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Role matters in understanding ‘quality’ in palliative care: a qualitative analysis of patient, caregiver and practitioner perspectives

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ABSTRACT

Objectives To compare the discussions from two panels on the concept of palliative care quality for patients with advanced cancer, exploring the priorities reflected in each group’s perspectives.

Design We convened two RAND-UCLA appropriateness panel discussions on palliative care quality in advanced cancer. Discussions were audio-recorded and transcribed verbatim. Panel transcripts were analysed thematically using a matrix approach to examine perceptions and experiences of quality.

Setting Discussions were framed within the context of advanced cancer care and palliative care.

Participants The patient–caregiver panel had 9 patients with current or a history of cancer and caregivers, and the practitioner panel had 10 expert practitioners representing fields of oncology, primary care, social work, palliative care, nursing, pain management and ethics.

Results Our analysis identified three thematic categories for understanding quality common across both groups and nine subthemes within those categories. At the highest level, quality was conceived as: (1) the patient and caregiver experience of care, (2) technical competence and (3) the structure of health system. Among the subthemes, four were present in only one of the two group’s discussions: ‘purpose and action’ was specific to the patient–caregiver panel, whereas ‘adhering to best medical practice’, ‘mitigating unintended consequences and side effects’, and ‘health system resources and costs’ were specific to the practitioner panel.

Conclusions While both panels aligned on the three key domains of quality, the particular dimensions through which they perceived quality varied in relation to their experience and role as a professional provider of care versus recipient of healthcare services. These differences suggest the importance of adopting a collaborative approach to quality measurement and improvement so that the values of all interested parties are represented in improvement efforts.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Qualitative analysis to explore differences in how patients–caregivers and practitioners conceptualise healthcare quality during panel discussions to prioritise quality measures for palliative care.
- ⇒ The study included patient–caregiver perspectives on quality in palliative care, which are not often incorporated in approaches to quality measure prioritisation.
- ⇒ Although panel participants were drawn from diverse healthcare settings across the USA, the majority of panel members were representatives from within the Veterans Affairs (VA) healthcare system and therefore some perspectives may be specific to the VA population.
- ⇒ As a secondary analysis of panel discussions, the panel format may have limited some individuals from fully verbalising their understanding of quality.

INTRODUCTION

Patient participation in co-designing healthcare services and measures to improve the quality of services is increasing.[1] Including patients in quality improvement is based on the belief that patients are experts in their care who are uniquely positioned to contribute to the design of the healthcare services they consume.[2] The engagement of patients at different levels of healthcare for the purposes of enhancing quality has been wide-ranging,[2 3] and more commonly, patients are being included in the prioritisation of quality measures,[4 5] though this is not consistent across health conditions.[6]

The inclusion of patients in defining quality measures has identified a challenge: patients and providers do not always align on the most important aspects of quality.[7 8] In a study on fertility, of 29 prioritised measures, only 5 were similarly prioritised among separate patient and provider panels.[8] Another study involving patients in quality measurement selection in the community showed that a collaborative process between patients and professionals led to greater prioritisation of generic aspects of quality, such as access to care, self-care support and shared decision-making, whereas professional-driven priorities emphasised technical care and service utilisation.[7] These studies demonstrate that important differences exist in how patients and professionals perceive and experience quality.

Palliative care quality among patients with advanced cancer is an area that is ripe for improvement as patients with advanced cancer typically have high symptom burden and frequent use of healthcare services.[9 10] As seen in other areas of care, recent efforts to prioritise quality measures for advanced cancer care also demonstrated variation in rank order between patients and caregivers, and practitioners.[11 12] Of quality measures for palliative care for patients with advanced cancer ranked for importance by separate patient–caregiver and practitioner panels, only two measures emerged as highest priorities for each: documentation of goals of care discussions in the chart and documentation of a pain management plan for patients with pain. Establishment of quality measures has largely been based on numerical rating and assessment; we know less about the qualitatively and structurally different ways that patients and practitioners engage with the concept of quality that might lead to observed variation in prioritisation. Understanding how these two groups think about and understand quality may shed light on why these variations exist, and how we can more meaningfully engage patients in the production of quality care. We therefore aimed to explore how patients and caregivers, and practitioners who care for patients with advanced cancer and organisational leaders conceptualise quality.

