

Dealing with death in cancer care.

Should the oncologist be an *amicus mortis*?

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Supportive Care in Cancer- forthcoming

Abstract

The way death is (not) dealt with is one of the main determinants of the current crisis of cancer care. The tendency to avoid discussions about terminal prognoses and to create unrealistic expectations of fighting death is seriously harming patients, families, healthcare professionals, and the delivery of high quality and equitable care. Drawing on different literature sources, we explore key dimensions of the taboo of death: medical; policy; cultural. We suggest that the oncologist, from a certain moment, could take on the role of *amicus mortis*, a classical figure in the past times, and thus accompanying patients towards the end of their life through palliation, and linking them to psychosocial, and ethical/existential resources. This presupposes the implementation of Supportive Care in Cancer, and the ethical idea of relational autonomy based on understanding patients' needs considering their socio-cultural contexts. It is also key to encourage public conversations beyond the area of medicine to re-integrate death into life.

Keywords: End of life care; Supportive Care in Cancer; ethics; psycho oncology; relational autonomy; death; *amicus mortis*.

1. Introduction

The way death is (not) dealt with is one of the main determinants of the crisis of cancer care [1]. One of the biggest challenges faced by oncologists and other healthcare professionals (HCPs) is how best to communicate with and care for patients and their families in end-of-life (EoL) situations [2]. EoL care often requires very difficult ethical and clinical decisions, intensified by a widespread uneasy relationship with death in our current society.

Addressing patients' emotions and existential suffering is often a necessary first step [2]. Research suggests that both patients and HCPs involved in EoL tend to value the following factors: preparing for death, making decisions about treatment preferences, managing pain and other symptoms, and being treated as a 'whole person' [3]. The discussion of at least some of these factors, particularly if accompanied by psychosocial and ethical/existential support, is linked to a lower likelihood of emotional distress for patients; less aggressive interventions and inadequate symptoms management [4]; more appropriate use of palliative and hospice care; and better bereavement on the side of the family and carers [5]. The alignment of patient and HCPs' goals tends to be poor unless these goals are made explicit – and such alignment is easier to reach if they are discussed early during the clinical pathway [2, 6]. Disclosure of terminal prognosis is important from a legal and ethical point of view – as it can enable patients to make treatment decisions which are consistent with their life goals, lowering the chance of being kept alive beyond the point of their benefit [2].

Nevertheless, research reports disparities in the availability of psychosocial and ethical/existential support for cancer patients across and within countries, and gaps in communication between terminally ill patients and HCPs [7]. A common argument is that health services worldwide are experiencing extraordinary pressure to work with limited resources, and thus they would struggle to find the time and resources required to provide more holistic care [8].

However evidence from healthcare systems in different countries suggests that lack of discussion and poor concordance can also contribute to HCPs' sense of job dissatisfaction, emotional distress and burnout, workforce retention [9] and increase of litigations [10]. This is also corroborated by surveys showing how HCPs would choose to forego life-sustaining medical treatments [11].

Lack of, or inappropriate, discussion and decision making around death can also have a detrimental effect to the delivery of high quality and equitable care within, and across

countries. The Lancet Oncology Commission reported that cancer care is in crisis – as it is driven by a ‘culture of excess and futile care’, i.e. overuse of care by patients and HCPs in high income countries [1]. Much cancer treatment can be prescribed by HCPs to be seen as ‘doing something’[12]. The taboo of death can be so strong that stigma towards palliative care may persist even after a positive experience with early palliative intervention [13]. It is not surprising that many oncologists have expressed concern that discussing prognoses and potentially referring to palliative care could have a detrimental effect on patient’s hope [14]. The taboo of death contributes to create unrealistic expectations of fighting disease and death, and to an increase of inequalities of care within and across countries. It is striking that at the same time many people around the world still die without access to morphine or basic care [15].

