

# Death of outrage over talking about dying

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## ABSTRACT

**Objectives** We examined public reaction to the proposed Center for Medicare and Medicaid Services rule reimbursing physicians for advanced care planning (ACP) discussions with patients.

**Methods** Public comments made on regulations.gov were reviewed for relevance to ACP policy and their perceived position on ACP (ie, positive, negative and neutral). Descriptive statistics were used to quantify the results.

**Results** A total of 2225 comments were submitted to regulations.gov. On review, 69.0% were categorised as irrelevant; among relevant comments (n=689), 81.1% were positive, 18.6% were negative and 0.002% were neutral.

Individuals submitted a greater percentage of the total comments as compared to organisations (63.5% and 36.5%, respectively).

**Conclusions** The US Medicare programme is a tax financed social insurance programme that covers all patients 65 years of age and older, including 8 in 10 decedents annually, and it is the part of the US healthcare system most similar to the rest of world. There has been a trend globally towards recognising the importance of aligning patient preferences with care options, including palliative care to deal with advanced life limiting illness. However, ACP is not widely used in the USA, potentially reducing the use of palliative care. Reimbursing ACP discussions between physicians, patients and their family has the potential to have a large impact on the quality of life of persons near death, which can greatly impact public health and the comfort in dealing with our ultimate demise.

## INTRODUCTION

There has been a growing global interest in aligning patient preferences with care received at the end of life, including palliative care. Operationalising this in the USA has proven to be challenging for multiple reasons, least of which includes political opposition. To be sure, in the USA, end of life care is mainly funded by the Medicare programme, which is a

tax-financed social insurance programme that covers all individuals over the age of 65 years (ie, there are more Medicare beneficiaries than individuals living in Canada). It is the part of the US healthcare system that is most similar to the healthcare systems of other high-income nations.

In July 2015, the Center for Medicare and Medicaid Services (CMS), which administers the Medicare programme, announced via the normal rulemaking process its intent to add payment for advanced care planning (ACP) to the Medicare programme.<sup>1</sup> A similar provision was removed from the draft version of the Affordable Care Act (ACA) which was passed in March, 2010, after it was labelled 'death panels'.<sup>2 3</sup> Similarly, when the Medicare programme sought to add the provision in late 2011 via an administrative process, it was again withdrawn because critics felt as though this change was not being carried out via a normal rulemaking process.

This paper analyses the public comments submitted during the 2015 rulemaking process to assess how controversial this provision was, based on the nature of the comments submitted. After the subsequent review, including public comments, Medicare announced in November, 2015, that physicians may bill Medicare US\$89 for a 30 min discussion, and US\$75 more for an additional 30 min beginning on 1 January 2016.<sup>4</sup> It is unclear how widely this benefit will be used and what effect it will have on patient outcomes and Medicare costs. Future analysis will focus in part on the usage of the reimbursement code that will provide an accounting of how widely this benefit will be used and it will allow for tracking of its downstream impact on cost.

This paper analyses the number and content of the public comments filled in

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response to the proposed rule and addresses the following two basic questions:

1. How many persons and groups commented on the new policy in 2015?
2. What was the content of the comments that were made?

A summary of these comments may provide a baseline assessment of public perception about the proposed rules.

## METHODS

A CMS proposed regulation or rule change addresses current problems or introduces new policies to facilitate the appropriate care for programme beneficiaries. When CMS proposes a regulation or rule change, it publishes the proposed regulation on the *Federal Register*, the US Government's Daily Journal. The rulemaking process allows for the public to provide comments on proposed regulations to improve the final version of the regulation. In this case, the proposed rule was posted on 15 July 2015 and comments could be made on the proposed rule until 8 September 2015. Beginning Thursday, 10 September 2015, as part of this study, one independent reviewer sorted comments made on Regulations.Gov regarding Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Medicare Part B for CY 2016. Each comment was assessed for relevance to ACP policy, and relevance was determined by direct applicability to the specific changes regarding ACP. Relevant comments were also simultaneously assessed for their stance towards ACP—positive, negative or neutral—and the source of the comment—individual or organisation (figure 1). The screening was concluded on Tuesday, 13 October 2015. Descriptive statistics were used to analyse the results. It deemed that approval of this study by the institutional review board was not needed as this is a review of comments made by the general population on a publicly accessible website.

## RESULTS

A total of 2225 comments were reviewed for relevance to the planned change in the Federal Register. Of the 2225 comments, 1536 (69%) were not germane to the proposed ACP provision (figure 1) and focused on other topics covered in the proposed rule (eg, concerns about colonoscopy payments, changes to the rules of where cataract surgery could be conducted and credentialing issues for physicians practicing in Puerto Rico). Of those public comments that were germane to ACP, 559 (81%) were positive, welcoming the proposed change. As an example, many persons submitted positive comments recounted personal experiences caring for a loved one and noting how such a discussion with a loved one's physician would have helped them. A total of 19% of the comments were negative, and <1% were neutral. Of the positive comments, 204 (37%) were made by

