Title

Milestones: a quality improvement study of an educational intervention to improve care in the last days of life in acute hospitals

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Abstract (250)

Background: Approximately 460,000 people die annually in England. Three-quarters of deaths are expected. Health Education England is prioritising upskilling of clinical staff in response to reports of poor care quality in the last days of life in acute hospitals, where almost half of all deaths occur. This study explores the impact of an end of life care (EoLC) educational intervention, *Milestones*, in acute hospital trusts in Greater London.

Methods: This is a mixed methods study. Learners completed a questionnaire pre- (n=462), immediately post- (n=495) and 3-8 months post- (n=37) intervention. The questionnaire measured learner confidence in EoLC covering the National Health Service adopted 'Priorities for the Care of the Dying Person'. Paired t-tests were used to determine statistically significant difference in learner confidence pre- and post-intervention. A convenience sample of learners (n=7) and educators (n=5) were recruited to qualitative semi-structured interviews that sought to understand if, how and why *Milestones* worked. Data were analysed using a thematic approach.

Results: A statistically significant increase in learner confidence across all five priorities of care' was sustained up to 8 months ($p < 0.001$). Interviewees wanted to discuss wider challenges in EoLC related to the organisations and cultural contexts in which they worked. Concerns included balancing hope when decision-making, learning as a multidisciplinary team and emotional impact.

Conclusions: The findings suggest that *Milestones* is a flexible, beneficial resource for teaching EoLC that facilitates enhanced learner engagement. Understanding generated about wider concerns can inform future educational material development, organizational process and research study design.

Main text

BACKGROUND

World Health Organisation (WHO) predicts global deaths will rise to >79 million by 2040 from 58 million in 2019.[1] This pattern is mirrored in United Kingdom data,[2-4] posing significant challenges including effective care for dying people.

Three-quarters of deaths are expected.[5] Most people would prefer to die at home[6] but many in England die in acute hospitals (45.4% of deaths in 2018).[7] While policy shifts may reduce proportions of patients dying in acute hospitals, rising death rates mean that absolute numbers are still likely to rise without further major changes in healthcare systems.[7]

High quality end of life care (EoLC) in acute hospitals is often lacking[8-9] impacting patients, carers and healthcare staff.[10] Better education and training is needed to support change.[11] Health Education England (HEE) aims to build a "flexible and adaptive workforce"[12] to ensure that the National Health Service (NHS) meets future demands.

The use of blended learning (defined as a combination of face-to-face learning and either synchronous or asynchronous e-learning[13]) to deepen knowledge in EoLC[14] and embed learning across settings may help.[15] A major problem for previous initiatives is failure to adequately consider the impact of existing organizational context and culture.[15-16]

There are no known studies evaluating acute hospital postgraduate education interventions on EoLC that meet the criteria of: (1) being modelled on experiential learning principles; (2) designed to be tailored to local needs, and; (3) run by *in situ* educators. We report qualitative and quantitative evaluation data from a study using *Milestones*: an EoLC education intervention to address the need for experiential situated learning.

METHODS

Aim

To evaluate learner and educator experiences and the potential impact of *Milestones*.

Study design

Our study was conceptually orientated to a constructionist approach, drawing on theories of experiential learning[17] in the design of the intervention and analysis. Mixed methods were used. A timeline is provided in figure 1.

Figure 1: Timeline of the development of Milestones and its evaluation process in North Central & East London (NCEL)

Insert figure 1 here

Ethical approval

NHS ethical approval was not required.[18] Informed consent was gained from participants. Data were collected and stored in accordance with UK Data Protection legislation.

Setting

EoLC educators from NHS Acute Hospital Trusts in the catchment area of UCLPartners Academic Health Science Network (a London-based partnership of academic organisations, NHS Trusts, industry, patients and others) were invited to a *Milestones* 'Train the Trainer' session over an initial period of 4 months. Once an educator had attended, access to *Milestones* was given. Implementation of *Milestones* during and after the study was supported by the creation of a Community of Practice, linking EoLC leads and educators from acute hospital trusts throughout London.