To understand the current unease to deal with death in (and beyond) cancer it is important to look beyond clinical practice. What information about prognosis, and what type of care is provided to terminally ill patients is influenced by broader sociocultural values and attitude towards death.

Drawing on different literature sources – medicine, clinical ethics, medical sociology, and medical humanities – we explore key dimensions of the taboo of death (section 2), and we to suggest a way forward (section 3). Although our focus is oncology, the issues we discuss may be transferable to EoL care as a whole.

2. Difficulty to deal with death

2.1. Medical aspects

A major obstacle that prevents HCPs to take into account patients’ values/preferences related to their quality of life and death, is the current trend to reduce the biopsychosocial model of medicine [16] to a biological model. Current over-emphasis on biomedical information can diminish the HCP-patient interaction. K. Sweeny captured very effectively the essence of this problem, already three decades ago, coining the term *information paradox*: “At a time when information is more abundant, more accessible and more vigorously appraised than ever before, doctors find themselves in a situation where the *predilection for refining biomedical evidence may impair the recognition and discharge of the primary function expected of the medical profession by any society, namely the relief of the suffering of citizens.*” [17 p.22 (our emphasis)]. The information paradox is a problem in many areas of medicine. However, oncology, and EoL represent two contexts in which the consequences of this paradox can become particularly harmful [18]. Rapid technological advances are producing a deluge of

data which may have diagnostic and prognostic relevance. This can represent a contributing factor which hinders the discussion of prognosis and illness trajectories between HCPs and their patients, because it can often be challenging for HCPs to interpret such complex data, and to assess their relevance to their patients. This does not only diminish patients and HCPs interactions (including glossing over or denying death), but it can also become a contributing factor to overtreatment. This is compounded by studies which reported that prognoses in EoL care tend to be overly optimistic [19]. The medicalisation of death and dying pervades medicine and society as a whole, particularly in the west, and is linked to the technological imperative [20] (see also section 2.3).

The increased technological complexity of medicine underpins the tendency to avoid death by “treating” it in a depersonalised way [21].

This issue is again nicely captured by Sweeney, who, reflecting on his own experience as a patient with malignant mesothelioma, observed that HCP’s technical expertise tends to be accompanied by a lack of relational skills, and in particular by a ‘hesitation to be brave’ [22], that requires the skills to have more ‘human’ interactions with the patient. However, this hesitation is influenced by the broader context in which HCP operate, in which the regulation and policy of clinical practice play an important part.

2.2 Policy aspects

HCPs operate in a regulatory environment which emphasises the centrality of patients’ choice and empowerment but tends to be underpinned by narrowly defined notions of autonomy and clinical utility. This ultimately affects patients’ care and HCPs’ professionalism.

Modern dying occurs in a service in which there often are competing expectations [23].

Spending time with patients to discuss prognoses and assess their needs is often not valued financially and/or it is not a performance indicator [24].

Moreover, compliancy points, financial rewards, and the increasing bureaucratisation of HCP’s work, can subvert HCPs’ clinical judgment and professionalism, leading HCPs to follow protocols which encourage treatment pathways that may not fit patient quality of life, (e.g. overtreatment), and contributing also to HCPs burnout and job dissatisfaction [12, 25].

Emotional responses and needs can vary considerably across patients – also with the same clinical profile [26]. Patients’ preferred degree of involvement in decision making depends also on their socio-cultural background [27], and preferences may change over time [28], particularly in a moment of high vulnerability such as EoL.

Current efforts to take into account patients’ cultural backgrounds are either lacking or tend

to be simplistic (e.g. *a priori* predictors of beliefs or behaviour) potentially leading to harmful stereotyping of patients and culturally insensitive care for the dying [29]. Taking seriously into account patients' variations of perceptions and 'value' of life and death is key to monitor and improve patients' experiences at the EoL, and to the development of more supportive programs for care of the dying [30]. A clinical environment underpinned by a deeper understanding of autonomy can benefit *both* HCPs *and* patients as it would more likely lead to an improved healthcare via a better expression of patients' and HCPs' agency [31].

