

Implementing structured, multiprofessional medical ethical decision-making in a neonatal intensive care unit

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ABSTRACT

Background In neonatal intensive care, a child's death is often preceded by a medical decision. Nurses, social workers and pastors, however, are often excluded from ethical case deliberation. If multiprofessional ethical case deliberations do take place, participants may not always know how to perform to the fullest.

Setting A level-IIID neonatal intensive care unit of a paediatric teaching hospital in the Netherlands.

Methods Structured multiprofessional medical ethical decision-making (MEDM) was implemented to help overcome problems experienced. Important features were: all professionals who are directly involved with the patient contribute to MEDM; a five-step procedure is used: exploration, agreement on the ethical dilemma/investigation of solutions, analysis of solutions, decision-making, planning actions; meetings are chaired by an impartial ethicist. A 15-item questionnaire to survey staff perceptions on this intervention just before and 8 months after implementation was developed.

Results Before and after response rates were 91/105 (87%) and 85/113 (75%). Factor analysis on the questionnaire suggested a four-factor structure: participants' role; structure of MEDM; content of ethical deliberation; and documentation of decisions/conclusions. Effect sizes were 1.67 ($p < 0.001$), 0.69 ($p < 0.001$) and 0.40 ($p < 0.01$) for the first three factors respectively, but only 0.07 ($p = 0.65$) for the fourth factor. Nurses' perceptions of improvement did not significantly exceed those of physicians.

Conclusion Professionals involved in ethical case deliberation perceived that the process of decision-making had improved; they were more positive about the structure of meetings, their own role and, to some extent, the content of ethical deliberation. Documentation of decisions/conclusions requires further improvement.

INTRODUCTION

Studies of end-of-life practices in neonatal intensive care units (NICUs) report that death of severely ill newborns is frequently preceded by a decision to withdraw or withhold life-sustaining treatment.^{1,2} Such decisions mainly concern neonates with serious birth defects, severe brain injury, severe sepsis, or a complicated perinatal course because of extreme prematurity. In the Netherlands, end-of-life decisions are the physicians' legal responsibility, but nurses' perspectives are also considered indispensable

in medical ethical decision-making (MEDM).^{3,4} In 2007, the American National Association of Neonatal Nurses 'recognised the NICU nurse as an essential contributor to the decision-making process regarding the care of the critically ill newborn for whom they provide care and treatment', (National Association of Neonatal Nurses, p.267)⁵ and acknowledged the right of the nurse to consider whether the parents' or physicians' decisions are appropriate actions to take.⁶ Discrepancies between personal moral convictions and legal regulations, institutional constraints, or actual care given may give rise to moral distress. Lack of consensus about care at the end of life between nurses and physicians is another factor contributing to moral distress for both parties.⁶⁻⁹ This is even more acute in neonatal care where the delicate balance between harm and benefit in neonates with a poor prognosis may give rise to doubts about 'the right thing to do'.¹⁰

Excluding nurses from ethical deliberations may lead to frustration, anger, guilt, feelings of powerlessness,¹⁰⁻¹² and moral distress among nurses,⁸ which, in turn, may add to burnout,¹³⁻¹⁶ whereas interdisciplinary collegiality which fosters respect for nursing contributions will reduce the intensity of moral distress in healthcare.⁵ In ethical deliberations, social workers and pastors may provide important information on parents' background, experiences, fears and wishes. These data suggest that ethical deliberations in neonatal care should include all professionals involved and appreciate their different perspectives to achieve balanced patient/family centred decisions about continuity of treatment and care, symptom management and (spiritual) support.¹⁷ On the other hand, these professionals may not always be well prepared for the task of multiprofessional MEDM.

Until 2008, nurses, social workers and pastors in our level IIID NICU¹⁸ were not always invited to take part in MEDM and had no formal role and responsibility therein. Nurses therefore could be unaware of the weighing of arguments that served as background for a treatment decision. Furthermore, doctors did not always adhere to the final decision, possibly owing to a change in the child's condition such that earlier agreements seemed no longer relevant. This was not always clearly communicated, however, which made nurses feel embarrassed, not knowing how to deal with such a situation and what to say to the parents and

colleagues. Another problem was the lack of a format for MEDM; for example, scheduling and preparation of the meetings was ad hoc and no formal structure was in place for conducting the meetings and the reporting thereof. Finally, meetings were chaired by physicians involved in the cases discussed; it was argued, however, that responsibilities of the physician in clinical patient care could be a source of bias and interfere with the role of chair, who should preferably be an impartial person with ethical and legal background knowledge. This independent chair could be an ethicist, who worked in another department and had no direct responsibility in daily patient care; he/she could concentrate on the role of guiding the process of decision-making.

