Collecting data on end-of-life decision-making: Questionnaire translation, adaptation and validity assessment

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Abstract

Little is known in Australia about current practice relating to medical end-of-life decisions preceding patient deaths. This study aimed to translate and culturally adapt a European questionnaire on medical end-of-life decisions and end-of-life care to the Australian context, producing a questionnaire to assess current medical practice in Australia and enable comparison with international studies. Following initial research team review, an English translation of the questionnaire was culturally adapted using four waves of cognitive pre-testing interviews with members of the target community: Australian doctors (n=27) from different specialties, clinical settings and geographical locations. Cognitive interviewing was used to identify potential problems with the translated questionnaire by examining the cognitive processes participants used to answer questions. Two experts in end-of-life research provided feedback on the questionnaire after the third wave of cognitive interviews. Research team review occurred again after the third and fourth waves of cognitive interviews. Interview notes were reviewed, coded and analysed using content analysis. A consensus approach was used to identify necessary adaptations, with all members of the research team endorsing the adaptations. Following cognitive pre-testing, an online version of the questionnaire was piloted with doctors, nurses and health law researchers (n=13). Improvements to questionnaire wording, flow/routing and design were identified during the cognitive interviewing and piloting process and implemented. Saturation in terms of face and content validity and acceptability of the questionnaire was achieved after four rounds of cognitive interviews. Participants generally agreed that the adapted questionnaire instructions were easy to follow, the questions were easy to understand, they felt comfortable answering all the questions, and the online questionnaire format was user friendly. The time taken to complete the questionnaire (average 9.2 minutes) was also acceptable to participants. Cognitive interviewing was a suitable method for identifying and solving challenges with

comprehension and applicability of the questionnaire within the Australian context. The final questionnaire was well accepted by doctors and is now being used in a study exploring the incidence and nature of medical end-of-life decisions involving adult patients in one Australian state (Victoria). This questionnaire may be suitable for use or further adaptation in research in other English speaking jurisdictions.
Keywords: End-of-life decision-making, Cognitive interviewing, Cultural adaptation, Questionnaires, Translation

Background

There are critical knowledge gaps about medical end-of-life decisions (ELDs) involving adult patients in current Australian medical practice. Medical ELDs in Australia commonly include withholding and withdrawing treatment and alleviating pain and other symptoms with medications. Little is known about the incidence and characteristics of medical ELDs, nor if there is variation relating to different patients, clinical settings or medical specialties. This contrasts with comparable Western countries, many of whom have undertaken extensive research on medical ELDs and so have a current evidence base. [1-11] The existing Australian studies which investigated medical ELDs are dated [12-16] or used methodologies that cannot provide population-level data [17-20].

Identifying the types of ELDs being made in Australia and the frequency and characteristics of these decisions would provide an evidence base to understand current practice and drive improvements. It is vital to discern the context surrounding different types of ELDs, including when they are made, by and with whom, and for whom. There are also limitations in the available data on palliative care service provision across health settings, including data on service provision for individual patients rather than episodes of hospitalisation [21, 22].

The absence of the aforementioned data has been noted along with calls for the necessary evidence base to be developed [21]. This data would provide a strong evidence base for planning the delivery and funding of end-of-life care and indicate areas in which further medical education or training may be warranted. Data are vital to ensure optimal regulation of end-of-life decision making. Doctors play a significant medico-legal role when they make ELDs [23]. They determine whether a patient has the capacity to make treatment decisions, who the decision-maker is if the patient does not have capacity, and determine whether an advance directive is applicable and, if so, interpret its meaning. Up to date information on ELDs in Australian medical practice could also facilitate an assessment of the extent to which decisions comply with current law and policy. There are some medical practices including palliative or terminal sedation [24] and voluntarily stopping eating and drinking [25], about which relatively little is known. More information about the extent to which such practices are taking place and the circumstances in which they occur will be of value in exploring their legal and ethical implications and developing appropriate regulatory responses. Further, the law in this area is complex and evolving. For example, since this study was undertaken, voluntary assisted dying has become legally available in the state of Victoria in limited circumstances with the *Voluntary Assisted Dying Act 2017* (Vic) (VAD Act) becoming operational on 19 June 2019. The legalisation of VAD will affect practice of medical ELDs, and may also have significant implications for health professionals, health administrators and health systems. For example, previous overseas research reported increased hospice referrals and greater efforts by medical practitioners to improve their knowledge of palliative care following the enactment of similar laws [9,26].