2.3 Cultural aspects

Fear of death has probably existed since the dawn of humanity. However, attitudes and practices around death have changed across history and cultures.

Death was more accepted in preindustrial Europe [32] (the *memento mori* practices from the ancient Greeks to the Victorian times represent just an example). Rather than being only an individual matter, death was dealt with by the family and the wider community of the dying individual, and it was 'tamed' – made sense of – with rituals, mostly of religious and cultural nature [32].

These rituals gradually disappeared with the industrial revolution and the advent of modern medicine. The industrial world of the cities led to a disaggregation of communities and to isolation [33]. During the industrial period death begins also to be physically displaced from home to hospital. Modern medicine, with the promise to defeat illness and death, further contributed to the devaluation of traditional rituals around death and dying – and to a loss of the ability to make sense of death and suffering, accepting them as part of life [34]. Death begins to be also 'existentially' and 'ontologically' displaced from life. From a culture that considered coping with illness and death as part of what it means to be alive [35], death began to be construed as an external threat, a failure of the body and of modern medicine, and something to be fought or ignored as much as possible [36]. Individuals have delegated the dying process to medicine and have lost faith in their ability to die. Death and dying have been made invisible, 'controlled' and postponed through hospitalisation and treatments [37]. Moreover, the shift from communities to a more individual conception of personhood has increased isolation and fed consumerism. Aggressive treatments can in fact represent a way to fill a void of community and culture. In Illich's parlance, dying has become the ultimate form of 'consumer resistance' [34]. But even this limit to consumerism may begin to be challenged. Cryonics (the expensive practice of preserving a human corpse – or for lower prices only the head – at low temperatures with the hope that resuscitation and restoration to

life and full health may be possible in the future) [38], is probably amongst the most extreme manifestations of the idea of denial and fight of death.

This very brief cultural excursion sheds more light on the EoL research, in particular the findings about the importance of concordance and shared understanding of goals and expectations between patient HCPs, family and caregivers (see §1). The value that both patient and HCPs assign to preparing for death and making decisions together seems to re- evoke the cultural and communitarian rituals of the past.

3. Oncologist as *amicus mortis*

We suggest that the oncologist, from a certain moment on, could also take on the role of *amicus mortis* (a friend at death) [32, 39], accompanying patients towards the end of their life both through palliation, and by linking them to ethical and psychosocial resources – according to their needs, and taking into account the patients’ network of relations.

The *amicus mortis* is scarcely mentioned in medical literature. Among the very few speaking about this issue there is Illich, who calls for a revival of the tradition of the *amicus mortis* – the friend who tells you the bitter truth and stays with you to the end – to reinstate our ability to die, and suggests that doctors could take such role [40]. Another reference is in a letter by a consultant surgeon Grogono who highlights the importance for the dying person to have a trusted friend who also has prescribing power to help navigate the clinical aspect of dying. His argument for the *amicus mortis* is in line with what we have already discussed (see §2.2). Current discourse and practices around care for death and dying are focussed on the autonomy and empowerment of the dying patient. However, the very process of dying entails also losing control. Grogono’s point is that maintaining control and making decisions about use of strong drugs can be difficult for the person who is dying. He argues that an *amicus mortis* with prescribing power can make this easier [39]. Death doulas or death midwives (people with a nursing background who assist in the dying process – similar to what the doula and midwife do during the birth process) may also have some similarities with the idea of *amicus mortis*, but they do not tend to be referred to with this epithet.

Our proposal of *amicus mortis* is broader. It encompasses palliation, psychosocial, and ethical/existential needs, and it aims to rebalance the information paradox so that HCPs do not only focus on cure, but especially on promoting care and reducing suffering, according to the main mission of medicine: to cure occasionally, to relieve often, to comfort always [41]. This proposal of *the amicus mortis* is also in line with the medical and scientific community which is increasingly recognising that cancer and EoL care should incorporate patient

centred care –particularly in the era of personalised medicine [2]. Making the role of the oncologist-amicus mortis explicit can contribute to implement such goals.