METHODS

The Improving Palliative Measurement Application with Computer-Assisted Abstraction (IMPACS) Study was funded by the Department of Veterans Affairs (VA) to evaluate how to incorporate the joint perspectives of patient–caregivers and practitioners in cancer quality measurement and improvement. We convened two RAND-UCLA appropriateness panel discussions in person in early March 2020, immediately prior to the onset of the COVID-19 pandemic. Full-day discussions covered a wide range of quality domains for palliative care among patients with advanced cancer. 'Quality' was defined as a generally accepted minimum standard for care, and 'quality measures' were defined as ratio measures that define the proportion of a population who receive a minimum standard of care. 'Palliative care quality' was defined for advanced cancer as quality of life enhancing care for cancer for which cure is no longer possible or very unlikely, typically for metastatic disease. Definitions and sources for measures were developed through extensive prior work[13] and were further characterised during the IMPACS Study; these were provided to participants for review prior to panel discussions. Building on our analyses of the numerical rating of measures,[11 12] we conducted a secondary qualitative analysis of the structure and content of discussions, and an explicit comparison of perspectives.

Population

The first panel was comprised of health system practitioner experts, and the second panel was comprised of patients and caregivers with experience of cancer from the VA health system. We used purposive key informant and snowball sampling approaches for panel recruitment.[14] For the expert practitioner panel, study team members identified and recruited VA and national leaders who oversaw clinical care that might be evaluated using palliative care quality measures and national leaders in palliative care quality measurement. Expert practitioners were purposively selected for representation in the following fields: oncology, primary care, social work, palliative care, pain management, nursing and ethics. For the patient/caregiver panel, the study team partnered with providers across the national VA network to request introductions to patients and caregivers. Patient/caregiver panellists had to have personal experience of cancer as a patient or caregiver, but did not have to receive care at a VA facility. The selection process of patients/caregivers was intended to maximise diversity in age, gender, race/ethnicity, cancer type, cancer status (ie, in treatment, remission), region and role (patient/caregiver) to the extent that was possible. Practitioners and patients/caregivers were recruited by telephone or email.

Data collection

Guided by previous research using patient panels,[7 8] we created two versions of the same quality measure background and evidence for discussion.[11 12] The practitioner panel guide included technical details (eg, 'effect sizes') and language (eg, 'analgesics'). With direct and iterative input of a layperson chair, the patient–caregiver panellists' information was modified to retain meaning, but be less technical (eg, 'impact of') and more colloquial (eg, 'pain medications'). Practitioner panellists reviewed 64 candidate measures,[15] but previous research and our layperson chair emphasised the need to restrict the patient–caregiver candidate measure list to allow for more understanding and discussion. We therefore limited the focus of the discussion at the patient–caregiver panel to the top 20 measures endorsed by practitioners, with additional time provided at the end for panellists to raise issues not addressed by the 20 measures. Panellists discussed their reasoning for ranking each measure individually, including how well it reflected their views on quality of care and importance for palliative care (see online supplemental material for measure guides). We perceive that data saturation was reached on the concept of quality as it was discussed repeatedly in relation to 64 measures in the practitioner panel and 20 measures in the patient–caregiver panel.

Using modified RAND-UCLA appropriateness panel methods,[16] the practitioner panel was chaired and facilitated by a physician researcher who was not a member of the study team to minimise bias and who was experienced in facilitating discussion among an interdisciplinary group to ensure equal participation among participants. The patient–caregiver panel was co-facilitated by a physician clinical expert and a layperson chair who was a patient/caregiver with experience in patient engagement in research. The physician clinical expert was consulted to provide clinical context and answer questions for the patient and caregiver group as needed during the discussion. Each panel was convened in person over a single day; members who were not able to participate in person were invited to call in by phone. Panel discussions were recorded with participant consent, transcribed and de-identified for analysis. Additional details of the panel content, conduct and quantitative results have been published elsewhere.[11 12]

