in the San Francisco Bay Area. *Journal of Palliative Medicine*. 2006; 9(6):1401–1411. [PubMed: 17187548]
- Cintron A, Morrison RS. Pain and ethnicity in the United States: A systematic review. *Journal of Palliative Medicine*. 2006; 9(6):1454–1473. [PubMed: 17187552]
- Cohen LL. Racial/ethnic disparities in hospice care: A systematic review. *Journal of Palliative Medicine*. 2008; 11(5):763–768. [PubMed: 18588409]
- Connor SR. Development of hospice and palliative care in the United States. *OMEGA Journal of Death and Dying*. 2007; 56(1):89–99.
- Coon D, Rubert M, Solano N, Mausbach B, Kraemer H, Arguelles T. Wellbeing, appraisal, and coping in Latina and Caucasian female dementia caregivers: Findings from the REACH study. *Aging & Mental Health*. 2004; 8(4):330–345. [PubMed: 15370049]
- Crawley LM. Racial, cultural, and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine*. 2005; 8(supplement 1)
- DeSanto-Madeya S, Nilsson M, Loggers ET, Paulk E, Stieglitz H, Kupersztoch YM, Prigerson HG. Associations between United States acculturation and the end-of-life experience of caregivers of patients with advanced cancer. *Journal of Palliative Medicine*. 2009; 12(12):1143–1149. [PubMed: 19995291]
- Evans BC, Coon DW, Crogan NL. Personalismo and breaking barriers: Accessing Hispanic populations for clinical services and research. *Geriatric Nursing*. 2007; 28(5):289–296. [PubMed: 17982809]
- Evans BC, Coon DW, Ume E. Use of theoretical frameworks as a pragmatic guide for mixed methods studies: A methodological necessity? *Journal of Mixed Methods Research*. 2011; 5(4):276–292. [PubMed: 22368533]
- Ezenwa MO, Ameringer S, Ward SE, Serlin RC. Racial and ethnic disparities in pain management in the United States. *Journal of Nursing Scholarship*. 2006; 38(3):225–233. [PubMed: 17044339]
- Fischer SM, Sauaia A, Kutner JS. Patient navigation: A culturally competent strategy to address disparities in palliative care. *Journal of Palliative Medicine*. 2007; 10(5):1023–1028. [PubMed: 17985954]

- Funk L, Stajduhar K, Toye C, Aoun S, Grande G, Todd C. Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998–2008). *Palliative Medicine*. 2010; 24(6):594. [PubMed: 20576673]
- Green C, Todd KH, Lebovits A, Francis M. Disparities in pain: Ethical issues. *Pain Medicine*. 2006; 7(6):530–533. [PubMed: 17112365]
- Haley W, Gitlin L, Wiszniewski S, Mahoney D, Coon D, Winter L, Ory M. Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: The REACH study. *Aging and Mental Health*. 2004; 8(4):316–329. [PubMed: 15370048]
- Hardy D, Chan W, Liu CC, Cormier JN, Xia R, Bruera E, Du XL. Racial disparities in the use of hospice services according to geographic residence and socioeconomic status in an elderly cohort with nonsmall cell lung cancer. *Cancer*. 2011; 117(7):1506–1515. [PubMed: 21425152]
- Healthy People 2020. Developing Healthy People 2020: HP 2020 Proposed objectives/comments heart disease and stroke HDS HP2020, 14. 2010.