In summary, we are suggesting that rediscovering the ‘ancient’ role of amicus mortis, and assigning such a role to the oncologists (rather than to the patients’ family, as was more common in the past) could counter the current technological imperative in medicine and related overmedicalisation of death. To perform this role, oncologists will require specific training, as indicated in several position statements on how to improve HCPs’ communication skills (e.g. [42]) and will also need to work in an enabling environment, to avoid common communication problems, including collusion [43].

3.1 Training to tame ‘loss of control’

Although specific training in areas such as communication with patients, self-reflective skills, clinical leadership, and multidisciplinary team working may be required, some ethical notion could be also part of a proper background [44]. Such training is more likely to be successful if offered from medical school onwards, and implemented in flexible ways including support groups and regular debriefing [45].

A cause of overtreatment is HCPs’ fears that to cease medical interventions, even in terminal situations, will leave them and their patients feeling helpless and out of control (see § 2.1). Therefore, training could address ‘positive models’ of control, e.g. learning when it is better to let go of active control in certain situation and focus on promoting healing and reduce suffering by dealing with psychosocial issues, rather than finding a cure [2, 46]. Accepting the limits of medicine and the inevitability of death in certain circumstances may help HCPs to overcome personal feelings of lack of control, and to be more present for patient and family, and appreciate their different perspectives. It could also make HCPs more aware of the risk of imposing their own norms onto the patient. Lack of appropriate training and of support for HCPs (e.g. debriefings, support groups), can lead HCPs to adopt distancing tactics in order to avoid getting close to their terminal patients' suffering. Distancing can in turn discourage patients from disclosing their concerns [47].

Learning how to tame loss of control could help to ‘tame’ death. Notably this is not in conflict with honouring patients’ hope. HCPs may still be able to preserve patients hope if they listen to patients preferences, use a compassion and dignity conserving care approach [48], explore psychosocial issues, and appropriately refer patient to ethical/existential and spiritual intervention when needed or requested [49]., according to the cultural background of patients and oncologists’ cultural competence .

Such training needs to be juxtaposed to a work environment which enables HCPs to put this training into practice.

3.2 Supportive Care in Cancer and relational autonomy

The model of Supportive Care in Cancer (SCC) can enable HCPs to balance the therapeutic imperative with a promotion of healing and reduction of suffering. The core tenets of SCC are prevention and management of the adverse effects of cancer and its treatment at all stages of the illness. This includes: control of complications of cancer and/or its therapy; management of pain, chronic complications and psychosocial support once oncological therapy is no longer curative; and end of life care[50]. SCC is based on a conception of quality of life and of dying which encompasses clinical, ethical, and spiritual dimensions. SCC deals with both clinical and psychosocial needs of cancer patients in order to provide optimal quality of life [51]. It includes control of acute complications of cancer and/or its therapy; the management of pain, and chronic complications; psychosocial, ethical/existential and spiritual support once oncological therapy is no longer curative; and the approach of the EoL. SCC promotes patient-centeredness and meaningful dialogues between HCPs and patients. In SCC the oncologist can act as a coordinator of the care received the patient linking the patient to a suite of other resources/professionals if/when needed. This can include psychologists, ethical and spiritual consultants as well.

The ethical value of SCC also extends beyond the patient. SCC can include family members or other caregivers, with the aim of helping HCPs to plan care in advance, and can also comprise bereavement support for the family [50]. SCC also has financial implications as it may reduce hospital admissions and may encourage collaborations between oncology and other medical specialties. The patient-centeredness of SCC implies that the level and amount of information and support provided is flexible to what patients and family want and need to know, bearing in mind their potentially high vulnerability [52]. Unsurprisingly SCC is increasingly regarded as a key aspect of the excellence of oncological care, and numerous international oncology association are advocating for its implementation [6, 53].

