HEALTH ECONOMICS (N KHERA, SECTION EDITOR)



Goal of a "Good Death" in End-of-Life Care for Patients with Hematologic Malignancies—Are We Close?

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Abstract

Purpose of Review The medical field has a critical role not only in prolonging life but also in helping patients achieve a good death. Early studies assessing end-of-life quality indicators to capture if a good death occurred demonstrated low rates of hospice use and high rates of intensive healthcare utilization near death among patients with hematologic malignancies, raising concerns about the quality of death. In this review, we examine trends in end-of-life care for patients with hematologic malignancies to determine if we are close to the goal of a good death.

Recent Findings Several cohort studies show that patients with blood cancers are often inadequately prepared for the dying process due to late goals of care discussions and they experience low rates of palliative and hospice care. More recent analyses of population-based data demonstrate some improvements over time, with significantly more patients receiving palliative care, enrolling in hospice, and having the opportunity to die at home compared to a decade ago. These encouraging trends are paradoxically accompanied by concomitant increases in late hospice enrollment and intensive healthcare utilization near death. **Summary** Although we are *closer* to the goal of a good death for patients with hematologic malignancies, there is ample room for growth. To close the gap between the current state of care and a good death, we need research that engages patients, caregivers, hematologic oncologists, and policy-makers to develop innovative interventions that improve timeliness of goals of care discussions, expand palliative care integration, and increase hospice use.

Keywords Good death · Hematologic malignancies · End-of-life care · Hospice · Palliative care · Goals of care discussions

Introduction

From Elisabeth Kubler-Ross's *On Death and Dying* in 1969 to Ira Byock's *Dying Well* in 1997 to Atul Gawande's *Being Mortal* in 2014, physicians have long sought to better understand death and to improve the dying process. As we advance our understanding of specific diseases and gain insights into the dying process, our understanding of what constitutes a good death continues to evolve. In 1997, the Institute of Medicine (IOM) defined a good death for cancer patients as "one that is free from avoidable distress and suffering for

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patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" [1]. More recently, a systematic review identified eleven themes of a good death, the top three of which were preferences for the dying process (being able to prepare for death and having wishes such as location of death honored), pain-free status, and emotional well-being [2]. While these themes and the IOM's definition of a good death provide a helpful overview of the factors that must be considered at the end of life, they do not provide an easy way to measure whether a good death is achieved.

In 2003, Earle and colleagues conducted focus groups of patients with incurable cancer and family caregivers to identify measurable indicators to assess end-of-life (EOL) care and quantitatively capture what a good death means. Indicators of poor quality EOL care that emerged fell under the category of medicalization of death (e.g., multiple emergency room visits, hospital admissions, or intensive care unit [ICU] admissions near the EOL), chemotherapy use very near death, and lack of or late hospice referral [3]. As these indicators can be feasibly measured



from administrative data, they are now endorsed as quality measures of EOL care. While these measures are merely proxies for a good death, many hematologic oncologists agree that these are acceptable to assess the dying process [4].

Until recently, much of the research around EOL care and death in oncology focused on patients with solid malignancies. However, during the past few years, there has been substantial growth in research on EOL care for patients with hematologic malignancies. In this review, we will discuss key elements of achieving a good death and the current state of EOL care among patients with hematologic malignancies. Next, we will highlight trends in EOL care and examine whether the field is getting closer to the goal of a good death. We will then discuss specific barriers to achieving a good death for patients with hematologic malignancies. Finally, we will propose potential interventions to improve EOL care.

Factors That Contribute to a Good Death

Four key elements of achieving a good death are goals of care discussions, avoidance of overly intensive healthcare utilization near the EOL, palliative care integration, and timely hospice use (Table 1). Goals of care discussions give patients the opportunity to communicate their preferences regarding the care they would like to receive and significantly increases the likelihood that they will receive EOL care that is aligned with their wishes. Moreover, when hematologic oncologists engage in these discussions, their patients are significantly more likely to enroll in hospice in a timely fashion, die at home or in a hospice facility, and are less likely to be admitted to the ICU close to death [5•, 6, 7•]. Given the centrality of goals of care

Table 1 Factors that contribute to a good death

discussions to high-quality EOL care, it is recommended that they should occur early in the disease course and be revisited as patients' preferences may change over time [7•].

