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Barriers to the provision of optimal care to dying patients in hospital: an international cross-sectional comparison study of nurses' perceptions

Authors

Jan Shepherd¹
Amy Waller¹
Sally Chan^{1,3}
Miyoung Kim⁶
Sook Jung Kang⁶
Carmen Chan⁴
Meyrick Chow⁵
Mathew Clapham²
Rob Sanson-Fisher^{1,2}

Author affiliations

- 1 University of Newcastle, University Drive, Callaghan, NSW, 2308, Australia
- 2 Hunter Medical Research Institute, Lot 1 Kookaburra Circuit, New Lambton Heights, NSW, 2305, Australia
- 3 University of Newcastle, Singapore
- 4 Chinese University of Hong Kong
- 5 Tung Wah College Kowloon, Hong Kong
- 6 Ewha Womans University, Seoul, Republic of Korea

Corresponding author

Jan Shepherd
Health Behaviour Research Collaborative
University of Newcastle
Hunter Medical Research Institute
Callaghan NSW 2308
Jan.Shepherd@uon.edu.au

ABSTRACT

Background: Nurses play an important role in caring for patients who are dying in hospital, so it is important to understand their perceptions of the factors that may influence the quality of that care. Much of the existing literature is focused on end-of-life care provision in western settings. Little is known about how nurses' perceptions of end-of-life care provision may differ across Asian and western locations. Understanding the similarities and differences between the perceptions of nurses in Asian and western locations about the barriers to the provision of high-quality end-of-life care may help guide education and policy initiatives to improve end-of-life care in each location.

Aim: To compare the perceptions of nurses from Australia, South Korea, and Hong Kong regarding barriers to high-quality end-of-life care provision for people dying in hospitals.

Methods: A cross-sectional study of hospital-based nurses from Australia (n=153), South Korea (n=241), and Hong Kong (n=188) completed a survey between December 2016 and June 2018. Nurses indicated the extent to which they perceived 40 items across five domains to be a barrier to high-quality end-of-life care provision.

Findings: Significant variation between the perceptions of nurses in each location was found in two-thirds of the survey items. The greatest difference was seen in the item *doctors continue life-sustaining medical interventions for too long*, which was considered a significant barrier by 60.1% of Australian nurses, 32.9% of South Korean nurses and 13.8% of Hong Kong nurses. The greatest cross-location agreement related to differences in religious beliefs and languages. These items were considered a significant barrier by fewer than one-quarter of nurses.

Conclusion: Nurses in Hong Kong, South Korea and Australia perceive a range of challenges to the provision of optimal end-of-life care. The significant differences observed in two-thirds of response items supports the hypothesis that strategies to improve the quality of end-of-life care in one location may not be effective in another. For interventions to be effective they must be tailored to the unique nature of care-provision in each location. Gaining an understanding of the potential reasons for these differences may highlight potential targets for interventions that address the unique factors associated with care provision in each location.

Problem

Barriers to the provision of high-quality end-of-life care in Asian hospitals may be different from those in western hospitals. Nurses are well-placed to understand the factors that can both hinder, and enhance, care provision, in each location. However, little is known about how nurses' perceptions of the barriers to end-of-life care provision in Asian hospitals differ from those of nurses in western hospitals.

What is already known about the topic?

- End-of-life care is increasingly being provided in hospital settings.
- Nurses have an integral role in supporting dying patients and their families.
- Few studies have explored the similarities and differences between the perceptions of nurses in Asian and Western locations about the factors that hinder end-of-life care provision across all domains of healthcare provision.

What this paper adds

- There are a number of differences between the perceptions of nurses in Western and Asian locations about the factors that hinder end-of-life care provision.
- Comparing the similarities and differences between the perceptions of nurses in each location can help develop an understanding of the potential for different practice styles, cultural considerations, and system-based factors to impact the provision of end-of-life care in hospitals.
- The findings of this international comparison study may help to inform education programs and policy initiatives to improve end-of-life care in Asian and Western hospitals.