Analysis

We took an interpretivist-constructivist approach to exploring the meaning-making processes of panel members in relation to their understanding and experience of quality.[17] Transcribed panel discussions were uploaded into NVivo for thematic analysis. Two researchers experienced in qualitative methods (LMH, RCG) conducted the analysis; RCG observed both panel discussions and LMH did not observe panel discussions but has conducted numerous studies in the area of palliative care. Researchers first read each transcript in full to familiarise themselves with the data and generate an initial codebook which included high-level categories and subcategories identified within the discussions that were common across panels. To facilitate comparison of themes across the panels, one codebook was applied to both transcripts. The researchers individually coded sections of the panel discussions, completing one domain at a time, and meeting regularly to discuss application of the codebook and emergent codes. New, emergent codes were discussed between coders and were checked for similarity in meaning against existing codes in the codebook and other emergent codes. For concepts that were the same, we used the existing code; for concepts that were similar, we checked whether an existing code could be broadened or amended to be inclusive of the new concept. Codes for concepts that were not the same or similar were left as is. Codes that recurred repeatedly within at least one panel discussion were integrated into the codebook. Coders also discussed how coded quotes related to the panel discussion as a whole to retain their relationship to the context of the discussion. Coding focused on how people defined quality, why they view quality in the way they do and what they think is important for high-quality palliative care for cancer. One coder, LMH, reviewed all newly coded data weekly to check for coding consistency using the coding stripes function in NVivo. Any discrepancies were noted and discussed by the coders during weekly meetings to resolve discrepancies. Any disagreements which were not resolved through discussion between the two coders were discussed with the wider research team for resolution. Coded data were then examined for consistency within each code, and data across codes were compared using a matrix to assess similarities and differences in categorisation.[18] Codes were reorganised and grouped until mutually exclusive thematic categories emerged. The final results were shared with selected panel members for feedback as a validation check.

Table 1 Description of panels and participants

	Practitioner panel	Patient/caregiver panel
Participants	10 (8 in-person, 2 telephone)	9 (all in-person)
Women/men	6 women, 4 men	2 women, 7 men
VA/non-VA	7 VA, 3 non-VA	8 VA, 1 non-VA
Health system experience	7 physicians, 2 nurses, 1 social worker	7 patients, 2 caregivers
Geography	California (1), Connecticut (1), District of Columbia (2), Maryland (1), New York (2), North Carolina (2), Washington (1)	California (2), Florida (1), Massachusetts (1), Michigan (1), New Jersey (1), Virginia (1), Washington (1), Wisconsin (1)

VA, Veterans Affairs.

Patient and public involvement

Patients and family members were involved in the conduct of the research. The patient–caregiver panel was co-chaired by a patient/caregiver who also vetted the materials sent to panel participants in advance of the meeting. A patient and family council provided input on aspects of the research process.

RESULTS

Participant characteristics for each panel are described in table 1. Ten clinical experts participated in the practitioner panel which lasted 6 hours and 43 min. Nine patients and caregivers participated in the patient/caregiver panel which lasted 6 hours and 22 min. Of the nine, seven participants had previously had or currently had cancer, and three participants had caregiving experience (two participants were both patients with cancer and caregivers). Patient and caregiver participants spoke widely about their experiences with cancer, reflecting on not only their own experiences of both current and past cancer, but those of friends, families and other patients they encountered while receiving care.

Our analysis identified three thematic categories for understanding quality that were common across both groups and nine subthemes within those categories. Quality was conceived in three distinct ways as: (1) the patient and caregiver experience of care, (2) technical competence and (3) the structure of health systems. While the themes and most subthemes were common to both groups, there were differences in understanding which emanated from the diverse experiences with illness personally and professionally, and understanding of the healthcare system. These different experiences aligned with the role that each group held within the healthcare relationship as either professional providers of healthcare or the recipients of healthcare services. Exemplar quotes for each subtheme are presented in table 2; subthemes that did not emerge in a panel discussion are indicated by * in the table.

Quality as the patient and caregiver experience of care

In the first theme, participants from both panels viewed quality as primarily represented in the patient and caregiver experience of care. There were three subthemes that characterise the ways in which quality was perceived as manifest in the patient experience: the respect for patient autonomy and person-centredness of care; transparency in clinical decision-making and sharing information; and the timeliness of care.

