



Desire for hastened death: exploring the emotions and the ethics

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Purpose of review

As we approach the end of our lives, many of us will have a desire for hastened death (DHD). Fortunately, our ability to respond to suffering at the end of life is improving. At the same time, in many jurisdictions, changes are underway to legislate physician-assisted death. This compels us as clinicians to explore DHD in a compassionate way – to reduce suffering and reduce premature death. This challenge is becoming more compelling as a large cohort of individuals, who value autonomy and control, age and experience illness.

Recent findings

Studies confirm that DHD is not always a request to die. Clarifying the intention behind the desire and exploring the individual factors and underlying reasons behind the wish have been described. Another theme questions our basic assumptions about these statements – a normal part of a human experience or an indicator of disease. This tension is also manifested in the appropriate balance between patient autonomy and preventing harm.

Summary

We have a professional responsibility to mindfully explore with the patient the suffering that can be relieved and the suffering that remains.

Keywords

depression, desire to hasten death, patient autonomy, physician-assisted death, suffering

INTRODUCTION

The desire for hastened death (DHD) is an imprecise term for a profound and complex human experience. It is imprecise because the literature does not always distinguish between the hope that an expected death arrives soon, a wish to shorten the dying period or a request for physician-assisted suicide or euthanasia [1]. Clarity about what a desire to hasten death truly means – a sense of ‘enough’, a cry for help, a hypothetical exit plan [2], a ‘rational suicide’ [3^a] or something different is necessary for healthcare providers to respond compassionately and effectively.

The review examines the recent literature regarding the DHD. This topic is inevitably intertwined with the physician-assisted death (PAD) debate (including physician-assisted suicide and euthanasia). The evolving understanding of the ethics involved in responding to such requests is also examined. This review is timely for many reasons. As a large cohort of our population ages, the DHD will likely increase. This is not only a question of numbers. We can often extend life, without necessarily increasing the quality of life. At the same time, our pursuit of longer lives

increases the likelihood of reduced function or dependence on others [4]. Increasingly fragmented families and a busy pace of life will make caring for dependent adults more challenging, and the possibility of feeling like a burden more likely. Different jurisdictions and countries are grappling with legislation to respond to increasing demands from the public for more control over the dying process. Medicine, and our Western society in general, is prioritizing autonomy over other values [5,6], which is likely to increase expectations of control over living and dying.

NATURE OF THE DESIRE

Previous studies have identified broad factors influencing DHD: physical symptoms, psychological

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KEY POINTS

- Desire to hasten death is a common but complex reactive phenomenon in response to emotional distress that often varies over time. It does not always indicate a wish to die. In general, psychosocial spiritual factors are greater contributors than physical factors – but these are not mutually exclusive.
- Although identification of risk factors is important, exploring what a patient actually wants and why wishing it is important to him or her is crucial. Consideration of intentions, reasons, motivations and functions as separate elements of the request may add clarity.
- Patients often need assistance in order to explore the DHD as a way of being understood and accompanied and in order to identify factors that are potentially remediable. Although significant barriers exist to open conversation, the possibility exists that without such conversations, the patient's sense of isolation, perceived burden and helplessness may increase.
- Persistent desire to die may be associated with patients wishing to exert control over their dying either as 'an ace up my sleeve' that is not acted upon, voluntary refusal of food and fluid or engaging in PAD or suicide. The possible role of culture and of the medical profession in contributing to DHD has yet to be elucidated.
- In approximately 50% of recorded cases of DHD in the literature, patients are not depressed. This gives birth to the concept of 'rational suicide'. It also reinforces the need to screen and treat depression.
- Depression, DHD and rational suicide occurring at the end of life are held in divergent ways: as pathological responses requiring medical intervention and as contextual, normative responses that may be mediated by human interaction.
- Death is a negotiated event but our language and attitudes may not have caught up to this new reality.

distress, social factors and psychoexistential suffering [7]. In particular, depression and hopelessness have been found to be distinct mutually reinforcing constructs [8]. They both mediate the effects of psychosocial and disease-related variables on DHD. Building on this, Monforte-Royo *et al.* [9] performed a systematic review and meta-ethnography of qualitative studies from the patient's perspective. They identified six main themes behind a wish to hasten death (WTHD): a response to physical/psychological/spiritual suffering, the loss of self, a fear of dying, the desire to live but not in this way, death as an escape from suffering and a kind of control over one's life or 'an ace up one's sleeve'. Overall, WTHD was viewed

as a response to overwhelming emotional distress that did not always imply the wish to die (WTD). This study supports findings from previous work by Nissim *et al.* [2] who categorized distinct forms of DHD: as a hypothetical exit plan, an expression of despair and a manifestation of letting go.