Intervention

Funded by HEE (North Central and East London) in 2015, *Milestones* was developed by the UCLPartners EoLC team. *Milestones* is a suite of materials to support the training of clinical and non-clinical staff in care in the last days of life. It comprises a 17-minute bespoke film following a patient and their carer during the last days of life in an acute hospital setting, and a comprehensive guide for five experiential interactive teaching sessions based on different aspects of care; a reflection on the overall trajectory, recognition of deterioration, effective communication, making an individualized plan of care and physical care in the last days of life. The material was piloted with professionals, patients and carers. The Priorities for Care of the Dying Person[5] are referenced throughout. Supporting materials also include advice on how to encourage learner interaction, modify session length and adjust to baseline knowledge.

Recruitment

A convenience sample of volunteer learners and educators from acute hospitals were recruited to the study on attending or teaching *Milestones* sessions respectively. Anyone attending a Milestones session as either a learner or teacher was eligible to volunteer for the study. Quantitative data were received from seven acute hospital trusts across London and Essex. Four trusts (3 in London and 1 in Essex) provided enough learner/educator information for follow up data collection. On completion of learner pre- and immediately post- confidence questionnaires / educator feedback forms, those who were willing to participate completed a consent form and provided details in order to complete a further electronic confidence survey. These learners/educators were then invited to participate in semi-structured telephone interviews, which took place 5 or 6 months after their *Milestones* education session.

Data collection

The process of data collection is shown in figure 2. Quantitative data were collected from learners through a standardized confidence questionnaire on paper pre- and immediately post- sessions, and

electronically after 3 to 8 months. Semi-structured interviews were carried out by RB. All educator and four learner interviews were by telephone due to the geographical area covered. Three further learner interviews were face-to-face. Field notes were made during and after each interview. Interviewees consented for the interviews to be audio-recorded and transcribed for thematic analysis.

Figure 2: The inclusion of learners and educators in the evaluation with rates of response

Insert figure 2 here

Data analysis

The questionnaire used a 7-point Likert scale for 9 questions, which covered all areas of the Priorities for the Care of the Dying Person (Recognise (1 question), Communicate/ Involve (4 questions), Plan and Do (3 questions) and Support (1 question)). Using paired t-tests, comparison has been made between pre-, immediately post- and 3-8 months post- training.

Interviews were transcribed verbatim then anonymized for analysis.[19] Field notes were also analysed. Coding was completed by RB and MM using inductive techniques. One learner interview was coded separately by MM and RB to develop an agreed coding framework. RB and MM then met with SY to discuss further emerging codes as coding progressed. SY also second coded three interviews to ensure consistency. RB, MM and SY developed initial themes and discussed with CS to agree metathemes. Constant comparison was undertaken with identification of examples to illustrate relationships between codes, themes, metathemes and the original narrative. Although the interviews focused on *Milestones*, participants talked about wider challenges and concerns in EoLC. The findings therefore reflect this broader context.

RESULTS

Nine trusts provided initial learner data after a total of 47 teaching sessions. One trust was excluded due to local reporting error (1 session). Data was missing from seven sessions across other trusts. Table 1 shows role and department of learners responding to the survey. The majority were staff nurses, either on General Medical or Care of the Elderly wards.

Table 1: Table to show the number and percentage of learners by role and department who completed the questionnaire pre- and/or immediately post- *Milestones* session, and those who completed it again at 3 to 8 months after session).

	Learners (%) n=595[1]	3 to 8 months post training (%) n=37
Role:		
Allied Health Professional	28 (4.7)	7 (18.9)
Senior medic (Consultant, SpR/Staff Grade)	16 (2.7)	2 (5.4)
Junior medic (SHO, FY2, FY1)	52 (8.7)	0 (0.0)
Medical Student	1 (0.2)	0 (0.0)
Senior Nurse (Matron, Clinical Nurse specialist)	9 (1.5)	2 (5.4)
Staff Nurse	295 (49.6)	24 (64.9)

Health Care Assistant	38 (6.4)	0 (0.0)
Other clinical	140 (23.5)	0 (0.0)
Unknown	16 (2.7)	2 (5.4)
Department:		
Acute services (A&E, AMU)	17 (2.9)	5 (13.5)
Medical, incl Care of the Elderly	273 (45.9)	14 (37.9)
Critical Care	42 (7.0)	5 (13.5)
Haemato-oncology	83 (13.9)	3 (8.1)
Surgery, including Obstetrics and Gynaecology, Orthopaedics	63 (10.6)	3 (8.1)
Other	26 (4.4)	5 (13.5)
Unknown	91 (15.3)	2 (5.4)
[1]Note: 452/595 pre-training questionnaires and 488/595 immediately post-training questionnaires were used in the analyses.		