Keywords

Nurses; acute care; terminal care; cross-sectional; Australia; South Korea; Hong Kong

INTRODUCTION

End-of-life care is defined as care that supports people with an advanced, terminal illness to live as well as possible until they die (Palliative Care Australia, 2010). As patients approach the end of their lives, such care is often provided in acute hospitals (Broad et al., 2013). The provision of high-quality end-of-life care that meets the wishes of the dying patient is an international healthcare priority (Virdun, Luckett, Davidson, & Phillips, 2015). Studies exploring patient and family perspectives have identified good symptom control, honest and effective communication, trust in the healthcare team, dignity, an opportunity to prepare for impending death, family involvement and not wanting to burden loved ones as important elements of a 'good death' (Heyland et al., 2006; Meier et al., 2016; Virdun et al., 2015). Quality indicators and policy documents have been developed internationally to support quality assurance and improvement in provision of end-of-life care across different care settings and patient populations (De Schreye, Houttekier, Deliens, & Cohen, 2017; Sanders et al., 2020).

Despite these efforts, there is increasing recognition that high quality end-of-life care is not consistently delivered (Clark, 2017; Wachterman et al., 2016). The last year of life can involve multiple emergency department visits and hospital admissions, longer hospital stays, burdensome care transitions and intensive care bed days (Bardsley, Georghiou, Spence, & Billings, 2019; Reeve et al., 2018; Teno, Casey, Welch, & Edgman-Levitan, 2001). Although many people indicate a preference for a home death, a majority will die in hospital (Broad et al., 2013; Virdun et al., 2015). Care in the hospital setting is often characterized by unwanted aggressive treatment, poor symptom management and suboptimal communication and information provision (Cardona-Morrell et al., 2016; Cardona-Morrell, Kim, Brabrand, Gallego-Luxan, & Hillman, 2017). Bereaved family members report extended grieving periods when end-of-life care does not adequately address the complex symptoms that often mark the actively dying phase (Odgers, Fitzpatrick, Penney, & Shee, 2018).

Those delivering end-of-life care in hospitals represent an important source of information regarding the factors that influence the quality of that care (Scholz et al., 2020). Nurses providing direct patient care offer a unique, yet largely missing perspective. Nursing and medical staff may have different perspectives about factors that contribute to the quality of care provided to people with terminal illnesses (Stajduhar & Doane, 2014). Unlike other healthcare providers nurses have a presence on the ward at all times, and are responsible for the provision of all personal care. As a result, nurses can develop a unique knowledge of the complex needs of dying patients and their families, allowing them to provide a much needed link between the patient and their family and

other members of the healthcare team (Beckstrand, Collette, Callister, & Luthy, 2012). Internationally, variations in end-of-life care provision have been linked to factors such as patient age, diagnosis, socio-economic status, cultural considerations, geographical location and limited availability of services such as palliative care (Bardsley et al., 2019; Chróinín et al., 2018; Davies et al., 2019; Kwon, Hattori, Lee, & Kim, 2015; Teno et al., 2001). Much of the existing literature examining barriers to optimal end-of-life care has focused on Western settings. No studies have compared the views of nurses providing end-of-life care in Asian and Western countries. An understanding of the similarities and differences in barriers to the provision of optimal end-of-life care in each setting may highlight potential targets for location-specific approaches to optimise end-of-life care in hospitals. Without this unique viewpoint, important barriers may be missed, limiting the potential effectiveness of interventions designed to improve the quality of hospital-based end-of-life care.

AIMS

To compare the perceptions of nurses from Australia, South Korea, and Hong Kong regarding barriers to high-quality end-of-life care provision for people dying in hospitals.

METHODS

Sample

A questionnaire-based, cross-sectional survey was completed by a convenience sample of registered and enrolled nurses (bachelor or diploma qualifications) working in three public hospitals in Australia (n=153), one university hospital in South Korea (n=241), and one public hospital in Hong Kong (n=188). This study forms part of a larger project and, as such, the socio-demographic data is included in other papers (Waller et al., 2020).

Procedure

Eligible nurses completed an anonymous survey between December 2016 and June 2018. Nurses were approached by the Nurse Unit Manager of participating wards. Nurses could complete the survey while on the ward and mail it directly to a member of the research team or return it within two weeks to a closed box located on the ward. Completion of the survey was taken as informed consent.

Ethics approval

The University of Newcastle Human Research Ethics Committee (H-2018-0112) and the ethics committees of the participating health services in Australia (16/12/14/4.09); South Korea (IRB:125-

13); and Hong Kong (KW/FR-17-036(109-01)) approved the study.