Avoiding overly intensive healthcare utilization near death (e.g., multiple hospital and ICU admissions) is another crucial element of a good death. Intensive healthcare utilization near the EOL is significantly associated with worse patient quality of life and higher risk of complicated grief for bereaved caregivers [8]. It may also prolong the dying process, which is a factor that has been identified by patients and caregivers to be detrimental to the quality of dying [2]. Patients who experience intensive healthcare utilization near death are robbed of the opportunity to spend more time at home with their families. The ability to spend more time at home in the last 6 months of life is increasingly being recognized as a patient-determined indicator of high-quality EOL care [9, 10].

Early integration of palliative care and timely hospice enrollment significantly increase the likelihood of patients experiencing a good death. Palliative care provides expert symptom-directed care that can address physical and emotional symptoms that patients experience near the end of life, with consequent improvement of quality of life [11, 12...]. In addition, palliative care integration increases the likelihood that patients with blood cancers will engage in goals of care discussions [7•, 12••]. For example, in a study of 963 patients with hematologic malignancies, palliative care integration was significantly associated with an increased likelihood of having a discussion about preferred place of death (OR 8.93, 95% CI 6.40 to 12.46) [7•]. Similarly, patients who enroll in hospice are more likely to experience better quality of life than those who die in acute care settings [8]. In addition, bereaved caregivers of patients who die in hospice are more likely to report

Factor	Contribution to a good death
Goals of care discussions	- Increases likelihood that patients receive care that is aligned with their preferences
	- Allows patients to prepare for the dying process
	- Increases the likelihood of hospice enrollment
	- Increases the likelihood that patients will die at home
	- Decreases the likelihood of dying in acute care settings
Limiting overly intensive care near the end of life	- Improves quality of life near the end of life
	- Reduces risk of complicated grief for bereaved caregivers
	- Increases days spent at home with loved ones near the end of life
	- Avoids prolonging the dying process
Palliative care integration	- Improves physical and psychological symptom burden
	- Improves quality of life
	- Increases likelihood of timely goals of care discussions
	- Increases likelihood of timely hospice use
Hospice use	- Improves quality of life near the end of life
	- Improves perception of good death by family members
	- Reduces the risk of complicated grief for bereaved caregivers



that their loved ones died in their preferred location and that they received excellent EOL care compared to caregivers of patients who die in acute care settings [13].

The State of End-of-Life Care for Patients with Hematologic Malignancies

Goals of Care Discussions

Data from both hematologic oncologists and patient records demonstrate that goals of care discussions often do not occur in a timely fashion for patients with hematologic malignancies [5•, 14]. In a national survey of 349 US-based hematologic oncologists, 42.5% of hematologic oncologists reported that they would initiate the first conversation regarding resuscitation status preferences either during an acute hospitalization or when death is clearly imminent. Similarly, almost a quarter of respondents would have the first conversation regarding hospice preferences only when death is clearly imminent [14]. In another study examining documented goals of care discussions in a cohort of 383 blood cancer decedents, the median time between first documented discussion and death was 15 days [5•]. These studies suggest missed opportunities to engage in goals of care discussions earlier in the disease course. Moreover, multiple studies have demonstrated that racial/ethnic minority patients have lower rates of goals of care discussions [6, 15] and are more likely to elect for intensive measures when these discussions take place [16]. The underlying causes of these disparities are multifactorial and include unequal opportunities for minority patients to engage in goals of care discussions [17], lack of effective clinician communication around advance care planning, religiosity, and medical mistrust [18, 19].

Intensive Healthcare Utilization Near the End of Life

Several studies have consistently demonstrated high rates of intensive healthcare resource utilization among patients with hematologic malignancies [15, 20–23]. A US-based study that examined EOL care of 816 cancer decedents found that patients with hematologic malignancies had significantly higher rates of dying in the ICU (33% vs. 4%) and hospital (47% vs. 16%) compared to those with solid malignancies [20]. These striking differences in intensive EOL care highlight the intensive treatment that patients with blood cancers often experience at the end of their lives. Similar findings of intensive healthcare utilization have been demonstrated in other countries [21-23]. For example, a French nationwide populationbased study of 46,629 patients who died of hematologic malignancies between 2010 and 2013 found that 18.1% of patients died in the ICU and 24.5% received chemotherapy in the last month of life [21]. Another study of more than 1700 cancer patients in Jordan showed that patients with

hematologic malignancies had double the odds of receiving chemotherapy during their final month of life compared to patients with solid tumors [23]. The fact that healthcare utilization near death is intensive for patients with blood cancers in various countries suggests that the drivers of intensity transcend cultural differences.