Table 2 provides learner confidence questionnaire results comparing pre- and immediately post- the *Milestones* session, and pre- and between 3-8 months after the *Milestones* session.

Milestones had a statistically significant improvement in confidence scores: both total score and in all sub-domains ($p < 0.001$ for all domains). On average, the participants total score increased by 10.01 points (95% Confidence Interval 9.26, 10.76) from pre- to immediately post- training ($p < 0.001$). The training had a long term effect with the 3-8 month post-training scores being consistent with those immediately post- training.

Table 2: Learner confidence questionnaire results

If participants were missing less than 50% of the questionnaire (4 or fewer items) we imputed the missing values to allow a total score to be calculated. If participants were missing greater than 50% of the questionnaire, the data was not used in the analysis (this occurred on 2 occasions pretraining and 4 occasions post training).

	Confidence pre training	**Confidence immediately post training**	**3-8 months post training**	**Comparison pre- versus immediately post training**			**Comparison pre- versus 3-8 months post training**		
	N = 452[2] Mean (SD)	N = 488[2] Mean (SD)	N=37 Mean (SD)	(N=427) Mean difference (95% Confidence Interval)	**Standardised mean difference**	**p-values**	(N=37) Mean difference (95% Confidence Interval)	**Standardised mean difference**	**p-values**
Total Score	38.90 (10.72)	48.63 (8.91)	48.9 (9.38)	10.01 (9.26, 10.76)	1.01	<0.001	10.00 (6.43, 13.5)	0.94	<0.001
Domains									

Recognise	4.77 (1.32)	5.60 (1.08)	5.78 (1.08)	0.87 (0.77, 0.97)	0.72	<0.001	1.02 (0.58, 1.45)	0.78	<0.001
Communicate / Involve[3]	16.34 (5.19)	20.98 (4.38)	20.7 (4.15)	4.85 (4.48, 5.22)	1.02	<0.001	4.37 (2.65, 6.08)	0.85	<0.001
Plan[3]	13.15 (4.12)	16.40 (3.33)	16.36 (4.49)	3.25 (2.96, 3.54)	0.86	<0.001	3.21 (1.81, 4.60)	0.77	<0.001
Support	4.65 (1.44)	5.65 (1.10)	6.05 (0.91)	1.04 (0.93, 1.16)	0.83	<0.001	1.41 (0.93, 1.88)	1.00	<0.001

[2]68 pre-training and 80 immediately post-training questionnaires had to be excluded because of incomplete data or local reporting error.

[3]Communicate/Involve domain was represented on the questionnaire by four questions and the plan domain was represented by three questions rather than the one question for the other domains (recognise and support), hence the higher total score attributed to the domain.

The seven learners and five educators interviewed were a convenience sample from three trusts. Tables 3-4 show demographic information for interviewees. To preserve anonymity data is numbered: educators E1-E5; learners L1-L7.

Table 3: Demographics of Learners and Educators interviewed

		Learners		**Educators***	
Characteristic		N=7	(100%)	N=5	(100%)
Gender	Female Male	7 0	(100) (0)	4 1	(80) (20)
Trust no.	1 2 3 4 5	3 4 0 n/a n/a	(43) (57) (0) n/a n/a	1 0 1 1 2	(20) (0) (20) (20) (40)
Clinical Background	Nurse Doctor Allied Health Professional	3 1 3	(43) (14) (43)	5* 0 0	(100) (0) (0)
No of sessions facilitated by Educators	0 1-4 5-10 11-15 >15	n/a	n/a	0 3 1 0 1	(0) (60) (20) (0) (20)
Time from *Milestones* training to interview	5 months 6 months	2 5	(29) (71)	n/a n/a	n/a n.a

*All Educators were, or had previously been, Clinical Nurse Specialists in Palliative Care. In interviews two educators gave their roles as End-of-life care facilitators, one as an End-of-life care programme manager, one as a clinical nurse specialist and one did not specify.

