Original Article

Development of a model and method for hospice quality assessment from natural language processing (NLP) analysis of online caregiver reviews

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Abstract

Objectives. With a fraction of hospices having their Consumer Assessment of Healthcare Providers and Systems (CAHPS®) scores on Hospice Compare, a significant reservoir of hospice quality data remains in online caregiver reviews. The purpose of this study was to develop a method and model of hospice quality assessment from caregiver reviews using Watson's carative model.

Methods. Retrospective mixed methods of pilot qualitative thematic analysis and sentiment analysis using NLP of Google and Yelp caregiver reviews between 2013 and 2023. We employed stratified sampling, weighted according to hospice size, to emulate the daily census of enrollees across the United States. Sentiment analysis was performed ($n = 3393$) using Google NLP.

Results. Two themes with the highest prevalence had moderately positive sentiments (S): *Caring staff* ($+.47$) and *Care quality, comfort and cleanliness* ($+.41$). Other positive sentiment scores with high prevalence were *Gratitude and thanks* ($+.81$), *"Treating the patient with respect"* ($+.54$), and *"Emotional, spiritual, bereavement support"* ($+.60$). Lowest sentiment scores were *"Insurance, administrative or billing"* ($-.37$), *"Lack of staffing"* ($-.32$), and *"Communication with the family"* ($-.01$).

Significance of results. In the developed quality model, caregivers recommended hospices with caring staff, providing quality care, responsive to requests, and offering family support, including bereavement care. All ten Watson's carative factors and all eight CAHPS measures were presented in the discovered review themes of the quality model. Close-ended CAHPS scores and open-ended online reviews have substantial conceptual overlap and complementary insights. Future hospice quality research should explore caregiver expectations and compare review themes by profit status.

Introduction

Over the past decade, the quality of hospice care within the United States has emerged as a public health concern (Carlson et al. 2004; Perry and Stone 2011; Wang et al. 2021). Existing studies have unearthed substantial disparities in the quality of hospice care services (Parast et al. 2018a, 2018b). In response to these quality concerns, the Centers for Medicare and Medicaid Services (CMS) has taken proactive measures by publishing Consumer Assessment of Healthcare Providers and Systems (CAHPS®) scores on their Hospice Compare website (CMS 2021). With less than one-third of California hospices having CAHPS scores reported on Hospice Compare (Rahman et al. 2021), there exists an untapped, rich resource of hospice quality data in open-ended online reviews that has yet to be explored, categorized into positive and negative reviews, and analyzed thematically.

Having different types of quality assessments, including both open-ended reviews and close-ended surveys, is essential for a comprehensive understanding of hospice care quality. While close-ended surveys provide standardized and quantifiable data, open-ended reviews add depth, context, and individual perspectives. Together, these assessments offer a more holistic view of caregiver experiences, enabling hospices to identify strengths, weaknesses, and areas for improvement in their services. By combining quantitative data from surveys with qualitative insights from open-ended reviews, hospices can make more informed decisions and implement targeted improvements to enhance the overall quality of care provided to patients and their families.

Advocacy for hospice consumers is bolstered not only by the Hospice Compare website but also by the burgeoning interest in online consumer health service reviews, seen on platforms like Yelp and Google (Rahman et al. 2021; Raths 2016; Scotty 2018; Yelp 2022). An extensive literature review found that 1 study compared open-ended reviews with closed-ended Hospice CAHPS scores (Rahman et al. 2021). Rahman and team

discovered that themes emerging from Yelp were broader and more varied compared to those on Hospice Compare. Nonetheless, they didn't contrast positive reviews with negative ones. We did find a study that examine only the negative reviews from large hospices (Brereton et al. 2020). In our investigative process, we pursued a caring model as a guiding framework.

Watson's theory of human caring

Jean Watson's theory of caring (Watson 1979, 1988) has clear relevance to the hospice care context (CMS 2022). Watson urged, "care and love are the most universal, the most tremendous, and the most mysterious of cosmic forces: they comprise the primal universal psychic energy" (Watson 1988, 33–34). Table 1 displays Watson's 10 carative factors as the basis of health care processes (Watson 1979, 1988). Employing Watson's human-valuing perspective in conjunction with our thematic analysis approach enabled caregivers to articulate their personalized interpretations of what hospice care means to them. Taking a user experience approach, this study's purpose was to develop a method and model of hospice quality assessment from natural language processing (NLP) of online caregiver reviews using Watson's carative model as an interpretive lens for understanding decedent caregiver needs.

Method

A retrospective user experience approach was taken leveraging thematic sentiment analysis. Human coding was used to identify initial topics. Inspired to delve directly into expressed hospice experiences, our preliminary pilot process was modeled after the "read-first" approach recommended by Rahman and colleagues. Utilizing a grounded theory methodology, their research team engaged human coders to interpret and categorize Yelp reviews of US hospices (Rahman et al. 2021). Our objective was to unearth both positive and negative themes presenting in these reviews, and subsequently, to decipher what these combined insights might divulge about hospice quality.

Complementing CAHPS surveys with open-ended reviews from hospice caregivers presents several advantages. First, such reviews allow caregivers to articulate their experiences and concerns unconstrained by a preset question set, facilitating the identification of issues potentially overlooked by closed-ended surveys. Second, they yield rich, contextually detailed information, as caregivers can express their perspectives, emotions, and personal narratives, enriching our understanding of their experiences. Lastly, these open-ended reviews provide personalized feedback, enabling caregivers to voice their unique needs, expectations, and preferences, thus identifying areas for service customization and enhancement.

Inclusion and exclusion criteria

Given the scarcity of online reviews for certain hospices, we sourced hospices from the Lexis-Nexis list of the 50 largest hospices (Shabbir 2021) with the aim of acquiring a sufficient number of reviews to form a representative sample of hospice experiences. We opted for the largest hospices to ensure the possibility of locating 30 reviews per hospice. The research team, consisting of 3 members, each undertook the task of finding 30 reviews for 5 for-profit hospices and 5 non-profit hospices, yielding a total of 15 hospices for each category. Following the review of these pilot responses, we identified themes and compiled a list of 25 initial themes.

