

these services. In this presentation, we report on results from a nationwide telephone survey of the availability of EoL care across AIAN tribes. We also present findings from in-depth interviews with local service providers on the challenges and successes they experienced in providing EoL care to their AI clients in one tribal community. Together, these findings will add to our growing understanding of the factors that inhibit and facilitate EoL service utilization, and suggest possibilities for improving access.

### STRENGTHENING OLDER INDIGENOUS NEW ZEALANDERS AT END OF LIFE: WHAT ROLE DO HEALTH SERVICES PLAY?

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Older indigenous people and their families draw on specific tribal care customs to support end-of-life care as these help to fortify and strengthen older people. New Zealand's health and palliative care services can either help or hinder families to utilise their care customs. The aim of the Pae Herenga study was to investigate the specific traditional care customs employed by older New Zealand Māori. This involved 60 face-to-face interviews with participants who had a life limiting illness (majority aged over 65), family carers, indigenous healers, spiritual practitioners, and health and palliative care professionals across four key geographical sites. Three digital story workshops involving 16 participants were also included. The study findings show that no matter what the older person's illness was, their cultural customs and protocols helped to fortify them and kept them spiritually safe at end-of-life. Hospitals and hospices helped families to action their customs by providing rooms large enough to host gatherings of thirty or more people; prayers, songs, speechmaking and communal sharing of food took place. However, incidences of racism, a lack of space, and a lack of support for indigenous plant medicines prevented the use of ancient traditional end-of-life care customs for older people. The findings suggest that health and palliative care services can help older indigenous people maintain their spiritual strength by providing them with culturally supportive care and environments equipped to host the dying and their families.

### FAMILY AND SOCIAL NETWORKS FOR AGE-RELATED PLANNING CONVERSATIONS: CHARACTERISTICS AND VARIABILITY

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Informal advance care planning (IACP) – that is, conversations with surrogate decision-makers about wishes for health care or end-of-life preferences – have been identified as equally if not more important than legal documentation for achieving a high-quality end-of-life experience. Fairly high rates of adults report having had these conversations; this is especially true of people who are older, sicker, or who have had caregiving experience. However, relatively little is known about the content and characteristics of these conversations, such as who people are talking to, what triggers the conversation, and what is actually said. This paper reports findings from interview-based research that asked 38 middle-age and older adult respondents (ages 55 to 74) about conversations related to several

areas of age-related planning, including planning for health care needs and wishes about end-of-life. The interactive interview protocol used the open-source EgoWeb software to elicit information about age-related planning conversations, family and social networks, and who within those networks served as conversation partners for the various topics. We will share results of the analysis of the networks and conversation topics. We found that some individuals more readily engage in discussions about future planning across topics than others, but that part of this is driven by the readiness of their family and friends to engage in these topics. This suggests that targeting individuals to increase rates of IACP has limitations when family and friends are resistant, and that dyadic interventions may be appropriate in some cases.

### CAREGIVER BURDEN, BENEFIT, AND PERCEPTIONS OF END-OF-LIFE CARE QUALITY

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End-of-life care quality (EOLCQ) gauges our success in providing quality care to dying individuals. EOLCQ measures rely on reports from bereaved family members who provide care for dying loved ones, but analyses seldom account for how caregivers' experiences influence their EOLCQ perceptions. Caregivers frequently experience burden, which is linked to poor health outcomes and may negatively bias EOLCQ reports. Individuals may also perceive caregiving benefits that can offset deleterious burden effects, but potentially encourage overly positive EOLCQ perceptions. This paper links National Study of Caregivers (2011) and National Health and Aging Trends Study (2011-2016) data, using regression analysis and a sample of 380 EOL caregivers to examine how caregiving burden and benefits perceptions shape and moderate EOLCQ reports. Caregiving burden is unrelated to EOLCQ in adjusted models. Benefits are associated with marginally greater odds of being informed about the dying person's condition and reporting their personal care needs were met. Burden and benefits moderate these two measures. Despite benefits, low burden caregivers report they were informed about the dying person's condition with 90% probability. Regardless of burden, high benefits caregivers report the same with 90% probability. Low burden and benefits caregivers report met care needs with 90% probability. High burden and benefits caregivers have 90% probability of such reports. Given these reports are used in formal hospice care evaluations by CMS, additional research should explore why caregiving burden and benefit are associated with some EOLCQ measures and why individuals reporting high burden and benefits provide more positive EOLCQ appraisals.