This unsatisfactory situation prompted the department's management team to set up a project group consisting of two neonatologists, a neonatal intensive care nurse, a nurse/psychologist, a nurse project worker and an ethicist. The members were given the task of introducing a formal MEDM procedure based on national reports,^{19–21} a guideline about non-resuscitation and discontinuation of life-supporting treatments,²² and previous work by neonatal intensive care nurses,^{23 24} As an important requirement, all professionals directly involved with patients and parents should be enabled to contribute to solving ethical dilemmas.

Objectives of the study

In this study we evaluated the effectiveness of an intervention consisting of (a) formulating a clear MEDM policy including involvement of all disciplines of the multiprofessional team; (b) setting up a structured MEDM procedure and (c) appointing an impartial chair.

METHODS

Ethical and legal principles

The project group first studied the relevant national and organisational documents,^{19–24} and additional published papers. According to Beauchamp and Childress's approach,²⁵ which was also adopted by the American National Association of Neonatal Nurses in their position statement on nurse involvement in ethical decisions,⁵ the following four principles are helpful in solving ethical dilemmas: *beneficence*,—that is, healthcare professionals should balance benefits of treatment against the risks and costs for the patient; *non-maleficence*—that is, healthcare professionals should avoid causing harm to the patient; although most treatment involves some harm, this should not be disproportionate to the benefits of possible treatment; *distributive, procedural and legal justice* and *autonomy*, referring to parents being the legal representatives of their child. The medical team, however, also has direct legal responsibility to the child. When, based on medical arguments, treatment is obviously futile and/or continuing treatment would harm the child disproportionately, physicians are not allowed to start, and are even obliged to stop, treatment. On the other hand, if parents ask to stop treatment, but the benefits for the child are evident to the medical team, the parents' wish can be disregarded. In these cases the parents should be informed cautiously, which requires excellent communicative skills.²⁶ When, however, the team is in doubt about the benefits of certain treatment, the parents' opinion is essential in deciding whether treatment is in the child's best interest. Five quality-of-life criteria are considered to be helpful^{20–22}: expected communicative skills; potential of self-care; degree of hospital dependency; degree of suffering and expected lifespan. In the newly formulated policy, MEDM

takes place within the context of these ethical principles and within legal boundaries.

Intervention

- ▶ MEDM meetings are scheduled on the second and fourth Tuesdays of every month. When healthcare providers or parents have doubts about the moral justification of a child's treatment, the case is scheduled for the next MEDM. Fictitious cases may be discussed when there is no actual patient. Ad hoc meetings are called when deliberations cannot be delayed until the next scheduled meeting;
- ▶ The coordinating nurse and physician select the patient to be discussed and prepare the meeting by a checklist guaranteeing that all steps are taken (eg, everyone is informed; the chair is invited, etc).
- ▶ The dilemma the team confronts (should we do A or B, or possibly C?) is analysed, following the steps of the Utrecht model.²⁷ This model was chosen because its five-step structure guides the discussion. The model is 'to the point' for our purposes; it encourages all professionals involved to contribute to the discussion. Additionally, it invites the chair to summarise and conclude on a step before moving on to the next. All this allows for more controlled discussion. The five steps are also followed in reporting.
 - Exploration: a representative of every professional group involved (physician, nurse, social worker and pastor) informs the other team members about the important aspects to be considered, providing a broad perspective of the patient's medical and nursing problems, as well as the psychosocial, cultural and religious context of the child and the family;
 - Agreement on the ethical dilemma and investigation of possible solutions: the dilemma that was described in advance is reconsidered and the chair verifies whether the initial question best describes the imminent dilemma; if not, the participants search for a better phrasing in the light of the information received;
 - Analysis: appraisal of possible solutions by describing the effects of different choices for the child and the parents, discussion among the participants about opinions, thoughts and arguments, listening to each other's points of view and trying to understand contradictory thoughts;
 - Decision-making: pros and cons are weighed, participants are invited to agree or disagree and explain why they do so. Subsequently, a decision is made, which is preferably based on consensus, but ultimately the physician in charge of the patient is responsible for the decision, having taken into account the other professionals' points of view. If subsequently the child's condition changes such that the situation is discussed again and a different conclusion is reached, this should be documented quickly and clearly. When an attending physician disagrees with the team decision for personal reasons, he or she should assign treatment to a colleague.
 - Planning actions: for example, deciding on the person(s) who will inform the parents and how, scheduling a subsequent meeting, or guaranteeing the child's comfort with medical and non-medical interventions.
- ▶ A standardised electronic form is introduced (online appendix 1), incorporating the same five phases of the Utrecht model. These form the 'leading thread' for the preparation, deliberation and report of ethical case deliberation. In addition, the Nijmegen method²⁸ shaped the forms' first, explorative phase, because this method elaborates on the