Recent studies examined the interplay of various mediating factors associated with DHD – the threat of hopelessness stimulating hope [10], the loss of dignity partially explaining the association between physical problems and demoralization [11], and the lack of correlation with survival [12]. This supports the model proposed by Rodin *et al.* (Fig. 1) [8].

Ohnsorge *et al.* [13[■],14[■]] interviewed 30 terminally ill cancer patients from various palliative settings in Switzerland. They propose that three dimensions are crucial for understanding and analyzing WTD statements: intentions, motivations and social interactions. The WTD may lie along a continuum of intentions (Table 1) [13[■]].

Furthermore, motivations can be further differentiated into: 1. Reasons: specific factors described by patients triggering a wish to die corresponding to a biopsychosocial-spiritual model 2. Meanings: larger narratives that reflect personal values such as sparing others, to preserve self determination, to end a life that is now without value, etc 3. Functions: sometimes patients intended an effect on themselves or others such as an appeal for reassurance, a vehicle to talk about dying, re-establishing agency and even manipulation [14[■]].

These studies remind us that we need to understand 'what a patient actually wants and why wishing it is important to him or her'. A score on the Schedule of Attitudes Toward Hastened Death or

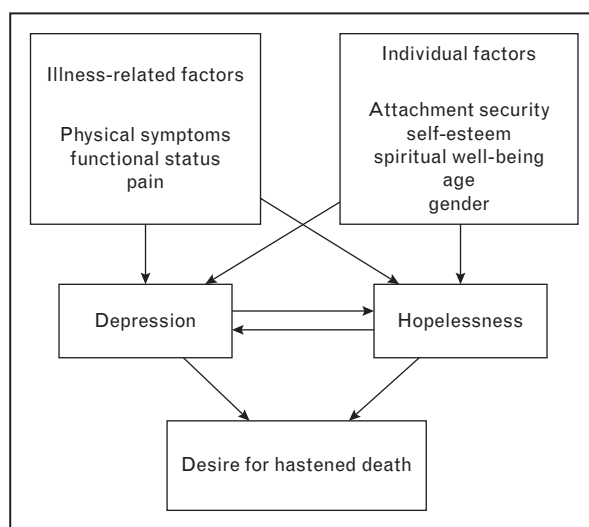


FIGURE 1. A heuristic model of the associations between illness-related factors, individual factors, and psychological distress [8].

Table 1. Intentions toward dying

Patients' statements expressing their wishes about the end of their life can fall into one or more of the following categories:	
Wish to live	
Acceptance of dying	
Wish to die	
Not considering hastening death	
1 Looking forward to dying	
2 Hoping that dying happens more quickly	
3 Desiring to die (but hastening death is not considered)	
Considering hastening death	
4 Hypothetically considering hastening death (in future, if certain things happen)	
5 Actually considering hastening death but at the moment (for moral or other reasons) it is not an option	
6 Actually considering hastening death is an (moral) option	
Will to die	
7 Explicit request	
8 Refusing life sustaining support (such as food or treatments) with the intention of hastening death	
9 Acting toward dying (such as suicide or assisted dying)	

Ohnsorge *et al.* [13[■]].

checkbox of symptoms is insufficient. This requires that healthcare professionals be able to facilitate and explore with the patient their personal narrative situated in their particular lives. Importantly, this exploration happens within the context of a relationship that may influence the content and the outcome of the discussion [14[■]]. Macleod [4] reminds us that 'euthanasia talks' may by themselves be therapeutic. A patient may be left feeling understood and accepted or judged either as morally wrong or abnormal – and thus alone.