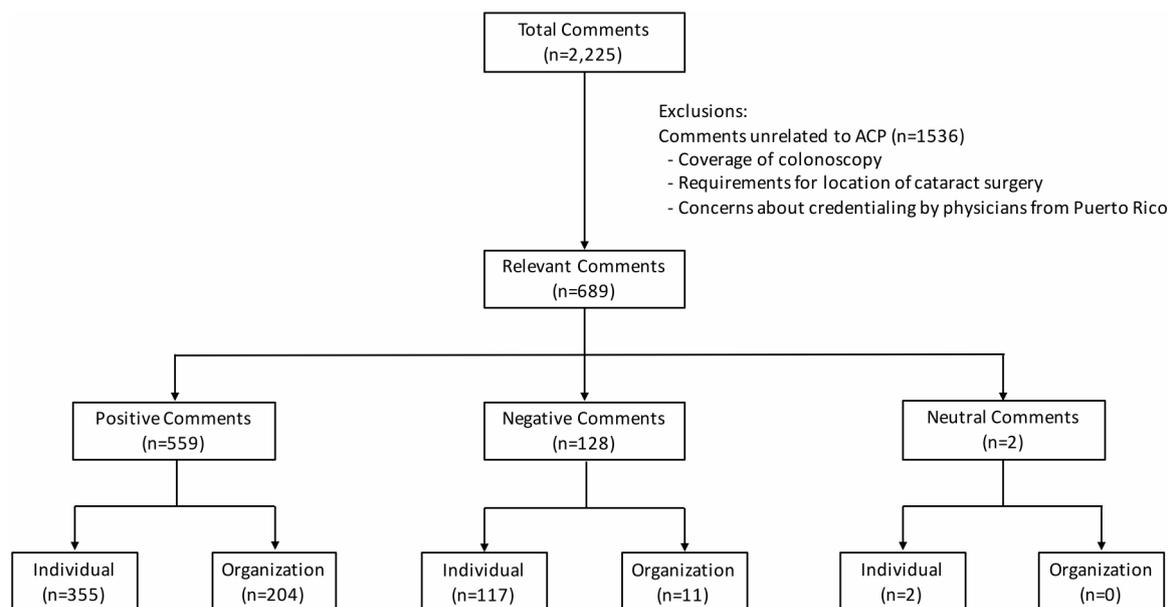
organisations and 355 (64%) by individuals. A total of 128 negative comments were made—117 (91%) by individuals and by 11 organisations (9%). Two neutral comments were recorded.

A relatively small number of organisations (N=11) filed negative comments to the proposed ACP rule. These 11 organisations include California Right to Life Committee, Society for Vascular Surgery, Coalition of State Rheumatology Organizations, American Association of Clinical Endocrinologists (AAACE), St. Colette Respect Life Ministry, Vital Decisions LLC, Association of American Physicians and Surgeons (AAPS), American Urogynecologic Society, Society of Gynecologic Oncology, American Academy of Allergy, Asthma and Immunology and American College of Mohs Surgery. These groups are heterogeneous but most focus on their understanding of what it means to protect human life or provide care for critically ill patients that may be chosen less if patients receive ACP.

## CONCLUSIONS

Public opinion about ACP and end of life discussions has changed since the initial approval of the ACA in 2010: what lead to charges of 'Death Panels' in August of 2009 as the law was being debated was approved with little fanfare in 2015. The approval of these changes suggests public opinion on expanding the ACA to cover end of life discussions may have changed and that politicians' views of either the policy or the political advantage they could garner by opposing ACP had changed. While some negative opinion surrounding ACP coverage persists, it is notable that a public forum (ie, the rulemaking comments process) did not see widespread letter writing campaigns to oppose the payment of ACP by Medicare. There were earlier signs that discussions of end of life issues were becoming less fraught politically. For example, during the fall of 2014, the Congress passed the IMPACT Act, a minor update of Medicare hospice provisions via a normal order process. Its passage was unique because legislation over a controversial subject—such as the ACA—rarely passes under a normal order process. What was notable about this was not the content of the law itself, but the fact that no one saw it in their best political interests to increase the 'death panel' and rationing rhetoric.

End of life care in the USA has had marginal improvements over the past 20 years, potentially due to how the discussion of end of life care is framed. The Institute of Medicine released a report in September, 2014, 'Dying in America', that outlined many of the same problems with access to hospice and related care at the end of life that was highlighted in a similar report during the 1990s.<sup>5</sup> However, there was a subtle shift from the earlier normative language of 'a good death' towards a focus on flexibility,



**Figure 1** Flow chart of comments reviewed and included in this assessment.

choices and making care decisions be ‘patient centered’. This suggests that the framing of discussions of treatment options as someone approaches end of life is far more palatable for persons of different political perspectives. With greater acceptance of what is meant by end of life care, there is the hope that end of life care will improve measurably over the next 20 years. It will be important to find quantifiable ways to measure these changes. Billing codes are one way but it is unclear how the new codes are being used (what specialties, what place of service, whether changes are driven by practice patterns or code approval issues) during the first quarter of 2016, and local, state and regional variation can be expected. Our study was notable in that we were able to ascertain a noticeable shift in tenor within the public on perceptions of end of life care. To the best of our knowledge, this is the first study to document a perceived change in willingness to pay for ACP discussion. Our study did have limitations as the comments collected were from a single forum. However, the forum is widely used by the public and freely available so do not expect that any one group would not be able to participate in it.

Dying is perhaps the only thing that every person in the USA (and every nation) will inevitably do. As medical technology progresses in prolonging organ function and life sustaining functions during acute injury, we need to provide the best information available for patients and families to have ACP towards the end of life and function inevitably decreases. The Medicare programme is the insurer for around 8 in 10 deaths annually, and so paying for ACP discussions between physicians, patients and their families regarding their care preferences has the potential to have a

large impact on the quality of life of persons very near death, which is best viewed as an important public health issue.

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**Competing interests** None declared.

**Ethics approval** The study was a review of comments on a publicly available website. Approval of the study by the institutional IRB was deemed not necessary.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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