Table 1. Watson's carative factors and caritas processes

Carative factors (Watson 1979, Watson 1988)	Caritas process (Sitzman and Watson 2014; Watson 2008, Watson 2021)
1. "The formation of a humanistic-altruistic system of values."	"Practice of loving-kindness and equanimity within the context of caring consciousness."
2. "The instillation of faith-hope."	"Being authentically present and enabling and sustaining the deep belief system and subjective life-world of self and one being cared for."
3. "The cultivation of sensitivity to one's self and others."	"Cultivation of one's own spiritual practices and transpersonal self going beyond the ego-self."
4. "Development of a helping-trust relationship."	"Developing and sustaining a helping trusting, authentic caring relationship."
5. "The promotion and acceptance of the expression of positive and negative feelings."	"Being present to, and supportive of, the expression of positive and negative feelings as a connection with deeper spirit and self and the one-being-cared for."
6. "The systematic use of the scientific problem-solving method for decision making."	"Creative use of self and all ways of knowing as part of the caring process; to engage in the artistry of caring-healing practices."
7. "The promotion of transpersonal teaching-learning."	"Engaging in genuine teaching-learning experience that attends to the unity of being and meaning, attempting to stay within others' frame of reference."
8. "The provision of the supportive, protective, and (or) corrective mental, physical, societal, and spiritual environment."	"Creating healing environment at all levels (physical as well as the nonphysical, subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated)."
9. "The assistance with the gratification of human needs."	"Assisting with basic needs, with an intentional caring consciousness, administering 'human care essentials,' which potentiate alignment of mind-body-spirit, wholeness, and unity of being in all aspects of care."
10. "The allowance for existential-phenomenological, spiritual forces."	"Opening and attending to spiritual-mysterious and existential dimensions of one's own life-death; soul care for self and the one-being-cared for."

To maintain the integrity and representation of caregiver reviews, we screened reviews based on specific inclusion and exclusion criteria. Reviews were excluded on the following grounds: first, if they were submitted by caregivers whose loved ones did not meet Medicare qualifications for admission, and second, in light of the information suggesting that around 10–25% of hospice reviews on Google or Yelp could potentially be fraudulent or authored by the hospice's own personnel (Rahman et al. 2021; Scotty 2018; Yelp 2022), we excluded reviews with no narrative component. Google and Yelp both use artificial intelligence to remove reviews likely to be fake (Ranard et al. 2016). Third, we dismissed reviews originating from non-caregivers. Following these quality-based exclusions,

we established our inclusion criterion, which specified that the reviews must come solely from caregivers of deceased enrollees, spanning a 6-year period from 2013 to 2023.

Analysis

Human theme coding

In our pilot sample, we utilized thematic analysis, informed by Watson's carative factors, to identify themes and categories within the reviews. A team consisting of 2 trained research assistants and a faculty member, who is also an experienced hospice professional, independently performed open coding of the reviews. Following this, a comparative analysis was carried out where team members discussed the identified themes side by side. Our operational definitions for each theme underwent iterative refinement from their original formulations. Additionally, we tallied the frequency of each theme's occurrence in 1–2-star and 4–5-star reviews, allowing for a more nuanced comprehension of themes predominantly associated with either positive or negative hospice care experiences.

Machine theme coding

We aimed to obtain a stratified sample, weighted by hospice size, mirroring the daily census of hospice enrollees among the largest hospices in the United States. To ensure a nationally representative sample of US hospice providers based on active hospice census, we set sample size criteria. For smaller hospices, comprising less than .30% of the hospice market capitalization, we aimed to collect a minimum of 30 reviews. Medium-sized hospices, representing .30–.50% of the market, required 50 reviews. Larger hospices, accounting for 0.50–1.0% of the market, necessitated 100 reviews. Lastly, for the largest hospices, those surpassing 1.0% of the market, we aimed for 200–250 reviews.

Sentiment analysis was performed on hospice reviews using a Google's NLP API (Blei et al. 2013; Schwartz et al. 2013; Schwartz and Ungar 2015). The dataset was preprocessed to remove stop words, punctuations, and Uniform Resource Locators. The remaining text was tokenized and converted to lowercase for consistency. We then used Google Cloud Natural Language to classify the sentiment of each review.

Sentiment scores ranged from –1 to 1, with –1 indicating extremely negative sentiment, 0 indicating neutral sentiment, and 1 indicating extremely positive sentiment. A sentiment score between –.25 and .25 is considered neutral, between –.25 and –.5 or .25 and .5 is mildly negative or positive, and below –.5 or above .5 is highly negative or positive. Magnitude scores ranged from 0 to 1, with 0 indicating a lack of emotion or intensity, and 1 indicating strong emotional intensity. A magnitude score between .1 and .3 is considered low, between .3 and .7 is moderate, and >.7 is high (Cambria and Hussain 2012).

We employed both manual and automated methods to discern the most recurrent themes within the reviews. Initially, a subset of the reviews was manually read and common themes were identified. Subsequently, a text mining approach was utilized to pinpoint additional themes automatically. This text mining was executed using the Python programming language along with the Natural Language Toolkit library, utilizing techniques like tokenization, part-of-speech tagging, and named entity recognition. The sentiment analysis of the hospice reviews led to the identification of the top 25 themes based on their frequency of occurrence. For each theme, we computed both the sentiment and magnitude scores.

Thematic co-occurrence

To develop a model for overall hospice quality, we ran co-occurrence analysis. We then calculated the Pearson correlation coefficient between the 2 matrices to determine the association between positive and negative themes in the reviews. To test the significance of the correlation coefficient, we conducted a permutation test by randomly shuffling the positive and negative themes and recalculating the correlation coefficient 10,000 times. We then compared the observed correlation coefficient with the distribution of correlation coefficients obtained from the permutation test to calculate a *p*-value.

Results

Pilot sample – theme identification and prevalence

There were 683 positive reviews (66.96%) and 337 negative reviews (33.04%) in the pilot sample. From the initial 25 themes, our team converged on 20 themes, which we arranged into 4 main categories: therapeutic relationships, clinical effectiveness, staff quality, and hospice competency. Table 2 shows each category, its associated themes, operational definitions, and sample reviews. Table 3 illustrates that through our identification process, we discovered 8 review themes that were directly linked with all 8 CAHPS indicators and their corresponding Watson's carative factor (Watson 1979, 1988). To maintain conciseness, our report prioritizes the 10 most dominant themes along with those associated with the 8 CAHPS measures.

Therapeutic relationships

Four themes comprised the therapeutic relationship category. Table 3 illustrates that through our identification process, we discovered 8 review themes that were directly linked with all 8 CAHPS indicators. The most frequently mentioned theme was *caring, compassionate staff*, identified in over half (46.22%) of all reviews. This theme comprised the nature of patients' care and whether staff treated patients and loved ones with kindness and compassion.

