

A SELECTION OF TEN CURRENT READINGS ON TOPICS RELATED TO ADVANCED CARE PLANNING AND END OF LIFE CARE

Selection of readings made by A/Prof Goh Lee Gan

READING 1. COMMUNICATION IN PALLIATIVE CARE

Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. Postgrad Med J. 2016 May 6. PubMed PMID: 27153866.

URL: <http://pmj.bmj.com/content/early/2016/05/06/postgradmedj-2015-133368.long> (Payment required)

ABSTRACT

Increasing evidence demonstrates the benefits of early end-of-life care discussions with patients with life-threatening illness and their families. However, these conversations often do not occur. This review explores some of the many barriers faced by clinicians in relation to end-of-life care discussions, including prognostic uncertainty, fear of causing distress, navigating patient readiness and feeling unprepared for these conversations. The value of core clinical communication skills, potential strategies for improvement and areas for future research are also discussed. It is essential that clinicians offer patients facing life-threatening illness, and those close to them, the opportunity to discuss end-of-life issues in line with their information and decision-making preferences. With a growing and ageing global population, supporting both generalist and specialist providers of palliative care in this task is key. With careful preparation, fears of undertaking these discussions should not be a barrier to initiating them.

PMID: 27153866

READING 2. ADVANCED CARE PLANNING COMMUNICATIONS

Lum HD, Sudore RL. Advance Care Planning and Goals of Care Communication in Older Adults with Cardiovascular Disease and Multi-Morbidity. Clin Geriatr Med. 2016 May;32(2):247–60. PubMed PMID: 27113144.

URL: <http://www.sciencedirect.com/science/article/pii/S0749069016000124> (Payment required)

ABSTRACT

This article provides an approach to advance care planning (ACP) and goals of care communication in older adults with cardiovascular disease and multi-morbidity. The goal of ACP is to ensure that the medical care patients receive is aligned with their values and preferences. In this article, the authors outline common benefits and challenges to ACP for older adults with cardiovascular disease and multimorbidity. Recognizing that these patients experience diverse disease trajectories and receive care in multiple health care settings, the authors provide practical steps for multidisciplinary teams to integrate ACP into brief clinic encounters.

PMID: 27113144

READING 3. ADVANCED CARE PLANNING DISCUSSIONS

Norals TE, Smith TJ. Advance Care Planning Discussions: Why They Should Happen, Why They Don't, and How We Can Facilitate the Process. *Oncology (Williston Park)*. 2015 Aug;29(8):567-71. PMID: 26281841

URL: <http://www.cancernetwork.com/oncology-journal/advance-care-planning-discussions-why-they-should-happen-why-they-dont-and-how-we-can-facilitate> (Free full text)

ABSTRACT

Recent data suggest that we are not successfully getting the message across about the importance of advance care planning for patients who have a life-ending illness. Half to three-quarters of patients with incurable cancer think that they might be cured by chemotherapy, radiation, or surgery. The source of this denial may lie with them, it may be traceable to their physicians, or it may be a combination of the two. This avoidance has consequences, since those patients with "prognostic awareness" have end-of-life care pathways that involve little use of the hospital, ICU, end-of-life chemo, or "codes" with almost no chance of success, and much more dying at home with hospice care. If we can successfully initiate advance care planning discussions with our patients and families, their end-of-life processes will improve, resulting in better care, less use of the hospital, and more honoring of newly discerned choices. We show how this can be done in regular oncology practice by introducing the Johns Hopkins "Palliative Care Temporary Tattoo" and by providing some ways to discuss cardiopulmonary resuscitation in settings where it will not be helpful.

PMID: 26281841 [PubMed - indexed for MEDLINE]

READING 4. ADVANCED CARE PLANNING IN PRIMARY CARE TODAY

Glaudemans JJ, Moll van Charante EP, Willems DL. Advance care planning in primary care, only for severely ill patients? A structured review. *Fam Pract*. 2015 Feb;32(1):16-26. PMID: 25381010.

URL: <http://fampra.oxfordjournals.org/content/32/1/16.long> (free full text)

ABSTRACT

BACKGROUND: Increasing medical possibilities, ageing of the population and the growing number of people with chronic illness appears to make advance care planning (ACP) inevitable. However, to what extent and how primary care providers (PCPs) provide ACP in daily practice is largely unknown.

OBJECTIVE: To provide an overview of the actual practice of ACP in primary care.

METHODS: We searched MEDLINE, EMBASE, CINAHL, PsycINFO and the Cochrane Library for empirical studies that described the practice of ACP with patients in primary health care. Studies focussing on non-adult patients, and hospital or nursing home settings were excluded.

RESULTS: Ten articles met the inclusion criteria. The content of the ACP varied from discussing to refrain from cardiopulmonary resuscitation to existential issues. The prevalence ranged from 21% of PCPs having ACP discussions with the general elderly population to 69% having ACP discussions with terminal patients and 81% with patients with mild to moderate Alzheimer's disease. ACP was more common among cancer patients than among patients with non-cancer patients. Whether health care professionals or patients initiated ACP varied greatly. Advance directives and the Gold Standard Framework were perceived as helpful to guide ACP.

