

Has the embrace of evidence-based medicine caused palliative care to lose its soul?

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Abstract

Background: Recent publications have suggested that palliative care may be detracting from its primary goal of providing holistic care by focusing almost entirely upon measurable clinical and scientific parameters, and neglecting psychosocial research. This paper aims to evaluate whether palliative care has indeed lost its way.

Methods: We employ the example of growing calls for the adoption of Relational Autonomy in the Singaporean end-of-life care setting, and the proffering of the Ring Theory of Personhood to explore the effects of the adoption of evidence-based approaches on palliative care.

Results: Evidence-based approaches of refuting efforts to employ Relational Autonomy within Confucian-led communities highlights not only the importance of the fusion of traditional empirical and psychosocial studies, but affirms the fact that palliative care continues to espouse a holistic approach.

Conclusions: Evidence seems to suggest that the embrace of evidence-based medicine does not detract from the holistic nature of palliative care.

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Introduction

The dearth of well-conducted clinical studies and randomised controlled trials (RCT) within the palliative care setting is seen to propagate the belief that palliative medicine has been slow to embrace research-led Evidence Based Medicine (EBM) [1]. Indeed, this lack of verifiable evidence to current clinical practice owes as much to inertia dating back to the early years of the hospice movement – when the ethos of palliative care under Dame Cicely Saunders was at odds with the transforming sphere of medicine, driven by the intention to cure at all costs and a world view that saw death as a failure rather than a natural process – as it does to clinical concerns posed by cultural and religious considerations, and ethical issues concerning research on this vulnerable group of patients [2–4]. Indeed, de Raeve [4] felt that palliative

care research was inimical to the ideals of palliative care and commented that: “*we are going to have to think of some compelling justifications to permit research on dying people*”. Meanwhile, Vere [5] argued that: “*ignorance has risks but they are largely unseen and unnoticed. Gaining knowledge has risks which are noticed but largely unpredictable and is very costly though less than ignorance. It focuses blame whereas ignorance dispels it. So maintaining ignorance often seems more attractive than gaining knowledge.*” More recently fears have focused on the increasing weight placed on pharmacological and potentially financially rich pharmaceutical work that is believed will overshadow the other key elements of palliative care research.

It seems a choice was made to embrace the tenets of EBM when this dichotomous relationship between

palliative medicine, which had been developing in relative seclusion, and evidence-driven general medical practice became untenable within a society that began to see progressive improvement in life expectancy and the rise of an aging population [4]. As issues regarding care for the elderly and the dying became more apparent, the need for structured, expert-led care became a societal imperative, providing the impetus for the hospice network to be reintegrated into the larger medical fold and, with that, the embrace of EBM but upon a largely scientific platform. Psychosocial and ethical study at the end of life, it would seem, had taken a backseat [3, 4, 6]. After all, though well-established and expanding to all corners of the globe, palliative care found that it too had to evolve and accept its responsibilities as well as face the demands of a society and medical fraternity still ruled by the Fuchian technological imperative, which saw "the desire of physicians to do everything that they have been trained to do, regardless of the benefit cost ratio" [3, 4, 6, 7]. Evidence-based justification for actions were called for and, in so doing, the embrace of EBM meant that palliative care needed to be robust and empirically appraised.

In its haste to meet the demands of EBM, as it was understood in prevailing medical literature, there was a risk that palliative care would lose its multidimensional approach to care by focusing almost entirely upon the measurable clinical and scientific parameters, which appeared to be the *lingua franca* of EBM. Psychosocial and ethical concerns appeared to pale in comparison as it struggled to meet the robust and practical measurability and reproducibility of clinical specifications.

The need for such action was all too clear. Faced with the responsibility of re-educating a society still clinging to cultural and familial-held taboos pertaining to death, and successfully meeting the primary needs of the dying and their family, meant that palliative care had little choice but to embrace the prevailing image of medical care at the time. It was perceived that such an evidenced approach would be key to maintaining Saunders's view of palliative care and tampering the exuberance of a technology-led, survival-driven medical field, which still perceived death as a failure of medicine. Scientific endeavour in the 'traditional' sense was required.