To gather data on current practice relating to medical ELDs and end-of-life care, reliable and appropriate instruments are needed. Various questionnaires measuring practices of medical

ELDs have been used in previous Australian research. The Baume [16], Stevens [15] and Neil [18] studies utilised different versions of a self-administered questionnaire on attitudes and practices relating to ELDs and euthanasia, developed for an earlier study by Kuhse and colleagues [13]. However, none of these studies reported assessing the content and face validity of the instrument prior to use. The Douglas [17] and Sheahan [19] studies both used different self-developed questionnaires, however they predominantly focused on opinions and experiences relating to intentional hastening of death. Kuhse and colleagues [12] used an English version of a Dutch questionnaire on practices of medical ELDs developed by van der Maas et al [27]. The original van der Maas questionnaire and its variations have been used extensively in the research literature, including studies undertaken in the Netherlands [6,8], Belgium [4,28,29], Germany [30], France [31, 32], the United Kingdom [33, 34], Canada [35] and New Zealand [36, 37], and comparative research across European countries [10].

To our knowledge, no Australian questionnaires exploring the broad range of medical decisions that may precede a patient's death has been assessed for content and face validity. Hence, this study aimed to translate and culturally adapt a European questionnaire on medical ELDs, to ascertain how the questions are understood by Australian doctors and whether its content is applicable to the Australian context. The questionnaire drew on those of the previous studies in Belgium, the Netherlands and other European countries, originally developed by van der Maas et al [27]. The Australian version of the questionnaire was developed over an extended period; the cultural adaptation and validity assessment process included cognitive pre-testing a paper version of the questionnaire with doctors and piloting an online version of the questionnaire. Cognitive interviewing is a method of assessing and developing self-report questionnaires [38]. It involves participants completing a draft questionnaire and providing verbal feedback on their thinking process as they read or hear

questions, interpret the meaning of questions, and formulate responses [39]. Participant feedback is used to inform improvements to the questionnaire which address identified issues and enhance questionnaire design [38]. Cognitive interviewing was used here to ascertain the extent to which Australian doctors understood the translated questionnaire items as intended and identify necessary changes to enhance interpretation of problematic questions. This process was also undertaken to ensure the questionnaire was consistent with the clinical realities of end-of-life care in Australia and was acceptable to participants. The value of this study is that it produced a questionnaire that can be implemented in future research to provide an evidence base to understand Australian medical practice relating to ELDs and end-of-life care, and to compare these results with previous international studies. The questionnaire may also be suitable for use or further adaptation in other English speaking countries.