CONCLUSIONS: ACP does not seem to have a systematic place in the care for all community-dwelling older people. Rather, it is used for specific groups, like patients with terminal disease, cancer and Alzheimer's Disease. Whether ACP might have beneficial effects for a broader primary care population, in terms of future care planning, is yet to be investigated.

PMID: 25381010

READING 5. MANAGING BREATHLESSNESS IN PALLIATIVE CARE

Chin C, Booth S. Managing breathlessness: a palliative care approach. *Postgrad Med J*. 2016 Jul;92(1089):393–400. PMID: 27053519.

URL: <http://pmj.bmj.com/content/92/1089/393.long> (Payment required)

ABSTRACT

Breathlessness is an important and common symptom globally, affecting patients with a variety of malignant and non-malignant diseases. It causes considerable suffering to patients and also their families, and is a significant cost to healthcare systems. Optimal management of the symptom should therefore be of interest and importance to a wide range of clinicians. Best practice in the management of breathlessness consists of both non-pharmacological and pharmacological interventions as evidenced by recent randomised controlled trials of multidisciplinary breathlessness support services. As well as providing evidence for integration of early palliative care into respiratory services, these revealed that patient distress due to breathlessness can be significantly reduced and better outcomes can be achieved at lower cost than standard care.

PMID: 27053519,

READING 6. OPIOID-INDUCED CONSTIPATION

Argoff CE, Brennan MJ, Camilleri M, Davies A, Fudin J, Galluzzi KE, Gudim J, Lembo A, Stanos SP, Webster LR. Consensus Recommendations on Initiating Prescription Therapies for Opioid-Induced Constipation. *Pain Med*. 2015 Dec;16(12):2324–37. PMID: 26582720; PubMed Central PMCID: PMC4738423.

URL: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4738423/> (Free full text)

ABSTRACT

OBJECTIVE: Aims of this consensus panel were to determine (1) an optimal symptom-based method for assessing opioid-induced constipation in clinical practice and (2) a threshold of symptom severity to prompt consideration of prescription therapy.

METHODS: A multidisciplinary panel of 10 experts with extensive knowledge/experience with opioid-associated adverse events convened to discuss the literature on assessment methods used for opioid-induced constipation and reach consensus on each objective using the nominal group technique.

RESULTS: Five validated assessment tools were evaluated: the Patient Assessment of Constipation-Symptoms (PAC-SYM), Patient Assessment of Constipation-Quality of Life (PAC-QOL), Stool Symptom Screener (SSS), Bowel Function Index (BFI), and Bowel Function Diary (BF-Diary). The 3-item BFI and 4-item SSS, both clinician administered, are the shortest tools. In published trials, the BFI and 12-item PAC-SYM are most commonly used. The 11-item BF-Diary is highly relevant in opioid-induced constipation and was developed and validated in accordance with US Food and Drug Administration guidelines. However, the panel believes that the complex scoring for this tool and the SSS, PAC-SYM, and 28-item PAC-QOL may be unfeasible for clinical practice. The BFI is psychometrically validated and responsive to changes in symptom severity; scores range from 0 to 100, with higher scores indicating greater severity and scores >28.8 points indicating constipation. **CONCLUSIONS:** The BFI is a simple assessment tool with a validated threshold of clinically significant constipation. Prescription treatments for opioid-induced constipation should be considered for patients who have a BFI score of ≥30 points and an inadequate response to first-line interventions.

PMCID: PMC4738423 PMID: 26582720

READING 7. PALLIATIVE CARE IN HEART FAILURE

McIlvennan CK, Allen LA. Palliative care in patients with heart failure. BMJ. 2016 Apr 14. PubMed PMID: 2707989

URL: <http://www.bmj.com/content/353/bmj.i1010.long> (Free full text)

ABSTRACT

Despite advances in cardiac therapy, heart failure (HF) remains a progressive, highly symptomatic, and deadly disease that places great demands on patients, caregivers, and healthcare systems. Palliative care is a multidisciplinary approach to care that focuses on communication, shared decision making, and advance care planning; provides relief from pain and other distressing symptoms; integrates psychological and spiritual aspects of care; and offers a support system to help families cope during illness and bereavement. Palliative care has applications across the stages of heart failure, including early in the course of illness, often in conjunction with other therapies that are intended to prolong life. However, the incorporation of palliative care into the management of heart failure has been suboptimal for several reasons: uncertainty in the disease trajectory, failure to reward communication between healthcare providers and patients, siloed care, lack of knowledge, overlay of comorbidity and frailty, life saving devices with complex trade-offs, and a limited evidence base. This review will summarise the current literature on the emerging role of palliative care in patients with heart failure and the challenges and opportunities for its integration into routine care. It will discuss current initiatives and future directions of the collaborative relationship between the palliative care and heart failure disciplines.