Table 4: Learner qualitative interview data code with corresponding number of participants in their *Milestones* session[1]	
Qualitative Data Code	**Number of participants in *Milestones* session**
L1	8
L2	3
L3, L4, L7[2]	24
L5	10
L6	8
[1]This table shows the range of groups that the learner data quoted is drawn from. [2]These learners participated in the same *Milestones* session	

Metathemes

Within the qualitative data analysis three metathemes were identified, each representing interrelated aspects of the intervention:

- Impact of *Milestones* and key elements for delivery
- Relation of education to wider practice culture
- System concerns

Impact of Milestones and key elements for delivery

The film, described as high quality (E2) and engaging, resonated with educators' and learners' experience, and was useful for facilitating conversations around good/bad practice (E1, E3, E5, L3, L6). . Learners reported an increased confidence in recognising the dying patient, and identifying emotions associated with dying:

"Having the confidence to say that [is this patient dying?] to a senior. That can be quite difficult but going on the course gave me a little more confidence to speak out because it reinforces the importance…and how you might know that" [L6]

Learners found it useful to view situations from the patient perspective (L3, L1, L7, L2, L6), uncovered aspects of care they were not previously aware of (L7), and reported use of the film boosted their recall of learning (L3, E2). Critiques included; the film plot could have included a wider multidisciplinary team (MDT), (L5) and some doctors felt it unhelpful the junior doctor was portrayed negatively (E1), despite acknowledging this was realistic:

"…in fact, I had a couple of them walk out, because I think that it hit on too much of a raw nerve" [E1]

This highlights the risk of disengagement and need for adequate support when using emotive examples in learning. There were also suggestions that covering disagreements between staff was limited (L4).

The film was emotive for both educators and learners:

"the video does strike a lot of emotion amongst some of the staff that are there" [E5]

Educators highlighted the need to manage distress during sessions; however most used this as an opportunity to explore emotional toil in practice and encourage learners to reflect (E1). One trust created a supplementary session covering bereavement, grief and staff support.

Learners appreciated differences to 'usual teaching', particularly reflection and group discussion (L5, L3, L6), with feedback from 'friendly' facilitators who could *'keep* [the training] *interesting'* (L3). The approach was also endorsed by educators (E1, E3, E5). Some reflected how they altered their teaching over time; moving from using slides to a more interactive approach:

"But now we very much allow them to interact, allowing them to really be part of the study day and not just let them sit there and be taught at" [E5]

Some extended interaction further by complementing material e.g. with a quiz (E3). Educators appreciated the flexibility of *Milestones* which supported them to adapt to individual learner groups (E1, E4, E5), while still recognizing the need for strong facilitation skills:

"It really does depend on the facilitator, I think, to bring to life the material. It's what you put into it to get it out…I've found people are engaged with it if you ask the right questions" [E4]

Training in very small groups (<4 learners) was considered less impactful; there was a richer discussion when personal experiences were shared, particularly from a range of professions (L5, L2, L6, L4). For example, having dieticians for nutrition/hydration conversations was valuable (E3). In contrast, some educators preferred a single learner group as they could focus on the role of that particular group (E2, E3). This may reflect confidence of individual educators:

"…but yeah the thought of carrying out a three hour session to like a mixed professional group would probably have me (laughs)…I don't know how other nurses feel about it". [E2]

Educators chose whether to deliver each session 'back-to-back' in a day/half day or as a series over time. The time needed to prepare did not have any negative effect on educators' views (E2, E3). Learners appreciated the intensity and continuity of whole day training (L1). Educators found learners were more likely to complete all 'modules' on whole day training due to the sense of achievement (E3), but were apprehensive about the time and space required to teach in this way (E2).

Relation of education to wider practice culture

Perceived tension between 'hope' and 'decision-making' was a strong theme. Learners described how treatment options were perceived as either 'giving up', or maintaining hope, rather than purely providing appropriate care:

"they need hope and they don't want to be given up on" [L4]

Effective communication was considered both desirable and extremely challenging:

"if you've got a Consultant who's not giving that news, or who's being a bit hopeful, or who's maybe… knows that somebody's going to die, but is still talking about the treatment, then… then how can you have those conversations" [L4]

Lack of MDT involvement in treatment planning contributed to apprehension and uncertainty around decision-making (L5, L1), negatively affecting staff wellbeing and ability to cope with patients' deaths.