Methods

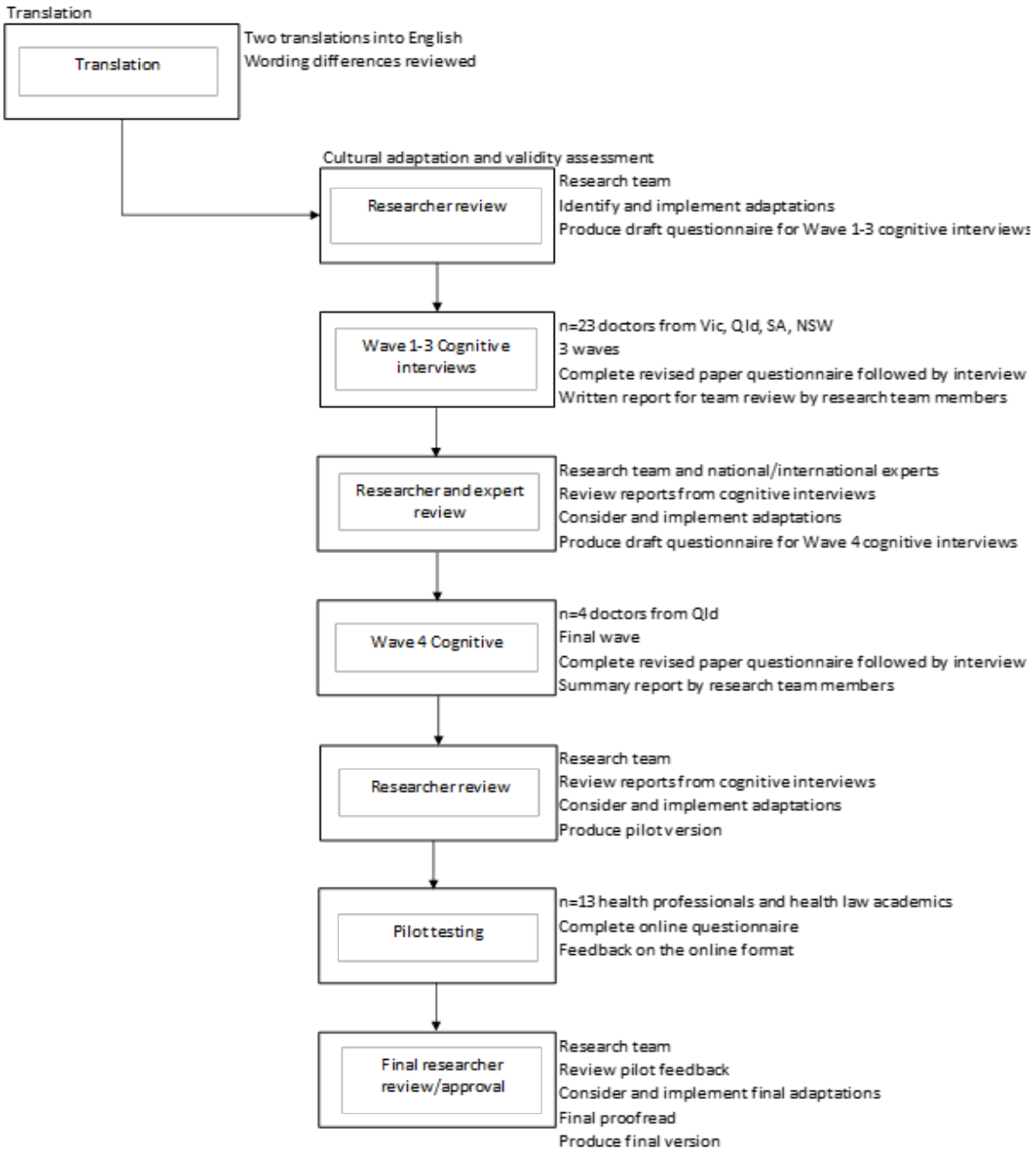
Overview

There were eight phases in the translation and cultural adaptation/validity assessment process depicted in Figure 1 below. Changes were made at the end of each phase. The cultural adaptation and validity assessment process followed translation of the European questionnaire into English. Cultural adaptations were informed by feedback from members of the target community (Australian doctors in specialties involved in end-of-life decisions). They were presented with the translated questionnaire and provided culturally specific feedback regarding the interpretation, relevance, and acceptability of the questions. Members of the target community were involved during the researcher review phase through representation in the research team, during the cognitive interviews through purposive sampling, and during the expert review phase through involving experts in end-of-life research.

The research team made initial adaptations to the questionnaire to enhance its suitability to the Australian context. After this, multiple waves of cognitive interviews were undertaken, with researcher and/or expert review occurring iteratively through this process, and at the conclusion of the interviews. Once the pre-final questionnaire had been settled an identical online questionnaire was developed, and pilot tested. Last, the paper and online questionnaires were finalised by the researchers.

When evaluating potential adaptations in the initial phases, the researchers sought to strike a balance between minimising changes to retain comparability with the European studies, but also ensure the wording was authentic and relevant to the Australian context. To illustrate, section 3 "medical practices" asks the key questions in the questionnaire that determine what medical ELDs were made and identifies the "last mentioned act" which is then the focus of most of the remaining questions. Therefore, adaptations to this section were kept to an absolute minimum and made with caution. Further, a maximum of six pages was set for the questionnaire. This was considered an appropriate length which balanced the need for consistency with the European questionnaire with the need for minimising questionnaire length. As doctors can be difficult to engage as research participants length was a key consideration to optimise participation.

Figure 1 Overview of the translation and cultural adaptation/validity assessment process



Study approval was obtained from the Human Research Ethics Committees of Queensland University of Technology, The University of Queensland and Vrije Universiteit Brussel. All participants gave their informed consent prior to their participation in the study.

Translation

The questionnaire implemented in the European Protocol [4] was translated into English by one of the researcher team members (KC) who is fluent in both Dutch and English, and a second time by an independent, nationally accredited translator. When the translators had chosen different terms, alternative wording was reviewed, and preferred wording agreed on via consensus within the research team. This approach had the advantage of the precision of an official translation but interpreted in light of KC's research expertise to ensure relevance to the end-of-life care setting.

Cultural adaptation and validity assessment

Researcher and expert review

This phase was performed by the research team comprising academics in medicine (1), nursing (1), health law (3) and sociology (1). Team members were subject-matter specialists, one was also part of an equivalent study in Belgium, and another was a member of the target community (an Australian doctor with knowledge of end-of-life care practices). Initially, research team review was undertaken to identify and implement necessary adaptations, and to determine potential issues to be further explored in subsequent cognitive interview and expert review phases. The questionnaire was reviewed independently by each team member. Other versions of the van der Maas questionnaire [10,33,34,37] were also examined to explore variations in wording. The group met several times to evaluate, revise and consolidate the instructions, items and response format of the translated questionnaire.