THE ISSUE OF DEPRESSION

Wilson *et al.* [15] have recently reported on a cross-sectional survey including 377 patients from eight Canadian palliative care programmes. In this secondary analysis of data from the Canadian National Palliative Care Strategy, patients completed the Structured Interview of Symptoms and Concerns. 30.5% of participants experienced a desire for death at least transiently with 12.2% expressing a desire that was an apparently genuine wish. Of the group with a serious desire for death, 52% met diagnostic criteria for depressive or anxiety disorder. In this group with a serious DHD at the time of interview, only 39% would have opted for euthanasia. This confirms previous studies that the expression of desire should raise a concern about possible mental health problems, but it is not necessarily indicative of a disorder. It also reinforces that expressing a DHD is not synonymous with acting upon it.

A concern has been raised about the undertreatment of depression in cancer. Sharpe *et al.* reported

on their experience integrating collaborative care for comorbid major depression in patients with cancer [16[■]]. In a parallel-group, multicentre, randomized controlled effectiveness trial, they demonstrated better outcomes with a manualized, multicomponent collaborative care treatment, delivered by a team of cancer nurses and psychiatrists in collaboration with primary care physicians, compared with usual care. Although it is encouraging to confirm the effective integration of treatment for cancer and depression at cancer centers, this same commitment to treat depression does always exist in jurisdictions where physician-assisted suicide is legally sanctioned [17]. Together, these studies reinforce the need to actively screen for and treat depression, regardless of the jurisdiction or disease.

TEMPORAL STABILITY

Rosenfeld *et al.* [18] looked at terminally ill cancer patients admitted to a palliative care hospital in New York. A random sample of 128 patients completed the Schedule of Attitudes Towards Hastened Death at two time points approximately 2 and 4 weeks apart. 65.6% maintained a low score, 17.2% maintained a high score, whereas 9.4% and 7.8% rose or fell over the time period. Among patients with low initial scores, several psychological distress variables significantly distinguished between those who developed higher scores and those who did not: depression, hopelessness, spiritual well being, quality of life and physical symptom distress. This study points out the possibility of change even in the last

weeks of life and confirms previously identified factors predicting DHD. It does not predict, however, which patients would avail themselves of physician-assisted suicide should that be available to them.

DHD is also being actively researched in amyotrophic lateral sclerosis (ALS) [19]. Although up to 56% of ALS patients consider DHD at the time of their ALS diagnosis, in the Netherlands 20% of patients with ALS die as a result of physician-assisted suicide and euthanasia. In Oregon, 5% of ALS patients request lethal ingestion. Stutzki *et al.* [19] conducted a prospective questionnaire study with 66 patients and 62 of their primary caregivers at ALS clinics in Germany and Switzerland. Fourteen percent of patients expressed a current WTHD at baseline and this was stable over 13 months. Half of the patients could imagine asking for assisted suicide or euthanasia. Depression, loneliness, perceiving to be a burden and low quality of life predicted WTHD in this study.

In general, the literature emphasizes the fluctuations in DHD rather than those patients who exhibit a persistent wish. There may be additional variables operating in this group. Smith *et al.* [20] compared 55 Oregonians who either requested PAD or contacted a PAD advocacy agency with 39 individuals with advanced disease who did not explore PAD. They found that PAD requesters had higher levels of depression, hopelessness and dismissive attachment style and lower levels of spirituality [20]. They point out that attachment style and sense of spirituality are aspects of an individual that are worthy of respect rather than intervention. PAD requesters may not see any opportunities for meaning in the dying process. For patients with a dismissive attachment style, enhanced connection with others through dependency needs may be viewed as a threat, rather than a potential vehicle for meaning. In a culture that emphasizes the importance of autonomy and self sufficiency, it is not surprising that the sense of neediness and burden that inevitably comes with dying seems incompatible with a positive sense of self (Dr Pauline Abrahams, personal communication). In patients in whom DHD may be an 'ace up my sleeve', the DHD often remains stable because of the perceived benefit of a sense of control [2]. For some this perceived sense of control is enough in itself, and for others it needs to be acted upon. Gamondi *et al.* [21] points out that some patients plan for hastened death even before a terminal illness. Persistent DHD may revolve more around fear for the future rather than suffering in the present moment. Thus, without knowing what lies behind the wish, it may not be clear how best to respond.