Survey development, translation and pilot testing.

Key domains and clinical items were derived from a search of published literature as well as clinical practice guidelines and standards. Eight nurses experienced in end-of-life care and a panel of experts who were partners in the study participated in three rounds of consultation to reach consensus about survey items. The survey was written and developed in the English language and administered in English in Australia and Hong Kong. The South Korean version of the survey was developed by forward translating the English survey into Korean, then back translating it into English by bi-lingual persons. Translation of the survey occurred simultaneously to ensure consistency in meaning. Changes were adopted across both versions of the survey. The survey was pilot tested with ten acute-care nurses from each location. The final survey included items assessing a range of end-of-life care issues; however only the items pertaining to nurses' perceived barriers to end-of-life care provision are presented here.

Measures

Barriers to optimal end of life care: Participants indicated the extent to which they perceived each of 40 items as a barrier to the provision of optimal end-of-life care in hospitals on a 4-point Likert scale ranging from 'no barrier' to 'significant barrier'. The items covered five domains: patient (e.g. *Patients have unrelieved symptoms*); families (e.g. *Families have unrealistic expectations of patient's prognosis*); nurses (e.g. *Nurses are too busy*), doctors (e.g. *Doctors don't adequately explain the dying process to patients/families*); and the hospital/health care system (e.g. *A lack of access to specialist palliative care and/or end-of-life teams*).

Nurse characteristics: Participants' self-reported their age and gender, as well as the following clinical items: highest education qualifications, years of experience, number of hours worked per week, area of practice, and the number of dying patients cared for in the previous six months.

Statistical Analysis

Statistical analyses were programmed using SAS software v9.4 (SAS Institute, Cary, North Carolina, USA). Cross-country comparisons of nurses' characteristics were made using chi-square or t-tests. The study measures (barriers) were summarised using frequencies and percentages of non-missing with exact (Clopper Pearson) 95% confidence intervals. Comparisons between countries were examined using p-values from chi square tests. Comparisons at a p-value <0.05 were considered statistically significant.

RESULTS

Surveys were returned by 153 Australian nurses (45% of approached); 188 Hong Kong nurses (21% of approached); and 241 South Korean nurses (96% of approached). The characteristics of the sample have been reported previously (Waller et al., 2020), and are summarised in Appendix 1. The majority of nurses were female (n=524; 90%), providing direct patient care (n=482; 83%) and had a Bachelor's degree (n=356; 61%). Three-quarters reported caring for at least one dying patient in the preceding six months (n=449; 77%). The mean age of participating nurses was 36 years (SD=12; range: 20-70 years).

Differences and similarities in nurses' perceptions of barriers by location

Statistically significant differences between the perceptions of nurses in the three locations were found in approximately two-thirds of the survey items. Table 1 presents the ten items with the greatest difference between nurses in each location (see Appendix for the full list of items). Of the top ten items demonstrating significant cross-location differences, Australian nurses ranked nine items as more significant barriers to the provision of optimal end-of-life care than nurses in either South Korea or Hong Kong. The exception was the item *doctors are too busy*, which was ranked as a significant barrier by 65% of South Korean nurses compared with 42.5% of Australian nurses and 35.6% of Hong Kong nurses. The greatest disparity was seen in the item *doctors continue life-sustaining medical interventions for too long*, which was considered a significant barrier by 60.1% of Australian nurses, 32.9% of South Korean nurses and 13.8% of Hong Kong nurses. Other items demonstrating high levels of cross-location differences included: *doctors provide insufficient/inappropriate pain and symptom relief* (Australia, 51%; South Korea, 37.5%; and Hong Kong, 11.2%); *doctors are unwilling to question or alter decisions of more senior doctors* (Australia, 51%; South Korea, 25%; and Hong Kong, 13.8%); *doctors don't adequately explain the dying process to patients/families* (Australia, 51.3%; South Korea, 40%; Hong Kong, 19.1%); and *dying patients have unrealistic expectations about consequences of 'life-saving medical interventions'* (Australia, 43%; South Korea, 15.8%; and Hong Kong, 13.3%).

