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ADDRESSING THE ELEPHANT IN THE ROOM: ADVANCE CARE PLANNING AND ITS RELEVANCE TO FAMILY PHYSICIANS TODAY

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ABSTRACT

Advance care planning (ACP) is a core tenet of person-centred care in serious illnesses. Family physicians provide relationship-based and continuing care. These are key in the endeavour to understanding our patients' healthcare preferences in serious illnesses. This is especially salient in an ageing population where people may experience cognitive and functional decline in their last years and modern medicine struggles to provide person-centred treatments. With the recent healthcare reform and Healthier SG, challenges and opportunities abound for family physicians in serious illness care. As co-creators of personalised care plans with each enrolled resident, primary care physicians will play an increasingly important role in ACP. The COVID pandemic has made stark the reality that anyone can suddenly and seriously fall ill at any time. The need to address this elephant in the room makes ACP urgent and relevant, especially today.

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INTRODUCTION

Advance Care Planning (ACP) is a process of discussion with an individual and his/her loved one(s) regarding values and preferences about future medical treatment options in the event that he/she falls seriously ill and has lost decision-making ability.

In this article, I will explore the implications of recent trends in healthcare reform on the role of the family physician in ACP and serious illness conversations as well as challenges and opportunities in ACP in the primary care setting.

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CASE STUDY 1

Mdm T is a 70-year-old woman who was followed up by myself for hypertension and hyperlipidaemia for two years in a polyclinic 15 years ago prior to my decision to train further in palliative medicine as a sub-specialty. In the course of my training and work, I developed an interest in advocating for the patient's voice in serious illness and became an advocate for ACP. One day in my palliative care clinic in the hospital, Mdm T presented to me as a "new" case with recently diagnosed Stage 4 angiosarcoma of the scalp. She recognised me instantly as the family physician who closely titrated her chronic disease medications many years ago. It took a few moments of banter before I recognised her and continued our doctor-patient relationship, albeit in a different setting. Over the next eight months, I journeyed with her. I titrated her morphine for pain and helped to refer her to home palliative care for shared care as well as to radiation oncology for palliative radiotherapy to painful lymphadenopathy. I spoke to her about her values, wishes, fears, and preferences during serious illness and documented her wishes in an advance care plan. She shared her fear of pain and her concern for her husband as well as her wishes for interventions that were not overtly burdensome. Her wishes were made known to the home palliative care service and were fulfilled, including her preferred place of death. After her passing, the social worker in our team continued bereavement follow-up for her elderly husband who stayed alone.

ADVANCE CARE PLANNING IN SINGAPORE

Singapore's population is ageing rapidly. It is estimated that by 2030, one in four persons will be aged >65 years old.[1] The number of elderly with more complex care needs and living in longer years of disability will likewise rise. Over the decades, ACP has become especially salient with technological advances that prolong life expectancies but may result in poor quality of life and missed opportunities to engage patients in discussions to understand what really matters to them.

Beyond calls for rationalisation of care, ACP endeavours to bring person-centred medicine and respect for autonomy into serious illness care. Healthcare providers must engage patients in meaningful conversations to help them understand their illnesses, potential healthcare scenarios, and treatment options, while simultaneously clarifying their values, beliefs, and goals of care.

Since 2011, Singapore has implemented a nationwide funded programme named Living Matters, which was modelled after the Respecting Choices framework of ACP from Wisconsin, USA. The Living Matters programme commenced as small pilot programmes in various

restructured hospitals and home care services. It was led by the National ACP Steering Committee in collaboration with the Agency for Integrated Care (AIC). The programme has grown over the years through systematic training of ACP facilitators, outreach programmes targeting both healthcare professionals and the public, formulation of standardised forms, as well as development of an electronic repository of ACP documents, which is synchronised with the national electronic health records system.

The launch of Healthier SG signalled the government's push for proactive population-based care with a focus on prevention, enrolment of residents with family doctors, community partnerships, and relationship-based care.

Serious illness and end-of-life care are not given short shrift and the Health Minister, Mr Ong Ye Kung, has advocated strongly for more open discussions about death.[2] To date, more than 27,000 ACP documents have been lodged and more than 5,000 ACP facilitators trained.[3]

However, most of these ACPs were completed in the hospital setting and with patients who are seriously ill and/or their family members. Very few are completed within the primary care setting and mostly by medical social workers within polyclinics. This is not ideal as conversations about care preferences should begin in the community as an iterative conversation. In my experience as a palliative care physician in a tertiary hospital setting, patients in the wards are frequently too sick or too stressed to have these conversations. About half the time, they have lost decision-making capacity and the medical team will then need to approach family members to ask questions such as "What do you think your loved one would have wanted?". This puts added burden and stress on the loved ones of patients. In the international literature, up to a third of surrogates cannot reliably predict the wishes of patients[5] and have identified their own values and preferences as influencing decision-making.[6]

ADVANCE CARE PLANNING IS RELEVANT TO THE FAMILY PHYSICIAN

The involvement of family physicians in serious illness conversations resonates with the cradle-to-grave ethos and holistic approach of family medicine. Building on trust and relationship-based care, family physicians working within the public and private healthcare sectors are ideally placed to be care navigators for residents they care for. Studies have shown that patients would like to have these conversations with their doctors, including their family physicians. When family doctors are involved in the ACP process, the conversations start earlier, highlighting the impact family physicians can have in improving the quality of the ACP process. This fulfils the ideal of ACP as an iterative and reflective process as well as a longitudinal conversation in a person's life course. Patients who had these conversations are more likely to have their wishes documented and respected when seriously ill,[6,7] and are less likely to receive potentially burdensome and futile treatment.[8] Their loved ones are more likely to report a better quality of death for the patient[8] and less likely to experience stress, depression, and anxiety post-bereavement.[7]

Understanding psychosocial factors and preferences in serious illness care is as important as understanding social determinants of health in chronic disease. When serious illness strikes or a chronic progressive condition suddenly deteriorates, it is usually like a bolt of lightning, highlighting the importance of pre-emptive conversations. It is always too early until it is too late.