Gratitude, praise (39.19%) was the third-most frequently mentioned theme. *Communication* (also a CAHPS measure) was the seventh-most frequently identified theme in 24.56% of all reviews. Poor *communication* was the most common grievance in negative (1-2 star) reviews. *Respect, dignity* (also a CAHPS measure) was the seventh least mentioned theme in online reviews (14.94% of all reviews).

Clinical effectiveness

This category comprised 6 related themes. The second most prevalence theme was *care quality and comfort* (45.29%). Positive (4-5 star) reviews had significantly more proclamations of high *care quality* (40.45%) than protests of inadequate *care quality* in negative reviews (34.90%).

The theme of *spiritual care, peace, and blessing* (14.32%, also a related CAHPS measure) captures values regarding worldview, religion, faith, and peace at end-of-life. Positive reviews (16.13%) had statistically significant more praises for *spiritual care* than laments in negative reviews (7.16%). *Pain and symptom management* (also a CAHPS measure) is related to whether the patient experienced pain or other symptoms and whether these were controlled or managed (12.43%).

Table 2. Review themes – categories, themes, operational definitions, and sample reviews

Category	Theme	Operational definition	Sample 5-star and 1-star narrative reviews
Therapeutic relationships	Caring, compassionate staff	Any reference to hospice staff being compassionate, caring, kind or friendly with the care unit, either presence of or lack of.	[b]"The softest, most compassionate people I have ever met. Every hour, on the hour they would visit with my dad, reposition him in bed so he was comfortable, talk to him, soothe him, comb his hair" [c]"The attitude and demeanor of the employees was rude, harsh, uncaring and care was frequently delayed causing much unnecessary suffering for both the patient and myself. I would never recommend this company to anyone"
	Gratitude, praise	Any comment related to feeling grateful, praising, thankful or offering a blessing to the agency.	[b]"We felt like we were in a welcoming home and we were so grateful for the kindness and care Mom received. We will never be able to adequately express our thanks to the caring staff at this facility. If she couldn't be at home, this was the next best place! Thank you!" [b]"I can't thank Esther and Olivia enough for helping us through this difficult time"
	Communication, returning calls[a]	Any mention of clear/poor communication between hospice providers and the care unit; lack of understanding or miscommunication.	[b]"Forever be grateful for them picking up on the late night, worried phone calls and giving advice that ultimately made him more comfortable. Thank you to the nurses, social worker and chaplain for making us comfortable as a family as well" [c]"Horrible Service … I've had way too many Visiting Nurses in less then a year!! They don't return phone calls"
	Respect, dignity[a]	Any reference to the staff showing respect or dignity (or lack of) for the care unit.	[b]"Dying with dignity can often be a clichéd expression, but Gilchrist lived up to that phrase with their care … and then some. The entire staff were professional and extremely competent with their jobs" [c]"They are very inconsistent, unprofessional, and inconsiderate"
Clinical effectiveness	Care quality, comfort	Any comment pertaining to the favorable or poor of quality of care, including references to the patient's comfort, or cleanliness.	[b]"They gave excellent care to my father-in-law. I would recommend this facility, without thinking about it. The staff is very caring" [c]"I could write a book on the poor care my husband received"
	Family, support, bereavement[a]	Any comment related to feeling supported, family support (or lack of) for the loved ones preceding or after the patient's death. Due to presence of anticipatory grief, bereavement support begins on admission to hospice.	[b]"Our son pass away in May. He was only 26. THANK YOU to all the hospice caregivers who have helped us through the pain and apprehension as we watched our loved ones going 'home.' I can never thank you enough for the kindness and care that you have shown not only for my Son but for us as we stood watch over him" [b]"They not only took care of him but also the whole family, meeting with us to make sure all of our questions and concerns were addressed" [c]"I have not heard from anyone at <hospice name> despite my reaching out, no grief support, no follow-up, nothing"
	Spiritual care, peace, blessing[a]	Any comment related to facilitating spiritual care, peace, serenity (or lack of) for the patient or loved ones. Spiritual care includes support for one's faith and religion but is also more broad and includes existential support in the facing of death.	[b]"Steve A was the Hospice Chaplain. He showed so much love to my stepdad as well as the caregivers. Something I will never forget is when he kissed my dying stepdad on the head and he was dirty by choice. His place was filthy, but it didn't stop them from taking care of him and showing all the love that could be given under the worst circumstances. I would highly recommend them" [b]"Larry, the chaplain was a source of comfort too. I highly recommend" [c]"We have not even receive a call offering condolences from any employee of this facility or even the chaplain"
	Pain, symptoms[a]	Any reference to pain or symptom management or lack thereof. Distress of any kind such as anxiety, agitation, sleeplessness or shortness of breath.	[b]"We are forever grateful for the nurse Cheryl who came to my parents' home to care for my dad and recognized that he needed to be moved to the Rush location in order to get his pain under control. It was the middle of the night and Cheryl stayed with us until the ambulance arrived to transport him; my mom and I followed behind. When we arrived a little after midnight, Anna the nurse on duty was so comforting, informative, and attentive. Thank you to Cheryl, Anna, and team for the care you provided to my father in his final days" [c]"Frequently delayed causing much unnecessary suffering for both the patient and myself"
	Training, education[a]	Any mention of education or training on the topic of hospice care; lack of understanding or miscommunication.	[b]"Hazel does a stellar job of educating our team on hospice care and the different resources that BCN offers. Personally, I was very impressed with their grief counseling team" [b]"Hospice stepped in and they handled everything and explained everything so we knew what to expect" [c]"I was never given a full explanation of services and procedures, consequently I was not able to make appropriate decisions as my spouses health deteriorated"

(Continued)

Table 2. (*Continued.*)