The initial researcher review process resulted in the development of the initial version to be pre-tested in the first wave of cognitive interviews. Minor changes to the translated questionnaire were made to ensure terminology reflected local usage. Changes were also made so that participants only report on an adult death (this study considered only adults, see

below). Last, the questionnaire was revised to incorporate additional questions about voluntarily stopping eating and drinking [10], and the availability of palliative care services. These questions have been included in recent European studies using the questionnaire and this data is currently lacking in the Australian context.

Researcher and expert reviews occurred again after the first three waves of cognitive interviews, the final Wave 4 cognitive interviews and following pilot testing. Each time, the researchers examined participant feedback on the questionnaire, considered and implemented adaptations and produced a revised questionnaire. After the first three waves of cognitive interviews, two experts in end-of-life research also provided feedback on the questionnaire. Between waves 3 and 4 of the cognitive interviews, changes were also made to adapt the questionnaire to the proposed method of questionnaire implementation (using database sampling based on medical specialties rather than death certificate sampling). The reason for this change in sampling method was that a relevant national agency was unable to provide the support needed to implement death certificate sampling. A research journal was kept with each adaptation being recorded, along with a detailed justification for the decision. Following pilot testing, the last researcher review involved undertaking a final proofread of the pre-final questionnaire and producing a final version.

Cognitive interviews

The researchers completed four waves of cognitive pre-testing with 27 doctors from various specialties, clinical settings and geographical locations. All participants had at least basic working knowledge of end-of-life care practices. Interviews occurred across four Australian jurisdictions (Queensland, New South Wales, Victoria and South Australia) to ensure the questionnaire took account of any jurisdictional differences. The doctors were recruited via

the researchers' professional networks, gained from working in end-of-life research for many years and therefore is a convenience sample. The investigators identified at least one doctor from each jurisdiction from a rural or remote location; at least one general practitioner; and the remaining doctors were from medical specialties known to provide care to end-of-life patients (e.g. palliative care specialists; intensivists; general, respiratory, renal and oncology physicians). We also recruited both males and females of various ages and experience levels.

Doctors were initially contacted via email by the researcher who nominated them. The email briefly outlined the study's aims and background and included a participant information sheet and consent form. Given doctors are extremely busy, and to enhance participation, the project's research associate (DP) telephoned the practice manager/personal assistant to flag that the email was on its way, prior to emailing. DP then sent the email and followed up a few days later with a telephone call asking whether the doctor would like to participate and scheduling an interview if consent was provided.

The first wave of cognitive interviews tested the translated questionnaire with five doctors in Victoria. The subsequent waves involved pretesting the questionnaire, as amended by the results from the previous wave. Four waves of cognitive interviews were needed until saturation was achieved.

Interviews were conducted face-to-face, over the telephone or via Skype depending upon doctors' location and preferences. Interviews took approximately one hour and were conducted in two parts. In Part 1, doctors were asked to think of a typical, hypothetical case gleaned from their experience of end-of-life care and complete the questionnaire accordingly. In Part 2, doctors were asked a series of questions designed to evaluate whether participants

understood the questions as the researchers meant them to, thus ensuring the questionnaire was capturing the intended information. These questions also sought doctors' feedback on their experience of completing the questionnaire. Questions asked varied somewhat across waves due to changes made based on earlier feedback. Questions were designed to elicit feedback on matters such as comprehension of instructions and terminology, redundant or missing questions, length and difficulty of questions, time to complete the survey, its layout and organisation, and queries related to specific questions.

Responses to the questionnaire (Part 1) were recorded by the participant, while answers to the interview questions (Part 2) were noted by the interviewer. Questionnaire responses were not analysed in terms of clinical practice, only in terms of participants' understanding of the questions. Interview notes were reviewed, coded and analysed using thematic content analysis. Content analysis focused on identifying challenges with comprehension (e.g. comprehension of instructions and terminology, length and difficulty of questions, concerns about the wording of specific questions, applicability to the Australian context), and other aspects of questionnaire design (e.g. redundant or missing questions, questionnaire layout, flow and organisation, time to complete the questionnaire). The researchers held round-table discussions to review the key issues and employed a consensus approach to identifying necessary adaptations to the questionnaire. Adaptations were adopted where all members of the research team were in agreement. Feedback was also analysed to ascertain if saturation had been reached. As each wave incorporated changes from the previous wave, saturation was defined as the point at which amendments made as a result of earlier interviews resulted in a questionnaire that did not require further substantive changes as no new issues were reported or suggestions made by participants, i.e. in the final wave.