BARRIERS TO ACP IN PRIMARY CARE

Multiple barriers to ACP in primary care have been reported. These include a lack of time, lack of renumeration for ACP in primary care, a perceived lack of skill and discomfort in having these conversations, as well as the fear of taking away hope.[9] Other challenges reported included the inability to transfer information electronically across settings, the handover of care of patients near end of life, and poor understanding of patients of future treatments.[10] These challenges are very real and likely account for the very low participation of family doctors in the community as ACP facilitators. Studies have shown that these barriers are not insurmountable. Enablers of ACP identified by primary physicians are greater community engagement, attitudes of the physicians, capacity building, and supportive policy changes.[10]

The rate of ACP can be improved in primary care through the use of multidimensional approaches, including prompts for ACP, breaking up the discussion into a few stages and visits, as well as concurrent use of education tools.[11]

OPPORTUNITIES FOR ACP IN PRIMARY CARE

Healthier SG aspires to move beyond transactional and episodic care towards longitudinal relationship-based care with the family physician in the community firmly at the centre of such care.

Each resident will develop a personalised care plan throughout his/her life trajectory including both medical and social care elements. Though this is at iterative phase and platforms for information sharing are being built and integrated, a one-care plan for each resident certainly includes his/her advance care plans. In the ecosystems of care that regional health systems will aim to foster in the Healthier SG plan, opportunities abound for family doctors to advocate for and facilitate ACP.

While ACP in Singapore developed primarily in the tertiary hospital setting, efforts at engaging the community in ACP awareness, including within HDB heartlands and the long-term care sector, have gathered pace in recent years. A substantial number of educational materials including videos and brochures have been developed as outreach tools. There are also noteworthy trends in Singapore to empower

citizens in end-of-life matters including the use of digital tools (e.g., https://www.mylegacy.gov.sg/).

In a 2017 survey of community dwellers in the HDB heartlands of Singapore, out of 406 respondents, only 14.4 percent have heard of ACP. However, after education about ACP, a majority were willing to initiate an ACP discussion.[12] Starting with engaging their patients on what matters to them, it is timely for family physicians to realise their full potential in serious illness care. Family physicians can either advocate for ACP with their patients and refer them to the appropriate services or facilitate ACP conversations. Services exist in the community for ACP facilitation which the family doctor may refer to.[13]

If a family physician hopes to be trained in ACP facilitation, he/she may do so by connecting with the regional health cluster in his/her region. Every regional health cluster has full-time ACP trainers whose role is to train and mentor healthcare professionals within the cluster and partner stakeholders in ACP facilitation. If the family physician works within a community hospital, polyclinic, or even a primary care network, other members of the multidisciplinary team such as the nurse or social worker may take on the role of the ACP facilitator.

Each successfully trained ACP facilitator is granted access to the national ACP information technology platform to lodge completed ACPs. Currently, there are no benchmarks regarding renumeration for ACP in primary care. Such benchmarks can be set after discussion between professional bodies representing primary care and the Agency for Integrated Care (AIC). If a family physician is a certified issuer of the Lasting Power of Attorney (LPA), he/she may pair ACP discussions with LPA services.

CASE STUDY 2

Mdm X is a 91-year-old woman with recently diagnosed locally advanced breast cancer who was recently seen by myself in my clinic. She declined all treatment for her breast cancer including any radiotherapy, hormonal treatment, or chemotherapy, citing poor outcomes she has witnessed in her friends and family. She is fiercely independent and valued being at home in her community. She is supported by a network of community care providers as well as by a nephew who visits occasionally.

In my conversation with her, she said she is Buddhist and views death as part of life. "Everyone has to walk this road", she replied. She expressed her wishes against interventions such as nasogastric tube insertions and to avoid hospitalisations as much as possible. She named her nephew as her nominated healthcare spokesperson. Otherwise, she was asymptomatic and I gave her a follow-up appointment for a few months later. While I documented her plans, I did not explore her preferred place of death and planned to do so at subsequent clinic encounters. Though this encounter took place within the setting of a palliative care clinic in a tertiary hospital, it could have very well taken place within a general practice clinic within the community. While such conversations may be sensitive, my personal experience is that when sensitively broached and normalised in a relationship of trust, most patients are open to initiating and completing ACP discussions.

CONCLUSION

As a society plugged into the global order, Singapore is at the crossroads of change. While we forge ahead with medical advances in addressing new diseases and as a resilient society, the holy grail of goal concordant care must not be forgotten.

As a key lever in person-centred care, ACP is not a false promise but an ethical imperative that brims with both challenges and opportunities. Treating a patient as a total human being is at the heart of medicine. As key stakeholders in Healthier SG and developing personalised care plans for each resident, the role of family physicians in ACP cannot be understated.

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