Category	Theme	Operational definition	Sample 5-star and 1-star narrative reviews
Hospice competency	Responsive, timely, helpful[a]	Any reference to the responsiveness of care delivery, or the lack thereof; can also reference staff helpfulness, customer service or attentiveness to care unit.	[b]"They were extremely helpful, compassionate, and professional. They did everything possible to ensure my wife was comfortable in her final days" [c]"They won't give me their phone number. I have to page through the nurse who is sometimes unresponsive" [c]"The senior staff and social worker was very unresponsive. Please carefully review any medical care that you are considering, people will take advantage of you during times of stress"
	Recommendation[a]	Any mention of recommending or not recommending the hospice, rating or not rating the hospice.	[b]"If you are considering hospice care for a loved one during their final days, look no further than Gilchrist. You will not regret that decision. [b]"I highly recommend this organization to anyone caring for a dying loved one. My kudos and heartfelt thanks to all who work and volunteer there with a special shout out to Karen" [c]"I would never recommend this company to anyone"
	Interdisciplinary, comprehensive	Presence (or lack) of embracing, all-inclusive, interdisciplinary care and support for the care unit. Including mentioning team members such as nurse, chaplain, social worker, aides, or complimentary therapies such as pet, music or art therapists.	[b]"Admin Nurse, Office Staff, Nurses (scheduled + on-call), Doctor, Social Worker, CNA and the Volunteers were AWESOME people. Even the one on-call nurse still gets 5 Stars, EVERYONE were professional, caring and compassionate with my Aunt, as well as with my mother and I, who took care of her" [b]"Each member of staff with whom we interacted, the nurses, the aides, the doctor, the chaplain, were all, without exception, caring, devoted and professional"
	Hospice management	Any comment related to the hospice agency's overall management, administration, or structure. Mentioning the hospice company or any organizational aspects.	[b]"Very good company. We refer folks to Heartland all the time and have a lot of respect for this company. Home Instead Senior Care loves the people at Heartland. Caring and professional organization!" [c]"Bad Company do not let your love one be cared by this hospice. They are rude and they treated my mother as a number instead with compassion"
	Supplies, equipment	Any reference to clinical or medical supplies or equipment. Whether provided or not; any reference to supplies or equipment being ordered or received on time, or not.	[b]"They brought supplies, delivered medications, coordinated the equipment, etc. No complaints." [c]"An aide was supposed to come but never did. Also never received supplies ordered from day one. When I fired them equipment pickup was equally disorganized and had to be rescheduled twice. The support staff are excellent at apologizing but nothing ever changed."
	Facility, setting, place	Any reference to hospice services being delivered in a facility, inpatient or otherwise. This theme consolidated around hospice as a place, where primary caregivers focused on visiting and attending to patient, as loved ones, while the hospice and/or facility provide the medical, custodial care for their loved one.	[b]"My mom went into Franciscan Hospice and died a week later. They were very friendly, compassionate, and took very good care of my mom. The rooms were very nice and offered more than what I expected. They had excellent facilities for the family. They had a kitchen where they served soup, cookies, coffee, and tea every day" [c]"I do not recommended this hospice facility. Our loved one passed away over one month ago and my family has not heard from the nurse or any other employees of this facility since that day. Apparently they only cared about the money and not the patient or the family"
	Money	Any mention of the hospice appearing to pay more attention to money, finances and/or numbers than care.	[c]"From my observations, Hospice is more about the money they get from Medicare, the wastefulness when ordering supplies and drugs (morphine, etc.)" [c]"This is by far the WORST hospice company out there. They only care about the money"
Staff quality	Staff professionalism	Any reference to staff as professional or unprofessional; also, staff behavior that is inferred to be either professional or not.	[b]"They were extremely helpful, compassionate, and professional. They did everything possible to ensure my wife was comfortable in her final days" [c]"They are very inconsistent, unprofessional, and inconsiderate" [c]"Unprofessional social worker and not dependable to deliver medication on time"
	Knowledgeable, skilled staff	Any comment related to the staff having (or lacking) the knowledge and skills necessary for caring for the care unit.	[b]"The Nurses, Chaplain, Case Manager and Social worker were very compassionate and professional. We were very happy with how quickly they responded to our calls and came to the house. I loved how they were so knowledgeable and explained everything to us. They made us feel very comfortable, like family, when they came to the house" [c]"All seem to treat him like 'just another patient.' Overall just a terrible experience and half the staff seem clueless and care more about towing the company line than helping those in their care"

(*Continued*)

Table 2. (*Continued.*)

Category	Theme	Operational definition	Sample 5-star and 1-star narrative reviews
	Patient safety	Any care that promoted or impaired the safety of patients; reports of poor outcomes related to poor care, clinical decision making, or treatment.	[c]"He has been experiencing monthly UTI's, some of them so severe that he spends time in the hospital, because of the uncaring attitude of case nurse B who catheterized him and caused permanent injury, and would not take responsibility for her actions" [c]"The employees here are so understaffed it's not a safe environment for the elderly"

Eight of our identified review themes were directly associated with all (8 of 8) caregiver-survey measures published in CAHPS scores.
[a]This coded theme is directly addressed by 1 of 8 items in the Hospice CAHPS survey to be posted on CMS's Hospice Compare.
[b]Five-star review.
[c]One-star review.

Table 3. Comparison of theme frequencies in online hospice reviews by star rating with equivalent CAHPS indicators ($n = 1020$)

Variable	Pilot reviews	Rank	Positive	Negative	CAHPS indicator equivalent
Number of reviews	1020	–	683	337	–
Percentage of reviews	100%	–	66.96%	33.04%	–
Agency response	23.47%	–	19.32%	30.07%	–
Caring, compassionate staff[a]	44.15%	1	51.09%	22.73%	–
Care quality, comfort, cleanliness	41.27%	2	40.45%	34.90%	–
Gratitude, praise	33.18%	3	44.05%	2.86%	–
Responsive, helpful, timely	31.19%	4	25.14%	37.95%	"Getting timely help"
Emotional, bereavement support	26.53%	5	27.18%	18.97%	"Emotional, spiritual, bereavement support"
Recommendation	25.85%	6	20.88%	34.73%	"Recommend" and "rate the hospice"[b]
Communication	23.24%	7	12.77%	42.42%	"Communication with family"
Interdisciplinary, comprehensive	22.44%	8	26.94%	8.59%	–
Staff professionalism	20.63%	9	14.00%	32.94%	–
Hospice management	17.95%	10	10.48%	32.94%	–
Facilities, place	17.73%	11	16.21%	17.90%	–
Knowledgeable, skilled staff	16.48%	12	14.82%	17.72%	–
Respect, dignity	14.94%	13	13.67%	15.93%	"Treating patient with respect"
Spiritual care, peace, blessing	14.49%	14	16.13%	7.16%	"Emotional, spiritual, bereavement support"
Pain, symptoms	11.93%	15	7.70%	18.62%	"Help for pain and symptoms"
Supplies, equipment	11.36%	16	9.42%	13.07%	–
Training, education	9.60%	17	9.42%	6.98%	"Training you need"
Medications	8.86%	18	2.78%	20.41%	–
Money	4.32%	19	0.66%	11.46%	–
Patient safety	1.99%	20	0.49%	5.37%	–

[a]Review themes begin with *caring, compassionate staff.* Positive reviews are 4–5 stars, negative reviews are 1–2 stars.
[b]Two global CAHPS measures – "Recommend" and "Rate the hospice."
Review stars mean for this pilot sample = 3.71.