roles of the participating professionals in more detail and was especially developed for ethical deliberations about children. It includes: medical diagnosis, diagnostics and results, prognosis, treatment effects, nursing problems, effects of nursing interventions and psycho-social effects of the disease for child and family (online appendix 1, phase 1: exploration). Completing this form provides a shared understanding of participants' roles and unequivocal presentation of the patient case and the ethical problem, explicitly from the four professional perspectives: medical, nursing, psychosocial and religious. The introductory section and the first phase of the form are completed before the meeting. Adaptations may be made if the meeting yields more or different information. The responsible physician afterwards completes the form's phases 2 to 5, prints and signs the form, which is then saved into the patient's electronic medical file;

- ▶ An ethicist chairs the meeting and facilitates ethical deliberation. Being from another department, this ethicist may be perceived as a more impartial chair than a physician who is directly responsible for clinical patient care and is involved in the team. Acting impartially, the ethicist could help team members to fully explore the patient case, following the steps of the proposed method.
- ▶ Participants who feel not (yet) confident with the procedure receive practical help from members of a working group of five nurses and two physicians with a special interest in MEDM. Structured multidisciplinary MEDM differs from clinical ethics committee meetings: in MEDM, all participants but the chair, who is primarily responsible for the process, are directly involved 'caretakers'. Clinical ethics committees are consulted in complicated or exceptional situations that require external expertise; such committees usually include one or more ethicist (s), lawyer(s), physician(s), nurse(s), social worker(s), pastor(s), manager(s) and sometimes lay person(s).^{29 30}

Implementation and evaluation

The intervention was implemented as follows:

- ▶ In introductory training sessions by the end of 2008, professionals of the NICU received information about legal and ethical aspects of MEDM in the Netherlands from a lawyer and an ethicist. Furthermore, one of the project group members introduced the procedure and a smaller group of attendees discussed a fictitious patient case, while the others observed.^{31 32}

For lack of a suitable instrument, we constructed a 15-item questionnaire to assess opinions on effectiveness of the intervention. A four-point Likert scale was provided for the response, ranging from 1 (fully disagree) to 4 (fully agree); higher scores were indicating more positive judgements. Exploratory factor analysis revealed an underlying four-factor structure.

Sample

At the start of the introductory training sessions, all 105 participants were asked to complete the 15-item questionnaire anonymously; 92/13 were female/male, mean age was 38.7 (SD 9.1; n=103), mean job tenure at this hospital was 10.5 years (SD 7.6; n=93). Project group members were excluded. The new procedure came into effect in February 2009. Eight months and 16 MEDM sessions later, the same questionnaire was distributed to all 113 professionals employed in the NICU at that time; again anonymously; 100/13 were female/male, mean age was 38.9 (SD 8.9; n=109), mean job tenure at this hospital was 11.0 years (SD 7.3; n=100). Project group and working group members were excluded.