COMMUNICATING A DESIRE FOR HASTENED DEATH

In the previous ALS study [19], no patients had discussed their WTHD with a physician, yet 50% of these patients would like to do so. Barriers to these conversations are numerous [4,22²³], and may include patient, professional, institutional and cultural factors. Context, including location, is a possible barrier as patients may perceive and experience different comfort levels of clinicians in having these conversations. For example, hospice may be an environment in which patients may not feel free to discuss openly a desire for accelerated death. Broom [23] completed in-depth interviews with 20 patients in an Australian inpatient hospice. The interviews were relatively unstructured and explored patient's understandings about inpatient hospice care, views on euthanasia and assisted dying and how organizational practices and values, including religious values, frame and shape the dying experience. Of note, one theme that emerged with some patients was a perception that hospice staff did not perceive euthanasia/assisted dying as a subject appropriate to discuss and considered it a practice that 'doesn't happen in hospice' [24, p. 232].

An important qualifier may be whether the hospice is located in a jurisdiction where PAD or euthanasia is legal. Loggers *et al.* [24²⁵] report on implementing a Death with Dignity Programme at a comprehensive cancer centre in Seattle, Washington. Over a period of 2.5 years, 114 patients enquired about the programme. Forty-four (38.6%) did not begin the process, whereas 30 (26.3%) initiated the process but either elected not to continue or died before completion. Forty participants received lethal doses of Secobarbital and all died – 24 after medication ingestion or 60% of those receiving prescriptions. It is important to ask ourselves whether we create the openness to discuss possible DHD in our own work environments – whether or not PAD is available.

The ability to communicate openly free of worry about potential legal implications also has a big effect on families. In the Seattle programme, family members expressed gratitude in receiving the prescription – whether or not it was used. Perceived quality of death may be better than patients dying in palliative care [25]. Conversely in Switzerland, euthanasia is against the law, but if certain conditions are met, assisted suicide is not prosecuted. Gamondi *et al.* [26] performed a qualitative interview study with 11 relatives of eight patients who died after assisted suicide. Before the suicide, moral dilemmas were encountered about whether and how to support the patient, and for some family

members these moral dilemmas continued after death. The relatives reported feelings of isolation during and after assisted suicide. In addition, they feared social stigma and did not openly disclose assisted suicide as the cause of death. In a related study, relatives felt that clinicians had difficulty with their own personal beliefs which interfered with their ability to be open to existential suffering and moral dilemmas in their patients [21]. Clearly, families and caregivers are impacted by these decisions – and context matters.

VOLUNTARY REFUSAL OF FOOD AND FLUID

As we continue to debate the appropriate role of physicians in assisting with dying, some individual patients make a choice for voluntary refusal of food and fluid (VRF) – with or without the aid of physicians. Ivanovic *et al.* [27] performed the first systematic search and review of voluntary stopping of eating and drinking (VSED) at the end of life. VSED (sometimes called VRF) was defined as an action by a competent, capacitated person, who voluntarily and deliberately chooses to stop eating and drinking with the primary intention of hastening death because of the persistence of unacceptable suffering. The authors concluded that the current quality of articles provided ‘marginal insight’ into VSED and called for more study. They point out that VSED may be ethically easier to support: there is time for the patient to reconsider the decision and it is neither physician ordered nor directed. Another advantage may be that with little or no bureaucratic barriers it may be faster than accessing PAD – should that be available. Are we prepared to respond to a competent patient requesting assistance with VSED?

DESIRE FOR HASTENED DEATH: EXPRESSION OF SUFFERING OR RATIONAL SUICIDE?

Our basic stance as healthcare practitioners towards DHD is not always clear. If viewed as an expression of suffering, then exquisite supportive and palliative care would seem to be the appropriate response. Yet study after study reveals the limits of palliative care to change all DHD [28]. Perhaps we can extrapolate data from Oregon and the Netherlands where 0.2% and 1.8% of all deaths, respectively, are PADs – most of whom were receiving or had access to palliative care [29]. We are left with a small but significant subset of competent patients who request assistance in ending their lives – even with palliative care. This may be called ‘rational suicide’ [30,31]. If a person is competent and not suffering from mental illness

that interferes with decisional capacity and suffering unbearably, they may be eligible for assisted suicide in jurisdictions where it is legal. (Some would argue that even in jurisdictions where it is illegal, some physicians are assisting in such suicides.) Macleod [4] points out that there is no formal definition of the term ‘unbearable’ so that ultimately the decision to enact rests on the doctor’s decision. ‘It could be argued that it is not patients exerting authority but doctors exercising power’ [4 p. 939]. Should a persistent request be seen as a treatment failure or rational choice? [31]

