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Clinicians' and public acceptability of universal risk-of-death screening for older people in routine clinical practice in Australia: Cross-sectional surveys

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Abstract

Background

Clinicians' delays to identify risk of death and communicate it to patients nearing the end of life contribute to health-related harm in health services worldwide. This study sought to ascertain doctors, nurses and senior members of the public's perceptions of the routine use of a screening tool to predict risk of death for older people.

Methods

Cross-sectional online, face-to-face and postal survey of 360 clinicians and 497 members of the public.

Results

Most (65.9%) of the members of the public welcomed (and 12.3% were indifferent to) the use of a screening tool as a decision guide to minimise overtreatment and errors from clinician assumptions. Supporters of the use of a prognostic tool were likely to be males with high social capital, chronically ill, and who did not have an advance health directive. The majority of clinicians (75.6%) reported they were likely or very likely to use the tool, or might consider using it if convinced of its accuracy. A minority (13.3%) stated they preferred to rely on their clinical judgement and would be unlikely to use it. Differentials in support for tools by seniority were observed, with more support expressed by nurses, interns and registrars than medical specialists ($\chi^2=12.95$, $p=0.044$), and by younger (<40 years) clinicians (81.2% vs. 71.2%, $p=0.0058$).

Discussion

The concept of integrating prognostication of death in routine practice was not resisted by either target group.

Conclusion

Findings indicate that screening for risk of death is seen as potentially useful and suggests the readiness for a culture change. Future research on implementation strategies could be a step in the right direction.

Keywords: frail older people; prognostic uncertainty; death prediction; screening; surveys

Introduction

The harm associated with unnecessary medical interventions near the end of life affects many countries and costs millions of dollars and co-exists with underuse of palliative care 1. More importantly, unnecessary interventions can lead to greater emotional and physical suffering for both the patient and their caregivers and can negatively affect quality of life 2,3. Over the past decade, the international Choosing Wisely campaign has encouraged the public to challenge their clinicians with questions about harms and benefits of treatments and implications of doing nothing, and researchers have attempted to monitor the routine monitoring of low-value care 4.

In an attempt to prevent or reduce end-of-life over-treatment, several predictive algorithms have been developed for use by doctors and nurses^{5,6} in hospital emergency departments 7, intensive care units 8, operating theatres 9, oncology rooms 10, palliative care settings 5, residential aged care 11, and general practice 12. They flag patients with high risk of death over the ensuing months. Tools have also been developed to prevent inappropriate prescribing or guide deprescribing of older people 13. Awareness of imminent death and discussions on benefits of reducing unnecessary medical interventions can lead to satisfaction with decision-making in end of life care 14. Yet, these predictive tools are not generally embedded in daily clinical practice to routinely link to prognosis discussions with patients and their families. There is failure to raise prognosis, life expectancy, survival rates and psychosocial concerns even during palliative care consultations 15. A combination of health system, patient and healthcare provider factors are implicated in this disconnect 3 .

The primary objective of this paper was to explore perceptions of the general public in Australia regarding the use of screening to predict risk of death by their clinicians. As a secondary objective, we aimed to ascertain the views of doctors' and nurses' in Australia on the routine use of screening to predict risk of death of their patients.

Methods

Design

The question of acceptability of prognostic tools was included as part of two larger surveys of clinicians and the Australian public examining attitudes, preferences and barriers to end of life discussions.

Survey instruments

Survey questions were adopted and modified from both national and international surveys and included specific questions that were developed by the study team to address the specific objectives and pilot-tested by older members of the public and clinicians. Survey questions were forced choice with additional open-ended questions allowing participants to enter further comments. The general focus of the two surveys was perspectives on end-of-life discussions and further details of the surveys are described elsewhere 16. We report here the question of acceptability of the prognostic tool separately from the rest of questions in the survey, as the topic of introducing a universal screening tool to prognosticate dying warrants its own space for debate. Socio-demographic and other personal perspective variables analysed in this article are listed in Supplement 1.

The question wording for the public survey was:

How do you feel about hospital doctors using a checklist to determine a patient's risk of death based on their clinical history? (response options below)

- Relieved, great idea
- Fine, no problem
- Indifferent
- Uneasy
- Somewhat concerned
- Very worried

Participants had the opportunity to enter additional information through an optional open-ended free text question on *why they felt that way about a checklist?* which followed immediately after.