There was no significant difference between the perceptions of nurses in each location for one-third of the survey items. Table 2 presents the ten items with the greatest agreement among nurses in all locations (see Appendix for the full list of items). Four of the five items with the greatest cross-location agreement related to differences in religious beliefs and languages. Nurses were also in agreement about the item *dying patients do not want to discuss end-of-life issues*. In each case, these items were considered a significant barrier by fewer than one-quarter of participating nurses.

Table 1 – Top ten items demonstrating the greatest difference between locations (greatest to least difference)

Item	Australia (n=153)	Hong Kong (n=188)	South Korea (n=241)	P-Value	Difference (%)
	% (95% CI)	% (95% CI)	% (95% CI)		
Doctors continue life-sustaining medical interventions for too long	60.1% (51.9 to 67.9)	13.8% (9.2 to 19.6)	32.9% (27.0 to 39.3)	<.0001	46.3
Doctors provide insufficient/inappropriate pain and symptom relief	51.0% (42.8 to 59.1)	11.2% (7.0 to 16.6)	37.5% (31.4 to 44.0)	<.0001	39.8
Doctors are unwilling to question or alter decisions of more senior doctors	51.0% (42.8 to 59.1)	13.8% (9.2 to 19.6)	25.0% (19.7 to 31.0)	<.0001	37.2
Doctors don't adequately explain the dying process to patients/families	51.3% (43.1 to 59.5)	19.1% (13.8 to 25.5)	40.0% (33.8 to 46.5)	<.0001	32.2
Dying patients have unrealistic expectations about consequences of 'life-saving medical interventions'	43.0% (35.0 to 51.3)	13.3% (8.8 to 19.0)	15.8% (11.5 to 21.1)	<.0001	29.7
There are inappropriate staffing levels that do not include a mix of senior and junior doctors and nurses	44.1% (36.0 to 52.4)	14.4% (9.7 to 20.2)	28.3% (22.7 to 34.5)	<.0001	29.7
Doctors are too busy	42.5% (34.5 to 50.7)	35.6% (28.8 to 42.9)	65.0% (58.6 to 71.0)	<.0001	29.4
Dying patients have not completed / participated in advance care planning (i.e. have not discussed end-of-life wishes, completed an advance directive and/or nominated substitute decision maker / proxy)	39.5% (31.6 to 47.7)	10.1% (6.2 to 15.3)	24.6% (19.3 to 30.5)	<.0001	29.4
Families of dying patients are themselves distressed by patient's unrelieved symptoms (eg. pain/delirium)	39.9% (32.1 to 48.1)	12.8% (8.4 to 18.4)	23.8% (18.5 to 29.6)	<.0001	27.1
Doctors have limited training in end-of-life care	45.8% (37.7 to 54.0)	20.2% (14.7 to 26.7)	37.1% (31.0 to 43.5)	<.0001	25.6

Table 2 – Top ten items demonstrating the least difference between locations (least to greatest difference)

	Australia (n=153)	Hong Kong (n=188)	South Korea (n=241)	P-Value	Difference (%)
	% (95% CI)	% (95% CI)	% (95% CI)		
Dying patients have different religious beliefs, language	10.5% (6.1 to 16.5)	11.2% (7.0 to 16.6)	13.8% (9.7 to 18.8)	0.5703	3.3
Families of dying patients have different religious beliefs, language	9.2% (5.1 to 14.9)	9.0% (5.4 to 14.1)	15.0% (10.7 to 20.2)	0.0897	5.8
Dying patients do not want to discuss end-of-life issues	23.5% (17.1 to 31.1)	17.6% (12.4 to 23.8)	24.2% (18.9 to 30.1)	0.2188	6.6
Nurses have difficulty dealing with different religious beliefs, language of patients /families	17.0% (11.4 to 23.9)	9.0% (5.4 to 14.1)	15.8% (11.5 to 21.1)	0.0589	8
Doctors have difficulty dealing with different religious beliefs, language of patients /families	15.7% (10.3 to 22.4)	8.0% (4.5 to 12.8)	17.9% (13.3 to 23.4)	0.0110	9.9
Nurses do not know how to access specialist-led palliative care (i.e. care provided to patients with an illness that cannot be cured)	20.3% (14.2 to 27.5)	9.0% (5.4 to 14.1)	18.8% (14.0 to 24.3)	0.0061	11.3
There is a lack of spiritual support services available to patients/families	24.3% (17.8 to 32.0)	12.8% (8.4 to 18.4)	22.1% (17.0 to 27.9)	0.0132	11.5
There is uncertainty about who is responsible for end-of-life decisions	23.0% (16.6 to 30.5)	13.3% (8.8 to 19.0)	26.7% (21.2 to 32.7)	0.0031	13.4
There is no place to record patient's end-of-life wishes that is easily accessible to all members of the care team	26.3% (19.5 to 34.1)	10.1% (6.2 to 15.3)	23.8% (18.5 to 29.6)	0.0002	16.2
Dying patients are often unable to communicate their wishes (eg. reduced conscious level, aphasic)	34.0% (26.5 to 42.2)	17.6% (12.4 to 23.8)	24.2% (18.9 to 30.1)	0.0022	16.4