Respect for autonomy and person-centredness

Both panels reflected that quality is judged through individual experiences of illness and healthcare, and thus good-quality care respects individual decisions and preferences. For example, in the context of treating dyspnoea, patients talked about the distress it can cause and how important it is for clinicians to recognise the importance of managing that symptom. Likewise, practitioners reflected that dyspnoea must be treated to the point where patients, who are best positioned to judge the outcome of their care, were satisfied with their care.

Transparency and sharing information

Quality was perceived as encompassing transparency in medical decision-making and sharing information with patients. The concept of transparency was more salient in the patient and caregiver panel as they described the importance of having all the information about their health status and care plans, and frustration with not having access to information. The concept of clear communication to patients was mirrored in the practitioner panel with concerns around communicating with patients who spoke other languages and with those who lacked health literacy.

Timeliness

Both panels anchored their perceptions of quality in relation to a point in time in the patient's cancer journey. It was acknowledged by both groups that advanced cancer care is dynamic; patients' needs and preferences in relation to their progressing disease often fluctuate. Good-quality care was perceived as responding to those needs in a timely manner. Practitioners perceived that in practice, care provided likely matched wishes, but that documentation in electronic health records may not keep pace with changing wishes or reflect decisions that are made in the moment. The concept of timeliness was also reflected by patients in pain management and following up in a timely way to check the effectiveness of prescribed treatments. However, practitioners tempered the ideal for timeliness of services with the real-world nature of treating illness within a complex healthcare system in which there are many factors that affect the timeliness of care, such as how quickly patients recognise needs and seek care.

Quality as technical competence

The second theme encompasses participants' perception that quality is encompassed in the skill of the healthcare provider and their technical competence and proficiency in medicine or clinical care. However, the basis of this perception was rooted in the different life experiences and knowledge of the individuals in each panel. For patients and caregivers who were not medically trained, technically competent care was embodied in their experience of care rather than adherence to an objective standard, and was exemplified by the purpose and action of health providers. In contrast, practitioners who had clinical training and professional experience reflected that technical competence was reflected in specific standards: adhering to best medical practice, and mitigating side effects and unintended consequences. The separate subthemes for each group reflect this differing orientation to medical care, but they are thematically grouped together as they represent judgements of the technical quality of medical care.

Clear purpose and action (patient–caregiver-only subtheme)

Patients perceived that technical competence was reflected in physician behaviours and processes; more specifically, health professionals were perceived as technically competent when the things they did had a clear purpose and led to an action. Patients and caregivers expressed higher confidence in physicians when they clearly understood the actions they were taking and why. Examples included intentionally using health surveys to inform care decisions, and rapidly acting on patient concerns or changes in health status.

Adhering to best medical practice (practitioner-only subtheme)

Much of the practitioner conception of quality assumed that clinicians are following best practice on the methods to diagnose and treat disease. This was reflected in the belief that physicians generally practise evidenced-based medicine, and that some practices had become standardised in areas with a strong evidence base and less standardised in areas where the evidence was perceived as weak. For example, for radiation and MRI, the evidence base was perceived as being well established for certain diagnostic testing and treatments by practitioners. For other practices, such as advance care planning, shared decision-making and even pain management, there was perceived to be an ongoing debate about the evidence base and whether certain practices were potentially flawed. It was therefore suggested that practices to improve patient care should be prioritised based on the strength of evidence.

Table 2 Themes and subthemes for how quality is conceptualised among patient–caregiver and practitioner panels