The question wording for clinician survey was: *If there was a checklist to help you determine risk of death within months of assessment, would you be likely to use it to initiate end-of-life conversations with your patients before they get to the last few weeks/days of life?* (response options below)

- Unlikely. I would rather rely solely on my clinical judgment
- It might consider using it if I'm convinced of its accuracy
- Unsure. I don't tend to use checklists in my clinical practice
- Likely. A tool could reassure me in my prognosis
- Very likely. I'd welcome objective scores to add certainty to my clinical judgment

A free text box was also offered for clinicians to optionally enter supplementary qualitative information.

Recruitment and procedure

An online survey of the general public was conducted. The survey was targeted at people aged 60 years and above (seniors) but younger responses from adults under 60 years were accepted if they showed interest in answering the survey. The seniors' survey was advertised in metropolitan and regional newspapers, public venues, pharmacies, residential aged care facilities and on a seniors Facebook page. The survey was completed by participants online, with paper-based surveys or interviewer-administered surveys for members of the public provided upon request. An online survey of doctors or nurses of any age working in either intensive care, emergency, palliative or aged care, and clinicians without specialty training who dealt with end-of-life issues was also conducted. The clinicians' online survey was advertised at aged care, intensive care and palliative care conferences, professional magazines for nurses and general practitioners, and via email to professional networks. Exclusion criteria included people <18 years, who could not read English language and health professionals who were not directly involved in end-of-life issues.

Both surveys were conducted simultaneously across Australia and ran for three months between beginning of May and end of August 2015. This paper reports on those respondents to both surveys who completed the question on prognostic tools.

Statistical analytic strategy

Comparative descriptive statistics used chi square techniques for proportions in the bivariate analysis, with a focus for the public survey on comparisons between Australian public respondents aged 60+ years and the younger participants. For clinician respondents age group sub-analysis compared younger respondents vs. older than 40 years and by professional seniority (trainee, vs. graduate and specialists). Logistic regression with odds ratio (OR) estimates and 95% confidence intervals was used to examine the determinants of acceptability of an instrument predictive of death in the short term. The models controlled for demographic factors and comorbidities; and for seniors, in addition, the following five questions: having a recent death in the family; views on extending life at the expense of painful procedures; views on aggressive care; preferred place of death; and wanting involvement in decision-making. All quantitative data was analysed using SAS version 9.4 (Cary, NC, USA) via Enterprise Guide version 7.1.

Qualitative analytic strategy

Thematic content analysis was used with the free-text qualitative data that participants entered in their online or written survey forms. Thematic analysis enabled a theoretically-flexible approach for identifying, analysing and reporting patterns in qualitative data which was considered useful for obtaining detailed insights into complex issues such as end of life care preferences and practices. 17 Qualitative responses were read by one researcher (RH) who, once familiar with the breadth and depth of content, undertook a focused line by line analysis of each of the surveys. Themes were generated from the initial coding and then grouped under broader categories through discussion with two research team members (MC; EL). The categories were then labelled with reference to the raw data. Interpretations of the data were resolved through discussion at each stage in this process. A subset of 25 of the qualitative responses (5%) was reviewed by researcher (MC) to validate the themes generated.

Results

A total of 497 members of the Australian public (65.7% female) aged ≥ 60 years (75.4%) responded to the survey of which 469 (94.4%) added free text comments to the prognostic tools question. A total of 360 doctors and nurses (75.5% female) aged ≥ 40 years (57.0%) responded to the survey.

Members of the public views on the use of a predictive tool

Almost two thirds (65.6%) of respondent members of the public agreed that hospital doctors using a checklist to estimate a patient's risk of death based on their clinical history was relieved/great idea or fine, no problem; 12.3% were indifferent, 19.1% were uneasy or somewhat concerned and 2.6% were very worried.

From the bivariate analysis, public supporters of the use of a prognostic checklist were likely males with high social capital, suffering from chronic illness stating a preference for institutional death rather than a home death and not having an advance care directive but having held an end-of-life conversation with families. After controlling for age, sex, chronic disease, history of health professional background and five survey questions explained in the methods, the statistically significant determinants of support for the use of prognostic tools in hospitals were being a male, having chronic disease, being in the high social capital bracket, and preferring death in an institution. Respondents older than 70 years were significantly less likely to support use of prognostic tools in routine care (Table 1). This combination of variables explained 62.7% of the variance.