Pilot testing

The researchers completed pilot testing of the online questionnaire with a convenience sample (n=13) recruited via their professional networks. As the questionnaire had already undergone extensive pre-testing, we did not specifically seek feedback on the questionnaire instrument itself (but were open to suggestions if issues were raised). Rather, we sought feedback on the experience of completing the questionnaire online (on a computer, tablet or smartphone), including accessing the questionnaire (using a link provided via email), questionnaire appearance and layout, number of questions per screen, amount of space provided for responses, navigating around the questionnaire, use of skip logic, submitting the questionnaire, and other relevant feedback.

Potential participants were invited to take part in the pilot via email. The email described the study and outlined what was requested if they agreed to participate. It also included a link to the online questionnaire and gave detail as to the areas in which we were seeking feedback.

The pilot testing process took approximately 30 minutes. It involved the participant completing the online questionnaire and then providing feedback on their experience. Pilot feedback was provided via email or telephone based on the participants' preference.

Pilot feedback was carefully considered, and potential adaptations were discussed among the researchers. Decisions whether to adopt an adaptation were based on consensus. Generally, changes were made when multiple participants suggested the same adaptation and/or if there was a clear case for making the adaptation.

Results

Participant characteristics

A total of 27 cognitive interviews were carried out with general practitioners (in training) and specialists (in training) from 11 specialty areas: anaesthesiology, dermatology, emergency medicine, geriatric medicine, haematology, intensive care, oncology, palliative care, psychiatry, renal medicine and respiratory medicine. Participants were 16 men and 11 women from Queensland (14), Victoria (5), South Australia (5) and New South Wales (3). Most (22) were from an urban location. Further demographic details of the participants are given in Table 1.

[Insert Table 1 here]

Questionnaire structure

The questionnaire had five semi-structured sections, plus a box at the end for free text so that doctors could clarify or expand on their responses.

Section 1 – Background information

In the first section, doctors provided their medical specialty, training in palliative care, and basic demographic information. Doctors also indicated whether they had been the treating or attending doctor in the case of the death of an adult in the previous 12-month period. For the purposes of this questionnaire, being the treating or attending doctor refers to a doctor being actively engaged in making ELDs with or for a patient. This does not mean that the doctor necessarily physically attended the death. Doctors who answered 'no' here were directed to go straight to the final free text question and leave blank all other questions (it was also emphasised that it was very important that the doctor still return their questionnaire).

Section 2 – Patient characteristics and care

Doctors were asked to consider the most recent death of an adult in the last 12 months for which they were acting as the treating or attending doctor. They provided information about the characteristics of the patient's illness and end-of-life care and treatment (including the provision of palliative care), whether the death was sudden and unexpected, and where the patient died.

Section 3 – Medical practices

The third section asked key questions about medical ELDs. The nature of medical ELDs were determined by establishing: (1) what act (or omission) the doctor or another doctor initiated; (2) whether or not the doctor's intention was to shorten the patient's life; and (3) if the patient explicitly requested the doctor to perform the act (or omission). The ELD that the survey identified was the 'last mentioned act', this ELD being the subject of most of the remaining survey questions, was then identified based on responses to the preceding questions. The survey logic was that if more than one medical ELD was made, the decision with the clearest intention to hasten death was given priority. If there was more than one medical ELD with a similar intention to hasten death, the administration of drugs was prioritised over withholding or withdrawing treatment.

Section 4 – The 'last mentioned act'

In the fourth section, the doctors were asked a series of questions about the identified last mentioned act, including: who was involved in that medical ELD (e.g., patient, family, and/or other health care professionals), what considerations guided the decision-making (e.g., the patient's degree of decision-making capacity) and whether the decision was discussed with the patient and/or substitute decision-maker. Doctors were also asked to name

what they would call this act and estimate the degree to which the patient's life was shortened (not at all; less than 24 hours; up to 1 week; 1-4 weeks; 1-6 months; more than 6 months).

Section 5 – Care and treatment

This section contained questions about deep sedation right up until death, and voluntary stopping of eating and drinking. It asked about the types of drugs used for the sedation (where this occurred), the length of the sedation, and the provision of artificial nutrition and hydration. The questionnaire asked about the presence of a request for sedation by the patient or the family, possible alternatives and whether a life-shortening intention was present.

Section 6 – Further comments

The questionnaire concluded with an invitation for the doctor to provide further information: "*If any of your answers require further clarification, or you want to make any other comments, please do so here*."