### ADULT CHILDREN'S UNDERSTANDING OF PARENTS' CARE AND LIVING PREFERENCES AT END OF LIFE

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Adult children who are uninformed about their parents' preferences for end-of-life care may not be prepared to

advocate on their behalf when the circumstances arise. The purpose of the current analysis was to examine how well adult children understand their parents' end of life preferences. We analyzed responses from adult children ( $n = 70$ ) of 40 older adults (65+) who participated in an intervention to improve family communication about end-of-life care. We compared children's and parents' responses on the same set of 6 questions about healthcare decision-making (e.g., "Which medical decision-maker has the final say?") and 4 questions about living preferences (e.g., "Would you want to move to a nursing home?"). We also examined demographic differences between children who had higher agreement ( $\geq 6/10$  questions correct;  $n = 32$ ) versus lower agreement ( $< 6/10$  questions correct;  $n = 38$ ). On average, children provided the same response as their parents on approximately 5 out of 10 questions. Overall, adult children answered more questions correctly about living preferences compared to preferences about healthcare decisions ( $t(69) = 6.59, p < 0.001$ ). In terms of demographic characteristics, there were no significant differences between children with higher and lower agreement with their parents' preferences on variables including gender, frequency of contact with parents, and living proximity to parents. Our results underscore the need for increased communication between adult children and their parents about topics likely to influence quality of care at end of life.

#### END-OF-LIFE CARE PREFERENCES AND WELL-BEING IN LONG-TERM CARE RESIDENTS

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Research on end-of-life care in nursing homes comes largely from the viewpoint of staff or family members. We examined patient perspectives on end-of-life care, preferences for care, and quality of life in long-term care settings. We hypothesized that fulfillment of the Self Determination Theory (SDT) needs of autonomy, competence, and relatedness would be related to better well-being and that the degree to which end-of-life care preferences are seen as possible in the setting would be related to SDT need fulfillment and well-being. Preliminary data, collected from older individuals at the end of life (over 55, presence of significant chronic disease, in long term care setting) ( $n = 72$ ), demonstrated that autonomy, competence, and relatedness measures were moderately and significantly correlated with well-being as measured by life satisfaction, higher positive affect, lower negative affect, and overall quality of life measures. The degree to which residents believed that their end-of-life care preferences could be honored in the setting was also significantly correlated with autonomy, competence, relatedness, positive affect, and psychological quality of life. These results are consistent with SDT and suggest that if long term care settings can promote autonomy, connection, and competence in making end of life decisions, possibly by discovering and fulfilling preferences for end of life care, individuals who end their lives on those settings have potential for greater satisfaction and happiness. These results suggest that SDT is a useful framework for ongoing research on how to improve the end of life experiences of older adults in long term care.

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#### PREVALENCE AND CORRELATES OF SYMPTOMS OF ANXIETY AND DEPRESSION AT THE VERY END OF LIFE

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Rates of psychological symptoms for patients with serious illness is high, but there has been limited research investigating psychological symptoms at the very end of life. The aim of this study was to better understand the prevalence, intensity and correlates of psychological distress at the very end of life. This cross-sectional study utilized caregiver proxy interviews. Caregivers were contacted after their loved one recently died after being on home hospice and invited to participate in a brief interview with a trained research assistant. Patient, caregiver and hospice utilization data were also abstracted from electronic medical records.  $N = 351$  caregivers were included in the study. According to caregivers, 46.4% of patients had moderate to severe anxiety, as assessed with a score of  $\geq 4$  on the Edmonton Symptom Assessment Scale (ESAS) and 43% had moderate to severe symptoms of depression in the last week of life. Symptoms of anxiety and depression were significantly associated with caregiver burden scores and inversely associated with the age of the patient. Psychological symptom management at the very end of life is essential to providing comprehensive hospice care. Our study revealed that nearly half of patients die with moderate to severe symptoms of anxiety and/or depression. Future research is needed to improve psychological symptom management at the very end of life in order to improve the quality of life for both patients and their families.

#### FREQUENCY OF CONTACT AMONG FAMILY MEMBERS AND END-OF-LIFE CARE PLANNING

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The purpose of the current analysis was to examine how contact between adult children and their older parents may relate to having end-of-life care conversations. We analyzed responses from adult children ( $n = 66$ ) of 36 older adults (65+) who participated in an intervention to improve family communication. Children reported the frequency of their in-person and phone contact with parents. They also completed the Conversations about Care Arrangements Scale ( $\alpha = 0.95$ ), 8 items that measure the extent to which adult children have discussed plans about future care with their parents (1=have not talked at all, 5=talked extensively). We calculated a composite from all 8 items (potential range 5-40). Participants reported that they had, on average, not talked extensively with their parent about plans for future care ( $M = 18.7, SD = 8.22$ ). Overall, 42.4% of children reported that they visited their parent one time or less per year. Children reported speaking on the phone with their parent an average of 4.74 times per week ( $SD = 6.80, \text{range} = 0-30$ ) and initiating an average of 2.59 of those calls ( $SD = 3.82, \text{range} = 1-20$ ). Frequency of weekly phone conversations between child and parent was significantly associated with having talked more extensively about future care plans ( $r = 0.25, p < 0.05$ ), as was frequency