Emotional, bereavement, family support (also a CAHPS measure) was the fifth most common theme (26.53%). Positive reviews (27.18%) had statistically significant more declarations of *emotional support* than concerns of nonsupport in negative reviews (18.97%). *Education or training* (also a CAHPS measure) was the fourth least mentioned theme in online reviews (9.50%).

Hospice competency
Four themes comprised this category. The fourth-most frequent theme in this study, *responsive, timely, or helpful* (also a CAHPS measure), was identified in 35.49%. Reviewers were more likely to report on *low responsiveness* than its presence. Negative reviews (37.95%) had statistically significant more mentions of *low responsiveness* than positive reviews (25.14%). Like the closely related *communication* theme, reviewers were likelier to report poor *responsiveness* in negative reviews than commend good communication in positive ones.

The sixth-most prevalent theme in this study is *recommending (or not recommending)* the hospice, as identified in 26.15% of the online reviews. This theme (also a CAHPS measure) is a global hospice quality measure like the hospice rating. *Interdisciplinary and comprehensiveness* of hospice services were identified as the eighth

most common theme (22.44%). This theme concerned whether the care was interdisciplinary and other services expected of hospice providers. *Interdisciplinary and comprehensive* care was routine in positive reviews (35.92%) yet rare in negative reviews (11.46%). *Hospice management* (17.95%) was a theme in this study. The reviewer's comments related to how well or poorly the agency seemed to have been managed. Some comments pertained to problems with staffing, billing, and organization.

Staff quality

This category comprised 3 themes. Comments in this category focused on *staff professionalism* (21.74%) and appropriate care during visits. Complaints about *staff professionalism* were more prevalent in negative reviews (32.94%) than commendations on the theme in positive reviews (14.01%). Eight review themes represent the 8 CAHPS score indicators (see Table 3). The *recommending* theme is equivalent to the 2 global CAHPS measures of recommending and rating the hospice.

Study sample – topic consolidation and sentiment findings

We required a hospice to have at least 30 reviews for inclusion, and 47 of the 50 hospices (94%) reviewed met this criterion. Solamor Hospice, Kaiser Permanente, and Hospice Advantage did not meet this criterion and thus were excluded. Also, we discovered that Hospice Advantage was acquired by Compassus in 2015. Compassus did meet this criterion and thus was included. With the LexisNexis top 100 list and to bring the total to 50, we then added the next 3 hospices Hope Healthcare of Rhode Island (51st largest), Hospice of Wake County–Transition LifeCare (52nd), and Hospice Care Network, New York (53rd). The average number of reviews per hospice was 69 among the 3393 total reviews.

We compiled and analyzed the reviews for machine coding using Google Cloud NLP. We refined our themes after the pilot and before the study sample analysis, and the themes of *Hospice management* and *Money* were combined into *Insurance, administrative or billing. Pain, symptoms* and *medications* were consolidated into *Pain, symptoms, medications. Bereavement services* was broken out as a separate theme; *Lack of staffing* was added.

In Table 4, the findings among the study sample ($n = 3393$) were similar to the above findings in the pilot sample ($n = 1020$). Besides *Gratitude, praise*, with its inherent positive sentiment, the themes with the highest positive sentiments (S) and magnitudes (M) were *Caring, kind, and compassionate staff* (S = +.47, M = .56), and *Care quality, comfort, and cleanliness* (S = +.41, M = .55). Other themes following with moderate-to-high positive sentiment and moderate magnitude were *Treating the patient with respect* (S = + .54, M = .52); *Help for pain and symptoms* (S = +.37, M = .52); and *Emotional, spiritual, bereavement support* (S = +.38, M = .51). Lowest sentiment scores were *Insurance, administrative or billing* (S = – .21, M = .50); *Lack of staffing* (S = –.17, M = .47); *Communication with the family* (S = – .01, M = .47); *Getting timely help* (S = .20, M = .46); and *Training you need* (S = .25, M = .43).

Figure 1 illuminates key thematic findings of this study through a theme flow diagram. The 8 most prominent themes from the sentiment analysis were the same 8 themes from the human coding in the pilot study. Two themes capture the process of getting care: *Getting timely help* and *Communication with family*. Then 7 themes are the caring aspects. *Emotional, spiritual, bereavement support* (for patients and families) were combined into 1 variable

Table 4. Sentiment analysis of online hospice reviews and equivalent CAHPS indicators ($n = 3393$)

Theme	Sentiment (S)	Magnitude (M)	CAHPS indicator equivalent
Caring, kind, compassionate staff	.47	.54	–
Care quality, comfort, cleanliness	.41	.53	–
Recommending the hospice	.50	.48	"Recommend" and "Rate the hospice"[a]
Communication, returning calls	−.01	.47	"Communication with family"
Respect, dignity, honor	.54	.52	"Treating patient with respect"
Knowledgeable, skilled staff	.48	.53	–
Responsive, timely, helpful	.20	.46	"Getting timely help"
Gratitude, praise, appreciation	.81	.76	–
Emotional, family support	.36	.53	"Emotional, spiritual, bereavement support"
Interdisciplinary, comprehensive	.38	.47	–
Facility, place, setting	.24	.49	–
Pain, symptoms, medications	.37	.54	"Help for pain and symptoms"
Staff attitude, professionalism	.42	.53	–
Insurance, administrative or billing issues	−.21	.50	–
Spiritual care, peace, blessing	.28	.45	"Emotional, spiritual, bereavement support"
Lack of staffing and staff turnover	−.17	.47	–
Training, education	.25	.43	"Training you need"
Safety concerns	−.18	.41	–
Supplies or equipment	.31	.52	–
Bereavement services	.34	.46	–
All themes	.28	.58	–

[a]Two global CAHPS measures – "Recommend" and "Rate the hospice."
Review stars mean for this pilot sample = 3.68.

