

Palliation in Advanced Heart Failure: Identifying Barriers in Malaysia

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Abstract

Introduction: An estimated 26 million people worldwide suffer from the heart failure, and more than half of new diagnosis is made in those aged 80 years and above. Furthermore, nearly 75% have at least one other comorbidity. Advanced heart failure, defined as 'advanced and persistent heart failure with symptoms at rest despite repeat attempts to optimize pharmacological and non-pharmacological therapy carry with it further problems including repeated hospitalizations, poor quality of life, disability and symptom burden, as well as reliance on intravenous support or device therapy, all of which have direct implications to both patients and their loved ones.

Objective: We explore the possible barriers that exist in initiating palliation in advanced heart failure patients, unique to an Asian and Malaysian population.

Discussion: We first explore the universal barriers towards palliation, including those revolving around limited evidence specifically surrounding heart failure palliation, communication breakdown, and accessibility and service provision limitation. We then explore specific barriers unique to Malaysia, surrounding its core value of being a multi-cultural, multi-faith nation.

Conclusion: Discussions surrounding heart failure palliation and palliative care remains taboo amongst patients and physicians. Heart failure remains an enigma and is often unpredictable in its course which leads to physician reluctance in discussing poor outcomes with patients. By understanding the barriers that exist, including that of culture and religion, we now know that early discussions and continuous involvement of both patients and their relatives in decision making may be the key in end-of-life care in advanced heart failure.

Keywords: Heart failure; Palliative medicine; Advanced heart failure; Socio-economic

Introduction: Burden of Heart Failure and Advanced Heart Failure-Consequence of Keeping Patients Alive?

Heart failure remains a prevalent disease, with high mortality, morbidity and readmission rates, with local data showing far worst rates amongst Malaysians [1,2]. An estimated 26 million people worldwide suffer from the disease, and more than half of new diagnosis is made in those aged 80 years and above, in which patients would then often be categorized as having advanced heart failure [3,4].

Advanced heart failure, defined as 'advanced and persistent heart failure with symptoms at rest despite repeat attempts to optimize pharmacological and non-pharmacological therapy and carry with it further problems including repeated hospitalizations, poor quality of life, disability and symptom burden as well as reliance on intravenous support or device therapy, all of which have direct implications to both patients and their loved ones [5]. Futility in majority of cases are often realised too late during the disease process with studies showing an average time of only 2 weeks between referral to palliative services to mortality, due to various factors [6]. In this essay, we explore the possible barriers that exist in initiating palliation in advanced heart failure patients, unique to an Asian and Malaysian population.

Universal Barriers to Palliation: Sharing the Burden

Most of palliative care development, at the beginning, was based around oncology, where in the event that chemotherapy and radiotherapy are felt to be futile, the disease trajectory with progression can be fairly predictable, as illustrated by Steinberg et al. [7]. However, this does not sit true with chronic diseases such as advanced-stages of heart failure, CKD or COPD. Unlike oncological diseases, heart failure has a vastly different disease trajectory, riddled with peaks and trough of disease activity throughout its progression [8]. This may deter

physicians, in most part, to recommend palliation as an option, fearing recommending such course of management too prematurely.

Poor communication and reluctance in discussing information on prognosis and course of the disease has also contributed to the issue. Amongst patients diagnosed with lung cancer, a study showed how conversations would quickly shift from discussion on disease prognosis and outcomes, to management options [9]. The traditional role of physicians as a 'healer' adds to the difficulty in relaying vital information on futility of treatment as well. In addition, various studies have shown substantial rates of non-acceptance and poor understanding of primary diagnosis as well as prognosis of conditions, often driven by ambiguity in information delivery and poor management of expectation [10]. Furthermore, when comparing heart failure to cancers, it often pales in comparison in terms of perceived severity, which 'down-plays' the true, poor prognosis of the disease [11].

Treatment options also provide a barrier to breaching talks on palliation. An interesting component in heart failure management often includes pharmacological-based treatment, as well as use and implantation of device therapies. This is not simply limited to the use of implantable cardiac defibrillators (ICDs) and cardiac resynchronization therapy (CRT) which has direct impact on heart failure prognosis, but

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indirect benefits gained from advancement in percutaneous coronary intervention (PCI) and valvular repair and replacements [12]. This is a recognized challenge in terms of prognostication of heart failure patients, as clinicians are faced with the question –‘Have you done enough for your patient?’ or ‘Is this truly the ceiling for clinical care?’ What we do need to remember is that despite studies showing improved mortality rates with implantable devices and PCI in chronic heart failure, its benefits in advanced heart failure patients remain unknown [13]. Furthermore, guidance on eligibility for such device therapy remain contentious, despite guidelines as it varies between countries and is highly determined by individual clinician judgement, as seen in the case of CRTs. For example current recommendation for ICD and CRT implantation as per the European Society of Cardiology (ESC) guidelines include having a ‘reasonable expectation of survival with good functional status of more than one year [14]. Unfortunately, to our knowledge, there are no existing risk tools that can objectively assist in predicting survival. We are ‘fortunate’ as routine device implantation is relatively uncommon at present in Malaysia due to its prohibitive cost, but may potentially be a dilemma faced in the near future.