UNDERLYING ASSUMPTIONS ABOUT DESIRE FOR HASTENED DEATH

Ben Rich articulates well the lack of consensus and the absence of clarity regarding our underlying assumptions about DHD [32]. One common assumption is that a request to accelerate dying represents a kind of disorder, likely including impaired decisional capacity. This disorder should respond to medical care, including psychotherapy. However, this assumption may not be accurate for individuals ‘who value control, dread independence on others, are ready to die, and assess the quality of their life as poor.’ [33] These individuals are more likely to request and to utilize prescriptions to end their lives. The underlying assumption here is that ‘rational suicide’ is, or could be, a nonpathological response to expressing one’s autonomy at the end of life. Both of these assumptions are subsumed within the medical paradigm which would suggest that if we label DHD as a ‘medical problem’, then it should be ‘fixed’ with medical solutions including palliative care, psychotherapy and potentially continuous deep palliative sedation, and lethal prescriptions. So perhaps the medical paradigm is too limiting to encompass the suffering at the end of life. Our basic assumptions about suffering are called into question. Is suffering in the dying period avoidable with medical interventions, or is it a deeply human experience that unites us all? Should we be able to bear suffering at the end of life and might there be some hidden redemptive power in it [23,32]? And most importantly, who decides?

In addition to the assumptions we hold about DHD, our belief systems strongly influence our stance towards DHD and how we might respond to the small minority who wish accelerated dying. A critical dimension of our belief systems is how we make ethical decisions. A consequentialist may approach the issue of assisting in accelerated death with the idea ‘If I assist in hastening death or not, the patient is dying. The outcome is the same’. On the contrary, a rule-based thinker may argue ‘All

shortening of life is wrong.' Given that many belief systems exist, it is unlikely that we will all agree [5]. The critical issue again becomes, 'Who decides?'

DEATH AS A NEGOTIATED EVENT

Over 20 years ago, Daniel Callahan [34] observed that 'death has been moved out of nature into human responsibility'. He suggested that there was rarely such a thing as 'a natural death' in our affluent Western world and that individuals have made many decisions that affect the manner and timing of their death long before the dying period. Much of our confusion and concern over DHD reflects our reluctance as individuals and as a profession to acknowledge our human role, or moral agency, in determining our own death. Many have pointed out the use of the word 'suicide', when indicating a choice by a competent individual already facing death, was not appropriate [35]. Others have pointed out that choosing to die with a lethal prescription was not a choice about living and dying, but between ways of dying [36[¶]]. Perhaps we need a new language that reflects this negotiation and choice about how we die, such as 'the right to choose death' [32[¶]], 'humane assisted death' [28] or even 'patient self administration of a lethal substance' [37].

ETHICAL CHALLENGES

The ethical challenges for physicians in responding to DHD and the underlying suffering are profound. Much confusion exists among members of the public – and physicians – over the clinical, ethical and legal limits of medical care [6,38[¶],39]. This limit is a slowly moving target. Withdrawing and withholding treatment is considered legal in all jurisdictions on the basis of autonomy and informed consent. The understanding, not always shared, is that the cause of death is the underlying illness. Some members of the public are frankly bewildered that other treatment decisions that hasten death, such as lethal ingestion, are not also legal. (This would be an example of consequentialist thinking.) Continuous deep palliative sedation is more accepted in the dying period of weeks to days with intractable suffering, where again the cause of death is the illness. It is more controversial with a longer prognosis, existential suffering and in combination with withdrawal of food or fluid [38[¶]]. Voluntary refusal of food and fluid is not well documented and is sometimes considered synonymous with starving oneself to death [27[¶]]. Conversely, physicians may feel poorly equipped to have conversations with patients

expressing DHD. On the other hand, if they accept a DHD at face value, they may feel pressure to offer a medical treatment that may potentially lead to a premature death, if in fact it is possible for patients to change their minds. And how do we respond to the small subset of patients with DHD insisting on their right to control their dying?