Additionally, some learners felt discouraged to discuss treatment choices or decisions (L7) and dismissed by senior medical staff (L2):

"*I think it… I think it's a, that challenging discussion that you have when you're trying to say it, as a therapist, "I really think this should happen", and perhaps the Consultant or someone is saying, "Oh no, we just want to do 24 hours more" or "We want to do this" and I… I say "Why? Why?", and it's difficult to challenge someone if they're the Consultant, but, I mean I do, but… And then they're saying, "Why do you think we should?", and I'm like, "Because of these reasons …"* [L7]

Similarly, many learners maintained the belief that the parameters of what was discussed with the patient belonged to senior medical staff. The data suggest that, regardless of how participatory a consultant might be in their approach, a hierarchical legacy associated with their role remains. Other professionals and junior doctors were uncertain of what, if anything, they should convey to patients without the senior medical team speaking first:

"Can the nurse say that [the patient is dying] *if the consultant hasn't given that news?*" [L4]

Junior doctors felt expected to make difficult decisions, such as withdrawing active treatment, under immense pressure, when they were unfamiliar with patients and less aware of their wishes than other staff (L6, L7):

"being on a busy ward with patients who are at the end of life can be very difficult and difficult to decide, especially as a junior, what's best and when you actively manage people and you have to decide when to stop and that's quite difficult" [L6]

Attending to multiple demands whilst retaining their own ideologies was difficult for learners:

"…but this time it was quite clear that he was saturating around 50% and it was going to be his last exhalation. I found it quite distressing not being able as a CT2… to have much time to spend with the family because there are another 30 patients that you need to look after. It's quite distressing not having much time…" [L6]

Learners recognized that involving patients and carers in care planning and allowing for flexibility facilitates good practice (L6) but can also create tensions (L7, L6):

"...sometimes we have to let people do it their way either to succeed or not, so they can see and not just because we are professionals. This is what I find working in this field because we are supposed to be doing it this way but it's not always the best way for the patient" [L5]

"We have the situation where patients accept it already" … "but members of the family don't want to accept it. Patients agree that they do not want to be resuscitated. The family will disagree with that and will make statements that the patient is not in the right frame of mind to make decision". [L2]

Some were concerned that patients and their carers might wrongly assume responsibility for important decisions, such as withdrawal of treatment or do not attempt resuscitation orders:

"...and I certainly pick up on lots who feel guilty, who say "I was made to turn off the machine, it was awful." You know, "I had to decide…" [L4]

while others struggled after incidents (e.g. falls) around the time of a person's death particularly if they were not present at the time of death or able to discuss with other professionals who were:

"…you have no clue what happens…you don't know if it's your fault that that person died" [L1]

System concerns

Learners highlighted various factors which, if addressed, could contribute to improved EoLC. These included acute ward environments and rules, such as visiting hours(L1, L3), poorly written records and handovers, and inconsistent practices between departments (L6, L4, L5, L2, L7).

Educators were frustrated with a lack of protected time for training, both for themselves to deliver and learners to attend (E3, E4)(E1, E2, E3, E4, E5). Some learners even attended in their personal time, due to difficulties getting released from clinical work (E3, E2). Conversely, educators appreciated support and engagement from senior trust staff (E3), as well as directives such as Commissioning for Quality and Innovation targets (CQUIN) (E1).

Access to psychological support varied greatly but was generally considered lacking (L3, L3, L1, L2). Some learners found their own ways to develop following difficult experiences, but this was by no means universal:

"You know, I always think, every scenario prepares me better for the next one. But I just realise how empty I was on the next one. Yeah, I think, I think…I'm getting there. Because I'm quite conscious of how much I want to do…so it makes me to just try to reflect a bit more every day. Could I have done this much better, could I have…You know…Otherwise…So there is that consciousness in me that is helping me to be better." [L1]

"I find it very difficult. Maybe it will take time for me to get used to but I have been there for 10 years already…at the end of the day you are human" [L2]

Learners suggested a pro-active approach to support staff, such as providing reflective sessions to debrief, review and share, may be helpful in reducing emotional burnout (L2, L3, L1).

DISCUSSION

The overarching aim of *Milestones* was to provide tools to help embed excellent EoLC. This evaluation revealed important underlying themes for EoLC educational interventions and suggests that *Milestones* is a beneficial resource.