- Hebert RS, Schulz R. Caregiving at the end of life. *Journal of Palliative Medicine*. 2006; 9(5):1174–1187. [PubMed: 17040156]
- Holley APH, Gorawara-Bhat R, Dale W, Hemmerich J, Cox-Hayley D. Palliative access through care at home: Experiences with an urban, geriatric home palliative care program. *Journal of the American Geriatrics Society*. 2009; 57(10):1925–1931. [PubMed: 19702614]
- Jang Y, Chiriboga DA, Allen JY, Kwak J, Haley WE. Willingness of older Korean-American adults to use hospice. *Journal of the American Geriatrics Society*. 2010; 58(2):352–356. [PubMed: 20374409]
- Johnson KS, Elbert-Avila K, Kuchibhatla M, Tulsky JA. Racial differences in next-of-kin participation in an ongoing survey of satisfaction with end-of-life care: A study of a study. *Journal of Palliative Medicine*. 2006; 9(5):1076–1085. [PubMed: 17040145]
- Johnson KS, Kuchibhatla M, Tulsky JA. What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of the American Geriatrics Society*. 2008; 56(10):1953–1958. [PubMed: 18771455]
- Johnson KS, Kuchibhatla M, Tanis D, Tulsky JA. Racial differences in hospice revocation to pursue aggressive care. *Archives of Internal Medicine*. 2008; 168(2):218–224. [PubMed: 18227371]
- Johnson KS, Kuchibhatla M, Tulsky JA. Racial differences in self-reported exposure to information about hospice care. *Journal of Palliative Medicine*. 2009; 12(10):921–927. [PubMed: 19807237]
- Johnstone MJ, Kanitsaki O. Ethics and advance care planning in a culturally diverse society. *Journal of Transcultural Nursing*. 2009; 20(4):405–416. [PubMed: 19597187]
- Kapo J, Macmoran H, Casarett D. "Lost to follow-up": Ethnic disparities in continuity of hospice care at the end of life. *Journal of Palliative Medicine*. 2005; 8(3):603–608. [PubMed: 15992202]
- Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*. 2005; 45(5):634. [PubMed: 16199398]
- Lackan NA, Eschbach K, Stimpson JP, Freeman JL, Goodwin JS. Ethnic differences in in-hospital place of death among older adults in California: Effects of individual and contextual characteristics and medical resource supply. *Medical Care*. 2009; 47(2):138. [PubMed: 19169113]
- LaVeist TA. Disentangling race and socioeconomic status: a key to understanding health inequalities. *Journal of Urban Health*. 2005; 82(3):iii26–iii34. [PubMed: 15933328]
- Loggers ET, Maciejewski PK, Paulk E, DeSanto-Madeya S, Nilsson M, Viswanath K, Stieglitz H. Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *Journal of Clinical Oncology*. 2009; 27(33):5559–5564. [PubMed: 19805675]
- Lorenz KA, Rosenfeld K, Wenger N. Quality indicators for palliative and end-of-life care in vulnerable elders. *Journal of the American Geriatrics Society*. 2007; 55:S318–S326. [PubMed: 17910553]
- Mack JW, Paulk ME, Viswanath K, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Archives of Internal Medicine*. 2010; 170(17):1533. [PubMed: 20876403]
- Mazanec PM, Daly BJ, Townsend A. Hospice utilization and end-of-life care decision making of African Americans. *American Journal of Hospice and Palliative Medicine*. 2010; 27(8):560. [PubMed: 21071435]

- McNeill JA, Reynolds J, Ney ML. Unequal quality of cancer pain management: disparity in perceived control and proposed solutions. *Oncology Nursing Forum*. 2007; 34(6):1121–1128. [PubMed: 18024339]
- National Research Council, Committee on National Statistics, Division of Behavioral and Social Sciences and Education. *Eliminating Health Disparities: Measurement and Data Needs*. 2004. Retrieved from http://www.nap.edu/catalog.php?record_id=10979
- Ngo-Metzger Q, Phillips RS, McCarthy EP. Ethnic disparities in hospice use among Asian-American and Pacific Islander patients dying with cancer. *Journal of the American Geriatrics Society*. 2008; 56(1):139–144. [PubMed: 18047496]
- Radina ME, Barber CE. Utilization of formal support services among Hispanic Americans caring for aging parents. *Journal of Gerontological Social Work*. 2004; 43(2–3):5–23.
- Rhodes RL, Teno JM, Connor SR. African American bereaved family members' perceptions of the quality of hospice care: Lessened disparities, but opportunities to improve remain. *Journal of Pain and Symptom Management*. 2007; 34(5):472–479. [PubMed: 17900854]
- Stajduhar K, Funk L, Toye C, Grande G, Aoun S, Todd C. Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998–2008). *Palliative Medicine*. 2010; 24(6):573. [PubMed: 20562171]
- Volandes AE, Paasche-Orlow M, Gillick MR, Cook E, Shaykevich S, Abbo ED, Lehmann L. Health literacy not race predicts end-of-life care preferences. *Journal of Palliative Medicine*. 2008; 11(5): 754–762. [PubMed: 18588408]
- Welch LC, Teno JM, Mor V. End-of-life care in Black and White: Race matters for medical care of dying patients and their families. *Journal of the American Geriatrics Society*. 2005; 53(7):1145–1153. [PubMed: 16108932]