Statistical analysis

Differences in professional representation of the respondents before and after implementation of the new procedure were tested with a Fisher's exact test; the significance level was set at $p=0.05$ (two-tailed). To compare before and after questionnaire scores, means (SDs) and standardised mean differences (SMDs) were calculated for the factors and the separate items. Analogous to Cohen's D, SMD=0.20 was considered a small effect, SMD=0.50 a medium effect and SMD=0.80 a large effect.³³ Since all distributions were (close to) normal, t-tests were performed to test the differences for significance. Because factor analysis suggested that the empirical structure is four dimensional, the significance level of the t-tests was divided by four to correct for multiple testing and set at $p=0.0125$ (two-tailed). In comparing scores on the four factors for the two largest groups of participants, nurses and physicians, before implementation and after 8 months, the intraindividual changes across time could not be assessed because the study was conducted fully anonymously. Therefore, the method of two-way analysis of variance for independent observations was executed to evaluate the differences between professionals (physicians, nurses) and additionally we estimated the changes across time and differences between the professionals across time by assuming that the correlations would be 0.50, while also taking into account that 71% of the professionals were assessed twice. Consequently, we used the t-test for related observations to test the changes across time. Subsequently, as the standard errors could be estimated for these changes, t-tests for independent observations were performed to evaluate differences between the professionals on the changes; the latter representing the possible interaction effect. Significance levels were set at $p=0.05$ (two-tailed).

RESULTS

Response rates were 91/105 (87%) for the first survey and 85/113 (75%) for the second survey; 71% of the participants who completed the second questionnaire also returned the first questionnaire. Distribution of the respondents' professions in both surveys is presented in table 1. Fisher's exact test revealed no significant difference in professional representation in both samples.

For scheduled MEDM sessions, adherence to the new procedure was 100%, except for documentation of conclusions, which was completed in 63% of cases. For ad hoc sessions, the procedure was not fully complied with.

Exploratory factor analysis (with varimax rotation) of the 15 questionnaire items with a cut-off point of 0.40 for item loadings in the pattern matrix and interpretability of the scales, showed a four-factor solution. The four factors demonstrated good internal reliability ($\alpha=0.73$ – $\alpha=0.86$,³⁴) and 68% explained variance. The factors were labelled: *structure of MEDM* (six items), *role of participants* (three items), *content of ethical*

Table 1 Professional representation before and after implementation

	Before, N (response %)	After, N (response %)	p Value*
			0.93
Nurses	63 (83)	63 (78)	
Nurse practitioners	4 (100)	5 (83)	
Physicians	19 (100)	14 (64)	
Social workers	2 (67)	2 (100)	
Pastors	2 (67)	1 (50)	
Missing	1	–	
Total	91 (87)	85 (75)	

*Fisher's exact test (two-tailed).

Table 2 Before and after factor and item scores

	Factor loading	Score range	First assessment Mean (SD)	Second assessment Mean (SD)	SMD	p Value*
Structure of MEDM ($\alpha=0.84$)		6–24	15.4 (2.86)	20.0 (2.57)	1.67	<0.001
We have a clear policy for MEDM	0.688	1–4	2.4 (0.70)	3.3 (0.60)	1.33	<0.001
MEDM is clearly structured by the chair	0.734	1–4	2.7 (0.63)	3.3 (0.66)	0.96	<0.001
The chair is impartial	0.663	1–4	2.5 (0.85)	3.5 (0.62)	1.34	<0.001
Ethical deliberation is well structured	0.706	1–4	2.4 (0.75)	3.3 (0.52)	1.45	<0.001
Generally, all disciplines concerned are represented	0.637	1–4	2.8 (0.80)	3.5 (0.57)	0.97	<0.001
The parents' opinion is represented objectively	0.433	1–4	2.8 (0.72)	3.2 (0.61)	0.52	<0.001
Role participants ($\alpha=0.86$)		3–12	8.1 (1.95)	9.5 (2.08)	0.69	<0.001
It is clear how I should prepare	0.640	1–4	2.3 (0.78)	3.0 (0.86)	0.81	<0.001
My own role in MEDM is clear to me	0.753	1–4	2.9 (0.72)	3.3 (0.73)	0.55	<0.001
I know what my input should be in MEDM	0.871	1–4	2.9 (0.76)	3.2 (0.71)	0.43	<0.01
Content of ethical deliberation ($\alpha=0.73$)		3–12	9.5 (1.45)	10.1 (1.46)	0.40	<0.01
It is evident what the ethical problem implies	0.454	1–4	3.1 (0.61)	3.4 (0.54)	0.45	<0.01
All treatment options are considered	0.494	1–4	3.3 (0.57)	3.3 (0.58)	0.02	0.91
All participants' points of view are considered	0.871	1–4	3.1 (0.70)	3.4 (0.63)	0.45	<0.01
Documentation/adherence to conclusions ($\alpha=0.77$)		3–12	8.7 (1.78)	8.9 (1.70)	0.07	0.65
During MEDM, clear agreements are made	0.499	1–4	3.1 (0.66)	3.2 (0.61)	0.14	0.35
Agreements are well documented	0.861	1–4	3.1 (0.71)	3.0 (0.76)	-0.10	0.53
Reasons for deviation from agreements are quickly and clearly documented	0.756	1–4	2.6 (0.78)	2.7 (0.72)	0.21	0.17