Cognitive interviews

Key findings from the cognitive interviews are presented under five headings which outline the main types of adaptations to the questionnaire to: (1) contextualise the questionnaire for the Australian context, (2) adapt it to the proposed method of questionnaire implementation (utilising database sampling based on medical specialties rather than death certificate sampling and focusing on adult deaths), (3) adapt it to ascertain more clearly the role of law in medical ELDs, (4) adapt it to improve comprehension, and (5) adapt questionnaire flow and routing (Table 2). This table sets out the main adaptations made to the questionnaire (italicised), including examples for each category. Question numbers are cited for each adaptation except where the relevant change was made multiple times or throughout the

questionnaire. It should be noted that the examples are not exhaustive, and do not include, for example, every minor wording change. In addition to the above main types of adaptations, we also changed design features of the questionnaire to encourage questionnaire completion. The paper questionnaire was professionally designed to improve format and aesthetics while the online questionnaire was developed by an independent fieldwork and data analysis agency. We ensured that the paper and online questionnaires appeared like each other and our promotional materials.

[Insert Table 2 here]

Acceptance and applicability

Overall, the participants provided positive feedback regarding the relevance and quality of the questionnaire. All participants felt that the questions were clinically relevant to the Australian setting. Many commented that it was easy to complete and clearly worded, except for a few specific questions where suggestions for improvement were made. The revised flow of the final questionnaire (in which demographic questions were asked first) was also endorsed.

Several participants commented on the sensitivity of the subject matter, particularly where questions related to decisions with the intention to hasten death. They perceived that the focus of some items on hastening death meant that the questionnaire was mostly (only) interested in unlawful practices such as euthanasia. A few doctors commented that in Australia, compared with some European countries, these issues are highly sensitive and controversial. These concerns may be addressed by questionnaire implementation adopting a

rigorous anonymity procedure, and effectively communicating that the questionnaire concerns the full range of medical ELDs, the vast majority of which involve lawful practices.

The questionnaire took an average of 9.2 minutes to complete (range 4-27.5 minutes), which was acceptable to participants. Whilst most participants expressed a preference for an online questionnaire, some preferred paper, and others didn't mind. We therefore concluded that it would be best to implement both paper and online versions of the questionnaire.

Pilot testing

Pilot testing was undertaken with five members of the research team and eight colleagues (three doctors, two nurses and three health law academics/researchers). All participants were working in end-of-life care clinical practice and/or research. Most comments obtained during the pilot testing process were positive about the areas in which feedback was sought. There was consensus that the experience of completing the questionnaire online was seamless, and that the appearance and layout of the questionnaire was at least adequate when viewed on computer, tablet or smartphone. No issues were identified with accessing or submitting the questionnaire, navigation or use of skip logic.

A few minor changes were made to the online questionnaire as a result of the pilot, namely changes to wording of an instruction to better suit the online format (referring to a section rather than question number), moving an instruction to increase its prominence, and changing spacing between question parts to ensure consistency. These changes were irrelevant to the hard copy format and so were not applied to the paper questionnaire.

Discussion

Appropriate questionnaires assessing current practice relating to medical ELDs and end-of-life care are required to establish an evidence base about how these decisions are made. This evidence can drive improvements in clinical practice and inform regulatory design, including law and policy. There is no up-to-date, Australian questionnaire designed to collect information describing medical ELDs. This contrasts with Europe where a validated questionnaire has been developed and implemented in several previous studies. Hence, in this study, we translated, culturally adapted and assessed the validity of an Australian version of a European questionnaire on medical ELDs.

The purpose of questionnaire adaptation is to ensure that it better fit the needs of a new language, location and population [40]. Each adaptation was recorded, along with a detailed justification for the decision, so that the process and types of adaptations could be reported. Validity is at least partially a property of the particular sample, context and purpose rather than being entirely a property of the questionnaire itself [41]. Hence, examination of the appropriateness of use of this questionnaire with an Australian sample of doctors (not previously undertaken) was required to ensure that consequent modifications to the questionnaire were appropriate and future research makes valid claims.

Cognitive interviewing demonstrated that using the original European survey would have adversely affected the comprehension and relevance/acceptability of the questionnaire with Australian doctors. Hence, the wording changes made were necessary to obtain accurate and credible results. The adapted questionnaire incorporated changes to contextualise it for the Australian context, improve comprehension, and improve flow, routing and design. Additionally, there is insufficient evidence about the extent to which doctors comply with the

law when making medical ELDs. Hence, we made wording changes to better understand the role of law in medical ELDs and facilitate conclusions about legal compliance of decision-making. We believe these adaptations will reveal further insights into current medical practice e.g., the extent to which treatment is provided with appropriate consent or authorisation. As it was intended to implement the questionnaire in a subsequent study, adaptations were also made to reflect the proposed methodology of that study, that is, a focus on adult deaths and database sampling based on medical specialties.