for this final model analysis. Finally, 2 themes capture the response to caring aspects: *Gratitude, praise* and *Willingness to recommend or rating the hospice*. Patient safety, though important, was a rarely
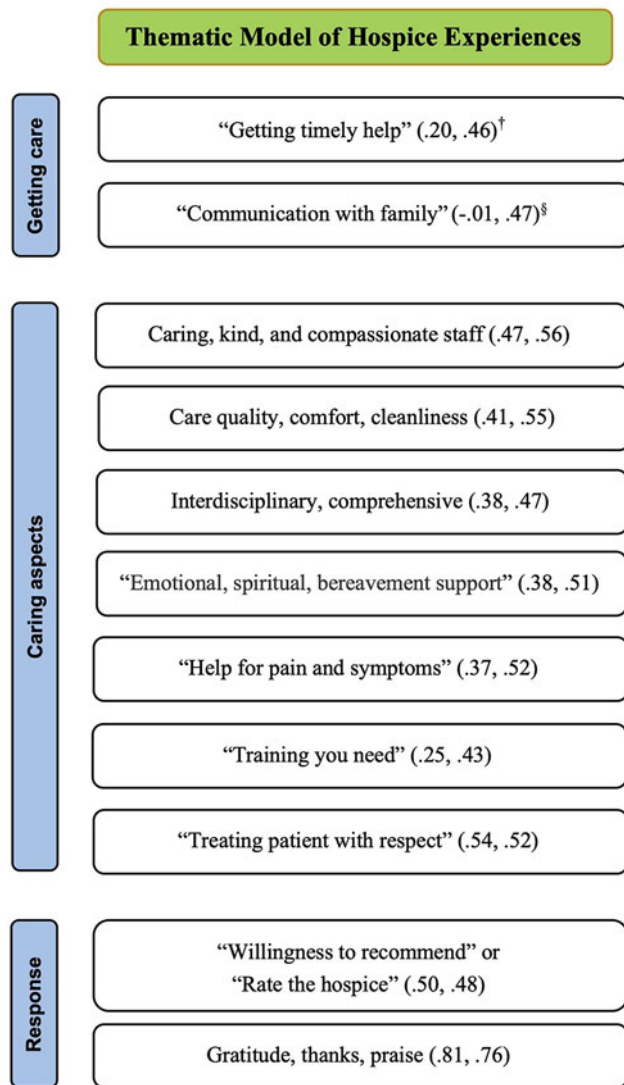
Figure 1. Thematic Model of Hospice Experiences
In parentheses are the (sentiment, magnitude) from natural language processing analysis. Sentiment ranges from −1 to +1. Magnitude ranges from 0 to 1. Themes in quotes are the CAHPS-related.

mentioned topic (1.99%) and so was not included in the final thematic model.

To test our model of overall hospice quality, we ran co-occurrence to analysis for the most common positive and negative themes. The results of the 10 most co-occurring themes are shown in Table 5. There was a significant negative correlation between the top 10 positive and top 10 negative themes ($r = −.45$, $p < .001$), indicating that reviews mentioning positive themes were less likely to mention negative themes, and vice versa. This provides evidence of an emerging model of hospice care quality from these themes. Figure 2 displays the final model of hospice quality developed from review themes, Watson's carative factors, and CAHPS indicators.

Discussion

This study aimed to qualitatively code themes in hospice caregiver reviews, discover review themes, and develop a model of hospice quality. In this section, we first explore topics, prevalence and sentiment arising from the caregiver reviews, their alignment to CAHPS measures and Watson's factors, and finally we comment on our methods.

Caring staff, care quality, and comfort

Watson's caring theory proved beneficial in interpreting the needs of caregivers of the deceased and the co-occurrence findings substantiate the model that was developed. All 10 of Watson's carative factors were reflected in the themes identified from the reviews (Figure 2). In the subsequent discussion, we exemplify areas where the review themes, CAHPS scores, and carative factors share conceptual congruence. The top 2 themes *Caring staff* and *Care quality* were represented by the first 2 carative factors, "(1) The forming of humanistic-altruistic value systems" and "(2) Installation of faith and hope." Watson advised that care should be delivered from a place of love (Watson 1988). Likewise, decedent caregivers agreed since they endorsed altruistic care and caring professionals most prominently of all themes. This finding is congruent with results from Yelp studies in hospitals (Ranard et al. 2016; Raths 2016), and nursing homes where caring and compassionate staff were frequently mentioned by reviewers (Johari et al. 2018; Schapira et al. 2016). Our findings also agreed with the Yelp hospice study by Rahman et al. (2021) and the Yelp hospital study by Ranard et al. (2016). Rahman's most prevalent themes were as follows: (1) compassionate, caring staff, identified in nearly half

Table 5. Co-occurrence analysis for most common themes (*n* = 3393)

Co-occurring themes in positive reviews	Rank	Frequency
Caring, kind, compassionate staff + Care quality, comfort	1	1056
Caring, kind, compassionate staff + Responsive, timely, helpful	2	848
Caring, kind, compassionate staff + Knowledgeable, skilled staff	3	800
Care quality, comfort + Responsive, timely, helpful	4	736
Care quality, comfort + Spiritual care, peace, blessing	5	704
Lack of staffing, staff turnover + Caring, kind, compassionate staff	6	672
Lack of staffing, staff turnover + Responsive, timely, helpful	7	656
Caring, kind, compassionate staff + Communication with family	8	624
Caring, kind, compassionate staff + Gratitude, praise	9	608
Knowledgeable staff + Responsive, timely, helpful	10	608
Co-occurring themes in negative reviews	**Rank**	**Frequency**
Lack of staffing + Inadequate care quality	1	432
Lack of staffing + Limited responsiveness	2	416
Lack of staffing + Uncaring staff	3	401
Inadequate care quality + Limited responsive	4	368
Inadequate care quality, comfort + Uncaring staff	5	368
Lack of staffing + Knowledgeable staff	6	352
Inadequate care quality + Lack of spiritual support	7	352
Uncaring staff + Limited responsiveness	8	336
Uncaring staff + Knowledgeable staff	9	336
Lack of staffing + Not recommending	10	304

Note: These themes represent the most common combinations of themes that occur in the reviews. The co-occurrence frequencies represent the number of times these themes are mentioned together in the reviews. For example, "Lack of staffing" and "Inadequate care quality" co-occur 432 times in the negative reviews. This provides evidence of an emerging model of hospice care quality from these themes.

(46.28%); (2) gratitude and recommending (44.74%); (3) timeliness or responsiveness (39.63%); (4) communication (23.37%); and (5) quality of care (21.05%). Caring staff, gratitude, responsiveness, communication, and care quality were shared between the 3 studies as commonly mentioned themes.