*t-Test (two-tailed).

MEDM, medical ethical decision-making; SMD, standardised mean difference.

deliberation (three items) and documentation of decisions/conclusions (three items). Table 2 shows factor and item scores before and after implementation.

A significantly positive effect was obtained for both the first factor *structure of MEDM* (SMD=1.67; $p<0.001$) and the second factor *role participants* (SMD=0.69; $p<0.001$). For the third factor *content of the ethical deliberation*, the overall positive effect was also significant (SMD=0.40; $t=2.64$, $p<0.01$), but this effect was not demonstrated for the item 'all treatment options are considered' (SMD=0.02; $p=0.91$). Implementation of the new MEDM-procedure did not have any effect on the fourth factor *documentation of decisions/conclusions* (SMD=0.07; $p=0.65$).

For easy understanding of the perceptions of nurses and physicians before and 8 months after implementation, comparisons of mean scores (SD) are shown in table 3. Statistical testing of the main effects of profession, changes over time and the interaction effect between profession and measurement is shown in online appendix 2.

Overall, on the factors 'structure of MEDM', 'role participants' and 'documentation of conclusions' nurses scored significantly lower than physicians ($p=0.043$, $p=0.001$ and $p=0.012$, respectively).

Analyses of main and interaction effects that incorporated relatedness between measurements (see online appendix 2) showed that on the factors 'structure of MEDM', 'role participants' and 'content of ethical deliberation' nurses and physicians together scored significantly higher after the introduction of MEDM' ($p<0.001$, $p<0.001$ and $p=0.01$, respectively). For all four factors, the change between the first and the second measurement was not significantly different between nurses and physicians.

DISCUSSION

Eight months after introduction of structured multidisciplinary MEDM, perceptions of *structure of MEDM* and *the participants role in MEDM* had significantly improved; policy as well as structure was perceived as clearer, an impartial chair was

present, all disciplines involved were represented and participants had better insight into their roles before and during MEDM.

Overall, a significant improvement was also demonstrated for the factor *content of ethical deliberation*; participants felt better informed about the ethical dilemma; therefore discussions might have been more focused. Also participants' points of view were considered to have received more attention during ethical deliberation, resulting in a fuller picture of the pros and cons. Whether the final decision to continue, limit or withdraw treatment would be different with or without the method has, not been evaluated. However, perceptions on the item 'all treatment options are considered' had not changed, perhaps owing to the relatively high baseline score on this item ($M=3.3$ on the four-point scale, both before and after implementation); possibly, a ceiling effect precludes further improvement.

Documentation of decisions/conclusions remains a point of serious concern, because this had not improved. Still, improvement is to be expected soon, seeing that access to the shared electronic file has been made easier and that working group members are providing more active support.

Finally, representation of parents' opinion (item six of the first factor) showed significant improvement, even though this

Table 3 Mean scores (SDs) for nurses and physicians, before and after implementation

Factor	Mean (SD)			
	Nurses		Physicians	
	Before	After	Before	After
Structure of MEDM	15.03 (2.51)	19.66 (2.27)	16.41 (2.51)	20.34 (3.33)
Role participants	7.60 (1.81)	9.18 (2.03)	9.53 (1.80)	9.86 (2.35)
Content of ethical deliberation	9.24 (1.24)	9.96 (1.50)	10.21 (1.47)	9.93 (1.33)
Documentation of conclusions	8.37 (1.71)	8.67 (1.59)	9.57 (1.57)	9.30 (2.00)

MEDM, medical ethical decision-making.

representation is 'by proxy' that is, via the professionals involved. After we have gained more experience we may ask parents to be present during the explorative phase of MEDM and invite them to convey their concerns, opinions and wishes, thereby increasing their autonomy as their child's representatives. Parents' wishes for their child's treatment and care are also especially important when it is decided to provide palliative care; fulfilling their wishes at the close of life appears to be extremely meaningful to parents and moving and gratifying for staff members.³⁵

The significantly lower scores for nurses than for physicians on three factors suggest that the problems were more pronounced for nurses. This is not surprising, because before implementation they were often not invited to participate in ethical discussions. They may have felt excluded, possibly resulting in frustration, anger, powerlessness or feeling disrespected. Documentation of the conclusions may have been more important for nurses because before implementation they often were not present when the patient was discussed and the decision was made.