Subtheme	Patient–caregiver exemplar quotes	Practitioner exemplar quotes
Theme 1: quality as the patient and caregiver experience of care		
Respect for autonomy and person-centredness	Because I think once you've had the experience of dyspnoea, once you've had that panicky sensation, you understand that that is super important and that you would be willing to live a month less if you could have a month more of breathing better, right? So it's those kinds of tradeoffs that only the patient can make for themselves. Not the physicians. (patient & caregiver, 302)	If a person lives at a dyspnoea level at a five, because of underlying COPD and just their FEV_1 is 15% of predicted, I think what we're trying to get at is that the patients are at a dyspnoea level that is satisfactory to them or that is to a certain extent comfortable to them. (practitioner, 200)
Transparency and sharing information	[A pain management plan] is the most important. Because it certainly explicitly suggests and mandates disclosure. That is, if you've got a plan, certainly it's saying that you've disclosed it to the patient. And so that's the reason why I give it the highest rating of all the pain questions. (patient, 305)	It is really the crux of care, so whether it's because it's a different language, or maybe it's a health literacy concern, or again, I can do functional—if, you know, I can do well enough to do the military things, but understanding the comprehensiveness of the medical things, I might benefit from extra support. (practitioner, 209)
Timeliness	And so we said something about what we wanted done on December the 1st, but in January our medical situation changed dramatically, and we're thinking about that change. We're not thinking about what we've put on paper a month or six months ago. (patient, 308)	Certainly we have the requirements to kind of notify and screen, but [advance directives] can be completed at any time and aren't necessarily going to be—kind of germane to the time when—or interpretable, at the time when decisions actually need to be made. (practitioner, 206)
Theme 2: quality as technical competence		
Clear purpose and action	I go back to my [oncologist]. And he was like—'is there anything out of the norm that you might want to talk about and bring up?' And I was like—'Yes, I really think this medication is just making me—you know, angry and hostile.' He was like—'Give me a second, I'll be right back.' So he steps out and he goes and confers with some of the other nurses and some other clinicians. Come to find out that that is one of the side effects with it. But he had never encountered anybody with it. And once he did assess that that was true, he actually got me an appointment—literally, like—'Okay, when you leave here I want you to go downstairs. You're going to go see this psychiatrist and you're going to talk about it.' And I was like—This never happens. Nobody ever reacts this fast. (patient, 310)	*
Adhering to best medical practice	*	I feel like there's some significant evidence that we didn't have here about the importance of emotional discussions. We should be doing this based on that kind of data, if that's really true. (practitioner, 205)
Mitigating unintended consequences and side effects	*	A lot of people are really fatigued and they're frustrated that nobody acknowledges it, so asking them about it is important, but if you ask everybody about it and then you do nothing about it, then that is even more frustrating. I don't know which is worse. (practitioner, 210)
Theme 3: quality as the structure of health systems		

Continued

Table 2 Continued

Subtheme	Patient–caregiver exemplar quotes	Practitioner exemplar quotes
Feasibility of enacting a practice	My experience is that at world class facilities, they do an overall assessment, but different people each have their compartmentalized assessment to do, and it's not clear that they're necessarily talking to each other in terms of coming up with a conclusion. (patient & caregiver, 307)	I am concerned about operationalizing (assessing patients' decisional capacity). So I mean, I know we're not supposed to be thinking about feasibility, but I was. (practitioner, 208)
Health system resources and costs	*	We used to give a course of palliative radiotherapy every two weeks or 10 fractions. And it's much more expensive and obviously bothersome to the patient, right? To come in to do that. When patients are at VA hospitals, we do single fraction, because we're trying to do the right thing for the patients and economize, whereas you send the patient out to the community, they're getting 10 fractions, because they can bill for that. (practitioner, 207)
Equitable care for all patients	So I would think that somebody who was suffering from cancer and given the spread of the quality of clinicians out there, again on the low scale and the high scale, and most of them in the middle. It's a good idea to have them screen for a problem that many cancer patients are going to have. (patient, 303)	In the medical centers that are not affiliated with academic medical centers that may not have the same kind of access and community hospitals throughout this country, they're not going to have the same kind of access to palliative care. And I think that […] we have to sort of think about the whole spectrum. (practitioner, 205)

*Theme not present in panel discussion.
COPD, chronic obstructive pulmonary disease; FEV_1, forced expiratory volume in 1 s; VA, Veterans Affairs.

Evidence was perceived broadly, including peer-reviewed literature, clinical practice guidelines and local, institutional norms around a practice.

Mitigating side effects or unintended consequences (practitioner-only subtheme)

Practitioners were attuned to the fact that treatments and health system processes can often lead to side effects or unintended consequences due to implementation. Treating advanced cancer was described as being complex, often with multiple treatments targeting the disease and symptoms, and with treatments that often have undesirable side effects. In some cases, such as fatigue, practitioners described that there were not effective treatments, and thus described the potential harm that can arise from either ignoring it as a symptom because there is no treatment, or asking about it, but then not having any solution available.

Quality as the structure of health systems

The third theme reflects the perception that healthcare happens within a structured and highly regulated system, and thus quality is a product of that system. Both panels expressed that quality care is a process which does not occur naturally, but rather requires an intentional structure to enable clinicians to provide good care.