Palliative Care Integration

Despite the benefits of palliative care, rates of palliative care consultation are low among patients with hematologic malignancies. In a large study that examined palliative care consultation rates in a tertiary cancer center, patients with blood cancers had significantly lower rates of palliative care engagement compared to solid malignancies. Specifically, only 33% of patients with hematologic malignancies had palliative care consultations compared to 47% of patients with solid malignancies [20]. In addition, a large population-based study of 139,191 older blood cancer decedents between 2001 and 2015 found that only 5.2% had any billing claims for palliative care services [24]. Another meta-analysis of 9 different studies found that patients with hematologic malignancy were 54% less likely to receive palliative or hospice care compared to those with other cancers [25]. Moreover, when palliative consultation occurs, it typically occurs very late in the disease course, as the median time from first palliative care consultation to death ranges from 7 to 12 days in various studies [20, 24, 26]. Such late integration limits the benefit that patients and their families derive from palliative care.

Hospice Use

There is a well described quality gap in death and dying with respect to hospice use for patients with hematologic malignancies [7•, 26, 27, 28•, 29, 30]. Patients with blood cancers have one of the lowest rates of hospice enrollment in oncology. In a UK-based study that included 892 blood cancer decedents, only about 10% of the cohort died in a hospice setting. Another study that examined hospice use among 290 AML decedents found that the enrollment rate was 23.2%. Moreover, when patients are, in fact, referred to hospice, their length of stay is typically short, with a median home hospice length of stay of approximately 9 days [30]. Of note, rates of timely hospice referral are significantly lower for patients that are transfusion dependent compared to those who are not transfusion dependent [28•, 31, 32].

Trends in EOL Care for Patients with Hematologic Malignancies

Some encouraging trends have emerged in EOL care for patients with hematologic malignancies in the past 5 years, suggesting



that the field is moving closer to a good death. Integration of palliative care with hematologic care is becoming more common. From 2001 to 2015, there was an absolute increase of almost 12.9% in rates of palliative care use among patients with blood cancers [24]. Some institutions have also developed collaborative projects integrating palliative care with usual hematologic care (e.g., combination with transplant care, integration in a myeloma clinic) [33, 34]. In addition, research on palliative care integration with hematologic care has burgeoned. Early randomized clinical trials (RCTs) of integrated palliative care largely excluded patients with hematologic malignancies; however, between 2016 and 2021, there have been two published RCTs integrating palliative care for patients with blood cancers [11, 12. The most recent RCT examining integrated palliative care versus usual hematologic care among 180 patients with high-risk AML showed significantly higher quality of life, lower rates of depression, anxiety, and post-traumatic stress disorder for up to 24 weeks in the palliative care arm versus standard hematologic care [12.]. In addition, patients on the palliative care arm who died before the end of the study were more likely to discuss their EOL preferences with their clinicians and less likely to receive chemotherapy near death [12...]. The increasing engagement of palliative care for patients with hematologic malignancies is encouraging; nonetheless, more efforts are needed to close existing gaps in care as the absolute rates of palliative care integration remain low and the timing of consultation is often still within 2 weeks prior to death [24].

Hospice use is also rising among patients with hematologic malignancies [29-32, 35]. In a SEER-Medicare analysis of 13,000 patients who died from AML, a significant rise in hospice use was demonstrated, with rates of enrollment increasing from 31 to 56% between 1999 and 2012 [35]. Another study of myeloma decedents demonstrated a significant rise in hospice use from 28.5% in 2000 to 56.5% by 2013 [32•]. Patients with myelodysplastic syndromes and lymphoma have also experienced significant increases in hospice use over time [29, 31]. Given that hospice care facilitates home deaths, the trends in hospice use have been accompanied by decreasing rates of hospital deaths. For example, in a study of over 951,000 hematologic malignancy decedents, hospital deaths decreased from 54% in 1999 to 38% by 2015 [16]. These observed trends likely signify greater awareness and openness to hospice care.