Although nurses' scores were significantly lower than physicians' scores on the first, second and fourth factor and overall scores on the first three factors were significantly higher after implementation of MEDM than before, none of the interaction effects was statistically significant, which means that contrary to our expectations, nurses' perceptions of improvement did not exceed physicians' perceptions of improvement. However, the absence of statistical significance may be partly due to the relatively small number of physicians, even though this represents clinical practice.

Overall, now that all important professionals are represented to add their unique professional perspectives to the patient's 'picture' and together discuss the ethical dilemma, we may conclude that those involved in ethical case deliberation perceived that the process had improved; they were more positive about the structure of meetings, their own role and, to some extent, the content of ethical deliberation. Awareness of the pros and cons of proposed solutions and the weighing of arguments that underlie the final decision, prevents uncertainty; then, nurses can explain the decisions more easily to their colleagues and better respond to parents' questions. Also, discussion of all aspects of the case may make it easier for doctors to adhere to the final decision.

Closely monitoring MEDM had the unforeseen advantage of achieving other quality improvements. In the 2-monthly working group meetings, every MEDM was briefly reviewed and solutions proposed for problems experienced; for example, reporting conclusions of MEDM, informing new team members, preventing mono-professional ad hoc sessions, or making a checklist of actions to be performed when parents prefer their child to die at home. In 2012, we will review the cases of structured MEDM, of the past 3 years wherein treatment was continued to investigate how these children's health and quality of life have developed. The outcomes may give reference points for future decisions.

Some limitations of this evaluation should be addressed. First, the lack of a control group makes it hard to tell whether the effect is the result of structured multiprofessional MEDM or the result of sensitisation of the team after completing the first questionnaire. However, this project was a change project rather than a research project; participants in the ward have welcomed it, but could also have rejected this change. Second, adherence to the procedure, except for documenting the outcomes, was very high for meetings scheduled in advance, but remarkably lower for ad hoc in-between sessions, which may

have reduced the positive effects demonstrated. We cannot fully explain this finding, but infer that decisions in ad hoc cases were taken during patient hand-over with all doctors present, which is easier than arranging a special MEDM meeting. Another possibility is that the more complicated patient cases were preferably discussed in the scheduled multidisciplinary meetings, while less complicated decisions were taken ad hoc, among physicians only. Motivating colleagues to adhere to the procedure for ad hoc meetings as well is another task facing the working group. Finally, changes in possible feelings of frustration, anger, powerlessness, stress and burnout among nurses¹³ owing to not being involved in MEDM (see Introduction) were not evaluated in this study.

In future research it will be worth trying to reproduce the effects of this intervention in other wards, where healthcare workers probably meet the same problems. However, adaptations may be necessary because this study dealt with neonates, who are a specific population in that they cannot express their wishes. The factor structure of the 15-item questionnaire, used in this study, needs further evaluation/confirmation in other populations also.

In conclusion, the process of ethical case deliberation in our NICU and representation of all the disciplines involved was perceived to have significantly improved after introduction of structured multiprofessional MEDM. Continuous efforts must be put into reporting decisions and conclusions of MEDM.

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Contributors CdB had responsibility for development of structured multiprofessional medical ethical decision-making (MEDM), introduction, assessment, data analysis and writing of the manuscript. GvB had responsibility for development of structured multiprofessional MEDM, introduction, assessment. MW had responsibility for development and introduction of structured multiprofessional MEDM and commented on earlier drafts of this manuscript. GvD had responsibility for development of structured multiprofessional MEDM and introduction, chaired MEDM and commented on earlier drafts of this manuscript. HJD supervised the design and performed the final data analyses.

Competing interests None.

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