It is important to highlight that the practice of SCC is in line with a relational view of autonomy. As observed earlier (see § 2.2), current medical practice and policy is characterised by a moral framework which envisaged persons as isolated, ideally independent, rational individuals. It is based on the idea that HCPs' competent and complete communication of biomedical information results in patients' informed choice and empowerment. However, this model can hinder rather than promote the autonomy of patients,

families, and HCPs. It can result in a delegation of responsibility to the patient; it can intensify current inequalities, as ‘vulnerable’ patients may be less able to engage with information and make informed choice; and it can lead to greater shift to a consumer-driven healthcare – in the case of EoL care potentially lead to more aggressive treatments (see for example the problematic success of the ‘Right to Try’ Laws [54]) .

Most current models of decision-making tend to be solely based on the patient and the HCPs. However, rather than being only an individual matter, decision-making processes at the end of life are shaped by familial, and sociocultural factors. Families are normally involved in EoL decisions [2]. Family-based decision-making is also common because many patients lose decision-making capacity before their death.

This ideal of independence and empowerment can foster a sense of individual responsibility to fight death, and to keep a sense of hope –and a sense of guilt if this is not possible.

Experiencing fear of death, wanting to seek help, or simply talk about such feelings may clash with the ideal of individual independence.

This can ultimately exacerbate the distress experienced by the terminally ill patient. In contrast, a focus on relationality can enable patients to appreciate their essential social nature, to normalise dependency, vulnerability and death – by making it more apparent that these are experienced by all human beings at different times.

Arguably individuals do not need to be ‘empowered’ to die but rather to be accompanied or ‘healed’ to death [34]. The oncologist-*amicus mortis* in a SCC environment, could become a gatekeeper who could link the patients to a suite of resources in the hospital and in the community (e.g. hospices) based on need. It could contribute to a more in-depth assessment of patients’ needs, in a way that is dialogical and flexible to patients’ diverse sociocultural background; to promote more patient (and family) participation and involvement, and ultimately contribute to ease patients (and HCPs) current uncomfortable relationship with death.

4. Conclusion

Denial and collusion are unfruitful approaches to deal with the inevitability of death, and are causing serious harm to patients, HCPs and healthcare systems. We propose that the oncologist could take on the role of the *amicus mortis* in cases of terminal prognosis, drawing on our exploration of key causative factors of the current taboo of death. The role of *amicus mortis* in a SCC environment (where the oncologist can link the patient to a suite of psychosocial, spiritual and ethical/existential support) can help HCPs and patients to accept

the limits of medicine; contribute to promoting health, even in the face of terminal suffering; and lowering the chance of patients being kept alive beyond the point of their benefit.

This conception of *amicus mortis* is likely to benefit the oncologist – as it can help them to overcome the taboo of death, have deeper interactions with patients and families, and reduce job dissatisfaction and burnout. It can also contribute to a more holistic care therefore improving healthcare provision. Ultimately it can benefit patients and their family members/carer – as it can help to tame death and to make them emotionally closer and more prepared to deal with an unavoidable event.

Although this role may represent an additional task for the oncologist, it is important to stress that denial and overtreatment come at a high cost (not only financial). Moreover, this model is more likely to promote autonomy, choice and empowerment [49] because it allows a in depth assessment of patients' needs, based on a relational conception of autonomy and choice. It is also important to foster more open dialogues about death outside the medical realm as broad societal and cultural factors shape our attitude and practices around death [55]. Death cafes; public engagement initiatives such as 'The Departure lounge'¹ the positive death movement; suggestions to introduce death education into schools; and improving the quality and relevance of funerals are current attempts to do so and may be reminiscent of the past traditions around memento mori and amicus mortis.

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¹ <https://acmedsci.ac.uk/policy/policy-projects/the-departure-lounge>

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