The cultural adaptation processes employed (researcher and expert review, cognitive interviewing and pilot testing) were useful in refining the adapted questionnaire, and the results of the study support the use of the adapted questionnaire as a tool for measuring practices of medical ELDs and end-of-life care in Australia. Cognitive interviewing demonstrated that with some relatively minor wording changes and adaptations to contextualise the questionnaire for the Australian setting, it demonstrated good acceptance and applicability with doctors. The face and content validity of the adapted questionnaire was also demonstrated in our sample.

The aim was to produce a questionnaire that can be implemented to provide evidence on Australian medical practice relating to ELDs and end-of-life care and enable comparison with international studies. To preserve comparability as much as possible, adaptations were kept to a minimum, particularly for the questions that determined what medical ELDs were made and identified the 'last mentioned act'. While we limited adaptations to what was required to ensure relevance and acceptability of the adapted questionnaire, it is acknowledged that some of these adaptations have implications for the comparability of the future results with the

international studies. Ultimately, the goal of producing a questionnaire that best fit the Australian context was given paramount importance.

The original questionnaire was extensively validated in the Netherlands [8,27] and in the 2001 study in six European countries [10]. However, to our knowledge, no previous studies have comprehensively documented this process, and few have involved such an intensive cognitive interviewing process. A strength of this study was that KC was involved in conducting many of the cognitive interviews, having also undertaken extensive research on medical ELDs using Belgian versions of the questionnaire. A limitation of our sample is that it was a small convenience sample and hence not representative of all doctors who make medical ELDs, and not all Australian jurisdictions were represented. However, our sample was sufficiently large and diverse with respect to demographic characteristics, professional background and geographical locations to capture a range of views and identify inter-state differences and saturation in terms of face and content validity and acceptability was achieved.

The adapted questionnaire is now available for use in Australian research and is currently being used to collect data from Victorian doctors in specialties likely to be involved medical ELDs and end-of-life care involving adult patients about their decision-making practices. Please contact the authors should you wish to receive a copy of the questionnaire. Future research will provide opportunities for psychometric assessment of the questionnaire and comparison of participation rates, completion times and response patterns between the online and hard copy questionnaires.

Conclusions

This study involved development and validity assessment of an English translation of a European questionnaire on practices of medical ELDs to use in Australia drawing on researcher/expert review, cognitive interviewing and pilot testing. The adapted questionnaire was tested for face and content validity and participants' understanding using cognitive interviews with doctors from various specialties, clinical settings and geographical locations. Study findings suggest that while the adapted questionnaire deals with sensitive subject matter, it was generally well accepted and is relevant and applicable to the Australian healthcare context. It is hoped that consistency with earlier versions of the questionnaire, particularly for the critical questions about the 'last mentioned act', will make it useful for obtaining findings that are comparable across countries.

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Table 1 Demographic characteristics of the participants in the cognitive interviews (n = 27)

Variable	**n**	**%**
Gender		
Male	16	59.3
Female	11	40.7
State		
Queensland	14	51.9
South Australia	5	18.5
Victoria	5	18.5
New South Wales	3	11.1
Urban-rural location		
Urban location	22	81.5
Rural or remote location	5	18.5
Specialty		
General practitioner/general practitioner in training	10	37.0
Specialist/specialist in training	17	63.0
- Palliative care	3	11.1
- Anaesthesiology	2	7.4
- Emergency medicine	2	7.4
- Haematology	2	7.4
- Oncology	2	7.4
- Dermatology	1	3.7

Variable	n	%
- Geriatric medicine	1	3.7
- Intensive care	1	3.7
- Oncology	1	3.7
- Psychiatry	1	3.7
- Renal medicine	1	3.7

Table 2 Types of questionnaire adaptations and examples

Type of adaptation	**Original questionnaire**	**Adapted questionnaire**	**Explanation**
(1) Contextualise for Australian context (a) reflect Australian terminology and language use	Q24 Why was no palliative care initiated?' Response option: A palliative care service had not been engaged because 'palliative care was not or insufficiently meaningful'.	Q16 (section 2) Why was no palliative care initiated?' Response option: A palliative care service had not been engaged because 'palliative care would not have *sufficiently benefited* this patient'.	The word 'benefited' was assessed as better reflecting the intent of the question than the translated word 'meaningful'.
(b) reflect Australian clinical practice, or approach to palliative care and the broader health system	Q4 Did you … take one or more of the following acts … taking into account the probability or certainty that this act would hasten the end of the patient's life?	Q18 (section 3) Did you … carry out one or more of the following actions … that probably or certainly hastened the end of the patient's life or *resulted in the patient's life not being prolonged*?	Many participants responded that actions carried out regularly at the end of life such as withholding or withdrawing treatment are better characterised as actions 'that do not prolong the patient's life' rather than