<Table 1 here. Public determinants of support to use a prognostic tool in hospitals (multivariate analysis) N=497>

Qualitative responses from members of the public

Five themes emerged from the qualitative answers that described why respondents were welcoming of the use of the prognostic tool: *expert knowledge, being informed on prognosis, avoiding overtreatment, minimising error* and *a useful guide for health professionals*. Those in favour of the use of a screening tool often presented views about trust in the health system and the expert or superior knowledge of healthcare providers should they adopt the use of prognostic checklists. (Table 2). Many respondents identified the value of a screening tool for being informed about their own condition and prognosis, allowing them to plan for the future, and also as a way of avoiding overtreatment and therefore unnecessary suffering and medical interventions at the end of life. The use of a screening tool for end of life care was considered in a similar way to checklists used to heighten patient safety in other healthcare contexts. Respondents supported the screening tool as a way of minimising error by providing a standardised and structured approach to assessing patients. Others supported its use simply as a guide for health professionals that would contribute to understanding and decision-making about end of life care.

Concerns were also raised about the use of a prognostic screening tool. A further four themes were revealed in relation to this: *reductionism, errors from assumptions, determinism versus uncertainty* and *implications for future care* (lower panel, Table 2). Some respondents' viewed a screening tool as reducing a patient to a set of clinical characteristics that would not take into account the individual and their unique context that may be subject to change when determining end of life care. Some respondents were concerned about the potential for errors from assumptions made based on clinical history, sometimes this was described in terms of their own experiences. Respondents often commented on the uncertainty of when death will occur and therefore considered using a checklist as deterministic and unnatural. A final concern voiced by respondents was about the practical implications and potential for the screening tool to reduce treatment options at the end of life.

<Table 2 here. Thematic content analysis of public reactions to the use of a checklist to predict death?

Clinicians' views on the use of a predictive tool

From the clinician perspective, when asked if a checklist were available to help determine the risk of death in patients based on objective criteria, 42.5% of clinical staff reported they were likely or very likely to use it, and another third 33.1% might consider using it if convinced of its accuracy. A minority stated they preferred to rely on their clinical judgement and would be unlikely to use it (or were unsure (11.1%). Support for prognostic tools was higher among nurses, interns and registrars than among medical specialists ($\chi^2=12.95$, $p=0.044$). Likewise, younger clinicians supported the concept more than older staff (81.2% vs. 71.2%, $p=0.0058$). Figure 1 shows the overall support for

prognostic tools (likely or very likely to use) across occupational groups except for specialists, with other nurses indicating more uncertainty about the use of prognostic tools. After adjusting for age and seniority, staff who found end-of-life discussions rewarding were more likely to support routine use of objective prognostic tools (OR1.64, 95%CI 1.05-2.55, p=0.03).

<Figure 1 here. Acceptability of the checklist to predict risk of death by occupational groups >

Demographic differences in support for checklists

Both clinicians and members of the public largely expressed positive views about the use of a checklist. Clinicians appeared to be familiar with the use of such tools and recognised the need for tools to be used in addition to clinical judgment. A small number of healthcare professionals suggested that checklists may miss important details and may lead to poorer care for those identified as dying. Lay respondents under the age of 60 were supportive of the use of predictive tools and more likely find them helpful for decision-making. Those over 75's were also generally positive about the use of a checklist and more often discussed their trust of the medical profession as experts in their care; however, a small proportion described a preference for their family doctor rather than a hospital doctor to be involved in decisions about end of life care. Males often described the broader implications of using a checklist, while females generally provided more detailed responses, but the key themes did not differ between these groups.

Discussion

We consulted 360 clinicians and 497 members of the public on their views of the use of checklist to determine risk of death in routine care to help us identify the readiness for a culture change. We found that both the Australian public (78.2% of respondents) and health professionals (75.6% of respondents) were supportive of the concept of introducing objective aids to help with prognosis. While some clinicians had some reservations about using them unless proven accurate, most participating members of the public were unreservedly ready for it. These findings highlight a possible culture change where the public are more ready for prognostic disclosure than previously thought.