Educators found the format of *Milestones* enabled a more interactive teaching style, and the variety of tools (film, role play, group activities) facilitated learner engagement. Learners highlighted the impact of relatable scenarios, and different methods for learning, including reflecting on different roles. Additionally, educators reported the modular design could be used to plan day-long sessions and provided a convenient resource for shorter sessions.

The demographic of the learner group was perceived to impact learning. This is perhaps related to the emotive nature of EoLC with more experienced staff better able to draw on their experience and share with others. Educators highlighted the educational skills and experience needed to manage difficult emotions that emerged during sessions, both their own and that of learners.

Both educators and learners had contextual, organizational and cultural concerns about EoLC including: difficulty in managing unrealistic patient and family expectations when false hope is given by more senior staff; lack of inclusive MDT decision-making and communication processes; lack of psychological support for staff working under emotional strain, and; need to improve organizational processes and procedures and to enable staff to attend in-house training.

Strengths and limitations

The study setting and participant cohort reflects the realities of EoLC training in acute hospitals: heterogeneous groups of learners, with varying numbers attending sessions is commonplace. As such, the findings are likely to resonate with frontline educators, and the meta-themes provide insight into underlying issues which need to be accounted for. The study timeframe was externally dictated by the intervention timetable, and sampling of participants was by convenience, consequently some key roles were not included (e.g. medical consultants) and others were not represented at follow-up. The dependence of the study team on facilitators reporting local questionnaire data meant errors could not be corrected and low numbers of returns at 3-8 months could not be addressed. Despite reaching theoretical saturation for our qualitative themes, there was only one representative from each profession other than nursing, therefore consideration of profession-specific themes was not possible . Learner recruitment was difficult, mainly as many had limited time to participate. This reflects the wider organisational challenges of attendances at training. It is possible that participants were those most interested in learning and improving EoLC, and in the absence of a control group we cannot be certain the observed changes are due to the intervention. This study does, however, provide a theoretically informed analysis of the processes at play in an EoLC education intervention in 'real life' contexts.

Implications and Recommendations

Learners highlighted a double bind for doctors, who were variously criticised for not leading decision-making and for not working collaboratively before taking decisions. Further research to enable better understanding about what stops doctors from consulting the MDT in decisions about treatment in the context of the dying patient could help. In addition, learners highlighted the difficulty of making decisions when there was uncertainty or tension, and so further research into impact on decision-makers would aid our understanding of how best to address learning needs.

The ability to better understand how prior learning, experience and knowledge impacts staff confidence would also enable us to better predict learner needs and so tailor educational interventions accordingly. The most significant challenge highlighted during this evaluation was that of providing good quality post-graduate training that allows learners to increase their confidence when they are in busy, high pressure environments, where time for learning is often limited. Limited opportunities to reflect is a concern. Training could be used to provide a space for reflection, but how best to do this requires further research.

CONCLUSIONS

Educators found *Milestones* useful, flexible and relevant. Learners reported *Milestones* increased confidence in team communication, recognising a dying patient, and identifying difficult emotions. Learners' confidence increased immediately post training session, across four domains, and this enhanced confidence was retained in the medium term. The wider findings should be considered in

future education intervention development, and in other interventions aimed at, or reliant on organizational or cultural change.

FIGURE LEGENDS

Figure 1: Timeline of the development of Milestones and its evaluation process in North Central & East London (NCEL)

Figure 2: The inclusion of learners and educators in the evaluation with rates of response

LIST OF ABBREVIATIONS

QI	Quality Improvement
EoLC	End of life care
WHO	World Health Organisation
UK	United Kingdom
NHS	National Health Service
HEE	Health Education England
NCEL	North, Central and East London
AHSN	Academic Health Science Network
LACDP	Leadership Alliance for Care of Dying People

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NHS Ethical approval was not required. We remained sensitive to potential ethical issues such as participant distress or concern about sharing experiences and gaps in knowledge. Consent to participate was undertaken and confirmed at each stage of data collection, this included consent for anonymized publication of quotations. It did not include consent for unanonymised data sharing.

The original data for this study is held by UCLPartners (endoflifecare@uclpartners.com). Milestones film and associated materials are available to download from: https://uclpartners.com/case-study-eolc/

Competing Interest
None declared.

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