In their recent review of palliative care research over the last 25 years, Bruera and Hui [8] make little mention of the lessons learnt in ethical and psycho-existential study within end-of-life research. Aziz et al [9] state that: *"much needs to be done in a number of key prioritized research areas in palliative and end-of-life care. This is especially true in the realms of health disparities research, communication, and decision making, and in the development and testing of, or the assessment of barriers to, models of optimal palliative and end-of-life care"*. In his review of psychosocial study within the palliative care setting, Rodin [10] acknowledges the dearth in this element of research, raising the question: has this change towards the reproducible, justifiable, evidenced-based practice come at the cost of the soul of palliative care and the neglect of other elements of the holistic spectrum of palliative care, including spiritual, psychosocial and ethical considerations?

Evidence-based medicine (EBM)

Studies have reported a paucity of sound evidence-based research within the field of palliative medicine [3, 11–14]. Even when present, palliative care research merely reflected extrapolations of the course of disease burden and symptomology based on disease trends from an earlier stage of the illness, rather than specific longitudinal studies. Indeed, Keeley [12] found that the quality of research in palliative care that was present suboptimal. Stevens et al [15] argued that such a deficiency could be attributed to a coadunation of three factors: logistical problems, ethical concerns and issues pertaining to the involvement of vulnerable subgroups such as children and the terminally ill.

Part of the logistical concerns blighting research in palliative care lies on the totemic position of randomised controlled trials (RCTs) within the EBM structure. RCTs were developed as a means of testing equipoise, examining the efficacy of standardized treatments on well-circumscribed study populations within very rigid conditions – a situation not commonly encountered in the palliative care setting. Indeed, RCTs are particularly difficult to implement in a small disparate population often plagued by a multitude of confounding factors [15]. Furthermore, the dependence on homogenous groups for such research further muddies the possibility of translating

the findings to the real world, as it were, where patients frequently require a tailored, multidisciplinary approach to their care rather than a ‘one solution fits all’ scenario [15,16]. Other concerns including restricted inclusion and exclusion criteria, poor estimates of life expectancy and high attrition rates further complicate the application of RCTs within the palliative care setting [15].

Yet, in adding to this list of concerns with regards to palliative care research, Walshe [17] takes a pragmatic view towards these concerns and states: *“You work in different fields, draw from different epistemological traditions, in different cultures and contexts, ask a wide variety of research questions and face emerging challenges. We should strive to refine and develop these recommendations through critical adoption, feeding back experience in our study reports in a positive manner to challenge and develop knowledge. There is no need to continue to complain about how difficult research in palliative care is, but to come of age and be positive about how we can achieve better research within such known constraints”*. The tide, it seems, is turning, at least for certain elements of palliative care research, and there is clear justification.

Justification of standard treatment

Indeed, such justification comes in the form of the duty of a physician, which is to provide the best possible care for his or her patients. The lack of robust study and review propagates the notion that palliative treatment was mostly ‘unproven’ and even potentially of no benefit and thus inimical to the provision of good care [18, 19]. Zimmerman et al [1] argued that, in fact, there is very little evidence that the present treatment options utilised in palliative care units provide any meaningful improvement for patients in terms of quality of life, patient and caregiver satisfaction or economic costs.

Such reasoning provides ample ethical imperative for physicians to carry out research to validate their treatment modes, given that it is only through such scientific research under the aegis of EBM that treatment options be found to be effective and safe for patients [2, 20, 21]. Such studies do not succumb to the same accusations that trials involving placebos or new treatment options would; rather patients are

treated with standard hospice treatment modalities, to ascertain the safest, most efficient and effective modality, whilst not imposing any additional risks to the patient. Meanwhile, evidence for such interventions allowed for the sustenance of the palliative care service, which still requires large financial input from the public sector. Indeed, evidence of the efficacy of palliative care interventions would also aid in determining appropriate referrals of patients for these treatments [22]. The presence of such data may also go some way towards convincing patients into overcoming their fears of hospice care – this may be particularly true of the Singaporean population, given the perceived association with ‘death houses’ [23].