DISCUSSION

This international comparison study examined the perceptions of nurses in western and Asian hospitals about the factors that hinder end-of-life care provision. Statistically significant cross-location differences were identified in two-thirds of the forty survey items, supporting the hypothesis that strategies to improve end-of-life care in one location may not be effective in another. For interventions to be effective they must be tailored to the unique nature of care-provision in each location. It is, therefore, important to understand the location-specific factors that impact end-of-life care in hospitals.

Nurses employed in all three locations considered doctors and nurses being too busy as a large barrier to delivering optimal end-of-life care. However, clinician workload was a significantly greater concern for South Korean nurses than it was for nurses in either Australia or Hong Kong ranking these two items as the most significant barriers overall. Clinician workload has long been acknowledged as a barrier to the provision of high-quality care across care settings in many countries (MacPhee, Dahinten, & Havaei, 2017; Nantsupawat et al., 2011), and steps have been taken to address this issue. For example, mandated nurse to patient ratios have been introduced into Australian legislation though there is some doubt that they lead to measurable improvements in patient care (Olley, Edwards, Avery, & Cooper, 2019). Such policies do not always make allowances for a mix of experienced and novice nurses and where there are insufficient senior staff to support novice clinicians, a corresponding reduction in the quality of care has been reported (Aiken et al., 2017). Legislation mandating staff to patient ratios does not exist in many countries. Instead, the effectiveness of staffing levels may be assessed by individual hospital management teams, or not at all. For example, the Hong Kong Hospital Authority conducts annual retrospective analyses of patient dependency and staffing levels to determine if care goals have been met (Chau et al., 2015). There is some evidence that nurses in South Korea are often required to care for twice as many patients than their Australian counterparts, leading to issues of burnout and concerns for the quality of patient care (Cho et al., 2015). Laws restricting working hours for medical residents in South Korea have not been accompanied by corresponding increases in staffing numbers, leading to increased workloads for other medical staff (Moon et al., 2019). Where staffing levels are inappropriate, the ability of both doctors and nurses to identify, discuss and manage the complex needs of dying patients and their families in a timely manner is often limited (Ball, Murrells, Rafferty, Morrow, & Griffiths, 2014). Efforts to address patient acuity as a component of mandated nurse to patient ratios may help to address many of the issues raised by nurses in studies such as this (Upenieks, Kotlerman, Akhavan, Esser, & Ngo, 2007).

Almost two-thirds of Australian nurses in this study consider doctors continuing life-sustaining medical interventions for too long to be the most significant barrier to high-quality end-of-life care. By contrast, one-third of South Korean nurses and just 14% of Hong Kong nurses perceived this as a significant barrier. There is widespread acknowledgement that high-quality symptom management and avoidance of suffering are important considerations for dying patients and their families (Clark, 2017; Meier et al., 2016; Virdun, Luckett, Lorenz, & Phillips, 2018) so it is not surprising that nurses would hold an unfavourable view of any treatment that may impact those factors. However, that comparatively few South Korean or Hong Kong nurses perceived continuation of invasive treatment to be a significant barrier to high-quality end-of-life care is worthy of further exploration. There is some suggestion that Asian clinicians are more likely than their Western counterparts to continue invasive treatments for dying patients (Phua et al., 2015). Economic, cultural, religious, and legal issues have been suggested as potential reasons for this (Azoulay et al., 2009; Phua et al., 2015) and it is possible that these same cultural and religious considerations are shared by the South Korean and Hong Kong nurses in this study. These factors are also likely to impact the treatment choices for families of patients dying in Asian hospitals, with comparatively few being willing to accept treatment withdrawal (Phua et al., 2015). Interestingly, this contrasts with the finding that, when compared with perceptions of Australian nurses, very few South Korean and Hong Kong nurses believed that dying patients had unrealistic expectations of the potential consequences of life-sustaining treatments.