The major ethical discourse for responding to persistent DHD is currently about autonomy. Autonomy alone should not trump other values such as preventing harm, including remediable factors leading to DHD. The claim that one should 'own' one's own death is based on autonomy. This claim is suspect for two reasons. First, our death touches many individuals, especially families and caregivers, who may be deeply impacted. Second, the right to decide one's own death is somewhat limited if clinicians are set up to be the final arbiters. We need to move the discourse towards compassion for our patients and families and for ourselves. We also need to move the discourse away from the sole focus on the individual, to consider the cultural context. Much of our suffering could be a cultural phenomenon secondary to a death denying, grief illiterate society (Dr Pauline Abrahams, personal communication). Approaching palliative care from a public health systems approach may be a way of alleviating suffering and sharing the load through education and public engagement [40[¶]].

SUPPORTIVE THERAPY

One theme that was conspicuously absent from the recent literature were new specific supportive interventions for individuals expressing a DHD. This is partly explained by the individuality of reasons, motivations and functions of a DHD [14[¶]]. Three areas are of particular interest for exploration as potential supportive interventions for those patients who wish to engage.

Motivational interviewing techniques [41] are designed to help patients explore the ambivalence behind change. Given that many patients with DHD are in fact ambivalent about how far to take the desire, the motivational interviewing technique of resisting the righting reflex – the tendency to fix – may be helpful. These techniques have been used with cancer survivors [42].

Compassion focused therapy techniques have been used by Gilbert and coworkers [43[¶],44] to teach patients to stimulate their own compassion to allow them to be with troubling emotions. While compassion focused therapy techniques have been used in patients with anxiety and those experiencing trauma, they well may be helpful for patients facing a terminal illness – as well as for

the clinicians treating them. Joan Halifax has recently published her heuristic model of enactive compassion. This model proposes how we might create the conditions for compassion to arise in our work and points to the possibility of transformation of suffering [45].

Mindfulness Based Cognitive Therapy has been developed specifically for cancer patients [46]. It has been shown to improve mindfulness, depression, anxiety and distress. These effects may have the ability to mitigate or reduce the incidence of DHD. In a similar vein, Padesky and Mooney propose a four step model of strengths based cognitive therapy to build resilience, which may be applicable to coping at the end of life [47].

CONCLUSION

Many fundamental questions about responding our patients' suffering at the end of life remain. A basic tension exists between the idea of suffering at the end of life (and perhaps also depression at the end of life [48[¶]]) as an unavoidable part of human existence and suffering at the end of life as a medical problem to be solved. Perhaps the truth lies somewhere in the middle. Patients feel this tension when we come to the limit of what we can legally or ethically offer. Patients may also feel this tension when as clinicians we have different ideas and beliefs than our patients. Failure to inquire about DHD or shutting down the conversation, consciously or unconsciously, may leave a patient feeling isolated, abandoned and judged. These may be triggers to increasing their DHD and potentially lead to premature deaths. Seeking to understand what a patient is actually requesting – a wish to live, an acceptance of death or a wish to hasten the dying period – is key. Underlying triggers include biopsychosocial-spiritual factors and also specific reasons unique to the individual. The request may also serve a function to illicit a response from those around them, which may include their clinicians.

What might the future hold? We can begin with humility about our ability to reduce suffering at the end of life [36[¶]] and make a continuous commitment to improve. We can honestly appraise whether some of our suffering could be a cultural phenomenon that we have created. We can consider how our profession contributes to this phenomenon where people arrive at the end of life totally unprepared or even traumatized by previous experience (Dr Pauline Abrahams, personal communication). We can accept that death is already a negotiated event with a shared individual and professional responsibility and agency. We can be open and curious about DHD without reducing it to a problem

that needs to be solved. In order to do this, we first must know and care for ourselves to be able to engage in these conversations – or to refer respectfully when we cannot. Most importantly, we could also learn to pay as much attention to the will to live [49] and resiliency enhancers such as meaning [50], dignity [51], social support, spirituality [52] and mindfulness [46] – *before* a DHD. As we do not have an agreed upon understanding of DHD, we do not have an agreed upon best outcome. Perhaps the best outcome is the compassionate, therapeutic engagement with the patient and a continued passionate debate in our society about supporting each other in dying.

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Conflicts of interest

There are no conflicts of interest.

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- of special interest
- of outstanding interest

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