In and amongst these considerations lie financial concerns, which are particularly pertinent given that care of most of these patients is carried out in charity-driven hospices, so cost-efficient measures are imperative in ensuring the future of the service [23]. Furthermore, in a society like Singapore where most patients bear the financial repercussions of their treatment, cost issues play a significant role in treatment choices and the future place of care [24–29]. Cost-efficient interventions are also an important requirement in considering not just the personal and clinical budget but, given a growing aging population, palliative care will need increased financial support from governmental services, which need to be efficient and supported by research evidence. However, research purely for financial security is not what is proposed, but part of a holistic exercise showing that palliative care cannot afford to neglect psychosocial aspects of care since it is an integral aspect of care, not just for the patient but the family. Nonetheless, there is no escaping the fact that financial considerations do matter to patients in their care determinations [24–29].

In turn, balancing these considerations hint at the rise of the pragmatic view adopted by Walshe, particularly when we consider the vast variability of end-of-life care across the globe [17]. It is here, within these confines of specific end-of-life care settings, that the need for holistic review becomes evident. It emphasizes the rationale for embracing evidenced psychosocial and ethical study, and dispenses with the view that the adoption of an EBM approach does not necessarily cause the loss of holistic palliative care.

Consider the example of the growing calls for the adoption of Relational Autonomy (RA) in the end-of-life care setting within the Singaporean healthcare setting.

The embrace of psychosocial and ethical study

Chan et al and Wilson et al argue that there is a need to adopt a RA approach to palliative care practice within family-centric societies [30,31]. Chan et al [30] suggest that within Confucian-inspired Singapore, RA would better meet the needs of the patient and the family in end-of-life care decision making where family involvement in such decisions breach the Western concepts of respect for autonomy dominating medical practice. Here, this paper will show that evidence-based study of local practice disputes this theoretically based idea, which in effect leads to the perpetuation of family-centric decision-making and – not infrequently – to the compromise of patient’s goals, wishes and sometimes care [25, 26].

The influence of family-centric thinking, which sees the propagation of familial decision-making in care determinations, particularly from a Confucian perspective, is well documented in Singapore [28, 29, 32]. Unsurprisingly, this practice is increasingly at odds with a healthcare approach progressively influenced by Western-inspired individualistic concepts [25,30]. In an attempt to assuage these concerns, Chan et al [30] and Wilson et al [31] argue for the employment of a RA approach to bridge the divide set out by supplementing the atomistic Western concepts of autonomy with a wider appeal that held to better align this approach with prevailing family-centric ideals, assuage regnant concerns of the advent of an overly atomistic perspective to healthcare decisions and soothe fears of a perpetuation of unattended family involvement within the deliberative process [33–35].

Close scrutiny of both Singapore’s culture, legislature, clinical practice and Confucian ideals, as they are practiced within the local end-of-life care setting, casts doubts not only upon the viability of this ‘solution’ within Singapore, but also further afield in Confucian-influenced communities such as China, Taiwan, Hong Kong, Japan and Korea, and in family-

centric societies such as India, Saudi Arabia, and Latin America [36-43]. Here, empirical data and psychosocial studies meld to provide strong evidence that the RA approach is both flawed and potentially damaging to the essential elements of holistic care at the end of life.

Reviewing the empirical data within the Singapore healthcare setting

Chan et al [30] employed empirical data to support their position, focusing upon the apparent evolution of sociocultural attitudes from a synergistic, dualist view to their personhood, which holds that an individual is simultaneously a distinct autonomous individual and a member of a family who must protect and advance familial interests; towards an individualistic view to decision-making. However, closer review of these data reveals that, despite Chan et al’s suggestions, attitudes have changed little, affirmed by review of the manner that personhood is conceived locally [30, 32, 44, 45].