Type of adaptation	Original questionnaire	Adapted questionnaire	Explanation
			'hastening the end of the patient's life'.
(c) account for differences in legal terminology	Q17 In your view, which term fits best with the last mentioned act? Response options: Non-treatment decision; symptom alleviation; palliative or terminal sedation; compassionate life ending; euthanasia; assisted suicide; other.	Q31 (section 4) In your opinion, which is the most appropriate term for the last mentioned act? Response options: Non-treatment decision; symptom management; palliative or terminal sedation; ending life out of compassion; *assisted dying*; euthanasia; assisted suicide; other.	The questionnaire was adapted for use in Victoria where the *Voluntary Assisted Dying Act 2017* had been passed foreshadowing a legal practice of 'assisted dying', although the time period being surveyed was prior to this law starting operation.
(2) Adapt to the proposed method of questionnaire implementation			

Type of adaptation	Original questionnaire	Adapted questionnaire	Explanation
(a) reflect database sampling based on medical specialties	Questions refer to a specific death that has been identified from a death certificate (see below). Accordingly, information about the deceased is known and not sought from the responding doctor.	Asks sampled doctors to consider their most recent adult death in the last 12 months. Q9-11 (section 2) are background questions about the deceased (gender, age, main cause of death).	The original questionnaire was implemented using death certificate sampling. The questionnaire included an accompanying letter which provided the doctor with enough patient information (from the death certificate) to identify the patient i.e. sex, date of birth, date of death and place of death. The adapted questionnaire includes an instruction on how to select a case about which remaining questions are answered and asks doctors to provide basic information about the deceased as this is now needed.

Type of adaptation	Original questionnaire	Adapted questionnaire	Explanation
(b) reflect a focus on adult deaths	Assigned death case includes patients aged one year or more at the time of death. Q12 on why the (possible) hastening of the end of life as a result of the last-mentioned act was not discussed with the patient included the response option 'the patient was too young'.	For Qs 7, 8 (section 1), questions and response options are worded to limit death cases to adult deaths. Q24 on why the probable or certain hastening of the end of life as a result of the last-mentioned act was not discussed with the patient excluded the response option 'the patient was too young'.	This questionnaire only collects data about adults, specifically the participant's most recent adult death.
(3) Adapt to ascertain more clearly the role of law in medical ELDs (a) facilitate conclusions about the legality of decision-making	Refers throughout to 'explicit intent'.	Refers throughout to 'primary intention'.	The terms 'explicit intent' and 'primary intention' were both correctly understood by participants

Type of adaptation	Original questionnaire	Adapted questionnaire	Explanation
			as meaning intended. However, the latter term also had the advantage of being consistent with other parts of the questionnaire (e.g. partly intended). It also facilitates conclusions about the legality of decision-making as the most critical element of the common law doctrine of double effect is primary intention.
(b) clarify the process for legal analysis	Q13 Was the decision concerning the last mentioned act made upon an explicit request of the patient? Response options: Yes, upon oral request/yes, upon written	Refers to 'express or implied consent'. Q27 (section 4) Was the decision about the last mentioned act made *with the consent (express or implied)* or at the request of the patient *or substitute decision-maker*? Response options: *Yes,*	The existing questionnaire did not account for other legally recognised decision-makers making the relevant decision. Further, participants raised the issue that consent could be either

Type of adaptation	Original questionnaire	Adapted questionnaire	Explanation
	request/yes, upon oral and written request/no	*with the express or implied consent of the patient/yes, at the request of the patient/yes, with the express or implied consent of the substitute decision-maker/yes, at the request of the substitute decision-maker/*no	express or implied, so this wording confirms both are intended.
(c) refer more overtly to substitute decision-makers	Q20 refers to 'relatives', 'family'.	Q32 (section 5) refers to 'substitute decision-makers'.	The original questionnaire did not account for other legally recognised decision-makers deciding about deep sedation right up until death.
(4) Adapt to improve comprehension Changes were made to the original questionnaire to ensure	Q12 refers to 'capable'.	Q26 (section 4) refers to 'legal capacity'.	The term 'legal capacity' more precisely reflects the concept being questioned (e.g. capable could also mean physically capable).

Type of adaptation	Original questionnaire	Adapted questionnaire	Explanation
clearer, simpler language, and consistency of wording throughout the questionnaire.			
(5) Adapt flow and routing	Questions on medical practices (including decisions with the intention to hasten death) were close to the start of the questionnaire.	Questions on medical practices were moved to a later section of the questionnaire. Has a longer general/background section, which included additional questions about the doctor (e.g. gender, age, specialty), and questions about palliative care training.	Questions were re-ordered so that "softer" questions were at the start of the questionnaire (also consistent with other questionnaire versions [33]).