While the overall hospice enrollment trends are positive, they are unfortunately accompanied by concomitant rises in late hospice enrollment and intensive healthcare utilization [29, 31, 35]. For example, in the study that demonstrated significant rising trends in hospice use for patients with AML, 47% and 28% of hospice enrollment occurred during the last 7 and 3 days of life, respectively; moreover, the rate of ICU admission in the last month of life significantly increased from 25.2% in 1999 to 31.3% by 2012 [35]. These findings illustrate that late hospice admissions are significantly less

likely to reduce the rate of intensive healthcare utilization near the EOL. To ensure that increases in hospice enrollment are truly impactful in promoting a good death, we need interventions to improve timeliness of hospice use.

Unlike other factors that contribute to a good death, there is a paucity of trend data regarding goals of care discussions among all patients with hematologic malignancies. A few studies have however examined documentation of advanced care planning specifically in recipients of hematopoietic stem cell transplant (HSCT). These studies, which include recipients of HSCT spanning 2001 to 2015, demonstrate consistently low rates of documentation of advance care planning ranging from 39 to 50% [6, 36–38]. These findings suggest lack of improvement in eliciting patients' preferences regarding EOL care and an urgent need to improve goals of care discussions.

Barriers to a Good Death

Understanding barriers to a good death for patients with blood cancers is a prerequisite for developing effective solutions to improve patients' experience and care near the EOL. Data from various studies show that these barriers are multifactorial and can be categorized into four domains, namely hematologic oncologist—related, patient-/caregiver-related, disease-related, and system-related barriers (Table 2)

Hematologic Oncologist-Related Barriers

Hematologic oncologists' perspectives and practices regarding goals of care discussions, palliative and hospice care, as

 Table 2
 Barriers to a good death for patients with blood cancers

Hematologic oncologist-related barriers

- Discomfort with end-of-life care
- Misperceptions regarding palliative care
- Concerns that goals of care discussions will take away patients' hope
- Not knowing the right thing to say for goals of care discussions

Patient-/caregiver-related barriers

- Misperceptions regarding prognosis
- Caregiver stress and burden
- Inadequate resources available to support caregivers

Disease-related barriers

- High prognostic uncertainty
- Rapidity of decline near the end of life
- Unpredictable disease trajectory

System-related barriers

- Limited availability of specialty palliative care programs
- Lack of access to palliative transfusions in hospice settings
- Restrictive payment models for hospice care



well as the dying process significantly influence the kind of death that their patients experience. Hematologic oncologists feel less comfortable with death and dying than solid tumor oncologists and are more likely to interpret their patients' decline as a failure on their own part [39, 40]. Such feelings about death and dying may contribute to a hesitancy to engage in goals of care discussions that acknowledge and prepare patients for the possibility of death. Indeed, hematologic oncologists have identified concerns about taking away patients' hope, undermining patients' trust, and not knowing the right thing to say as barriers to engaging in these discussions [4, 41]. Avoidance of or delays in these crucial discussions with blood cancer patients ultimately limit the ability to fulfill patients' wishes regarding their EOL care.

Existing research also shows that a significant proportion of hematologic oncologists harbor misconceptions about palliative care [42–44]. The majority of hematologic oncologists think of palliative care as synonymous with hospice care and would typically only consider palliative care when all diseasedirected options have been completely exhausted [42, 43]. Such views contribute to delayed engagement of palliative care among patients with blood cancers. In addition, hematologic oncologists who feel less comfortable with death and dying are even more unlikely to engage with palliative care services [40]. This paradox highlights how hematologic oncologists under-utilize palliative care specialists when they may need them most. Given that palliative care services are important to address symptom burden and adequately prepare patients and their families for a good death, hematologic oncologists' limited engagement with palliative care poses a barrier to achieving a good death.