Religion, Culture and Beliefs: Wolves in Sheep’s Clothing?

Alas, a legitimate challenge in implementing palliative care within Malaysia roots from our very pride of being a multi-racial and multi-faith nation [15]. Although it varies between individual communities, studies have shown evidence of aversion to the use of palliative care medications and services. For example, efforts in establishing a community-based palliative service in Sarawak met barrier in the form of families favouring traditional treatments as an alternative and fear of opioid addiction [16]. Opium use dates back to the 1800’s, and the devastation from opioid abuse is widely publicized, with actions taken to combat drug offences such as capital punishment for drug trafficking in countries like Singapore and Malaysia and development of narcotic bureaus in various countries [17, 18]. Such stigma linked to opioid may have a bearing on its underutilization in the medical field, and will continue to provide a challenge.

In fact, resistance towards morphine use has been clearly reported in the past, which stems from a lack of appreciation in its effectiveness in symptom relief (pain and dyspnoea in most case). International Narcotics Control Board reports an underutilization of opioid-based analgesia in 121 countries, and studies from Indonesia reveals underuse of opioid when clearly indicated [19]. This is partly due to reluctance and misconceptions on the physician’s part as well [20]. Prescription of opioids are often subpar and referrals to palliative services were often late, allowing only a few to benefit from end-of-life care. Interestingly, this was similarly witnessed in a Japanese study as well where close to 50% of relatives felt that palliative treatments were delivered too late [21].

The role of fatalism and under-reporting of symptoms is also well documented [22]. Beliefs such as karma, or repercussion, play into a patient’s misconception of having to bear with symptoms related to the disease they are suffering from, as it is inevitable [23]. Furthermore, the traditional, paternalistic relationship of doctor and patient remains common amongst Asian communities and leads to belief that complaining of symptoms precludes patient’s from being a ‘obedient, good patient’ [24].

Collusion, the act of concealing devastating news on a terminal condition out of love, is also a common, but under-reported amongst

Asian healthcare providers [25,26], Collusion is largely influenced by individual cultures and community-based beliefs and is common amongst Chinese and Japanese communities out of filial and community obligations, and wanting to go ‘all-out’ and not give up. There is also an aversion to communicating about death and dying amongst Asian communities [27,28], Despite years of having adopted laws and legal obligations based on patient autonomy and principles of informed consent in most Western countries, Asian countries including Malaysia have yet to implement such rulings, likely due to cultural and community factors, and is seen as a way to empower the family to provide their best for the terminally ill.

A unique interplay between cultural needs and service provision also exist amongst Asian patients. Unlike the Chinese and Japanese, it has been shown that Malaysians, specifically Muslim, Malays, preferred to die at home, surrounded by loved ones [29]. However, current services lack ways to provide palliative care in the community. Similar to Indonesia, majority of palliative services is based within big cities, and therefore ill-distributed to meet the needs of the masses [30].

Clinical Implications: Modernization and Tradition in Unison

The issue with palliation amongst heart failure patients does not lie on the fact that there is not any advancement in the field of heart failure therapy. On the contrary, heart failure remains an area that is ever expanding with introduction of new-age pharmacotherapy such as sacubitril/valsartan (Entresto) and empagliflozin (Jardiance) as additional tools in combating the disease [14,31]. However, it has become more challenging to ‘draw the line’ as the unique combinations of therapeutic advancements alongside traditional beliefs provide a much unwanted gap in having a ‘conversation on dying’.

Conclusion: Let’s talk about dying

Discussions surrounding heart failure palliation and palliative care remains taboo amongst patients and, interestingly physicians as well. Heart failure, as a disease, remains an enigma and is often unpredictable in its course which leads to physician reluctance in discussing poor outcomes with patients. However, it is this very ‘unpredictability’ that is needed to be discussed to ensure patients and their relatives, continue to understand their condition better and make informed choices on management. Unlike our Western counterparts, we are also faced with difficulty in establishing a structure palliative service to cater for a multi-cultural, multi-faith nation. Between pushing for a more community-centred palliative service and providing structured inpatient comfort care, we are currently at a crossroad, limited by financial and manpower constraints. By understanding the barriers that exist, including that of culture and religion, we now know that early discussions and continuous involvement of both patients and their relatives in decision making may be the key in end-of-life care in advanced heart failure.

Declarations

Ethics approval and consent

Approved by the Universiti Teknologi MARA Ethics Committee. The manuscript does not report on any human (or animal) data or tissue. Consent was obtained from patient.

Availability of data and materials

The data that support the findings of this study are available from Hospital Sungai Buloh but restrictions apply to the availability of these data which were used under license for the current study and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of Hospital Sungai Buloh.

Author's contribution

REFRS: Data collection & analysis, drafting of manuscript; DK: Data collection & analysis, drafting of manuscript; LCW: Drafting of manuscript, revision of manuscript; SSK: Drafting of manuscript, revision of manuscript

Competing interests

There are no financial or non-financial interests to declare.

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