Feasibility of enacting a practice

Panel members in both groups repeatedly considered the feasibility of enacting care practices within the complexity of the health system which is often siloed and with a myriad of competing demands and limitations. Indeed, practitioners were often unable to decouple feasibility from relevance or importance when thinking about how to prioritise measures, typically reflecting on whether it was feasible to implement or execute an action indicated by a quality measure within their own healthcare organisation. Patients and caregivers thought about feasibility in terms of whether quality measures prompted reasonable action on the part of providers based on their prior experiences in engaging with health systems and providers. Both groups recognised that healthcare processes are often connected, such as assessment and a treatment plan, but that all parts of that process had to be actionable to achieve high-quality care.

Health system resources and costs (practitioner-only theme)

The concept of quality as being constrained by available resources and costs was primarily reflected in the practitioner panel. Among practitioners, system barriers related to reimbursement were perceived to inhibit the creation of processes or developing teams that might most effectively deal with important patient issues. For example, in non-VA settings, it was noted that single-fraction radiation was not incentivised for physicians because it impacted their payment from Medicare. Likewise, social workers were noted to be of high value, but hiring sufficient social workers may reduce the number of oncologists that can be hired, which would then negatively affect metrics on oncology access. Value-based care was viewed as a potential solution to that problem.

Equitable care for all patients

Quality as equitable care was discussed with nuanced differences in each panel. Whereas patients reflected that inequitable care might stem from variations in the technical competence of individual physicians thus leading to inequitable patient outcomes, practitioners understood inequity as stemming from variability in the availability of resources in different health settings, such as spiritual support or mental health services, which would lead to inequitable patient and caregiver experiences and outcomes.

DISCUSSION

We sought to explore how patients, caregivers and practitioners understand and conceptualise quality, which may shed light on why patients and practitioners differentially prioritise quality measures and improvement efforts.[11 12] To our knowledge, this is the first study to qualitatively explore differences in how patients–caregivers and practitioners conceptualise healthcare quality. We identified three themes and nine subthemes that categorised how patients and practitioners understood quality. While each theme applied to both panels in their conceptualisation of quality, four of the subthemes were specific to only one panel and were markedly different in relation to the understanding of quality as technical competence. Although both panels conceived of quality in relation to the expertise and skill of health professionals, the particular dimensions through which they perceived that varied in relation to their personal experiences and role as either a professional provider of care or recipient of healthcare services. Patients are recipients of care, and thus their understanding of technical competence was embodied in the behaviours and actions of health professionals, such as how they responded to patient concerns and how doctors communicated about care processes. In contrast, practitioners perceived that technical competence reflected their training and professional experience in providing healthcare. Though these perceptions both reflect the concept of technical competence of professionals, the differing experiences of patients and caregivers, and practitioners in the healthcare relationship mean that the basis for how they understood quality as technical competence was different. One implication is that health systems should be specific in their questions when soliciting feedback from patients about perceived quality of care as patient responses reflect this differing orientation to quality, and thus their responses may be misinterpreted by care providers and quality improvement efforts misdirected.

The different ways that patients and caregivers, and practitioners conceptualise quality within the three themes may help explain why previous studies have found variation in some of the priorities in relation to quality among the two groups in non-cancer settings.[7 19 20] While there has been some variation in the priorities among patients and practitioners, there is also generally overlap in the high-level indicators of quality. Our findings indicate that there are more similarities than differences in understanding of quality between patients and caregivers, and practitioners. However, because there is not perfect congruence in the understanding of quality between the two groups, a collaborative approach to quality measure selection is likely needed to ensure that both the givers and receivers of healthcare perceive that their views of quality are represented in improvement efforts.[7] The RAND-UCLA appropriateness panel approach taken in this study, or similar Delphi methods which include patients as expert groups,[5 21] are potential examples of methodological models for the development of quality measures. However, these approaches typically keep stakeholder groups separated, with researchers consulting independently with practitioners and patients. There may be benefit in facilitating collaboration between representatives of both groups to harmonise views and reach a consensus on quality measures across all stakeholders as it is evident from this and prior research that the two groups prioritise quality measures differently.[7 8] Future methodological research might explore feasible ways of facilitating greater collaborative work that is sensitive to complex power dynamics in healthcare.