Patient- and Caregiver-Related Barriers

Patients with hematologic malignancies often lack an adequate understanding of their illness course, including the severity of illness and the probability of cure [45–47]. Patients tend to overestimate the probability of cure. In a longitudinal study of 100 older adults with AML, 91% of patients believed that they were "somewhat or very likely" to be cured of their AML, while hematologic oncologists estimated this chance of cure for only 31% of patients [47]. Similar levels of prognostic discordance were demonstrated in a multicenter study of patients with various hematologic malignancies [46]. Hematologic oncologists have highlighted these mismatched patient-provider expectations as an obstacle to high-quality EOL care [4]. Indeed, lack of awareness of one's prognosis hinders appropriate preparation for the EOL, which consequently leads to challenges in achieving a good death.

Achieving a good death requires a team of support, oftentimes including caregivers at home. While many patients may desire to die at home, achieving that wish often requires 24-7 support from family caregivers. Although caregivers wish to support their loved ones, they bear substantial emotional and physical burden from caregiver activities that may limit their ability to provide the care that is needed. Without support for caregivers, physical and emotional burnouts are prone to occur. Indeed, primary caregivers have endorsed that their own well-being has an impact on the quality of their home care services [48]. Ultimately, due to limited resources, some caregivers may not be able to provide the level of care their loved one needs to die at home. In cases where caregivers are unable to manage the high level of caregiving responsibilities to facilitate a home death, these caregivers come to view inpatient death as the appropriate outcome given the extenuating circumstances [49]. Caregiver stress is thus a critical factor that influences the dying experience.

Disease-Related Barriers

The heterogeneous and unpredictable nature of hematologic malignancies creates unique barriers to achieving high-quality EOL care. The disease trajectory is unpredictable both in that patients can undergo rapid deterioration and in that there is often a possibility of cure even in advanced cases, unlike in advanced solid malignancies. In addition, the recent surge in novel therapeutics, (e.g., targeted therapy, immunotherapy, chimeric antigen receptor T-cell therapy), while positively impactful on survival outcomes, has further compounded prognostic uncertainty for patients with blood cancer. The heightened unpredictability and prognostic uncertainty have been identified by hematologic oncologists as significant contributors to late goals of care discussions and delayed initiation of EOL care [4, 50, 51]. These disease-related barriers also likely contribute to observed rising trends of intensive care near the end of life despite rising trends in palliative care and hospice

System-Related Barriers

System-level barriers influence palliative care engagement and hospice enrollment for patients with hematologic malignancies. Although there has been a growth of palliative care programs in the past decade, approximately 33% of hospitals in the USA that have more than 50 beds still lack specialty palliative care services [52]. In addition, institutions that have palliative care specialists may not have sufficient numbers of clinicians to match the level of need. This limits access to the expert physical and psychological symptom management that palliative care specialists can provide near the end of life. Another critical system-level barrier is the limited access to blood transfusions in many hospices. Although transfusions are often palliative in nature for blood cancer patients and can provide symptomatic relief near the end of life [53], many hospices do not provide access to red blood cell or platelet transfusions due to reimbursement constraints. Lack of access



to transfusions fosters the view that hospice may be less relevant for patients with blood cancers, with 47% of hematologic oncologists in a national survey reporting home hospice services as inadequate for the needs of their patients [54]. Patients with hematologic malignancies with limited life expectancy and bereaved caregivers have also attested to the importance of transfusions for improved quality of life [55]. Indeed, patients who are transfusion dependent are less likely to enroll in hospice [31] and have shorter stays in hospice [28•, 32], and when patients disenroll from hospice, the most frequent reason for doing so is to resume transfusions [35]. This highlights the broad impact of this system-level barrier.

Interventions to Move Closer to a "Good Death" for Patients with Blood Cancers

To achieve a state where the majority of patients with hematologic malignancies consistently experience a good death, we need changes in clinical practice, research, and policy changes to improve timeliness of goals of care discussions, expand palliative care integration, and increase hospice use.