PMID: 27079896

READING 8. CONSERVATIVE CARE OF THE ELDERLY CKD PATIENT

Raghavan D, Holley JL. Conservative Care of the Elderly CKD Patient: A Practical Guide. Adv Chronic Kidney Dis. 2016 Jan;23(1):51–6. PMID: 26709063.

URL: [http://linkinghub.elsevier.com/retrieve/pii/S1548-5595\(15\)00111-1](http://linkinghub.elsevier.com/retrieve/pii/S1548-5595(15)00111-1) (Payment required)

ABSTRACT

Palliative care is a branch of medicine dedicated to the relief of symptoms experienced during the course of illness. Renal palliative medicine or kidney supportive care is an evolving branch of nephrology, which incorporates the principles of palliative care into the care of CKD and ESRD (dialysis, transplant, and conservatively managed) patients. Conservative (non-dialytic) management is a legitimate option for frail, elderly CKD patients in whom dialysis may not lead to an improvement in quality or duration of life. Patients with advanced CKD have a high symptom burden that often worsens before death. Palliative or supportive care by visiting nurses, palliative care programs, or knowledgeable CKD programs should be routine for conservatively managed CKD patients. Decision-making about dialysis or conservative management requires patients and families be given information on prognosis, quality of life on dialysis, and options for supportive care. Advance care planning is the process by which these issues can be explored. In addition to advance care planning, because patients with ESRD have a high symptom burden, this needs to be addressed. Patients with ESRD have a high symptom burden, which needs to be addressed in any treatment plan. Common symptoms include pain, fatigue, insomnia, pruritus, anorexia, and nausea. Symptoms appear to increase as the patient nears death, and this must be anticipated. Recommendations for management are discussed in the article. Hospice care should be offered to all patients who are expected to die within the next 6 months, and supportive care should be provided to all CKD patients managed conservatively or with dialysis.

PMID: 26709063

READING 9. CULTURE AND SPIRITUALITY IN PALLIATIVE CARE

Speck P. Culture and spirituality: essential components of palliative care. *Postgrad Med J.* 2016 Jun;92(1088):341–5. PMID: 26933233.

URL: <http://pmj.bmj.com/content/92/1088/341.long> (Payment required)

ABSTRACT

Palliative care advocates a holistic, multiprofessional approach to the care of people with life-threatening disease. In addition to the control of physical symptoms attention should also be paid to psychosocial, cultural and spiritual aspects of the patient's experience of illness. Guidance documents and research evidence reflect the complexity of the patient's journey and the need to regularly assess these areas of need over time. Cultural background can shape how patients respond to life-threatening illness, as can the beliefs held by the patients, whether religious or more broadly spiritual. Research evidence shows the importance of identifying and addressing cultural and spiritual aspects of care held by patients, families and staff. These are often neglected in clinical practice due to the focus on biomedical concerns and staff discomfort in engaging with beliefs and culture. Recent studies have highlighted gaps in the research, and some methodological difficulties and indicate many patients welcome healthcare staff enquiring about the importance of their beliefs and culture. Identifying research priorities is necessary to guide future research and strengthen the evidence base.

PMID: 26933233

READING 10. NEW PUBLIC HEALTH APPROACH TO END-OF-LIFE CARE

Sallnow L, Richardson H, Murray SA, Kellehear A. The impact of a new public health approach to end-of-life care: A systematic review. *Palliat Med.* 2016 Mar;30(3):200–11. PMID: 26269324.

URL <http://pmj.sagepub.com.libproxy1.nus.edu.sg/content/30/3/200.long> (Payment required)

ABSTRACT

BACKGROUND: Communities play an increasingly significant role in their own health and social care, and evidence demonstrates the positive impact of this work on a range of health outcomes. Interest is building regarding the application of the principles of the new public health approach to those facing the end of life and their families and communities.

AIM: To review the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

DESIGN: A systematic review employing narrative synthesis. Both meta-ethnography and the use of descriptive statistics supported analysis.

DATA SOURCES: Eight databases (AMED, ASSIA, BiblioMap, CINAHL, Cochrane Reviews, EMBASE, MEDLINE and PsycINFO) were searched from the earliest record to March 2015 using set eligibility criteria.

RESULTS: Eight articles were included in the analysis. Three main themes emerged from the meta-ethnography: making a practical difference, individual learning and personal growth and developing community capacity. The quantitative findings mapped to the meta-ethnography and demonstrated that engaging communities can lead to improved outcomes for carers such as decreased fatigue or isolation, increase in size of caring networks and that wider social networks can influence factors such as place of death and involvement of palliative care services.

CONCLUSION: Evidence exists for the impact of community engagement in end-of-life care. Impact assessment should be an integral part of future initiatives and policy makers should recognise that these approaches can influence complex issues such as carer support, community capacity, wellbeing and social isolation.

PMID: 26269324