Nurses in Hong Kong consistently reported fewer barriers to high-quality end-of-life care than their Australian and South Korean counterparts. For example, only 11% of nurses in Hong Kong considered inadequate pain/symptom relief to be a significant barrier, compared with 38% of South Korean nurses and 51% of Australian nurses. A potential reason for this difference may be Hong Kong's establishment of a number of novel programs to enable an ageing population to both live well, and to transition to an end-of-life process that focuses on dying in place and minimises unnecessary hospitalisations at the end of life (Wong et al., 2020). The development of an on-call service providing palliative care support to patients dying in hospitals and residential aged care facilities is key among these services (Wong et al., 2020). Though the percentage of people who die outside of hospitals is comparatively low, these efforts to improve end-of-life care may be positively impacting on nurses' perception of the quality of care provided to patients dying in hospital.

Limited training in end-of-life care for doctors and nurses was comparatively highly ranked by nurses in all three locations. This result is consistent with previous studies reporting inadequate

provision of communication skills training and a lack of preparedness among clinicians' to care for those approaching the end of their lives (Scholz et al., 2020). Open and clear communication is a key component of high-quality end-of-life care, reducing patient anxiety and improve outcomes for bereaved family members (Granek, Krzyzanowska, Tozer, & Mazzotta, 2013; Scholz et al., 2020). Integration of programs to better equip novice doctors and nurses is necessary to consistently improve the end-of-life experience of patients and their families (Sanson-Fisher et al., 2019; Scholz et al., 2020; White & Coyne, 2011).

Of the items demonstrating the greatest cross-location similarities, the most noteworthy was that of religious and/or language issues. Nurses in all three locations reported that these factors did not impede end-of-life care provision. Similar results have been reported in previous studies examining the perceptions of nurses about the factors that impede the provision of optimal end-of-life care (Beckstrand et al., 2012), and can be explained, at least in part, by the relatively homogenous populations in South Korea and Hong Kong. People speak similar languages and each location has a dominant religion. In Australia, as with other countries, caring for people from culturally and linguistically diverse backgrounds has been a component of education programs for many years (Choi & Kim, 2018; Leung et al., 2020).

A number of items were ranked as significant barriers by nurses in all three locations. In particular, existing clinician workloads were identified as substantial barriers. Importantly, barriers may occur at the ward level, across individual hospitals, or at a jurisdiction or national level. Consequently, change is more likely to occur when multifactorial interventions across varying levels are used (Minary et al., 2019).

STRENGTHS AND LIMITATIONS

The large sample sizes are strengths of this study. Although the response rates are comparatively low for the Australian and Hong Kong samples, they are comparable with other studies in this field. The broad range of nursing roles represented may also increase the generalisability of the results. Limitations to this study include the differences in socio-demographic characteristics and training between nurses in each location. For practical reasons, nurses in this study were not asked to describe their perceptions of the quality of care actually being delivered in each setting.

CONCLUSION

Nurses in Hong Kong, South Korea and Australia perceive a range of challenges to the provision of optimal end-of-life care. The significant differences observed in two-thirds of response items

supports the hypothesis that strategies to improve end-of-life care in one location may not be effective in another. For interventions to be effective they must be tailored to the unique nature of care-provision in each location. Gaining an understanding of the potential reasons for these differences may highlight potential targets for interventions that address the unique factors associated with care provision in each location.

DECLARATIONS

Authorship

Jan Shepherd, Amy Waller, Sally Chan, and Rob Sanson-Fisher (Australia): study concept, design, and development; data acquisition, analysis, and interpretation;
Miyoung Kim and Sook Jung Kang (South Korea), Carmen Chan and Meyrick Chow (Hong Kong): study design; and data acquisition, analysis and interpretation;
Matthew Clapham: statistical analysis and interpretation of the data.
All authors have read and approved the final version to be published and agree to be accountable for this work.

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Declaration of conflicts of interest

The authors declare there are no conflicts of interest.

Data management and sharing.

Datasets are available from the authors upon reasonable request.

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