Changes in Clinical Practice

One potential way to mitigate the problem of late goals of care discussions is to use various clinical signposts as triggers to prompt hematologic oncologists to initiate or revisit these discussions. Potential signposts that have been identified by hematologic oncologists include development of relapsed/refractory disease, central nervous system involvement of disease, or worsening performance status [56]. The "surprise question" has also been identified as a tool that can be used to prompt timely goals of care discussions [57]. Importantly, automated cues, perhaps via electronic medical records, that recognize the emergence of new signposts may be helpful reminders for physicians to initiate or revisit these EOL discussions. Given that hematologic oncologists identified "not knowing the right thing to say" as a barrier to goals of care discussions [4], communication training and use of established conversation guides [57, 58] may foster skills and greater comfort with these conversations, reducing the tendency to avoid or delay these discussions. In addition, to mitigate racial/ethnic disparities in goals of care discussions and quality of EOL care, respectful and rapport building communication and addressing patients' religious/spiritual values are critical in facilitating goals of care discussions among minoritized populations [19].

Integrating palliative care with hematologic care requires close collaboration between hematologic oncologists and palliative care clinicians and an appreciation of the various skills and roles each clinician brings to the care of blood cancer patients [44]. This may mean embedding a palliative care team in hematologic clinics or inpatient hematologic teams to promote

bidirectional training and collaboration [33, 34]. Close collaboration will help to foster unified communication and provision of high-quality EOL care. To address the problem of late palliative care engagement for this population, applying triggers for consultation that are needs-based (e.g., complex physical/psychological symptoms, difficulty coping with disease) and evidence-based (autologous or allogeneic HSCT, high-risk AML diagnosis) would be helpful in improving timing of palliative care engagement [11, 12••, 59]. The surprise question has also been shown to effectively identify patients with high palliative care needs; accordingly, it could also be used as a trigger for timely palliative care referrals [60].

Research

The role of research in improving the dying process for patients with blood cancers cannot be over-emphasized. Rigorous scientific inquiry to identify additional factors that constitute a good death for patients with blood cancers may help to better tailor care to the needs of this population. Qualitative research is important to develop an in-depth understanding of the challenges patients face in achieving a good death. Such data are critical in ensuring that we develop interventions that are relevant to the needs of this population. In addition, innovative interventions to support caregivers of patients with blood cancers will be useful in not only increasing caregiver quality of life but may also increase the likelihood that patients who wish to die at home realize that desire. Given the heterogeneity of hematologic malignancies, studies examining different models of palliative care integration for various hematologic malignancies and the impact on EOL care may help to maximize efficiency and quality of EOL care for this population. Finally, implementation and dissemination studies will be essential to promote "real-world" progress in attaining the goal of a good death for patients with hematologic malignancies.

Policy Changes

Policy changes to dismantle systems-based barriers are also critical in the quest for a good death. Policy change is desperately needed with respect to lack of transfusion access in many hospice settings. Although hospices may consider transfusions palliative, the ability to offer transfusions is limited due to reimbursement challenges. For example, in the USA, hospices are paid less than \$200 per diem per patient regardless of the level of care provided. We thus need policy changes that promote innovative payment models to enable access to palliative transfusions. Moreover, robust systems to allow safe administration of home-based palliative transfusions will allow patients to spend more time with family near the end of life. Such interventions are likely to increase hospice referrals by hematologic oncologists, given that about 3 out of 5 hematologic oncologists report that they would refer more patients to hospice if red cell or platelet



transfusions were available [54]. Moreover, access to such palliative transfusions are likely to improve patients' experiences near the end of life, as both patients with advanced blood cancers and their caregivers consider palliative transfusions to be vital for their quality of life [55].

Conclusions

Patients with hematologic malignancies often experience delayed or absent goals of care discussions, high rates of intensive healthcare utilization near death, limited palliative care integration, and low rates of timely hospice use. These factors have been associated with poor quality of life near death and are reflective of suboptimal quality of death and dying. While the goal of a good death seemed elusive for patients with blood cancers for several years, recent data demonstrate improving trends with rising rates of palliative care and hospice use. Moreover, there is a growing body of research focused on improving EOL care for this population. Yet, there remains ample room for improvement. To close the gap between the current state of care for patients with hematologic malignancies and the goal of a good death, we need innovative solutions, such as automated triggers to improve timeliness of goals of care discussions, increased integration of palliative care with hematologic care, and policy changes that support palliative transfusions in hospice. Importantly, we need the next wave of research to actively engage patients, caregivers, hematologic oncologists, and policy-makers to develop and test innovative interventions that will help patients with blood cancers attain a death that is "free of avoidable distress and suffering [1]."

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Declarations

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Conflict of interest The authors declare no conflict of interest.

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