On the topic of staffing, findings on the *Lack of staffing* highlight the reality that staff retention is a prevalent issue in the US hospice industry. It is incumbent on providers to strive for improved staff retention, as continuity of care is a critical aspect expressed by decedent caregivers. Also, governing agencies should be intervening to provide development, education and training incentives and opportunities for nurses and nursing aids for healthcare, in general, and end-of-life care specifically. Staffing is required for responsiveness and good communication.

Responsiveness and communication

The third most prevalent theme, *responsiveness*, aligned conceptually with the carative factor, "(9) Assistance with the gratification of human needs." Given that many hospice patients are cared for in their homes, the importance of swift responses to care requests is quite understandable. The looming reality and inevitability of death heightened the need for prompt responsiveness. Reviewers expressed that they anticipated a high degree of responsiveness.

Good *communication* is at the core of the carative theme, "(4), Development of a helping-trust relationship." Poor *communication* was more likely to be reported than good communication in this study. One explanation is that caregivers come to hospice expecting good listening and attentiveness. They likely report this as good care quality or caring staff since these aspects are likely perceived as hallmarks of good service. However, when communication falls short, the care process deteriorated, as seen in many negative reviews where poor communication is a primary grievance. In negative reviews, inadequate communication and lack of responsiveness emerged as the most frequent complaints.

Emotional, spiritual, bereavement support

Emotional, family support, and *bereavement services* were harmonious with the carative factor, "(5) The promotion and acceptance of the expression of positive and negative feelings." Reviewers reported that emotional and bereavement support during and after hospice was vital to them. In the CAHPS survey, CMS assesses both aspects as well. One of the 8 CAHPS indicators of hospice quality is "emotional and spiritual support." The theme of *spiritual care, peace, and blessing* appeared in one-fifth of all reviews. *Spiritual care* harmonized with the carative factor, "(10) The allowance for existential-phenomenological, spiritual forces." Hospices should always bear in mind the importance of providing care to the entire family, particularly considering that the primary caregiver will represent the patient and their loved ones when offering feedback about hospice care during the CAHPS process.

Recommending, gratitude, and management

In our understanding, endorsements and expressions of gratitude from caregivers typically represent a positive response to excellent care, just as criticisms about management often signal inadequate service. Signs of gratitude suggest the establishment of a therapeutic bond. Caring behaviors and good communication were associated with the outcome of caregiver satisfaction as expressed in grateful language in review narratives. It is likely that caregivers who make an effort to write reviews and express thanks to the hospice team feel a sense of connection to the compassionate professionals who built relationships with them. The high incidence of negative reviews is concerning, suggesting that certain hospices may not be providing effective care to a significant number of their admitted patients.

Interdisciplinary and comprehensive care

The *interdisciplinary and comprehensive* theme showed up in comments about all-inclusive and holistic care. *Pain and symptom*
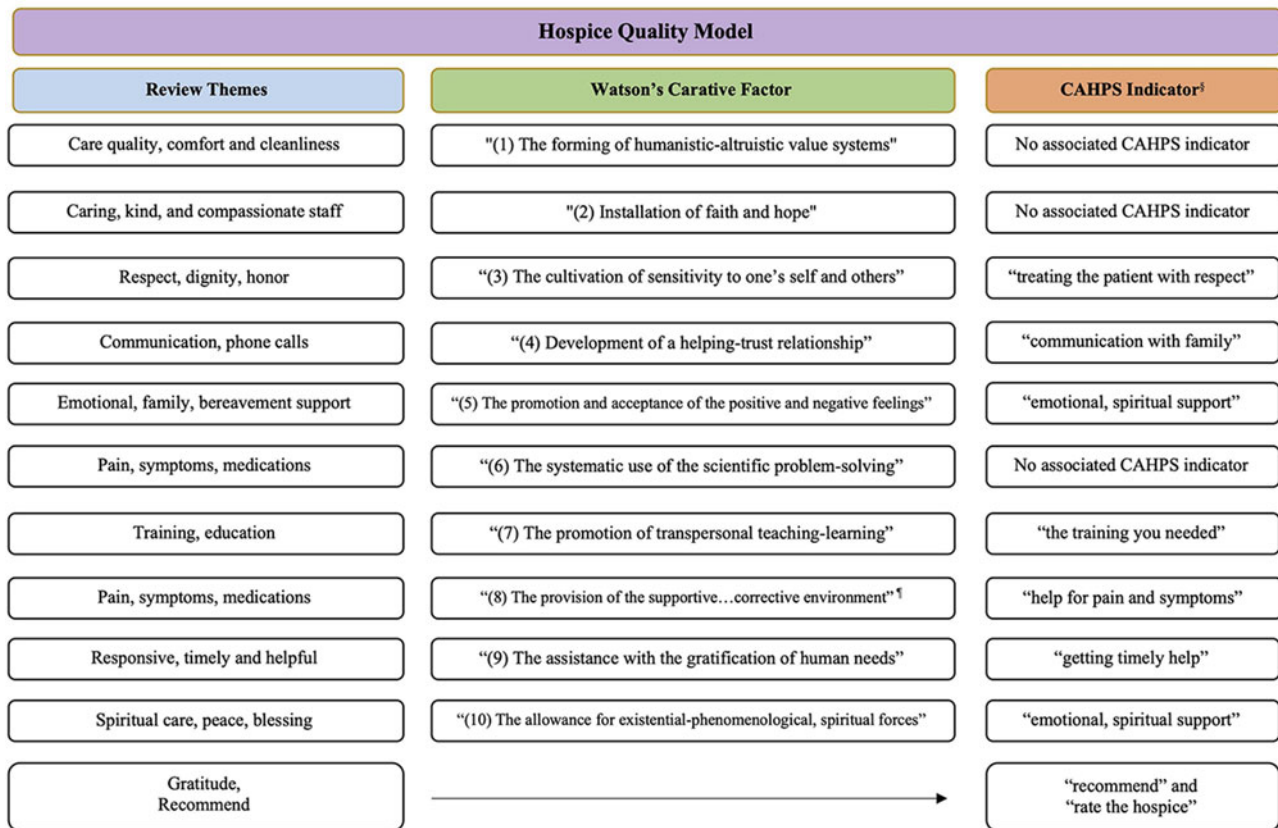
Figure 2. Hospice Quality Model
CAHPS = Consumer Assessment of Healthcare Providers and Systems; the CAHPS survey has 47 questions which form 8 indicators. [a]Themes occurring among online decedent caregiver reviews. [b]"(8) The provision of the supportive, protective, and (or) corrective environment."

management, also a critical CAHPS measure, is the central goal of palliative care that aligns well with Watson's carative factor "(8) The provision of the supportive, protective, and (or) corrective mental, physical, societal, and spiritual environment." *Education or training*, a CAHPS measure with 6 survey questions, aligns with Watson's factor, "(7) The promotion of transpersonal teaching-learning."