Ching et al [28] and Phua et al [46] both reveal that less than 10% of alert patients were actually consulted on their end-of-life care. Foo et al [29] report that up to 59.9% of physicians would override the wishes of a previously competent patient in favour of the family, reaffirming reports of the continued domination of the family within local end-of-life decision-making [24–28].

Critically, there is little proof of the presence of the shared decision-making process required for the employment of a RA framework [24–29]. Local evidence would suggest that collusion, and the tendency to circumnavigate direct patient involvement in the deliberative process, prevents such a platform from forming and instead precipitates concerns surrounding the integrity of the basic tenets of RA [24–29].

Furthermore, evidence would suggest that patients do not hold to a synergistic, dualist view of personhood [44,45]. Critically, the Ring Theory of Personhood (Ring Theory), proposed by Krishna et al [44], provides empirical evidence that local conceptions of personhood imbue wider considerations than those afforded by RA frameworks.

The Ring Theory of Personhood

Krishna et al's studies of conceptions of personhood amongst oncology patients in Singapore, shows personhood to be perceived as a dynamic concept set at preserving the unique individual characteristics of the patient in changing conditions [32, 44, 45]. The Ring Theory proffered as a result of these findings finds personhood to be made up of four interrelated, equally important domains, which are delineated by four concentric rings: Innate, Individual, Relational and Societal Rings (Fig. 1) [32, 44, 45].

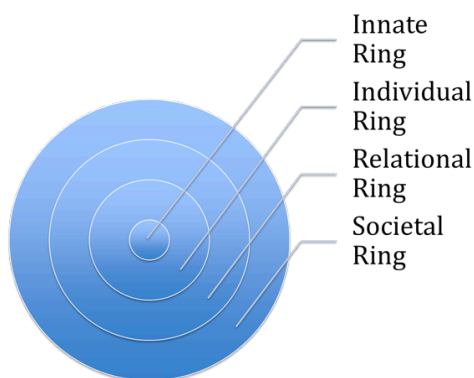


Figure 1. Schematic of the Ring Theory of Personhood

The innermost ring is the Innate Ring, which highlights the dignity and rights owed to all as a result of Divine and/or human connections “irrespective of their stage of development or deterioration” [32, 44, 45]. The Individual Ring that encapsulates the Innate Ring revolves around the presence and display of conscious function and a continuing identity over time [32, 44, 45]. The Relational Ring houses “those personal relationships that the patient considers important”, whilst the outermost ring, the Societal Ring, contains “the social, professional and familial ties that are not felt to warrant a place in the Relational Ring by the patient” and “the societal, professional and familial expectations and standards that the patient and those within their various rings are subject to” [32, 44, 45].

The pertinence to the present discussion is that no domain is given preference over the others and the interrelatedness of the four rings bestows the ability for conceptions of personhood to evolve in the face of

changing clinical conditions, primarily to preserve the unique identity of the individual [32,44,45]. Furthermore, personhood is maintained by competent patients displaying ‘psychological continuity’ which, when incompetent or incapable of maintaining an “uninterrupted connection concerning a particular person of his or her private life and personality”, have their personhood endowed by those within their Relational and Societal Rings in an effort to ensure that personal characteristics, values and beliefs and familial, cultural, religious and social norms and values attributed to them remain as close to the patient’s own concepts as possible [32, 44, 45].

Conclusions

Does the embrace of EBM detract from the holistic richness of palliative care? The evidence suggests not. The example of the employment of the Ring Theory, and the parallel application of empirical evidence, highlights the growing importance of wider empirical study and the importance of using it in conjunction with other sources of evidence. Indeed, this example of refuting efforts to employ RA within Confucian-led communities highlights not just the importance of the fusion of traditional empirical and psychosocial studies, but affirms the fact that palliative care continues to espouse a holistic approach. As Rodin states, psychosocial research has “*begun to have an impact on clinical practice in palliative care*” [10].

Palliative care, it would seem, has not lost its way as it traverses the path to evidence-based practice and a legitimate acceptance amongst the other medical specialties.

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