Our findings among the general public are consistent with another cross-sectional hospital survey reporting that generally inpatients with incurable illness support the idea of being told their prognosis¹⁸. It is unfortunate that while recommendations for timing and manner of initiation of end-of-life discussions have been disseminated¹⁹, discussions on the specifics of poor prognosis²⁰ and frameworks or tools to improve prognostic certainty are not as widely used^{21,22}. Lack of

exposure to and inadequate training on prognostic tools during formative years, followed by difficult in accessing them and time demands in applying them are the major limitations cited 22,23.

Another online survey reported that 92% of hospital physicians believed the use of predictive tools would benefit their patients, and 73% considered prognostic tools helpful if prognostic scores were automatically calculated and integrated in the medical records 22. Prognostication based on objective clinical indicators was perceived as useful to trigger end-of-life conversations on preferences for non-cancer conditions in a qualitative study 24. Likewise, a qualitative study found that physicians perceived clinical prediction models useful in enhancing prognostic certainty at end-of-life care but they also expressed concerns in regards to potential overconfidence to the detriment of consumers' interests as persuasion rather than discussion may disempower patients 25.

Clinicians have an ethical obligation to prepare patients for critical health trajectories and eventual death 26. Tools that predict death for cohorts of patients with certain risk characteristics can be used as a trigger for earlier advance care planning with individuals matching that risk profile. Clinician familiarisation with those tools is recommended, followed by a gradual, consultative approach over time. This is important for frail older people and caregivers as they have varying and diverse information needs and may have greater levels of detail desired 27, especially as their preference may change as the disease progresses. It is acknowledged that respect of patient rights not to know prognosis where some may find explicit prognostication challenging or unwarranted 26,28. Openly disclosing prognosis to patients with advanced cancer has shown to be helpful, rather than distressing or associated with loss of hope 29. Screening for risk of death may be confronting, time-consuming, or impractical; however, it appears to be not only helpful in the face of uncertainty but also assists in the decision-making process 10 by discussing interventions to be avoided and enhancing satisfaction with care 14.

As no individual risk factor accurately predicts risk in older people 30, and there is still variability in the degree of multifactorial risk estimation 6, and outcome prediction 5, future research could focus on enhancing the predictive accuracy of prognostic tools to support clinical judgment 31. In addition, future research could incorporate questions on clinician and patient acceptability of the inherent uncertainty in predictive tools. Further evaluation of the effectiveness of curricular changes that include systematic use of prognostic tools in improving risk communication and informing medical decisions is warranted. It remains to be seen if the appetite for end-of-life discussions with patients varies by medical specialty or by ethos across countries. A systematic review may shed light on these aspects.

Among the strengths of this study, the two target groups were surveyed in parallel in the same country and the surveys were widely advertised in professional and public venues; participation by several hundred members of the public corroborated the feasibility of investigating this sensitive issue. Limitations included the mostly online nature of the questionnaire which may have precluded participation and representation of older people without access to internet; we attempted to address this by offering face to face surveys in hospitals, pharmacies, primary care venues and aged care facilities. While the sample represented a wide range of clinicians and members of the public, participants who responded to the invitation may have been keener to discuss the sensitive topic, or held stronger views than other members of either target group. We acknowledge that generalisability of these results is limited as the sample was not randomised, neither ethnicity nor religious affiliation of respondents were documented, and the characteristics of non-participants are not known.

Conclusion

High level of public support for the concept use of objective prognostic tools to predict risk of death among clinicians and members of the public suggests that it is time for clinicians to embrace its use in routine practice to enhance their own prognostic certainty, improve patient engagement in their future terminal care, and meet their ethical obligations with patients in the last months of life.

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Authors' contributions

Conception and design: MC, EL, MN, KH. Data collection, analysis and/or interpretation of data: MC, EL, SS, ST, MN, RH. Drafting of the article and/or critical revision for important intellectual content: EL, MC, SR, CS, KH. All other authors made a substantial contribution to subsequent versions.

Approval of the version to be published: all authors.

Conflict of interest

None to declare.

Compliance with ethical standards

Conflict of Interest

None

Informed consent

All participants completed a single consent question online after reading the purpose of the survey and before proceeding with the questionnaire.

Ethical approval

Ethical approval for the clinicians' survey was granted by the University of New South Wales Research Ethics Advisory Panel (project #HC15177). The survey of the general public was endorsed by the Human Research Ethics Advisory (HREA) Panel G: Medical and Community, of The University of New South Wales; (project HC #15081).

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