The structure of the themes and subthemes identified in this analysis appears to resonate with much of the current thinking of quality, which may support the credibility of our findings. The three themes and nine subthemes appear to reflect of the Institute of Medicine's six elements of quality: quality as the patient and caregiver experience of care encompasses aspects of patient-centredness and timeliness; quality as technical competence encompasses patient safety and effectiveness; and quality as a structured process encompasses efficiency and equity.[22] Additionally, there are echoes of the structure, process and outcome organisation of Donabedian's model[23] for assessing quality embedded within the themes. However, Donabedian's original model focused on factors within the care delivery system only.[23–25] Engaging patients and caregivers into the design and delivery of healthcare has become increasingly common and demonstrates potential for multiple benefits to healthcare quality.[26] By including patient and caregiver perspectives in understanding quality, we have expanded our understanding of whether 'good' medical care has been applied'[23] (p. 694), especially that respecting patient autonomy and using a person-centred approach are important processes in healthcare which are linked to patient satisfaction outcomes[27] though were not evident in Donabedian's original model.[24]

This study had several limitations. This was a secondary analysis of panel discussions to prioritise quality measures for palliative care, and thus the panel format may have limited some individuals from fully verbalising their understanding of quality. However, we perceived that the repetitive format of discussing quality in relation to 64 measures (practitioner panel) and 20 measures (patient–caregiver panel), and group discussion over 6 hours each may have mitigated that risk. While both panels discussed the same domains of care, for feasibility, the patient–caregiver panel discussed only the 20 measures within those domains rated highest by the practitioner panel and not the full list of 64 measures; thus, there may have been discrete aspects of quality not discussed by patients–caregivers. To mitigate this risk, the patient–caregiver group was given additional time at the end of their panel discussion to suggest new measures. This led to the creation of two additional measures under the domain of 'pain'; therefore, we perceive that the discussions about the domains of care within each panel were comprehensive. Additionally, although both panels included experts from inside and outside the VA health system, the majority of panel members were representatives from within the VA and therefore some perspectives may be specific to the VA population.

CONCLUSION

Patients, caregivers and practitioners largely align with the three key domains of quality: patient experience, technical competence and health system structure. However, there are important nuances within these domains between the two groups which stem from their different positions within the care relationship and inform how they perceive quality. These differences suggest the importance of adopting a collaborative approach to quality measurement and improvement so that the values of all interested parties are represented in improvement efforts.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval This study involves human participants and was approved by the Institutional Review Boards at VA Greater Los Angeles (#2018-100944), Stanford University (IRB-47133) and VA Boston (1577890-3). Participants gave informed consent to participate in the study before taking part.

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Supplement Table. Codes applied within each panel discussion by sub-theme

Sub-theme	**Practitioner panel**	**Patient-Caregiver panel**
Quality as the patient and caregiver experience of care		
Respect for autonomy and person-centeredness	• Patient autonomy and choice • Patient centeredness • Convenience or disruption to patients	• Patient autonomy and choice • Patient centeredness • Convenience or disruption to patients
Transparency and sharing information	• Sharing information • Transparency, disclosure to patients	• Sharing information • Transparency, disclosure to patients
Timeliness	• Timeliness • Following up or closing the loop • Disconnect between documentation and action	• Timeliness • Following up or closing the loop
Quality as technical competence		
Clear purpose and action	(no codes applied)	• Following up or closing the loop • Actionability, action follows assessment
Adhering to best medical practice	• Best medical care or practice • Practices that may be flawed • Clinical importance, relevance • Evidence quality	(no codes applied)
Mitigating side effects	• Consideration of side effects • Unintended consequences	(no codes applied)
Quality as the structure of health systems		
Feasibility of enacting a practice	• Feasibility and operationalization • Incentive structures • Linking processes to measures	• Feasibility and operationalization • Actionability, action follows assessment
Health system resources and costs	• Health system costs of care • Policy and external influences • Context of implementation – existing practices, available resources	(no codes applied)
Equitable care for all patients	• Equitable care • Concerns about variation in practice due to provider characteristics	• Equitable care • Concerns about variation in practice due to provider characteristics