Implications for hospice quality evaluation

To encapsulate, both close-ended CAHPS scores and open-ended online reviews offer significant conceptual similarities and offer supplementary insights. Particularly in the case of hospices with sparse CAHPS results, it is crucial to employ various quality evaluations to comprehend the full scope of hospice care quality. While close-ended surveys supply standardized, quantifiable data, open-ended reviews offer added dimensions of depth, context, and individual viewpoints. Through the amalgamation of these different types of evaluations, hospices can achieve a more comprehensive understanding of caregiver experiences, which allows them to pinpoint strengths, areas needing enhancement, and potential areas for service improvement. This eventually leads to an overall enhancement in the quality of care provided to patients and their families.

These findings suggest that hospices should consider actively engaging with and responding to their reviews. This not only demonstrates that the hospice staff genuinely cares but also helps to validate the experiences of patients, be they positive or negative,

potentially triggering enhancements in service delivery. Another inference drawn from these results is that since caregivers frequently mentioned caring staff and overall quality in their reviews, it would be beneficial for CMS to integrate at least one question for each aspect into their 47-question survey. For example, "Do you feel the hospice staff cared about you and your loved one?" Hospice care services are intimately linked to, and evaluated in light of, the caring, or uncaring, people providing the services.

Watson's caring theory serves as a valuable framework for understanding, and all the carative elements found expression in the themes we discovered and developed. The reviews emphasize the significance of the human-centric and holistic aspects of hospice care – compassionate caregivers, quality of care, and emotional, spiritual, and bereavement support (Barry et al. 2012). In contrast, CAHPS scores are oriented to government-evaluated service measures (CMS 2021). There was construct agreement between the 8 CAHPS score indicators, 8 review themes, and Watson's caring theory. Reviewers appeared to endorse caring people, availability, and timely caring experiences as top of mind when they reviewed the hospice. Recommending is the highest compliment a hospice can receive.

Strengths, limitations, and future research

This study had certain significant strengths and limitations. Among the key strengths were the utilization of both human and machine coding methods with considerable sample sizes, enabling us to determine 10 central themes. By confining our research to the 50

largest providers, we ensured a sufficient number of reviews per hospice, thereby preserving the study's validity, though this meant excluding some smaller providers. However, as Google and Yelp reviewers are not randomly selected but volunteer contributors, the sample in this study may display a bias toward the demographics of those who post reviews.

On our methodological process, for anyone seeking to conduct this type of sentiment analysis, we strongly recommend also reading in the star ratings of the reviews as the narrative review portion is processed. This allowed us to narrow negative topics to negative reviews to increase the accuracy of sentiment analysis, and reduce false negatives. Such that, negatively oriented themes, for example "Family support, less than expect" do not trigger in any positive sentiments.

TextBlob is an alternative to Google NLP that does not require setting up a Google NLP API account. However, we found that it is not as effective at detecting sentiment direction. Both Google NLP and TextBlob produced nearly the same prevalence results, within $\pm 3\%$. In this study, we normalized our magnitude scores to range from 0 to 1, which made analysis more straightforward, since other variables matched. However, we noticed that using the raw scores (allowing them to range from 0 to infinity) offered a better comparison of emotional intensity and review length, we plan to use that method in future studies.

The sentiment analysis carried out in this study presents certain advantages and drawbacks. The application of NLP techniques allows for the handling of vast volumes of unstructured text data, offering valuable insights into the sentiments expressed in the hospice caregiver reviews (Liu 2012). The sentiment analysis approach employed in this study is based on machine learning algorithms and lexicon-based methods, which have been widely used in sentiment analysis research (Pang and Lee 2008).

Nevertheless, it is crucial to recognize several limitations. First, the quality and representativeness of these reviews could differ, and potential biases in the amassed data might be present (Cambria and Hussain 2012). Second, sentiment analysis techniques may not capture the full complexity of human sentiment and emotions. While efforts have been made to develop accurate sentiment analysis models, the interpretation of sentiment can still be subjective (Cambria and Hussain 2012; Nasukawa and Yi 2003). The sentiment scores and magnitude assigned to the review themes are based on algorithms and predefined lexicons, which may not fully capture the nuances of the caregivers' experiences and emotions (Liu 2015).

In this study, over 95% of the reviews received were either 1-star or 5-star reviews, indicating caregivers perceived their experiences as either excellent or terrible. This fact was utilized as an advantage in this study, as the distinct themes of negative criticisms and positive praises could offer insights into the user experience at both extremes of high and low hospice performance. As our central interest lay in sentiments derived from the narrative section of the reviews, potential floor and ceiling effects from bimodal data, that could influence the outcomes, are not considered significant. In this context, the star ratings of the reviews were only presented as descriptive data and were not included in the analysis.

The caregiver perspective is vitally important, but enrollees often expect more than is in-scope with the Medicare benefit. A final limitation was that we were not able to assess where caregiver's expectations were out of scope; however, in a parallel study published using the same dataset, we assessed that about 1 in 6 review expressed expectations outside the scope of the hospice Medicare benefit (Hotchkiss 2023). Thus, for a well-rounded understanding of the quality of hospice care, it is crucial to embrace diverse viewpoints and include feedback from various stakeholders (Cambria and Hussain 2012). Another hospice quality study linked employee satisfaction to caregiver satisfaction (CAHPS) scores (Hotchkiss 2022).

When considering factors about the researchers that could impact the study, such as personal attributes, experiences, and preconceived ideas, it should be noted that the primary researcher is an experienced hospice professional who has observed the highest and lowest levels of hospice quality. If there exists any bias, it could potentially lean toward unearthing deficits in hospice quality and urging hospices to elevate their standards. Further research on hospice quality should investigate caregiver expectations and draw comparisons between review themes based on their profit status.

Conclusions

Hospice caregivers were most likely to recommend hospices with caring staff, providing quality care, being responsive to requests, and offering family support, including bereavement and supportive care. Close-ended CAHPS scores and open-ended online reviews have substantial conceptual agreement. Open-ended reviews place more value on the human and big-picture elements in hospice – caring people and overall care quality. All 10 of Watson's carative factors and all 8 CAHPS measures were presented in the discovered review themes.

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